Loss and transcendence in couples living with MND: An Interpretative Phenomenological Analysis

Bridget Mary Ann Hanley

Degree of PhD

Edge Hill University

August 2012

Contents Page

Abstract

Bridget Mary Ann Hanley

Degree of PhD

Loss and transcendence in couples living with MND: An Interpretative Phenomenological Analysis

Aim

The aim of this qualitative study was to explore couples' experiences of living with MND (MND). Previous research has not focussed on the experiences of both people with the disease *and* their partners, but tended to look at each separately. In examining the experiences of both side by side and reflecting on each other, the aim of this study was to explore an overlooked aspect of the experience of living with MND and make an original type of contribution to the extant literature.

Method

Most previous research into MND has relied upon quantitative methods. The study used a qualitative method and collected two types of data. The longitudinal case study comprised analysis of one couple's journal of their experiences of MND, spanning the period of one year, from the diagnosis to death of the individual with the disease. It also incorporated a narrative interview of the couple. Narrative interviews were also carried out with 12 couples. Interpretative Phenomenological Analysis was used to analyse the data.

Results

From the analysis utilizing Interpretative Phenomenology, themes were derived from the data. The super-ordinate themes of *altered body, diminishing self, altered temporality* and *transcending embodiment* were established, with many subordinate themes deriving from these. The study reveals that although couples experienced significant physical deterioration and emotional and social losses, they developed new understandings of themselves and each other, in relation to the abstractions time and embodiment, which enabled them to cope with living with the disease.

Conclusion

The study suggests that living with MND can be understood as something individuals with the disease and their partners respond to in ways that intimately link them together. The study proposes that couples may be better supported by psychological services and considers how this might occur.

Key words: MND; embodiment; loss; transcendence; psychological; phenomenology

Chapter 1. Background and Literature Review

Introduction

Motor Neurone Disease (MND) is considered to be a disease which is 'rare, serious and poorly understood' (Locock *et al*. 2009:1043). The rapid progressions of symptoms and the terminal nature of the disease means MND is a catastrophic diagnosis for the individual diagnosed with the disease; '*effectively a death sentence*,' (Goldstein and Leigh, 1999:193). To date, research in this area has tended to rely on quantitative methods and there has been limited research into the lived experiences of couples living with this diagnosis, particularly with regard to the ways in which they make sense of, and assign meaning to, these experiences. Living with such a terminal disease can be frequently traumatic and is likely to have serious psychological repercussions for both the individual and their spouse or partner. This study intended to contribute to the evidence base, by utilising a qualitative methodology which was both longitudinal and contemporaneous, in order to illuminate these experiences and provide a greater understanding.

This chapter summarises the pathology of MND followed by a review of literature and research relating to this study. In the review, I discuss how previous research helped me to frame my research question, and to identify ways in which my research represents an original contribution to knowledge. I then evaluate studies undertaken to investigate the many psychosocial implications of living with MND for individuals with the disease and their carers.

Background to MND

MND is the name given to a group of progressive neurological disorders which manifest in the degeneration of upper and lower motor neurones in the Central Nervous System (CNS). The destruction of these neurones causes the associated skeletal muscles to atrophy. The disease is specific to motor neurones; the sensory neurones and sensory pathways remain unaffected, (Talbot, 2004).

Those diagnosed with MND suffer relentless progressive paralysis, characterised by muscle weakness and diminished control over movement and respiration. Onset can occur at the different neurological regions of the CNS including bulbar, cervical or lumbar and the clinical features of the condition will vary accordingly. Bulbar onset causes deterioration and cell death of lower motor neurones (which is referred to as Bulbar palsy, leading to facial weakness, decreased movement of the palate and weakness and fasciculation of the tongue. Upper motor neurone involvement in the bulbar region (Pseudobulbar palsy) can result in emotional lability and brisk jaw jerk. Frontal

Temporal Dementia (FTD) is associated with frontal lobe impairment which is common in this condition. Studies claim FTD is a feature in 3-4% of cases (Neary, *et al*. 2000; Talbot, 2004), although some studies have suggested that FTD is more prevalent than previously thought and could be present in more than 50% of patients (Lomen-Hoerth, *et al*. 2002; 2003; 2004). In both subtypes of MND, patients can develop dysarthria (motor speech impairment) and dysphagia (swallowing difficulties).

Cervical onset presents in the upper limbs, and symptoms may include weakness in the hand, arm or shoulder, representing lower motor neurone involvement, upper motor neurone involvement, or both. Lumbar onset is associated with lower motor neurone involvement and presents with weakness in the legs, or *'foot drop'* (Mitchell and Borasio, 2007).

The condition was first classified in 1874 by Jean–Martin Charcot, who named the disease Amyotrophic Lateral Sclerosis (ALS) (Meininger, 1999). The term is often used to describe the most common form of the illness and is used synonymously with MND (Leigh, *et al*. 2003). A number of possible contributory factors to onset are both environmental (Armon, 2001) and physical and toxic (Mitchell, 2000; Sutedja, *et al*. 2009). Although in the majority of cases aetiology is unknown, approximately 5-10% of cases can generally be linked to a genetic factor with an autosomal-dominant pattern of inheritance (Shaw, 1999; 2005; Sreedhan, *et al*. 2008). However the nature of this genetic abnormality remains uncertain (Mitchell and Borasio, 2007). The incidence of the disease is one to three cases per 100,000 population per year worldwide (Riviere, *et al*. 1998; Logroscino, *et al*. 2008). In the UK, MND affects approximately one in 50,000 people (Talbot and Marsden, 2008).

MND appears to be age related. There is increased likelihood of developing the disease with age, and the peak age of onset is between 60 and 65 years of age. However, 5-10% of patients present at below 40 years (Talbot, 2004). Studies have consistently demonstrated a male to female ratio of 1.5:1 (ibid). The course of the disease is variable, but prognosis is poor as there is no curative treatment and the majority of patients die within two to five years following diagnosis (Chancellor, *et al*. 1992; Leigh, *et al.* 2003; Talbot and Marsden, 2008).

At present there is one drug, Riluzole (Rilutek)[1] which has been approved internationally for the treatment of MND. Clinical trials have demonstrated that life is prolonged by two to three months

[1] Riluzole (Rilutek) is a benzothiazole which has shown potential to function as a neuro-protective agent

on average (Bensimon, 1994; Doble, 1996; Lacomblez, 1996; Miller, *et al.* 2003). Despite ongoing scientific studies investigating possible causes and treatments for MND, with no current solution, the focus of care for patients remains on the maintenance and improvement of their quality of life (McLeod and Clarke, 2007).

The comprehensive disability resulting from MND inevitably forces patients to become dependent on others to provide care and to access a wide range of health, social and palliative care services as their condition deteriorates. The disease's rapid progression and its fairly rare incidence represent huge challenges for health and social services. Studies have revealed that patients' and carers' needs are not always met adequately (Tejlingen, *et al*. 2001: Hughes, *et al.* 2005: O'Brien, *et al*. 2011a; O'Brien, *et al*. 2011b; Whitehead, *et al*. 2011). The majority of caring tasks are often undertaken by the spouse or partner of the person with MND; they spend approximately eleven hours per day, on average, caring for the individual (Krivickas, *et al*. 1997). Caring for people with MND poses a multi-dimensional challenge, as is acknowledged for instance by Mockford, *et al*. (2006).

A structured review of the literature relating to the psychological impact of MND on patients and their carers was undertaken and appears next in this chapter.

Part 1. Literature Review of studies investigating psychological impact of MND on patients and their carers.

An extensive and systematic search for appropriate articles was undertaken. Carrying out a thorough literature review reduces the possibility of duplication or omission of research studies and is considered the foundation for '*substantial, useful research'* (Boote and Beile, 2005:1). The following key words (Motor Neurone Disease, Amyotrophic Lateral Sclerosis, psychosocial, psychological distress, coping, resilience, anxiety, depression, hope, spiritual, self, identity, quality of life, patients, carers) were entered as search terms using the databases, CINAHL, PubMed, PsychINFO, Embase, and MEDLINE for the period of 1990 to 2010. Relevant publications were identified in the database; they were analysed, reviewed and evaluated and relevant information was extracted from them. Articles which met the inclusion criteria were included in the review (See table 1)

Inclusion Criteria	Exclusion Criteria
Written or translated to English language	Written in foreign language
Paper published within timescale 1990 to 2010	Paper published outside timescale 1990 to 2010
Either quantitative or qualitative methodology	n/a
Any design	n/a
Investigating MND	Investigating other neurological disorder
Investigating or measuring psychological, social and spiritual impact of disease (quality of life, burden, distress, coping.)	Investigating physical impact of disease (respiration, muscle weakness.)
Investigating impact on patient or family carer	Investigating experiences or perceptions of professionals or paid carers

Table 1: Inclusion and exclusion criteria used in literature review

A total number of 127 articles were located and 73 met the criteria and were therefore included in this review (see table 2).

Quality of life and depression	Sample size	Methodology
Krivickas, *et al*. (1997),	98 patients	Quantitative study using postal survey with patients and carers and ALS-FRS (ALS Functional Rating Scale). USA.
Gelinas, et al (1998)	72 patients	Quantitative, cross sectional study with patients and carers. Using Health Status Survey (SF-12) and ALS Quality-of-Life Index (ALSQLI) as well as the ALS Patient Caregiver Form. USA.
Simmons, *et al*. (2000)	96 patients	Quantitative study with patients using McGill Quality of Life (MQOL) instrument, the Idler Index of Religiosity, the Sickness Impact Profile (SIP)/ALS-19, and several measures of strength and physical function. USA.
Jenkinson, *et al*. (2000)	551 patients	Quantitative study with patients and carers using three assessments; the SF-36, a generic measure of wellbeing and functioning, the ALS Functional Rating Scale and the Carer Strain Index. UK.
Robbins, *et al.* (2001)	60 patients	Quantitative study with patients. Longitudinal using MQOL (McGill Quality of Life Questionnaire), religiosity (Idler Index of Religiosity), ALS-specific health-related quality of life (SIP/ALS-19), and ALS-specific function (ALS functional rating scale). USA.
Clarke, *et al* (2001)	26 patients	Quantitative study with patients with MND using Schedule for the Evaluation of Individual Quality of Life (SEIQOL) Functional Rating Scale (ALSFRS). Hospital Anxiety and Depression Scale (HADS). Ireland.
Kraub-Wittemer, *et al*. (2003)	52 patients 52 carers	Quantitative study comparing patients using Profile of Mood States and the Munich Quality of Life Dimensions List. Germany.
Trail, *et al.* (2004)	66 patients 61 carers.	Quantitative, cross-sectional study with patients and carers using checklist of concerns and Appel ALS Rating scale. USA.
Nelson, et al. (2000).	100 patients	Quantitative, cross-sectional study with patients using a global questionnaire about present QOL and 25 item survey and the Appel ALS Rating Scale. USA.

Neudert, *et al.* (2004)	42 patients	Quantitative study, longitudinal with patients using ALS-FRS; SIP (Sickness Impact Profile); SF36 (Short Form 36) and SEIQOL-DW (Schedule for evaluation of Individual Quality of Life Direct Weighting). Germany.
Goldstein, *et al.* (2002)	31 people with MND	Quantitative, cross sectional study with patients using SEIQOL (Schedule for evaluation of Individual Quality of Life); SIP (Sickness Impact Profile); ALS Severity Scale. UK.
Nelson, *et al*. (2003)	100 patients	Quantitative, cross sectional study with patients using postal survey including following measures: Appel ALS Rating Scale (AALS) and ALS Quality of Life Assessment Questionnaire. USA.
Chio, *et al*. (2004)	80 patients	Quantitative, cross sectional study with patients using SEIQOL(Schedule for Evaluation of Individual Quality of Life);PLACS (Pathological Laughing and Crying Scale; MQOL (McGill Quality of Life Questionnaire); (MMSE)Mini Mental Status Examination; Idler Index of Religiosity; ZDS (Zung Depression Scale); BHS (Beck Hopelessness Scale;)SSQ (Social Support Questionnaire); SWS (Social Withdrawal Scale); PSQ (Psychosocial Questionnaire). Italy.
Lo Coco, *et al*. (2005)	37 patients 37 carers	Quantitative, cross-sectional study with patients and their respective caregivers, using both health-related (WHOQOL-BREF) and individual (SEIQoL-DW) QoL instruments. Italy.
Nygren and Askmark, (2006)	26 patients	Quantitative study with patients using questionnaires. Sweden.
Epton, *et al*. (2008)	n/a	Systematic review
Foley, *et al*. (2007).	Five participants	Qualitative study using interviews with patients. Thematic analysis. Ireland
Gauthier, *et al*. (2007)	31 patients 31 carers	Quantitative study with patients and caregivers, using Zung Depression Scale (ZDS), McGill Quality of Life Questionnaire (MQOL); Caregiver Burden Inventory (CBI); Self-Perceived Burden Scale (SPBS).
Williams, *et al*. (2008)	19 carers	Mixed methods study using concept mapping and interviews with family caregivers and SF-8 Quality of Life Measure. USA.
Roach, *et al.* (2009)	55 patients 53 carers	Quantitative study, with patients and caregivers using MQOL (McGill Quality of Life Questionnaire). USA.
Lou, *et al*. (2010)	412	Quantitative, longitudinal study with patients. Using MQOL (McGill Quality of Life Scale) and ALS FRS-R (ALS Functional Rating Scale Revised).
Bocker, *et al.*(1990)	59 patients	Quantitative study with patients using range of scales. Germany.
Hunter, *et al.* (1993)	181 patients	Quantitative study, cross sectional using General Health Questionnaire with patients. UK.
Hogg, *et al*. (1994).	52 patients	Quantitative study using HADS (Hospital Anxiety and Depression Scale), SIP (Sickness Impact Profile), WOCC (Ways of Coping Checklist); AOI (Acceptance of Illness); PAQ (Positive Attributions Questionnaire); HLOC (Health Locus of Control Scale). UK.
McDonald, *et al.* (1994)	144 patients	Quantitative, longitudinal study, using BDI (Beck Depression Inventory), BHS (Beck Hopelessness Scale) and WOCC (Ways of Coping Checklist) in patients.
Tedman, *et al*. (1997)	40 patients	Quantitative, cross sectional study using BDI (Beck Depression Inventory) and HADS (Hospital Anxiety and Depression Scale); Medical Outcomes SF36 Questionnaire; Barthel Index of Activities of Daily Living in patients. UK.
Krivickas, (1997)	(see above)	(see above)
Goldstein, *et al*. (1997)	44 patients	Quantitative study comparing patient and caregivers scores on HADS (Hospital Anxiety Scale), SIP (Sickness Impact Profile), WOC (Ways of Coping). UK

Goldstein, *et al.* (1998)	19 patients and carers	Quantitative study using ALS Severity Scale; SIP (Sickness Impact Profile); Ways of Coping Checklist (WOCC); HAD (Hospital Anxiety and Depression Scale (HAD); Acceptance of Illness (AOI); Self-esteem scale (SES); Multi-dimension Health Locus of Control (MHLOC); Intimacy Scale; Strain Scale; Cognitive Failures Questionnaire (CFQ); Dysexecutive Questionnaire (DEX). UK
Moore, *et al.* (1998)	18 patients	Quantitative, cross sectional, using Beck Depressive Inventory; HADS (Hospital Anxiety and Depression Scale);EPQ (Eysenck Personality Questionnaire); Norris Rating Scale; Holmes and Rahe Scale to evaluate patients. UK
Ganzini, *et al.* (1999)	100 patients 91 carers	Quantitative study using BHS (Beck Hopelessness scale); DIS (Depression Inventory Scale), SIP (Sickness Impact Profile) and ZBI (Zarit Caregiver Burden Scale) with patients and carers. USA
Johnston, *et al*. (1999)	38 patients	Quantitative, longitudinal study using HADS (Hospital Anxiety and Depression Scale) with patients.
Rabkin, *et al*. (2000)	56 patients 31 carers	Quantitative, cross-sectional, study using structured interviews, self-report scales BDI (Beck Depression Inventory), BHS (Beck Hopelessness Scale), DSM-IV, ZBI (Zarit Caregiver Burden Scale). USA.
Clarke, *et al.* (2001)	26 patients	Quantitative study using HADS (Hospital Anxiety and Depression Scale); SIP (Sickness Impact Profile).
Bolmsjo and Hermeren, (2001)	8 patients 8 carers	Qualitative study using interviews with patients and family members. Thematic analysis. Sweden.
Brown, (2003)	5 patients, 5 carers and 9 professionals	Qualitative study using interviews with patients, care-givers and professionals. UK
Dawson and Kristjanson (2003)	16 carers (5 carers of people with MND)	Qualitative study, using interviews with family caregivers. Australia.
Lou, *et al.* (2003)	25 patients	Quantitative study with twenty-five ALS subjects using questionnaires: the ALS Functional Rating Scale, Multidimensional Fatigue Inventory, multidimensional McGill Quality of Life, Center of Epidemiologic Study—Depression Scale, and the Epworth Sleepiness Scale. USA.
Hecht, *et al.* (2003)	37 carers	Quantitative study using two self rating scales BSFC (Burden Scale for Family Caregivers) and CCI (Cost of Care Index). Influencing factors (functional impairment of the patient, additional carers, participation in support groups) were also assessed. Germany.
Nelson, *et al*. (2003)	(see above)	(see above)
Hillemacher, *et al.* (2004)	41 patients	Quantitative Study using D-S (self report scale) in longitudinal study with patients.
Bungener, *et al*. (2005)	27 patients	Quantitative study with patients using semi-structured interviews, Montgomery-Asberg Depression Rating Scale (MADRS), the Covi anxiety scale and the Depressive Mood scale and WOCC (Ways of Coping Checklist). France.
Chio, *et al*. (2005)	60 patients 60 carers	Quantitative study with carers using Caregiver Burden Inventory and the Self-Perceived Burden Scale. Italy.
Rabkin, *et al.* (2005)	80 patients	Quantitative study, longitudinal semi structured interviews conducted monthly and range of scales used with patients (Patient Health Questionnaire; Beck Depression Inventory; Mini-Mental State Examination; Memorial Delirium Assessment Scale; Beck Hopelessness Scale; Holland Systems of Beliefs Inventory; Schedule of Attitudes of towards Hastened Death;

		Quality of life Enjoyment and Satisfaction Questionnaire; Bradburn Affect Balance Scale; ALS Functional Scale; Visual Analog Scale. USA.
Kubler, *et al*. (2005)	76 patients	Quantitative study using ALS Depression Inventory and BDI (Beck Depression Inventory) with ventilated and non-ventilated patients.
Herz, *et al*. (2006)	8 former carers 3 current carers	Qualitative study using focus groups with family carers. Australia.
Ray and Street (2006)	18 primary caregivers and 6 peripheral caregivers.	Qualitative, ethnographic case study conducted with family carers. Australia.
Ray and Street (2007)	18 primary caregivers and 6 peripheral caregivers.	Qualitative, semi-structured interviews with family caregivers. Australia.
Goldstein, *et al.* (2006)	50 carers	Quantitative study with carers, using range of measures including CPQ (Close Persons Questionnaire); Marital Intimacy Scale; SIP (Sickness Impact Profile); Emotional Lability Scale; Dysexecutive Questionnaire; Short Inventory of Minor Lapses; ALS Severity Scale. UK.
Wicks, *et al*. (2007)	190 patients	Longitudinal, quantitative using different assessment tools including The Beck Depression Inventory (BDI), The Hospital Anxiety and Depression Scale (HADS) and the Spielberger State-Trait Anxiety Inventory (STAI) with patients. UK.
Macleod and Clarke (2007)	n/a	Systematic Review
Williams, *et al*. (2008)	(see above)	(see above)
Murphy, (2009)	75 carers	Quantitative study with family carers using a range of scales (Social Problem Solving Inventory-Revised(SPSI-R);Dyadic Satisfaction subscale; Spiritual Perspective Scale; Idler Index of Religiosity; Quality of Life Inventory; BSI (Brief Symptom Inventory). USA.
Rabkin, *et al*. (2009).	71 patients 71 carers	Quantitative study. Longitudinal with family caregivers. Measures used: Patient Health Questionnaire-9; BDI-II Beck Depression Inventory Revised; Manne Scales of positive and negative dyad support; Caregiver burden and satisfaction; ALSFRS (ALS Functional Rating Scale); Chalder Fatigue Scale; Folkman's Ways of Coping Scale. USA.
Felgoise, *et al.* (2010)	111 patients	Quantitative study, using ALS FRS (ALS Functional rating scale); Manual Muscle Testing; BSI (Brief Symptom Inventory) with patients. USA.
Ganzini, *et al*. (1998)	100 patients 91 carers	Quantitative study using the BHS (Beck Hopelessness Scale), DIS (Diagnostic Interview Schedule), SIP (Sickness Impact Profile) and ZBI (Zarit Cargiver Burden Index). USA.
Ganzini, *et al.* (1999)	(see above)	(see above)
Rabkin, *et al.* (2000)	(see above)	(See above)
Plahuta, *et al*. (2002)	136 patients	Quantitative Study, using HLC (Health Locus of Control) and PIL (Purpose in Life) scales, SSQR (Sarason Social Support Questionnaire Revised) and BHS (Beck Hopelessness Scale). USA.
Felgoise, *et al*. (2010)	(see above)	(see above)

Albert, *et al*. (2005)	80 patients	Quantitative study using BDI (Beck Depression Inventory) and the BHS (Beck Hopelessness Scale) with patients. USA.
Matuz, *et al.* (2010)	12 patients	Quantitative study based on stress-coping model comparing patient measures on the ALS functional rating scale, Beck Depression Inventory and individual quality of life. Germany.
Lou, *et al.* (2010)	412	Quantitative study using the Single Item McGill Quality of Life Scale (MQoL-SIS) score and disease duration, ALS Functional Rating Scale Revised (ALSFRS-R) score, Forced Vital Capacity (FVC), and survival rate and the impact of NIV and PEG on QoL also measured. USA.
Self-perceived burden		
Ganzini, *et al*. (1999)	(see above)	(see above)
Ganzini, *et al*. (2002).	50 patients	Quantitative study with patients using questionnaire and standardised measures of social support, religiousness, hopelessness (the Beck Hopelessness Scale), and depression (the Diagnostic Interview Schedule). USA.
Chio, *et al*. (2005)	(see above)	(see above)
Gauthier, *et al.* (2007)	(see above)	(see above)
Burden		
Goldstein, *et al.* (1998)	(see above)	(see above)
Rabkin, *et al.* (2000)	(see above)	(see above)
Kraub–Wittemer, (2003)	(see above)	(see above)
Goldstein, *et al*. (2000)	19 carers	Quantitative study with family caregivers using ALS Severity Scale; HADS (Hospital Anxiety and Depression Scale); Attribution Measures. UK
Hecht, *et al*. (2003)	(see above)	(see above)
Chio, *et al*. (2005)	(see above)	(see above)
Goldstein, *et al*. (2006)	(see above)	(see above)
Gauthier, *et al.* (2007)	(see above)	(see above)
Coping and resilience		
Earll, *et al.* (1993)	50 patients	Quantitative, cross-sectional study using semi-structured interview and questionnaires HADS (Hospital Anxiety and Depression Scale); Bradburn Well-being: Affect Balance Scale. Self Esteem (Rosenberg); ALS Severity Scale.
Hogg, *et al*. (1994)	(see above)	(see above)
McDonald, *et al*. (1994)	(see above)	(see above)
Gelinas, *et al.* (1998)	(see above)	(see above)
Young and McNicoll, (1998)	13 patients	Qualitative study using interviews with patients. USA.
Goldstein, *et al*. (1998)	(see above)	(see above)
Goldstein, *et al.* (2000)	(see above)	(see above)
Lee, *et al.* (2001)	23 people with MND	Quantitative study, cross-sectional, employing Scale for Disability in MND; HADS (Hospital Anxiety and Depression Scale; MND Coping scale and COPE scale. UK.
Centers, *et al*. (2001)	n/a	Qualitative study, exploratory case study. USA.
Hecht, *et al*. (2002)	41 patients	Quantitative study with coping questionnaire and self-rating scale of depression. Germany.
Nelson, *et al*. (2003)	(see above)	(see above)
Bungener, *et al.* (2005)	(see above)	(see above)
Rabkin, *et al.* (2000)	(see above)	(See above)
Martin and Turnball, (2001)	32 carers	Quantitative, questionnaire study with former carers of MND patients. Canada.

Spirituality		
Ganzini, *et al.(*1998)	(see above)	(see above)
Young and McNicoll, (1998)	(see above)	(see above)
Goldstein, *et al*. (1998)	(see above)	(see above)
Rabkin, *et al.* (2000)	(see above)	(see above)
Murphy, *et al*. (2000)	(see above)	(see above)
Dal Bello-Hass, (2000)	60 patients	Quantitative study with MND patients using A Spiritual Well-Being Scale (SWBS) and its religious (RWB) and existential well-being (EWB) subscales. A subsample also completed the Sickness Impact Profile (SIP). USA.
Hecht, *et al.* (2002)	(see above)	(see above)
Trail, *et al.* (2003)	27 patients 19 Carers	Compared patients and carers using BDI (Beck Depression Inventory).
Bremer, *et al*. (2004)	162 patients	Longitudinal quantitative study using questionnaires and the McGill Quality of Life Scale. USA.
Fegg, *et al.* (2005)	64 patients	Mixed methods study using self-report questionnaire concerning personal values and a semi-structured interview on their iQoL. Germany.
Albert, *et al*. (2005)	(see above)	(see above)
Fanos, *et al.* (2008)	16 patients	Qualitative study using interviews with patients and content analysis. USA.
Murphy, *et al*. (2009)	(see above)	(see above)
Social support		
Hogg, *et al*. (1994)	(see above)	(see above)
Bromberg, *et al*. (1996)	3 patients 2 carers	Mixed methods study using functional rating scale, BDI (Becks Depression Inventory), interviews with ventilator dependent patients and interviews with carers. USA
Ganzini, *et al.* (1998)	(see above)	(see above)
Ganzini, *et al*. (1999)	(see above)	(see above)
Rabkin, *et al*. (2000)	(see above)	(see above)
Goldstein, *et al*. (2000)	(see above)	(see above)
Martin and Turnbull, (2001)	(see above)	(see above)
Rigby, *et al.* (2002)	23 patients at varied stages of MND.	Quantitative study, with self-rating scale of social withdrawal and HADS (Hospital Anxiety and Depression Scale and Scale for Disability in MND. UK
Hecht, *et al*. (2002)	(see above)	(see above)
Hecht, *et al*. (2003)	(see above)	(see above)
Kraub-Wittemer *et al. (*2003)	(see above)	(see above)
Trail, *et al.* (2003)	(see above)	(see above)
Chio, *et al*. (2005)	(see above)	(see above)
Love, *et al.* (2005)	75 Carers (33% response rate)	Quantitative study using Carer Network Scale and GHQ-12 (General Well-being). Australia.
Ray and Street, (2005)	18 carers	Mixed method study using survey with carer network scale and ethnographic case study. Australia.
Ray and Street, (2006)	(see above)	(see above)
Ray and Street, (2007)	(see above)	(see above)
Narrative Studies		
Brown and Addington-Hall, (2008)	13 patients	Qualitative study using narrative interviews with people with MND.

Locock, *et al.* (2009)	35 patients 11 carers	Qualitative study using narrative interviews and analysis to explore the construction and content of narratives of people with MND and their carers.
IPA Studies with people with MND		
O'Brien (2004)	7 patients	IPA study exploring information seeking in people with MND
Hugel, *et al*. (2006)	13 patients	IPA investigating experience of diagnosis process in people with MND
Ando, (2010)	10 patients	IPA study exploring experiences of declining and withdrawing from NIV (non-invasive ventilation).

Table 2: List of studies included in the literature review

The themes of quality of life, psychological distress, social support, coping and resilience, hope and spirituality were identified and will be discussed in turn.

Quality of life

One of the major areas of previous research carried out into the impact of the disease on people with MND and their carers has been quality of life. The World Health Organisation (1993:153) defines quality of life as:

> *'an individual's perception of their position in life, in the context of the culture and value systems in which they live, and a broad ranging concept effected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of the environment'* and added subsequently '*their personal, religious and spiritual beliefs'*.

According to this global conception of quality of life, therefore, even individuals with severely impaired physical functioning will be affected adversely only to the extent to which this aspect of their lives is regarded as significant and in comparison with family life, friendship, finances, religious faith, occupation, autonomy, and ability to influence their surroundings.

The impact of quality of life on people with MND

The importance of enabling individuals with MND to maintain a good standard of quality of life, by means of high-quality and comprehensive care, has been recognised by the British Association of Neurologists, (Campbell, 1999). Moreover a number of recent health policy documents (DoH, 2005; 2008; 2010) recommend better co-ordinated and more effectual provision of support and services for people with long-term conditions such as MND, specifically to enhance quality of life. Mitsumoto and Del Bene (2002:329) state that:

> '*Our goal as healthcare professionals is to continually strive to improve QOL through comprehensive medical and psychosocial interventions, so as to close the gap between a patient's hopes and actual experiences*.'

They also acknowledge that the experience of MND can have a shattering impact on a person's perception of health and wellbeing; the person's sense of hope, their self-worth and dignity, their freedom of activity and potential to attain their goals, their ability to maintain paid employment, their ability to thrive in familial and social roles, their potential for participation in recreational activities, their self-esteem and independence can be adversely affected. A number of quantitative studies have measured quality of life in people with MND. The majority of these have found that quality of life is negatively correlated with physical status and that perceptions of quality of life in people with MND are manifest in relation to psychosocial factors such as loss of meaning in life, degrees of spirituality, and levels of social support.

No correlation was found between physical severity and quality of life measured by studies conducted by Simmons, *et al*. (2000); Clarke, *et al.* (2001) and Neudert, *et al.* (2004). Simmons, *et al*. (2000) used a range of measures including the McGill Quality of Life (MQOL) instrument, the Idler Index of Religiosity, the Sickness Impact Profile (SIP)/ALS-19, and several measures of strength and physical function to correlate physical deterioration and quality of life in 96 patients. In the study conducted by Clarke, *et al*. (2001), illness severity was assessed with the ALS Functional Rating Scale (ALSFRS) and compared with levels of psychological distress measured by the Hospital Anxiety and Depression Scale (HADS) and individual quality of life using the Schedule for the Evaluation of Individual QOL (SEIQoL) and found that levels were in the normal range. Neudert, *et al*. (2004) compared the change over time of individual quality of life (QOL) versus health-related QOL (HRQOL) and functional status in palliative care patients with amyotrophic lateral sclerosis (ALS) with a sample of 42 patients. Using a variety of assessments including the ALS functional rating scale (ALSFRS), the Sickness Impact Profile (SIP), the Short Form 36 (SF-36), and the Schedule for the Evaluation of Individual QOL-Direct Weighting (SEIQOL-DW) they noted a significant decrease in the patients' functioning but found that individual quality of life remained stable over time. They concluded therefore that quality of life may be valuable in palliative care.

Goldstein, *et al*. (2002) used the SEIQOL, the SIP (Sickness Impact Profile) and the ALS Severity Scale in a cross-sectional study in the UK. Their findings also suggest that quality of life is not merely a result of physical deterioration and that emotional support appeared to be one of the most significant factors involved. However, the results of this study may have been affected by the small

sample size and the large number of analyses undertaken. Similar findings have been made by Nelson, *et al.* (2003) in a study using a postal survey including the Appel ALS Rating Scale (AALS) and ALS Quality of Life Assessment Questionnaire USA. The results of this study demonstrated that meaning in life, spirituality, personality and social factors impact on quality of life. Furthermore, Chio, *et al*. (2004) carried out a study in Italy using a range of quality of life measures with 80 patients including the SEIQOL, the PLACS (Pathological Laughing and Crying Scale; MQOL (McGill Quality of Life Questionnaire), the (MMSE)Mini Mental Status Examination; Idler Index of Religiosity, the ZDS (Zung Depression Scale), the BHS (Beck Hopelessness Scale, the SSQ (Social Support Questionnaire), the SWS (Social Withdrawal Scale) and the PSQ (Psychosocial Questionnaire). It was concluded from the study that existential factors were most important to quality of life including social support, depression and socioeconomic status and religiosity. Another study carried out recently by Matuz, *et al*. (2010) used a logistic regression to compare the results of 27 patients between illness severity (measured by duration of illness (month since diagnosis), dependence on life-sustaining treatment (ventilation and nutrition), physical disability (ALS Function Rating Scale), quality of life using the schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) and levels of depression measured by the Beck Depression Inventory (BDI). The results confirmed that severe functional impairment does not inevitably lead to poor quality of life and found instead that perceived social support was the strongest predictor of quality of life.

All of the above studies, although informative, have relied on cross-sectional designs and therefore cannot account for changes in quality of life over time. Robbins, *et al.* (2001) used a longitudinal design over six months with 60 patients using the MQOL (McGill Quality of Life Questionnaire), religiosity (Idler Index of Religiosity), ALS-specific health-related quality of life (SIP/ALS-19), and ALS-specific function (ALS functional rating scale). Their findings revealed an association between physical decline and loss of quality of life. Questionnaires were used in a longitudinal design study by Nygren and Askmark, (2006) which measured quality of life for a period of up to 28 months with 26 patients. The disease progression was measured using the ALS functional rating scale (ALS FRS). The authors determined that quality of life levels did not alter over time despite worsening of physical symptoms. They also concluded that psychological factors had more significance than physical ones. However, this study is once again limited by using a small sample of patients.

In contrast to many previous studies investigating quality of life, a recent study by Lou *et al*. (2010) does suggest a correlation with physical factors. Using the Single Item McGill Quality of Life Scale (MQoL-SIS) score and disease duration, ALS Functional Rating Scale Revised (ALSFRS-R) score, forced

vital capacity (FVC) measure, and survival rate with 412 patients, they found a decrease in quality of life alongside deterioration in functional status over time. The study also revealed that Percutaneous Endoscopic Gastrostomy (PEG) and Non-Invasive Ventilation (NIV) had a significant positive impact on quality of life levels. They suggest the fact that the sample in their study were also participating in a clinical trial at the time of this study may explain differences in their results with previous studies as participants may have had higher expectations of physical recovery.

A detailed and useful systematic review of research studies measuring quality of life in people with MND has recently been carried out by Epton, *et al*. (2008) which revealed a number of difficulties with previous research. They highlight the lack of consensus amongst researchers as to the most appropriate instrument for the measurement of quality of life within this population which results in difficulties when attempting to draw comparisons between findings. Furthermore, the numerous and diverse statistical procedures undertaken by researchers to determine quality of life measurements and the limited sample size have also been criticised. Another major methodological difficulty lies with the length of quality of life instruments which may be fatiguing for MND patients to carry out and can jeopardise study completion. These design flaws clearly reduce the validity, generalisability and use of the majority of studies carried out in this field.

Despite the various methodological criticisms of quantitative research into quality of life, studies using qualitative methods to investigate perceptions of health and meanings of quality of life in people with MND have surprisingly remained extremely scarce; only one was identified by the literature search for this project (Foley, *et al*. 2007). This qualitative study used semi-structured interviews with a small sample of five participants. The study supported findings from quantitative studies, concluding that quality of life is a multi-dimensional concept and that patients regard psychological, spiritual and social factors as having more significance than physical deterioration understood purely as loss of function.

Carers

Despite the claim that caregivers for people with MND experience greater demands and burden than those of other diseases (Krivickas, *et al*. 1997), studies investigating quality of life in carers for people with MND, have remained limited. Furthermore, the majority have adopted a quantitative approach using a variety of questionnaires and rating scales (Gelinas, 1998; Jenkinson, 2000; Bromberg and Forshew, 2002; Trail, *et al.* 2003; Kraub-Wittemer, *et al*. 2003; Gauthier, *et al*. 2007; Roach, *et al.* 2009).

Gelinas, *et al*. (1998) were unable to make comparisons regarding levels of quality of life in patient-carer couples due to the severity of the physical status of the patients. In a study using surveys with 551 patients and using results from three outcome measures including the SF-36, ALS Functional Rating Scale and the Carer Strain, Jenkinson, *et al*. (2000) revealed that the quality of life of both patients and carers was affected adversely by the disease. In contrast, a fairly high level of quality of life and no significant difference between patients and carers was reported by Trail, *et al.* (2003). However, they highlight that a study with a larger sample and longitudinal design is necessary to substantiate these findings and the survey they used has not been validated. A study by Kraub-Wittemer, *et al*. (2003) concluded that quality of life was rated generally high for patients and carers in the group with non-invasive ventilation and in the group with tracheostomy, quality of life was moderately good for patients. However, the inclusion of too many items on the questionnaire, the possibility of bias, the limited size of the sample and the lack of sensitivity of the response scales unfortunately all represent limitations with this study.

Lo Coco, *et al*. (2005) found that MND impacted negatively on quality of life for both patients and carers and factors such as degrees of social support, spirituality and impact on family role and position were significant variables in both groups. One failing is that this study only used a cross-sectional design and cannot account for changes in quality of life over time. The authors of the study also acknowledge a weakness in that some significant variables were not included in the study (hopelessness) and they suggest that other variables yet to be identified may have influenced the patient-caregiver relationship and quality of life. A mixed design was used by Williams, *et al*. (2008) to explore quality of life with family caregivers. The study revealed that living with the individual with the disease negatively impacted on the carers' quality of life. A longitudinal design was employed by Roach, *et al.* (2009) to measure quality of life in patients and carers and concluded that individual differences such as demographics and disease progression are factors which may have an impact on their quality of life.

Despite the variety of findings from these studies, research into quality of life in carers for people with MND does suggest, as is the case with individuals with the disease, that psychosocial factors affect quality of life adversely. In the case of carers these include reduced socialisation, feelings of helplessness, feelings of being over-burdened, lack of social support and low morale (Trail, *et al.* 2003; Lo Coco, *et al*. 2005).

In this review, I now examine the findings of both quantitative and qualitative research which concentrate on the impact of psychosocial factors upon quality of life of individuals with MND. I have identified distinct but intimately connected aspects of experience, including anxiety and depression, hopelessness, self-perceived burden, burden, coping and resilience, spirituality and social support.

Psychological Distress

Depression

Depression in people with MND has been the focus of a large number of studies (Hogg, *et al.* (1994); McDonald, *et al.* (1994); Tedman, *et al*. (1997); Goldstein, *et al. (*1997); Moore, *et al.* (1998); Ganzini, *et al.* (1999); Johnston, *et al*. (1999); Rabkin, *et al*. (2000); Clarke, *et al.* (2001); Lou *et al.* (2003); Hillemacher, *et al.* (2004); Kubler, *et al*. (2005); Bungener, *et al*. (2005); Rabkin, *et al*. (2005); Wicks, *et al*. (2007; Averill, et al (2007); Felgoise, *et al*. (2010). Hogg, *et al.* (1994) revealed a significant correlation between measures of physical impairment and depression in a quantitative study using a range of measures including the HADS (Hospital Anxiety and Depression Scale), SIP (Sickness Impact Profile), WOCC (Ways of Coping Checklist), the AOI (Acceptance of Illness) the PAQ (Positive Attributions Questionnaire) and the HLOC (Health Locus of Control Scale). They also demonstrated that these levels were significantly less in individuals who were more accepting of their disease. However Averill, *et al* (2007) note the form of the Ways of Coping Checklist (WOC) used in this study may have been inappropriate for people with MND. A longitudinal study was carried out by McDonald, *et al.* (1994) using outcome measures from the BDI (Beck Depression Inventory), BHS (Beck Hopelessness Scale) and WOCC (Ways of Coping Checklist) in a sample of 144 patients. 24% of the sample was found to have experienced psychological distress. However, one criticism of this study is that one of scales used had not been properly validated. Depression measures including the BDI (Beck Depression Inventory), the HADS (Hospital Anxiety and Depression Scale) and the Medical Outcomes SF36 Questionnaire and Barthel Index of Activities of Daily Living in patients were conducted and compared in patients with MND and MS by Tedman, *et al*. (1997). The research team concluded that depression is as common in patients with MND as other neurological diseases. However, Moore, *et al.* (1998) used the same measures as Tedman, *et al*. (1997) but their findings suggested that prevalence of depression and anxiety is less in MND. Levels of depression in patients were found to be similar to those of caregivers and '*not indicative of depression*' according to Goldstein, *et al. (*1997:117) in their quantitative study comparing patient and caregivers scores on HADS (Hospital Anxiety Scale), the SIP (Sickness Impact Profile), and the WOCC (Ways of Coping Checklist). Ganzini, *et al.* (1999) found correlations between measures of depression and suffering in

people with MND using the BHS (Beck Hopelessness scale); DIS (Depression Inventory Scale), SIP (Sickness Impact Profile) and ZBI (Zarit Caregiver Burden Scale) with 100 patients and 91 carers.

A longitudinal study over six months was conducted by Johnston, *et al*. (1999) with 38 people with MND and found moderately high depression in patients. Another study by Rabkin, *et al*. (2000) with 56 patients and 31 carers used a range of measures and interviews with a clinical psychologist and reported low levels of depression (only 2% major depressive disorder). A study conducted by Clarke, *et al.* (2001) with 26 patients also indicated low levels with a mean depression score of 4.76 (SD=2.88) however those patients who were considered too distressed were not approached to participate which therefore limited the range of participants recruited. Lou, *et al.* (2003) identified depression in 44% of the sample of 25 patients. They also noted a correlation between fatigue and depression. However one criticism of this study was that the sample was fairly small. In a longitudinal study by Hillemacher, *et al.* (2004) with 41 patients, levels of depression were found to be higher in MND patients than in healthy controls. Nevertheless, this study could be considered limited by its used of a self-report scale not commonly used with this client group with no cut off point.

Research conducted by Kubler, *et al*. (2005) compared levels of depression between ventilated and non-ventilated patients using a specific measure for use with MND patients and revealed there was no difference between the two groups. However, quite high levels of depression in 48% of the sample of 76 patients were identified. Using semi-structured interviews, the Montgomery Asberg Depression Rating Scale for depression (MADRS), the Covi Anxiety Scale, the Depressive Mood scale and WOCC (Ways of Coping Checklist in a sample of 27 patients, Bungener, *et al*. (2005) did not find that any of the patients in their study met the DSM-IV criteria for major depression. According to an interesting study by Rabkin, *et al*. (2005) with 80 patients, major depression in people with MND is rare and is unlikely to worsen over time but the authors concluded that transient symptoms of depression can occur. However they admit that there may be possibilities of sample bias as participants were only drawn from one treatment centre and that the sample of participants would have benefited from greater demographic variability. A range of measures to compare levels of depression including the Beck Depression Inventory (BDI), the Hospital Anxiety and Depression Scale (HADS) and the Spielberger State-Trait Anxiety Inventory (STAI) was used with a large sample of 190 patients in a study by Wicks, *et al*. (2007). However, the study revealed a significant variability in the results. In their study, using ALS FRS (ALS Functional rating scale), Manual Muscle Testing; BSI (Brief

Symptom Inventory) with 111 patients, Felgoise, *et al*. (2010) concluded that patients showed high levels of depression and anxiety.

In conclusion therefore, there remains very little consensus in these studies and prevalence of depression has been found to vary greatly from 0% (Clarke *et al*. 2001) to 75% (Kubler *et al*. 2005). However studies with larger samples have indicated a prevalence of depression between 11% and 15% (Macleod and Clarke, 2007). These figures are particularly significant in view of studies which demonstrate positive correlations between poor psychological status and poor survival rates in individuals with MND, (Mcdonald *et al.* 1994; Johnston *et al*. 1999). Variation in findings is considered likely to result from the reliance on a wide range of report scales and small samples in the studies (Rabkin, *et al*. 2000; Felgoise, *et al*. 2010). Further methodological limitations such as reliance on cross-sectional data and limited generalisability are considered to be a characteristic feature of most of the studies measuring depression in people with MND (Averill *et al*. 2007) and Rabkin, *et al*. (2000:271) consider much of the work carried out in this area to be '*limited and inconsistent*'.

Some researchers in the field of palliative care have concluded that identifying and measuring depression in patients in advanced stages of terminal diseases poses problems for clinicians and health researchers for a number of reasons.

Critique of depression studies in palliative care populations

Discriminating between 'appropriate sadness' (Lloyd-Williams, *et al.* 2004) or 'preparatory grief' (Axtell, 2008) in someone who is approaching the end of their lives and a depressive illness is clearly difficult as the symptoms are similar and thoughts of death and dying are frequent in this period of a person's life (Quill, 2005). Therefore, psychological distress may be mistakenly attributed to a normal reaction to being diagnosed with a terminal disease. Secondly, concealment of depressive symptoms is common amongst the palliative care caseload (Hinton, 1994; Lloyd-Williams, 2000). Furthermore, whilst the diagnosis of depression within a physically healthy population relies on the presence of a persistent low mood and at least four other symptoms (including changes in sleep patterns and appetite and increased fatigue), as these physical symptoms are often synonymous with mobility difficulties in terminal disease, a number of researchers have queried their reliability to signal psychological morbidity (Lloyd-Williams and Friedman, 2001; Quill, 2005; Felgoise, *et al*. 2010). In accordance with these criticisms, it is imperative, therefore to adjust depression scales or employ more suitable screening tools when applied to severely ill, dying patients and there remains some

doubt as to whether the previous studies reviewed here provide an accurate portrayal of levels of depression.

Previous studies regarding psychological distress in people with MND have also been criticised for focusing too narrowly on depression (Averill, *et al*. 2007; Felgoise, *et al.* 2010). Although a few studies have found that level of physical disability contributes to depression in people with MND (Bocker, *et al.*1990*;* Hunter, *et al*. 1993; Hogg, *et al*. 1994), the majority have suggested that other factors represent predictors of poor psychological status in people with the disease such as suffering (Ganzini, *et al*. 1999), hopelessness, hastened death (Albert, *et al*. 2005) and social withdrawal (Rigby, *et al*. 1999). The importance of incorporating other areas beyond depression into the assessment of psychological morbidity in people with MND has been emphasised by Felgoise, *et al*. (2010). This is in keeping with the emerging consensus in the literature on the use of the broader concept of *distress* which is thought to better encapsulate the psychological experience of patients in the palliative care setting (Akechi, *et al*. 2006; Thekkumpurath, *et al*. 2008). This concept has been described by the National Comprehensive Cancer Network (2001:2) as:

> *'a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature. Distress extends along a continuum from common normal feelings of vulnerability, sadness to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential crisis.'*

The following section outlines the findings of previous research carried out with people with MND in relation to these other aspects of psychological distress.

Hopelessness

A definition of hopelessness has been provided by Farran, *et al.* (1995; 25) who describe the concept as a *'feeling of despair and discouragement; a thought process that expects nothing; and a behavioural process in which the person attempts little or takes inappropriate action.*'

Hopelessness is thought to result from external stresses or crisis and an impaired ability to cope (Bonner and Rich, 1991). Illness represents such a crisis or external stress and individuals who consider their illness negatively and believe they can do little to alter the disease or its consequences are found to be highly susceptible to developing hopelessness (Dunn, *et al.* 2005). Moorey and Greer (1989:458) state that when a patient experiences helplessness or hopelessness;

> '*…the illness is seen as a loss and the patient regards the prognosis as an inevitable negative outcome, thinks that it is impossible to exert any control over the illness and manifests no active strategies for fighting the illness.'*

Levels of hopelessness have been measured using scales with patients with various diseases including cancer and heart disease have frequently revealed high scores. Studies have also demonstrated hopelessness to have a significant bearing on the psychological wellbeing of patients (Akechi, *et al*.1998) and is strongly predictive of suicide ideation (Chochinov, *et al*. 1998; Jones, *et al.* 2003). Furthermore hopelessness can impact detrimentally on the patient's physical health status as it has been associated with increased risk, lower health outcomes and mortality (Anda, *et al.* 1993; Everson, *et al*. 1996; Watson, *et al.* 2005).

A diagnosis of MND *'threatens hope, rewriting life's plans, dreams and expectations,'* (MCleod and Clarke (2007:7). Previous studies in this area have illustrated a moderate to high degree of hopelessness (McDonald, *et al.* 1994; 1996; Plahuta, *et al*. 2002; Rabkin, *et al*. 2000; 2005; Chio, *et al*. 2004;) and an association between high scores of hopelessness with depression, suffering and suicidal ideation (Ganzini, *et al*. 1998; 1999; Rabkin, *et al.* 2000; Plahuta, *et al*. 2002; Albert, *et al*. 2005; Felgoise, *et al*. 2010). Some interesting findings were made by Plahuta, *et al*. (2002) as they revealed that those patients more reliant on an external locus of control (events are perceived as beyond an individual's control) and having a limited sense of purpose in their lives were more likely to experience hopelessness. However, the study did not evaluate whether there was a change in levels of hopelessness over time. Research carried out by Breitbart, *et al*. (2000) suggests finding ways and means of addressing hopelessness in terminally ill patients is challenging and that further research into therapeutic interventions which may address existential issues, help individuals find meaning in life and therefore decrease hopelessness, is required. Other studies have emphasised the importance of the health professional's role in maintaining hope in people with MND (Kim, 1989; Li, 2000).

Self-perceived burden

The last decade has seen research emerge in the field of palliative care which evaluates the impact of 'self-perceived burden' (McPherson, *et al*. 2007). This concept represents the sense of being a burden to others that a number of patients of serious or advanced disease have reported feeling. McPherson, *et al*. (2007:425) have articulately defined it as:

> '*an empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility and diminished sense of self.'*

This sense of burden results, therefore, from feelings of dependency and reliance for physical assistance from others but also incorporates concern for others in having to deal with the challenges of coping with the disease. McPherson, *et al.* (2007) also suggest that self perceived burden could be considered a construct of '*existential distress*' as the individual is highly cognisant of their reliance on others and their inability to fulfil previous roles all of which impact on their sense of dignity and self esteem. It is evident that self-perceived burden results represents a component of psychological distress and a number of studies have indicated it to be a significant contributory factor in an individual's wish to hasten death (Breitbart, *et al*. 2000; Wilson, *et al*. 2005; Kelly, *et al*. 2003).

Self-perceived burden has been shown to be prevalent in people with MND; a study by Ganzini, *et al*. (1999) with a sample of 100 found that 91% of patients considered their condition was a cause of stress for their family members, 65% believed they were a burden to their families and 48% thought that their condition resulted in financial hardship. In a study carried out by Chio, *et al*. (2005) self–perceived burden was high and was significantly correlated to patients' scores on the ALS-FRS scale. They concluded that patients have a good perception of their clinical status and the impact on caregivers. Ganzini, *et al.* (1999) demonstrated that self-perceived burden has a positive association with depression, suffering and suicide ideation.

Psychological distress in carers

A number of studies have investigated the effects of the disease on the psychological wellbeing of carers of people with MND. Evidence does suggest that the demands of the disease on the primary caregiver may cause intense burden, anxiety and depression (Krivickas, 1997; Goldstein, *et al.* 1998; 2006; Rabkin, *et al*. 2000; Hecht, *et al.* 2003; Chio, *et al*. 2005; Murphy, 2009), however identifying the causes of these symptoms remains inconclusive (Rabkin, *et al*. 2009).

Research by Williams, *et al.* (2008) with 12 carers of people with MND, used a novel design, combining concept mapping and interviews with outcome measures on the SF-8 Quality of Life scale. The results showed that family caregivers who reside with the person with MND have poorer mental and physical health. The study therefore has a number of implications for supporting carers through respite. According to research by Goldstein, *et al.* (1998), psychological distress in carers depends less on the patient's level of physical disability and more on the carers' own assessment of the impact of the disease on the patient's life. The researchers also concluded that carers' anxiety was greater, the shorter the duration of their partners' symptoms. The psychological status of caregivers of people with MND has been found to decrease over time (Goldstein, *et al.* 2006). Psychosocial

factors, other caring demands, changes in the controllability of emotional expression and the carers' nature of social support and their satisfaction with their social relationships, have been found to be particularly important in determining the psychological distress of carers of people with MND (ibid). Rabkin, *et al*. (2009:453) found that carers demonstrated fairly low scores on scales measuring depression but concluded that such quantitative methods do not fully capture the '*reality of family caregiving in Amyotrophic Lateral Sclerosis'* but instead suggest that qualitative data provides a more realistic picture. They conclude that the common experience of carers of people with MND is one of distress rather than psychopathology.

Some qualitative research has been undertaken in this area and resulted in some interesting findings regarding the psychological experiences of carers of people with MND. Bolmsjo and Hermeren, (2001) found that carers frequently desired some form of counselling to discuss their experiences. Research carried out by Brown, (2003) demonstrated that extreme changes to their lives were perceived by carers. Interviews carried out with five carers revealed that they experienced increased distress and vulnerability and a concern of what might happen to their partner if they themselves were to become ill. A study conducted by Dawson and Kristjanson (2003), demonstrated that carers experienced a wide range of feelings, emotions and grief and highlighted gaps in supportive care for this client group. The findings from both of these studies would have been strengthened with a longitudinal design as they were reliant on one-off interviews which can only provide a snapshot view of the participants' experiences (O'Brien, *et al.* 2011). Focus groups were used by Herz, *et al*. (2006) to explore the experiences of carers and former carers of people with MND. Their findings highlighted that the disease had a significant psychological impact and there was an emotional cost to the role of carer. The authors recognise that the difficulties they experienced in recruiting carers may have limited the findings of the study. Ray and Street (2006) confirmed the claims made by these previous studies by demonstrating caring for a person with MND resulted in emotional vulnerability. The authors used an ethnographic case study with 18 primary caregivers and six peripheral carers. They identified that the significant bodily deterioration experienced by people with MND led to a significant increase in their carers' *'emotional labour'* (dealing with feelings and managing emotions) for which they are frequently untrained and unprepared.

Burden

Burden has been associated with depression, fatigue and reduced quality of life in the carer of someone with MND. Gauthier, *et al*. (2007) used a number of rating scales to measure correlations

between 31 carers and 31 patients including the Zung Depression Scale (ZDS), McGill Quality of Life Questionnaire (MQOL), Caregiver Burden Inventory (CBI); Self-Perceived Burden Scale (SPBS). The results of the study demonstrated a significant increase in burden associated with a decrease in quality of life in carers of people with MND over a nine month period and found depression increased proportionally more in carers than in patients. The burden experienced by the caregiver of MND patients with mechanical ventilators is particularly high in another quantitative study carried out by Kraub–Wittemer, (2003). However, the methodology of this study has been queried earlier in this review. Rabkin, *et al.* (2000) used the Zarit Caregiver Burden Scale with 56 patients and 31 carers and found a high concordance in distress levels between the two groups. They suggest this may result from the correlation between the patient's perception of being a burden, and levels of the carer's distress. In their quantitative study with 19 carers, Goldstein, *et al*. (2000) found perceived burden was greater in carers who viewed the illness as having more of a global impact on their lives. They also found gender differences as female carers anticipated less strain than male carers. Other quantitative studies carried out by Hecht (2003) and Chio (2005) have found that patient's physical disability may predict caregiver burden. Loss of perceived marital intimacy, the extent to which the illness is affecting various aspects of the carer's life and reduction in social contacts have also been linked to caregiver burden (Goldstein, *et al.* 1998;2006).

Coping

Coping has been defined as the cognitive and behavioural efforts to manage stressful situations and the negative and positive emotions which accompany them (Lazarus and Folkman, 1984; Lazarus, 1993; Folkman 2008). The coping appraisal model has been applied to illness (Jenkins and Pargament, 1984; Bombardier, 1990; Pakenham, 1994; Shotton, *et al*. 2007). Moos and Schaefer, (1984) suggest three processes which result from a crisis of illness including cognitive appraisal which consists of an evaluation of the implication of the illness on their life by the individual; adaptive tasks whereby the individual carries out tasks considered beneficial, for example, preserving relationships with others, and coping skills. Linked to coping is the concept of resilience; this is a psychological term which is used to describe '*a process whereby people bounce back from adversity and go on with their lives,*' (Dyer and McGuiness, 1996:276) or '*the maintenance of physical and psychological health in the face of risks or threats*,' (Mehta, *et al*. 2008:239).

Coping and people with MND

Research in the area of coping and resilience in people with MND has remained limited. Early studies investigating this area did not find an association between emotional outcomes and certain coping

styles and found that very few people with MND employed avoidant coping strategies (Earl, *et al.* 1993). However, the findings are quite dated now and the authors of the study recognise the possibility of sampling bias in the study. McDonald, *et al*. (1994) found that a large proportion of patients searched for positive meaning from the disease. Young and McNicoll, (1998) listed humour, thought control, reminiscing and living a day at a time as strategies which people with MND employed to help them live with the disease. More recently, Bungener, *et al.* (2005) found people who had received their diagnosis within the last six months used emotion focused strategies more frequently and had greater emotional distress than those individuals who had had their diagnosis for longer. They also revealed age appeared to be a factor, as individuals under 50 years of age were found to be more likely to employ problem focused strategies. Studies of people with MND have tended to support the general literature regarding coping, as a study by Lee, *et al.* (2001) found individuals who tended to confront problems indicated lower levels of anxiety and depression, whilst wishful thinking and denial have been shown to be inept strategies for coping which result in higher anxiety and depression (Hogg, *et al*. 1994). However, Centers, *et al.* (2001) suggest that denial may have an adaptive function in the short term as it allows people to come to terms with particular aspects of the disease. Hecht, *et al*. (2002) discovered *rumination*, commonly thought to be a negative coping strategy, was frequently used by people with MND and was correlated with depression. Lee, *et al*. (2001) have developed a specific coping scale for use with this client group and suggest management of coping strategies of people with MND could be of great benefit. However, the scale requires further validation in order for any conclusions to be verified.

Averill, *et al*. (2007) maintain that resilience and managing psychological distress in people with MND and its possible impact on their quality of life and survival remains under-researched and poorly understood. Evidently this is an area which warrants further research.

Coping and carers

With regards to carers, a study by Martin and Turnbull (2001) revealed that only a fifth of the 32 carers participating in their study reported coping well. However the study drew a small sample size from one centre, so generalisations are limited. Maladaptive coping such as avoidance and denial has been shown to increase carer distress (Goldstein, *et al.* 1998; Goldstein, *et al.* 2000) whilst research has revealed that finding meaning in care-giving works as an adaptive and effective coping strategy (Rabkin, *et al.* 2000). This study was conducted in the context of a clinical trial and therefore may have resulted in selection bias as more optimistic patients may have been recruited. Carers have been found to rely more on problem solving and reorienting to a greater extent than

patients as a coping strategy, however they concluded that the use of strategies varied over time and there is a need for people to be flexible in their use (Goldstein, *et al.* 1998). They also found an association between coping and the level of satisfaction with the services that carers receive. In a study by Gelinas, *et al.* (1998), more coping was evident in carers who accessed support networks and respite and they were shown to experience less feelings of guilt. Social problem solving skills and psychological morbidity were highly correlated in a study by Murphy, *et al.* (2009) with 75 carers, and they revealed that carers who had a positive problem orientation (perceived difficulties positively rather than a threat) and a rational behavioural response style frequently experienced the highest levels of quality of life. Their conclusions would have been strengthened by a more diverse sample that included more carers experiencing greater levels of psychological distress.

Studies using qualitative methodology have revealed that carers frequently attempt to 'maintain normality' as a means of coping with MND (Brown, 2003) and avoid thinking or talking about the future (Aoun, *et al*. 2011) which can lead to added strain and difficulties (Bolmsjo and Hermeren, 2003; Dawson and Kristjanson, 2003). Studies have also indicated that family caregivers search for positive outcomes in their carer role such as learning new skills (Brown, 2003) or as a proof of their love (Herz, *et al.* 2006) which enable them to make sense of and find meaning in their situation.

In relation to coping, a number of diverse factors including personality, social support and spirituality appear to have a positive influence on a person's capacity to adapt to illness (Averill, *et al.* 2007). These factors are outlined in the following section.

Personality factors

According to Blazer and Hybels, (2005) a number of characteristics are considered to better enable a person to cope with illness. These include a tendency to perceive stressful events positively, low levels of neuroticism and having an internal locus of control (they view themselves as active agents upon the external world and situations within their control).

Studies of people with MND have identified personality traits as significant factors which enable people to cope with the disease (McDonald, *et al,* 1994; Nelson, *et al.* 2003; Young and McNicoll, 1998; Rabkin, *et al.* 2000). Patients with higher levels of quality of life described themselves as '*facing the disease with optimism, feeling in control, using a sense of humour and fighting with persistence and stubbornness'* Nelson, *et al*. (2003:422) . According to Plahuta, *et al.* (2002) severity

and length of illness are not predictive of hopelessness and depression and suggest instead that psychological distress results from an external locus of control and lack of meaning in life.

Caregivers who are equipped with greater cognitive behavioural resources are thought to have an increased likelihood of adjustment to the role of carer with minimal emotional distress (Grant, *et al*. 2006). It appears that this is also true in carers of people with MND as Murphy, *et al*. (2009) found problem solving to be a major determinant of carer wellbeing.

Spirituality

Research has demonstrated that numerous elements of spirituality are associated with physical and psychological wellbeing, particularly when coping with adversity (Park, 2007) and has been identified as a factor which promotes resilience (Maddi, *et al*. 2006). In the context of illness, particularly when terminal, existential questions regarding life and death frequently arise; spirituality is thought to provide some sense of control and appears to enable adaptation for the patient (Macleod and Clarke, 2007). Spiritual wellbeing is thought to offer protection from end of life despair as patients are less likely to have depression and express a wish for hastened death, (McClain, *et al*. 2003). The proposition that spirituality represents a component of resilience for a person with illness has also been indicated in the studies with people experiencing MND. Evidence suggests an association between religiosity and lower levels of depression, (Rabkin, *et al.* 2000) and sustained higher levels of quality of life (Bremer, *et al.* 2004; Fegg, *et al*. 2005). Furthermore, religion and spirituality have been found to provide support, as well as offer meaning and hope for people with MND (Murphy, *et al*. 2000) and appears a very effective coping mechanism (Hecht, *et al.* 2002; O'Brien and Clark, 2006). Although Hecht, *et al.* (2002) recognise that sampling bias may account for the high level of significance that religion showed in their study.

Religious practice has been associated with higher levels of quality of life (Dal Bello-Hass, 2000) and Albert, *et al*. (2005) found that patients who demonstrated less comfort in religion reported less optimism, more hopelessness and a greater wish to die. Spirituality has also been shown to act as a protective factor for carer strain when supporting people with MND (Ganzini, *et al.*1998; Goldstein, *et al*.1998). Trail, *et al.* (2003) found that a large number of their participants sought support from regular attendance at church. A correlation between spirituality and quality of life in caregivers has been demonstrated by Murphy, *et al*. (2009) and suggests that further research in this area is necessary. A number of thought processes utilised by people with MND to sustain hope and positive

wellbeing, including spiritual beliefs, which limit the impact of living with the disease and increase self-transcendence are highlighted in a study conducted by Fanos, *et al.* (2008).

Social support

Research evidence has demonstrated an association between social support and psychological wellbeing (Cohen and Wills, 1985; Cohen, 1988) and a growing number of studies demonstrate an emerging link between social support and morbidity and mortality, (Burkman, *et al.* 1992; Brummet, *et al*. 2005). Low levels of family cohesion and social support have been found to be related to high rates of a wish to hasten death in people with advanced disease (Chochinov, *et al.* 1998). Social support is considered to have a number of benefits including promotion of self-esteem, intimacy, belongingness, control, purpose in life and thereby improving a person's general sense of mental and physical wellbeing (Cohen and Wills, 1985; Uchino, 2006). This in turn is thought to increase health promoting behaviours and physiological states. Similarly, social support for carers has also been found to impact on their wellbeing.

Social support represents a significant factor in maintaining psychological wellbeing; limited social support has been correlated with depression (Hogg, *et al*. 1994; Rabkin, *et al*. 2000; Rigby, et al. 2002; Hecht, *et al*.2002) and hopelessness (Ganzini, *et al.* 1999). In a study by Chio, *et al*. (2005) social support was found to be the most significant factor in maintaining positive levels of a patient's quality of life. The research also highlighted that family, friends, and community bonds were frequently mentioned as sources of support.

Greater levels of social support have been identified as a significant factor in alleviating distress and burden in carers of people with MND (Bromberg, *et al*. 1996; Ganzini, *et al.* 1998). Goldstein, *et al*. (2000) found that availability of support from family and friends was a significant factor in reducing anticipation of strain in carers and Goldstein, *et al*. (2006) suggest that social support and satisfaction with social relationships function as long term predictors of carer wellbeing. However, due to the excessive and overwhelming demands involved in caring for someone with MND the social relationships of carers and participation in social activities are frequently reduced (Trail, *et al.* 2003). Qualitative studies with carers of people with MND have also demonstrated the reduction in social networks of carers (Ray and Street, 2005) and the impact such a loss of social support has on carer wellbeing (Love, *et al.* 2005), highlighting how it can often result in anxiety, depression and distress. As in the case with all qualitative research, these studies rely on small samples and therefore generalisations cannot be drawn from them.

Part 2. Literature review of qualitative studies investigating experiences of people living with neurological, chronic and terminal disease.

This next section discusses previous research in which similar methodologies to my own study have been undertaken.

Social constructionist studies

A social constructionist perspective of illness has been a major area of research in the last fifty years. The key proposition of constructionism is that the illness experience is 'constructed;' underpinned by symbolic interactionist and phenomenology theories suggesting reality is created by active agents who engage in and act upon their world (Conrad and Barker, 2010). In regards to illness, people are considered to '*enact their illness and endow it with meaning'* rather than merely representing '*passive entities to whom things are done*' (Conrad and Barker, 2010:S71). This approach perceives language as crucial in the development of social reality and an individual's cognition and behaviour, (Harre, 1979; 1991; Shotter, 1984; Gergen, 1985). In accordance with this school of thought, human reality is produced through conversation or discourse; '*our talk works in a rhetorically responsive way, as a means or implement in 'shaping' the further living of our lives in relation to those of the others around us*.' (Shotter, 1995:161). Obtaining an insight into subjective experiences of illness from the patient's perspective originated with the work of sociologists in the 1960s (Glaser and Strauss 1965; Goffman 1970; Strauss and Glaser 1975). Conrad (1987:4-5) developed the approach by suggesting:

> '[The] *sociology of illness experience must consider people's everyday lives living with, and in spite of, illness. It needs to be based on systematically collected and analyzed data from a sufficient number and variety of people with an illness. Such a perspective necessarily focuses on the meaning of illness, the social organization of the sufferer's world, and strategies used in adaptation*.'

Research of this kind tends to use data drawn from in-depth interviews which enable the researcher to focus on the subjective illness experience and thereby allow access to the 'insider's view.' According to Conrad and Barker (2010:70) '*such a perspective is well positioned to examine how individuals construct and manage their illness, and with what consequences'*. Studies from this field have explored people's construction of illness and the impact of disease on a person's sense of self or selves. Ashmore and Jussim in Smith and Osborn, (2007:519) refer to the self:

> '*as a stable but dynamic collection of core beliefs, affects or cognitions that are utilized by the individual to define or represent themselves both privately and in their presentation to the outside world*'.

Smith and Osborn (2007:519) maintain that the concept of the self is therefore integral to the '*sense-making process'* which occurs in illness and is instrumental when exploring '*the inter-relationship between individuals, their bodies, larger relational, social and cultural systems and between the private and the public domains of our own experience'.*

In the area of chronic disease, Charmaz*,* (1982; 1995; 2000), revealed an individual experiences a loss of 'selfhood' and in turn relies more heavily on those around them for validation, with limited success. Individuals will frequently avoid, resist and '*reject identities founded in invalidism. They do not wish to be patients first and persons second*', (Charmaz, 1997:286). Loss of purpose and social role, the uncertainty of the causality and diagnosis and stigma of the illness are commonly experienced (Kotaba, 1983; Charmaz, 1983; 1991; 1995; 2000; Osborn and Smith, 1998). Similar types of studies have been undertaken to explore people's experiences of living with Multiple Sclerosis (MS) (Finlay, 2003; Toombs, 1992; 1995; 2002; 2005). Toombs (1995:12) asserts that a changed bodily pattern of walking, talking and body language not only alter one's own experience of self, but also alter greatly our relations to the world; the disease represents a '*disorder which incorporates a changed relation with one's body, a transformation in the surrounding world, a threat to self, and a change in one's relation to others'*. Finlay (2003; 172) applied an existential–phenomenological approach to one individual's experience of living with MS and claimed that during this time the person's *'sense of self-body unity, inter-subjectivity and life projects are threatened.*' Interesting studies exploring the identity in dementia have been undertaken by Sabat and Harre (1992); Sabat and Collins, (1999); Sabat, (2002); Sabat, *et al.* (2004). Over the course of the disease, two or three forms of self exist and will be affected in different ways. Whilst the personal singularity remains intact despite the disorder, those aspects of personhood which are socially or publicly presented can be lost as a result of disease; *'Loss of self is directly related to nothing more than the ways in which others view and treat the sufferer'* (Sabat and Harre, 1992:15).

Narrative research

The narrative structure of human lives has been outlined by Sarbin, (1986). According to this viewpoint, narratives not only are the vehicle by which we perceive the world and make sense of it but our reality is actively constructed through them and we live through the stories told by others and by ourselves – they have ontological status. These constructed stories provide a sense of order

and unity to our lived experience by organising the various disparate aspects and components of our lives into a meaningful whole. In addition, Ricoeur (1984; 1985) suggests that through a process of story-telling, identity comes into being; '*Subjects recognise themselves in the stories they tell about themselves.'* (Ricoeur, 1988:247) It is thought that through the creation of narratives we construct and define ourselves:

> *'We learn how to become the narrator of our own story without completely becoming the author of our life'* (Ricoeur, 1987:437).

These narratives do not take place in a vacuum but are shaped by people's social context, as Frank (1995:75) states: '*people tell their own unique stories but they compose these stories by adapting and combining narrative types that cultures make available to them.*' A number of researchers have used narratives to illustrate the devastating impact of disease on people's lives. Frank (1995) has described illness as a '*narrative wreckage'*, outlining narrative types of '*restitution', 'chaos'* and '*quest'* which he frequently discovered underlying people's stories of illness. Kleinman, (1988) describes illness as an '*ontological assault'* and Bury, (1982; 2001) developed the term '*biographical disruption'* to explain the way in which chronic illness disrupts an individual's expectations and plans for the future, forcing them to rethink their biography and self-concept and having to seek ways in which they can restore these fractured meanings.

A small number of narrative studies have been carried out to explore lived experiences of MND (see table 2, page 10). Brown, (2003:210) describes how people undergo an '*existential shock'* when receiving a diagnosis of MND and the way in which they are forced to develop a new, '*dynamic normality'*. Brown and Addington-Hall (2008:204) researched narratives of 13 people with MND and identified four narrative types including *'sustaining, preserving, enduring* and *fracturing'*. Locock, *et al*. (2010:1047) conducted a narrative study with 35 people with MND and 11 carers which investigated concepts of '*biographical disruption'* and '*repair'* in relation to this client group. They developed the concept of *biographical abruption* which was thought better conveyed the finality of a diagnosis of MND and loss of future experienced by many people with the condition.

Embodiment

The phenomenological viewpoint emphasises an essential groundedness in our bodies which is the necessary condition for self-reporting subjectivity (Merleau-Ponty, 1945). This phenomenological account is concerned with the embodied nature of our being and our experiences of the world are always rooted and situated within the body-subject:

> '*The relations between things or aspects of things having always our body as their vehicle, the whole of nature is the setting of our own life, or our interlocutor in a sort of dialogue.*' (Merleau-Ponty, 1945:373)

Accordingly, if the body represents a *'vehicle'* for human experience then experience takes place within it and we make sense of our experiences through it. If this is the case, then this has implications for the way in which narrative construction occurs and the way in which we formulate our personal identity (Beadon, 2009).

A number of researchers have drawn upon the phenomenological viewpoint outlined by Merleau-Ponty to explore embodiment and the relation between body and illness and has resulted in some interesting theoretical propositions (Leder, 1984; Lawler, 1997; Lawton, 1998; Twigg, 2000). The lived body phenomenon has significant implications for medical practice and theory according to Leder (1984) and she draws greatly upon these ideas in her theory of the '*absent body'*. Lawler, (1997) demonstrates the way in which the body is objectified and depersonalised by the field of medicine. She emphasises the way in which bodily functions are hidden and made taboo subjects rendering them inaccessible. Lawton (1998:144) conducted an observation study with approximately 280 terminally ill patients and their families accessing care from a hospice in the UK and an in-depth case study of one individual. Her study revealed that social withdrawal accompanied their bodily deterioration which greatly impacted upon their sense of individual and social identity. She argues such individuals are isolated from mainstream western society, enabling the reinforcement of '*certain ideas about living, personhood and the hygienic, sanitised, somatically bounded body.'* This implies that a fuller understanding of people's withdrawal from social life would investigate the ideas in circulation in society as a whole, and amongst friends and relations in particular, about 'medicalized' bodies.

The term 'body work' was devised by Twigg (2000) to express elements of carework which have negative connotations and which are in general shied away from in society. Surprisingly very little research has been undertaken which has explored these ideas with specific regards to MND. Only one study has drawn upon these ideas to explore the experience of carers of people with MND in Australia, (Ray and Street, 2005). This study used a mixed method of a survey and case study with 18 carers. The authors expressed the need to ensure that social boundaries of the body and the impact of emotional attachment are included in concepts used to describe caregivers experience.

All of these studies contribute to a long tradition of qualitative studies in medical sociology and provide useful accounts of living with disease which are relevant to the work carried out here. Nevertheless, Smith (1996) noted that similar forms of studies within psychology remain scarce and advocated the use of Interpretative Phenomenological Analysis (IPA) as a psychological research approach to:

> '*…examine in detail the concerns of particular individual faced with specific conditions through an intensive examination of the texts produced by respondents*.' (1996:267).

IPA has also been previously used in some studies with people with MND; the method was used in a study by O'Brien (2004) exploring individuals' experience of information seeking. Using data drawn from interviews with seven people, the author identified three distinct information-seeking categories including active seekers, selective seekers and information avoiders. The study noted that all participants found exposure to unsolicited information, often in the form of media coverage as having a negative impact on them. Hugel, *et al*. (2006) used IPA to develop understandings of patients' experiences of the diagnosis of MND. Interviews were carried out with thirteen people with MND and identified the need for a multi-disciplinary, coordinated approach for patients from diagnosis onwards. The reasons for declining and withdrawing from NIV were explored by Ando, (2010) using semi-structured interviews with a sample of ten individuals with MND. Four themes were identified from the analysis including preservation of the self, personal perception of intervention with NIV, negative experience with the healthcare services, and not needing NIV. The researcher concluded that not engaging with NIV can represent an attempt by individuals to maintain a sense of autonomy, dignity and quality of life.

However, to the authors' understanding there have been no previous IPA studies which have employed this specifically psychological approach to investigate the psychological and existential impact of MND on couples experiencing living with the disease. IPA is considered particularly suited to this form of study as it enables the researcher to gain insight into individuals' perception of their personal experience. However, Finlay (2006) states that studies employing phenomenological approaches to explore the intersection between the individual and the social have remained limited. The study outlined in this thesis has also sought to amend this shortage by exploring the experiences of the individual and their spouse or partner in unison and investigate their experiences as a couple.

Systemic studies of psychological impact of disease

Until recently psychological research into stress, coping and adaptation to illness has focused solely on the individual and has not investigated the way in which these processes may occur within a couple or family:

> '*As many chronic stressors and life strains involve the whole family – if not the neighbourhood, community and school – it is time to extend the study of stress, coping and adaptation beyond the individual level of analysis.'* (Revenson, 2003:530)

The experience of any disease does not occur in isolation; frequently the person with the disease has a spouse or partner. DeVellis, *et al.* (2003) maintain that a greater understanding of the interdependent nature and reciprocal processes within dyadic relationships will enhance our comprehension of adjusting to illness as a whole. Evidence suggests that shared perceptions between couples appear to be more adaptive. The systemic model (Mackinnon and James, 1987: Campbell, 1999) provides a useful means of understanding the way in which living with a disease impacts upon their relationship, sense of identity and beliefs and ideas. Robinson, *et al.* (2005) used a systemic framework to examine how people with dementia and their partners or spouses adapt to the disease's impact and suggest that the collaborative construction of a joint understanding of their situation enables them to cope more effectively with the disease.

Although a number of qualitative studies have been carried out with people with MND and their carers, these have tended to involve separate interviews and have focused on the nature of the individuals' experience. Until now, no study has used systemic framework to study the experience of living with MND beyond an individual level of analysis. Furthermore, there has been little research in this area studying the impact of the disease within the context of marriage or intimate relationships, with the exception of Atkins, *et al.* (2010). Nevertheless, some previous quantitative studies of people with MND and carers have highlighted the complex relationship between burden and patients' and carers' level of psychological wellbeing. In research undertaken by Rabkin, *et al*. (2000) a correlation between the mental state of caregivers and the physical, psychological and existential wellbeing of patients was identified. The authors maintain that there is a need to investigate both patients' and carers' responses simultaneously and that attending to the mental health needs of caregivers may also alleviate the patient's distress.

Rationale for this study

From the above detailed and intensive literature review, it is evident that a number of studies have focused on quality of life and psychological distress and in relation to people with MND and their spouses or partners. However, the majority of the psychological research carried out, has tended to be founded on a cognitive model of psychology and has therefore relied on a variety of different rating scales in order to define, measure and categorise quality of life scores, psychological symptoms such as level of depression and coping strategies used by individuals. Whilst this type of research is undeniably informative, difficulties with these methodologies have been highlighted above and furthermore the measurements gained do not allow any insight into the meaning of the experience of MND. Quantitative methodology, by its nature, cannot reveal the subjective perspective of the person with the disease or their partner. In accordance with the World Health Organisation's definition of quality of life, gaining an understanding of the patient's own perception and evaluation of the impact of the illness on their life provides a good indicator of their quality of life.

In the UK there is currently growing emphasis on supporting the needs of the patient and carer as outlined in the National Service Framework for Long Term Conditions (DH, 2005); the National End of Life Care Strategy (DH, 2008); Living and Dying Well, (Scottish Government, 2008); NatCen survey on attitudes towards dying, death and bereavement, (Dying Matters, 2009) all of which highlight the need for offering a range of physical, emotional, spiritual and social support to people with terminal diseases and their partners. Therefore, there is a need to further our understanding of the psychosocial experiences and needs of couples with long term diseases such as MND. Furthermore, the Long Term Conditions Positive Practice Guide - Improving Access to Psychological Therapies' (DOH, 2008) and the NICE guidelines for depression (2010) acknowledge that depression and anxiety may exacerbate perceived physical symptoms and increase the person's distress.

There remains a paucity of published research to date which has used qualitative methodology to explore the psychological experience of living with MND and can incorporate the perspective of individuals (either the carer or the patient) who may be experiencing psychological distress as a consequence of the disease. Macleod and Clarke (2007) maintain that qualitative research is necessary to explore these issues further. Moreover, Albert, *et al.* (2005:1) suggest that the psychological risks of MND manifest as '*end of life despair'* incorporating hopelessness, existential suffering and loss of purpose of life, all of which cannot be accurately assessed using rating scales

but require '*a broader inquiry into existential and personal domains with which the patient is trying to come to grips.'*

Finally, there has been very little research undertaken with couples living with MND using a systemic framework where the focus of analysis is on the couple, rather than on the individual participants. Therefore, it appears there remains a need to obtain couples' shared perspectives of experiencing MND.

Summary

This chapter has outlined previous research undertaken in the area of MND regarding the various psychosocial aspects of living with MND. It has indicated a need for qualitative research which allows for the investigation of these factors within the context of family relationships in order that we can better understand the nature of the psychological experience for both the individual living with the disease and their partner providing care for them. The following chapter discusses the method employed in the study.

Chapter 2 - Methodology and Methods

Introduction

In the previous chapter, the aim of the study to conduct a detailed exploration of the perspectives of people with MND and their partners was outlined. The review highlighted that although previous studies have measured quality of life, depression and other psychological factors, there remains a need for research studies to obtain the shared perspectives of people with MND and their partners to gain further insight into their psychological reactions to the disease as a couple unit and how the disease influences their relationship. The review illustrated that research evidence regarding the impact of disease upon concepts of self and identity in people with MND and their partners remains limited, particularly within the context of a couple relationship. It was also emphasised in the previous chapter that gaining a greater insight into these areas may further our understanding as to how couples living with MND may be better supported through psychological intervention.

This chapter provides an outline of the theoretical approach underpinning this study, justifies the methodology used and presents the methods undertaken. A discussion of ethical considerations and the way in which reliability and validity were assured for data collection, management and analysis is also included. Firstly I delineate the conceptual framework of Interpretative Phenomenological Analysis (IPA).

Theoretical Approach

Interpretative Phenomenological Analysis

In order to fulfil the aim of this study, an IPA approach was deemed suitable as it represents a '*specifically psychological method*' (Willig, 2001:68) for qualitative analysis and was originally designed to *'gain insight into individual participants' psychological worlds'*. IPA is also considered of positive use when the subject matter being studied is:

> '*dynamic, contextual and subjective, relatively under-studied and where issues relating to identity, the self and sense-making are important*' (Smith, 2004: 520).

This method has been widely used across sub-disciplines in psychology and has witnessed a rising popularity in research which engages with applied concerns.

Traditionally mainstream psychology has drawn upon empiricism as its epistemological position which observes relationships between events and particular to psychology is the observation of behaviour and cognition. This has led to the majority of studies employing quantitative research

methods which can identify and measure the effects between stimulus and response. By contrast phenomenological psychology is concerned with the experiential, subjective levels of analysis and is focused on how people make sense of their experiences. IPA is considered to provide a systematic and phenomenologically focused approach to understanding first person accounts (Reid, *et al.* 2005) through inter-subjective inquiry and analysis. Inter-subjectivity refers to the way in which human engagement in the world is thought to be shared and relational and accounts '*for our ability to communicate with, and make sense of, each other*' (Larkin, *et al*. 2011:319).

I considered IPA an appropriate method for the subject of this study as it has been shown to be particularly relevant for understanding subjective responses to illness. Smith, *et al*. (1997:68) maintain that the use of IPA in health research studies can enrich '*the way mainstream psychology conceives of the individual's experience of health and illness'*. IPA has been used in a number of previous studies related to health psychology (Bramley and Eatough, 1995; Carradice, *et al.* 2002; Reynolds and Prior, 2003; Lavie and Willig, 2005). In addition, Reid, *et al*. (2005:21) suggest that the popularity of IPA in health psychology may be due to the fact that it provides a means of obtaining the perspective of service users and clients which is in accordance with the national service frameworks currently in force within the NHS. Furthermore they suggest that IPA can enable participants to become *'less disease and deficit focused*' by allowing them to speak of alternative aspects of their experience such as health, strength and quality of life.

For all these reasons, it was expected that the use of IPA in this study would yield a very full picture of the psychological meanings which constitute the lived experiences of people with MND and their partners.

Phenomenology

IPA is informed by the philosophical approach of phenomenology which derives from the work of Husserl (1859-1938) and others who have expanded on his views, such as Heidegger (1962; 1927), Sartre (1978) and Merleau-Ponty, (1962). Phenomenology has been described as a theory which intends to seek to describe the essence of phenomena:

> '*[It] emphasises the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experience'* (Moran, 2000:4).

There are two major strands of phenomenology, the first represents the earlier phase of this philosophical approach, and is described as *transcendental phenomenology,* which originated in the

work of Husserl, whilst the second strand is known as *existential* or *hermeneutic phenomenology* and is associated with Heidegger, Merleau-Ponty and Sartre. I will now discuss both of these forms of phenomenology in turn.

Transcendental phenomenology

Husserl (1970) considered experience to be 'a system of interrelated meanings', a 'life-world'. An individual consciously relates the world around them to his own personal experience through a process of reflection and clarification of meanings. Husserl maintained each one of us holds a 'natural attitude' to the world which is based upon numerous assumptions and suppositions. Although these frequently enable us to engage in the world, he argued that they also obscure and misrepresent any real understanding of the world. In order to study and understand a phenomenon truly, it is necessary to be free of this foreknowledge and any prior suppositions, ensuring the phenomenon is investigated as it appears, '*as themselves only*' (Larkin, *et al*. 2011:319). This is why Husserl's phenomenological approach is often referred to as 'transcendental phenomenology' as it seeks to 'transcend' the personal and contextual properties of the experience and instead endeavours to strip back experience to its core and essential features '*back to the things themselves*!' (Husserl, 1913;1982:35).

The revealing of meanings takes place via a process of reduction which comprises a shift from our natural attitude (our everyday assumptions about how things are) to the phenomenological attitude (a more focused approach to understanding). The term eidetic abstraction refers to the way in which our natural attitude is suspended; our former knowledge is bracketed and set aside in order that the essential features of the thing can be identified. According to Husserl the three phases involved in the eidetic process include epoche, phenomenological reduction and imaginative variation. Epoche comprises the deferment of our prior knowledge, existing suppositions or understanding, enabling us to be open to the emergence of the phenomenon and be completely aware of it. Finlay (2008:2) argues that there is frequently a mistaken interpretation of this aspect of the bracketing process as representing *'an effort to be objective and unbiased'*. Instead, the aim of a researcher using a phenomenological approach is '*to be open to and see the world differently'* and involves *'putting aside how things supposedly are, focusing instead on how they are experienced.*' Through a process of phenomenological reduction the essential features of the phenomenon are identified; '*that which makes a thing what it is (and without which it would not be what it is)*,' (Van Manen, 2003:177). This occurs through a detailed description of every aspect of the phenomenon including its physical features (shape, colour and texture) and experiential features (thoughts and feelings in our

consciousness). Lastly, imaginative variation questions what conditions and attributes are necessary to this experience (time, space or social relationships). Through an integration of these aspects, we are able *'to arrive at an understanding of the essence of the phenomenon*' (Willig, 2001:52).

Finlay (2008:2) states that '*the challenge for phenomenological researchers is twofold: how to help participants express their world as directly as possible; and how to explicate these dimensions such that the lived world – the life-world - is revealed.'* The aim of this phenomenological study therefore, was to understand what the experience of living with MND is like, the meanings of this experience for the participants and how it presented itself to themselves and to others.

Existential phenomenology

Existential phenomenology (Heidegger, 1962; 1927) represents a shift towards a different philosophical position and conceives the world around us and our experience of it as inseparable. In accordance with this viewpoint, the process of phenomenological reduction outlined by Husserl is not feasible because our understanding is always made from our own perspective and objects and subjects must be 'perceived' as something by us to represent our reality. Because our observations are always situated in the world from which they cannot transcend, they remain interpretations. As Gallagher and Zahavi, (2007:40) explain:

> *'There is no pure third-person perspective, just as there is no view from nowhere. . . . This is not to say that there is no third-person perspective, but merely that such a perspective is exactly a perspective from somewhere . . . it emerges out of the encounter between at least two first-person perspectives; that is, it involves inter-subjectivity.'*

'Dasein' or the translation 'there-being' is the term Heidegger uses to explain how individuals are engaged with and represent an integral part of the world. Individuals are 'thrown in' to a pre-existing, mutually constituting, world of people, objects, language and culture to which they are forever bound. Heidegger's term '*dasein'* or '*throwness in the world'* captures man's situatedness in a particular, cultural, historical, and familial world. It is an inseparable relationship between existence and the world, in as much as neither category can be understood or even conceptualised separately from the other:

> *'Each one of us is what he pursues and cares for. In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of*.' (Heidegger, 1975:158)

Heidegger, therefore, illustrates how the individual's place in the world is always temporal, influenced by perception and in relation to something. The individual's perception of a phenomenon (intentionality) is characterised by experience specific to the individual, this experience is framed by universal qualities, common to us all, such as 'temporality', (we all experience time), 'spatiality' (we live in space) 'subjective embodiment' (we are in bodies), inter-subjectivity (there is 'I' and 'others'), selfhood (there is emphasis on 'I'), personal project (the things 'I' wants), moodedness (emotion), and discursiveness (speech).

The research approach of IPA is strongly influenced by this form of phenomenology and accepts that experience cannot be accessed directly from accounts but instead takes the view that it is necessary to conduct a process of inter-subjective meaning-making. The aforementioned universal qualities or interlinked fractions (Ashworth, 2003) which I as a researcher experience in common with everyone '*act as a lens through which to view data*' (Finlay, 2008:2). The aim of the researcher is to reveal something of a person's relationship to a specific phenomenon, in a certain context, at a certain time and *'to bring out these dimensions and show the structural whole that is socially shared while also experienced in individual and particular ways*' (Finlay, 2008:2). The intention is to enable a greater insight into our understanding of this phenomenon; to '*describe and elucidate the lived world in a way that expands our understanding of human being and human experience*,' Dahlberg, *et al.* (2008:37).

Embodiment

Similarly to Heidegger, the existential phenomenologist, Merleau-Ponty (1962) acknowledges the contextual and interpretative features of the 'life-world'. He also acknowledged that phenomenological reduction can ever be fully achieved, due to the fact that we cannot avoid our own situatedness in the world. However, Merleau-Ponty emphasises the 'embodied' nature of our situatedness and relationship to that world. He describes our status as 'body subjects' by maintaining that the seat of perception is one of bodily awareness of sights, sounds, and tangible surfaces. Therefore the body represents the vehicle by which we achieve intentionality, '*our means of communication with the world*' (Merleau Ponty: 1962: 106) and through its engagement with the world, human subjectivity is expressed. As Matthews (2006:51) explains:

> *'I see with my eyes, hear with my ears, act through moving my arms and legs, speak through moving my vocal chords, smile through arranging my face in a relevant way and so on. I could not have a subjective response to the world unless I had a body and I could not have typically human subjective responses unless I had a typically human body*'.

Similarly, Thomas, (2005:71) asserts that if the link between body and world is altered or disturbed, *'a person's existence is profoundly shaken,'* and the following quotations explain why this occurs:

> *'A person's experience of the world and self are bound up with her/his experience of her/his body… the body anchors the individual in a world of things and other people.. A person's ties to her/his body are perhaps made most clear when something about the body goes awry… Most people are aware then – whether they view their bodies as enabling or limiting – of both being and having a body'* (Ainley, 1989: 21-22)

> '*We take our life-world, including the bodily subject, for granted as long as everything works well. When I walk, I do not think of walking but of other things. But just a blister is enough to draw attention to my foot. If I have a severe toothache, all my attention will concentrate on my tooth. The more ill I am, the more I concentrate on my body. The parts of my body that are affected are changed to 'objects'. The more a patient's body is changed to an object, the more limited is his or her life world. In extreme cases the life world can be restricted to the patient's body'* (Plugge, 1967:13).

Merleau-Ponty (1962:143) explains how individuals who experience bodily changes through illness or disablement are sometimes able to find a new way of living within *'restrictive potentialities*'. The disabled body is thought to comprise '*two distinct layers'*; the '*habitual body'* and the *'body at the moment'* (Merleau-Ponty, 1945:95). This habitual body recalls intentions and ways of relating to the world which can no longer be operated on – that is, extant only in the past - and serves as a constant reminder of what has been lost. It is thought that over time a person may achieve a sense of a '*modified habitual body'*, by which they are able gradually to accept their disability and cease projecting their previous form in the present.

The increasing number of IPA studies in the health field highlights the relevance of Merleau-Ponty's work to this method of analysis. As this study was concerned with the experience of living with a terminal disease, it was expected that experiences of the body and how these are interpreted by participants would represent a significant concern and the ideas of Merleau-Ponty were considered a useful basis from which to form my interpretations.

Hermeneutics

IPA also aligns itself with the hermeneutic branch of phenomenology, which is focused on understanding and interpretation as vital aspects of deriving meaning from discourses and experiences; meanings are not simply 'given' in any positivist or absolute sense.

> '*Texts and documents do not offer a direct access to what they mean; they have to be interpreted in order to discover what the text or author of the text meant*' (Van Langenhove, 1995:13).

Through a deliberate process of description of aspects of experience, interpretation occurs (Van Manen, 1997). The hermeneutic approach therefore enables the researcher to interpret the participants' construction of their life-world whilst acknowledging the inevitability of personal and cultural perspectives colouring these interpretations; '*the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations*' (Bunge, 1993: 231).

> *'The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings'* (Gadamer, 1990; 1960:269).

Conversely, our personal views and understanding and our beliefs about the world allow us to accept and situate other individuals' viewpoints. Therefore, according to the phenomenological hermeneutic approach, the complex of assumptions underlying the researcher's point of view represent a pre-requisite for interpretation and thus their understanding of a person's account. This process is reflexive as the researcher enjoys *'a spirit of openness*' (Smith, *et al*. 2009:27), remaining conscious that any interpretation made derives from a particular point of view.

Therefore the aim in this research study was not to establish an objective reality from the responses of the participants but instead to provide an interpretation of their accounts capturing as closely as possible the essence of their '*life worlds'* and offering a range of insights into them.

The 'hermeneutic circle' is a key construct of the hermeneutic phenomenological approach. This proposes a dynamic relationship between parts of phenomena and the whole thing, which together permit understanding (Smith *et al*. 2009). In order to gain insight into a part, for instance of a leaf's structure, one should first examine and commit to understanding the entire leaf; reciprocally, examining it in parts will cement the total understanding.

The hermeneutic circle is integral to the method of IPA. Rather than merely a linear, step by step process, analysis in IPA has a circular form and is 'iterative' in that the researcher will shift through a variety of reflections and perspectives of the data to obtain a fuller understanding of the phenomenon being studied.

> *'The idea is that our entry into the meaning of text can be made at a number of different levels, all of which relate to one another, and many of which will offer different perspectives on the part-whole coherence of the text*' (Smith, *et al.* 2009).

Therefore throughout the analytic process in this study, my engagement with the data involved an understanding of numerous part-whole relationships such as a single word and its connection with a sentence; a particular extract and its relation to the entire transcript; or a single interview and the entire data-set. By accumulating an understanding of these various relations and connections within the study, I consider my interpretation of the couples' experience more complete.

Idiographic approach

IPA studies are idiographic and through the use of small, purposive samples, the intention should be to provide an in-depth interpretation of individuals' experiences (Smith, *et al*. 2009). By limiting the number of participants recruited to the study, it is thought that the researcher is better able to conduct a detailed analysis on each case, looking at the depth and richness of the articulations of each individual in turn, thereby revealing the full context of their experiences (Reid, *et al*. 2005).

Idiography (Allport, 1962) is concerned with the particulars of individual experience and what makes it unique and distinctive. This theory contrasts with the nomothetic approach which assumes that the behaviour of a particular person is the result of laws applicable to all. Idiography regards this approach, which is only concerned with group averages rather than particular cases, as unable to say anything that can be held to be true for any *particular* person (Smith, *et al*. 1995). Instead a commitment to gaining an understanding of the perspective of certain people in a particular context of a specific 'experiential phenomena' is preferred.

Furthermore, Warnock (1987:123) states that *'if the balance between the particular and the universal* [experiences] *is achieved, what will be presented is a unique individual, whose knowledge of himself we can share.*' Therefore, Smith, *et al*. (2009) maintain that IPA with its idiographic focus, allows us, through a process of probing into the individual, to become closer to the universal.

Symbolic interactionism

By undertaking an IPA approach, this study is also rooted in the assumptions of symbolic-interactionism (Mead, 1934; Blumer, 1969) which assert that mind and self are products of social interaction. Meanings are considered to originate from interaction and discourse in a social context: the particular culture in which the individual is immersed. Language and linguistic symbols are the system by which these meanings are shared socially. One assumption which derives from this theory of thought is that internal cognitions and external communication are the result of the same process, so thought and word are equivalents. Furthermore, when 'internalising' thoughts and

symbols, the self is enmeshed in this process. Meanings are interpreted and adapted through a process of social negotiation and self-reflection: '*self-interaction is interwoven with social interaction and influences social interaction*', (Blumer, 1981:153).

Symbolic interactionism has been described as an early social constructionist theory (Ashworth, 2008). In accordance with this framework an individual's sense of self is therefore reliant upon the socially situated co-operation of others, and accordingly social recognition or lack thereof has a profound impact on the ways in which the individual is viewed and treated.

> '*It is in the constant interplay of mutual recognition of one's own and the other's position that the particular version of self is constructed*' (Sabat and Harre, 1992: 447)

Systemic model

In accordance with the social constructionist perspective, therefore, the experience of living with MND for both the individual and their partner does not occur in isolation but within a social context. The physical symptoms are not only devastating but can lead to psychological problems and social withdrawal (Hogg, *et al*. 1994; Goldstein, *et al*. 1998). Psychosocial function of the individual and/or the partner can often be impaired as they experience significant changes in their interpersonal relationships and social roles. Feelings of being a burden, isolation and a loss of control over their lives are often common (Goldstein, *et al*. 2006). As relationships and personhood are developed through social interaction, it is likely that these experiences will impact upon the self and sense of identity. This research drew upon a systemic model (Mackinnon and James, 1987; Campbell, 1999) of understanding these experiences. It aimed to investigate the effect of MND (MND), not only as an account of physical symptoms for the individual, but by including multiple voices of both the individual and the spouse. The perception of these changes within the context of the couple's relationship was prioritised. The intention was to gain further understanding of the participants' interpretation of their bodily experiences, the meanings which they assign to them, and the impact of these meanings on identity and social functioning within the couple.

Clinical application

Lloyd (2006) maintains that providing the opportunity for a patient or carer to express and attempt to understand their thoughts, beliefs, feelings or desires can be an effective means of informing service provision by making them more responsive, flexible and suited to individual needs.

> *'Failure to seek an understanding of individuals' experience beyond the results of medical, cognitive and functional assessments brings with it the risk of delivering inadequate care provision and support'* (Cohen, 1991).

IPA allows a careful examination of patient and carers' experiences. A number of studies in the area of health and psychology have had significant implications for clinical practice and have been used to determine effective psychological interventions. Wyer, *et al*. (2001) used IPA to investigate the likelihood of attending cardiac rehabilitation programmes in people who had recently experienced a myocardial infarction and found the theory of planned behaviour and self-regulatory model was a useful framework in explaining behaviour. In a study using IPA to investigate ex-professional footballers' experience of osteoarthritis, Turner, *et al*. (2002) revealed that restricted mobility had a significant impact on their identity and outlined a number of coping strategies. Howes, *et al*. (2005) in their IPA study exploring the experiences of women with acquired brain injury found that the participants underwent a series of losses and recommended the use of interventions which enabled them to gain greater control and problem solving. Reynolds and Lim (2007) used IPA with women living with cancer and found that art had a positive impact on their self-esteem, enhanced their social identity and acted as a distraction from the illness.

As has been discussed in chapter one, IPA has also been previously used to conduct qualitative research in MND to investigate various aspects of patients experiences including information seeking (O'Brien, 2004), the diagnosis process (Hugel, *et al*. 2006) and reasons for declining and withdrawing from NIV (Ando, 2010). It was therefore hoped that by employing IPA methodology in this study and drawing upon the systemic model to explore the ideas and beliefs as a couple rather than as individuals, would provide better understanding of psychological needs and offer some suggestions as to the ways in which services may better alleviate psychological distress and improve quality of life for both the person with the disease and their partner.

Research Aims and Objectives

1. To explore the psychological reactions and perceptions of people with MND and their partners.
2. To explore concepts of self and identity in people with MND and their partners.
3. To determine the scale and type of need for psychological support for people with MND and their partners.

Research design

This study arose from a larger study entitled 'Optimisation of Services for People with MND' funded by the National Institute for Health Research (O'Brien, *et al.* 2010: 2011). The study used thematic analysis to evaluate health, social and palliative care service delivery from the perspective of patients and carers. It identified a need for better joined up services and the need for greater access to psychological services. The study outlined in this thesis, is discrete and contributes to new knowledge as it focused on a smaller sub-sample of participants and IPA methodology was employed to explore the experience of MND from both the person with the disease and their partner's viewpoints within a couple. This type of study is thought to develop '*a more detailed and multi-faceted account of the phenomenon being studied*' (Reid, *et al.* 2005:22) and represents a form of triangulation which can increase validity. A longitudinal case study of one couple was conducted using data drawn from a journal and an interview. The second part of the study comprised interviews with twelve couples. The data collection procedures and validity are outlined in further detail later in this chapter.

Research setting

Due to the physical status of many of the research participants, it was necessary to ensure that the research process presented as little disruption to them as possible and that they were able to access any care and support required. Therefore the collection of data was carried out in participants' homes. According to Yardley, (2008:247) sensitivity to the '*perspective and socio-cultural context'* of participants is a significant measure of good qualitative research and demonstrates the researcher's awareness that the research setting may have a significant impact upon the participants' responses. I considered that undertaking the interviews in the participants' homes would be beneficial for a number of reasons, firstly by choosing a familiar setting which also ensured confidentiality, the individuals were more likely to feel at ease during the interview and therefore allowing a greater rapport between the researcher and themselves to form. Furthermore by conducting the research in a non-clinical environment, the potential perception of researcher as expert and an unequal power balance forming between the participant and the interviewer was considered to have been reduced. It was hoped that consideration of these factors may have enabled a greater likelihood of a more successful interview and elicited a more honest and open account of the phenomena being studied.

Frequently couples demonstrated a desire to partake in the interviews jointly. Partners often voiced concerns for the people with the disease and were keen to have joint interviews in order to reduce

fatigue or emotional distress – as was the case in a study by Beaver, *et al.* (1999). Due to the nature of the disease a number of participants experienced speech impairments; in some cases individuals relied on their partners to translate their utterances as they were more familiar with their partner's speech. This represented another reason for undertaking the interviews jointly.

Participants

The study was carried out through a MND Care and Research Centre based in the north west of England serving a population of 1.8 million people. A purposive sample comprising 13 couples was recruited to participate in the study through their contact with the centre (see appendix 1). This form of sampling method was deemed appropriate as Smith, *et al*. (2009) states that the aim in IPA studies is to recruit participants who can offer a relevant and meaningful insight into the subject being studied.

Statistical representativeness is not viewed as a requirement in qualitative approaches and in IPA the requirement for a particular sample size is refuted, (Smith, *et al*. 2009:51) with the emphasis being on utilising an ideographic approach to data collection. The intention in IPA studies, therefore, is to provide a detailed, in-depth analysis of each case in the data. As this represents a time consuming process and requires a great deal of commitment and attention to detail from the researcher, it is thought that this type of analysis can only really be fully achieved with a small sample (Reid, *et al*. 2005).

It is suggested that maximising the homogeneity of the sample group as much as possible enables the researcher to draw out the similarities and variance between the participants (Smith and Osborn, 2008) and *'examine in detail psychological variability within the group, by analysing the pattern of convergence and divergence which arises,'*(Smith, *et al*. 2009; 50). Therefore the participants involved in this study shared a number of characteristics; all were either people living with a diagnosis of MND or partner of a person living with the disease, all participants were living in the same region of the UK and accessing care from the same care centre, all were aged between 55 and 80 years of age and all the couples were married and living together.

As the findings in qualitative research are always based on the researchers' interpretations it is impossible to replicate findings in other contexts. Theoretical transferability is therefore suggested as a better measure of quality in IPA studies (Smith et al, 2009); this refers to whether the reader considers the study reflective of the extant literature, their own professional and personal experiences and whether the findings can be considered as relevant to others with the same or

similar experiences. In order for a reader to ascertain this it is essential to provide them with contextual information regarding the participants and to '*situate the sample'* (Elliot, *et al*. 1999:220). Therefore additional and further details regarding the sample were presented, as far as was possible without jeopardising anonymity, such as the social-cultural background, ethnicity, employment, hobbies, and interests of the participants (see chapters 3 and 4).

A number of recruitment strategies were used in the study. Specialist nurses informed individuals about the study who, if they demonstrated an interest in participating, were subsequently contacted by me to arrange an interview. Summaries of the study were placed in newsletters aimed at the MND community and information sheets were distributed by allied health professionals who were in contact with the families (appendix 2). Eleven people declined participation, mainly due to ill health or time constraints.

Ethical considerations

Throughout the study in order to meet high quality thresholds and achieve best practice, my research was based on and guided by certain ethical values or principles. Beauchamp and Childress (2001) outline four moral principles; respect for autonomy, non-maleficence, beneficence and justice. These are commonly referred to, and expanded on, in various ethical frameworks in the field of health. My interpretation of these principles influenced my own ethical deliberation and dictated how I functioned as a research practitioner. At every stage in the research project I was aware that the autonomy and interests of participants should take precedence over my agenda.

Ethics is a major concern in the field of palliative care research, largely because of the involvement of participants who are dying from a terminal disease. Palliative care patients are regarded as '*vulnerable*' and therefore '*relatively or absolutely incapable of protecting their own interests'* (Levine, 1986 in Casarett and Karlawish, 2000: 130). This study raised a number of ethical issues for consideration and as Seymour and Ingleton (2005:65), acknowledge, the researcher in the field of palliative care needs to ensure '*that the participants' rights to autonomous choice, informed consent, lack of harm, confidentiality and anonymity, respect and dignity are protected throughout the course of study.'* Throughout the entirety of this study, I endeavoured to ensure that the participants' rights were upheld in regards to informed consent, confidentiality and support; I will now discuss each of these areas in turn.

Informed consent

In order to obtain informed consent, this study focused on the three areas outlined by Alt-White (1995): freedom to decide, clarity of information and the decision-making capacity of the individual. All potential participants were provided with a clearly written information sheet which briefed them fully as to the purpose and the procedure of the research. They could read this at their own leisure and discuss the implications of taking part in the study with family members. This sheet also included an account of my background and qualifications. Participants were given an opportunity to ask me any questions they may have had about the study and discuss what their involvement would entail, which enabled me to establish that they were fully informed about the study before consenting to take part using a written form (appendix 3).

Usher and Arthur (1998: 693) acknowledge obtaining informed consent is not a static '*once and for all'* event but an '*active, dynamic process of renegotiation between the researcher and the participant'*. Accordingly, process consent was used; whereby participants are consulted at regular intervals to ensure their consent is on-going. MND is fatiguing and it was a possibility that people with the disease might have found being involved in the research more exhausting than they first expected, or that they could have felt particularly unwell the day I visited and therefore not able to complete the interview. The emotional impact of their terminal condition, particularly as this study was addressing some of the more emotive, sensitive areas of their experiences, may have meant that participants found taking part more distressing than they had envisaged. As speech problems are also a common symptom of the disease, and at times participants may not be always physically able to say they are unwilling to continue, I therefore needed to ensure their answers were unambiguously clear, regardless of the means of communication they utilised, before I accepted them.

Another risk in conducting research with vulnerable individuals is that their decision to take part comes from feelings of obligation. My own position as an independent researcher and not involved in any way with patients' care, emphasised that their part in the study would not jeopardise their care. The participants were therefore continually assured that, since their participation was voluntary they were free to withdraw at any time; their care and treatment would not be affected in any way and confidentiality would be maintained at all times throughout the study.

Confidentiality

Ensuring anonymity and confidentiality throughout the research process are other means of reducing harm to participants. These were assured by limiting access to personal data exclusively to those involved in the study, (myself and the research supervisors). Once the interviews had been transcribed the digital files were deleted. All data were stored on computer files and access was restricted. To maintain confidentiality regarding any information which was given, transcripts were anonymised by removing all names and other potentially identifying data from the interviews. Participants were assured that in any reports or publications resulting from the study, no identifying features would be used. Participants were given the opportunity to withdraw any of their comments which they did not wish to be included in the final transcript.

Support

It was recognised that the subject matter of the study could be distressing for both the partner and the person experiencing the disease and that participants may perceive time spent carrying out interviews as detracting from valuable time they would rather spend in other ways, or as imposing additional burden on family members. Parkes (2006) suggests that, in the likely event that a participant becomes distressed during the course of the interview, 'scientific detachment' should be disregarded. Moreover if a participant requires emotional or other support, the researcher should provide it and other sources of help or counselling should be available if any of the participants require them.

Arrangements were made to provide additional emotional and psychological support through the MND Care and Research Centre in case such a situation arose and a participant required additional support as a result of taking part in the study. In accordance with the ethical guidelines provided by the NHS in the research governance framework (Department of Health, 2005), the participants' considerations always took priority over the research agenda; if at any time a participant felt too distressed to continue with the interview, non-maleficence dictated that the interview would be ceased immediately. During the course of the interviews, however, although participants were given the option to stop, no participants felt so distressed that they did not want to continue. Another means of safeguarding against unwarranted distress in participants was the involvement of supervisors on the study, who had a sound knowledge of the concerns of palliative care, methodology and ethical demands.

Ethical approval

In order to aid the design of an ethically responsible research study, approval was sought from both the internal ethics committee of the Faculty of Health and Social Care at Edge Hill University and the NHS. The study strictly adhered to the ethical guidelines of both institutions and the research and governance requirements as stated in the 'Research Governance Framework for Health and Social Care', (2005) which outlines the principles and procedures for carrying out research within the health service. The importance of data protection, ethics committees, informed consent and confidentiality, as well as the need to involve service users in research design are all emphasised in the framework. Prior to the commencement of this study an ethical approval was provided by the North Manchester NHS Research Ethics Committee (REC), entirely independently of the organisations funding or hosting the research (appendix 4). In addition, research and development approval was granted by the Lancashire Teaching Hospitals NHS Foundation Trust (appendix 5). I was continually aware that having gained ethical approval from the NHS did not guarantee that the study would be conducted in an ethical manner; I understood that ethical decision making was an ongoing process and that it was my responsibility as a researcher to identify and address any ethical issues that may arise throughout duration of the study.

A final ethical concern in this study was the question raised by Beaver, *et al.* (1999) as to whether carrying out research with terminally ill people for the purpose of academic work is in keeping with ethical principles of beneficence and non-maleficence. It could have been argued that this question should be applied to my study as it was hoped it would result in personal gain for myself, in the form of an academic qualification, and also by way of professional development. Parkes (2006) states that any benefits for the researcher, academic or professional, should derive from the quality of the research in a field dedicated to advancing our knowledge of the condition, and the best ways to help people with it. Accomplishing work which will contribute to improving care and services for those with the disease must be paramount for a researcher properly guided by ethical principles.

Data collection

As the aim of any phenomenological research *'is to understand the lived experience from the perspective of the respondents*' (Taylor, 2005; 47), it was considered necessary to employ methods of data collection which would capture the participants' own words with minimal direction or influence from the interviewer. The following section describes the two components of the study and discusses the methods of data collection employed.

Part 1: Case study

The longitudinal case study comprised a journal and interview conducted with a couple living with MND. In order to maintain anonymity the pseudonyms *Jackie* and *Frank* have been used throughout. The couple kept a personal journal for the period of one year, which was completed on a daily basis and sent to the researcher by email at the end of every month. Jackie and Frank carried out the diary using a computer and uploaded it as an online blog which was password protected and accessed by friends and family only. As Jackie experienced physical deterioration resulting from the MND, she was able to use voice activated software to continue to complete the journal.

This longitudinal aspect to the study, allowed me to examine how the couple made sense of their experiences over time. It provided me with a valuable insight into the couple's intimate experiences of MND for the entire disease trajectory of one year, from the time of diagnosis up until the death of the individual with MND.

The use of diaries or journals as a method of data collection in qualitative research has, until the last decade, remained fairly scarce. However, they are beginning to be increasingly used in studies in health-related fields (Jones, 2000; Rancour and Brauer, 2003; Midtgaard, *et al.* 2007). Diaries and journals are considered to provide *'a fresh and personal insight into participants' lives'* (Valimaki, *et al*. 2007) and represent an extremely useful source of data, which allows the researcher to examine individuals' sensations, thoughts and emotions in daily life in a relatively unobtrusive manner for the participant. The use of diaries for palliative care research has been recommended (Valimaki, *et al*. 2007) and were therefore considered a useful technique for obtaining data from participants in this study, who were either experiencing a terminal disease or were married to someone with the disease. Milligan, *et al*. (2005:1883) outline the strengths of using this form of data collection; firstly it enables the study to be participant led as the individual themselves prioritises areas or issues which they consider to be the most significant. Secondly it offers potential for researching highly sensitive and emotive issues which may be difficult to broach using interviews, such as trauma, abuse, death, illness. Thirdly, the quantity and quality of the data will often be superior to that gained via questionnaire or interview techniques, as diaries or journals '*can capture an event, close to when they unfold and have the potential to trace events over continuous time and across space*' and are not subject to memory loss. The participants in this study were provided with brief instructions as to how to carry out the diary, requesting them to describe how the disease was affecting their lives and included some prompts such as physical symptoms, emotional mood and feelings, people involved in their care and use of equipment and adaptations (appendix 6).

Part 2: Interviews

By employing a qualitative approach in this study, I was enabled to explore the subjective experiences of couples living with MND. According to Willig (2003) interviews can claim a number of benefits, which include flexibility, access to subjective meanings, perspectives and interpretations, the acceptance of individual differences and sensitivity to diverse forms of expression. Therefore by incorporating this type of data collection into the study my aim was to learn *'what is important in the mind of the informants: their meanings, perspectives, and definitions; how they view, categorize and experience the world*.' (Taylor and Bogdam, 1989:88).

Interviews with open and exploratory questions are considered to provide the researcher with the flexibility to understand the world from the 'insider's perspective' (Conrad, 1987), as they allow accurate reflections of the patient's and carer's experiences and capture in the participants' own words, their thoughts, perceptions and feelings. It was envisaged that this method, therefore, would give me the opportunity to discuss and explore with the participants and to probe more deeply into their accounts. Reid, *et al*. (2005) and Smith, *et al*. (2009) suggest that loosely structured interviews are considered one of the best ways to obtain rich and detailed data for IPA studies.

Narrative interviews were used to collect data in this study. This form of interview is considered to provide a story of events or life experience which closely reflect the respondents' personal, potentially disjointed reaction, without forcing any consistency on their way of thinking (Jovchelovitch and Bauer, 2000) and have been shown to be used effectively with people with MND in previous studies (Brown and Addington-Hall, 2008; Locock, *et al.* 2009). The interviews followed the same format as that outlined by Wengraf, (2001) and used by Brown and Addington-Hall, (2008). The first question used to guide the narrative was '*I am interested in learning about how you are living and coping with MND. Please begin wherever you like. I will listen first, I won't interrupt you. I'll just take some notes in case I have any questions when you've finished telling your story.*' The second part of the interview involved the researcher seeking further clarification or detail regarding some of the issues arising in the narrative and a series of prompts was also developed and informed by relevant literature (appendix 7) which included diagnosis, experience of service provision, end of life issues. The final section of the interview included more general questions such as '*How has MND changed the way you live?*' This narrative interview structure enabled the participant to lead the interview but also allowed me as the researcher to maintain a scheme of topics to be covered during the interview. These initial topics were modified in light of the participants' responses and I was able to probe interesting or significant topics which arose during the course of the interview which

ensured that the interviews were not guided by my own assumptions or agenda but shaped by the participants themselves.

The interviews varied in length from 40 minutes to 1.5 hours. Tuckett (2005) argues that prior engagement with literature can enhance qualitative research by sensitising the researcher to the more subtle features of the data. The questions posed were both broad and open ended to allow participants to divulge information they felt was most salient. All interviews were digitally recorded and transcribed verbatim. Topics raised in initial interviews were subsequently raised by the researcher in following interviews with other participants.

The vulnerable nature of the client group and the emotive subject matter being researched meant that it was essential for me to consider how the methodology and procedures used to obtain data in this study were appropriate and sensitive. Liampruttong, (2007) states that conventional qualitative research methods such as interviews are frequently unsuitable for vulnerable individuals and innovative and flexible methods should be adopted which are more tailored to the individuals' needs. She lists a number of different strategies which have been used with other vulnerable client groups including telephone interviews (Wenger, 2002), interview proxies, (Morse, 2002) and conjoint interviews (Morris, 2001). Furthermore, in their work with people with dementia, Kitwood and Bredin, (1992a, 1992b) advocate the use of a helpful and empowering social psychological approach in order to dispel the concept of a "*malignant social psychology*" outlined by Kitwood (1990:181) which can frequently result in disempowerment and stigmatisation. This is also relevant to my study as, Lloyd, *et al.* (2006) suggest that individuals experiencing other forms of neurological impairment may also be vulnerable to such infringement. It has been suggested that listening to views of the individuals themselves represents a significant advancement towards enabling this process of empowerment (Procter, 2001) and qualitative interviews can provide a voice to individuals whose perspectives are frequently under-represented, *'validating and publicising their views*' (Burman*,* 2003:51). Therefore, in order to ensure that the voices of all the individuals' participating in this study were documented, including those who were experiencing extreme physical degeneration and difficulties with speech as a consequence of the disease, alternative interview options were available. These included telephone interviews, interview responses written by email and conjoint interviews allowing supported communication via their spouse or partner.

Data management

Transcription of the data set was carried out verbatim and saved as individual Word files. Checks were made by the researcher to ensure accuracy and rigour between the transcripts and recordings by detailed proof reading and repeated listening to the recordings.

Analysis

As Smith (2011:10) acknowledges, an experience cannot be '*plucked straightforwardly from the heads of participants*'. In order for a researcher to gain an understanding of another person's lived experience it is necessary to undertake a process of engagement and interpretation. Furthermore, the individual is also engaged in a process of interpretation of trying to make sense of their experiences. For this reason, IPA has been described as comprising a two-stage interpretation process, or a '*double hermeneutic'* (ibid). The researcher has to both empathise with the individual's perspective, and ask questions about the information gleaned from that perspective. "*The participant is trying to make sense of their world. The researcher is trying to make sense of the participant trying to make sense of their world*" (Smith and Osborn, 2003:54). My '*making sense'* required an awareness of how my process of interpretation '*depends upon, and is complicated by [my]…conceptions*'. I therefore remained alert to ways in which, for example, the participant might be delivering information to comply with what they imagined I wanted to hear or how my own expectations and assumptions may be influencing my interpretation of their account.

IPA adheres to idiographic enquiry, (Smith, *et al.*1995) as the researcher engages in an interpretative relationship with each individual case. One transcript is analysed and examined in great detail before moving onto others and the aim is to progress from features in particular transcripts to common characteristics. Smith (2007) describes IPA as an iterative and inductive cycle which is characterised by a series of strategies, outlined in five steps by Smith *et al*. (2009), which take place during the IPA process. Inductive is considered as meaning to take a bottom up approach rather than top down:

> *'Asking the participant as expert to talk about the way they think about an issue, rather than using a priori hypotheses to make assumptions about how people think*.' (Smith, *et al*. 2009: 135)

IPA is also committed to an iterative approach in that it allows the researcher, to adopt a circular rather than linear process of analysis. The researcher is encouraged to move backwards and forwards across different stages of the data analysis, to ruminate and adapt their propositions in light of new evidence.

The six steps which were adhered to during this research study for analysing the journal extracts and the interview transcripts are illustrated in a flow chart below.

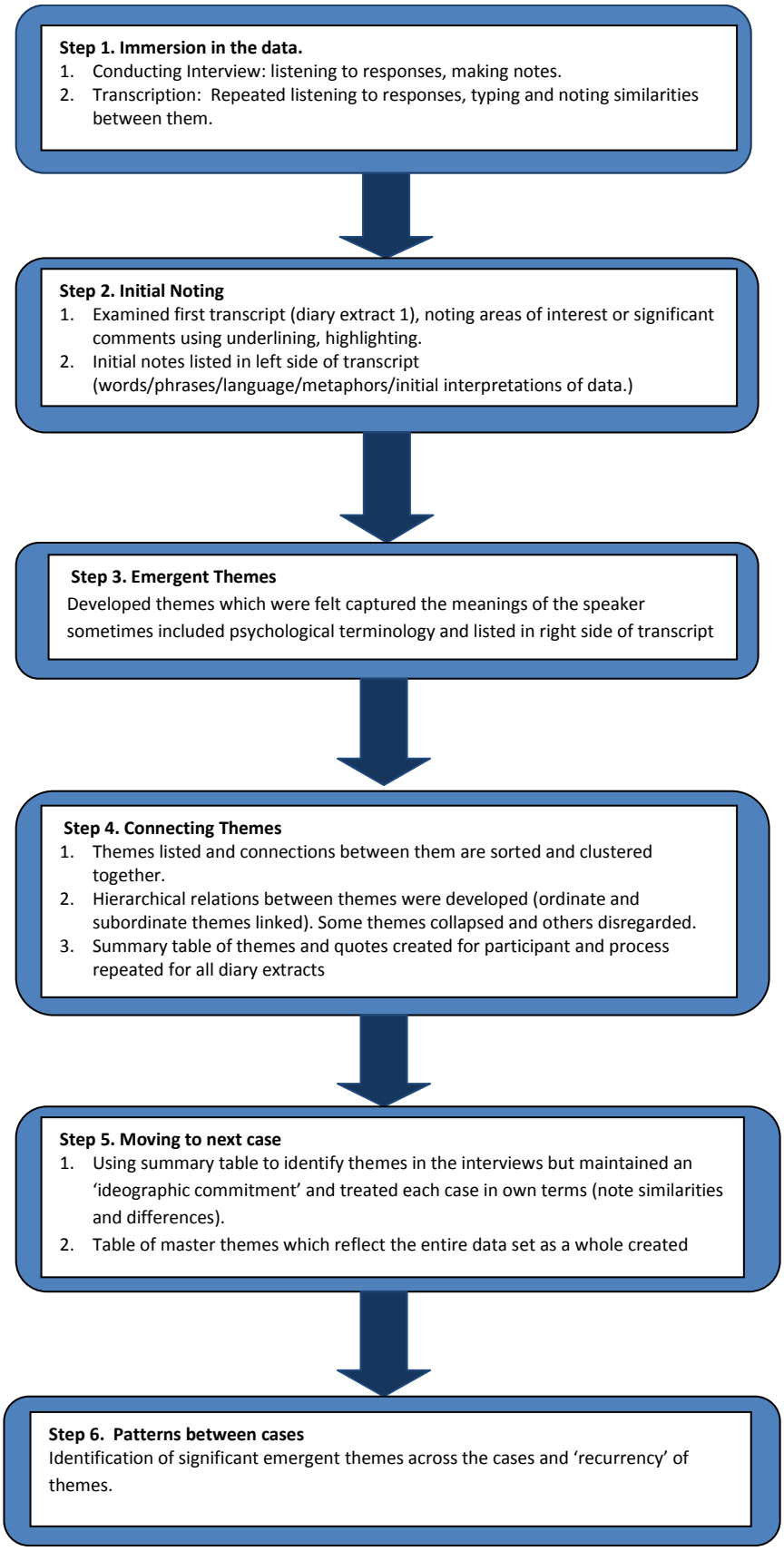

Figure 1: Chart showing six analytical steps undertaken in this study.

Step 1. Immersion in the data

The aim of this first step was for me to enter a '*phase of active engagement with the data'* (*ibid*). My initial exposure to the data was through direct participation in the interviews; I listened to the individual's responses and began to identify patterns and differences in them. This continued with the production of a verbatim, orthographic transcription of every verbal utterance of the interview (appendix 8). Bird (2005) and Braun and Clark (2006) emphasise the critical nature of the stage of transcription in qualitative analysis and especially the importance of retaining the essential 'truth' of the original format. Therefore punctuation was added to the transcripts so that the original meanings of the utterances would not be lost or misconstrued. Immersion in the material was further enhanced via repeated listening to the recording and reading of the written text of the first transcript. During this process I made notes of anything I recollected about the interview situation, such as interruptions or ambient noise. I was acutely aware of the requirement at this stage to ensure the focus of the analysis was on the participants (people with the disease and their partner). Smith, *et al*. (2009) suggest that such close repeated reading of the transcript allows a researcher to familiarise him or herself with the ebb and flow of the interview, enabling observations of the transitions from the 'general' to 'particular'.

Step 2: Initial noting

This stage involved scrutinising the text carefully, for anything within it that appeared interesting or significant. I made notes, underlined, highlighted any striking features within the text. At this early stage, I attempted to assume the unbiased and consistent interpretation of the data. Smith, *et al*. (2009) suggest these initial notes frequently consist of descriptive comments (key words or phrases which the participant uses), linguistic comments (language use and semantic content) and conceptual comments (interpretative understandings of the respondents' comments).

Step 3: Developing emergent themes

The next stage involved a more focused and systematic examination of the transcript. I sought emergent themes from the various exploratory notes elicited from the data set to reflect the most salient meanings within the individual's narrative. Themes should be a combination of both the authentic utterances of the participants and the analyst's interpretation, furthermore thematic labels should capture the meanings of the speaker (Biggerstaffe and Thompson, 2008; Smith, *et al.* 2009). Labelling was a gradual and changing process whereby initial codes were allocated and reallocated as new themes emerged.

Step 4: Searching for connections across emergent themes

Emerging patterns across the themes were then identified and similar themes were clustered together. Throughout this stage I was determining the relationship between the various themes, and some were identified as super-ordinate themes, others sub-ordinate and those themes lacking prevalence or enough substantial evidence to support them were discarded. As Biggerstaffe and Thompson, (2008:218) highlight, frequency of themes does not equate with significance and themes should not be selected as super-ordinate on recurrence alone. They emphasise that the '*richness*' of the selected account is important to consider. Some themes were recognised as being essentially the same and were merged together; others were noted as demonstrating diverse or distinct subjects and separated accordingly. For example, the theme 'loss of social self' became split into two sub-themes entitled 'loss of social purpose and participation' and 'social marginalisation and diminished relationships'. At this point in the analytic process, verification of my themes was conducted by my supervisors and members of the IPA online forum, (www.IPA.bbk.ac.uk), in order to refine and review the themes. The forum has been set up at Birkbeck University by Smith (2009) and a number of experienced researchers in the IPA field as an online support network for researchers and students. Once the themes had been clarified and I was satisfied that they provided a clear and accurate overview, a graphic representation of the categorised themes in a concise and structured format was produced (see tables no 3 and 4, chapters 3 and 4).

Step 5: Moving to the next Case

After having completed the steps for the above process for the first case (Jackie and Frank's nine extracts of diary and interview transcripts) I then moved onto the next case (interview transcripts of the remaining data set) and repeated the same procedures of reading, initial note-taking, developing emergent themes, and searching for connections. In undertaking these procedures, I attempted to adhere to the principles of 'analytic induction' (Hammersley, 1989; Robson, 1993), examining each new case in turn. In accordance with the IPA 'ideographic commitment', I was required to treat each case in its own terms and also maintain an inductive emphasis by allowing new themes to develop whilst retaining objectivity, and resisting being overly influenced by the findings from the previous analysis.

Step 6: Looking for patterns across cases

The final stage involved looking for most significant emergent themes across the cases. This involved deciding which themes were 'recurrent'. Smith, *et al.* (2009) suggest when working with larger samples of participants (six or more), a super-ordinate theme should be present in at least a third of

the cases and classed as recurrent in order to ensure validity. Furthermore, in IPA, the aim of the analysis is to consider both the ways in which the themes across all the cases are convergent (similar) and divergent (different) in order to develop a balanced account of the individual experience (Reid, *et al*. 2005; Smith, *et al*. 2009). By including those aspects which do not fit with the rest of the data demonstrates that analysis given is not just one-sided (Yardley, 2008). She also suggests that the exclusion of negative cases from the analysis can also reduce the generalisability as it is possible that they are representative of a larger portion of the population as a whole. There is also the possibility that divergent themes may suggest interesting topics for the discussion and potential avenues for further research.

The challenge for me at this stage in the analytic process was to stay true to the 'hermeneutic circle'; to make assertions for a large group whilst still preserving the ideographic focus and individuality of each case. The result of integration of all the cases analysed was the generation of a list of super-ordinate themes which was thought to capture the phenomenon under investigation and provide an insight into the essence of the phenomenon itself.

Themes were then written up into a narrative, which contained detailed extracts and illustrative quotations from the individual's transcript, in order to provide a *'convincing account of the nature and quality of the participants' experience of the phenomenon under investigation*' (Willig, 2001;60).

The '*insider's perspective'* (Reid, *et al*. (2005:22) should be developed by following this inductive and iterative procedure and represented accordingly in the researcher's interpretative account. Reid *et al*. (2005) emphasise the necessity of balancing the 'emic' (insider representation) and the etic (outsider interpretation) whilst conducting this analysis. I have sought therefore to ensure that the narrative accounts of the analysis findings in this study include an equal mix of verbatim quotes from the participants and my own interpretations of them.

Validity and reliability Issues

The concepts of validity and reliability are integral to both quantitative and qualitative research enquiry and as Morse, *et al*. (2002:2) states *'without rigour, research becomes worthless, is a fiction, and loses its utility.*'

However, there has been a growing unease as to whether the validity and reliability are sufficient as criteria conferring rigour upon qualitative research (Lincoln and Guba; 1985; Graneheim and

Lundman, 2004). In their place a number of researchers have suggested alternative terminology such as *trustworthiness, credibility* and *transferability*. As Yardley, (2008) states validity is an important consideration but it is necessary to evaluate research in accordance with appropriate criteria. I thus familiarised myself with a number of published guidelines for assessing quality and validity in qualitative and IPA studies (Elliot *et al*. 1999; Yardley *et al*. 2000; Smith *et al.* 2009; Smith, 2011) to ensure that this study met these specific criteria. I will consider these issues in detail in the discussion chapter.

As the analysis undertaken in this study relied on my own interpretation of the data it was necessary to ensure that this interpretation was as credible as possible. Therefore an independent 'audit' was carried out on my initial themes by my supervisory team. As analysis is a subjective process and each person will draw out their unique interpretation, inter-rater reliability should not be the aim of the audit. The intention of the audit is instead to verify whether the interpretations can be drawn from the data (Wyer, *et al*. 2001). Collaborative verification techniques can also help to identify missed themes and to clarify the coding and labelling of themes, ensuring that the analysis is comprehensible to the reader (Yardley, 2008; Smith, *et al*. 2009). I sought further verification checks through the use of the online IPA forum (www.IPA.bbk.ac.uk). I formed a small group with other members and shared my analysis with them, who were then able to provide feedback and suggestions. All identifying features had been removed at this stage and confidentiality was assured between the group members.

One significant measure of validity in qualitative research is that there is sufficient evidence provided for the themes. In IPA this should be demonstrated by the inclusion of authentic quotations taken from the data which are considered to be good examples of the interpretation made by the researcher. Smith (2011) provides specific guidance as to how many quotations should be included for each theme and suggests that in studies with a sample of more than eight, there should be at least three quotations for each theme discussed. He also states that these should be taken equally from across the data set. The inclusion of tables of prevalence in studies with larger samples which can clearly illustrate the representativeness of the analysis is advocated by a number of IPA researchers (Reid, *et al*. 2005; Smith, 2011) (see chapters 3 and 4). By including the authentic representations of the perspectives of participants, contextualising these findings and emphasising commonalities within the wider literature, I have endeavoured to ensure there is a sufficient grounding for valid results in this study.

Triangulation is another way in which the validity of this study has been strengthened by enhancing the depth of the analysis. Flick (1992) suggests that the drawing of others' accounts provides a greater understanding of the phenomenon by ensuring that it is viewed and considered from different perspectives. Yardley (2008:240) suggests that triangulation through the inclusion of data gathered by different groups of people or via different methods in the research study can '*enrich our understanding*.' Thus the seeking of understandings from couples (people with the disease and their partners) and the combination of analysis of both interview data and diary data in this study, can be considered ways in which triangulation has been used to increase validity.

Another essential way of ensuring validity in IPA studies is through the incorporation of reflexivity. As stated earlier, there is never "*a view from nowhere"* (Gallagher and Zahavi, (2007:40) and all research will be influenced by the researcher's own assumptions, beliefs and experience. As Biggerstaffe and Thompson (2008) state, rather than seeking to achieve the unfeasible task of limiting the researcher's influence in the analytic process, in IPA the role of the researcher is acknowledged and explored:

> '*The interviewer's thoughts and feelings are admitted as explicit and thus legitimate components of the enquiry, and their congruence or divergence from those of the participant are matters of proper enquiry.'*

In this thesis, therefore, I have included a reflexive chapter (chapter 6) which uses sections of my reflexive diary to emphasise my own position in the research process and explores the ways in which this may have contributed to the interpretations I arrived at.

Morse, *et al*. (2002) propose that the verification strategies of ensuring methodological coherence, sampling sufficiency, data collection and theoretical thinking and development need to be incorporated within the research design itself in order to maintain rigour throughout the study:

> '*Together all these verification strategies incrementally and interactively contribute to and build reliability and validity, thus ensuring rigour. Thus the rigour of qualitative inquiry should be beyond question, beyond challenge and provide scientific evidence that must be integrated into our developing knowledge base*' (Morse, *et al.* 2002: 13).

I have sought to ensure all of these strategies have been considered and incorporated into the methodology from the very conception of this study.

Potential difficulties and practical issues relating to methodology and method

There were a number of potential methodological difficulties which could have arisen in this study resulting from the nature of the participants' terminal condition. Addington-Hall (2002) and Steinhauser, *et al*. (2006) discuss a number of problems to which palliative care research is susceptible, such as failure to identify and recruit sufficient numbers or broad sample of participants, high attrition rates and incomplete data. However, the ideographic nature of the IPA sampling method which requires only small samples, meant that this was not a difficulty in this study and was therefore considered very appropriate to research with this particular client group.

Steinhauser, *et al*. (2006) acknowledge that recruitment can often be hindered by practical considerations such as time constraints and lack of incentive. Moreover access to participants has to be negotiated by specialist palliative care providers and despite their best intentions to support such studies, the clinicians' priority is immediate care to patient. Moreover, previous research has demonstrated that staff are likely to refer individuals they consider as amenable and avoid those they perceive as particularly vulnerable or perhaps difficult. 'Gatekeeping' such as this may have been a potential issue in this study as clinicians recommended potential participants to take part in the study based on their own personal criteria and knowledge of the patients. However, poor recruitment was not found to be a difficulty in this study.

Another methodological problem, which is recurrently cited as a feature of longitudinal palliative care research, is sample retention. Withdrawal may occur for a number of reasons, including ill health, comorbid conditions, the need to receive treatment, patient and caregiver levels of stress and death of participants. Higher retention is better maintained when the study requires fewer data collection points (Beaver, *et al*. 1999) and Steinhauser, *et al*. (2006:752) state that the initial design of the research is paramount in sustaining both participation in the study and a healthy balance between participant considerations and the research agenda:

> '*Investigators must carefully weigh maintaining low burden against the desire to document the patient and caregiver experience, and associated needs at the end of life. Recording that complexity is both the research challenge and the source of multi-dimensional evidence necessary to improve the formal care rendered to this vulnerable population*.'

I was therefore mindful to not intrude too much on the couples' time and contact and visits to their homes were kept to a minimum. A pilot study may have further ensured the participants' needs, but this was not feasible due to time limitations. However, the interview design had been used

successfully in previous studies with this client group (Brown and Addington-Hall, 2008; Locock, *et al.* 2009).

In addition, retention of participants has also been shown to be influenced by the rapport between the research team and the participants (*ibid*). Therefore from the outset, I endeavoured to ensure that this was achieved by establishing an honest and open relationship with individuals participating in the study. I encouraged trust between myself and the individual by conducting the research in a location in which the person felt comfortable and at ease and by being flexible and sensitive to their needs throughout the research process.

Summary

This chapter has provided an outline of the phenomenological approach and its assumptions which were used to frame this study. In addition, the methodology and methods employed in this study, (IPA) have also been described and an overview of the issues regarding ethical considerations, validity, reliability and methodological practicalities have been discussed. The following chapter presents the findings of the analysis of the data from the diary and chapter four reports the findings from the interviews.

Chapter 3. Findings from the longitudinal case study (analysis of one interview and journal kept by one couple living with MND.

Introduction

This chapter details the findings of the analysis of a longitudinal, case study of one married couple, Jackie and Frank, who experienced living with MND for the period from just following Jackie's diagnosis until the time of her death. The pseudonyms Jackie and Frank have been used to maintain anonymity. Approximately two months following Jackie's diagnosis of MND, an interview was carried out with the couple. The data from this interview has been analysed alongside data taken from a journal which the couple kept for just over 11 months. The case study comprised a journal of nine entries, spanning the entirety of the couples' lived experience of MND. The extracts varied in length and incorporated different time periods. For instance the first extract incorporated the partners' first four months of living with the diagnosis whilst later extracts just detailed one month. Both Jackie and Frank wrote their own sections of the journal separately in a Word document on a computer and the journal was also used as an online blog for friends and family to keep them informed of what was taking place in their lives. The blog was set up with password protection to ensure confidentiality. As Jackie's voice deteriorated as a result of the disease she used voiced activated software to enable her to continue to provide accounts of her experiences. The final extract carried out by Frank, describes the last days of Jackie's life. By analysing both the interview and the journal, I was able to interpret the couple's experiences over time and provide an intimate portrayal of the way in which MND impacted on the many different areas of their lives. The couple reported their experiences of seminal life events, their family, friendships, holidays and provided a moving insight into how they were trying to make sense of what was happening to them.

Participants

The couple were white, middle-class and lived in the north west of the UK in a rural area. Both Jackie and Frank turned 60 years of age during the course of the year that the study took place. They had both recently taken early retirement from their occupations; Frank had previously been a teacher and Jackie a social worker. The couple had been married for over 30 years and they had three adult children who lived in different regions of the UK. They also had two grandchildren. Up until the diagnosis they had both been active and enjoyed sports such as mountaineering, walking and swimming. Prior to the onset of the disease Jackie was a regular church goer and described herself as having a strong Christian faith.

Analysis

As discussed in chapter 2, interpretive phenomenological analysis of the journal entries yielded four super-ordinate themes and 17 ordinate themes which captured the essence of the couple's shared experience of living with MND. All themes that emerged from the data are detailed in table 3, appendix 9.

The following sections present the four super-ordinate themes and their constituent themes which were derived from the data. Each theme is discussed in turn and anonymised quotations which were considered best exemplars of these themes have been taken from the interview and diaries to corroborate my claims. An indication of the time span of the quotations is given but they are categorised according to themes rather than ordered in a temporal sequence.

1. Altered body

Reflecting on the experience of living with, and living in, a body that has undergone significant changes as a consequence of disease progression was a prominent theme found in both the interview and journal data.

1. i Awareness of the body

This theme encapsulates the ways in which the couple revealed an acute awareness of the changes occurring in Jackie's body as a result of the MND and the disturbance this set in motion regarding her self-concept. Throughout the journal, Jackie describes her recognition of the degeneration of her limbs and sense of a gradual loss of strength and sensation in her body:

> '*I am aware of the disease progressing. My legs are weaker and I cannot stand for very long …. The muscles in my calves are quite wasted.* (Jackie, journal 5, 8 months following diagnosis, line no. 124 - 125)

As the disease progresses, Jackie tracks the physical alterations she is undergoing and connects them with particular losses of physical capability. Automatic activities such as eating or drinking now pose extreme difficulty for Jackie, and she is conscious she can no longer take it for granted that meals will be enjoyable.

> *'Eating is becoming more laborious. Chewing takes ages. My food goes cold before I am halfway through a meal. I have to be careful with drinks and find them difficult to swallow at times.'* (Jackie, journal 8, 11 months following diagnosis, line no. 40)

Her husband, Frank shares this heightened bodily awareness and at times throughout the journal he acknowledges that the degeneration she is experiencing is both unpredictable and dramatic in its effects:

> *'One week she was able to walk a couple of miles along the coast of Holy Island, the next week she was unable to walk around a supermarket.'* (Frank, journal 1, 4 months following diagnosis, line no. 643-644)

Frank lives with his wife Jackie and shares life with her every day. Despite this familiarity with her advanced condition, he has moments of sudden realisation of the extent to which she has physically deteriorated, and his description of these episodes makes it evident that they are also quite disturbing for him:

> *'Even I, who am helping Jackie all the time, was shocked when the physio was checking out the mobility in her left arm. He was asking her to raise it as high as she could, and move it out to the side etc. I could see her willing it but it only moved a cm or two – the only way she lifted it was to use her other hand.'* (Frank, journal 4, 7 months following diagnosis, line no. 267-272)

Frank has a definite idea of what Jackie ought to be capable of in terms of particular physical movement. At other junctures he connects physical capability with how Jackie must be feeling when unable to express herself, demonstrating an acute awareness of the way in which the bodily degeneration and emotional state are mutually dependent:

> *'Jackie is physically much worse and is finding being unable to talk clearly very difficult. Emotions are difficult for her to control and then her speech becomes unintelligible.'* (Frank, journal 7, 10 months following diagnosis, line no. 157-58)

It appears to Frank that when Jackie struggles with an aspect of physical co-ordination, a reaction is caused in her whereby her emotional response worsens the original physical manifestation. Frank describes how this awareness of bodily deterioration can be all consuming and can result in constant planning when fine gradations of effort made versus energy held in reserve are balanced against each other.

> *'Will Jackie be able to get upstairs to the loo? Is it going to tire her too much and is it worth paying the price for that over the next week? This means we can become over cautious.'*
> (Frank, journal 1, 4 months following diagnosis, line no. 656)

Jackie recognises the centrality of planning and managing her condition to a strategy that will enable her to cope and face an uncertain future. Knowing what to expect can in some way assuage her fear of the future, knowing that as she loses bodily control, options will remain to her if they have been properly planned.

> *'And I'm a person who needs to know exactly what I'm in for and how it's going to be managed because actually I'm shit-scared about the future, shit-scared about how it's all going to be and I need to know what they'll do and I need to know what my options are.'* (Jackie, interview, 2 months following diagnosis, line no. 71-73)

It is clear that at an aspect of Jackie and Frank's planning is to establish times when they are not to think about Jackie's condition. It would become all-consuming without periods of respite when its current effects and Jackie's prospects are not being contemplated. They face a difficulty when trying to establish an equilibrium of when, and when not, to think about Jackie's issues. Despite their best efforts at planning, medical and other appointments arise which force them to sacrifice mental 'space' for the sake of further information that is not always welcome.

> '*We try and live from day to day and we do not avoid talking about the future and we have been quite good at certainly planning for physical needs. The problem with appointments is that they force you to think about these matters then and there and not necessarily when you want to do so*.' (Jackie, journal 4, 7 months following diagnosis, line no. 235-237)

Frank also concedes that appointments at times compel the couple to understand that the disease is advancing. This information, whilst accurate is not necessarily welcome or beneficial as coping with the disease requires protected periods of respite.

> *'Talking about what Jackie was (and wasn't) able to do highlighted the disease's progress. We are aware of that but this time when she blew into a machine her lung function registered 98% instead of 120%.'* (Frank, journal 4, 7 months following diagnosis, line no. 330-331)

1. ii Alienation of the body

With Jackie, the progression of the disease is identified by loss of physical function in tandem with an altered perception of herself. Her body is becoming less like a part of her, and more like a burdensome object or alien.

> *'My left arm is totally useless and very heavy. In bed I have to lift it every time I want to move. My right hand and arm is getting weaker… My facial muscles are affected a little bit and I have a lopsided smile. I feel numb around my mouth and it takes me longer to chew my food. I am also aware that I am beginning to slur my words sometimes. When I cry I feel my mouth being pulled downwards. It feels as if it is dragging and I cannot control it.'* (Jackie, journal 5, 8 months following diagnosis, line no. 126-131)

Her left arm has lost its instrumental function as a useable limb and has now become only '*heavy'.* Moreover, in the above quotation, she reveals an awareness of changes in her facial muscles which are altering her voice and facial appearance, both emblems of her personality and individuality. Her personality appears to be adapting to the emotional upheaval experienced. '*When I cry'* appears to reference an increasingly familiar and inevitable state, in as much as crying does not warrant special comment here. Jackie appears also to be beginning to feel that her body shape is altering as it loses its function. Her choice of the word '*dragging*' implies she sees herself as having undergone extreme and dramatic alteration. Jackie later describes how she feels the crying now occurs without her wish or need to and her description of '*horrible noises'* evokes again her sense that her body is responding in ways that are unfamiliar and strange to her:

> *'It is very awkward because often I cry when I do not want to and it is not the sort of crying that makes me feel better. I make horrible noises and I feel worse.'* (Jackie, journal 8, 11 months following diagnosis, line no. 17-18)

On another occasion she describes not being able to control her crying and how this is humiliating for her:

> '*Now I am losing some of my facial muscles it is difficult for me to cry quietly and I certainly didn't want to make a terrible noise and spoil it for (name of friends)!'* (Jackie, journal 6, 9 months following diagnosis, line no. 139-140)

The sense that her body has been overtaken by an alien force is again stressed in the diary when she reflects that she *'was like a zombie'* (Jackie, journal 3, 6 months following diagnosis, line no. 154). She clearly finds these bodily experiences disconcerting and describes her sense of losing control of previously automatic functions:

> *'It is very strange becoming aware of all these changes and not being able to do anything at all about it.*' (Jackie, journal 5, 8 months following diagnosis, line no. 136)

At one point in the journal, Frank describes Jackie's complaint with her shoulder. The above quotation provides a demonstration of the *'medicalisation'* of their relationship. At this and other points throughout the diary when he is describing his wife's body Frank uses purely physiological terms:

> *'As the use of muscles in the arm are lost, the shoulder is no longer held together firmly and this puts strain on the joint. Those few muscles which still work are trying to compensate and go into spasm… In bed Jackie uses an extra pillow to try and support the arm. I massage the shoulder with oil when the muscle spasms are really bad…*' (Frank, journal 3, 6 months following diagnosis, line no. 67-73)

The biological terminology and the use of *'the'* rather than '*her*' has a distancing and alienating effect, suggesting the shoulder is somehow apart from the rest of Jackie and no longer under her control.

1.iii Entrapped embodiment

Initially, her awareness that her body is in transition from being reliable and familiar to one that is no longer able to carry out physical exertion is merely frustrating and disconcerting. Having been a keen walker all her life, losing mobility and the use of her legs has a tremendous impact on Jackie and perhaps makes this loss particularly devastating:

> '*Had a strop at (name of lake). Everyone going for walk and I knew I could not keep up. Decided to flounce off to the Lake but could not tie my boots! Cried and laughed at the situation.'* (Jackie, journal 1, 1 month following diagnosis, line no. 91-92)

Eight months following diagnosis, her participation is completely denied and she experiences an even greater sense of devastation:

> '*The problem with lovely sunny autumnal weather is that it makes me want to get out and tramp the hills. I thought I had got used to not being able to do this but yesterday in the [name of place] I found myself getting quite upset just looking at the hills and not being to get into them*.' (Jackie, transcript 5, 8 months following diagnosis, line no. 4-8)

On occasions she describes a sense that her spirit is trapped inside a '*sick body'*. There is a clear sense that the failings of her physical body are holding her back and this is extremely restrictive:

> '*In my spirit I was walking high up, with my boots on, and my rucksack on my back. I was striding out along mountain paths, clambering up rocks, crossing streams and arriving breathless on the summit. However, in my body, I was just making the most of what I am able to do.*' (Jackie, journal 4, 7 months following diagnosis, line no. 177-181)

As she describes her fear of the future when the disease has progressed further, a sense of incarceration becomes more acute. The word *'trapped'* clearly indicates her feelings of being imprisoned in her own body:

> *'I try to envisage being trapped in my body unable to communicate.*' (Jackie, journal 6, 9 months following diagnosis, line no. 197-198)

At times, Jackie voices a sense that her body is no longer reflecting her real self and is distorting external perceptions of her inner state:

'My voice also makes me sound miserable even though I am not.' (Jackie, journal 8, 11 months following diagnosis, line no. 30)

Frank also expresses in the interview a full awareness of the sense of entrapment his wife is experiencing as a result of her body's decline:

'Jackie needs to go out in the fresh air. She needs to feel as if she can walk and do things and she can't do that and that's really hit her hard.' (Frank, interview, 2 months following diagnosis, line no. 291-293)

The word '*needs*' emphasises how this is particularly distressing for Jackie because of her previous active and energetic way of life.

1. iv Self in the physical world

Evidently, as Jackie's '*body–intentionality*' or embodied relation to the world, has altered greatly so does her perceptual view and understanding of the world. Jackie recognises that her understanding of the changes in her body are continually expressed and made sense of in relation to external objects:

'Physically the disease is progressing but I am only aware of this when I look back and realise that I can no longer do things I once did.' (Jackie, journal 3, 6 months following diagnosis, line no. 242-243)

It is evident from numerous statements made by the couple, that Jackie's body dysfunction has completely altered their physical relationship with the world. This recognition becomes apparent when Jackie describes the way in which objects have now become problematic to control:

'…I had to try different types of taps and shower controls and realised just how useless my left hand and arm has become.' (Jackie, journal 2, 5 months following diagnosis, line no. 78-80)

Simple household objects which were once easy habitual and familiar have now become arduous to manipulate:

'My good hand is weaker. I no longer have the pressure to switch the table lamp on. Using my mobile phone is tricky too.' (Jackie, journal 8, 11 months following diagnosis, line no. 37)
'Also I cannot hold a heavy cup. Sometimes I use a straw.' (Jackie, journal 8, 11 months following diagnosis, line no. 44)

Every day and mundane activities, such as typing, which were once customary and taken for granted are now complex and awkward, frequently result in failure or error. For instance Jackie describes the trials and tribulations of typing out the diary:

> *'I have just spent quite a lot of time talking to my computer and doing this week's entry for the diary. And then, idiot that I am, I have pressed all the wrong buttons and lost what I wrote.'* (Jackie, journal 3, 6 months following diagnosis, line no. 234)

Visiting the toilet is another example of the way in which, customary actions now pose hazardous and possible risk:

> *'One night earlier this week when I got up to go to the toilet I managed to fall. This is the first time this has happened and luckily I got away with only a bruised knee.'* (Jackie, journal 8, 11 months following diagnosis, line no. 32-33)

Frank too illustrates this essential body intentionality through his description of their daily routine. In the quote below, bathroom items which were clearly once habitual and familiar now represent challenging obstacles which need to be overcome or mastered with great effort:

> *'I'm listening for the shower to stop now – that is my cue to get the bath towel and drape it round her shoulders – something she cannot do without an enormous effort. It is a huge bath towel which means she just sits on another towel on the loo with her feet on the bath mat and waits for the water to be soaked up by the towels. The next step will be helping her fasten her bra and sometimes do up the trouser fastenings. She's been quite ingenious opening and using the shampoo and shower gel and so far is managing with the toothpaste although I've got to remember not to screw the top on too tight (those pump action ones get far too stiff to use).'* (Frank, journal 2, 5 months following diagnosis, line no.182-192)

The couple's body-intentionality is also altered by their reliance on various items of equipment, which is increasingly present in the couple's lives as Jackie loses physical functions. This humorous description of the couples' use of a mattress raiser clearly highlights the way in which their relationship with the world has been significantly transformed and at times assumes a surreal quality:

> *'This is a device which fits under the top of the bed, between the mattress and the base, and has an electric lever which lifts the top few feet of the bed... Unfortunately it tends to slide her down the bed instead or to lift the pillows as well and they end up falling on her! On the second day of using it she ended up with her feet hanging out of the foot of the bed and in danger of sliding the whole way out. (Name of daughter) suggested a trap door at the bottom of the bed with strategically suspended knickers and trousers, etc, as per Wallace and Grommet!'* (Frank, journal 7, 10 months following diagnosis, line no. 182-185)

2. Diminishing self

2. i. Loss of social purpose and participation

There are a number of instances when Jackie demonstrates an increasing awareness that her previous habitual ways of relating to the world (the activities and roles she used to maintain) are no longer available to her:

> '*I can no longer knit… couldn't do the cooking or cleaning. Oh, to do ordinary things*.' (Jackie, journal 1, 2 months following diagnosis, line no. 157/159-160)

These examples highlight how habituated ways of relating to the world become separate and distinct when no longer available. In addition to having her sense of self disorientated after bodily change and deterioration, her sense of self as a person depending on certain habits, pastimes and dependable relationships is also thrown into question by her condition. The physicality implied by ordinary household chores, 'cooking' or 'cleaning' illustrates how Jackie's thoughts of herself as an individual were defined by habitual ways of doing. Similarly her place in the rituals of church service is in doubt which also detracts from her ability to maintain her own personal worship:

> *'I enjoyed listening to the music but found it sad that I could not sing hymns or choruses. I used to enjoy singing - must be my Welsh blood!'* (Jackie, journal 2, 5 months following diagnosis, line no. 15-17)

These present losses leads to her projecting forwards in time and speculating about a future with further loss of participation in social and habituated norms 'it is highly unlikely I will be able…', perhaps reflecting back on an increasingly 'painful' perception of the present.

> '*It is highly unlikely that I will be able to do Christmas cards this year. I cannot write and I cannot put cards in envelopes…'* (Jackie, journal 4, 7 months following diagnosis, line no. 52-53)

The above quote is striking, as it is evident that the task of writing Christmas cards is bound up with a sense of her previous identity:

> '*I have always bought the cards and been the one to keep in touch with people.'* (Jackie, journal 1, 1 month following diagnosis, line no. 130-131)

She describes the recognition of such losses as greatly affecting her and leading to *'another low moment*.'(Jackie, journal 1, 2 months following diagnosis, line no. 132). Frank reveals his own frustrations and distress at not being able to continue to do activities that they used to enjoy together and articulates this as a sense of loss:

> *'The Spa is something that we joined together and we enjoyed swimming and relaxing together. Instead it brought it home to me that [Jackie] wasn't the only one who has to cope with constant loss.'* (Frank, journal 4, 7 months following diagnosis, line no. 320-322)

Jackie also describes how the significant roles of mother and grandmother are also lost to her as she is no longer physically strong enough to care for her grandchildren:

> *'Roles have changed. I can no longer look after my grandson one day a week. We cannot help out in any of the ways we used to…'* (Jackie, journal 1, 3 months following diagnosis, line no. 366-367)

There is a sense that being no longer able to carry out these activities results in a withdrawal of her relations with her grandson:

> *'I miss looking after (Name of grandson) on Mondays and feel not so involved with him as I was.'* (Jackie, journal 1, 4 months following diagnosis, line no. 300-301)

Frank also states his awareness of how the couple dynamic is altered in response to Jackie's illness and the impact this may have on his relationship with his wife:

> *'I'm a full time carer. I'm aware of that.'* (Frank, interview, 2 months following diagnosis, line no. 382-383)

Frank's recognition of this is particularly striking as it took place so soon following Jackie's diagnosis. Jackie also acknowledges that her husband's role is also changing as a result of his involvement in caring for her:

> *'Frank no longer has the time or energy to help the family out with practical tasks.'* (Jackie. journal 6, 8 months following diagnosis, line no. 140-142)

For Jackie participation in family life, understanding that such participation is not 'static' but implies active agency in useful and complementary roles, is another aspect of her loss of habitual behaviour and self-identity. '*No longer one-day-a-week*' illustrates how a predictable and dependable position of usefulness appears coupled with personal disappointment. Her usefulness is now in severe doubt, as is clear when she says '*we cannot help out*'. It appears here and elsewhere that Jackie's retreat from usefulness is understood the same as the burden of responsibility on her husband is scrutinised and occasions guilt: '*No longer has the time or energy*'. The inclusive '*we used to…*' gestures towards perceiving herself and her husband as a dual identity in the eyes of the family, one of whose expectations of grandparents is as providers of help.

Relations with family also become problematic as a result of the disease as the parents are no longer able to provide the support their children are used to and previous relational roles are in flux:

> *'But there have been problems there. Kids need support. They always do. And our children are no exception. (Name of son) is trying to get through a degree, and he's finding it very difficult, he's actually deferred because of the pressures of work. (Name of daughter) is trying to cope with the pressures of nursing. She's getting close to... Well, she got signed off for a couple of weeks sick. Because she's been working on nights far too long and is trapped in her job and she's finding difficulty with her job. And the other daughter, they're going through marriage breakup at the moment, so it's difficult… You know, they've given as much support as they can given they've all got families and problems'* (Frank, interview, 2 months following diagnosis, line no. 447-52)

> *'We've always been there for them and now we're not going to be, they're going to have to get on with it.'* (Jackie, interview, 2 months following diagnosis, line no. 116.)

There is evidence of rootedness in customary roles, although the context in which the roles are found is drastically altered. For Frank the responsibility of parenting, even '*children'* who are actually adults with children of their own, appears not to recede with age but intensify as adult *'children'* encounter difficulties associated with adult life. As has been mentioned Jackie was saddened by her loss of meaningful participation in family roles, and here Frank's evidence illustrates the complex, reciprocal obligations inherent in family life. He is acutely conscious of problems relating to '*pressures…working…marriage breakup'*, whilst Jackie concedes *'they're going to have to get on with it'*. Meanwhile Frank accepts of his children, '*they've given as much support as they can'*.

Not being able to carry out these previous roles and what she views as not being of '*use*' leaves Jackie feeling devoid of a sense of purpose:

> '*It is so strange not to have a purpose in life. I have always been a busy person, working, bringing up a family, looking after parents, etc. I know it is important to be and not just to do… but it is not something I find very easy.*' (Jackie, journal 3, 6 months following diagnosis, line no. 29-31)

Jackie also expresses her difficulty in accepting a transition from being a carer (both in her former employment as a social worker and in her personal life when caring for her father) to being cared for:

> '*She [health professional] offered me counselling which at the time I refused because it was just too strange being on the other side of the fence, I mean she was talking about loss and grief and I've got bookshelves of books on loss and grief and its taking me a bit to get my head round being cared for instead of being the carer… I could probably do with it, but I've avoided it because it's a change of role for me.'* (Jackie, interview, 2 months following diagnosis, line no. 193-195)

She reveals negative feelings towards this '*sick*' self, reflected in the derogatory terms she uses to describe her activities for example, 'trundled' or when her daughter is looking after her she describes this as '*babysitting'*. At certain points she reveals her desire to maintain this former self:

> *'For a week I could pretend that I was my old self and not this person with MND that I have become.'* (Jackie, journal 1, 2 months following diagnosis, line no. 277-278)

She notes that when sat round the table enjoying a meal with friends and her physical disabilities are not visible, she is able to retain her previous sense of self:

> '*At such times I felt 'normal' and no different from the others,'* (Jackie, journal 2, 5 months following diagnosis, line no. 277-278)

2. ii Guilt and burden

Jackie describes an increasing sense of guilt associated with the illness. She somehow starts to believe that she herself is responsible for having the illness.

> '*Must try and stay positive but I can't help blaming myself for what has happened however illogical that is.'* (Jackie, journal 1, 4 months following diagnosis, line no. 603-604)

Jackie reveals her sense of frustration at no longer being able to participate in the way she would normally. Her description of '*doing nothing*' implies she feels inadequate and suggests a sense of guilt that she is not doing the work herself:

> *'I do hate not being able to do things and it is especially hard when I feel I want to be making a special effort for his birthday. It is so frustrating sitting doing nothing and letting him do all the work.'* (Jackie, journal 2, 5 months following diagnosis, line no. 107-109)

As time goes on, Jackie reveals an acute awareness of the impact that caring for her is having on her husband and this too is linked to feeling of remorse associated with her sense of being the cause of his distress:

> *'He spends so much time looking after me and doing all the jobs that he does not have time to look after himself.'* (Jackie, journal 8, 11 months following diagnosis, line no. 65-67)

Her comments reveal an increased concern for his wellbeing and sadness that she can no longer support him in the ways that she is previously used to:

> *'He looks very tired and drawn at the moment. I am so used to trying to cheer him up or make things better for him when he is down that it is difficult now that I cannot do that*

anymore. I do worry about him.' (Jackie, journal 3, 6 months following diagnosis, line no. 127-129)

Although it is the disease which is the cause of this, her language often seems to suggest a sense of guilt and self-perceived burden; for instance the words '*pampering', 'mollycoddling'* and '*lazy'* evident in the quotation below all have connotations of being indulged and reflect her sense that she is unworthy of the care that her husband is now providing for her:

'He is pampering me and to some extent mollycoddling me... however, this means that I have a lazy time of it whilst he is always busy. The poor man is worn out.' (Jackie, journal 2, 5 months following diagnosis, line no. 187-190)

As Jackie experiences greater immobility, she reveals a sense of being dependent and needful which is clearly frustrating for her:

'(Name of daughter) has offered to 'babysit' me so Frank can go.' (Jackie, journal 8, 11 months following diagnosis, line no. 81)

These feelings of burden increase over time and Jackie accumulates feelings of self-blame:

'I keep beating myself up that I am ruining his life even though I know intellectually that it is not my fault that I have this disease.' (Jackie, journal 2, 6 months following diagnosis, line no. 222-224)

These feelings mount up and can lead to feelings of desperation:

'Last night I felt suicidal. Realisation of the situation seems to have hit home. I felt that as I was going to die, that I might as well get it over with and save everyone the hassle and anguish of the next months to come.' (Jackie, journal 1, 3 months following diagnosis, line no. 436-438)

Jackie later acknowledges herself that suicide ideation can be linked with feelings of burden:

'My main concern is not to wear [Frank] out. I can see that there could be pressure to end one's life simply to spare relatives the pain.' (Jackie, journal, 7, 10 months, line no. 85)

Frank rebukes her for thinking in this way and emphasises that he views his caring role as part of his love for her:

> '*I certainly do not want Jackie to feel any pressure in this respect. My love for her gets stronger...'* (Frank, journal 7, 10 months following diagnosis, line no. 105-106)

However, it is evident from moments in the journal, that at times Frank's caring duties do take their toll and prove to be physically demanding:

> *'To cap it all I have hardly been able to walk because I have pulled a muscle in my back – probably from completing rearranging the bedrooms.'* (Frank, journal 7, 10 months following diagnosis, line no. 145-146)

He also admits to finding it difficult to maintain his own emotional equilibrium, in the face of Jackie's feelings of hopelessness:

> *'I found it hard to cope with the suicidal lows she had.'* (Frank, journal 2, 5 months following diagnosis, line no. 208-209)

2. iii Social marginalisation and diminished relationships

This theme describes the inter-subjective characteristics of identity and the way in which these become more prominent in the face of multiple, recurrent diminishing of the individual self. The decrease in mobility, feeding and toileting problems mean that Jackie feels unable to access social occasions so frequently:

> *'I could get the wheelchair in but could not access the toilet so there is no way I could go to the dinner in a few weeks' time. I had already decided I would not go as the difficulties of talking and eating in a large gathering are too great, but today convinced me not to try.'* (Jackie, journal 8, 11 months following diagnosis, line no. 85-89)

In his description of attending his grandson's nativity play, Frank also demonstrates the way in which Jackie's restricted mobility can draw attention to themselves at social occasions. The quote below also highlights the way in which the couple have to become accustomed to a heightened sense of incongruity and greater self-awareness.

> *'She insisted on going at the end of the row and so needed moving etc. It pays not to be self-conscious! – It is quite common to have silence descend on a room whilst this goes on.'* (Frank, journal 7, 10 months following diagnosis, line no. 111-112)

Fatigue resulting from the MND also impacts on Jackie's ability to participate in life as she once used to. It appears to impede her ability to even interact with friends:

> '*It was lovely to see them but yet again I found myself very tired afterwards. I think I make an effort, without realising it, to chat and to catch up because I really enjoy it. I just forget that it does make me tired*.' (Jackie, journal 5, 8 months following diagnosis, line no 39-41)

The disease also hinders her access to valued support networks:

> *'I am going out less and haven't made it to church for a few weeks, which I miss*.' (Jackie, journal 8, 11 months following diagnosis, line no. 71-73)

Jackie demonstrates that the individual self is not sufficiently strong to enable her to cope with the experience of living with MND. She repeatedly voices her need for social contact and friendships and that being alone can be detrimental for her emotional wellbeing:

> *'If I have too much time on my own I get too introspective and then the self-pity starts which I absolutely hate.'* (Jackie, journal 3, 6 months following diagnosis, line no. 27)

Jackie perceives a change in her personality as a consequence of the disease and senses a difference in the way she is now to how she used to be. The phrase '*live in my head*' suggests that the disease has forced a departure from the external world into herself, which leads to increased introspection and reduced physical interaction:

> *'I seem to live in my head a lot these days. I think of things in a way I never did when life was fast and furious.'*(Jackie, journal 1, 4 months following diagnosis, line no. 389-390)

Two months later, Jackie describes how the disease is forcing both her and Frank to withdraw further into their individual selves. The word '*twilight zone'* suggests that this can feel a strange and alien existence where they are no longer participating with the world around them. They are therefore aware of the need to incorporate others in their lives to ensure they maintain some sense of social integration.

> *'Sometimes I feel I live in a twilight zone as I spend a lot of time on my own resting and reading or catching up on TV programmes with i-player. [Frank] also spends a lot of time on his own doing jobs and doing all the things that I can no longer do. So this contact with our friends and family is very important to us both in different ways.'* (Jackie, journal 3, 6 months following diagnosis, line no. 164-168)

Frank also describes this experience of alteration to the couple's '*life-world*' as a result of the disease. There is a sense expressed by Frank that this experience is isolating them both from others who cannot fully relate to what they are experiencing. In the two quotes below, Frank uses terms

such as the '*other side'* or a '*different world'*, both of which provide an indication of his feelings of being distanced and removed from the lives of their friends and acquaintances:

> *'I need to keep in touch with friends and 'be in the loop' but I still feel as though I'm on the 'other side'.'* (Frank, journal 2, 5 months following diagnosis, line no. 320-322)

> *'I went next door for mince pies and mulled wine on Christmas eve and found the talk between our neighbours about the respective weight of turkeys and who was coming for dinner a different world.'* (Frank, journal 7, 10 months following diagnosis, line no. 192-194)

There are those, Frank suggests, to whom one can '*talk about it'*, though they might not have been expected to listen and those with whom a dialogic connection remains absent:

> *'I find it difficult, and it really is difficult, it's very interesting when you talk to friends, how some people ignore the fact that [Jackie]'s got this disease, cannot cope with a problem, so they'll talk about anything except that and I find that awkward. You soon find out who you can be open to and who, you know, perhaps it's not a good idea to see anymore... I know a few friends I can talk to about it. Surprising sometimes who... who, you know, who your friends who you think you could talk to about it and don't turn out to be the ones who you can talk to, and those who you perhaps don't know that well who you can talk to about some of the problems.'* (Frank, interview, 2 months following diagnosis, line no. 349-354)

As Jackie reveals in the quotation below, this lack of understanding shown by others can at times be extremely distressing for the couple:

> '*I was doing quite well and feeling fairly strong until someone, without meaning to and probably without realising it, upset me by giving me what felt like a lecture into [Frank]'s needs. I don't need reminding what this is doing to [Frank] and I was heartbroken all over again.'* (Jackie, journal 2, 6 months following diagnosis, line no. 220-222)

Frank describes the previous relational, social self they both used to depend upon:

> *'We are members of a large mountaineering club... that we've been in for the last 40 years... 35, 40 years... And I've been very involved with it… And they are like a second family to us because we haven't got brothers and sisters, we're both only ones,'* (Frank, interview, 2 months following diagnosis, line no. 420-424)

As the disease progresses and Jackie loses her bodily functions, this former relational self also becomes increasingly problematic:

> *'but the problem is because they're all active people, like going in the hills, meeting up with them tends to be at the climbing hut, they tend to go off walking and then they tend to be planning all the next expeditions. So that isn't good...The fact that we can't go walking is a problem… most of my friends are mountaineers and quite active mountaineers, the*

> *conversation... you know, I find it difficult, in that, that's difficult with some of them, talking to them, we find it difficult meeting with them sometimes because they want to talk about where their next trip is, what their next mountain is and we know quite well that we won't be going up any mountains again unless it's in a cable car or something. Er, so that's quite hard.'* (Frank, interview, 2 months following diagnosis, line no. 427-430/356-361)

As with the distinction made between *'discursivity'* and simply '*talking*' above, there is an awareness here of the difference between friendship as a relational state, and as an act or series of acts. Frank's account of the mountaineering club gestures towards his awareness of the centrality of acts in human relationships; in this context there is no compensating equipment. Frank and Jackie simply cannot participate. Similarly discourses and discursive representation, (as opposed to the more fundamental '*speech acts'*, above), serve to delineate and separate: '*planning all the next expeditions'*. Frank touchingly alludes to the difficulty with discursive representations which are concerned with future states of affairs '*where their next trip is'*. Again there is a sense that time is urgently limited for Frank and Jackie in way unperceived by the others, and that this sense of limitation is a function of socially grounded experience of the future.

2. iv Adaptation

Jackie has to compromise with her changed state in order to adjust to the disabilities. She frequently describes her reliance on her husband for physical support in activities she previously could manage alone:

> *'Frank has to cut up my food but I still manage to feed myself with my right hand. I have got very proficient with my right hand!'* (Jackie, journal 1, 3 months following diagnosis, line no. 288-289)

Throughout the journals there are also a recurrent signs that Jackie is now having to compensate for deficits in certain areas of physical functioning by using props or equipment or altering her usual manner of carrying out an activity:

> *'I even managed to do a little bit by sitting on a cushion and using my good hand to pull out some of the bigger weeds.'* (Jackie, journal 2, 6 months following diagnosis, line no. 247-248)

It seems at times that by making these reassessments of herself and ways of doing things she is able to incorporate her altered body into understanding of herself. This allows her to develop a new way of 'being-in-the-world' in which she can accept the changes occurring:

> *'It is very frustrating not being able to help in the garden and it felt good to have done something useful.'* (Jackie, journal 2, 6 months following diagnosis, line no. 249)

Frank too has to keep finding ways to adapt to accommodate the changes occurring to Jackie:

> *'I am buying more ready meals to make it easier as I need to help her much more with personal things. I have also got to be careful not to offer drinks in heavy pot mugs or fill them right up. It has to be the small china ones as her right hand is now very weak.'* (Frank, journal 7, 10 months following diagnosis, line no. 175-177)

There are moments throughout the diary when it appears Jackie's incorporation of her altered body-subject has enabled her to reach a level of acceptance:

> *'The scenery is wonderful and I am getting used to just looking at it instead of being able to be in it 'properly'.'* (Jackie, journal 3, 6 months following diagnosis, line no. 17-18)

This acceptance allows Jackie to reach an 'authentic' experience of being as she recognises she will die:

> *'What is happening to me is outside my control. My body will continue to deteriorate and I will die. There is no point in raging against it any longer. I have to accept this now.'* (Jackie, journal 1, 4 months following diagnosis, line no. 543-544)

Jackie acknowledges this process of adaptation enables her to formulate a new way of '*being-in-the world*' which although different has somehow provided a more authentic way of being:

> *'The key to living with MND seems to be to keep adapting. Life is not over yet, just very different. It is not as good as it was but it is still worth living and in many ways, [Frank] and I are closer than ever.'* (Jackie, journal 3, 6 months following diagnosis, line no. 306-308)

However, for Jackie, there is no plateau of degeneration and loss of function of one part of the body is subsequently followed by deterioration in another; thus very little adjustment can take place before further disability ensues. Jackie finds it impossible to avoid the constant awareness of the handicap and any acceptance of the disease remains transitory:

> '*I managed to get to a stage of acceptance and peace. Then I discovered this was not a constant state of being. The longer it goes on the more I realise how much there is to accept. Neither of us have 'normal' lives. The change has been huge. Coming to terms with one stage is fine but then we know the next stage is only round the corner.'* (Jackie, journal 5, 8 months following diagnosis, line no. 159-161)

It is clear that Jackie's bodily deterioration prompts her to think in more holistic terms of '*being*' in its entirety. This concept appears to entail thoughts of inevitability and consequences lying beyond the control of Jackie and Frank. Tragically '*coming to terms'* is itself an imperfect and transitory

response to the profound alteration in Jackie's circumstances and prospects. Similarly Frank acknowledges difficulties in trying to attain some equilibrium or means of compensating which would enable them to live with the disabilities:

> *'Perhaps we were told to live day by day because, with this disease, planning ahead is so difficult - if not impossible. The moment one problem is solved another appears. It isn't easy to plan holidays or visits, or to find ways to cope with [Jackie's] increasing lack of use of her body and increasing fatigue.'* (Frank, journal 1, 4 months following diagnosis, line no. 638-641)

As is discussed below, a prominent feature of the situation is altered sensitivity to time. There is a sense of double powerlessness in that loss of control leads to diminished capability to '*plan ahead*', whilst Jackie's position is unalterable and in a sense '*pre-ordained*'. Conversely, time becomes for Frank somewhat dislocated because continuity of action is hard to envisage. Life is lived '*day-to-day*' not in any liberating, post-structuralist sense of recursive '*becoming*', because it is accompanied by powerlessness.

There is, moreover, a continual haunting of the present, habitual body by a more deteriorated future one. For instance, Jackie indicates this when she describes her awareness that the MND symptoms are now affecting her ability to communicate:

> '*I am beginning to learn to live within my physical limitations but the thought of not being able to communicate is too awful to contemplate*.' (Jackie, journal 2, 5 months following diagnosis, line no. 87-88)

Both Frank and Jackie demonstrate how they are able to cope with the illness for certain lengths of time until certain junctures are reached and physical ability declines further.

> *'Although the disease continues at the same rate throughout its course, there are times when it feels as if there are big changes and this is one of those.'* (Jackie, journal 8, 11 months following diagnosis, line no. 20-21)

Another stage, which signals how much deterioration has taken place, is when Frank and Jackie moves their bedroom to downstairs, as getting up and down the stairs has become too challenging:

> *'Having left the top floor has made life easier but was a big step psychologically.'* (Frank, journal 7, 10 months following diagnosis, line no. 121-122)

It is evident that the couple have to become accustomed to physical separation as a result of the disease symptoms:

> *'We have slept in different rooms for the last couple of nights and last night I slept through for the first time for months.'* (Frank, journal 2, 5 months following diagnosis, line no. 210)

However, adaptation is a key feature here as the couple try and find ways of ensuring physical contact and closeness:

> *'We have the added advantage of a single <u>and</u> double bed in the bedroom – we can have a cuddle if we want but if one of us is restless I don't have to go in another room.'* (Frank, journal 7, 10 months following diagnosis, line no. 123-124)

Attempts to sustain togetherness and to fend off any unremitting separation are also evident in Frank's reports of the ways in which he tries to find new activities they can still carry out together.

> *'[Jackie] used to enjoy gardening because it was a way of getting out and having some fresh air even if we didn't go for a walk. I suppose the garden centre is a substitute. At least access is not a problem.'*(Frank, journal 5, 8 months following diagnosis, line no. 87-89)

Frank acknowledges that trying to maintain the usual mode of '*being*' and normal life is his way of coping with the illness. He recognises that by trying to find practical solutions to immediate difficulties enables him to distract his mind from the inevitable larger future issue which cannot be resolved:

> *'I suppose I'm trying to bury my head at the moment by only trying to solve the problems quickly and easily, trying to organize ourselves, … and I try and busy myself by doing things, because I know it's going to get worse… So I'm avoiding… Its avoidance.'* (Frank, interview, 2 months following diagnosis, line no. 475-476/485-487)

Continual lifestyle changes and transitions which occur as a consequence of the disease work as a reminder of the fact that they are no longer able to function in their '*habitual*' way:

> '*The reality of having to move downstairs struck me very forcibly and upset me more than I wanted to acknowledge. It is another emotional hurdle though practically it makes a lot of sense.'* (Jackie, journal 5, 8 months following diagnosis, line no. 186-188)

Having to contemplate the acceptance and use of certain items of equipment also highlight the further degeneration and the ultimate end:

'The one piece of equipment which [Jackie] really does not want to have is a 'hospital bed', she calls it her death bed.' (Frank, journal 7, 10 months following diagnosis, line no. 175-176)

2. v Equipment and self

Not only does Jackie have to incorporate her altered body but also equipment such as the wheelchair. During the initial stages of the disease there is clearly a dichotomy taking place in Jackie's mind. In the quotation below, at the same time as recognising the usefulness of the wheelchair, Jackie also voices her aversion to the use of it as a substitution to her loss of mobility:

'We had wheelchair assistance at the airport but although I hated it, it did save my energy.' (Jackie, journal 1, 3 months following diagnosis, line no. 187)

Feelings of incapacity and lack of freedom are often described in relation to her reliance on using the wheelchair as physical support:

'It is quite a hassle trying to find places in the countryside that are wheelchair accessible. Now I am stuck in a wheelchair it seems that the only places that I can get to are visitors centres and the like which tend to be very busy places.' (Jackie, journal 5, 8 months following diagnosis, line no. 7-10)

Frank, also is fully aware of the restrictions that the wheelchair has on their lives:

'To get in one has to ask the doorman to fold the revolving door and put a ramp over the steps. The ramp, however comes very close to the edge of the pavement – and there isn't a ramped kerb of course. [Jackie] would have to first ask the doorman to put the ramp over the kerb – then she would have to manoeuvre to one side whilst it was moved to the door – then a turn that would take one set of wheels very close to the edge of the pavement before a ninety degree turn to get on the ramp!' (Frank, journal 4, 7 months following diagnosis, line no. 282-290)

However, Jackie also describes a gradual, transitional process of incorporating her wheelchair; '*Each time we go out I get a little bit better at it and a little bit more confident.'* (Jackie, journal 2, 5 months following diagnosis, line no. 245-246). Evidently as time progresses and Jackie becomes familiar with the wheelchair, a gradual acceptance of it takes place:

'I went to church on Sunday morning and took the wheelchair for the first time. I felt a bit conspicuous and tried to hide at the back but was persuaded to move alongside some friends right in the middle of the aisle. I felt a bit like the Queen on the throne!' (Jackie, journal 4, 7 months following diagnosis, line no. 163-165)

The above quote illustrates that Jackie's humour is a feature of her resilience, and evokes the truism that humour helps us to accept what we cannot alter.

Over time, Jackie starts to use a power chair rather than a wheelchair, which gives her even a greater sense of autonomy. Links between self, surrogate embodiment and equipment are indicated as Jackie's emotional state is indexed to this interconnection. When she is more independent, and the frailties of her condition supplemented *'artificially'*, the effect is deeply personal and reflected by Frank. For him there is an intimate correlation between emotion, emotional strength and independence, which are tied to physical mobility underwritten by technical help from the right equipment.

> *'A week ago [name of company] delivered our Motability WAV (Wheelchair Adapted Vehicle) which has made such a significant difference to the quality of our life. Jackie has regained some of the independence she has been losing and every time we go out she can motor around, on her own, in the electric wheelchair she has a grin from ear to ear!'* (Frank, journal 3, 6 months following diagnosis, line no. 173-177)

As the following quote demonstrates, over time this piece of equipment has become incorporated into Jackie's own understandings of herself. Gradually a process of assimilation takes place between Jackie and the power chair and a stronger sense of self is able to develop:

> '*I use my wheelchair all the time and it gives me such great freedom… I love going to the supermarket and helping with the shopping and this week I was able to go around Marks & Spencer's choosing lots of clothes to try on at home…. I don't know what I'd do without the wheelchair and I am so grateful that I can get out into such beautiful countryside so quickly and easily.*' (Jackie, journal 4, 7 months following diagnosis, line no. 43-45/198-199)

Previous references to maintaining normative roles here intersect with the current theme. Shopping and country excursions compensate for difficulties with sending Christmas cards and singing hymns, mentioned above. Jackie's re-embodiment and commensurate freedoms represent aspects of herself regained in a publically recognisable sense. As with Frank's commentary upon alterations in experienced time, another profound abstraction, '*freedom*' is here in play. Frank recognises that the acceptance of the wheelchair has increased his wife's wellbeing and emotional mood:

> *'It was also good that Jackie found that she was able to deal emotionally with us going out and leaving her. It cannot be easy accepting loss all the time. I think that the increased mobility independence she now has is a help.' (*Frank, journal 3, 6 months following diagnosis, line no. 229-231)

Jackie makes an interesting contrast between her experiences of being a wheelchair user and then of being in the power-chair.

> *'I have noticed that when I am being pushed in the manual wheelchair that I seem invisible and no one talks to me or makes eye contact. However, when I am in the power-chair driving myself about, lots of people say hello. This makes such a difference as it makes me feel so much better*.' (Jackie, journal 3, 6 months following diagnosis, line no. 158-162)

The register of this excerpt is altered from previous ones, in as much as it constitutes Jackie's reflective account of what it is like to be '*seen'.* Jackie has become sufficiently used to her circumstances to observe herself, although she could not be described as objective or detached. It could be argued that Jackie is conscious of the alteration, and in some respects the wheelchair is strange and estranging, from those who will not make eye contact. A raft of psychological possibilities could be inferred here, for example as to why others greet her when mechanically powered but not manually, as if the power chair is a part of Jackie's person or personal identity. In addition, the power-chair has in some significant sense been accepted by Jackie as a functioning part of her social self, to which others can for some reason relate better than when she is dependent.

3. Altered temporality

This theme details the way in which Jackie and Frank's interpretations and understandings of their temporality and ways of being in the world are transformed by their experience of her having a terminal disease.

3.i Awareness of time

There is an acute sense that time is now limited:

> *'We are racing against time'* (Jackie, journal 1, 3 months following diagnosis, line no. 320)

Celebrating family occasions or certain milestones also brings the future into reality:

> *'Talking last night we both acknowledged that we knew in our hearts that this was our last Christmas together. Jackie is not looking forward to heralding in the New Year.'* (Frank, journal 7, 10 months following diagnosis, line no. 158-160)

Carrying out the diary also is a constant reminder of the passing of time:

> '*It is the end of another month and time to send the September diary to the researcher. It always makes me aware of the passage of time.'* (Jackie, journal 4, 7 months following diagnosis, line no 206)

There is an evident desire to '*make the most of time'* and enjoy what time is left:

> *'I'm trying to make the most of the time that we've got and the fact that we can go out, we can meet people, we can have sex. We can cuddle each other, we sleep in the same bed, you know, all that.'* (Frank, interview, 2 months following diagnosis, line no. 472-473)

> '*I am holding on to the fact that there should be some time to make the most of life.'* (Jackie, journal 1, 1 month following diagnosis, line no.164)

However, as a result of the loss of function, time becomes consumed by the rituals of caring and activities of daily living. The descriptions of a *'day disappearing'* in the quote below emphasises the couple's sense that time is eluding them and that days are now shortened:

> *'We get less and less done now in a day. Because we are awake in the night we usually end up going back to sleep and then not waking up till late - often nine o'clock. It takes at least two hours to get me breakfasted, showered and dressed. By the time [Frank] has made the beds, put the washing in etc, it is lunchtime. The day disappears with neither of us achieving anything very much at all. It must be very frustrating for him.'* (Jackie, journal 8. 11 months following diagnosis, line no. 64-70)

Time or energy spent in mundane appointments or sorting out issues with the illness are perceived as using up the little time left:

> '*In many ways the appointments seem a waste of time as all that is happening is that my deterioration is being monitored…*' (Jackie, journal 4, 7 months following diagnosis, line no. 238)

And using up '*precious time'* and energy on mundane activities is viewed as a waste:

> *'I really resent getting tired from appointments to do with bureaucracy or prescriptions.'* (Jackie, journal 3, 6 months following diagnosis, line no. 171)

One way which helps both Jackie and Frank to cope with the disease is by trying to focus on the present, here and now. Jackie repeatedly speaks of her attempts through meditation and religion to enable her to focus on the present-day and her current existence:

> *'I am learning to live in 'the now'. It is taking some practising but it is very worthwhile. In any case, the future means further deterioration and I don't want to dwell on that. So I am grateful for what I can do now and hope that it is some time before things get much worse.'* (Jackie, journal 4, 7 months following diagnosis, line no. 21-23)

At different stages both Jackie and Frank voice this desire to fend off the future by living in the now but both share the recognition that this is challenging for them to achieve:

> *'I try not to dwell on the future and most of the time manage to live day-by-day but sometimes I just cannot do it.'* (Jackie, Journal 3, 6 months following diagnosis, line no.51-52)

> *'The secret is living in the present and not worrying about what will come. Most of the time we can do that but sometimes it is not possible.'* (Frank, journal 5, 8 months following diagnosis, line no. 162-164)

Waiting for the inevitable end to come was at times conceded to be incredibly difficult. Early on in the journal, Jackie describes her feelings of a future with all its bleak prospects which is oppressive and at times impossible to evade:

> *'Some days you just sort of get on with it and you think well, I'm here now so let's do what we can now and then other days, the whole thing gets a bit overwhelming and you think, well, if you're gonna die, why don't you just do it and get it over with rather than having to go through the process.'* (Jackie, interview, 2 months following diagnosis, line no. 110-111)

3.ii Loss of expected future time

In the interview, Jackie describes how being given a diagnosis of MND eradicates all her hopes and plans:

> *'…then I got my diagnosis and … the future was taken away.'* (Jackie, interview, 2 months following diagnosis, line no. 99)

The future comes to represent a desolate proposition and it is clear that the thought of what is to come is extremely daunting for Frank as well as Jackie:

> *'Thinking ahead and planning for the future can be very depressing: when/if [Jackie] cannot use the computer keyboard; when/if she cannot talk; when/if [Jackie] cannot get upstairs; when/if she cannot wipe her own bum… Trying to keep a positive attitude is not easy.'* (Frank, journal 1, 4 months following diagnosis, line no. 651-654)

There is a sense that it is necessary to be aware of what is to come but this is not something they want to dwell on:

> *'I want to know all there is to know about the future but at the same time it is hard to think about it.'* (Jackie, journal 2, 5 months following diagnosis, line no. 85-86)

Both Jackie and Frank express in the interviews, their sense of bitterness and regret that they will not have the time now that they had been looking forward to enjoying and that they have been

cheated out of life. Frank describes how the disease has shattered his previous expectations that this period of retirement in their lives would be one of relaxation and liberty which they could enjoy together:

> *'I feel extremely cheated, pissed off, because we've been looking after [Jackie]'s mum and dad now for ten... for the last ten years, and I mean looking after them, they have needed more and more attention as we've gone along. And I was looking forward to a period of time where [Jackie] and I might have freedom to go off and do what we wanted to do when we wanted to... And that hasn't happened. So that's a bit of a... bummer to be honest with you...'* (Frank, interview, two months following diagnosis, line no. 362-372)

In the above quotation there are interestingly contrastive perceptions of time as both '*drawn-out*' and telescoped. The perception of time appears to operate in what might be called a *'dialogic'* way. In other words, it is perceived as longer or shorter relative to time experiences around it. '*Looking after mum and dad*' feels prolonged not only in itself but because of the dramatic foreshortening immediately after. The prospect of unallocated time in later life is presented by Frank as a *'freedom'* earned after ten years of conscientious care. Jackie too describes her sense of being resentment that time she had anticipated is no longer available to her:

> *'In fact the one regret of my life is that I have not travelled more widely. After university I thought of doing VSO but then I met [Frank] and didn't pursue it. After we married we had no money to go far - a social worker and a teacher don't earn the sort of money to travel the world especially when there are three children and a mortgage. Still, it didn't bother me as I thought that when I was 60 and drew my pension I would have a lump sum and have a gap year late. I was going to make up for lost time. I didn't reckon on getting MND!'* (Jackie, journal 5, 8 months following diagnosis, line no. 92-98)

With Jackie the various reflections upon time lead her to a summative evaluation of how '*successful*' her life has been in respect of time unfulfilled. In this passage she presents her life as leading up to a period of freedom and travel constituting true freedom after years of obligation, though her family obligations were welcome. Her comments on social work and teacher salaries position her life socially; these are '*worthwhile*' professions but not recognised by society to be worthy of great financial reward. Again social selves are implicitly in play, as is compensation of Jackie by herself for having lived a '*worthy*' but not (financially) well rewarded life. This anticipated loss of future time clearly is devastating for Jackie:

> *'…not being able to watch the grandchildren grow up, not having any life doing the things we wanted… I cried for all I had lost and would lose… and was overwhelmed with sadness for all that was and all that will never be.'* (Jackie, journal 9, 11 months following diagnosis, line no 14-15)

Whilst Frank also expresses his feelings of foreboding and anxiety towards the future and in this quotation explains his desire to shut off the future:

> *'It's going to be shit at the end. I know that. We're under no illusions. Yeah ... Shit. I'm quite scared about what's going to happen, to [Jackie], to us... I don't want to lose her… I know it's going to end. So I don't want that* at all.' (Frank, interview, 2 months following diagnosis, line no. 476-477)

Jackie states that having plans enables her to avoid considering the bleak future that awaits them:

> *'I also need to have some plans otherwise I start thinking that all I have to look forward to is deterioration and death.'* (Jackie, journal 3, 6 months following diagnosis, line no. 28-29)

4. Transcending Embodiment

This super-ordinate theme describes the ways in which the couple find ways of '*transcending'* or escaping the numerous losses and alterations to identity and temporality which the couple experience as a consequence of the disease, outlined in the earlier themes.

4.i Dyadic self

The impact of the disease is felt intensely by both Jackie and Frank. The disease's impact is often described in a way that includes each other, emphasising that this is joint experience which is affecting both of them, and that impact is a shared emotional one:

> ***'**But we have found that it is the emotional impact of this disease that has had the biggest effect on both [Frank] and me. In the immediate months after diagnosis we were both on a rollercoaster of emotions. The shock of what we were dealing with was a big one. It took a lot out of us and took a long time for us to get to grips with it.*' (Jackie, journal 5, 8 months following diagnosis, line no. 143-156)

Though Frank and Jackie continue to speak individually and for themselves, their emotions converge in a single entity, united by shared suffering and uncertainty. Jackie's reference to a '*rollercoaster*' is a fairly conventional way to make the suffering intelligible. She refers repeatedly to the dual nature of the experience for *'us'* and '*we'*. Frank includes the concept of fate, implying a shared suffering and powerlessness, which neither individual can postpone or divert:

> *'There are all sorts of thoughts and feelings going around my head: anxiety, fear, sadness and anger at the cruel twist of fate that has dealt us this.'* (Frank, journal 9, 11 months following diagnosis, line no. 8-10)

In the following quote, Jackie's register is co-ordinate with Frank's, when she expresses a dyadic understanding of her life with him as '*equal*'. Again, an aspect of the sadness follows now from the relationship having become so emotionally close but also unbalanced, with need flowing from one individual to the other:

> *'We have had such a fantastic marriage and a wonderful relationship built on being equal partners. I did not want him to become my carer and for me to have to become so dependent.'* (Jackie, journal 1, 3 months following diagnosis, line no. 333-335)

Numerous reflections are made regarding the shared understanding both Frank and Jackie enjoy. For instance, Frank demonstrates a keen insight into how Jackie feels about losing her independence:

> *'I'm a very independent person. Extremely independent ... I like to do things myself. I would hate to be like [Jackie]. I would be throwing things around the place, I know, because I would be so frustrated. And I understand how frustrated she feels with not being able to do things.'* (Frank, interview, 1 month following diagnosis, line no. 399-401)

Frank appears confident when putting himself in Jackie's place, as there is great familiarity between them and understanding of how each will react to small but highly significant occurrences. Frank also appears willing to offer understanding and forgiveness for frustration Jackie might express, claiming that he in fact would behave with less restraint than she has managed. This again implies a very intimate level of care and understanding. In the quote below, there is an implied reassurance in the phrase '*he knows'* and it suggests that Jackie finds comfort in sharing her fears with her husband:

> *'[Frank] said that he will find a way to connect with me until the end. He knows how scared I am of losing the ability to communicate.'* (Jackie, journal 1, 4 months following diagnosis, line no. 294-295)

There appears to be a great deal of reassurance in Frank's presence, enabling Jackie to express her innermost fears and placing implicit trust in Frank's ability to deal with them. From early on in the advance of Jackie's condition, the couple share a mutual concern for each other's well-being and a commitment to care for one another. In the following quote Frank reveals the depth of his personal dependency on Jackie, despite having to cater increasingly for her physical needs, which again illustrates the depth at which their relationship is working.

> *'We will look after each other at the same time.'* (Frank, interview, 2 months following diagnosis, line no.394)

> '*[Frank] worries about me, I worry about him and all that he has to do*.' (Jackie, journal 5, 8 months following diagnosis, line no. 178)

Jackie reveals that her care for herself is matched for her concern for Frank and the strain he is under. It is as if neither partner cares especially for him or herself rather than the other, but each is prepared to face the situation as a whole with equal involvement. This can be described as an interconnectedness of their identities, an idea made evident when the couple's thoughts and ideas grow so interconnected it is not clear, as in the following quote, whether Jackie is talking about her own or Frank's love:

> *'My love comforts me. But this is hard for him as well.'* (Jackie, journal 6, 9 months following diagnosis, line no. 198-199)

A particularly poignant example of this intimacy of thought and emotion is revealed when Frank describes his decision not to resuscitate his wife if she goes unconscious following a medical crisis. The passage reads as if Frank is looking for the slightest signs of life in Jackie and that there is a great deal of comfort in her response to him. Frank evidently craves for Jackie's recovery and is confident from the barest response that Jackie perceives his presence.

> *'In my heart I believed that there was hope that Jackie would improve and, whilst not recovering to where she was, would at least be in this world. In my head I know that this is as good as it can get. I'm sure she can hear and understand we are with her. She responds to touch – I managed to relax her right arm and hand last night, which had been tense and drawn into her chest. However it can only go down from here. Jackie has battled against the effects of this disease and we have made the most of a limited life. She said she was not ready to die yet, before all this happened, but I have to be realistic and do not want her to endure yet more trauma.'* (Frank, journal 9, 11 months following diagnosis, line no. 174-181).

Frank is prepared to sacrifice his own desire to keep Jackie alive if she slips into unconsciousness, for the sake of releasing her from suffering. Again the couple appear to be functioning for the sake of each other and attempting to make the best decision for the benefit of both. At an earlier stage of the disease's progress, it appears that their feelings for each other intensify as the situation worsens.

> *'My love for her gets stronger'* (Frank, journal 7, 10 months following diagnosis, line no. 90)

> *'Life is not over yet, just very different. It is not as good as it was but it is still worth living and in many ways, [Frank] and I are closer than ever.'* (Jackie, journal 3, 6 months following diagnosis, line no. 308)

The disease appears to confer clarity on each individual about their feelings for the other, which as the examples above illustrate, develops into an intertwined and intimate sense of identity, which is in a sense fostered by the adverse conditions. The reassurance of support from her husband provides Jackie with the courage to face the disease and what lies in store:

> '*But no doubt we'll face it. I've got a fantastic husband who has always solved practical problems and will carry on solving practical problems for as long as he can…'* (Jackie, interview, 2 months following diagnosis, line no. 113)

Jackie identifies Frank's prowess as a practical man, indicating her trust in him and that the situation, no matter how trying, will throw up the kind of problems Frank is used to solving. Frank embraces his role as practical person and carer, and for him, the act of caring represents his love for her and an expression of his sense of duty:

> *'... I'm happy to go along with that because it's a positive decision that I want to care for [Jackie] as long as is possible in the home…I mean, I've got to be around for [Jackie]'* (Frank, interview, 1 month following diagnosis,. line no. 347-349)

4.ii Social and familial self

The obverse of Frank and Jackie's social selves becoming diminished in terms of friendship groups, is the increased emphasis on their relationships with particular (and '*true'*) friends. They are perceived as an essential in the couple's lives, providing a great deal of much needed support following the diagnosis:

> **'***Family and Friends continue to be a great source of support.'* (Jackie, journal 2, 5 months following diagnosis, line no. 301)
>
> *'We are grateful for everybody's offers of help, cards, letters, e-mails and telephone calls, and visits… I am grateful to the people who ring up and offer to come and see me and don't give up on me when I say, 'no, I'm too tired' or 'no I'm going away'… With a lot of prayer and support from friends and family, we pulled ourselves round and started to cope.'* (Jackie, journal 5, 8 months following diagnosis, 138-144)

There is less emphasis here on the content of the '*cards, emails*…' than the fact that they were sent. The importance of these actions by friends and family lies in what such missives imply when the reactions of esteemed others appear to have been disappointing. Unsurprisingly perhaps, Jackie praises actions which are less often found in typical social situations; namely resilience and persistence in the face of apparent indifference or rejection. There is recognition that these intra-relations are facilitating Jackie's ability to cope with the disease:

> *'Emotionally I am fairly strong and am convinced that this is because of all the prayers, e-mails, cards, letters, and thoughts of all our friends.'* (Jackie, journal 3, 6 months following diagnosis, line no. 271-272)

> *'My friends are so important to me and a real blessing. You have all supported [Frank] and myself in so many different ways during the last months.'* (Jackie, journal 6, 9 months following diagnosis, line no. 179)

Reflections throughout the journal also centre upon significant familial relations and increasingly prominent by the couple are affirmations of the family's bond:

> *'Well, family's been very supportive. The children, by family I mean… They are all very supportive.'* (Frank, interview, 2 months following diagnosis, line no.446)

> *'All the family have now been seen. We have all cried together and it is good to feel their love and support.'* (Jackie, journal 1, 2 weeks following diagnosis, line no 68)

The couple reflect on the strength of the family unit and it appears that this tragic experience is actually renewing and reinforcing these relationships:

> *'The children have been close and a great support to each other and me… The whole family are here – at least for the weekend. It is good to have them around.'* (Frank, journal 9, 11 months following diagnosis, line no. 111/228)

Jackie reveals a sense of the permanence of this familial bond and how this will remain following her death. There are numerous reflections made by Jackie and Frank which seem to emphasise their heightened awareness of the cyclical nature of their lives; there are numerous comments regarding their grandchildren and how fast they are growing up, which are accompanied by a sense of the couple's own ageing or mortality:

> '*We went to see (name of grandson) in his nativity play earlier in the week. It was lovely to be there but I had to force myself not to think that it would be my last.'* (Jackie, journal 7, 10 months following diagnosis, line no. 100-101)

This awareness of the transience of her life and its mortal nature becomes increasingly apparent when Jackie reflects upon a conversation with her daughter:

> *'(Name of daughter) wanted to ask what would happen to my ashes when I died…. She feels that she needs a special place or a bench or somewhere where she can come and talk to me when I am no longer here.'* (Jackie, journal 2, 5 months following diagnosis, line no. 130)

4.iii Convergence of time

Within the diary extracts, there are numerous reflections regarding the past, whether it concerns friends, family, or experiences. Past memories and events seem to be increasingly prominent in the diary extracts. At certain times it appears that Jackie is reflecting on who she is now compared to who she was previously. It is possible that she is trying to validate her sense of self by actively remembering the past:

> *'I remind myself that when I took early retirement they all sent cards and letters saying how helpful I had been. It mattered that they thought so. It mattered that I had made a difference.'* (Jackie, journal 1, 1 month following diagnosis, line no. 217- 219)

Jackie shows an awareness that she is attempting to bring the past more into reality as this represents a sanctuary from the current situation:

> '*If you have no future your mind starts thinking about what has happened in the past and I have started to do this. It is a very strange feeling remembering things I thought I had forgotten.'* (Jackie, journal 3, 6 months following diagnosis, line no. 301-302)

Frank also reveals his own desire to reflect on the past:

> *'Looking at all the photos has been good – We have packed a lot into life over the years.'* (Frank, journal 3, 6 months following diagnosis, line no. 85-86)

At times, it appears that the normal, linear perception of time is replaced by a mingling of the past, present and future into the present. For instance Jackie recounts a recent visit to a church and reflects on all the connotations with numerous significant life events it holds for her:

> '*It is such a beautiful church and I found being there very emotional. Apart from being the church I had attended for so many years, it is where (names of family) were married, where (name of grandson) was christened and where my mother had her funeral service.'* (Jackie, journal 6, 9 months following diagnosis, line no.136-138)

This sense of invoking the past and future into the present is also apparent here:

> *'Today would have been my mother's birthday. I think of her quite a lot. For many years she was very disabled. She was very stoical and never complained about the situation she was in. I hated watching her lose all her abilities. I wonder how my son and daughters will deal with my deterioration. They are three exceptional people so they will find a way. I am so looking forward to seeing them next weekend when all the family come to stay to celebrate Frank's 60th birthday.'* (Jackie, journal 2, 5 months following diagnosis, line no. 65-69)

4.iv Spiritual self

For Jackie, church represents one form of social support, which initially, having MND does not impact upon:

> *'Church friends are very good. Church helps.'* (Jackie, interview, 2 months after diagnosis, line no. 129)
>
> *'I am so blessed. I know that I am held in prayer and this helps me a great deal*.' (Jackie, journal 3, 6 months following diagnosis, line no. 34-35)

Despite not sharing her faith, Frank too recognises the supportive role it has for her:

> *'So I think Jackie's found the social life with the church really good because she can get to church. She can go to an evening cell group and she can just sit there and talk and be like the rest of them. And they came round here, we had a meal here as well.'* (Frank, interview, 2 months following diagnosis, line no. 434-435)

Following the diagnosis, Jackie is able to seek some solace from her faith in God:

> *'I am so grateful for my Christian faith. I never did say 'why me Lord?' but I did ask God how he was going to get us through this.'* (Jackie, journal 1, 3 months following diagnosis, line no. 340)

However, one month later, Jackie voices her experiences of difficulties with her faith and therefore accessing social support from church becomes disrupted:

> *'I do need to sort my head out as far as God is concerned… didn't go to church again. Told myself I was too tired but really I just could not cope with going*.' (Jackie, journal 1, 4 months following diagnosis, line no. 459/604)

She acknowledges that maintaining faith in God with such a devastating diagnosis is challenging:

> *'There has been a lot of media coverage about assisted suicide. It is hard to make a decision about such matters. Sometimes counting my blessings and resting in God is easy but other times it is much harder but it is the only way.'* (Jackie, journal 5, 8 months following diagnosis, line no. 179-181)

Jackie at times in the journal, responds to her emotions of sadness and sorrow with a sense of self-loathing:

> '*Really, I am useless and pathetic*'. (Jackie, journal 1, 4 months following diagnosis, line no 453)
>
> *'I am a wet mess again.'* (Jackie, journal 2, 5 months following diagnosis, line no. 80)

She explains later in the diary that she considered having a Christian faith withdrew her right to get upset at what was taking place and instead she felt should maintain stoicism in the face of the disease. It is almost as if she perceives the disease as a test of her faith:

> *'Initially, as a Christian, I felt I should be able to cope and didn't allow myself to get upset without feeling guilty.*' (Jackie, journal 6, 9 months following diagnosis, line no. 73-74)

However, it is her recognition that this experience is altering her entire world and exceeds her own capacity that she is able to reconnect with her faith:

> *'I realised I was not weak in the way I have dealt with it all, but that what is happening to us is so huge.'* (Jackie, journal 1, 4 months following diagnosis, line no. 633)

In the following quotation although she is describing her use of the wheelchair, it also represents an analogy for what is happening to her as a whole. Her life is spiralling out of control, she recognises that she has no control over what is happening to her and she is reminding herself that she just has to hold on to her belief in God.

> *'Got a mobility scooter and hit the town!!! It is scary as there is no brake! When you let go the lever, it just stops. Going downhill you just have to have faith!'* (Jackie, journal 1, 4 months following diagnosis, line no. 454-455)

She also perceives God's hand in surrounding her with friends and family to help her through the disease:

> *'I have always known how important friends and family are but I suddenly realised how much God was doing for me through all these people.'* (Jackie, journal 4, 7 months following diagnosis, line no. 59-61)

Jackie articulates a sense that it is through transcendence of her physical body that she is able to expand her reduced corporeal selfhood and find a more spiritual way of being:

> '*But I can still breathe, see, hear, taste and feel. I can think and pray. I can love, dream and hope. I am still me. I am more than my body. I am. I must live for now and trust God with the future.'* (Jackie, journal 6, 9 months following diagnosis, line no. 199-204)

This moving quotation reveals how Jackie perceives her '*self*' as extending beyond her bodily state into a greater and more inclusive entity which incorporates more sublime acts including to love, dream, hope, think and pray. It is clear that by viewing herself in this way brings her closer to her understanding of '*God*' and enables her to accept whatever '*the future'* may bring.

4.v Authentic being

As Jackie and Frank become more aware of Jackie's mortality, the couple voice a desire for a more '*authentic*' way of being, concentrating on truly valuable experiences and relationships whilst trivial past times fall away. Jackie comments on her realisation that in some ways accepting the inevitably of death has enabled her to be honest about her true feelings, whereas previously she might have been more reticent or guarded:

> '*Knowing I am dying at least gives me the opportunity to tell people how much I love them.'* (Jackie, journal 1, 4 months following diagnosis, line no. 479)

Revising priorities becomes a feature of the couple's lives as both Jackie and Frank repeatedly highlight which aspects of their lives have truth and the most significance for them. It is clear from the quote below, that for Jackie this represents spending time with the most significant people in life, her husband, friends and family:

> '*All I really want is to have time with Frank and to do ordinary things, peaceful things, be in the hills or at the coast, on boats, looking at sunsets, looking at birds, or having a laugh with friends and having meals with them, or seeing my family, being with grandsons*.' (Jackie journal 1, 4 months following diagnosis, line no. 614-617)

Accepting her situation makes her more selective about pursuits that are worthy of her time. These include activities that are commonly associated with greater tranquillity and space to meditate or feel some of the poetic aspects of natural beauty. There is a strong sense in which this phase of Jackie's existence permits her to combine the natural and ordinary with a heightened appreciation that such things are in fact most valuable. Frank too voices his wish to make the most of his time with his wife and savour the moments he still can share with her:

> *'I don't want to spend so much time doing this that I lose precious time with her. We have always been close and I know I am going to lose her. I want to enjoy her love and company as much as possible whilst we are able to talk, laugh, smile and even cry*.' (Frank, journal 2, 5 months following diagnosis, line no 312)

Both individuals needed to be much more selective with their use of time and for Frank the priority clearly became time spent with Jackie. In this passage Frank accepts that the pair will not necessarily be diverted from the inevitability of death, but still wants to enjoy the full range of emotions connected with Jackie's life. In the final days of Jackie's life, Frank reveals that putting so much time aside is a choice he does not regret:

> *'I am so glad I spent as much time as I could with [Jackie].'* (Frank, journal 9, 11 months following diagnosis, line no. 150)

Jackie also comments that the diagnosis has provided her with a sense of freedom and liberation as she is now able to truly value the essential aspects of life. She also recognises that these are not always appreciated in the modern world, implying that previously she might not have taken full advantage of the simple pleasure, natural beauty and time with loved ones available to her.

> '*How ironical that MND has freed me up to enjoy things other people take for granted.'* (Jackie, journal 1, 3 months following diagnosis, line no. 221-222)

Jackie's use of the word '*precious time'* is recurrent throughout the journal when she describes moments spent with the family. This phrase indicates that as she becomes increasingly aware that time is running out for her she is more able to cherish these special instances in her life:

> *'A trip to visit family. Good food to enjoy, rich wine to taste. Wheelchair trundles give me the movement I crave. Children's chatter to enjoy. Precious time with those I love.*' (Jackie, journal 6, 9 months following diagnosis, line no. 193-194)

In the above passage she uses particularly sensory language such as '*trundle', 'chatter*', and the like. suggesting that the experiences have been vividly enjoyed and greatly stimulating. Throughout the journals there are a number of reflective passages which emphasise a sense of 'authentic being' by revealing how significant experiences allow Jackie to reflect on more expansive thoughts and a brighter mood. Jackie reflects on nature and there is an apparent inner peace and at oneness with the world around her:

> *'I am sitting in my recliner chair downstairs watching the birds on the feeders and looking at the clouds scurrying across the sky. Today there are patches of blue amongst the grey and it's actually not raining… What a glorious day today! After the extremely wet summer the last week of dry and often sunny weather has been very welcome. Today was especially warm with blue skies, white fluffy clouds and the beginning of autumn colours creeping into the landscape.'* (Jackie, journal 4, 7 months following diagnosis, line no. 167-171)

Again the sensory detail of the writing implies that Jackie is giving the scene her full attention, as if wishing to perceive it truly in every detail and express her emotional response to the scene. As the diary progresses, Jackie's sensations become more intensified and it appears she is increasingly finding solace in her surroundings and a new zest for the world around her:

> '*I smell the sea, feel the energising wind, hear the screeching gulls, watch the dazzling winter sun shimmering on the waves. Taste the salt in the breeze…'* (Jackie, transcript 6, 9 months following diagnosis, line no. 185- 186)

Often the language she uses is packed full of vitality and life. She uses poetic language which brings the landscape to life and is perhaps evidence of how her imagination is pressing to connect with the scenes around her in the most eloquent way she can.

> '*I am sitting in the apartment looking at the light fading behind the hill. It has been a glorious autumn day. We have seen overflowing lochs, bursting rivers, tumbling streams, gushing waterfalls, glowing forests and remote mountains. The colours have been glorious reds, yellows, browns, russets, golds, oranges and green. The mountain tops have been capped with white snow brilliant against the blue sky. The sun has shone all day.*' (Jackie, journal 5, 8 months following diagnosis, line no. 100-105)

The vivid descriptions of colour, texture and sounds of the natural world in the above two extracts magnify the vibrancy of life which Jackie perceives all around her whilst her condition is advancing. It is perhaps appropriate to reflect here that the immediacy of death gives a relish for life rarely found in those who do not feel vulnerable and have no limit set to their lives. The notion that life and death are intrinsically linked and in sense express aspects of one another, is evoked by Jackie's final words in the diary.

> *'Still, today was magical: snow powdered fells, iced over streams, frozen tarns… the sky was pastel shades of blue, grey and pink shafted with gold. All was still, silent, chilled; an iron landscape.'* (Jackie, journal 8, 11 months following diagnosis, line no. 93- 94)

These words were written just a few days before a sudden medical emergency resulted in hospital admission and Jackie's death in a hospice shortly after. Jackie's words eerily convey the idea of death encompassing life and something of the *'magic'* – the allure and the mystery of both. Frank's comments in the final extract of the diary describing his thoughts immediately following the death of his wife at the hospice, also reveal a desire to find significance in natural beauty and a willingness to find human emotions reflected in the landscape.

> *'I'm looking out of the study window at (name) – the last mountain she walked up. It is covered by a sprinkling of snow which fell during the storm last night. From time to time the sun breaks through the clouds and lights it up, on the surrounding mountains, like a jewel… Today however the weather, on the journey back from the hospice, was bright and clear with the verges and fields showing just a hint of snow or frost and the hills standing out clearly in the sunlight.'* (Frank, journal 9, 11 months following diagnosis, line no. 236-245)

This comment soon after her death indicates how the couple come to echo one another's way of seeing. Both individuals have incorporated simple images into their perceptions and expression, which give a magnificence to their reflections and lift them above the mundane.

4.vi Diary

Jackie explains the couple's decision to carry out a public online journal and how it enables them to keep in contact with friends without having to repeat it every time they speak or meet someone which they find distressing:

> *'The hardest thing is in updating them when they ring. I hate going over it all again. So I might start a blog and put this diary on it so they know where we are 'at'.'* (Jackie, journal 1, 3 months following diagnosis, line no. 360-361)

The diary also represents a way in which they can still connect with friends and create a '*dialogue*' with others:

> *'Several of my friends who read my diary said it had helped them to understand my situation and my family think it is useful too and have encouraged me to continue.'* (Jackie, journal 2, 5 months following diagnosis, line no. 7-8)

At another point Jackie explains how the diary has enabled '*authentic*' relationships with those around them. The diary is interactive in the sense that her family form an audience giving her feedback and encouraging her to write. Jackie thereby is made aware of the impact she is having and the necessity of continuing with the work. Moreover, by using the diary to chronicle events, she describes being able to personalise individual correspondences:

> '*Doing the diary has been both difficult and rewarding for both of us. The irony is that by 'going public' we have retained our privacy. The fact that people do not have to either wait for us to e-mail them or telephone us to find out our situation means that we are able to keep in touch much more easily, and that phone calls and e-mails can be shorter and more meaningful.'* (Jackie, journal 3, 6 months following diagnosis, line no. 276-280)

It is clearly significant that the couple wish to retain control over the quantity and content of information released and fear that excessive amounts will involve too many others too often and trivialize their right to privacy. Moreover the diary has the potential to represent their lives more accurately and truthfully. There are a number of times when they mention their need for the diary to be an '*authentic*' account:

> *'Today is a very bad day and as the whole point of this diary is to describe, honestly, how my life is whilst dealing with MND, I have to admit that it is' (Jackie, journal 2, 6 months following diagnosis, line no. 258)*

There is then a confessional dimension to Jackie's writing which requires her to be brutally frank about her moods and her outlook. The diary therefore serves the vital function of forcing her to be plain about her condition, painful though it undoubtedly is to have to be so.

> '*I have just read what I have written and nearly deleted it all for sounding too depressing but Frank insists that the whole point of this diary is to be honest.'* (Jackie, journal 3, 7 months following diagnosis, line no. 135-136)

As this quote illustrates the couple maintain the diary jointly and its construction becomes another aspect of how the disease is articulated in the ways they conduct their relationship and co-author how it is represented in the journal. Keeping up the diary is described as a useful outlet for both Jackie and Frank. Jackie finds that the acts of expressing herself candidly is in itself beneficial.

> *'I found it very therapeutic to write down my thoughts and feelings of dealing with MND.'* (Jackie, journal 2, 5 months following diagnosis, line no. 6-7)

The diary enables her to be candid in ways she might not otherwise be able to face. The resulting text helps her to mediate the effects of the condition as a mode of representation that others wish for and is necessary to keep them up-to-date. However there is liberation for Jackie in being able to say things once because meaning is lost after frequent repetition.

> *'It has been very therapeutic for me to do this and it is also such a relief to know that I will not have to keep repeating the same old things to people.'* (Jackie, journal 2, 5 months following diagnosis, line no. 248)

For Frank it represents a way in which he can express his thoughts and feelings more easily than having to admit feelings and moods directly to another person. Reflecting on the process of maintaining the diary allows Frank to position himself as a writer and service user relative to the effects of the disease whilst keeping his sense of perspective and sense of humour.

> *'I suppose I've opened up more in this diary than I could ever do face to face – that's a Man thing! It's been useful for me to be grumpy about things which don't work, take a long time to get or are bureaucratic nonsense, but it has also been therapeutic to talk about the effect it is having on me. Besides which, it will save a fortune in counselling!'* (Frank, journal 4, 7 months following diagnosis, line no. 260-262)

During Jackie's final days, Frank continues to write the diary whilst his wife is in hospital in order to keep friends informed of her progress. The diary has a straightforward informative purpose but also permits him to adopt a friendly and personable tone appropriate to the occasion, further evidence of how each individual is given a kind of agency by the compositional process knowing that an audience is willing to read what they write.

> *'I will attempt to update this journal as soon as things change. It helps me and I know there are a lot of you out there who care about Jackie.'* (Frank, journal 9, 11 months following diagnosis, line no. 154)

Frank comments here indicate how carrying out the diary even during such a difficult and tragic time has enabled him to make sense of his experiences and feel more connected with others. The journal becomes an important tool representing Frank's obligation to keep others informed and reciprocally others' concern for the couple's difficulties.

Jackie comments on the numerous ways she regards the diary as beneficial. An economy of information exchange emerges in which the journal permits the careful and considered expenditure of her dwindling resources of energy. Similarly by using the journal to chart the story of her condition there is a much clearer demarcation of the disease from other areas of life which become more prominent in '*person-to-person'* exchanges such as phone conversations.

> *'The benefits of writing this diary are enormous and have been in so many unforeseen ways and on many levels. Gradually, it has been given to just about everyone we know and it saves having to answer questions continually from friends who want to know how we are. Instead, if they want to know they can log on and read it. Then any phone calls or emails can be about other things than the progression of my MND. Also, we have maintained contact with so many people all who send messages which in turn support us. So by taking the risk and being open and honest, we have gained in ways we did not think of. Many of my friends have reappraised their own lives and made positive changes as a result of what is happening to us, so that again has been a positive thing. Also, if it helps anyone to understand the ever changing nature of this disease that is good and if services can be speeded up as a result that is even better! '* (Jackie, journal 4, 7 months following diagnosis, line no. 2-16)

The diary becomes for Jackie a narrative of the many-dimensioned relationships she has kept up and affected positively. She and Frank use the diary to maximize coverage of the condition and this has kept levels of response and encouragement particularly high. She is surprised and gratified to find that others are pondering her position and making necessary changes in their own lives, further evidence that her suffering is not meaningless and that their story could be generally beneficial, to ordinary people and service providers alike.

Summary

This chapter has described the findings from the analysis of case study comprising both interview and the journal completed by one couple living with MND for the period of 11 months. The findings have been categorised into the four main themes: 1. altered body, 2. diminishing self, 3. altered temporality and 4.transcending embodiment. 'Altered body' and its subordinate grouping of 'awareness of the body', 'alienation of the body', 'entrapped embodiment' and 'self in physical world' details the way in which the couple's understanding of the body altered as the disease progressed. The super-ordinate theme 'diminishing self' incorporated the sub-themes 'loss of social purpose and participation', 'burden and guilt', 'social marginalisation and diminished relationships', 'adaptation' and 'equipment and self' and explained the various ways the changes of the disease affected the couple's understanding of themselves and sense of identity. The third main theme 'altered temporality' identified, along with its sub-groupings, 'awareness of time' and 'loss of expected future time' the way Jackie and Frank's experiences of time were forced to adjust. The fourth main theme, 'transcending embodiment', included the sub-themes 'dyadic self', 'social and familial self,' convergence of time', 'spiritual self' and 'diary'. The next chapter will describe the findings of the analysis undertaken with the interview data of 12 couples.

Chapter 4 – Analysis of Data from Interviews

Introduction

In this chapter I have examined the findings of the analysis of interviews carried out with twelve married couples who have been living with MND. Narrative Interviews were used with the couples and these ranged in length from 45 minutes to two hours. Eight couples were keen to carry out the interview together, whereas four couples preferred to do the interview separately.

Participants

The interview data of twelve couples were analysed for this study. The couples were all married and living in north-west of the UK and accessing health care from the same MND care centre. They were aged between 51 and 79 years of age. People with the disease varied in the type of MND they were experiencing and the length of time since diagnosis. The characteristics of these couples are illustrated in appendix 1.

Analysis

Interpretive Phenomenological Analysis of the interview data produced four super-ordinate themes and 14 ordinate themes. These emergent themes from the data and their recurrence are detailed in table 10, appendix 10.

The four super-ordinate themes and 14 ordinate themes which resulted from analysis of the data are discussed in the following sections of this chapter. As in the previous chapter, each individual theme is discussed and anonymised quotations which were considered best exemplars of these themes have been taken from the interviews to support my interpretation of the couples' accounts.

1. Altered body

Throughout the interviews, many couples reflected on the changes that were occurring to the body of the individual with MND. This set of responses is encapsulated by the theme 'altered body'.

1.i Awareness of the body

The body became the focus of attention for the couples and a consciousness of deterioration and loss of an autonomous body became increasingly evident. These changes were gradual and appeared to creep up on people:

> '*Every week I notice there's something else that I can't do that I could do last week.'* (ID46 – female individual with MND, aged 56 years, 11 months since diagnosis)

In this case the decline is situated specifically. '*…every week…could do last week…*' implies a host of lost capabilities, perhaps centring on the practicalities of the week. The following example is also evocative of an individual monitoring carefully a steep decline:

> *'I've no energy, I can't do anything, so frustrated, and yet my brain is 100 per cent so it notes every day all the deterioration,'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

This person is in a sense condemned to remain sharp-witted as the disease takes hold ('*…it notes everyday…'*). The final clause suggests a kind of doubleness in the mind's understanding of itself. There is inevitability about what is happening – the changes are bound to be noticed. However, it is as if with the final clause the *actual* noting of the change is confirmed. It is perhaps the case that as the individual rationalised his situation, he hoped to discover that what he suspected was occurring to him was not really taking place.

Even functions such as breathing or swallowing, which had previously been automatic, now required a concerted effort from one individual:

> *'I had to be on this machine because I can't breathe, being laid down I can't breathe so then they had to teach me how to breathe with my mouth open while they did the operation, I said a lot of teaching going on here for an old fella,'* (ID9 – male individual with MND, aged 56 years, 11 months since diagnosis)

Both people with the disease and their spouses described how these bodily concerns had taken over their lives and involved excessive planning and thinking in order to cope with it all:

> *'We have to think when we go out anywhere, access, disabled access for anything. Yeah, be prepared.*' (ID203 – husband to individual aged 74 years, 18 months since diagnosis)

Some found this dissipated their enjoyment of activities as they could no longer do things on the spur of the moment:

> '*You can't be spontaneous, you know spontaneity is completely gone, because everything has to be planned.'* (ID46 – female individual with MND, aged 56 years, 11 months since diagnosis)

> *'Although we occasionally go to the theatre, it's not a relaxing it can't be a relaxing spontaneous event, because there is such planning that has to go into it, about getting the seats, where you are going to park, is the catheter going to be alright, all the things you have got to take,'* (ID46 – female individual with MND, aged 56 years, 11 months since diagnosis)

This transition from a previously reliable physically healthy figure to one of degeneration was extremely alarming for people with the disease. In the following example, there is a sense of incredulity at the alteration. Unlike in the example immediately above, the same individual here uses an expressive mode to convey their emotions directly to the interviewer:

> *'It's so frightening, it's terrifying, I've always been an active person, physically fit, mentally fit, the thoughts of being totally immobile are terrifying.*' (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

The individual's response begins ('…*it's so frightening, it's terrifying…*') with a direct emotional response unincorporated into the narrative of the disease. After it a more descriptive, conceptual way of talking comes in (*'I've always been this sort of person')*. As has been suggested, the body is represented as the site of this disjunction in self-presentation, between a coherent narrative of fear of the future, and as yet undigested panic that must be expressed.

Also partners or spouses described finding their work around the body extremely intensive and straining:

> '*…the rest of the time it's me, it is really hard work, I think, it's hard work, physically it's demanding, emotionally it's demanding,'* (ID218 - husband to individual aged 56 years, 11 months since diagnosis)

This person also explained how bodily concerns were all consuming for him now and that the only respite from thinking about them was when he was asleep:

> *'All I really look forward to is being asleep, at least if you are asleep you don't have to think about it.'* (ID218 - husband to individual aged 56 years, 11 months since diagnosis)

1.ii Alienation of the body

This theme describes people's sense of estrangement from their bodies. One example is given here:

> '*…my condition is deteriorating, my speech is getting worse, my arm is getting worse, strength is going, I have difficulty in lifting it, I can move the arm there but I can't lift it any further, I can manage to get the food into my mouth but it's not easy.*' (ID6 - male individual with MND, aged 79 years, 11 months since diagnosis)

This person was conscious of diminishing capability, relatively late in the cycle of the disease. Changes were recited and degrees of difference noted ('…*getting worse*…'). The individual was

aware of loss of motor function, and of the implication of the loss for purposive action ('…*get the food in my mouth*…'). Strongly implied here is the sense that normal and essential personal routines were to be severely disrupted. The individual's body increasingly resembled a useless object. There was a sense of foreboding in the interview as if he was forcing himself to contemplate a chronically difficult near future. Grammatically speaking, the repeated 'I' highlights how in one sense, the person was under discussion in his entire being; in another sense, using 'the' rather than 'my', emphasised how parts of the himself were separated and scrutinised. The separation between the person with MND, and how he was beginning to regard malfunctioning parts of himself were increasingly pronounced.

This 'alien' body was now responding in unpredictable ways which led to a sense of losing control which was clearly disconcerting for many people:

> *'I would just trip up over nothing… and it was the tripping up that really got to me, because at first it was only a little bit but then it was quite regular,*' (ID86 – female individual with MND, aged 52 years, 33 months since diagnosis)

Continuing the problem of impaired functionality in the quote above, this individual is regarding herself as someone who can no longer *do*. As with the previous example, a challenge to the individual's entitlement to regard herself as a whole entity is being mounted. It appears to be the case, that contracting MND alters body-perception and personal identity. Parts of the self become far more self-conscious as they are rendered problematic. Perhaps most shockingly for any previously able-bodied person, the most elementary motor-skills pose humiliating problems. This woman explained how the tripping up '*really got to me'*. To an able bodied person, the tripping up is inexplicable, she is tripping up over '*nothing'.* There is no 'good reason' to be tripping up, but she still does. It is as if this individual still sees her situation as her old self would have. In the past she might have expected a physical obstacle to make her trip. Due to the disruption in her self-perception caused by the MND, it seems the individual cannot really accept why she is tripping, so she calls it *'nothing'*.

The following quote further highlights the sense of disengagement between self and the body. The body appears to have taken on a life of its own which cannot be controlled or mastered:

> '*…and she kept saying to me stop running with me, I'd say, I am not running with you, I am trying to hold you back because the top half of her body wanted to go faster than her legs could take her,'* (ID213 – husband to individual with MND, aged 72 years, 18 months since diagnosis)

From this quote, it is evident, that the respondent has lost her sense of the body being her own and looked for external reasons (her husband) as to the cause of the movement. There was emphasis of an internal, inner '*mind'* being disembodied and disenfranchised from the '*outer'* body. Many people commented on the distress they experienced as their mind remained intact whilst their body declined:

> '*Amongst all this carnage, is that my brain and mind still functions as normal. I struggle with it now, because my brain wants to do things but my body doesn't want to, and the worse that that gets, then it could drive me crazy being in that position...'* (ID20 - male individual with MND, aged 52 years, 11 months since diagnosis)

'Carnage' suggests a state of utter wastage and confusion, and in this case there is a retreat by the self to the 'normal'. There is an implied powerlessness in the way the brain is constructed as acting independently upon an uncooperative body, and the self is left watching helplessly on. There is a strong sense that the repercussions for the mind will be drastic, the word 'crazy' heightening the idea of loss of control and disorientation. As well as being distressing, this decline in the body and its unreliability was shown to be extremely anxiety provoking:

> ***'…****now I'm always worried about, you know, what happens if my catheter bag bypasses…'* (ID46 - female individual with MND, aged 56 years, 11 months since diagnosis)

Falls became increasingly common for individuals and were a source of concern for a number of the couples:

> '*It's her balance that is the problem if she has got nothing to hold onto, I think she is frightened of falling…'* (ID213 - husband to individual with MND aged 72 years, 18 months since diagnosis)

One respondent described a terrifying experience of nearly drowning in the bath as he had lost control of his body and could no longer keep himself above water:

> '*Yeah, I slid off the chair, …I was going under, I thought oh God...so I thought I can't be doing with this, I'd sooner be dirty than like this,*' (ID9 – male individual with MND, aged 56 years, 11 months since diagnosis)

Both individuals and spouses found changes to the body worked in an interconnected set of problems that altered capability and had knock-on effect on participants' identities. Of particular note was the idea that apparently simple motions could be disastrous and even life threatening; this created anxiety which seemed pervasive and even relentless when problematic movements were contemplated.

1.iii Entrapped embodiment

Some of these experiences, what might be called descriptive encounters in the interview situation, with a dividing and increasingly pressurized self, led to a sense expressed by a number of individuals, of being imprisoned within a defunct body:

> *'Now she's a prisoner of her body,'* (ID201 - husband to individual with MND aged 67 years, 92 months since diagnosis.)

> '*… you know mentally you are ok but you … are totally imprisoned in your own body and you can't do anything.'* (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis)

The metaphor of incarceration again represents a 'doubleness' in a divided self turned against itself. Striking here and throughout this chapter, is the way in which the body becomes objectified for the consciousness, as the individual attempts to find words to express its alteration. With 'imprisonment' comes an overtone of punishment, as the individuals surrender to, or are overwhelmed by, the changes without accepting them or understanding why they must occur.

> *'… it's not my life I'm living now, I know it is not the life I lived previously, it's devastated,'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

It seems here that mentally it is swifter and more fitting to envisage life as irrevocably altered, rather than to adopt inadequate-sounding descriptions. Some individuals expressed succinctly this feeling of a decaying bodily form:

> '*…you're not in pain but your body's dying around you'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

The contrast between the degenerative body, and the 'I' reflecting upon it, is increasingly dramatic. The expression sounds quite precise, as if the individual wants to convey specifically how they feel and the thought processes generated. The individual also sounds as if a common association of pain and death is missing, which is a very unsettling occurrence. The self is depicted as a kind of backdrop ('… *around you*…') against which the individual's description occurs. Therefore though the description does not sound distanced, there is a distinct separation of the self from the body.

One individual demonstrated a conflict between her previous bodily form and the one she now experiences. The individual concerned appeared still to be wrestling with the changes. The following excerpt is notable for its slightly illogical flavour:

> *'I always tend to wonder why, why me, I were strong, yeah always been strong, I am strong now, yeah,'* (ID54 - female individual with MND aged 58 years, 41 months since diagnosis)

The individual concerned was in a wheel chair and could not move. The self appears to have bisected, and is telling alternative stories about itself. On the one hand there is regret and recrimination ('…*why me*…') aimed at the disease, the situation and perhaps even fate itself. This response suggests powerlessness and even submission to what has happened ('…*I were strong*…') without acceptance. On the other hand, she represents herself still as strong, wherein the more defiant and perhaps optimistic sound of her personal voice can still be heard.

The invisibility of some of the symptoms of MND led to some individuals feeling that other people could develop misconceptions regarding their state of health and sometimes question the credibility of their disability. The following individual remarks upon this disparity between how she is feeling and how she appears:

> '…*they see me sat here and they go away and they say oh (name) you seem fantastic, look really, really well,*' (ID46 – female individual with MND, aged 56 years, 11 months since diagnosis)

There is a kind of discursive, conversational idiom particular to 'well' people confronted with the sick ('…*oh, you look really well*…'). Such utterances are surely intended to comfort, even when the actual state of the individual is not inquired about.

1.iv Self in physical world

The disease symptoms were frequently understood and described in terms of bodily operations of objects and carrying out functional actions:

> '*You need someone to take you to the toilet, pull your trousers down, you need somebody to give you a drink, you can't do anything all you can do is turn the television over with your foot.'* (ID214 – wife to individual with MND aged 51 years, 30 months since diagnosis)

> *'She can't get out of her chair… and now it's affecting her upper limbs, and she can't write, she can't use a computer the same, she can't feed herself now because she is so weak she can't lift her arms up,'* (ID218 – husband to individual with MND aged 56 years, 11 months since diagnosis)

For some participants, simple, everyday tasks such as cleaning, which had previously been taken for granted, were now perceived as posing difficult challenges and many described their feelings of frustration at not being able to carry out everyday activities:

> '*I can't stand at the sink to prepare meals, I can't do bedrooms, the everyday part of it is sort of slipping away,'* (ID86 - female individual with MND, aged 52 years, 33 months since diagnosis)

This clearly expresses how her former mode of relating to the world has now become one of extreme effort and difficulty, where even the most mundane task poses an insurmountable challenge. Again, there appears in the above example to be a clear psychological ramification, in as much as the identity of the individual is being challenged too. With the loss of capability comes consciousness that life as it has been lived the '*everyday*' is 'slipping away'.

2. Diminishing self

Individuals' previously held ideas about their lives, and in particular what they had taken for granted about what they could *do,* and therefore *who they were*, were severely knocked as the disease took hold. Accompanying this was the diminution in the idea of self or personal identity, because sense of self was linked in many ways with practical and social action.

2.i Loss of social purpose and participation

Employment, activities and hobbies which people had enjoyed and were integral to individuals' identities became impossible to engage in. There were a number of descriptions of people's sense of loss when they could not undertake these activities, which drastically curtailed the variety of their entertainments and cultural participation:

> *'I'm too tired in the evenings to go out and really it's because we're great theatre goers and there is no point going to the theatre if you can't concentrate on the play, we were great walkers…I loved cooking yeah, you know, everything I loved has gone.'* (ID46 - female individual with MND, aged 56 years, 11 months since diagnosis)

This individual found diverse aspects of her social self diminished. She categorises herself as a 'theatre goer', someone habituated to this practice, and understanding herself as such. At theatre performances, the culture portrays itself to the audience. It is likely that this individual felt debarred from a special, poetic form of cultural participation, in addition to forfeiting a favourite pastime. There is a sense of not being able to respond at the high level demanded of a theatre audience, and feelings of inadequacy ('…*if you can't concentrate on the play…*'). She uses 'we' to represent the loss of walking, which represents another social and active dimension of life forfeited and also emphasises the mutual, dyadic nature of the impact of the disease.

The loss of social and active pastimes is echoed in the following excerpt. This individual associates the passing of his active, able self with selling off cherished equipment. His language contrasts with the previous individual; the language is more concise:

> '*It's totally devastated my life, I used to fly fish, fly fishing and shooting were my hobbies, got rid of them, sold my guns, broke my heart, fishing equipment that I can't bring myself to do anything with..'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

The lost supports of selfhood are '*hobbies'* – perhaps less significant sounding than '*theatre-going'*. It is as though this individual is struggling to articulate certain feelings which are expressed in the devastation of '*broke my heart'.* The person with MND appears to want to divest himself of the reminders of his lost capacities, whilst not quite making the final step ('…*I can't bring myself*…'). It appears to be the case that individuals begin to schedule their activity in a more ad-hoc way. They lose the capacity to plan in advance and choice makes way for a pragmatic attitude. Patients described their feelings of frustration and sadness at the loss of former roles as a consequence of their disability. Along with hobbies and pastimes, which are subsumed in some cases by a pragmatic intent to make the most of spare energy, personal identity hinged on the parts individuals played in the lives of other people. This individual also felt diminished by losing his active relationship with his family. Perhaps the individual suffered particularly from the cultural expectation that grandparents will remain sprightly and energetic well into old age, for the sake of their families. There is a suggestion of self-criticism, from the disapproving viewpoint of an onlooker, when he talks about not being a '*proper*' granddad. The most significant facet of the role, being able to *'play'* is what has vanished and constitutes the most dramatic loss:

> *'I can't play with my grandchild, and that's the one thing that upsets me,… I'm not, I can't be a proper granddad, I can't play so that really upsets me, in the day to day living with the disease,*'(ID73 – male individual with MND, aged 58 years, 16 months since diagnosis)

There was a sense of changes to the dynamic of family and spousal relations accompanied by a reluctance to accept them. Couples voiced their awareness of the transitions taking place in terms of roles:

> *'So I'm having to do the jobs and that… And I know it, it affects [husband] because he was the man of the house and did the jobs and the fire in there, that was his pride and joy but he's trained me up well, and says ''well done'','* (ID204 - wife to individual with MND aged 58 years, 16 months following diagnosis)

> '*Last Saturday I made a cheese and onion pie, rolled out the pastry under direction, supervision and the dreaded finger; whatever it means I've got to work out. She always points to the kitchen and there's a thousand objects in the kitchen…*' (ID201 - husband to individual with MND, aged 67 years, 92 months since diagnosis)

Holidays, having dinner with friends and finding ways of participating in activities enabled them to sustain a sense of selfhood. However, frequently the participation was reduced or diminished in some way. For instance this individual was able to watch his team play football but it was evident that this was not the same as prior to the illness:

> '*You managed to go to Chelsea on Tuesday, big Chelsea fan, with his brother, but the worse thing about it was that he had to miss extra time and penalties because they were on a train, that's one down side of it isn't it? Normally he would have stayed so that were a bit of a disappointment but at least he got to Chelsea.'* (ID214 - wife to individual with MND aged 51 years, 30 months since diagnosis)

Many people expressed anguish at the way in which this disease was forcing their personalities to change. The changes were understood both as loss of personal abilities and capacities, and also as qualitative changes in character:

> '*I've always been a very confident person, especially the job I've been in but I haven't got the same confidence.*' (ID83 - female individual with MND, aged 74 years, 18 months since diagnosis)

Loss of confidence was another common finding, suggesting that 'confidence' is a subtle construct in our personalities which can be accumulated and also forfeited in various ways. In this example, the individual was keen to think of herself as a '*confident person'*, the character trait is used to define herself in a very positive light. Here again (see above), the distinction was being made between the identity of the person and the traits making up that identity ('…*confidence*…'). In the following example, the individual was beginning to realise that with the slippage of time and erosion of various functions, his personal identity was fragmenting:

> *'In the early days, it was as though it wasn't happening, for twelve months or so, I was basically still the same person, wasn't I? …Because what you see before you isn't me.'* (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

It seems that this individual was concerned to '*rescue'* a sense of the departed person he once was, at least for the duration of the interview process. In one respect he admitted that he was no longer but at the same time wanted to convince the interviewer that the lost person still remained in essence ('…*because what you see before you*…').

2.ii Burden and guilt

Feelings of dependency on others and loss of autonomy was also a recurrent theme in the interviews, reinforcing the view that self-determination and independent decision making are the fulcra of selfhood. In face of this loss, patients often developed a sense of burden and feelings of guilt when perceiving themselves the cause of so much strain for their partners. In the following example the man speaking was envisaging his death as a reason for general relief, and uses language designed to make it appear as unobtrusive as possible.

> *'I don't want to cause her any more frights than I already have, so if I can quietly shuffle off this mortal coil that will do for me. Just quietly drift off.'* (ID73 – male individual with MND, aged 58 years, 16 months since diagnosis)

This participant is tormented by feeling a burden to such an extreme degree, that it would be simpler if he died. This unfortunate example reveals how individuals' sense of how their partner saw and felt about them became distorted. This person equates the '*frights*' experienced by others with a reason for ending his life quickly – the most convenient solution. The language used in this case is quite calm and serene, even light–hearted and colloquial ('*shuffle off this mortal coil*'), and by being so masks deep-seated and despairing feelings.

> *'I feel with (name of spouse) that I am holding him back because like, (name of spouse) is very active, with his computer upstairs and different things, his hobby with the garden.'* (ID83 - female individual with MND, aged 74 years, 18 months since diagnosis)

This woman also revealed how a sense of burden had become very troubling to her. She cited quite specific-sounding causes for her feeling ('…*computer…garden*…') which perhaps do not equate with the generalised and emotional sounding ('*I feel…I am holding him back'*). As well as considering specific problems, this woman is comparing her life as a whole with her spouse's using some evaluative schema of her own devising, according to which her husband's life is becoming more important than her own.

Individuals also demonstrated a loss of self-worth as a consequence of their new *'sick'* identity. This example reveals the person with MND striking an optimistic note, having found something she is still capable of doing. However this exemplifies the sense of hopelessness accompanying failure to complete mundane tasks, which might be thought of as the bedrock of the self:

> '*I make cards and I do patchwork quilting, so that keeps me occupied, knowing I can't do anything else but I can do this, I can sit here and do this, I am doing something not sitting*

here thinking what's the point of me being here when I can't do anything.'(ID86 - female individual with MND, aged 52 years, 33 months since diagnosis)

Spouses did comment at times of the physical and emotional exertion that caring for their husband or wife required. It was evident that assuming a role of caring did frequently lead to feeling overburdened, as this wife indicates in the following quotation:

'…it's frustration because … one day he can do it and then next day he can't and the amount of effort it took for me to look after him on my own, I did it for nine months and I just couldn't cope anymore, so we had to get help in, hadn't we?' (ID210 – wife of individual with MND aged 56 years, 11 months since diagnosis)

Partners or spouses had a sense of guilt for various reasons. Sometimes because they were worried that they were overburdening their families or as a result of having snapped under the strain of their experiences:

'*I just needed to vent my anger really and she was the only person there and I felt lousy after I had done, because it is horrid, she is in a very vulnerable position I felt a heel after doing it,' (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis)*

Whilst couples found (see below) they were often content in one another's exclusive company, the difficulty came with emotions such as anger, roused by the pressure of the situation as a whole, as opposed to an individual's failings. The couple in this case turned in on itself and the sense of burden was followed by recrimination and guilt.

2.iii Social marginalisation and diminished relationships

Many people revealed that they no longer interacted socially as a result of the disease. The following example quotations demonstrate how couples frequently retreated into their own worlds quite shut off from outside:

'*…we used to be always out somewhere everyday but now everything seems to have ceased…so it has altered our life dramatically, hasn't it? To virtually stopping, confined to two rooms basically, bedroom and kitchen, sometimes, on a nice day we just go and sit in the garden and that's as far as we get,*' (ID207 - husband to individual with MND aged 58 years, 41 months since diagnosis)

'Well, I can't go out, you can't go anywhere, so I am virtually here in this area all day every day.' (ID45 - male individual with MND, aged 74 years, 8 months since diagnosis)

In both these quotations there is a sense that the couples' worlds are shrinking and folding in on themselves and the outer reality is becoming more distant and removed. It appears to be the case that couples become more reliant on each other as their social world shrinks. Shrinkage is not instant but incremental so that couples witness the departure from their previous habits ('*everything seems to have ceased'*). Subsequent sections reveal that couples are compensated for the loss of social contact by the deepening of existing ties with friends and family. Moreover in the first quotation there is a dismayed but not despondent tone, a sense of toughness and resilience also comes through to the reader.

Another participant described how the disease left him incapable and reluctant to leave the house:

> *'I've only been out the house twice since Christmas to the MND clinic, my choice, I don't want to go, I've no energy, I can't do anything,'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

This respondent does perhaps appear to be somewhat defeated by the implications of the disease. His wife revealed that his social withdrawal also stemmed from a sense of humiliation and concern of how others perceived him:

> *'…we used to try and have a walk up town every day and when he was unsteady, he said 'people will think I'm drunk' and I said 'it doesn't matter, does it really?'…but he was always aware of what others were thinking about him.*' (ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis)

The level of care and concern within couples is again revealed. The complex effects of the disease on personal identity are again prominent. This quote suggests that actual physical effects are closely tied to individuals' perception of the effects and how they think others will react. As the wife attempts to change the husband's attitude to the social reaction he fears, it is again evident that a complex interplay of physical symptoms – anxiety – mutual concern is at work. In another interview, a husband illustrated how his wife had similar concerns of how she would be negatively perceived and the way in which this had significant repercussions on their social lives:

> '*I don't have a social life full stop. I mean we are supposed to be, we have been invited to a sixtieth birthday party this weekend, just round the corner, the people are having a marquee in the garden, it should be accessible but, (Name of patient) will meet a lot of people there that she hasn't seen for a long time, she feels uncomfortable about being in the wheelchair, about difficulty eating in a public place because she can't lift her glass up so she has to have a straw, she can't lift food up, and the worry about the catheter, so going out jointly, it's very, you are on edge the whole time,'* (ID218 - husband to individual with MND, aged 56 years, 11 months since diagnosis)

The couple feel potentially excluded from a greatly symbolic occasion ('*sixtieth birthday party*'). The physical symptoms clearly erode confidence in relationships, as though the couple fear that rather than receiving sympathy they will be judged. There also appears to be a nervous need to constantly anticipate the immediate future and the worst possible occurrences, leading to further negative expectations and distancing from others. As a consequence loss or deterioration in friendships was frequently described by couples in the interviews. One spouse reported that whereas previously friendships had kept going without conscious effort, now maintaining friendships became increasingly difficult:

> '*…in the end if you are not working at a friendship you tend to lose your friends a little bit because you can't get involved in the things that you would previously have been involved in with them,'* (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis)

Couples appeared to become conscious that their friendships had been built upon kinds of shared activities or contact and suspected that as these things declined, the relationships themselves were revealed as lacking substance. Some people reflected on the loss of friendships:

> *'There are people that rang that I don't hear from any more.'* (ID94 - male individual with MND, aged 54 years, 6 months since diagnosis)

For some there was an air of acceptance that losing friends in such circumstances was perfectly natural:

> '*…but people don't visit, I wouldn't have done either, I hated seeing people struggling, so I didn't visit and I understand why they don't want to, so apart from my daughters there is only a couple of people that I see.*' (ID73 - male individual with MND, aged 56 years, 16 months since diagnosis)

This frank admission highlights why friends have vanished – the sight of people struggling is unpleasant. Whilst there is a kind of impressive candour in recognising this, perhaps the individual is also rationalising why friends have disappeared and normalising it. People expressed a view that friendships were no longer on an equal footing and sometimes their friends had reacted with pity:

> *'I have a friend, and at first she tended to mollycoddle me, and she was here all the time and (name of spouse) had to speak to her and say (Name of Patient) is still (Name of Patient), there's no difference…'* (ID86 – female individual with MND, aged 52 years, 33 months since diagnosis)

It seemed important to respondents that friendships, if they were to be maintained, had to remain on previous terms. In this case the friend seems to have been close enough to be told this and

accept it. In other cases the friendships did not have that capacity and couples found it expedient to deal with the issue another way. For some, friendships of this nature were no longer sustainable:

> '*To a degree, I've dropped them all really… yeah. I don't want them coming round here feeling sorry for me, that's it.*' (ID45 - male individual with MND, aged 74 years, 8 months since diagnosis)

Whilst this statement has a tough and almost defiant tone, it perhaps reflects adversely on the nature of relationships that are better dropped than re-negotiated. It was not surprising therefore that a sense of isolation was frequently commented upon by individuals and their spouses:

> *'I think you feel fairly isolated and you feel fairly lonely in it really,'* (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis)

Individuals often retreated into the couple and the home, although this was reported in different ways as a process that they had been forced to endure, or had somewhat shaped as they adapted to diminishing mobility and less participation in social activity.

2.iv Adaptation

People described how they had to get used to a new way of using their bodies in order to accomplish routine tasks and activities. In the following example the respondent remains relatively 'up-beat' about the difficult situation. The individual tries to keep up with daily tasks whilst needing to improvise props and support as difficulties arise:

> '*Hoovering and dusting, well I can dust if I hold on to something at the same time, …(laughs) I can walk around the house as long as I can get hold of something.*' (ID86 - female individual with MND, aged 52 years, 33 months since diagnosis)

A very strong strand in the responses centred on making use of and improvising a means of physical support. For example, partners and spouses were frequently relied on to enable individuals to carry out daily activities. In the next excerpt, a spouse related how he supplied strength and mobility to his wife's feet so that she could walk:

> '*…and I used to get down on my hands and knees and just lift her feet up and move it along, one at a time whilst she pushed her frame and we went on alright for a while like this..'* (ID201 - husband to individual with MND aged 67 years, 92 months since diagnosis)

The wife also supported herself with a frame where she could, so that physical movements required co-ordination across types of motion leading to a complex, successful movement forward. It

emerged that individuals were reflecting on the complex interplay of responsibility between self and partner involved in simple bodily routines like washing.

> *'…(name of spouse) has to wash my back, wash my feet, dry my feet and my back, there is sometimes, he needs help with like a hook for my bra, things like that..'* (ID83 - female individual with MND, aged 74 years, 18 months since diagnosis)

The female individual appears to have accepted that she can no longer fulfil many simple tasks and that her husband will call on her when she is needed. There is a sense here that her relative dependence has been accepted and incorporated into routines so that it is treated as normal behaviour. People described how they modified their ways of carrying out activities, adjusting their expectations so that changes became normalized as routines. One individual had taken to listening to audio tapes as he could no longer read:

> *'I used to read three books a week but I can't even read the paper cause my arms are so weak so I get the audio books off there, and listen to them in bed of an evening.*' (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis)

In the above example, '*of an evening'* illustrates how the adaptation has become part of a relatively settled and satisfactory new pattern of coping. The partners of individuals with MND described ways of adapting to new situations also centring on the formation of different types of routine and exceptions to them. For instance one husband described how he was getting used to different foods in order to accommodate his wife's eating difficulties:

> *'Well, we don't have the same meals as we used to do cause she can't swallow very well so it tends to be soft food but I like a steak and grilled things are out but we can accommodate that, if we go out for a meal then I can have a steak then. But otherwise I have a varied diet, I don't mind what we're eating at all.*' (ID 203 – husband to individual with MND aged 74, 18 months since diagnosis)

The husband appears to be accepting of the relatively minor inconvenience caused to him and illustrates how the couple have settled relatively easily into a 'normal' routine. The new routine still allows for him to have what he enjoys on occasion. In this case as with the next, the spouse appears to be relatively content with the change to routine which is presented as an adjustment to existing pleasures rather than a major upheaval. This spouse described how they had adapted recreational hobbies to enable his wife still to take part:

> '*I took her out yesterday, I get her out most days cause I do a lot of bird watching now whereas I used to do a lot of walking, across the mere and what have you, now I go round*

> *different places in the car and she loves it, she's sat there and she takes an interest in what's going on so round (names of place) up to (name of place) you know on different days,'* (ID201 - husband to individual with MND aged 67 years, 92 months since diagnosis)

Another spouse articulated the domestic pleasure of being a carer centring on the tranquillity of an accepted routine:

> '*I'm happy doing things at home, potter about in the little garden, and out in the back garden, pot plants so I've just got that routine now of caring for him.*' (ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis)

As with previous examples, the mode of narration with these spouses differs markedly from the view of individuals with MND, whose views are inevitably more personalised around immediate bodily need and reflect the individuals' preoccupation with their physical condition. Having to adapt to the changes that were occurring in the body meant that individuals had to develop new modes of existing in the fullest sense of the idea, or 'being'. Sometimes, as illustrated in the next two examples, individuals' reflections in this mode suggested that a new kind of agency was being sought to enable them to face the harshest implications. This sounded like a test of will to which the individuals needed to respond, by finding ways of coping with an uncertain future.

> '*But we do try very hard not to let it be dominant, you can't fight it but you don't have to give in to it.*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

> *'…just because you have got it, you can still make adaptations, to do things with people that you did things with before.'* (ID86 - female individual with MND, aged 52 years, 33 months since diagnosis)

In these cases reflections obviously eclipsed relatively minor concerns like efficiently planned routines. Individuals appeared to be taking stock in a more substantial way of what they thought about the disease and were positioning themselves relative to its worst affects. Individuals were realistic about their chances but still voiced determination and defiance, as in the first example immediately above. A number of participants revealed a resigned acceptance of the disease as they remarked about getting used to the changes and learning to live with the changes:

> *'I've come to terms with it, I can't do anything about it.'* (ID6 - male individual with MND aged 79, 11 months since diagnosis)

In another case, individuals made sense of the disease by realising that they were powerless to alter its course and with this too came a degree of insight. The following spouse had learned with her partner that acts of defiance were futile and effectively a waste of time:

'…that there is nothing we can do about it, fighting, banging, screaming, shouting, striking not going to make any difference, we talked about it and we just take each day as it comes, I just pray to God that it takes him one night peacefully and he doesn't have to go right to the bitter end.' (ID210 - wife of individual aged 56 years, 11 months since diagnosis)

The couple appeared to appreciate they needed to be clear-headed about the individual's prospects ('*take each day as it comes'*), implying a degree of sober acceptance but not total despair. However, the challenges of coming to terms with a disease which is constantly worsening and which in many cases offers no period of remission or plateau, was focused upon in the interview data. In the following example, the individual reveals he has attempted to master the problem through will power and perseverance, but the prospects are far from encouraging. He is left with little to feel certain about apart from the strain of constant effort.

> *'…do things as long as you can, and when you can't do it, you find another way to try and do it, and keep going like that, just try and be positive which isn't, it's a lot easier to say than it is to do, but I think we are making the best out of a bad deal but who knows? Its hard work, isn't it?*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

In the above instance, the self is trying to battle with the situation by defining itself through positive action, reacting and recovering in the most trying of circumstances, rather than being defined only by sickness. In the following example, the psychological pressure attending this constant effort without positive results is again expressed. A note of hopelessness is discernible and it is clear that a sense of gain is hard won and fleeting.

> *'…it just feels all the time that you are just battling against this constant deterioration, and you know it doesn't matter what you do and how much you battle, ultimately there isn't, there is nothing, there is no future really'*(ID218 - husband of individual with MND aged 56 years, 11 months since diagnosis)

Both individuals and spouses found positive ways to adapt and often reflected on adaptation with optimism and good humour. The types of narrative differed, spouses often emphasising the details of routine against a backdrop of care, individuals with MND adding to this a sense of personal, physical, need and dependency. Both types of respondent illustrated very strong character and determination when adapting to the severity of the disease, and were analytical about how best to cope, even when appearing to accept there was little they could do to mitigate its effects. The last sentence of the final quote in this section, '*there is nothing, there is no future really,'* sums up the

nature of responses at its most pessimistic, when both individuals and spouses contemplated their prospects with least hope.

2.v Equipment and self

This theme describes the ways in which people with the disease used different technologies to support themselves during the disease, and reviews the different reactions in terms of couples acclimatising to its use and how sense of selves were affected. Some participants struggled with accepting and using equipment such as wheelchairs or items to support their daily living as it was felt they would draw attention to their altered body-subject:

> '*Well I didn't really think it, I couldn't see myself walking down [name of place] pushing that thing [trolley] quite honestly… Well cause I'd sooner walk with a stick or not at all than go with a thing like that.*' (ID45 - male individual with MND, aged 74 years, 8 months since diagnosis)

This example illustrates how body-concept and self-image were tied to awareness of the appearance of technologies in the eyes of others. This individual was prepared to forego potential benefits for the sake of appearances; being a public spectacle would apparently be worse than being inconvenienced by leaving the walking trolley at home. Both individuals with MND and their spouses became quite animated in discussion of the imposition of technologies which were potentially invasive.

> *'They suggested putting a hoist in the front room, so she could sit in one of the lounge chairs, but you didn't want that did you? They did try and press it with you slightly but you didn't want that did you, you said you would prefer to sit in here than go in the front room, you reckoned that they were too fussy, didn't you? I don't know, I think it was just the thought of having another hoist in the front room which put you off.'* (ID 207 – husband of individual with MND aged 58 years, 41 months since diagnosis)

In this example there is a dichotomy between 'us' and 'them'. 'They' are the ones apparently foisting the technological aid upon unwilling recipients. The recipients, as with the previous example apparently have a strong desire to uphold accustomed norms and to resist the intrusion of foreign aids and abnormal devices. In the case immediately above, there is a bit of a stand-off ('*you reckoned that they were too fussy*') as the two sides have rival ideas about how far 'normal' levels of inconvenience can be stretched to incorporate an unwelcome device that might help the sufferer but is unwelcome. Others commented on how equipment could not fully replace their loss of body function and that it detracted from their participation in activities and practices:

> *'I loved shopping. I do go shopping but it's not the same shopping from my wheelchair, yeah it impacts on everything.'* (ID46 - female individual with MND, aged 56 years, 11 months since diagnosis)

Again the strong sense arises that ideas participants had about 'normal' practices were very much tied to 'normal' ways of doing them. Individuals were concerned therefore about changes to a complex blend of established patterns of behaviour with social significance and visibility that defined and reflected their horizons of what was usual and acceptable. However, as time progressed and with increasing use, it was evident that people living with MND could become accustomed to, and accepting of, the equipment.

> *'…I can get round quite well on the scooter and I can get out'*, (ID213 - individual with MND, aged 72 years, 18 months since diagnosis)

There was evidence that the equipment made a massive difference to people's lives enabling freedom and autonomy:

> *'It made your life brilliant for twelve months, that scooter has been brilliant for twelve months…'* (ID210 – wife of individual with MND aged 56 years, 11 months since diagnosis)

In the last case, it was the carer rather than the individual who saw the benefits in such glowing terms. Individuals with MND, whilst acclimatizing to the benefits and often recognizing significant improvements to their capability, had reservations particularly in early use. This was because new devices were accompanied by a sensitive awareness to bodily image and self-identity, which in turn reflected individuals' ideas about normal routines and appearances and how far these ought to be altered for the sake of physical comfort.

3. Altered temporality

This theme represents time not as a 'given' underlying experience but as a construct that has altering significance as the disease progresses. Respondents often found that they focused intently on the present instant because the remaining time was so precious to them. On the other hand there was a sense of having to remain fixed on the present because future time was too unpredictable and ultimately troubling to contemplate.

3.i Awareness of time

Living with a diagnosis of a terminal disease, altered people's perception of time. For some, there was a sense that time had slowed down, so that the present was perceptible in separate instants, each having a significant impact:

> '*I can feel every second of the day.'* (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

For others there was the feeling that time had speeded up and that they were now racing against it. In some cases there was a sense that couples were attempting to cram the rest of their lives into what little time they had left. In the following example, the spouse notices changed behaviour through her husband's heightened consciousness of time:

> '*I've got to say that I think [husband] rushes a lot of things now. We tend to be doing things at 200 miles an hour, whereas we wouldn't normally do that,*' (ID205 - wife to individual with MND aged 58 years, 6 months since diagnosis)

Another spouse reflected on the possible motivation behind the changed behaviour in relation to severely limited remaining time. Her comments suggest the intrinsic links between life expectancy, attitude to remaining time and mental positivity:

> *'You can't live like that, just all sad and depressed all the time, you have got to make the most of what you have got while you have got it, you know and then deal with it when you haven't got it.'* (ID210 - wife of individual aged 56 years, 11 months since diagnosis)

In this example there is a suggestion that the couple are making a conscious effort to take a 'positive' stance on time, connected with the necessity of not looking too far into the future. The wife here has in a sense 'compartmentalized' her attitude to time, in as much as awareness of future time is alluded to ('*deal with it when you haven't got it'*), but is being kept in reserve for a later state of consciousness in different conditions. Conversely some couples appeared to have a more ambivalent attitude to the future. The following individual does not appear to have 'compartmentalized' time in the same way as the previous respondent. There is perhaps reluctance to articulate the worst prospects for the future, as understatement is used ('*I'm not looking forward to it'*):

> '*Well, I'm not looking forward to it but as I say there is nothing I can do about it so I just have to sit here and wait.'* (ID6 - male individual with MND, aged 79 years, 11 months since diagnosis)

There appears to be a sense of resignation here that the course of the disease will not change and that this cannot be denied ('*just have to sit here and wait'*). Another man with MND used idiomatic expression to characterise his situation:

> '*You are in God's waiting room aren't you?*' (ID94 - male individual with MND aged 58 years, 6 months since diagnosis)

There is a level of informality and perhaps familiarity in this mode of expression, and the idea of 'heaven' which is in some sense evoked here might provide a degree of comfort. Another respondent expressed a pro-active mentality to the task of waiting for time to unfold:

> *'So, we will just wait for things to happen… so I've a lot time where all I can do is just think about what's happened, what may happen, what's going to happen.*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

In this case there is a strong sense that waiting is itself a kind of action, particularly since there is much important contemplation of the future to undertake. This example reveals how individuals expressed a very pronounced conception of time as past, present and future rather than as a single continuity. This individual reflects upon the past ('*think about what's happened*') as this in some important sense appears linked to purposeful and courageous thought about the future ('*what may happen, what's going to happen'*).

The present often appeared to be projected as living in the moment and holding off future time was a common theme found in the data:

> *'I don't like looking too far ahead in the future because well, you know what the end result is but, you don't know when it's going to be, so we kind of take things I won't say a day at a time, but a week,*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

Again I would suggest that choosing a form of words was difficult for respondents. In this instance there is again use of understatement or perhaps euphemism ('*you know what the end result is*'). It was common in the data as this instance illustrates it, for respondents to distribute their notions of time into much smaller and more significant units, so that a week at a time becomes a manageable period in which the future can be contemplated, or even less than a week:

> '*The future, you don't look at the future, you look at the next day.*' (ID94 - male individual with MND, aged 58 years, 6 months since diagnosis)

In contrast and in keeping with the pattern of wanting to think positively about the future and thereby compartmentalise the worst prospects by focusing on the positive, the next respondent explained that she and her husband consciously pursued a strategy of staying busy with relatively small-scale but frequent diversions:

'That's why we do try to have stuff planned all the time, to keep going out, going out all the time, we've just had a few days down south.' (ID214 - wife to individual with MND aged 51 years, 30 months since diagnosis)

3.ii Loss of expected future time

Many people expressed their sorrow and grief for the loss of future time which MND had taken from them. Often couples alluded to a period late in life which would bring earlier plans to fruition and for which the earlier sacrifices had been made.

'*I'd just retired and so it was going to be, [husband]'s a little younger than me, so it was going to be he'd work till 60 and then we'd go off travelling and do all the things you hadn't been able to do,*'(ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis)

One couple expressed a sense of being 'robbed':

'…Cheated is a good word, because we've always tried to do the right thing,' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

This couple revealed an almost protestant work ethic and having worked hard and always lived a good and honest life that deserved to be rewarded, as though the disease represented a kind of unfairness or injustice that the worthiness of their lives to date had been designed to avoid:

'Yeah it's like you've said, you know, you've worked all your life, you've never been off sick, never done anything, you've always played football, kept fit, you know, we've been together since we were teenagers, (cries) had two kids, paid your mortgage, you know what I mean, and you just think, life were getting really good,' (ID214 - wife to individual with MND aged 51 years, 30 months since diagnosis)

Other couples voiced this sense of grievance that injustice was being done to them, because the lives they had led to this point should have earned them a very different conclusion to life. The appearance of MND in their lives seemed beyond rational explanation and therefore a form of punishment:

'*It were awful because of the shock of it and then the anger, why? Because he has never done anything wrong to anybody, why should he have to, it's a horrible thing…'* (ID210 - wife to individual with MND aged 56 years, 11 months since diagnosis)

Having the future cut off so abruptly and the loss of prospective occasions and celebrations was extremely upsetting for many individuals, who regarded lost time in respect of the lost opportunities to bear witness to the lives of loved ones.

> *'…it upsets (Name of patient) that she will probably won't be here to see either of them get married, and she will probably not be here to see either of them have children and all those things you just assume...*' (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis)

In many cases as with the one above, individuals reflected ruefully on having lived with the mistaken assumption that future plans would ripen as they predicted and there was a discomfort in acknowledging being wrong about this. Individuals could not help considering a future time that would take place in their absence:

> '*You are sat on your own, with pictures of my grandkids and I think I'll miss them and they will miss me, hopefully,*'(ID9 - male individual with MND, aged 56 years, 11 months since diagnosis)

Some commented that painful though it was to have to do, at least there was time to prepare to say good bye and there was some comfort to be taken from this:

> '*It's making the best of what time you've got left and we've a friend whose husband had a heart attack in the night, next to her in bed, they didn't get a chance to say goodbye and I said at least we're getting a chance to put our house in order and say goodbye…*'(ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis)

Individuals very bravely took a positive stance on the situation, remarking as in the example above that they were fortunate to be able to round up their affairs and take significant departure from loved ones. In the next example the participant also tried to take heart from the predictability of the condition in the sense that there would be no sudden and unexpected ending.

> '*In one respect with the way this thing is, you're eventually dying so I suppose it does prepare people for that conclusion, in that it's not like going out one morning and being hit with a car, or going out and that's it*,' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis)

Experiencing time differently was a highly prominent theme with participating couples. Couples aimed to enjoy the remaining time as pleasurably as possible but there was also an element of diversion or self-distraction in this and acknowledgment of where the condition would inevitably

lead. Couples reflected on the importance of 'instants', of contemplating the future in a way that was informed by an appreciation of the past and voiced a sense of injustice that well-earned time for enjoyment late in life was being denied.

4. Transcending embodiment

With this super-ordinate theme, the ways in which respondents experienced and reflected upon the effects of their deteriorating bodies, are emphasised. The couples found ways of overcoming and seeing beyond the physical problems and difficulties, finding life meaningful in other ways.

4.i Dyadic selves

It was evident from the interviews that living with the disease had a huge emotional toll for both individuals and their spouses. One couple found that each could act as an emotional catalyst on the other, so that awareness of the disease ran like an emotional undercurrent that could rise up at any time:

> '*Occasionally, if I am hoovering I just burst into tears and I have to fight it back, you know, but then I do, I get a grip on myself, I have a good talk to myself if he sees me crying he says get out because you will start me off, get out, you know and that's how it is..*' (ID210 - wife of individual with MND aged 56 years, 11 months since diagnosis)

In the above instance the couple share a heightened sensitivity to a shared difficulty through which they connect emotionally. The individual with MND seems to want to withhold a full-blown emotional reaction for the sake of keeping up the appearance of emotional equilibrium and normality ('*get out because you will start me off*'); a sense of normality is heightened by the everyday activity of hoovering. Frequently, individuals found it was their partner who was able to understand and relate to their experiences:

> '*…cause he understands, it's difficult to get other people to understand*' (ID86 - female individual with MND aged 52 years, 33 months since diagnosis)

Moreover there was often a reliance on each other for emotional support and accepting the role of carer was a demonstration of their love for their partner. As with the example above, in the next quotation, there is a strong suggestion that couples facing the difficulty of MND re-assert or re-emphasise the features of the relationship that have given it substance and stability:

> '*Be strong… Be strong for [husband]… caring for him… I've known him for 42 years and … those vows that we made… to look after one another… are very strong… I think that is my job, I call it a job, it's what I want to do and what I need to do, so it's to make [husband] as*

comfortable as possible…'(ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis)

In contrast to the desire for a shared space of 'emotional stability' in the 'hoovering' example, in this case it is a sense of duty accumulated over time that motivates the carer. The reference to 'vows' is particularly powerful as the carer may be referring to religious vows, which imply a transcendent dimension as both individuals are subsumed by the power of a shared ritual. This level of devotion was striking, yet frequently demonstrated through the immense effort that spouses often made to provide support to their partner for the catalogue of physical needs that surfaced throughout the course of the disease:

'So our day starts with me getting out of bed, when I'm ready, I wake up for half an hour, …and then I get (name) up off the bed, put her in the wheelchair, take her to the toilet, sit her on the toilet and I come back and have a shave in the bathroom, then I go back for her bring her back to the bed, In the meantime I've left a big bath towel on the bed, I lie her on that and I wash her from head to toe. I do that every day. Once a week she has a proper bath as we call it, I sit her in the bath, lower her down in the water, splash about all over her and that's how we go on. And I bring her downstairs for breakfast. She has her breakfast, and then she goes on the toilet and we're ready for the day, whatever it's going to bring us.' (ID201 - husband to individual with MND aged 67 years, 92 months since diagnosis)

The near-total dependence of one person upon the other is evident here. What is particularly striking in this case is the language used by the carer. The list of duties performed is articulated in a very 'matter-of-fact' way, suggesting routine which is well ingrained and rehearsed. The routine comprises the preparation for the day of both individuals, so that both their needs are accommodated in a single process of action. In the final phrase, ('*whatever it's going to bring us'*), the carer combines both self and partner in a single agency. The relationship between the couples often became more intensified in such circumstances. Some stressed how important being part of a couple was in their lives:

'We are really happy everyday together, I mean there is only us two together so there is nobody to fall out with apart from ourselves and we don't do that,' (ID207 - husband to individual with MND aged 58 years, 41 months since diagnosis)

'We are quite happy to be together in this house, so that's us, that's the main thing,' (ID212 - husband to individual with MND aged 52 years, 33 months since diagnosis)

In the first example, the apparent intensity of isolation is counteracted with a note of humour. It is even implied that the couple relate better together as a discrete unit than they would by mixing more generally in the world. The second quote says much the same; there is a sense of contentment rather than claustrophobia at being mostly at home in each other's company.

4.ii Social self and family selves

Running parallel with the feeling of self-sufficiency as couples looking after each other, there was a recognition that social support and contact with close friends was essential for coping with the vicissitudes of the disease:

> *'We're not cut off completely from society, I wouldn't let that happen, because I think social skills are very important.'* (ID203 – husband to individual with MND aged 74 years, 18 months since diagnosis)

This quote suggests that the skills associated with maintaining friendships were considered as significant as the friendships *per se.* It emerged that respondents categorized friendship into different kinds, from less to more meaningful and the truly authentic friendships were valued most:

> '*…one thing I would say is about something like this is that you do really, really find out who your true friends are and that does give you something's very special that perhaps you didn't know you had before.'* (ID46 - female individual with MND, aged 56 years, 11 months since diagnosis)

Some friendships appeared not only to stand the strain of MND but also to strengthen and deepen because they were tested by the altering circumstances. Similarly respondents commented upon receiving support from close friends and family:

> *'So we have, we are fortunate in that, if you can be fortunate that we do have a lot of support from family and friends which does help,'* (ID20 - male individual with MND aged 51, 30 months since diagnosis)

As with their appreciation of 'authentic' and enduring friendship, there was a sense that with family, couples felt very fortunate when family members rallied round them and made special efforts to be supportive. Some couples reflected on the precious time spent with family in such circumstances:

> '*…in September, our two boys came to Portugal, they stayed with us for five days and then they went home, and that was, we had a really good time, didn't we? …we laughed for five days,'* (ID214 - wife to individual with MND aged 51 years, 30 months since diagnosis)

Another individual remarked how having MND had made her prioritise her time. Relative to the importance of family members, previous pastimes and responsibilities faded from the scene and this was thought to be a good thing. Of spending more time with her family this individual said:

> *'I spend more time with the kids than probably I would have done previously cause I would have been busy working and doing things, so I've made more time to spend time with them, we've done more things together so in some ways there is a positive side to it.'* (ID86 – female individual with MND, aged 52 years, 33 months since diagnosis)

Again the idea emerges that couples increasingly found comfort in significant relationships which rendered previous aspects of life less important and altered the way they thought about and understood their priorities. The notion of sharing is very prominent, especially when shared experiences seemed to combine and connect people in intricate patterns of shared love, duty, family ties and responsibility.

4.iii Convergence of time

Previous sections illustrate how couples found future time and waiting for the culmination of the disease particularly difficult. However memories were often treasured because they put the limited future prospects into perspective. It was noted above that couples were often smarting from the injustice of the 'punishment' of MND when they felt they had led worthy and upright lives. In the following example, the opposite seemed to be the case – the past was weighed in the balance with future prospects with a sense of gratitude that the couple had experience their fair share of good times:

> *'…but we can look back, that's the only way to look at it, and look back at it, what we've had, it's been good.'* (ID214 - wife of individual with MND aged 51 years, 30 months since diagnosis)

Sometimes couples appeared to take comfort from the fact that others had already passed away and this led to some touching reflections. For this male respondent, future time altered its aspect, making the future merge with memories into an almost reverie like contemplation of life and the end of life:

> *'…but I like going round the cemetery I have a lot of relatives there and I go and have a talk to them,'* (ID9 - male individual with MND, aged 56 years, 11 months since diagnosis)

It was sometimes the case that couples managed to construct a unity from the discontinuity MND had created in their lives, and that the past, present and future were unified and led to some profound moments of contemplation of existence.

Summary

The findings from the analysis of interviews with twelve couples who were living with MND have been outlined in this chapter. The summary table of themes produced in the analysis of the case study (as described in the chapter three) was used to identify themes in the interviews and the four main categories of 'altered body', 'diminishing self', 'altered temporality' and 'transcending embodiment' were used to classify the findings. An idiographic commitment was maintained throughout the process, allowing each interview to unfold meaningfully in its own right, in tandem with the process of classification. Analysis demonstrated that as couples experienced living with symptoms of MND, their understanding of the body shifted greatly and these transitions are described by the super-ordinate theme 'altered body' and its ordinate themes 'awareness of the body', 'alienation of the body', 'entrapped embodiment' and 'self in physical world.' Change and loss to the couples' ideas of selfhood and sense of identity were categorised in the theme 'diminishing self' which incorporated the ordinate themes 'Loss of social purpose and participation', 'burden and guilt', 'social marginalisation and diminished relationships', 'adaptation' and 'equipment and self.' The super-ordinate theme 'altered temporality' was identified in the interviews and encapsulated the couples' complex and changing sense of time detailed in the ordinate themes, 'awareness of time' and 'loss of expected future time'. 'Transcending embodiment', represented the final super-ordinate theme and findings differed to the case study as only three ordinate themes including 'dyadic self', 'social and familial self,' and 'convergence of time' were identified in the interviews. The final chapter will draw conclusions from the study and discuss the clinical implications of my findings as well as suggesting further avenues for research.

Chapter 5 - Discussion

Introduction

This chapter discusses the findings of the study in relation to existent literature. The phenomenological analysis of the case study and interviews revealed a number of themes. These themes were grouped around the assumption, intrinsic to phenomenology, that individuals inhabit 'life-worlds'. By exploring the interweaving of the *'life-worlds'* of Jackie and Frank and 12 other couples living with MND in this study I have examined how people understand themselves in relation to others. This examination highlighted the importance, and fluidity, of personal 'boundaries'. In a general sense, the boundaries identified were between the individual and his or her spouse or partner. The boundaries extended to friends, family and the wider social context. Moreover these boundaries have been found to be provisional and permeable. The points at which individuals' 'life-worlds' intersect are not static, but change as the relationships change.

Analysis of the journal extracts and interviews has yielded four over-arching themes and 17 ordinate themes which describe the impact of the disease on Jackie and Frank and 12 other couples' life-worlds. In accordance with the IPA methodology, in this chapter, I consider the identified themes in relation to the existing literature in the field, placing them within the academic, intellectual and research contexts. As Smith, *et al*. (2009:113) acknowledge, the nature of IPA can take the researcher into *'new and unanticipated territory*'. This was certainly true in my case. My analysis of the data took me deep into the wilderness of existential phenomenology. I use the word *'wilderness'*, because phenomenological analysis requires a considerable amount of engagement on an abstract level. Moreover, my interpretation is not cemented once-and-for-all, but developed piece by piece. As I was dealing with close-to-death narratives and accounts, the material was often challenging to record and difficult to interpret in a way that did it justice. In my efforts to accomplish this, I have undertaken a form of analysis which has reflected some of the profundity of the couples' experiences, whilst requiring the reader to adopt a philosophical mind set.

Discussion of findings

Discussion of the research findings now follows. As mentioned above, the findings were grouped into four main themes and 17 ordinate ones and are all detailed in table 1 below. Themes were identified when types of data prompted specific kinds of analysis with sufficient internal coherence to be presented as a theme. Three themes were derived from the analysis of Jackie and Frank's journal data which were not emergent from the interview data (narrative self, spiritual self and authentic being) and possible reasons for this divergence in the themes are discussed below.

Super-ordinate Themes	Ordinate Themes
1. Altered Body	Awareness of the body Alienation of the body Entrapped embodiment Self in physical world
2. Diminishing Self	Loss of social purpose and participation Burden and guilt Social marginalisation and diminished relationships Adaptation Equipment and self
3. Altered Temporality	Awareness of time Loss of expected future time
4. Transcending Embodiment	Dyadic self Social and familial self Convergence of time Narrative self ***journal only** Spiritual self***journal only** Authentic being****journal only**

Table.3: Table demonstrating themes extracted from the journal and interview data of couples

The first main theme, 'altered body' and its subordinate groupings concentrates upon how individuals' bodies changed as the disease took hold. The second main theme, 'diminishing self' describes how the changes affected them and the impact on notions of identity. The third main theme 'altered temporality' identified, along with its sub-groupings, how people's experiences of time were affected by the disease. Altered experience of time was found to be intimately connected with questions around existence. The fourth main theme, 'transcending embodiment' describes how people in the study developed new ways of understanding themselves which helped them combat the disease. I use the word 'transcendence' for ways in which people tried to adopt 'greater' meanings to put their sufferings in perspective. The idea of 'selfhood' is critical in this section, and throughout the analysis. My working definition of selfhood, is the life of the individual, as understood and experienced by them. In this chapter it is revealed that selfhood can present a complex entity, defined in relation to self and other in intimate interconnection. I have emphasised the voices of both patient and carer, presenting how they illuminate each other's responses and the shared experience of a being married couple.

1. Altered body

'Altered body' is my umbrella-term for people's experience of alteration which was evident in the data, comprising four sub-themes discussed below.

Awareness of the body

'Awareness of the body' is the theme used to describe the recognition of the bodily form as it deteriorated, a phenomenon described as the '*dys-appearance'* of the body by Leder (1984, 1990). Throughout this study, individuals revealed a heightened consciousness of the body accompanying the disease, reflecting on the symptoms and numerous bodily changes taking place, and their concerns surrounding them. They recounted how parts of the body no longer functioned and how automatic bodily responses such as breathing or swallowing were now something they consciously monitored or had to adjust. Spouses also frequently reported on the increased visibility and dependency of the body, describing the various ways in which they now had to support and care for the individual. The physical deterioration was visible to themselves and others, and carried with it intensified self-consciousness and even shame about being so dependent.

People described in detail how the 'body' (whether their own or that of their partner or spouse) now had become the focus of their daily lives. As a result of the body's altered and unpredictable nature, activities and events had to be organised and planned to an excessive degree. For instance people commented on their need to always ensure that wheelchairs were available, or that shops, places to visit, facilities or hotel accommodation had disabled access in order to accommodate their needs. For example, one participant noted:

> *'We have to think when we go out anywhere access, disabled access for anything. Yeah, be prepared.'* (ID203 – husband to individual aged 74 years, 18 months since diagnosis. Chapter 4. Section.1.i)

Some people lamented the lack of spontaneity now present in their lives which resulted from this. This finding subscribes to the statement made by Toombs, (1995:12) that when enduring illness, the individual *'must – as a matter of course – constantly take [their] body into account.'*

For the individual with the disease, the harrowing experience of body 'dys-appearance' manifested itself via intense emotions of fear, anger and grief; *'It's so frightening, it's terrifying'*(ID73 - Male individual with MND, aged 58 years, 16 months since diagnosis, Chapter 4. section 1.i) Spouses who were frequently the main carers involved in the daily care of the individual often described their own

feelings of emotional distress, fears and anxiety in response to their bodywork (Twigg, 2000), in caring for their partner's disintegrating body. Feelings of isolation, strain and a sense of grief were common in the data reiterating findings in Ray, *et al*'s (2006) study.

This increased awareness of bodily incarnation can be explained using phenomenological theoretical suppositions. The body is, according to some of the existentialist approaches adhered to in this work, the instrument for taken-for-granted perception (Merleau-Ponty, 1945). Most of the time, we do not particularly notice our bodies. Bodies automatically bring with them a set of instincts and decision making processes which we generally follow without too much examination, or questioning our motives.

However, attention is drawn to the body in circumstances of abnormality and anomaly such as bodily injury or illness (ibid). This was found to be the case with individuals in this study. As one participant reflected:

> '*Every week I notice there's something else that I can't do that I could do last week.'* (ID46 – female individual with MND, aged 56 years, 11 months since diagnosis. chapter 4: section1.i)

From the analysis of the data, it is evident that the physical deterioration as a consequence of MND experienced by the couples, forced them, and the people with the disease in particular, to reflect upon their own embodiment. Because their understanding and perception of life was bound up with bodily 'normality', their self-perception and understanding was affected, which resulted from physical change.

Alienation of the body

A disruption between self and body was also at times identified by individuals and their spouses. People no longer felt the certainties associated with a healthy body, as the body had now become burdensome and alien to them. They frequently described their own body as becoming disengaged from them, with a noticeable absence of possessive articles during their commentaries, for example, 'the arm' rather than 'my arm'. The body was no longer considered to be under the individuals' control and at times the analysis revealed it was as if an external force had taken over them*: 'When I cry I feel my mouth being pulled downwards. It feels as if it is dragging and I cannot control it.'* (Jackie, journal 5, 8 months following diagnosis, line no. 126-131. Chapter 3, section 1.ii,). Another individual described her initial sense of tripping up over an invisible obstacle without realising it was her own body that was at fault: *'I would just trip up over nothing… and it was the tripping up that*

really got to me, because at first it was only a little bit but then it was quite regular..,' (ID86 – female individual with MND, aged 52, 33 months since diagnosis. Chapter 4, section 1.ii). These descriptions are reminiscent of the observations made by Finlay (2003:167) of an individual with MS:

> *'The comfortably familiar body which represents her continuing perspective on the world, now contains both an absence and a new, unfamiliar aspect. Her old arm is no longer there and it is as if she has gained a new appendage: an "it," an unseeable, unpredictable attacker, who does things without her volition. It feels out of her control, as if an alien infiltration has arbitrarily taken over'*

Such descriptions reflect the assertion made by Charmaz (1995:662) that people with multiple body losses frequently experience a sense of estrangement from their bodies. She states *'At best, the body is now a failed machine, an obstacle to be repaired, overcome or mastered. At worst, it has become a deadly enemy or oppressor.'* In this study people did evoke a sense of a body as an enemy force which refused to co-operate or succumb. One individual described an inner conflict occurring whilst his *'brain wants to do things but [his] body doesn't want to.'* (ID20 - male individual with MND, aged 52 years, 11 months since diagnosis. Chapter 4, section 1.ii)

Svennaus (2000:125) labels this sensation as the 'body uncanny' whereby the body is deemed as 'other' to oneself, *'The body is alien, yet, at the same time, myself.'* Although the individuals with MND remained the master of the body, they found they could no longer regulate it. Jackie draws attention to this when she states:

> *'It is very strange becoming aware of all these changes and not being able to do anything at all about it.*' (Jackie, Journal 5, 8 months following diagnosis, line no. 136. Chapter 3, section 1.ii)

The analysis revealed that the unpredictability and loss of control experienced as a result of this was shown to be an extremely disturbing and unsettling experience for both the individuals and their spouses. A number of couples in the interviews described their heightened anxiety and concerns regarding their increased vulnerability and risk of falls or injury.

Entrapped embodiment

Another significant theme drawn from the data was 'entrapped embodiment'. This describes the feelings of incarceration within a deteriorating body. Toombs (1992) suggests this takes place as a result of the disjunction between self and the diseased body. Above, I provided a working definition of selfhood, as the life of the individual as understood and experienced by themselves. A disjunction

between the self and the body, indicates a state in which the individual no longer perceives the body as they once did, which is similar to the experiences of people with chronic pain described in a study by Hellstrom (2001). The strange and changed body no longer fits with the idea the person has of him or herself. Because the body is such an important component of selfhood, its 'strangeness' affects the individual's ability to have a coherent and complete sense of themselves.

Throughout the data (both in the diary and in the interviews) there was evidence of the couples developing a corresponding and connected awareness of being bound to a limited and diminishing body-subjectivity. This was described by both individuals with the disease and their spouses using language of entrapment, shrinkage of capability and being restricted (see Section 1.iii in chapter 3 and 4). There was a sense of being bounded by, even trapped within, a degenerating bodily form; as one spouse described it as being like *'a prisoner'* in their own body (ID201 - husband to individual with MND aged 67 years, 92 months since diagnosis. Chapter 4, Section 1.iii). This reflects the findings of Thomas (2000:692) in her study of chronic pain. Similarly to the findings here, through the use of various phrases such as '*locked off, roped off, or caged off*' she identified that individuals experienced a of bodily incarceration, separating them from the world and people around them.

Jackie described her nostalgia and immense sense of loss at not being able to enjoy hill walking which is conveyed as her spirit being trapped inside a 'sick body'. Her vivid descriptions reveal a sense of a restrictive physical body:

> '*In my spirit I was walking high up, with my boots on, and my rucksack on my back. I was striding out along mountain paths, clambering up rocks, crossing streams and arriving breathless on the summit. However, in my body, I was just making the most of what I am able to do.*' (Jackie, journal 4, 7 months following diagnosis, line no. 177-181. Chapter 4, section 1.iii)

The '*body uncanny'* (Svennaus, 2000:125) is also apparent within this theme as a number of Individuals voiced a sense that their body no longer reflected their real self and was having a distorting effect on external perceptions of their inner state. For Jackie, her concern was that her body was in fact portraying a depressed individual which was not how she really felt, *'My voice also makes me sound miserable even though I am not.'* (Jackie, journal 8, 11 months following diagnosis, line no. 30. Chapter 3, section 1.iii)

During the interviews, there was a sense that the invisibility of many of the symptoms of the disease meant people's true state of being was not observable to the outside eye. As one participant described it:

> '*…they see me sat here and they go away and they say oh (name) you seem fantastic, look really, really well,*' (ID46 – female individual with MND, aged 56 years of age, 11 months since diagnosis. Chapter 4, section 1.iii).

Self in the physical world

This theme detailed the alteration to the couple's 'body-intentionality' and perceptions of their embodied selves in relation to the world around them, as a result of changes accompanying the disease. The theme represented a particularly rich source of data which has been demonstrated in other phenomenological works with people with MS (Toombs, 1992; 2002; Finlay, 2003).

Self-perception was affected by the control individuals had over their own motor-functions in the context of personal and social relationships. Reference was frequently made to individuals' limited and worsening ability to manipulate objects and participate in the external environment. Toombs (1992:130) contrasts the way that when healthy the world frequently '*presents itself as a field of practical significance'* to that of motor disorders when suddenly objects are perceived as *'unaccustomed obstacles to the body.'* This was certainly apparent in this study where everyday objects and mundane tasks came to assume a daunting significance in themselves and more significantly perhaps, became emblems of their symptoms. This was evident in a number of descriptions by Jackie and Frank throughout the journal, for example when she states: *'My good hand is weaker. I no longer have the pressure to switch the table lamp on. Using my mobile phone is tricky too.'* (Jackie, journal 8, 11 months following diagnosis, line no. 37. Chapter 3, section 1.iv)

The disease's progression and its resulting impact on individuals' stance in the world around them was also verbalised by the couples in the interview data. Various descriptions were made of experiences of not being able to take off or put on clothes, or the loss of the ability to manipulate objects such as holding a cup or using a knife, or turning on the television or radio. One partner used these descriptions to vividly convey the absolute dependency and loss of autonomy that her husband now experienced on a daily basis as a result of his loss of motor function:

> '*You need someone to take you to the toilet, pull your trousers down, you need somebody to give you a drink, you can't do anything all you can do is turn the television over with your foot.'* (ID214 – wife to individual with MND aged 51 years, 30 months since diagnosis)

There appeared an accumulation over time of individuals' losses of ability to co-ordinate and interact with the physical world around them which left them estranged from their former mode of what Heidegger terms '*being-in-the-world*'. Toombs (1992:130) characterises this phenomenon as one in which the particulars of the external world come to embody the distinct nature of the problem:

> *'Space constricts, not only in the sense that actions become severely circumscribed but in the sense that the physical features of the surrounding world themselves assume a restrictive character.'*

A possible interpretation of Toombs' idea is that the individual's identity is fluid, and the condition represents a crucial facet of that identity. Therefore over time as motor functions become imprecise, ordinary objects begin to embody the problem and eventually become problematic in their own right - they participate in the identity of the condition.

2. Diminishing self

This theme comprises four sub-themes all of which describe different aspects of the way in which the couples' identities were disrupted on account of the bodily deterioration experienced.

Loss of social purpose and participation

In this study, it was confirmed that selfhood is not tied exclusively to the body (Lawton, 2000) and that the self is developed socially, in our relationships with others (Goffman, 1970). Loss of physical capability resulting from MND was also shown to jeopardise people's fulfilment of previous social roles (Charmaz, 1995). It interfered with individuals' customary practices and behaviour in socially meaningful situations. These were found to be every bit as significant for sense of self as deterioration of the body. Both were perceived as integral to sense of self.

The individuals in the study demonstrated a continual desire to maintain what I refer to as 'practices'. A practice is something which people commonly do and which forms a part of the fabric of life. I define a practice as a grouping of actions or activities into a coherent whole with recognised social significance. Hobbies and interests are practices, for example, as are household routines. When individuals' loss of functionality undermined their ability to participate in such meaningful practices, they expressed devastation. Several people described experiencing great difficulty with mundane routines and household chores such as cooking a meal or doing the ironing. For example one participant stated: '*I can't stand at the sink to prepare meals, I can't do bedrooms, the everyday*

part of it is sort of slipping away,' (ID86 - female individual with MND, aged 52 years, 33 months since diagnosis. Chapter 4, Section 2.i)

Problems with participating in hobbies such as fishing or crafts and walking were also mentioned and represented as losses. As a consequence of these losses, there was a sense expressed of being lesser people because their bodies did not function properly. The individuals and their carers revealed that they felt compelled to reappraise themselves, which was devastating for formerly energetic and active people. This was expressed by several people as grief, sorrow, anger and frustration:

> '*It's totally devastated my life, I used to fly fish, fly fishing and shooting were my hobbies, got rid of them, sold my guns, broke my heart, fishing equipment that I can't bring myself to do anything with'* (ID73 - male individual with MND, aged 58 years, 16 months since diagnosis. Chapter 4, Section 2.i)

Respondents also mentioned losing confidence with family activities such as babysitting grandchildren. This was also expressed in terms of losing the ability to sustain previous roles such as 'mother' or 'grandfather' which had been deemed an integral part of their sense of self. As Jackie reflects at one point: *'Roles have changed. I can no longer look after my grandson one day a week. We cannot help out in any of the ways we used to…'*(Jackie, Journal 1, 3 months following diagnosis, line no. 366-367. Chapter 3, section 2.i)

Spouses too reported relinquishing or adapting to new social roles or employment in order that they could fulfil caring duties and meet their partners' needs adequately. As one participant comments:

> *'So I'm having to do the jobs and that… And I know it, it affects [husband] because he was the man of the house and did the jobs and the fire in there, that was his pride and joy but he's trained me up well, and says ''well done'','* (ID204 - wife to individual with MND aged 58 years, 16 months following diagnosis. Chapter 4, section 2.i).

Spouses frequently grieved for loss of activities that they had shared together, for instance Frank describes his own sense of loss at not being able to go to the spa together with his wife.

All of these activities and hobbies were represented as practices in the sense provided above in the data. They were undertaken for their own sake in the socially meaningful situations whereas formerly individuals had done them unselfconsciously. These practices now represented the significant actions and routines which gave substance and purpose to their lives. At this juncture, it is appropriate to return to 'existence' in the sense introduced above. The practices mentioned by

participants, were a vital part of existence. As such, these practices formed an important part of their sense of purpose and identity. This reflects the observation made by Charmaz (2006:27) that such activities may begin to represent part of the individual's self-concept and they come to signify '*who they are and are becoming.'*

This certainly seemed apparent in this study, as for instance on the occasion when Jackie talked about being able to enjoy a meal with friends or family and feeling 'normal.' It was apparent that occasions such as these represented a means of validation of selfhood and humanity for the couples.

Burden and guilt

Individualism has historical connotations of '*self-reliance, confidence and self-affirmation'* (Sennett and Cobb, 1973:66). As illustrated above however, individuals in this study were very aware that former practices were no longer available to them. As a result the identities they had formed on the basis of these practices proved to be obsolete. Thus they frequently perceived themselves as devoid of purpose or significance now they could no longer participate as before.

Having no role, function or ability to perform practices led to many experiencing feelings of guilt and worthlessness. Jackie described her difficulties in no longer having a *'purpose'* and her struggle '*to be and not just to do…'* (Jackie, journal 3, 6 months following diagnosis, line no. 29-31. Chapter 3, section 2.ii). She also described her sense of guilt and frustration at the inequity now found in her relationship with her husband. Wear (1985) maintains that the concept of health as 'virtue' and illness as a sign of wantonness and sin has deep roots in the protestant tradition. The findings revealed participants held a sense of social 'virtue' and that maintaining social role fulfilment and keeping up relationships were intrinsically worthy; simply 'being' was perceived as insufficient as identity and self-worth were clearly linked to social or familial roles or employment. This reflects the findings of studies with people with chronic illness and pain, (Charmaz, 1983; 1995; Smith and Osborn, 2007.) The data did indicate attempts by people with the disease to re-appraise who they were and salvage a purpose in life, as they wrestled with their fears of being perceived as a burden. For instance, this participant remarked about her need to maintain her hobbies and craft skills in order to sustain a valued existence:

> '*I make cards and I do patchwork quilting, so that keeps me occupied, knowing I can't do anything else but I can do this, I can sit here and do this, I am doing something not sitting here thinking what's the point of me being here when I can't do anything.'*(ID86 - female individual with MND, aged 52 years, 33 months since diagnosis. Chapter 4, section 2.ii)

This theme also comprises the increased feelings of burden and guilt which were frequently articulated as accompanying the participants' loss of autonomy and reliance on others for help. Numerous comments were made by individuals regarding the distress they felt on causing physical and emotional strain to their partner or spouse. One individual described his guilt at causing anxiety for his wife by falling over, *'I don't want to cause her any more frights than I already have...'* (ID73 – male individual with MND, aged 58 years, 16 months since diagnosis. Chapter 4, section 2.ii). Whilst Jackie frequently commented on her guilt at being a strain for her husband; *'It is so frustrating sitting doing nothing and letting him do all the work'* (Jackie, Journal 2, 5 months following diagnosis, line no. 107-109. Chapter 3, section 2.ii). These feelings expressed by participants appeared to correspond with McPherson, *et al*'s (2010) concept of self-perceived burden. The voiced concerns regarding becoming a burden to their loved ones were frequently intertwined with participants' desire for euthanasia or a hastening of death which reflects conclusions drawn from previous quantitative research with people with MND (Ganzini, *et al*. 2000; 2002).

At times, the spouses did disclose they were experiencing strain and burden as a result of caring for their wife or husband, confirming previous findings (Krivickas, 1997; Goldstein, *et al.* 1998; 2006; Rabkin, *et al*. 2000; Hecht, *et al.* 2003; Chio, *et al*. 2005; Murphy, 2009). Experience of physical strain is described by some of the spouses, for instance Frank states at one point he has injured his back as a result of rearranging the bedrooms and is *'hardly able to walk'* (Frank, journal 7, 10 months following diagnosis, line no. 145-146. Chapter 3, section 2.ii). Another individual described how frustrating she found her partners' increasing loss of physical function and felt she was unable to cope with the caring duties alone: *'… the amount of effort it took for me to look after him on my own, I did it for nine months and I just couldn't cope anymore, so we had to get help in, hadn't we?*' (ID210 – wife of individual with MND aged 56 years, 11 months since diagnosis. Chapter 4, section 2.ii). Nevertheless, these admissions were quite often accompanied by the partner and spouse's own feelings of guilt that they were not able to cope better or that they were being selfish at letting their own needs take priority. One spouse admitted to feeling guilty after losing his temper with his wife on one occasion: *'I felt lousy after I had done, because it is horrid, she is in a very vulnerable position I felt a heel after doing it*.' (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis).

Social marginalisation and diminished relationships

The couples frequently articulated their sense of diminishing subjectivity in terms of the negative impact on relationships with friends, and negative implications for social interaction. This finding mirrors the conclusions of Lawton (2000:160) regarding the 'making' and 'unmaking' of self through

social connections. According to this idea, the self is not a static entity, but is constantly renewed through interaction. Lawton (2000) emphasises the importance of interpersonal relationships in this process, and suggests that if a person becomes detached from their interpersonal network (as is the case for those experiencing terminal illness) their sense of selfhood is lost. The 'making' and 'unmaking' of self can be articulated in the language of phenomenology. Living within the *dasein***,** we are social beings, necessarily in relation to each other; our perception of our self and others is interdependent.

Clearly from the analysis, a diminution in participants' lives had occurred. Many of them had been exuberant, sociable people before the illness. Both individuals and their spouses reported a decline in their opportunities for social interaction with others and a negative impact on friendships, confirming previous findings in the MND literature (Love, *et al*. 2005, Ray and Street 2005b, Ray, *et al*. 2006).

Social attenuation appeared frequently for people in this study. Their social lives, identities and purposes were greatly weakened as a result of the 'stigma' associated with illness. Much has been written about stigma and the way in which it can jeopardise a person's social identification by labelling them as devalued in some way (Goffman, 1963; Jones, *et al,* 1984). Goffman (1963:12) maintains that body deformity can represent an attribute which can render an individual, '*different*' from other people and '*reduce'* them to *'tainted and discounted'.*

Frequent difficulties involving eating or toileting were given as causes for social disengagement. At one point in the diary Jackie decides not to go to a meal as '*the difficulties of talking and eating in a large gathering are too great,'* (Jackie, Journal 8, 11 months following diagnosis, line no. 85-89.Chapter 3, section 2. iii). One spouse described his wife's reluctance to attend social occasions and therefore his simultaneous withdrawal because of her feelings of embarrassment at eating in public and also fear of the catheter failing:

> *'…she feels uncomfortable about being in the wheelchair, about difficulty eating in a public place because she can't lift her glass up so she has to have a straw, she can't lift food up, and the worry about the catheter, so going out jointly, it's very, you are on edge the whole time,…'* (ID218 - husband to individual with MND, aged 56 years, 11 months since diagnosis. Chapter 4, section 2,iii)

This reflects Charmaz' (1995:285) suggestion that a person's incapacity to maintain *'basic social rules about cleanliness, bodily function and sociability'* in public domains can lead to feelings of shame and guilt. This concept has been discussed widely in health literature; *'abjection'* is the term used by Kristeva (1982) to describe the subjective and/or societal view of an unclean and disorderly body, which is unbound or leaking, and therefore rendered unbearable and may be rejected or sequestered (isolated). Madioni, *et al.* (1997) describe the '*shameful body'* in the context of chronic illness, while Twigg (2000), in her work on carers, has detailed how occupation with 'dirty' aspects of the body are viewed negatively. Whilst Lawton (1998:140) suggests that social identity as well as individual sense of self are destabilised by the development of an '*unbounded*' body in palliative care patients.

Many couples in this study considered themselves no longer suited to the social activities they had previously found so enjoyable. As one spouse commented '*I don't have a social life full stop'* (ID218 - husband to individual with MND, aged 56 years, 11 months since diagnosis. Chapter 4, section. iii). A number of individuals commented on how previous friends now found it difficult to spend time with them. Conversely, as the disease progressed, the couples themselves became prone to avoiding social contact. There was an acceptance by the couples that other people did not want to be reminded of illness and mortality. Some reported how friendships changed from being on equal footings as they now found themselves at times being '*mollycoddled*' (ID86 - female individual with MND, aged 52 years, 33 months since diagnosis. Chapter 4, section 2.iii). They received special attention and consideration that nevertheless was not seen to be completely sincere. Some individuals intentionally isolated themselves from social interaction to avoid being pitied and therefore treated unequally. Withdrawal by the individual sometimes led to isolation for their partner as well. *'I think you feel fairly isolated and you feel fairly lonely in it really,'* (ID218 - husband to individual with MND aged 56 years, 11 months since diagnosis. Chapter 4, section 2.iii).

In both the journal and the interviews, the couples referred to an involuntary retreat into their 'inner worlds'. One couple described being '*confined to two rooms basically, bedroom and kitchen, sometimes, on a nice day we just go and sit in the garden and that's as far as we get,*' (ID207- husband to individual with MND, aged 58 years, 41 months since diagnosis. Chapter 4, Section 2.iii). However this withdrawal could often be marked by further doubt and insecurity relating to sense of self and perception of the world. This was frequently accompanied with emotional feelings of sadness and loneliness. Jackie likens this retreat to a '*twilight zone'* (Jackie, Journal 3, 6 months following diagnosis, line no. 164-168. Chapter 3, section 2.iii) implying that life had taken a

nightmarish quality. In existential phenomenological terms, 'true' being and authentic existence were found in social relationships and practices. In comparison, the 'inner'-world of selfhood and self-examination became problematic and lacking in substance for some of the couples.

Loss of friendships sometimes resulted from a divergence occurring between individuals' perceptions and those of their friends. This sometimes distanced the couples from those who had previously been close and in tune with their sensibilities. In the journal, for instance, a disparity was shown to exist between those friendships Jackie and Frank came to regard as true and authentic (friends able to provide the genuine understanding and empathy), and those friendships which worsened or remained superficial, whose conversation was reminiscent of Heidegger's term *'Gerede'* (prattle).

When Frank visited neighbours at Christmas time, he found a dramatic contrast between his life and the apparent concerns of his fellow guests. He noted the talk revolving around turkeys and dinner guests, and he describes it in comparison to his and Jackie's lives, as '*a different world.*' On other occasions he talks about being with friends to whom he can no longer connect. He likens it to being '*on the other side'* or behind a '*different world '* (Frank, Journal 2, 5 months following diagnosis, line no. 320-322.Chapter 3, section 2.iii). It would appear that Frank has become *'drawn into ways of seeing and experiencing the world with which family and friends could not empathise*.' (Lawton, 2000:185).

Adaptation

The theme 'adaptation' was continuously present within the journal entries and the interviews. A number of individuals described how, as the disease progressed, they began to become accustomed to new and innovative ways of carrying out tasks and activities in their everyday lives. Frequently this entailed modifying their bodily posture and using the body differently, for example by switching hands or distributing weight differently to fulfil a task. It also required them to use new kinds of objects in different ways, and to think about practical tasks differently by employing innovative strategies to complete them. These adaptations permitted the individuals to participate in hobbies such as gardening, and in some cases to take up new and less physically strenuous hobbies such as bird watching. The adapting individuals were also enabled to complete tasks such as shopping and doing laundry. For instance Jackie stated: *'I even managed to do a little bit by sitting on a cushion and using my good hand to pull out some of the bigger weeds.'* (Jackie, Journal 2, 6 months following diagnosis, line no. 247-248. Chapter 4, section 2.iv).

Spouses often reported encouraging the individual with the disease to engage in substitute activities that would not be as fatiguing, and searching for equipment and strategies that would enable their partner to participate in activities and interests they had previously shared. Their attempts to ensure that they '*carry on as before'* or 'continue with life as normal' confirms the view of Corbin and Strauss (1988) that normalising represents a useful coping strategy which can reduce the fears and threats associated with illness. Previous studies also revealed that carers of people with other diseases have found normalising a comfort to them (Hunt, 1989; 1991; Rose, *et al.* 1997). It also reports the assertion made by King, *et al*. (2009:750) in their study with people with MND, that people who were *'resolved to find ways in which to incorporate a change into daily living'* were able to recover a sense of control and greater self-esteem.

The adaptations soon solidified into new routines, which themselves became customary. The altered state became 'normalised' (Charmaz, 2003:283) and individuals' thoughts about themselves followed the new pattern. They were enabled to consider themselves and their new life as customary and the norm (Kelleher, 1988). For instance, one wife described how being at home more and increasingly doing things around the house and gardening had become a 'routine' she was comfortable with: '*I'm happy doing things at home, potter about in the little garden, and out in the back garden, pot plants so I've just got that routine now of caring for him.*' (ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis. Chapter 4, section 2.iv). This theme reiterates Brown's (2003:210-212) concepts of 'dynamic' and 'false' normality which she found present in people living with MND. The term 'dynamic normality' refers to the sense of 'everything the same but not the same but trying to keep the same'. 'False normality' describes the way partners of people with MND, in the face of the many ongoing changes to their normal way of doing things, attempted to enforce *'a sense of coping through deliberate routines'.*

Complete acceptance of this altered body in this way evokes the concept of '*surrender'* (Charmaz, 1995:672). Charmaz understands surrender as an active process which allows the individual to regain a unity between body and self, enabling a new '*sense of wholeness of self*' which occurs when the individual ceases *'pushing bodily limits'*, and '*stop(s) fighting the episode or the entire illness'*. Charmaz (1995) differentiates between '*surrendering*', a voluntary act carried out by the individual providing a sense of freedom and transformation of selfhood, and between resignation or defeat to the illness which can result in despair, depression and a loss of hope.

Analysis of the interviews and the journal revealed that participants were themselves aware of this difference. Some spoke of their acceptance that they could not fight the illness, '*But we do try very hard not to let it be dominant, you can't fight it but you don't have to give in to it.*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis. Chapter 4, section 2.iv). However as evident here in this quotation, the same individuals were determined not to completely capitulate to the disease, which they perceived as being detrimental to them. Understanding the situation in this way was found to be helpful as it gave individuals hope and courage. It was felt to be a sign that the individuals were emotionally strong and resilient. Jackie in particular, attempted such surrender, evident when she states *'My body will continue to deteriorate and I will die. There is no point in raging against it any longer.'* (Jackie, Journal 1, 4 months following diagnosis, line no. 543-544. Chapter 3, section 2.iv)

The idea of 'authenticity' is introduced to help elucidate the findings of the study. In this study, the term is used in its specifically existentialist (Heideggerean) sense. Very briefly, life is considered 'authentic' if it is lived in a certain way. Most of us do not live authentically, because we do not fully recognise that we will soon die. An 'authentic' life fully acknowledges this fact. An authentic life is therefore free from illusion and triviality and is lived to the full. This has relevance here as Jackie remarks that once she has accepted what is taking place to her physically, and the deterioration of her body, she is able to find a sense of peace and wellbeing. She is able to realise the true beauty in her life and importance of friends and family. In existential terms, through a process of 'surrender' she is able to develop a more 'authentic' way of being.

Unlike other diseases, physical deterioration in MND is often relentless. The individuals and their spouses commented that acceptance proved to be incredibly difficult, if not impossible. Individuals were able to form a '*modified habitual body'* (Lanker, 1989:32), with a new equilibrium based on adaptation to change, and sense of freedom. However, very quickly new symptoms would appear, destabilising the adaptation and rendering new forms of behaviour obsolete. This inevitably reminded individuals of their true situations.

King, *et al*. (2010:752) detail a similar finding from their study with people with MND and conclude that any period of normalisation achieved by individuals was problematized because of *'ongoing'* changes. As was the case with this study, the '*windows of normality'* (ibid) were transient and short-lived as the disease continued to take control. This did not represent 'authentic' life in the sense given above. Rather, for the individuals concerned, as evidenced in the analysis, life appeared to be

stripped of meaning entirely. As one spouse stated: *'ultimately there isn't, there is nothing, there is no future really,'* (ID218 - husband of individual with MND, aged 56 years, 11 months since diagnosis) Chapter 4, section 2.iv).

Equipment and self

A number of individuals in the interviews, and Jackie in her diary, voiced their initial reluctance and dislike in using a number of items of equipment. People expressed their sense that the character of the activity changed for the worse, for example shopping, when it was done from a wheelchair. The social practice with its attendant place in social relationships and personal identity becomes mundane, and the individual's presence becomes diminished to utilitarian concerns such as how long before they get tired or where is the wheelchair going to go?

The diary reveals a crux in proceedings is reached for Jackie and Frank with the advent of a second chair. It makes her independent as the wheels are all-terrain and the steering is under her control. Jackie does not need Frank behind her because the chair is electric and self-propelling. Her feelings pass through ambivalence to a more nuanced and eventually quite positive take on her new situation. Jackie's experiences with the wheel chair reflect the findings of Standhal (2009). In his study, participants voiced a transformation in their perception of the wheelchair from one of a '*foreign body that they resisted*' to viewing it as '*an integral part of their bodies'*. Merleau-Ponty (1945:176) explains this mental process which is experienced when utilising equipment over time using the example of a blind man and his stick. He articulates the stick begins to assume an actual bodily function and as such, becomes incorporated into the body form, it is a '*bodily auxiliary, an extension of the bodily synthesis.*'

Over time and usage, the wheelchairs developed new experiential qualities for individuals and it appears that what Standhal (2011:179) terms a '*dual process of incorporation/becoming en-wheeled*' took place. In this process, Standhal explains the wheelchair '*becomes a part of the user's body (incorporation, apparently an inward movement*)', and in obverse '*the wheelchair user becoming a part of an external object (en-wheeled, a movement outward towards the external world)*.' Thus, the wheelchair acts in some way to repair the fragmented self and body concept experienced by the individual with the disease. Both Jackie and Frank recognised how this incorporation led to her developing a greater sense of well-being and self-esteem. Her place in social practices returns to a more customary footing. She is able for instance to attend her grandson's school's nativity play, which she had done for years previously. Jackie was entitled to play the role of grandmother again,

and the technology was to some extent harnessed to attain this equilibrium. Similarly analysis of the interview data also provided a similar finding as both individuals and their partners commented on the difference wheelchairs could make to their lives:

> *'It made your life brilliant for twelve months, that scooter has been brilliant for twelve months…'* (ID210 – wife of individual with MND aged 56 years, 11 months since diagnosis. Chapter 4, section 2.v)

Full integration appears to happen, in Merleau-Ponty's sense, above. The technology is fully incorporated into routines of physical action and ultimately, a robust and positive-minded self-concept.

3. Altered temporality

The third super-ordinate theme found in the analysis was 'altered temporality'. The analysis of the data demonstrated that, as the disease took hold, the couples began to experience and understand time differently. The two ordinate themes which were drawn from the analysis were, awareness of time and loss of expected future time. In general, the participants had a heightened consciousness of time passing, that precious time was slipping away and had to be used to the full.

Clearly, time is integral to our existence. We experience ourselves and the world in the medium of time. However we are not usually conscious of time passing from instant to instant. Our experiences appear to be unified in time, just as objects in the real word appear to exist continuously. We do not often think about time as a succession of moments. Rather we think of the present instant as unified with the past and the future.

Phenomenologists such as Heidegger and Merleau-Ponty talk of time as a succession of instants in the present. The past and the present intrude on this self-renewing perception of the *'now.'* (See chapter 2 for fuller explanation of Heidegger and Merleau-Ponty). A particular aspect of phenomenological thought is especially relevant here. Phenomenology reminds us that time is a kind of experience we have. It appears to us in different ways in a way that reflects other aspects of life. Time is considered to be experienced subjectively and does not represent '*a system of objective positions through which we pass, but a mobile setting that moves toward and away from us'* (Pollio, *et al*. 1997:160). As is highlighted below, living with illness was one of the variables in life which was found in this study to affect the experience of time.

Heidegger and Merleau-Ponty's thinking is particularly suggestive at this point. Couples participating in this study, often seemed to experience time more like a succession of instants than a unified whole. In particular, they often experienced the desire to try to 'cut off' the present from the future. However the future returned with a sense of inevitability accompanying the illness. The findings in this part of the study reiterate a number of observations made by researchers in health who have used phenomenological approaches to explore peoples' understanding of time during illness (Toombs, 1990; Thomas, 2000; Hellstrom, 2001; Finlay, 2003; de Witt, 2010). Frank (1995:55) also describes this lost sense of temporality experience by people with serious illness in narrative terms, defining it as '*narrative wreckage'* whereby the *'present is not what the past was supposed to lead up to and the future is scarcely thinkable.'*

Awareness of time

In this study, the present was revealed to become elongated by the couples' own intentional attempts to try to frustrate the passing of time. Many described their reduced '*prospective time horizon'* (Hellstrom, 2001:88) and contrasted this with their more comfortable, previous perceptions of time. Gordon (1994:308) states, '*learning of a terminal illness brings the future into foreground*' of their lives and insists that people *'confront it face to face.'* However, in this study, some couples placed emphasis on their desire to concentrate on the now, and avoid contemplating the future, for instance, one individual stated: *'I don't like looking too far ahead in the future… so we kind of take things I won't say a day at a time, but a week,*' (ID20 - male individual with MND, aged 51 years, 30 months since diagnosis. Chapter 4, section 3.i). Some attempted this frustration by planning and upholding future projects such as holidays and outings: *'That's why we do try to have stuff planned all the time, to keep going out, going out all the time we've just had a few days down south.*' (ID214 - wife to individual with MND, aged 51 years, 30 months since diagnosis. Chapter 4, section 3.i). Other researchers (Hellstrom, 2001) have identified this as characteristic of individuals attempting to protect and extend a sense of wellbeing. Conversely, people also stated they no longer made significant plans for the future, as activities like outings or holidays were no longer feasible.

Other individuals attempted to busy themselves with activities. They wanted to 'fill up' days with as many small-scale projects and pass-times as possible, to stave off thoughts of the future. This finding is similar to that made by Fanos, *et al*. (2008:473) who found that people with MND were determined to '*live in the moment.*' It is also reminiscent of De Witt, *et al's* (2010:1702) study of women with dementia. Many of them were found to be '*holding back dreaded future time'* and allowed them to '*hold onto the present or the now.'*

In this study, the present was shown to have become commensurately critical for the couples as a manageable place whose implications are containable. However, their attempts to confine experiences to the present were stymied by an awareness of the future which inevitably intruded in their thoughts. Several couples made continual reference to a sense of time contracting, commenting on how little time they had left, making them count time passing at every moment. Jackie describes her sense of '*racing against time'* (Jackie, journal 1, 3 months following diagnosis, line no 320. Chapter 3, Section 3.i).

Family gatherings or seasonal festivities were often perceived as ominous reminders of time passing. Time seemed to feature in all aspects of the couples' lives. Some reported their awareness of time often being wasted and activities were frequently judged as representing a good or bad use of their time. Many people commented on the frustration of 'waiting' for the remaining time to pass and the inevitable end and one individual evoked a vivid sense of this, when he likened having MND to being in '*God's waiting room aren't you?*'(ID94 - male individual with MND aged 58 years, 6 months since diagnosis. Chapter 4, section 3.i). These comments echo Toombs' (1990: 237) identification of the *'stagnating present',* which she explains commonly accompanies a diagnosis of illness.

The phenomenon of altered awareness of time reflects Thomas' (2005:72) suggestion that '*Time only periodically bursts into consciousness.'* During crises, time becomes a different phenomenon. It becomes a scarce commodity and its passage is more dramatic than previously. As has been illustrated above, the data revealed a shift of focus in the couples' priorities. Many were thinking about time much more than before, and time itself had become a different kind of experience. It was being jealously hoarded by all the couples, but at the same time couples attempted to ignore its passing or try and think about other things. Living with a diagnosis of MND represents one of those moments in life when time appears to 'burst' into human consciousness.

Loss of expected future time

Some of the couples interviewed, and both Jackie and Frank in the journal, displayed common assumptions regarding the continuity and linearity of time. They reflected on their previous certainty that time would continue to unfold predictably, and that the course of their lives would run quite straight and uninterrupted. They had assumed they would get the chance to fulfil all the plans they had made.

According to Heidegger, '*human existence continuously looks ahead, choosing among many possibilities of being-in the world*' (De Witt, *et al*. 2010:1702). However, it is evident that with the couples in this study, the disease dramatically altered this sense of future possibility. Frequently, couples described how the future had been pulled out from underneath them. The future was often considered to be a place of daunting possibilities that couples now were dreading. Frank's following comment demonstrates this clearly: *'It's going to be shit at the end. I know that. We're under no illusions. Yeah...Shit. I'm quite scared about what's going to happen, to [Jackie], to us...I don't want to lose her… I know it's going to end. So I don't want that* at all.' (Frank, interview, 2 months following diagnosis. line no. 476-477. Chapter 4, section, 3.ii).

A number of couples expressed deep distress and a sense of grief at having been '*cheated*' out of time (ID214 - wife to individual with MND aged 51 years, 30 months since diagnosis. Chapter 4, section 3.ii) and that was felt by some couples as a type of torturous punishment. This theme echoes what Hellstrom (2001:88) terms '*frozen futures'* whereby *'the frustration of a desired future lost and of dreams rendered impossible'* haunts the person's remaining time. For instance Jackie describes the sadness she experiences when she considers the future she will not be able to be part of: *'…not being able to watch the grandchildren grow up, not having any life doing the things we wanted… I cried for all I had lost and would lose…and was overwhelmed with sadness for all that was and all that will never be.'* (Jackie, Journal 9, 11 months following diagnosis, line no. 14-15. Chapter 3, section 3. ii). The illness in many ways causes the couples to become '*stranded*' (Scannell, 2000:57) or '*entrapped*' (Hellstrom and Carlsson, 1996:42) in present time, where they cannot avoid contemplation of their lost future: '*most of the time you only think about it when you are sat on your own, with pictures of my grandkids and I think I'll miss them and they will miss me hopefully,*'(ID9 - male individual with MND, aged 56 years, 11 months since diagnosis. Chapter 4, section 3.iii)

4. Transcending embodiment

This main theme details how the couples found ways in which they could overcome the impact of the altered body and accompanying fractured sense of selfhood and temporality. In order to explain this, the concept of 'self-transcendence' (Coward and Reed, 1996) is used. The backdrop to the usage of 'self-transcendence' in this thesis, is a particular sense of self. At this point, it is sufficient to define the 'self' as the location of one's personal identity and experience in a particular place and time. The integrity of the self is put under extreme pressure by MND.

'Transcendence' points towards the notion that the particular circumstances of our individual identities are not as finite as they appear. We can reach beyond our current horizons when we are tested and need to find new ways of living. This ability can be thought of as 'pan-dimensional experience' (Coward and Reed, 1996: 276)**.** This concept describes the different levels at which an individual in potential crisis finds ways out of the problem, through a complex new elaboration of selfhood. The following quote captures some of the different facets of the idea of 'pan-dimensional experience'.

> '[It is the]…*expansion of personal boundaries inwardly, as through increased self-awareness and introspection; outwardly, in terms of investing oneself in relationships with others and the surrounding environment; and temporally, by integrating perceptions of one's past and future in a way that enhances the present life.*' (Reed, 1991: 5).

In this analysis, the individual examines every aspect of their life as it is currently lived. They find ways of forcing life into new patterns and acceptable forms of interpretation. The purpose of working on oneself in this way, is to compensate oneself to some extent for one's suffering. Crises or certain major life transitions have been found to precede experiences of transcendence, particularly illness; including breast cancer (Coward, 1990), AIDS (Coward, 1995; Coward and Lewis, 1993), Dementia (Acton and Wright, 2000) and a number of studies have revealed it to have a healing function for people nearing the end of their lives. Fanos, *et al*. (2008:474) talk about the experience of transcendence with people with MND as '*the culmination of the relinquishment of the current and past and being able to bear the unbearable, that is, the total loss of self and body*.'

From the analysis of the journals and the interviews in this study, it is clear that with some of the couples, living with MND led to different kinds of self-transcendence. Despite the fact that the couples had to battle with the condition, there was increased emphasis upon mutual concern and sharing of life, within couples and extending to the wider social context. There was also concerted effort by couples to develop new ways of understanding and talking about time. Analysis of the journal by Jackie and Frank revealed that this couple thought more carefully about spirituality and experiencing the sacred, and their attempts to find authentic and truthful ways of living.

These findings support the work of Fegg, *et al*. (2005) who said that MND patients rated self-transcendence very highly in their lives. The different kinds of self-transcendence associated with the couples in this study, will now be illustrated in five ordinate themes. They are dyadic self, social self, narrative self, spiritual self, authentic being.

Dyadic self

MND had serious implications for the couples' social lives and relationships. Their places in social networks became difficult to uphold and maintain. In some cases, the withdrawal from social life was comprehensive, resembling '*social death'* (Lawton, 2000). It appeared from the analysis of the data that the couples' own relationship began to compensate for these aspects of lost social recognition. For many in the study, the couples' relationships increased in significance. The participants continually referred to 'we' rather than 'I' throughout their accounts, confirming Skerrett's (2010) assertion that couple stories reflect a mutual identity and in terms of 'We-ness.'

Mutuality and reciprocity were common motifs throughout the journal and interviews. Patients and their spouses demonstrated heightened empathic understanding of one another's situations, recognised that helping and supporting each other was their main motivation, and a crucial means of coping with their experiences. Integration of the other's perspective into one's own is considered to be adaptive, through increased resilience and self; as one carer described the relationship between each other was the most important thing in their lives *'We are quite happy to be together in this house, so that's us, that's the main thing,'* (ID212 - husband to individual with MND aged 52 years, 33 months since diagnosis. Chapter 4, section i).

Kayser, *et al*. (2007:416) explain how mutuality enables '*effective coping'* through needed support, that enables individuals to manage emotions related to serious illness such as anxiety, sadness and fear. This was evident in my study as a number of couples spoke about relying on each other for support and the ways in which they comforted each other. One wife described her role as carer as incredibly important to her: *'caring for him… I've known him for 42 years and … those vows that we made… to look after one another… are very strong… I think that is my job, I call it a job, it's what I want to do and what I need to do'* ID204 - wife to individual with MND aged 58 years, 16 months since diagnosis. Chapter 4, section 4.1).

Aron and Aron (1986:48) explain that strong relationships share a '*cognitive closeness'* which can be understood as an '*overlapping of selves',* involving the incorporation of a significant other into one's own experience of self*:' …the self in relationship comes to experience the world as though one were, at least in part, merged with the close other.'* Jackie and Frank clearly indicate that as the disease progresses, their relationship is strengthened. Frank states *'My love for her gets stronger.'* (Frank, journal 7, 10 months following diagnosis, line no. 90. Chapter 3, section i) and Jackie highlights that they '*are closer than ever.'* (Jackie, journal 3, 6 months following diagnosis, line no. 308. Chapter 3, section i).

Social and familial selves

Analysis of the interviews and the journal emphasised the couples' increased reliance on particular friends and associates. In part this reliance reflected the need to sift and prioritise the most important relationships and put them at the centre of life. Fegg, *et al*. (2010), in their quantitative study of people with MND, describe a 'response shift'. This can take place when people modify their values and standards in life to enable them to cope better with crises. In this study, couples reported the need to find 'authentic' social relationships. People described discovering who their 'true' friends were at this time. For instance, one individual noted: '*…one thing I would say is about something like this is that you do really, really find out who your true friends are and that does give you something very special that perhaps you didn't know you had before.'* (ID46 - female individual with MND, aged 56 years, 11 months since diagnosis. Chapter 4, section ii). Similarly, Jackie and Frank described numerous encounters and social interactions, in which the 'authenticity' of their friends was paramount. Amongst other characteristics, authentic friends were those individuals with whom a true dialogue could be achieved. Other individuals also commented on how they had discovered who their 'true' friends were now and that they were really valued in their lives. These 'real' friends were recognised by the couples as essential to their sense of well-being, identity and purpose, as well as providing an indispensable link to the world.

Many couples recounted experiences of renewed love, understanding and acceptance within the family unit. For example, one individual reflected that whereas previously she would have been working or busy doing other things, she now really valued having the opportunity to spend time with her children:

> *'…I have spent more time with the kids than probably I would have done previously cause I would have been busy working and doing things so I've made more time to spend time with them, we've done more things together so in some ways there is a positive side to it.'*(ID19 - female individual with MND, aged 72 years, 18 months since diagnosis. Chapter 4, section 4.ii).

Jackie and Frank also recounted a consolidation of their familial relationships as the love felt between them, but not often expressed, was finally openly acknowledged. It became apparent that for many of the couples, with the certainty of death came the need to fully engage in 'family' life. Moments with the family presented themselves to the couples as ones to be treasured; one couple described a recent holiday with their sons as a special and memorable time. In another resonant example, in her final month of life, Jackie had to attend the school nativity play in her wheelchair, making it a troublesome visit. She had gone to watch her grandson perform, and was conscious that

this might be her last time, making it all the more precious. Decisions such as these, to prioritise and place greater value on families and family life, are reflected in the findings made of Finlay (2003:170). She explains that in such circumstances individuals have now the '*freedom to choose to live a more "authentic" life—a "For-itself*, *making itself*' which previously had been *'constrained by family/society expectations'.*

Convergence of time

As shown earlier in this chapter, the experience of living with the disease shook the couples' preconceptions regarding time. In response to this sense of disorientation in time, Scannell (2000) maintains that individuals attempt to find new ways to define selfhood as continuous throughout time and Levenson*, et al*. (2005) explains that an increased understanding of continuity with the past and the future is a feature of self-transcendence. From the analysis, it appeared that couples in this study altered their perception of time and began to reflect increasingly on memories and past events: *'…but we can look back that's the only way to look at it, and look back at what we've had, it's been good*' (ID214 - wife of individual with MND aged 51, 30 months since diagnosis. Chapter 4, section 4. iii). This supports the findings of Fanos, *et al.* (2008) who also found that many people with MND found reminiscing about their past comforting.

Frequently these memories of the past were interspersed with a sense of the future generations and what would follow after them. This was particularly evident in the journal, as Jackie's showed a keen sense of forthcoming departure from life accompanied with an awareness of the cyclical nature of life as a whole. One poignant example is when she reflects on the church she attends for a blessing ceremony and contemplates the numerous significant life events which took place there. '*It is such a beautiful church and I found being there very emotional. Apart from being the church I had attended for so many years, it is where (names of family) were married, where (name of grandson) was christened and where my mother had her funeral service.'* (Jackie, journal 6, 9 months following diagnosis, line no.136-138. Chapter 3, section 4.iii). Another example was the solace that one man evidently drew from visiting his local cemetery and contemplating his deceased relatives: *'…I like going round the cemetery I have a lot of relatives there and I go and have a talk to them,'* (ID9 - male individual with MND, aged 56 years, 11 months since diagnosis. Chapter 4, section 4.iii).

These quotations reflect Brough's (2001:40) claims that that once the immediate shock of an altered perception of time has ceased, a new '*more profound and enhanced grasp of temporal continuity*' is allowed to take shape. Murphy (2000:62) describes this phenomenon which takes place in people

experiencing illness as a sense of time '*running backward as well as forward, with life spread out as on a landscape,'* as their memories and thoughts of the future become increasingly intertwined.

The following section is exclusively taken from Jackie and Frank's written accounts, as data for these themes did not arise in the interviews. It is possible that the subsequent themes are unique to this couple. However, I believe it is due to the kind of response invited by keeping a diary and that the diary offered a means of reflecting on certain aspects of their experience which would be more difficult to verbalise in an interview (Grinyer, 2006). I will reflect on the potential of diary writing further below and in particular in the reflective section.

Narrative self

The act of carrying out the journal by Jackie and Frank was considered a way in which they were able to rebuild cohesion between the past and the future. It was clear that producing narratives enabled Jackie and Frank to organise, unify and make sense of their past and present experiences. Narrative has been recognised as an essential way of providing meaning and order to human experience (Bruner, 1986; Sarbin, 1986; Brody, 1987) and also construction of self (Ricoer, 1986). The 'restorative' function of narratives at times of crises and illness has been outlined by a number of writers (Frank, 1995; Becker, 1997; Bury, 2001; Crossley, 2001) and a study by Locock, *et al* (2009:1043) found that narrative enabled people with MND and their carers to *'make sense of their remaining life, restore normality and control'* and find '*new meaning and identity.*'

Both Jackie and Frank reflected openly and honestly in the diaries about things they might not usually have shared with others. They also discussed the diary writing with each other and commented on the nature of the other's entries. Jackie was enabled to disclose to the diary how low and depressed she felt, having been tempted to delete the entry, but kept it after being encouraged to be as honest as possible by Frank. Frank also talked about the therapeutic value of writing his diary, shortly before Jackie's death. He disclosed to the diary information that would otherwise been appropriate for counselling. This finding supports a number of studies which have suggested that writing about emotional experiences can have a positive impact psychologically (Pennebaker, 1997; DeSalvo 2000; Bolton, 2001; Wright and Cheung Chung, 2001; Lowe, 2006).

The couple emphasised their wish to be honest and truthful in accounts of their lives in order to present the 'truth' of their experiences as fully as possible. Moreover the journal represented a mode in which the couple could conduct an act of 'phenomenological reflection' and 'hermeneutical

meaning recollection' (Ricoeur, 1970). Both were seeking to provide themselves with deeper insight into the meanings of their experiences, and to render these meanings intelligible to a researcher hoping to present the findings as a version of 'truth' to a scientific community. (I use inverted commas for the word 'truth' in recognition that written texts can be interpreted different ways). The diary form, if it is to be effective, necessitates a shared honesty based on intimacy from the couple if it is to lead to the 'authenticity' for which they are searching.

Frank (1995:143) argues that personal narratives, if they are to attain the stature of lived testimony, need to be shared.

> *'I tell myself stories all the time but I cannot testify to myself alone. Part of what turns stories into testimony is the call upon another person to receive that testimony.'*

By calling witnesses to these testimonies, Frank (1995) maintains that individuals are enabled to become '*communicative bodies'* (existing for the other) inviting others into a '*dyadic relationship'* (empathic relations or '*brotherhood'*) with them. He states that '*The communicative body communes its story with others, the story invites others to recognise themselves in it. Thus the communicative body tells itself explicitly in stories,*' (p.50). Through the completion of the journal which was written-up as an online blog, Jackie and Frank illustrated their willingness to involve a large number of friends with the reflective process. This served to renew connections with family members. By reading the journals, friends and family could deepen their understanding and perhaps empathise more meaningfully with the couple's lives. Conversely, the couple took responsibility for the format of that representation and for the particularities of the portrayal. Arguably therefore, (and indeed the journals confirm it), the diary was perceived as a way in which the couple could cement key friendships and family relationships in dialogue, whilst feeling satisfied that they had portrayed and reflected upon their experiences as they really were. It is apparent therefore, that the journal represents far more than just a record of the couple's experiences of living with the disease but has in fact come to represent their testimony:

> *'... we have maintained contact with so many people all who send messages which in turn support us. So by taking the risk and being open and honest, we have gained in ways we did not think of. Many of my friends have reappraised their own lives and made positive changes as a result of what is happening to us, so that again has been a positive thing. Also, if it helps anyone to understand the ever changing nature of this disease that is good and if services can be speeded up as a result that is even better! '* (Jackie, journal 4, 7 months following diagnosis, line no 2-16. Chapter 3, section 4. iv)

It appears to be the case that a key element in testimony is that experiences should have some generalisable significance, perhaps this makes them, paradoxically, all the more personal. It seems important to Jackie that her and Frank's experiences resemble other people's to the extent that others can reflect meaningfully upon them and alter their lives for the better. There appears to be a general relevance which is important to Jackie in two senses; having an effect upon friends and also unknown others who form the background of all our lives and will rely on services as she has.

Spiritual selves

Fahlberg, *et al*. (1992) links the phenomenon of self-transcendence to spirituality as outlined by Acton, *et al.* (2000:146):

> '*Spiritual emergence is the result of successfully moving from a self-identity to a broader transpersonal identity. The outcome of self-transcendence as spiritual emergence is enhanced feelings of peace, unity, and social consciousness.'*

Both Jackie and Frank recount how attending church, saying prayers and having contact with people from church enables Jackie to maintain wellbeing in the face of the disease confirming the finding by Sowell, *et al* (2000) that engaging in spiritual activities reduces emotional distress. This also supports previous work regarding spirituality with people with MND which has been shown to contribute to better quality of life (Dal-Ballo Hass, 2000) and less desire to consider suicide (Albert, *et al*. 2005) and can act as a valuable coping mechanism (O'Brien and Clark, 2006). Recent research has also demonstrated that the patient having greater spirituality and meaning in life may also benefit the psychological wellbeing of their partners and family members (Pagnini, 2011).

The expansion of Jackie's spirituality, detailed in the diary, also represents another way of understanding how, especially *in extremis*, self and the world are shown to intertwine. It appears to be the case that, at intervals, Jackie achieves a transcendence of the body which enables her to achieve an expanded sense of self. As the disease takes hold, mountaineering is no longer possible for Jackie, but she reflects in the journal, '*But I can still breathe, see, hear, taste and feel. I can think and pray. I can love, dream and hope. I am still me. I am more than my body. I am. I must live for now and trust God with the future.'* (Jackie, journal 6, 9 months following diagnosis. line no. 199-204. Chapter 3, section iv). Despite losing bodily capacity and with it, the identification of herself with an active body, Jackie just *is,* in the grammatical sense explored by Husserl. She still *is* in the sense that 'mountaineer', 'breathe', 'taste', 'feel' and other bodily hyponyms are appropriate to, but not exhaustive of the category 'Jackie'. 'Jackie' is itself a category subsumed by the larger and more

comprehensive terms, 'God', and 'the future'. This reiterates findings from Copp (1997); Hall, (1998); Thomas and Retsas, (1999), demonstrating participants at the end of their lives begin to increasingly perceive mind and body as separate and distinct. Increased spirituality leads to a discovery of their 'true' self as a non-embodied entity, which may transcend the dysfunctional corporal body. As Do Rozario (1997:433) explains the '*experiences of dissolution and decay'* common to people with significant disability and illness can lead to a 'wholing' process whereby they rediscover their sense of true self and their relation to the world around them.

During her journal of her experiences of the illness, Jackie describes a loss of previous faith which subsequently returns. What seems to precipitate this resurgence of a belief in Heaven is her renewed understanding of life's purposelessness without God. Her personal relationships with God and her social relationships are re-appraised so that belonging to a spiritual community, charity and self-sacrifice suddenly are more important in her life. This spiritual and personal growth she describes echoes Viktor Frankl's (1995:114) words that '*Suffering ceases to be suffering in some way at the moment it finds a meaning ...'*

It appeared from Jackie's comments, therefore, that a new sense of fundamentals has helped her concede the loss of health with equanimity. A discourse of divine rescue and the sacred is interwoven with this sense which conveys Jackie's apparent uncovering of something already there: her *'true'* self.

Authentic being

As with the previous two sections on journal and spiritual selves, this section draws exclusively on data from Jackie and Frank's diaries. Their responses (see chapter 3) at times became profound and poetic, especially when describing landscapes, family experiences and each other. It is possible that the intrinsic potential in the diary form, enabled Jackie and Frank to express themselves more freely and at greater length than in interview. It is likely therefore, as is developed below, that the diary format encouraged Jackie and Frank to respond as they did.

It is evident from my analysis that Jackie and Frank, in several ways, evolved a new consciousness of time, and new ways of being in time. The concept 'being' is being used here in its existential sense. In this sense, 'beings' are always already 'in the midst of things', they are 'thrown' (Heidegger) in to life. There is no vantage point from which we can see our identities, apart from being on the conveyor belt toward death, and the sooner we realise this, according to Heidegger, the more

authentic our experiences and our 'being' becomes. Jackie and Frank were very aware of having little time left. This was very difficult for them to accept and to adjust to. However, it also made them more determined to take full advantage of the remaining time. Time became more 'authentic' in as much as the couple accepted Jackie's mortality, and their priorities shifted accordingly. Thus the nature of the time they spent, and with whom they ought to spend it, was a far greater consideration than before. This re-calibrating of priorities is echoed in the findings of Gordon (1995:308) who relates how individuals latch onto those remaining moments which they consider worthwhile and significant, '*Living the continuity of the family, sustaining life as normally as possible, actualises the hope of life, of continuity and connection with one's social group.*'

Although greatly distressing for them both, it is apparent from their reflections in the diary that a new level of consciousness was awakened in Jackie and Frank through their experience of living with MND. This reiterates the observation made by Levine (1982) that accepting the reality of death frequently leads to life becoming a more conscious process of growth. There is a vibrant and vital nature to Jackie's descriptions of the present here and now, where Jackie's physical sensations of the world were amplified and became more vivid:

> *'I smell the sea, feel the energising wind, hear the screeching gulls, watch the dazzling winter sun shimmering on the waves. Taste the salt in the breeze.'* (Jackie, transcript 6, 9 months following diagnosis, line no. 185- 186. *Chapter 3, section v)*

She uses language with a similar feel and tone when describing special relationships and family moments. Frank too comes to mirror this poetical use of language in the journal. It appears that the couple found new ways to express themselves which were appropriate to the heightened, 'authentic' sense of life as it became apparent that Jackie's life neared its close. This echoes the words of Santayana (cited in Yalom, 1980:163) who claims that the '*The dark background which death supplies brings out the tender colours of life in all their purity.'*

Summary

This chapter has outlined the main findings of the study and discussed them in the context of phenomenological ideas and related them to relevant, previous literature. The themes in this study are 'altered body', 'diminished self', 'altered temporality' and 'self transcendence'. Within these are secondary themes discussed above. It was discovered that couples living with MND experienced fluctuating identities, mediated through changes to their bodies and adjustments to body functioning, changes to their social status within relationships, and altered perception of themselves as part a loving couple.

Individuals with MND found that their perception and understanding of time was affected by the condition. The past seemed to merge with the present and the future was contracted. Everything appeared to happen 'in the moment' and the functional linearity of time was lost. Transcendence represents a way couples attempt to cope with these changes, incorporating a dyadic notion of self in which intimate connections with others, particularly spouses, play a central role in supporting a more fluid identity. Time seemed to converge when individuals were taking stock of significant things in the past and considering the legacy they would leave behind. Individuals found ways of creating a sense that time was a continuous and meaningful whole.

With Jackie and Frank, there were various approaches to selfhood which supported them. The journal they kept emphasised their meaningful relations with others who kept up with their entries, making it socially significant 'testimony'. Spirituality became very important, Jackie connecting with God at the end of her life and finding spiritual meaning in natural beauty. 'Authentic being' seems to sum up the couple best, as they became conscious of the essential vitality of everyday life as Jackie neared death, resolving to live every moment to the full.

In the next chapter, some of these preliminary comments about the nature of diary writing will be expanded, to comprehend the journal I kept as a researcher. In the chapter, I interrogate my style of writing and where some of my motivations as a writer may have come from. The following chapter will also include an appraisal of the study and the relative strengths and weaknesses of what I have undertaken will be discussed.

Chapter 6 – Researcher Reflections on the Study and Strengths and Limitations of Study

Introduction

This chapter provides a consideration of some of the factors that may have influenced my approach to this project and positioned me as a researcher in the process of gathering and interpreting information. These factors include my personal characteristics, personal history and assumptions, and social influences. All of these play a part in my characteristic ways of understanding and interpreting. They are also susceptible to interpretation themselves, and I consider some of the ways my background may have influenced my written account of this study, when I analyse the journal I kept throughout the project. The second part of this chapter will outline and appraise the various strengths and limitations of the study.

1. Reflexive account

In the first part of this chapter I provide a hermeneutic reflection of my experience of conducting this research project. My intention here is to provide the reader with a greater insight into the nature of my personality, my relationship with participants, and also into the process of decision-making I undertook, thereby increasing the transparency of this study. The inclusion of a reflexive component is considered to be a significant feature of high-quality, qualitative research (Hammersley, 1987; Mays and Pope, 2000; Crist and Tanner, 2003; Langridge, 2007).

Rationale for carrying out a reflective diary

Smith and Osborn (2003) stress the importance of the double hermeneutic in the IPA process; the researcher making sense of the participant, who is making sense of their experience. This involves a '*close, interpretative engagement*' (Smith, *et al*, 2009:35) by the researcher, carried out through their own '*experientially-informed lens'* (ibid:36). Moreover interpretation of the data is always situated from some standpoint. Heidegger articulates the embedded nature of our standpoints and interpretations, with the concept *dasein.* Our individuality is founded on a shared understanding of the world with common features available to us all. The writer on hermeneutics, Schleiermacher, (1998:92-93) describes how this inter-subjectivity is the fulcrum of our sense-making, as individuals living with others.

> *'Interpretation depends on the fact that every person, besides being an individual themself, has a receptivity for all other people. But this itself seems only to rest on the fact that everyone carries a minimum of everyone else within themselves, and divination is consequently excited by comparison with oneself.'*

Rather than attempt to set my individuality and its history aside, in accordance with the interpretative phenomenological approach I have undertaken, I acknowledge it inevitably dictated how I interpreted the data. I do not claim to have produced a *'definitive or true reading of participants' accounts'* (Willig, 2000:61), instead the analysis represents '*a co-construction between participant and analyst in that it emerges from the analyst's engagement with the data in the form of the participant's account*' (Osborn and Smith, 1998:67). Furthermore, it is implicit in this kind of analysis that my interpretative predispositions are construed as *adding* to the meanings on offer and enhancing them in ways the person might have done for themselves, had the language and conceptual means been available to them; *'the interpretative analyst is able to offer a perspective on the text which the author is not*,' (Smith, *et al*, 2009:23). Moreover Benner (1994) acknowledges that the reader may not advocate the interpretation at which the researcher has arrived; differences of interpretation are perhaps inevitable. It is essential that an interpretation can be justified by the researcher and the reader can follow the justification.

As discussed in chapter 2, I decided that writing a reflexive diary would enrich both my experiences as a researcher and my findings. Whilst I could never assume a completely objective distance from my own language and conceptual background, I thought it worthwhile recording my thoughts on different occasions in the research cycle. I hoped to be able to study myself like another strand of data, creating distance from my reactions to see how mental habits and snapshots of my history, whether recognised by myself or coming as something of a surprise, were to emerge. I undertook to record myself not merely for curiosity's sake, but to demonstrate another aspect of the study's rigorous approach '*We cannot escape our presuppositions, all we can do is make our approach as explicit as possible*' (Von Eckartsberg, 1986:98). According to Alvesson and Skoldberg, (2000:6):

> *'…reflection can be defined as the interpretation of interpretation and the launching of critical self-exploration of one's own interpretations of empirical material.'*

Incorporating this reflexive analysis is considered to bring a number of benefits; increased understanding of the researcher (Cassell, 2005) and the enhancement of the *'transparency, trustworthiness and accountability*' to the research process (Finlay, 2002:531).

Reflective discussion

Below are four extracts from my research diary which represent a means of examining these presuppositions in written form; a method foreshadowed by Finlay (2003). Finlay's intention is to furnish a complete picture of her underlying assumptions and commitments, both interactively with

her journal text; and by confessing to her reader the interplay of influences that might distort her interpretations of her interviews with fellow health-professionals. Echoing Finlay, I have posed myself a raft of questions about my own tendencies and leanings. Unlike her, I have elected not to articulate them independently of my diary entries. Four of my diary entries are included for consideration below. These four examples have been chosen as I think they are more revealing of the writer than any consciously formulated set of questions could have been. I interpret the diary entries not to expose my biases and exclude them from consideration, but as Finlay does, to recognise them as part of myself and as such constituents of interpretative faculty. Finlay remarks how she turned with *'relief'* to the realization that '*we are always embedded in our social world'* (2003:105); a world consisting in the intersection of others' lives and our own histories.

Diaries represent a conventionalised form of making meaning, in which personal views and emotions are expressed. They are widely employed and considered useful in the academic practice of reflexivity (Nadin and Cassell, 2006). Because one participating couple in my study wrote a journal, my writing a diary illustrates how these participants and myself, share a common method of accommodating and situating the self, through writing, in a culturally specific way. In phenomenological terms, our life-worlds currently intersect, and are derived from common sources. As has been considered in my discussion, reflection through the diary offers a means of seeking authenticity. Warnock (1970:57) describes this authentic searching as a kind of realisation that 'authentic man' has tremendous power to interpret the world, but that he is not free to utilise it as he likes:

> '*Realizing that is the uniqueness of his position as a human being, he may see the force of his own reflective capacity, namely that he and he alone is responsible for the world's having significance'*

What follows is what might be called a hermeneutic textual analysis. I identify and interpret the different ways I might be said to be 'present' in my own text, in addition to being its author. As such, some of the ways in which I wrote myself into the diary extracts appear to me now as either glaring or subtle. Despite being its author, I acknowledge that I have no interpretative exclusivity rights; my analysis on this occasion stands as an alternative to other interpretations by suitable others, in a potential exchange of perspective;

> *'Dependent on positions and perspectives,* [from which] *different researchers might therefore access different, although equally valid, representations of the situation that is studied. In qualitative research, these different ways of approaching the same subject result in an increased understanding of complex phenomena, not in a failure of reliability.'* (Malterud, 2001:484)

Diary extract one

The first diary entry was written when I arrived home after the first interview with Jackie and Frank. It is the end of the day.

Diary extract one: April 3rd 2008

Just got back from the [name of area] where I interviewed Jackie and Frank today in their home. (I reflected on the things they said during my drive home). The long journey home allowed me to reflect on the many things they said. They are the same age as my parents and this brought their experiences into sharp focus for me. I remember when I met them at the MND clinic at the hospital, I first explained the nature of the study to them. I remember I saw them waiting to go into the appointment and noticing how concerned her husband was for her and how he wanted to be there for her, I found his facial expression so moving. He had the same expression today, whilst she was talking.

When it came to visiting them, their house was quite difficult to find and I didn't have time to prepare myself mentally for the visit, I was driving so fast (later note: and picked up a fine for speeding!). I eventually made it and met [research supervisor] *there. We sat and had coffee together first. They (later note: the couple) were laughing and joking with each other which struck me as a sign of strength in their relationship. They live in a beautiful house in lovely surroundings which they only have just moved into - the cruelty of the disease struck me, this is a couple who have just retired and obviously were looking forward to enjoying their time together, but it is being taken away.*

We emphasised how we would like to carry out the interviews separately, in order for them to tell their own story in their own words. They were happy to do this but wanted to stay in the room whilst each interview took place. I was worried that this might influence the content of the interviews and possibly make the data less rich and 'honest' – I thought they were probably unlikely to say certain things in front of each other in order to protect each other's feelings. But it was their prerogative, of course. They clearly found it reassuring to be close when talking about what was occurring to them.

I interviewed [Name] *the husband first. It seemed to go well, but was emotional for me, and him obviously. He expanded a lot on the diagnosis and how difficult it was to accept. He spoke at length about finding it difficult to relate to friends. I found it particularly interesting and saddening how friends seem to have fallen away. He seems a very level headed man and very practical minded as he described numerous inventive ways of trying to enable his wife to participate in activities. He*

discussed how he wanted to go with her to the Hebrides and how difficult it is to go away. My partner and I went there last summer, so my ears pricked up at this point. We had had an amazing, special time, but this experience would be very different. If I was given little time to live I would return there too, but it felt strange and a bit inappropriate to make this sort of comparison mentally. I was surprised by his frankness, at one point he mentioned sex and I was taken aback but I found that reassuring that he wanted to be open with us during the interview.

[Name] *went next. She talked about the impact on her but she did seem to struggle to talk about things and at times she 'dried up', as she put it herself. It was sad and difficult as previously she had seemed so verbose and confident. I think that talking about it in an interview situation was very difficult for her and perhaps having two of us (myself and my supervisor) added to the pressure. She seemed to be struggling and trying to say things in a correct way for us. I get the sense she is very angry about what is happening to her. She talked about feeling cheated by life as all her hopes for the future were destroyed. She described her experiences of the services and how she has found some of the health professionals who have visited unhelpful or insensitive. This information was very helpful for our project, but we didn't pursue it too far or pry. She and her husband have agreed to carry out the diary so hopefully that will reveal more of her thoughts and feelings.*

I found it difficult to stay detached and not get upset by what I heard. The stories are so moving and I can't help but wonder how my partner and I would react in such circumstances. I cannot help but feel quite helpless hearing how terrible things are for people but I am in no position to help or make things better anyway.

Several things strike me about this extract; firstly that subsequent interpolations ('*later note: and picked up a fine for speeding*') jar with the tone and emotional fabric of the initial text. Secondly I adhere to a predictable beginning-to-end chronology. Thirdly, I incorporate generic features of diary writing such as recounting key episodes and actions ('*he had the same expression today'*), using external description to locate places and orientate the reader ('*they live in a beautiful house with lovely surroundings'*), and supply a running commentary of personal reflection upon the incidents recounted (*'the cruelty of the disease struck me'*). I am highlighting how conditioned my reactions appear to have been by certain ways of making meaning implicit in the diary format; a conditioning shared with my co-respondents who also wrote diaries. Both our methods of response are rooted in a shared cultural convention, with its own history and creative assumptions about how to construct and communicate meanings.

The fragility of my parents is a theme to which my mind habitually returns, almost like a nervous tic. In the daily round I often register small happenings which remind me of my parents' vulnerability, imagined (by me) ill-health, and likelihood of being caught unawares – by an accident, a freak happening, a crime. I am sure there is nothing unusual in any of this. Indeed, it is in my reader's relationships with their parents that I hope one of my foci in this study, to do fluent, malleable and shared subjectivity, will reverberate. For many of us, our parents represent and embody our own voices and being. In the first diary entry, I explain that the experiences of Jackie and Frank, reminded me they are my parents' ages, more or less. Unsurprisingly, I do not follow '*this brought their experiences into sharp focus for me'*, with further explanation. In a linguistic sense, it is elliptical. The implied meaning is clear. Whether or not I recognised another resemblance with Jackie and Frank is unspecified, but I am fairly sure I was taken unawares by an insight into 'being-towards-death' – a phenomenological term representing authentic experience, and as such needing no further comment. I am fairly confident another competent reader would infer the meaning I have left elliptical without prompting. I think it is clear that the writer of the extract fears for the well-being of her parents.

Although I do not think my '*professional self*' is as prominent as it might be expected to be in the following extract, it is signalled through some of the word choices ('*signalled', 'data'*). I think the professional self is most conspicuous in the voiced concern about both interviewees remaining present throughout: '*I was worried that this might influence the content of the interviews and possibly make the data less rich and 'honest'*. As a reflexive reader, a host of emotions rise as I re-read. I am aware of the distancing and detachment from a situation that comes with the professional relationship. I am also conscious that automatic behaviour furnishes the professional with a kind of tact that might conceal a different kind of thought process. Lastly, I see that professional concerns require a certain preoccupation with process, and with it intermittent removal from the profound implications of what is happening, to ensure the outcomes are the best they can be. Whether a non-professional would find my attitude a little cold and calculating here, I cannot say.

Finally, I am becoming conscious of a reaction I am having to myself as a character in my own text. I am polarising different presentations of myself in a judgemental way. I am sure my judgements reverberate with what would be a common reaction in the culture at large. I want to locate the empathetic, heartfelt and caring 'I', the one I am tempted to think *actually* wrote the extract, whilst

adopting a tougher professional exterior. There seems to be a kind of common sense in wanting to do this. My professional self is after all, a relative late-comer in my entourage of inner voices.

When I say '*this is a couple who have just retired and obviously were looking forward to enjoying their time together, but it is being taken away'*, it reads now like just such a reminder to myself that caring, empathy and regret for the couple are the best reaction. There is another moment which strikes me now, and might be interpreted similarly by someone reading me as pure *'text'*, devoid of authorial intention. At one point, after fretting about the quality of the data, I remark, *'But it was their prerogative, of course'*. It seems an obvious reproach to myself, a prod in the ribs. There was a certain, selfless way I ought to have been thinking at that point, but it had slipped for the time being.

I realise that I felt obliged to try to contain my emotions, rather than communicate them. I suppose the researcher's instinct always is to avoid influencing a situation, and let it unfold naturally. This reaction now appears perhaps a little artificial, as sharing emotion is a very natural thing to do and there is no reason to think it will distort research findings. Having said this, I clearly was concerned to appear objective and impartial as a researcher: a deeply ingrained habit. I cannot help but speculate what I would do if the situation were mine rather than the interviewees'. This feels like another very natural reaction. Perhaps it is a natural reflex of the imagination to explore what someone else is going through. Inevitably I find a parallel between these individuals' lives and mine with my partner. I begin to suppose that this situation is mine, not theirs. Perhaps I do it as a substitute for something that will truly help the couple – it is obvious from the extract that I could not see what real help I could possibly represent to them.

Diary extract two

The second extract was taken from my reflexive diary a few weeks later during the analysis stage of the diary data. During my re-reading of the second extract, I was reminded of my time as a student of English Literature. I describe journals entries as 'poetic', which sounds to me now almost as a slippage from the correct academic register. 'Poetic' makes the entry sound more symbolic than actual. However I used to use 'poetic' as a student to explain a type of effect in literary texts that is difficult to pin down. Something, which has a literal meaning but is also evocative. I see now that the bench in the garden, where daughter can commune with the spirit of mother, represents this kind of symbol. It is obvious from subsequent comments that I feel a little ashamed of this reaction, and want to remind myself that I need to be responsible to the kind of text I am reading, and the situation in which it is produced, and not take the words too far from their contexts.

I raise in my diary a point which has much preoccupied me as a researcher – the interpretative act. I worry about reading things into situations which are not really there, but I would like to be there for the sake of research findings. Whitehead (2004:513) talks of '*academic pressure to go beyond description and 'light' interpretation.'* I am very wary of the effect of what Dreyfus (1991:276) calls "levelling to banality", in which the findings become "mere assertion". I think in my diary there is evidence of my awareness of this difficult compromise and persistent pressure in academic work to stay true to the source whilst elucidating and enhancing it - I appear to reach a satisfactory (provisional) conclusion that reading is inevitably a 'constructive' process. It seems to me now I was hopeful at the time that my background in literature would help with this, by enabling me to be responsive to the journals.

Diary extract two: November 14th 2008

I have been reading some of the diary data. Some of it is extremely moving. There are passages written by the participants' adult children which upset me, making me imagine losing my own mother to this disease. The description of a conversation where mother and daughter discussed the need to have a bench in a garden where she could go and talk to her mother after her death, was extremely poignant. Their descriptions are so poetic and honest, I feel honoured that I am able to read such personal accounts but I'm struggling to find the right way to react. I need to keep an academic distance but cannot stifle my natural response. More than anything, working on this project has made my own worries seem so trivial – I am constantly vowing to appreciate the good things in my own life more. Which is something that Jackie herself comments that she hopes the diary will encourage others to do.

I am trying to interpret these passages, which sometimes comes easy but at others I wonder if I am perhaps going too far and seeing things which are not really there. In some ways this analytical process is like reading any other text. I have the mental habits established in my time as an English undergraduate, but that was reading Tess of the D'Urbervilles, not an MND patient's diary! I can't get away from the fact that reading is as constructive a process now as it was then, though the context is much more real now and immediate to me.

I feel a sense of personal guilt when they talk about the difficulties they have experienced regarding services provision. It is certainly making me think about my own practice and the way in which I relate to patients. Have there been times when I too have been insensitive to the patients' needs? I suppose there must have been. It is a never-ending challenge to put the patients' needs first, when you are short of time, need to be somewhere else, etc.

My own recent experience of a close family member being diagnosed with a neurological disease also coloured my interpretations. I certainly feel a measure of guilt about his condition, though clearly I did not cause it in any way. I am sure the guilt is displaced from other things, from the time before he was unwell. It is as if by having been better to him before, I might have changed what happened. It is difficult to understand why people accuse themselves with such thoughts; I think there is probably some form of displacement occurring from what we would like to have influenced but did not, onto what we could have affected.

The guilt and attendant frustration makes me question myself further. I see now that I was satisfying a general guilt by doing so. These people were suffering and I was not. There was no reason for things to be that way, they simply were. When people are faced with inevitabilities like this, they examine every detail of their conduct to find fault. Maybe it is part of some instinctive levelling process. We can find no particular reason for being spared from suffering, it is down to luck. I think I was raising a serious point with myself too, about patients' needs, and how easy it is for them to become overridden by other urgencies. As McCaffery (1983:95) puts it in the context of nursing, "pain is what a patient says it is and exists when it says it does". Whitehead, (2004:517) talks in her study, about how nurses must promote and protect "the interests and *dignity* of patients and clients" (my italics). I was determined throughout the study, and always will be, to put patients first. I regularly make this kind of statement to myself as a mental note and recognise it happening in the journal.

Whitehead (2004) talks about how, looking back on her notes, she inevitably brought prejudice to her interpretation of her findings. It is clear to me that my background is also working through the way I interpret and respond to the data being provided to me. Being aware of the factors influencing outcomes can help the researcher and reader have confidence in the authenticity and accuracy of the research.

Diary extract three

This third extract is taken from the reflexive diary following an interview with one of the participants in the second data set of the study.

Diary extract three: December 16 2008

Yesterday I carried out particularly long and moving interview with a husband of someone with MND. The interview I found incredibly sad as he was clearly struggling with all he found he had to do now in

caring for his wife. He was extremely honest as he described in detail his experiences and feelings of living with the disease, even mentioning how he sometimes felt annoyed with his wife, and disliking himself for it, because he feels exhausted by it all. So it was terrible to come back and find that the interview had not recorded as the device had run out of power. I feel so guilty and incompetent – why did I not check this properly before carrying out the interview? I feel bad for him as it had obviously been difficult talking about it all and now it is for nothing and I am also frustrated with myself as the data was so rich and I keep thinking of what has been lost for the study.

I have spoken to my supervisor asking for advice regarding a research quandary I have recently found myself in. I was aware I had to inform the participant of what had occurred as he was keen to contribute to the study in the hope of benefiting others. But I was not sure if it would be ethical to ask him whether he would mind repeating the interview. My supervisor says that as he was motivated to have his voice heard it is important to offer him the choice of repeating the interview but I have to ensure he does not feel obliged to do it again. I am aware that doing the interview second time around will clearly lose some of the richness of the data but I will just have to accept that.

I phoned him and explained what had occurred. I felt terribly unprofessional and thought it must look bad. However, he has been very understanding and agreed to do it again next week. Such a relief!

Re-reading the third excerpt, I am a little surprised by the consistency of tone across the three diary entries. It is clear to me that consciously or not, I utilised a certain style and narrative voice which felt appropriate for the entries. Although all of the entries become emotional in different ways, each begins in a style that is considered and makes it seem that I have reflected upon the experiences before writing about them. In the above extract, my report that the interview was "long and moving" makes it sound as if I had come to an interim judgement on how the experience had affected me. It is possible that such evaluations rob the actual experiences of some of their emotional impact by conferring a label on them; on the other hand, it is necessary to categorise and define to direct the reader to appropriate interpretations.

It strikes me now how difficult it must have been for the respondent to admit he was having to fight the resentment he felt to his wife. Fatigue clouds our judgements and extreme tiredness is surely one of the greatest burdens borne by carers. In addition to the difficulty of being a carer, the husband had to deal with involuntary feelings of resentment, whilst perhaps knowing they were not justified. I still quiver with embarrassment about failing to record the interview properly. I re-read

that part as anyone else must, wondering how this person managed to be so incompetent. I feel most distanced from myself re-reading this part, and the excuses I offer are as unconvincing to me as they must have sounded to others at the time.

I am reminded how inter-dependent professionals are. I had to ask my supervisor what to do because I did not have the experience to deal with the situation. It strikes me how real professional authority represents the ability to interpret the rules in the most constructive way. As an inexperienced researcher I was most concerned with my failure in losing the data, but my supervisor, rightly I now perceive, diagnosed the ethical problem. The interviewee had the right to be heard, and upholding this right represented the nub of my ethical responsibility. It was this advice that made me confident when approaching him again, and ensured that he got his chance to be heard; without my supervisor's experience and collaboration this would not have happened.

Finally with this extract, I can see how elated I was that the interviewee was willing to do it again, and to restrain whatever dissatisfaction he may have felt. I greatly appreciated this at the time, and I can see that 'data' only tells a part of the research story. In addition to the information generated in research situations, there is a network of relationships enabling it to happen which the data does not fully credit. Forming these temporary relationships and handling them emotionally is a key aspect of succeeding as a researcher. The generosity and candour of many of the interviewees contributes in no small part to the emotional tone underlying my journal entries.

Diary extract four

The fourth extract is an account taken from the reflexive diary, following the death of Jackie.

Diary extract four: . January 23rd 2009

Heard today that Jackie died. A very strange thing to take in. I did not really know her, I only met her a couple of times and yet I have had this very intimate insight into her life and her thoughts and feelings. I feel as upset as if I had heard news of an acquaintance dying. Life is so real. What does that mean? I think I mean the people I have been immersed in reading about and the diary extracts seem more poignant than ever. I don't want to do this anymore. That's not true, I do but I don't want to do it now. It doesn't seem right to treat her words like another data set. I have a duty to finish the project and make sure that her voice is heard but I can't face it right now.

(later) *I received the final instalment of the diary in which the Frank describes Jackie's last days with*

such honesty and love. It reminds me that others have to be far stronger than I have to be, and that I need to gather myself and do a proper job. I really hope I can do justice to the data. All I can do is interpret their story to the best of my abilities.

The first paragraph above is notable for its staccato style ("Heard today…a very strange thing…"). There is an elliptical quality where the beginnings of the sentences are truncated (that is, there is no *I* heard, nor *it is* a very strange thing. In both cases the subject of the sentence is missing). It seems to me now that I was writing quite automatically without fully elaborating the grammar one would expect. This makes it appear that I was either reeling from the impact of Jackie's death, and/or representing this upset in the way I was writing.

The first paragraph is disjointed and I can see that I was struggling to express myself. The uncertain nature of my relationship to Jackie must have played a part in this. I felt as someone close to her would feel upon her death, although our relationship was purely professional. Again, I am reminded of the multi-faceted and in some essential sense *personal* nature of the professional relationship which intends to generate honest and lucid data. From a linguistic point of view, I chose to express myself in abstract nouns ('life', 'real', 'mean'), as does anyone groping for meaning in a situation that is radically altered. It is clear to me that I felt suffocated by the proximity of professional relationships and emotional demands, and there is a struggle between my desire to recoil from the pain and confusion, which is met by the more sober and determined sounding resolution to do my duty.

In the final paragraph my use of abstract nouns continues ('love', 'justice'). Though I cannot recollect the particulars of the day with any clarity, there is always some reconstruction of circumstances taking place as meanings are created. I obviously returned to the journal after receiving Frank's final instalments. It seems to me now that I was distracted throughout the day by the nature of more 'fundamental' matters in life such as love and justice. Perhaps this response was to be expected because of the ways in which professional and personal lives inevitably blend. But another avenue of interpretation suggests itself to me now; I was humbled by Frank's fortitude and determined to do 'justice' to the data. Perhaps the terminology is strange but the word 'justice' implies I felt a sense of duty as well as professional commitment. I was thinking about what I *ought* to do as well as what I felt capable of doing.

In hermeneutic phenomenology, the issue of 'reactivity' (Hammersley, 1990) is thought to be resolved only by ensuring that the researcher includes a full description and evaluation of the potential effect of the researcher on the data. In this chapter I have sought to do this, by providing a reflexive analysis of my own position as a researcher; detailing how my cultural, social and professional background may have impacted on my decisions throughout the research process and considering the ways in which the findings of this study have resulted partly from my own experience and assumptions. By including such an explicit account, I hope the integrity and credibility of the research project will be enhanced.

I submitted an analysis that depended upon examples and interpretation, as opposed to categorical statements. This reflects the idea that the interpreting self, just like the other selves explored in this study, does not exist singly and fixedly in one place and time. Moreover the self is understood, from a phenomenological view, as something which appears to itself as a collection of phenomena. Hence it is ripe for reportage and interpretation. My ability to interpret myself rests upon a relationship with the written accounts, which themselves were responses to a fluid, dynamic and at times dramatic, social world.

This study and its findings emerged in a specific context, reliant upon a very specific convergence of individuals and opportunities. An alteration in one component would have changed the entire landscape. It is crucially important for me as a researcher committed to the ethics, methods and principles of IPA, that I am conscious of the part played by my assumptions in the meanings the study uncovers. Moreover, fathoming all the ways in which one inserts one's interpretative commitments into the world is in a sense an impossible task; my ability to appraise my own background is itself a product of that background. Instead I view the interpretation of *dasein* as a perpetually open-ended work in progress. Though self-analysis will never be completed, it can be conducted rigorously and honestly. To this end, I have offered here an extensive account of my personal and professional histories with critical commentary, and excerpts from the reflexive journal kept during the research process, revealing my reactions as they occurred at the time.

2. Strengths and limitations of the study

Introduction

The following section of the chapter outlines the strengths and limitations of the study. It is argued that it is well designed as it contains a longitudinal analysis of a couple and findings are triangulated with data derived from interviews with twelve couples. It is proposed that data is rich and suggestive

and that the design fits well with the methodology used, which is IPA. This section also indicates how guidelines for ensuring quality and validity (Eliot, *et al.* 1999) in qualitative studies have been applied throughout the study.

According to Smith (1999:424) the first step when evaluating any idiographic research should be to determine *'how illuminating it is of the particular cases studied.'* A positive feature of the phenomenological method is '*its ability to capture the richness of lived experience through describing ordinary, mundane daily living'* (Finlay, 2003:175). In addition to analysing semi-structured interviews of 12 couples living with MND, I have also employed a phenomenological method to examine the diaries of one husband and wife spanning the year from diagnosis to death. This combined study design of analysing two data sets has not only allowed me privileged access to the couples' life worlds but the triangulation of the findings has also ensured a unique and rigorous account of their experiences.

The longitudinal and contemporaneous aspect of the data collection enabled the couple to narrate episodes in their story as they unfolded; the diary format required them to utilize a personalised language to portray their experiences. The nature of diary writing is to depict subjective experiences without interference from the researcher. The diary format lends itself to writing in an authentic and committed style, raising the possibility of interpretation concerned with philosophical categories such as 'being' and 'existence'. Moreover such writing has the potential to move with its honesty and at certain junctures it left me marvelling at the human capacity for suffering and hope. Data collection using diaries or journals, with people experiencing illness, have been advocated by a number of researchers in health (Jones, 2000; Rancour and Brauer, 2003; Milligan, *et al*. 2005; Midtgaard, *et al.* 2007; Liampruttong, 2007; Valimaki, *et al*. 2007). It has been acknowledged that use of diaries as a research collection tool provides a number of benefits including flexibility, privacy and autonomy and is more suitable for the exploration of highly sensitive issues. The use of journal in the case study enabled Jackie and Frank to record their thoughts in accordance with their own needs and wishes without the intrusion of a researcher.

I would concede that interviews as a data collection method did not allow participants such autonomy or privacy as the journal and this may have been reflected in the reduced 'richness' of the data in some of the interviews. Nevertheless, unstructured or semi-structured interviews are regarded as one of best means to collect rich and detailed data for IPA studies (Smith, *et al*. 2009), as they enable the participants to discuss at length their own stories and experiences of the

phenomenon being studied; encouraging the participant to reflect on these experiences without being overly constrained by the researchers' questions (Smith, *et al.* 2009). I did attempt to follow this guidance by avoiding directing the interviews in any particular course and allowing the stories to enfold according to the participants' own interests and wishes. It was my intention throughout, that by adhering to this process of interviewing, the voices of the participants would be allowed to come through unhampered in the findings, thereby enhancing the quality of the data collected.

Another strength concerning data collection in this study is the fact that the interviews were conducted in an environment chosen by the participants. On all occasions this was their own homes. This sensitivity to context including the participants' needs and wishes are one measure of validity of qualitative research outlined by Yardley (2008). By undertaking the interviews in the participants' homes, thus ensuring greater privacy and security, it is likely the participants felt more at ease in discussing their experiences which again may have improved the data quality.

In this study I have identified the super-ordinate themes 'altered body', 'diminishing self', 'altered temporality' and 'self transcendence' which together represent and articulate some of the existential impacts of living with MND. However, as is the case with any qualitative study, generalisations to wider relevant populations are precluded. As this study comprises a case study of one couple and analysis of interviews from a small sample of couples I cannot claim the conclusions drawn are representative of the experience of MND in other individuals, or characteristic of the widespread experience of MND. Furthermore, the sample was recruited from one MND centre and it is likely that their characteristics are diverse from those of others living in the UK or internationally. The analysis in IPA is always an interpretative, subjective process and it would be impossible to derive the same findings in a different context. Therefore, rather than measuring the study's 'generalisability', the criteria 'theoretical transferability' is more appropriate to determine whether the study's findings are transferable. Theoretical transferability refers to whether the reader considers the findings relate to previous literature, their own professional and personal experiences (Smith, *et al.* 2009) and whether they think the findings would be relevant to others with the same or similar experiences. In order to ascertain this, it is necessary that the study provides contextual information and 'situates the sample' (Eliot, *et al.* 1999; Smith, *et al*. 2009). These aspects of the study are discussed below.

Moreover, Smith (2004:43) maintains the value of the case study, for which the tool of interpretation is IPA, lies in the opportunity to understand the *particular* person within the *specific* situation, and in doing so illuminate something more fundamental and widespread:

> *'…the very detail of the individual also brings us to significant aspects of a shared humanity and the particular case can therefore be described as containing an 'essence''.*

Therefore, though it might seem a contradiction in terms, it is the specific universal nature of IPA analysis which renders a case study of even one individual, sufficient sample size; depending on the topic and scope of the investigation (Malterud, 2001). This idiographic approach lends itself particularly to the study of MND as it is an idiosyncratic disease and no two cases are the same (Bedlack, *et al.* 2007; Baek, *et al*. 2007). It was therefore deemed appropriate to concentrate on the particulars of the couples' story, as it enabled me to view a particular 'life-world' through a magnifying lens. The intention was to use this magnified picture to illuminate our shared existence through its vividness, clarity and honesty, rather than because '*generalised invariant structures of experience'* (Finlay, 2005:175) had been discovered, or even sought.

The claim to making a significant contribution to knowledge is made by my departure from previous psychological research in the area of MND, which has tended to be influenced by the cognitive model of psychology and is characterised by reliance on quantitative methods (Krivickas, *et al.* 1997; Gelinas, *et al*. 1998; Goldstein, *et al.* 1997; 1998; Simmons, *et al*. 2000; Jenkinson, *et al*. 2000; Robbins, *et al*. 2001; Clarke, *et al*. 2001; Kraub-Wittermer, *et al.* 2003; Trail, *et al.* 2004; Foley, *et al*. 2007; Gauthier, *et al*. 2007; Lou, *et al*. 2010. As evidenced in the literature review, many studies conducted previously have focused upon the measurement of, and search for, correlations between, psychological factors including depression, anxiety, hopelessness, quality of life and coping strategies. I found many of these studies were limited to a cross-sectional design and used small samples. There has been some research of the type I have done, which has used qualitative methods to explore the experiences of patients with MND and their partners (Brown, 2003; 2008; Locock, 2010). However, these are scarce and moreover practically uniform in their use of qualitative methodology, with the majority of studies employing narrative analysis. Despite being informative, such studies could benefit from a more substantial repertoire of data-gathering and interpretative approaches.

To my understanding, to date, there are no published studies where an interpretative phenomenological analysis has been employed to study the psychological impact of MND on

married couples. My study is made distinct, by my use of a specifically psychological method which draws upon phenomenological theory to enable a greater insight into couples' experiences. I have employed IPA with a longitudinal case study of one couple using interview and journal data and a larger cross–sectional data set of interviews with 12 couples. This has provided me with an in-depth account of the interpretations of couples' bodily and psychological experiences.

Methodologically, I would maintain this study has met with the criteria for a 'good' IPA study outlined by Smith (2011). This study has a *clear focus* centred on exploring the impact on couples living with MND. It has utilised *strong data* as the diary extracts were extremely rich and detailed in their descriptions of the couple's lives; the study is *rigorous* with its inclusion of numerous verbatim and reported quotations from the journal and interviews to substantiate my claims. Themes identified are *elaborated* in a way which enhances the discursive richness of the themes and their potential applicability outside the confines of the study. Furthermore, the findings have been *interpreted* rather than provided only as elaborated data, fulfilling the philosophical premises of phenomenology in general and in particular, goals associated with successful research using interpretative phenomenology.

Elliot, *et al*. (1999) set out guidelines for assessing quality and validity in qualitative psychological research, guidelines advocated by Smith, *et al.* (2009). Elliot, *et al.* (1999) acknowledge a number of commonalities between qualitative and quantitative research, and the primary section of their evaluation criteria is proposed as relevant to both types of methodology. It includes, for example, methodological appropriateness, informed consent, ethical research conduct, and clarity of presentation. The criteria comprise seven guidelines which are specific to qualitative research and I will now describe how my study adhered to these criteria through the collection, management and analysis of data.

1. Owning one's perspective

By acknowledging his or her prior and arising *'theoretical orientations and personal anticipations'* (Elliot, *et al.* 1999) a researcher enables readers to interpret data and gain a fuller understanding of the findings. My study drew upon three subjective viewpoints: those of the person with MND, the spouse and myself. The study was intended to record the subjective reactions of the first two parties and to reflect upon the strategies of deriving knowledge from them in the third. I needed to be confident about the interpretative acts underlying the findings of the study, but recognised that these acts must make their approaches and conclusions to some extent provisional, and liable to be

influenced by further research, and also that these acts would be coloured by my own values, assumptions, beliefs and biases. Johnson and Duberley (2003) assert that a researcher becomes 'reflexive' by being critically minded about his or her epistemological assumptions. Alvesson and Skoldberg (2000:6) suggest *'Reflection can be defined as the interpretation of interpretation, and the launching of critical self-exploration of one's own interpretations of empirical material.'* With these and other authorities in mind, throughout the project I have been vigilant when interrogating the influence of my values, interests and assumptions on my interpretations. Secondly, an audit trail of my decisions in the form of a research diary, validated reflections upon my research practices and assumptions throughout the process, by comprising an on-going '*self- critique and self-appraisal*' (Koch and Harrington, 1998) which took into account the moral, social, political and personal stances intrinsic to the approaches I undertook.

2. Situating the sample

The inclusion of details regarding the participants and their circumstances, is advocated by Elliot, *et al.* (1999) in order to enable the reader to appraise the range of people and situations to which the findings may be relevant. Therefore in order that this study offered the reader with further context for the themes and quotations, I provide background information on various relevant characteristics of the participants, including gender, age, form of MND, disease duration, (see appendix 1). I also included biographical details (for example, hobbies, life events, and the like) of Jackie and Frank, who were analysed as a case study. This is in accordance with the recommendations made by IPA theorists (Reid, *et al*. 2005; Smith, *et al.* 2009; Smith, *et al*. 2011).

3. Grounding in examples

To ensure transparency of the analytic procedure and the conclusions drawn from it, provision of data is necessary, as it allows the reader to appraise the conclusions drawn by the researcher and consider possible alternatives. Consistency of approach and analysis was indicated in this study by the use of themes which provided a 'grounding for results' (Madill, *et al*. 2000), with participants' actual descriptions alongside them in the form of quotations. The inclusion of examples of data to evidence the interpretations arrived at by the researcher in this way, represents a significant measure of validity in both qualitative and IPA studies (Yardley, 2008, Smith, *et al*, 2009). In addition, Smith (2011) states that IPA studies with more than eight participants should include a measure of prevalence of themes. An account of the recurrency of the themes has been provided in this study (see appendix 10) allowing the reader further certainty that the themes are truly representative of all the participants taking part of the study.

The guidelines set out for a IPA studies suggests that similarities should be sought between the accounts and that divergent themes and cases which do not agree with the consensus should also be included and explored (Reid, *et al.* 2005; Smith, *et al*. 2009; 2011) as the aim of IPA is to provide a detailed but balanced account of both the similarities and differences between the individuals. Yardley (2008) states that including data which does not fit with the argument and examining the differences between cases confirms that the account presented is not one–sided. She also maintains that by excluding these from the data set may limit the generalisability of the findings as it is possible that the negative cases are also representative of a large portion of the population studied. It is also suggested that negative cases may result in some interesting findings and also point to areas of further research. I undertook this process in this study, as themes derived solely from the analysis of the case study have been discussed in detail. By documenting both the similarities and the differences across the two data sets means that the validity of this interpretative account of the participants' experiences is enhanced.

4. Providing credibility checks

A number of different verification strategies can be utilised by the researcher in order to check the credibility of the findings (Elliot, *et al.* 1999); (i) checking understandings with the original informants, (ii) using multiple qualitative analysts, (iii) comparing two or more varied qualitative perspectives, and (iv) triangulation with external factors or quantitative data. A number of verification strategies were therefore used to ensure cross validation. The design of this study allowed comparison of the findings by a number of means: firstly it employed a multi-perspectival approach (patient and carers' perspectives), secondly, two forms of data were employed in the study (interviews and diaries); thirdly the data had been collected for a much larger study. According to Yin (1989), validity checking can be obtained by the collation of all relevant study data which enables someone to 'follow the chain of evidence' running through the study. I collected all relevant documents for the study, including the initial notes, research proposal, ethics proposal, the interview schedule, annotated transcripts, table of themes and draft reports so that the rigour of decision-making could be demonstrated. An independent mini audit was also undertaken by my supervisors; the initial codes, categories and themes on the first transcript created by me were read and comments made to ensure validity in my analytic approach. In addition I joined the IPA online forum which enabled me to contact two other more experienced researchers who were using the same methodology and we each agreed to exchange one analysed case and provide feedback on the analysis. By undertaking this independent check, my themes were verified and new insights were provided which further validated the study.

5. Coherence

Elliot, *et al*. (1999) assert the necessity for coherence in the study, that is, the findings from the study should be presented in an integrated and logical form whilst remaining true to the subtleties of the participants' responses. The independent audit carried out by supervisors and members of the IPA forum also comprised a review of the meanings uncovered ensuring 'internal coherence', (Smith, 2011) providing comments and suggestions which prompted me to refine and supplement the thematic account. A combination of verbal narrative and summary tables were utilised to present the findings and illustrate the hierarchical relationships between the themes. Temporal sequencing helped guide the reader through the narratives of the participants' experiences. Any ambiguities or contradictions found in the data were included and explained. Furthermore I ensured that the study always adhered to the principles of IPA and the theoretical frameworks of phenomenology and hermeneutics from which it derives.

6. Accomplishing general versus specific research tasks

As the objective of a qualitative study is to gain a 'general understanding' of a phenomenon, claims should arise from an 'appropriate' range of instances (informants or situations), (Elliot, *et al.* 1999). Furthermore, the researcher should acknowledge the limitations of their findings as they are context specific. In this study therefore, I followed IPA guidelines regarding sample size and a detailed and intensive analysis of one case (interview and journal of one couple) was supplemented by the examination of the rest of the sample (12 couples). This form of triangulation of the findings is considered a useful means of enhancing the validity of the study (Reid, *et al*. 2005; Yardley, 2008; Smith, *et al*. 2009). Yardley (2008:240) acknowledges that when incorporating multiple perspectives through triangulation in this way, the aim is not to provide a *'single, consistent account of the phenomenon'* but to *'enrich'* our understanding of it. As has been acknowledged above, the scope for applying generalisations about service provision to contexts beyond those belonging to this study are limited. The study has provided an enriched account of particular experiences and it is anticipated these will have some resonance with the experiences of other couples living with MND and will therefore be 'theoretically transferrable'.

7. Resonating with readers

The findings of the study were presented in such a form so that they achieved 'resonance' in its readers, (that is, those who read the study consider it to be an accurate and informative representation of the subject). The intention was to bring the interviewees' experience to life. Yardley (2008:250) concludes that the real test of a study's validity is whether it tells the reader

something interesting, important or useful; she advises that *'the study will have impact and importance if it builds on what we already know to take us a step further, and answer questions that matter to people and society.'* It is suggested that this study has achieved this. The following chapter will detail the direct clinical implications that the findings of this particular study might have to this client group and also outline some interesting areas for further research. The chapter will also further emphasise what this study has added and how the findings have made a new contribution to this field of research.

Limitations

IPA, with its affiliation to, and consistency in, the ideas and approaches of hermeneutics, rejects the assumption that truth is objectively 'revealed' by the interview's disclosures. Truth is instead a standard of interpretative skill and accuracy, brought into play as the interviewed and the interviewer make sense of their realities through the exchange of narrative and attentive, sympathetic reporting. Inherent to this is the acknowledgement that personalised ways of seeing and understanding, each situated in a variegated cultural perspective of shared and divergent assumptions, is intrinsic to each person in the interview encounter. One of interviewer's responsibilities is to make explicit and rigorous the necessary process of reflection on these assumptions, and their potential impact on the nature of the account produced (Robinson, *et al*. 2005). Similarly to Robinson's study, where the data was produced jointly by the individual and the carer, couples were able to view each other's commentaries. Another variable is thereby implied in the achievement of academic rigour. It is likely, one assumes, that the closeness of the couples' relationship influenced what each felt it was possible and helpful to say in the circumstances (Clare and Shakespeare, 2004). It is a risk inherent in self-reporting, and particularly when it is written and there is more time to reflect, that participants will deliberately position themselves and each other in specific ways to avoid creating upset and to provide comfort. In the circumstances, the participants' candid, forthright and painfully honest contributions therefore seem all the more remarkable. At a number of points in the diary Jackie and Frank acknowledge their desire to provide an account that is honest and accurate version of events:

> *'Today is a very bad day and as the whole point of this diary is to describe, honestly, how my life is whilst dealing with MND, I have to admit that it is' (Jackie, journal 2, 6 months following diagnosis, line no. 258)*

However, it is useful to note that Robinson, *et al*. (2005) suggest triangulation, with separate interviews of the individual and spouse, would have enabled greater monitoring of the influence of

the participant's subjectivity. This was achieved with some of the participants, however, limited time, accessibility and meeting people's needs and wishes made this unfeasible in many cases. Nevertheless, the form of triangulation used in this particular study which compared analysis of the two data sets (both journal and interviews) has enabled me to draw comparisons and find similarities between the couples' experiences and ensured a greater degree of rigour in the findings.

Summary

This chapter has engaged in hermeneutic reflection. It has centred on the necessity for the researcher to become aware of the process I employed for making sense of recorded experience. Therefore the chapter has brought myself into the foreground, highlighting how I have at times struggled with my role. On the other hand, some moments in the project had a particular, even poetic, resonance and by examining my written account of important occasions during the project, I pursued a process of reflection to make me conscious of my role in shaping the material for the reader. The purpose of this process was to make sure that the couple's experiences were related and analysed as transparently as possible, making the reader aware of my subjective influence at all times. In this chapter I also reviewed some of the strengths and weaknesses of the study.

This chapter is succeeded by the final chapter, in which I draw conclusions and map some of the implications for clinical practice and further research raised in this study.

Chapter 7 - Conclusion and implications for policy, practice and research

Introduction

I have undertaken in this study an in-depth exploration of the social, psychological and existential impact of living with MND in couples. A unique design of IPA methodology has been employed to triangulate two diverse data sets: a longitudinal case study of a journal kept for one year by one couple and data drawn from interviews with 12 couples. The analysis has generated a collection of themes that both appropriately and fully characterise the data and are themselves clear, distinct and supported by theoretical sources. The themes describe the lived experience of these 13 couples. By using this method to explore the ideas and beliefs of couples living with MND, I have achieved the research aims outlined in chapter 2, page 44. I will now outline how my findings may increase understanding of the psychological needs of couples living with MND and offer some suggestions of interventions which may benefit both the person with the disease and their partner or spouse.

The limitations of this study have already been discussed in detail in chapter 6. As with any qualitative research which uses a small sample, there is a need to be cautious regarding the drawing of insights from this study and giving them general application. Having made this proviso, it should be noted there was a great deal of convergence between the themes drawn from both data sets in this study and many of the participants made similar reflections regarding their experiences. There appeared to be a significant degree of 'theoretical transferability' (Smith, *et al.* 2009) in this study (discussed in chapter 6) and many of the findings of this study were shown to be consistent with previous research carried out with people with other terminal diseases. Therefore I would suggest that despite its small scale, there is significant applicability for my findings beyond this particular study, and therefore is potentially highly relevant in its particular and related fields.

Implications for practice

This study has significant implications for clinical practice in the area of MND. There is currently very little in the way of psychological support for people with MND and their spouses or families in the UK (All Party Parliamentary Group on MND, 2011). Furthermore, there is a lack of guidance regarding appropriate interventions within the literature, according to McCleod and Clarke (2007).

As is presented in chapters two through to six, four main themes were identified from the analysis of the data; 'altered body', 'diminished self', 'altered temporality' and 'self transcendence.' What is evident from the discussion of the themes is that as a result of living with the disease, the identities of couples were destabilised and thrown into disarray, leading to psychological and emotional

distress. Insecurities regarding individual identity resulted from changes to physical capability and reactions to it; further effects were caused by and reflected in changes to relationships between the spouses, often occurring in tandem with contracting or adjusting social and familial relationship and attitude toward social situations. Couples living with MND began to experience time very differently as the future became both less certain and more significant, with commensurate 'knock-on' effects in the present and regarding the past. The perception of the 'present instant' also changed.

Self-transcendence (Coward, 1990; 1993; 1995; 1998; 2003; Coward and Reed, 1996; Coward and Kahn, 2005; Reed, 1991; 2003; 2009) is an empirical theory of nursing which derives from the lifespan movement of the 1970s and Rogers' (1980; 1994) idea of the unitary nature of human beings. It is representative of a '*developmental maturity wherein there is enhanced awareness of the environment and orientation toward broadened perspectives of life.'* (Reed, 2003; 147). The theory developed from the researcher's recognition in clinical practice that frequently, people experiencing life-threatening illness come to perceive their lives as more meaningful and show an increased ability to maintain purposes which enhance their self-worth. According to the theory, individuals who experience self–transcendence, undergo an expansion of 'self-boundaries' in three ways. Firstly 'intra-personally', where the person has an increased awareness of themselves, a heightened perception of sensitivity to the world around them and clarification and expansion of their highest ideals. The person may also experience the expansion 'temporally' whereby the individual learns to integrate past and future in a way that has meaning for present. Secondly 'inter-personal' expansion describes the way in which a person may experience enhanced relations to others and their social and physical environment. Finally, 'transpersonal' expansion can take place when individuals develop a firmer belief in a power greater than his or herself, or a form of life after physical death which enables them integrate the illness and gain positive insights about life and death.

Previous studies have revealed that self-transcendence is beneficial to people approaching death (Coward and Reed, 1996; McCoy, *et al.* 2000) and also the family carers of terminally ill (Enyert and Burman, 1999; Salmon, *et al*. 2005). Two studies carried out with people with MND have also identified self-transcendence as having a positive impact on their well-being (Fegg, *et al*. 2005; Fanos, *et al.* 2008). As Reed acknowledges:

> *'Reaching out toward others, reaching inward for new perspectives and new understandings about oneself, and acceptance of unchangeable situations are all manifestations of self-transcendence that may promote healing.'* (Reed, 1991)

In this study, aspects of 'self-transcendence' were evident in enabling the couples to attempt to cope with changes which were occurring as a consequence of MND. In terms of 'inter-personal transcendence', the couples in this study revealed that the development of 'dyadic' and socially-inflected ideas of selfhood and the increased connection with others in their lives, helped to compensate for the loss and fluctuation of individual identities. Regarding 'intra-personal transcendence', the study demonstrated that a convergence of time took place when couples were able to maintain a sense of time as a continuous and meaningful whole. This frequently occurred through the re-appraisal of the past and consideration of the legacies they may leave to the future. The case study carried out with Jackie and Frank revealed that 'authentic being' was an essential part of 'intra-personal transcendence', in that they were capable of finding meaning and a renewed perception of key experiences in the face of fractured senses of selfhood. The analysis of the journal also demonstrated that 'transpersonal' aspects of self-transcendence were helpful as spirituality came to have more importance in the couple's lives.

The findings of this study, therefore, have confirmed that forms of 'self-transcendence' can provide relief to couples living with MND; helping both individuals and their spouses to endure suffering and make sense of what is taking place to them. However, it is also evident from my findings that attaining and maintaining self-transcendence is challenging. This is reflected in Cowards' findings that a great degree of effort is required from individuals to actualize their capacity for self-transcendence. She quotes one participant from her study: "*The hardest thing to learn is that, when you can't do, to just let be*" (Coward, 1990: 167). This quotation directly echoes a comment made by Jackie in her journal in this study:

> *'I know it is important to be and not just to do… but it is not something I find very easy.*' (Jackie, Journal 3, 6 months following diagnosis, line no. 29-31)

Coward and Reed (1996) emphasise that self-transcendence is not a mind-set which comes easily to people and a level of mindfulness and intentionality attaining and sustaining it is necessary. This study suggests that finding ways of helping people achieve self-transcendence should be a focus of psychological interventions with this client group. A number of different approaches could be drawn upon to encourage 'self-transcendence' and thus attend to the needs of the whole person including the existential, psychological, social, and spiritual aspects of their experience. According to the findings of the study, to attend to the 'whole person' should be a main aim of professionals. This is in accordance with recent policy frameworks such as the National Service Framework for Long Term Conditions (DH, 2005); the National End of Life Care Strategy (DH, 2008); Living and Dying Well,

(Scottish Government, 2008) and the NatCen survey on attitudes towards dying, death and bereavement, (Dying Matters, 2009) all of which emphasise the importance of providing a range of physical, emotional, spiritual and social support to people with terminal diseases and their partners. Moreover, the 'Role of Psychology in End of Life Care' (British Psychological Society, 2007) emphasises the importance of a holistic approach to care which incorporates both the needs of the client and their families with the aim of maintaining quality of life for as long as possible.

1. Interpersonal aspect of transcendence

Frank (1995:36-37) acknowledges the way in which medicine tends to encourage isolation and individualism, through the reinforcement of what he terms the '*monadic body'*:

> *'Patients relate individually to medical staff, not collectively among themselves, and this pattern of relating seems to result from how medical spaces are designed and how movement within them is orchestrated. Modernist administrative systems not only prefer the monadic body, but the disease model that grounds medical practice does little to admit any other concept of the body. The monadic body of medicine articulates well with modernist society's emphasis on individual achievement in education or in the market place.'*

Participants in this study revealed how isolating it was to be 'on the receiving end' of the administration of their treatment which made them resemble disconnected, individualised bodies and little more. They reported a sense of being estranged from others, which was often disturbing and difficult. This study identified that couples living with MND developed new ways of understanding selves including the dyadic self, familial and social self as projections of 'individualistic' selfhood were diminished. Developing or maintaining a connectedness with others, whether it was the partner or spouse, family or friends, or other people, was shown to be fundamental to the 'interpersonal' aspect of 'self-transcendence' for the participants in this study. The findings thus reflect the ideas of Merleau- Ponty, (1945: 354) regarding the importance of our underlying connections with others in the world which we can re-discover and extend through dialogue whereby '*our perspectives merge into each other, and we co-exist through a common world.'*

In order to encourage people to find ways of accomplishing 'interpersonal' transcendence, the adoption of relational approaches in medicine or psychology whereby intervention is provided to couples or families as a unit seem more appropriate than focusing on just the individual with the disease. Furthermore, the need for health professionals to facilitate dialogic connection, and not merely 'instrumentally' efficient administration of therapeutic treatment, appears imperative (Benner, 1996; Thomas, 2000).

Finding ways in which individuals with the disease and spouses can maintain access to their social networks and connect with others is essential. This notion supports the work of Ray, *et al*. (2005). A number of studies have demonstrated that 'self-transcendence' is obtained by finding meaning in one's own adverse experience by using that experience to assist another (Coward, 1990, 1995; Coward and Lewis, 1993; Fryback, 1993). In my study, Jackie and Frank revealed how maintaining a public journal represented a way of reaching out to others in this way. Thus journal keeping could be a way in which couples experiencing MND may make adversity into a positive and connective experience and there is evidence to suggest that it may represent a therapeutic process as studies with other client groups have found (Pennebaker, 1997; DeSalvo 2000; Bolton, 2001; Wright and Cheung Chung, 2001; Lowe, 2006). Encouraging couples to participate in research studies may represent another way, as a number of previous studies have demonstrated that people with terminal diseases find participation a valuable and altruistic experience (Terry, *et al*. 2006; White and Hardy, 2010).

2. Intrapersonal and temporal aspects of self-transcendence

Couples in this study revealed a sense of loss of identity, altering roles, estrangement from bodies and adjustments to body functioning. Psychological interventions which enable individuals to 'expand' inwardly - to clarify and integrate a greater understanding of themselves – facilitate 'self-transcendence' in people. As has been discussed self-transcendence also involves the development of new perceptions of time which allow individuals to formulate a greater cohesiveness and sense of continuity in their lives, which are disrupted by MND. I will now outline a number of psychological interventions which drawing upon the findings of the study, may represent useful ways of mediating and conveying the means of fostering cohesion and continuity.

Narrative therapy (White and Epston, 1990; White, 1995; 2007; 2011) is a psychological technique which uses the exploration of personal narratives to enable people to make sense of themselves. White, (1995:1314) states:

> *'Stories constitute this frame of intelligibility…. it is the story of self-narrative that determines which aspects of our lived experience get expressed, and it is….self-narrative that determines the shape of our lived experience….these stories actually shape our lives, constitute our lives….'*

By encouraging individuals to tell alternative stories of themselves and recognise the exceptions and *'unique outcomes'* in their lives, people are released from the stories which have imprisoned them in

closed and limiting visions of themselves, their relationships and views of the world. Narrative therapy has been found to be a successful method of psychotherapy with various client groups and has been proposed as a way of preventing illness related stress disorder (Petersen, *et al*. 2005). As it was evident from my study that the use of narratives enabled Jackie and Frank to arrange a unified and coherent sense of their past and present experiences, it would appear that this may represent a useful technique for couples with MND. Furthermore the facilitation of 'we' narratives (Skerrett, 2010) through this form of therapy may encourage the mutuality that so many of the couples in this study reported finding beneficial.

Levenson, *et al*. (2005) have found that meditation practice is positively related with self-transcendence and openness to experience. It is therefore likely that the psychological intervention mindfulness, which derives from Eastern spiritual practices may also be useful. Mindfulness involves '*intentionally bringing one's attention to the internal and external experiences occurring in the present moment, and is often taught through a variety of meditation exercises'* (Baer, 2006:125). Mindfulness has been shown to have positive outcomes for people experiencing other diseases such as cancer (Carlson, *et al*. 2003; Foley, *et al*. 2010), Parkinson's Disease (Fitzpatrick, *et al.* 2010) and people in palliative care (Chadwick, *et al*. 2008). Beadon (2009) suggests that mindfulness approaches may also enable people to accept altered body experiences and encourage mind-body connectivity.

Reminiscence is a psychological technique employed in which individuals take time to think and talk about their lives. It can be provided to clients on a structured or unstructured, group or individual basis. Reminiscence therapy encourages individuals to recall past events, feelings and thoughts to facilitate pleasure, quality of life, or adaptation to the present (McCloskey and Bulechek, 2000). Life review represents a form of reminiscing and occurs at particular points in the lifetime, frequently at times of crises such as approaching end of life. The intervention involves the review of the individual's entire life span with the aim of helping the individual to find meaning. Both reminiscence and life review have been shown to have a positive impact on reducing psychological stress in individuals experiencing illness (Lazarus, *et al.* 1996; Trumann and Parker, 2001; Jones, *et al.* 2003; Woods*, et al*. 2005). An evaluative study of the use of reminiscence with older people (Stinson and Kirk, 2005) suggests that this form of intervention may have a positive impact on increasing 'self-transcendence'. It is likely therefore that similar interventions may be beneficial to couples living with MND.

Developing an 'authentic' way of being and appreciating 'living in the moment' was also shown to be an important feature of self-transcendence in this study. Therefore 'self-transcendence' seems to be linked to the couples' ability to develop new meanings and purposes in their lives. This confirms the work of Chochinov (2006), Dobratz (2002) and Radway *et al,* (2009) which demonstrate the positive impact of finding ways to live life to the full in individuals with terminal disease. Ways in which this could be encouraged involve enabling people to find ways of making sense of their own suffering through participation in activities that are personally meaningful. Such activities should clearly be unique to the individual, and would require consultation with the client to make sure they are employed in a non-threatening yet effective way. Activities increasing a feeling of being at one with nature and the universe, and altruistic activities are examples.

The psychological approaches listed above, could be beneficial to people's ability to sustain personal meaning in the face of impending death. It is anticipated that the use of any such approaches with people with MND and their partners or spouses may alleviate psychological and existential distress.

3. Transpersonal aspect of self-transcendence and providing a spiritual environment.

In terms of the transpersonal dimension of 'self-transcendence', interventions which enable participants to explore spiritual values and existential concerns are thought to be ways in which people approaching the end of their lives may find meaning (Frick, *et al*. 2006; Lambert, 2006) and come to terms with their mortality. Reed (2003) suggests that increased provision for privacy for prayer and permission to discuss beliefs surrounding God and the after-life can be beneficial. The findings support the claim therefore that more should be done to ensure that people with MND and their partners or spouses have such opportunities within health care settings, for instance through the inclusion of chaplains or other alternative spiritual care professionals within the multi-disciplinary provision of care (Mitsumoto, *et al.* 2005).

Summary

This study has identified self-transcendence as a means of helping couples who live with MND, find meaning and psychological well-being. A number of ways in which 'self-transcendence' can be encouraged in couples living with MND have been proposed in this conclusion:

- Relational/systemic approaches in medical and psychological treatments for people with MND.
- Increased dialogic connection with patients and carers during health intervention.

- Emphasis on and importance of improved social networks for people with disease and partners or spouses.
- Maintaining journals or participation in research studies as ways of connecting with others and alleviating others' distress.
- Use of psychological interventions to encourage new understandings of self and time through narrative therapy, mindfulness, meaning making, reminiscence and life review therapy.
- Provision of outlet for spirituality such as prayer or discussion.

Implications for research

There are a number of ways in which further research is implied by this study. The interventions outlined above are suggested as ways in which 'self-transcendence' may be facilitated in couples living with MND. As discussed above, previous studies have identified their positive uses with other client groups but there is a scarcity of studies evaluating their use with people with MND. Therefore, evaluative studies using both quantitative and qualitative methods and the aforementioned interventions, are necessary in order to provide an evidence base for clinical practice with people with MND.

Furthermore, interventions have tended to be trialled exclusively with the individual experiencing the disease. As this study has identified the diminution of individual and expansion of dyadic and social identities, the emphasis is placed on the need to treat not only the individual but the couple simultaneously. This reiterates the findings of Rabkin, *et al*. (2000) who suggest that attending to the mental health needs of caregivers may also alleviate the patient's distress and vice versa. Therefore, any evaluative studies of the above interventions should incorporate both the individual with the disease and their partner or spouse.

Although, this study has largely focused on the dynamic between couples, highlighting the importance of dialogic connection with people with MND and their partners or spouses, it has also identified the need for health professionals to adopt more systemic/relational approaches when working with this client group. Therefore, this focus could be expanded in further research studies, by investigating the relations between couples and health professionals with a view to providing a greater understanding of ways in which health professionals may relinquish the '*monadic body*' (Frank, 1995:36-37) and incorporate dyadic and social understandings of identity.

Conclusion

According to the guidelines 'The Role of Psychology in End of Life Care' (British Psychological Society, 2007:16), psychologists have an important role in supporting individuals and their families at the end of life:

> *'…there comes a time for all of us when death becomes a reality and for some there becomes an awareness of a dying status. The ways in which an individual develops a personal meaning of life and death will include emotion, reason, social and experiential aspects. Thus psychologists are particularly well placed to understand the individual experience of dying and death and to support the individual, the family and others in this and the resultant grief which follows.'*

The title of Frank's final journal extract is *'Diamonds are made under great pressure'.* He explains in the journal these striking words are taken from a mural spreading across a wall of the hospital he walked past when used to visit Jackie. It is clear the quote has a special meaning for him; he says it *'brings tears to my eyes each time – I don't know why.'* (Frank, journal extract 9, 12 months following diagnosis. line no.2653). For me the words encapsulate what I hope this study has shown. The experience of couples living with MND is one characterised by the greatest of pressures, devastation and loss and despite this potential for tragedy, it is possible for couples to transcend the desolation and wreckage that MND inflicts on their lives. In this study it is revealed that couples are capable of finding meaning and even a sense of wonder and beauty, like a glinting diamond. Some of the interventions I have outlined above may enable psychological and health services to better support couples trying to do this.

References

Acton, G. J., & Wright, K.B. (2000) 'Self-Transcendence and Family Caregivers of Adults with Dementia' *Journal of Holistic Nursing.* 18 (2) pp.143-158

Addington-Hall, J. (2002) 'Research Sensitivities to Palliative Care Patients' *European Journal of Cancer Care.* 11 (3) pp. 220-224.

Akechi, T., Okuyama, T., Sugawara, Y., Shima, Y., Furukawa, T. A. & Uchitomi, Y. (2006) 'Screening for Depression in Terminally ill Cancer Patients in Japan' *Journal of Pain and Symptom Management.* 31 (1) pp. 5-12.

Albert, S.M., Rabkin, JG., Del Bene, M.L.D., Tider, T., O'Sullivan, MS., Rowland, L.P., Mitsumoto, H. (2005) 'Wish to Die in end-stage ALS' *Neurology.* 65 (1) pp. 68-74.

All Party Parliamentary Group on Motor Neurone Disease. Inquiry into Access to Specialist Palliative Care for People with Motor Neurone Disease in England. http://www.mndcampaigns.org/assets/0002/8370/APPG_Report_final_3_.pdf [accessed 17 March 2012].

Allport, G. (1962) 'The General and the Unique in Psychological Science' *Journal of Personality.* 30 pp. 405-22.

Alt-White, A. C. (1995) 'Obtaining "informed" consent from the elderly' *Western Journal of Nursing Research.* 17 (6) pp. 700-705.

Alvesson, M. & Skoldberg, K. (2000) *Reflexive methodology: New vistas for qualitative research*. Thousand Oaks, CA: Sage Publications.

Anda, R., Williamson, D., Jones, D., Macera, C., Eaker, E., Glassman, A., et al. (1993) 'Depressed affect, hopelessness, and the risk of ischemic heart disease in a cohort of US adults' *Epidemiology.* 4 (4) pp. 285-294.

Aoun, S., Kristjanson, L. & Oldham, L. (2006) 'The challenges and unmet needs of people with neurodegenerative conditions and their carers' *Journal for Community Nurses.* 11 (1) pp.17-20.

Armon, C. (2000) 'Environmental risk factors for Amyotrophic Lateral Sclerosis' *Neuroepidemiology.* 20 (1) pp. 2-6.

Ashworth, P. (2008) 'Conceptual Foundations of Qualitative Psychology' In: Smith, J (eds.) *Qualitative Psychology: A Practical Guide to Research Methods.* 2nd Edition. Thousand Oaks, CA: Sage Publications. pp. 4-25.

Ashworth, P. (2003) 'An Approach to Phenomenological psychology: the contingencies of the lifeworld' *Journal of Phenomenological Psychology.* 34 (6) pp. 145-156.

Atkins, L., Brown, R.G., Leigh, P.N., Goldstein, L.H. (2010) 'Marital relationships in amyotrophic lateral sclerosis' Amyotrophic *Lateral Sclerosis*. 11 pp. 344-350.

Attride-Stirling, J. (2001) 'Thematic networks: an analytic tool for Qualitative Research' *Qualitative Research.* 1 (3) pp. 385.

Averill, A. J., Kasarskis, E. J. and Segerstrom, S. C. (2007) 'Psychological health in patients with amyotrophic lateral sclerosis' *Amyotrophic Lateral Sclerosis.* 8 (4) pp. 243-254.

Axtell, A. (2008) 'Depression in Palliative Care' *Journal of Palliative Medicine.* 11(3) pp. 529-530.

Baek W.S & Desai, N.P. (2007) 'ALS: pitfalls in the diagnosis' *Pract Neurol.* 7 pp. 74-81.

Barnes, J. & Campbell, C. (2010) 'Palliative care in multiple sclerosis and motor neurone disease' *British Journal of Hospital Medicine.* 71 (1) pp. 21-25.

Beauchamp, T. L. & Childress, J. F. (2001) *Principles of Biomedical ethics.* Oxford: Oxford University Press.

Beaver, K., Luker, K. & Woods, S. (1999) 'Conducting research with the terminally ill: challenges and considerations' *International Journal of Palliative Nursing.* 5 pp. 13-17.

Bedlack R.S., Traynor, B.J., Cudkowicz, M.E.(2007) 'Emerging disease-modifying therapies for the treatment of motor neuron disease/amyotrophic lateral sclerosis' *Expert Opin Emerg Drugs.* 12 (2) pp. 229-252.

Benner, P. E. (1994) *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness.* Thousand Oaks, CA: Sage Publications.

Bensimon, G., Lacomblez, L., & Meininger, V. (1994) 'A controlled trial of riluzole in amyotrophic lateral sclerosis. ALS/Riluzole study group' *The New England Journal of Medicine.* 330(9) pp. 585-591.

Biggerstaffe, D & Thompson, A. (2008) 'Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research' *Qualitative Research in Psychology*. 5 pp. 214–224.

Bird, C.M. (2005) 'How I stopped dreading and learned to love transcription' *Qualitative Inquiry*. 11 pp. 226-48.

Blazer, D.G and Hybels, C. F. (2005) 'Origins of depression in later life' *Psychological Medicine.* 35, pp. 1241-1252.

Blumer, H. (1981) George Herbert Mead. In: Rhea, B (eds.) *The Future of Sociological Classics.* Boston: George Allen & Unwin. pp. 174-193

Blumer, H. (1969) *Symbolic Interactionism.* Englewood Cliffs, New Jersey: Prentice Hall.

Bocker, F., Seibold, I. & Neudorfer, B. (1990) 'Disability in everyday tasks and subjective status of patients with advanced amyotrophic lateral sclerosis' *Fortschr Neurol Psychiatr.* 58 pp. 224–236.

Bolmsjö, I. (2001) 'Existential issues in palliative care: interviews of patients with amyotrophic lateral sclerosis' *Journal of Palliative Medicine.* 4 (4) pp. 499-505.

Bolmsjo, I. & Hermeren, G. (2003) 'Conflicts of Interest: experiences of close relatives of patients suffering from amyotrophic lateral sclerosis' *Nurse Ethics.* 10 pp. 186-198.

Bolmsjo, I. & Hermeren, G. (2001) 'Interviews with Patients, Family and Caregivers in Amyotrophic Lateral Sclerosis: Comparing Needs' *Journal of Palliative Care.* 17 (4) pp. 236-240.

Bolton, G. (1998) 'Writing or Pills? Therapeutic writing in primary health care' In: Hunt, C., & Sampson, F., (eds.) *The self on the page: theory and practice of creative writing in personal development*. London: Jessica Kingsley Publishers. pp. 8-92.

Bombardier, C. H., D'Amico, C., & Jordan, J. S. (1990) 'The relationship of appraisal and coping to chronic illness adjustment' *Behaviour Research and Therapy.* 28(4) pp. 297-304.

Bonner, R. L., & Rich, A. R. (1991) 'Predicting vulnerability to hopelessness: A longitudinal analysis' *Journal of Nervous and Mental Disease.* 179(1) pp. 29-32.

Boote, D. N., & Beile, P. (2005) 'Scholars before researchers: On the centrality of the dissertation literature review in research preparation' *Educational Researcher.* 34 (6) pp. 3-15.

Bramley, N. & Eatough, V. (2005) 'The Experience of living with Parkinson's disease: An interpretative phenomenological analysis case study' *Psychology & Health.* 20 (2) pp. 223-235.

Braun, V. & Clarke, V. (2006) 'Using Thematic analysis in psychology' *Qualitative research in psychology.* 3 (2) pp. 77-101.

Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M., Nelson, C. J. and Brescia, R. (2000) 'Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer' JAMA*.* 284 (22) pp. 2907-2911.

Bremer, B., Simone, A., Walsh, S., Simmons, Z. and Felgoise, S. (2004) 'Factors supporting quality of life over time for individuals with amyotrophic lateral sclerosis: The role of positive self-perception and religiosity' *Annals of Behaviour Medicine.* 28 pp. 119-125.

British Psychological Society (2007) *The Role of Psychology in End of Life Care.* A report published by the professional practice board of the British Psychological Society.

Bromberg, M.B., Forshew, D., Laderosa, S., McDonald, E. (1996) 'Ventilator Dependency in ALS: management, disease progression, and issues of coping' *J Neurol Rehab.* 10 pp. 195- 216.

Bromberg, M. B. (2007) 'Assessing quality of life in ALS' *Journal of Clinical Neuromuscular Disease.* 9 (2) pp. 318-325.

Bromberg, M. B. & Forshew, D. A. (2002) 'Comparison of instruments addressing quality of life in patients with ALS and their caregivers' *Neurology.* 58 (2) pp. 320-322.

Brott, T., Hocking, C. and Paddy, A. (2007) 'Occupational Disruption: Living with Motor Neurone Disease' *The British Journal of Occupational Therapy.* 70 (1) pp.24-31.

Brown, J. (2003) 'User, carer, and professional experiences of care in motor neuron disease' *Primary Health Care Research & Development.* 1 pp. 249-52.

Brown, J., Lattimer, V. & Tudball, T. (2005) 'An investigation of patients and providers' views of services for motor neurone disease' *British Journal of Neuroscience Nursing.* 1 (5) pp 249-252.

Brown, J. & Addington-Hall, J. (2008) 'How people with motor neurone disease talk about living with their illness: a narrative study' *Journal of Advanced Nursing.* 62 (2) pp. 200-208.

Brummett, BH, Mark, DB, Siegler, IC, Williams, RB, Babyak, MA, Clapp-Channing, NE, et al. (2005) 'Perceived social support as a predictor of mortality in coronary patients: Effects of smoking, sedentary behavior, and depressive symptoms' *Psychosomatic Medicine.* 67 pp. 40-45.

Bunge, M. (1993) 'Realism and anti-realism in social science' *Theory and Decision.* 35 pp. 207-235.

Bungener, C., Piquard, A., Pradat, P., Salachas, F., Meininger, V. & Lacomblez, L. (2005) 'Psychopathology in Amyotrophic Lateral Sclerosis: a preliminary study with 27 ALS patients' *Amyotrophic Lateral Sclerosis.* 6 (4) pp. 221-225.

Burkman, L.F., Leo-Summers, L. (1992) 'Emotional support and survival after myocardial infarction' *Annals of Internal.* 117 (12) pp. 1003-1009.

Burman, E. (2003) 'Interviewing' In: Banister, P., Burman, E., Parker, I., Taylor, M., and Tindall, C., (eds.) *Qualitative Methods in Psychology: A Research Guide.* Buckingham: Open University Press. pp. 49-71.

Bury, M. (1982) 'Chronic illness as biographic disruption' *Sociology of Health and illness.* 4 (2) pp. 167-182.

Bynum, H. & Rogers, J. (1987) 'The use and effectiveness of assistive devices possessed by patients seen in home care' *Occupational Therapy Journal of Research.* 7 (3) pp. 181-191.

Carradice, A., Shankland, M. C. and Beail, N. (2002) 'A qualitative study of the theoretical models used by UK mental health nurses to guide their assessments with family caregivers of people with dementia' *International Journal of Nursing Studies.* 39 (1) pp. 17-26.

Casarett, D. J. & Karlawish, J. H. T. (2000) 'Are special ethical guidelines needed for palliative care research?' *Journal of Pain and Symptom Management.* 20 (2) pp. 130-139.

Cassell, C.M. (2005) 'Creating the role of the researcher: identity work in the management research process' *Qualitative Research*. 5 (2) pp. 167-179.

Chancellor, A., & Warlow, C. (1992) 'Adult onset motor neuron disease: Worldwide mortality, incidence and distribution since 1950' *Journal of Neurology, Neurosurgery & Psychiatry.* 55 (12) pp. 1106-1115.

Charmaz, K. (2002) 'The self as habit: The reconstruction of self in chronic illness' *OTJR: Occupation, Participation and Health.* 22 (1) pp. 31-42

Charmaz, K. (1993) *Good days, bad days: The self in chronic illness and time.* New Jersey: Rutgers University Press.

Charmaz, K. (1983) 'Loss of self: a fundamental form of suffering in the chronically ill' *Sociology of Health & Illness.* 5 (2) pp. 168-195.

Charmaz, K. (1995) 'The Body, Identity and Self' *Sociological Quarterly.* 36 (4) pp. 657-680.

Cheung, J., & Hocking, P. (2004) 'Caring as worrying: The experience of spousal carers' *Journal of Advanced Nursing.* 47 (5) pp. 475-482.

Chio, A., Gauthier, A., Montuschi, A., Calvo, A., Di Vito, N., Ghiglione, P. and Mutani, R. (2004) 'A cross sectional study on determinants of quality of life in ALS' *Journal of Neurology, Neurosurgery & Psychiatry.* 75 (11) pp. 1597-1601.

Chio, A., Gauthier, A., Calvo, A., Ghiglione, P. and Mutani, R. (2005) 'Caregiver burden and patients' perception of being a burden in ALS' *Neurology.* 64 (10) pp. 1780-1782.

Chochinov, H.M., Wilson, K.G., Enns, M., Lander, S. (2000) 'Depression hopelessness and suicidal ideation in the terminally ill' *Psychosomatics.* 39 pp. 366-370.

Clare. L., & Shakespeare, P. (2004) 'Negotiating the Impact of Forgetting Dimensions of Resistance in Task-Oriented Conversations between People with Early-Stage Dementia and their Partners' *Dementia***.** 3 (2) pp. 211-232.

Clarke, S., Hickey, A., O'Boyle, C. and Hardiman, O. (2001) 'Assessing individual quality of life in amyotrophic lateral sclerosis '*Quality of life research.* 10 (2) pp. 149-158.

Cohen, S., & McKay, G. (1984) 'Social support, stress, and the buffering hypothesis: A theoretical analysis' *Handbook of Psychology and Health.* 4 pp. 253-267.

Cohen, S & Wills, T.A. (1985) 'Stress, social support and the buffering hypothesis' *Psychological Bulletin.* 98 (2) pp. 310-357.

Cohen, S. (1988) 'Psychosocial models of the role of social support in the etiology of physical disease' *Health psychology.* 7 (3) pp. 269-297.

Cohen, D. (1991) 'The subjective experience of Alzheimer's disease: The anatomy of an illness as perceived by patients and families' *American Journal of Alzheimer's Care and Related Disorders and Research*. 6 pp. 6-11.

Conrad, P. (1987) 'The experience of illness: recent and new directions' *Research in the Sociology of Health Care.* 6 (1) pp. 31.

Conrad, P & Barker, K.K. (2010) 'The Social Construction of Illness: Key Insights and Policy Implications' *Journal of Health and Social Behavior.* 51 (S) pp.S67–S79.

Coward, D.D. (1990) 'The Lived Experience of Self-Transcendence in Women with Advanced Breast Cancer' *Nurs Sci Q***.** 3 (4) pp. 162-169

Coward, D.D., & Lewis, (1993) 'The lived experience of self-transcendence in gay men with AIDS' *Oncology Nursing Forum*. 20 (9) pp.1363-8

Coward, D.D. (1995) 'The Lived Experience of Self-Transcendence in Women with AIDS' *Journal of Obstetric, Gynecologic, & Neonatal Nursing.* 24 (4) pp. 314–320.

Coward, D.D. & Reed, (1996) 'Self-Transcendence: A Resource for Healing at the End of Life' *Issues in Mental Health Nursing*. 17 (3) pp.275-288.

Crist, J & Tanner, C. (2003) 'Interpretation/analysis methods in hermeneutic interpretative phenomenology' *Nursing Research*. 52 pp. 202-205.

Dal Bello-Hass, V., Andrews- Hinders D., Bocian J., Mascha, E., Wheeler, T., Mitsumoto, H. (2000) 'Spiritual well-being of the individual with amyotrophic lateral sclerosis.' *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*. 1 pp. 337-41.

Dahlberg, K., Dahlberg., H & Nystrom, M. (eds.) (2008) *Reflective lifeworld research.* 2nd Edition. Lund, Sweden: Studentlitteratur.

Dawson, S. & Kristjanson, L. J. (2003) 'Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease' *Journal of Palliative Care.* 19 (1) pp. 36-42.

Department of Health (2005) The National Framework (NSF) for Long term Neurological Conditions.http://www.dh.gov.uk/PublicationsAndSctatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4105361&chk=jl7dri[accessed 29 February 2009]

Department of Health. (2008) End of life care strategy. Promoting high quality for all adults at the end of life.
Http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance [accessed 30 July 2009].

DeSalvo, L. (2000) *Writing as a Way of Healing: How Telling Our Stories Transforms Our Lives.* Boston: Beacon Press.

Devellis, R. F., Lewis, M. A. & Sterba, K. R. (2009) 'Interpersonal Emotional Processes in Adjustment to Chronic Illness' In: (eds.) Suls, J. & Wallston, K. A., *Social Psychological Foundations of Health and Illness.* . Malden, MA, USA: Blackwell Publishing Ltd.

Doble, A. (1996) 'The pharmacology and mechanism of action of riluzole' *Neurology. 47*(6) 4 pp. 233S.

Dreyfus, H.L. (1991) '*Being in the World. A commentary on Heidegger's Being and Time.'* Cambridge: MIT Press,

Dunn, A. L., Trivedi, M. H., Kampert, J. B., Clark, C. G., & Chambliss, H. O. (2005) 'Exercise treatment for depression: Efficacy and dose response'. *American Journal of Preventive Medicine.* 28(1) pp. 1-8.

Dying Matters Coalition. NatCen survey on attitudes towards dying, death and bereavement commissioned on behalf of Dying Matters, July-September 2009.Http://www.dyingmatters.org/site/dying-to-talk-report. [accessed 2nd October 2009].

Dyer, J.G & McGuinness, T.M. (1996) 'Resilience: Analysis of the concept' *Archives of Psychiatric Nursing*. 10 (5) pp. 276-282.

Earll, L., Johnstone, M. & Mitchell, E. (1993) 'Coping with motor neurone disease - analysis using self-regulation theory' *Palliative Medicine.* 7 (2) pp. 21-30.

Eatough, V. & Smith, J. A. (2008) 'Interpretative phenomenological analysis' In: Willig, C & Stainton-Rogers, W (eds.) *The Sage Handbook of Qualitative Research in Psychology.* Thousand Oaks, CA: Sage Publications. pp. 179-194.

Elliott, R., Fischer, C. T. & Rennie, D. L. (1999) 'Evolving guidelines for publication of qualitative research studies in psychology and related fields' *British Journal of Clinical Psychology.* 38 (3) pp.215-229.

Epton, J., Harris, R. & Jenkinson, C. (2008) 'Quality of life in amyotrophic lateral sclerosis/motor neuron disease: A structured review' *Amyotrophic Lateral Sclerosis.* 10 (1) pp. 1-12.

Everson, S. A., Goldberg, D. E., Kaplan, G. A., Cohen, R. D., Pukkala, E., Tuomilehto, J., et al. (1996) 'Hopelessness and risk of mortality and incidence of myocardial infarction and cancer' *Psychosomatic Medicine.* 58 (2) pp. 113.

Fanos, J.H., Gelinas, D.F., Foster, R.S., Postone, N., Miller, R.G. (2008) 'Hope in Palliative Care: From Narcissism to Self-Transcendence in Amyotrophic Lateral Sclerosis' *Journal of Palliative Medicine*. 11 (3) pp. 470-475.

Farber, E. W., Schwartz, J. A. J., Schaper, P. E., Moonen, D. E. J., & McDaniel, J. S. (2000) 'Resilience factors associated with adaptation to HIV disease' *Psychosomatics.* 41(2) pp. 140.

Farran, C.J., Herth, K.A., Popovich, JM. (1995) *Hope and hopelessness: Critical clinical constructs.* Thousand Oaks. CA: Sage.

Fegg, MJ., Wasner, M., Neudert, c., Domenico Borasio, G. (2005) 'Personal values and individual quality of life in palliative care patients' *Journal of Pain and Symptom Management.* 30 pp.154-159.

Felgoise, S. H., Chakraborty, B. H., Bond, E., Rodriguez, J., Bremer, B. A., Walsh, S. M., Lai, E. C., McCluskey, L. & Simmons, Z. (2010) 'Psychological morbidity in ALS: The importance of psychological assessment beyond depression alone' *Amyotrophic Lateral Sclerosis.* 11 (4) pp. 351-358.

Finlay, L. (2008) *Introducing Phenomenological Research.* http:/www.lindafinlay.co.uk/phenomenology l+&btnG=&hl=en&as_sdt=0%2C5[accessed 12/01/11].

Finlay, L. (2003) 'The intertwining of body, self and world: A phenomenological study of living with recently-diagnosed multiple sclerosis' *Journal of Phenomenological Psychology.* 34 (2) pp. 157-178.

Fitzpatrick, R., Peto, V., Jenkinson, C., Greenhall, R., & Hyman, N. (1997) 'Health-related quality of life in Parkinson's disease: A study of outpatient clinic attenders' *Movement Disorders.* 12(6) pp.916-922.

Foley, G., O'Mahony, P., & Hardiman, O. (2007) 'Perceptions of quality of life in people with ALS: Effects of coping and health care' *Amyotrophic Lateral Sclerosis.* 8 (3) pp. 164-169.

Foley, G. (2007) 'What are the Care Needs for People with Motor Neurone Disease and How can Occupational Therapists Respond to Meet these Needs?' *The British Journal of Occupational Therapy.* 70 (1) pp. 32-34.

Folkman, S. (2008) 'The case for positive emotions in the stress process' *Anxiety, Stress, and Coping*. 21 (1) pp. 3-14.

Frank, AW. (1995) *The Wounded Storyteller.* Chicago: University of Chicago Press.

Gadamer, H. (1990/1960) *Truth and Method.* 2nd revised edition. New York: Crossroad.

Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W. and Lee, M. A. (1998) 'Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide' *New England Journal of Medicine.* 339 (14) pp. 967-973.

Ganzini, L., Johnston, W. S. and Hoffman, W. F. (1999) 'Correlates of suffering in amyotrophic lateral sclerosis' *Neurology.* 52 (7) pp. 1434-1436.

Ganzini, L., Silveira, M. J., & Johnston, W. S. (2002) 'Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington' *Journal of Pain and Symptom Management.* 24 (3) pp. 312-317.

Gauthier, A., Vignola, A., Calvo, A., Cavallo, E., Moglia, C., Sellitti, L., Mutani, R. and Chio, A. (2007) 'A longitudinal study on quality of life and depression in ALS patient-caregiver couples' *Neurology.* 68 (12) pp. 923.

Gelinas, DF., O'Connor, P., Miller, RG.(1998) 'Quality of life for ventilator-dependent ALS patients and their caregivers' *J Neurol Sci*. 160(S1) pp. S134-136.

Gent, C., McGarry, J. & Pinnington, L. (2009) 'Motor neurone disease: carers' experiences, behaviour and coping methods' *British Journal of Neuroscience Nursing.* 5 (12) pp. 567-573.

Gergen, Kenneth J. (1985) 'The social constructionist movement in modern psychology' *American Psychologist*. 40(3) pp. 266-275.

Glaser, B. & Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago: Aldine.

Goffman, E. (1970) *Strategic Interaction.* Oxford: Blackwell.

Goldstein, L., Adamson, M., Jeffrey, L., Down, K., Barby, T., Wilson, C. & Leigh, P. (1998) 'The Psychological Impact of MND on patients and carers' *Journal of Neurological Sciences.* 160 (S1) pp. S114-121.

Goldstein, L. H and Leigh, P. N. (1999) 'Motor neurone disease: a review of its emotional and cognitive consequences for patients and its impact on carers' *British Journal of Health Psychology.* 4 (3) pp. 193-208.

Goldstein, L.H., Adamson, M., Barby, T., Down, K., & Leigh, P.N. (2000) 'Attributions, strain and depression in carers of partners with MND: a preliminary investigation' *J Neurol Sci.* 180 pp. 101-106.

Goldstein, L Atkins & PN Leigh (2002) 'Correlates of Quality of Life in people with motor neuron disease (MND)' *Amyotrophic Lateral Sclerosis.* 3 (3) pp. 123-129.

Goldstein, L., Atkins, L. & Leigh, P. (2003) 'Health-related locus of control; does it change in motor neurone disease (MND)?' *ALS and Other Motor Neuron Disorders.* 4 pp. 27-30.

Goldstein, L. H., Atkins, L., Landau, S., Brown, R. & Leigh, P. N. (2006) 'Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: a longitudinal study' *Psychological Medicine.* 36 (6) pp. 865-875.

Goldstein, L. H., Atkins, L., Landau, S., Brown, R. G. and Leigh, P. N. (2006) 'Longitudinal predictors of psychological distress and self-esteem in people with ALS' *Neurology.* 67 (9) pp. 1652-1658.

Gordon, D.R. (1994) 'The Ethics of Ambiguity and Concealment around Cancer. Interpretations through a local Italian world' In P. Benner (Ed.) *Interpretive Phenomenology. Embodiment, Caring and Ethics in Health and Illness*. p.279-317.Sage: London.

Graneheim, U. H. & Lundman, B. (2004) 'Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness' *Nurse education today.* 24 (2) pp. 105-112.

Grant, J. S., Elliott, T. R., Weaver, M., Glandon, G. L., Raper, J. L., & Giger, J. N. (2006) 'Social support, social problem-solving abilities, and adjustment of family caregivers of stroke survivors' *Archives of Physical Medicine and Rehabilitation.* 87 (3) pp. 343-350.

Grbich, C., Parker, D., & Maddocks, I. (2001) 'The emotions and coping strategies of caregivers of family members with a terminal cancer' *Journal of Palliative Care.* 17 (1) pp. 30-36.

Hammersley, M. (1989) *The Dilemma of Qualitative Research; Herbert Blumer and the Chicago Tradition.* London: Routledge.

Hammersley, M. (1990). *Reading Ethnographic Research. A Critical Guide*. London: Longman.

Harre, R. (1979). *Social Being.* Oxford: Blackwell.

Harre, R. (1991) 'The discursive production of selves' *Theory & Psychology.* 1 (1) pp. 51-63.

Haverkamp, L. J., Appel, V. & Appel, S. H. (1995) 'Natural history of amyotrophic lateral sclerosis in a database population. Validation of a scoring system and a model for survival prediction' *Brain.* 118 (3) pp. 707.

Hecht, M., Hillemacher, T., Grasel, E., Tigges, S., Winterholler, M., Heuss, D., Hilz, M. and Neundorfer, B. (2002) 'Subjective experience and coping in ALS' Amyotrophic Lateral Sclerosis and other Motor Neuron Disorders. 3 (4) 224-231.

Hecht, M. J., Graesel, E., Tigges, S., Hillemacher, T., Winterholler, M., Hilz, M. J., Heuss, D. and Neundorfer, B. (2003) 'Burden of care in amyotrophic lateral sclerosis' *Palliative Medicine.* 17 (4) pp. 327-333.

Heidegger, M. (1962/1927) *Being and Time.* Oxford: Blackwell.

Herz, H., McKinnon, P. M. and Butow, P. N. (2006) 'Proof of love and other themes: a qualitative exploration of the experience of caring for people with motor neurone disease' *Progress in Palliative Care.* 14 (5) pp. 209-214.

Hinton, J. (1994) 'Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives?' *Palliative Medicine.* 8 (3) pp. 183.

Hocking, C., Brott, T. & Paddy, A. (2006) 'Caring for people with motor neurone disease' *International Journal of Therapy and Rehabilitation.* 13 (8) pp. 351-356.

Hogg, K., Goldstein, L. and Leigh, P. (1994) 'The psychological impact of motor neurone disease' *Psychological Medicine.* 24 (03) pp. 625-632.

Holmes, T. (2005) 'Motor neurone disease and the NSF for long-term neurological conditions' *Primary Health Care.* 15 (9) pp. 27–31.

Howard, R. & Orrell, R. (2002) 'Management of motor neurone disease' *Postgrad Med.* 78 pp.736-741.

Howes, H., Benton, D. & Edwards, S. (2005) 'Women's experience of brain injury: An interpretative phenomenological Analysis' *Psychology and Health.* 20 pp. 129-142.

Hughes, R., Sinha, A., Higginson, I., Down, K. & Leigh, P. (2005) 'Living with motor neuron disease: lives, experiences of services and suggestions for change' *Health and Social Care in the Community.* 13 pp. 64-74.

Hunt, D. and Smith, J. (2004) 'The Personal Experience of carers of stroke survivors: an interpretative phenomenological analysis' *Disability and Rehabilitation.* 26 pp. 1000-1011.

Hunter, M., Robinson, I., & Neilson, S. (1993) 'The functional and psychological status of patients with amyotrophic lateral sclerosis: Some implications for rehabilitation' *Disability & Rehabilitation.* 15 (3) pp. 119-126.

Husserl, E. (1970) *The Crisis of European Sciences and Transcendental Phenomenology.* (D. Carr Trans). Evanston: Northwestern University Press.

Hughes, R. A., Sinha, A., Higginson, I., Down, K. & Leigh, P. N. (2005) 'Living with motor neurone disease: lives, experiences of services and suggestions for change' *Health & Social Care in the Community.* 13 (1) pp. 64-74.

Jenkins, R. A., & Pargament, K. I. (1988) 'Cognitive appraisals in cancer patients' *Social Science & Medicine.* 26 (6) pp. 625-633.

Jenkinson, C., Brennan, C., Fitzpatrick, R., Bromberg, M. and Swash, M. (1999) 'Development and validation of a short measure of health status for individuals with amyotrophic lateral sclerosis/motor neurone disease: the ALSAQ-40' *Journal of Neurology.* pp. 246.

Jenkinson, C., Fitzpatrick, R., Swash, M. and Peto, V. (2000a) 'The ALS Health Profile Study: quality of life of amyotrophic lateral sclerosis patients and carers in Europe' *Journal of Neurology.* 247 (11) pp. 835-840.

Jenkinson, C., Fitzpatrick, R., Brennan, C., Swash, M.C. (2000b) 'Evidence for the validity and reliability of the ALS assessment questionnaire: the ALSAQ-40' *Amyotrophic Lateral Sclerosis.* 1 (1) pp. 33-40.

Johnson, P. & Duberley, J. (2003) 'Reflexivity in Management Research' *Journal of Management Studies.* 40 (5) pp. 1279-1303.

Johnston, M., Earll, L., Giles, M., McClenahan, R., Stevens, D. & Morrison, V. (1999) 'Mood as a predictor of disability and survival in patients newly diagnosed with ALS/MND' *British Journal of Health Psychology.* 4 (2) pp. 127-136.

Jones, R. K. (2000) 'The unsolicited diary as a qualitative research tool for advanced research capacity in the field of health and illness' *Qualitative Health Research.* 10 (4) pp.555.

Jones, J. E., Hermann, B. P., Barry, J. J., Gilliam, F. G., Kanner, A. M., & Meador, K. J. (2003) 'Rates and risk factors for suicide, suicidal ideation, and suicide attempts in chronic epilepsy' *Epilepsy & Behavior.* 4 pp. 31-38.

Jovchelovitch, S & Bauer, MW. (2000) 'Narrative Interviewing' In: Bauer, M.W., & Gaskell,G., (eds.) *Qualitative researching with text, image and sound: a practical handbook*. Thousand Oaks: Sage.

Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F. & Robertson, M. (2003) 'Factors associated with the wish to hasten death: a study of patients with terminal illness' *Psychological Medicine.* 33 (1) pp. 75-81.

Kiebert, G. M., Green, C., Murphy, C., Mitchell, J. D., O'Brien, M., Burrell, A. & Leigh, P. N. (2001) 'Patients' health-related quality of life and utilities associated with different stages of amyotrophic lateral sclerosis' *Journal of the Neurological Sciences.* 191 (2) pp. 87-93.

King, S. J., Duke, M. M. & O'Connor, B. (2009) 'Living with amyotrophic lateral sclerosis/motor neurone disease (ALS/MND): decision-making about 'ongoing change and adaptation'' *Journal of Clinical Nursing.* 18 (5) pp. 745-754.

Kitwood, T. (1990). 'The dialectics of dementia: With particular reference to Alzheimer's disease' *Ageing and Society*. 10 pp. 177-196.

Kitwood, T., & Bredin, K. (1992) 'Towards a theory of dementia care: Personhood and well-being' *Ageing and Society*. 12 pp. 269-287.

Kleinman, A. (1988). *The Illness Narratives*. New York: Basic Books.

Koch, T. & Harrington, A. (1998) 'Reconceptualizing rigour: the case for reflexivity' *Journal of Advanced Nursing.* 28 (4) pp. 882-890.

Kotarba, J.A. (1983) *Chronic pain: Its social dimensions.* Beverley Hills, CA: Sage.

Kraub-Wittemer, D., von Steinbuchel, N., Wasner, M., Laier-Groeneveld, G. & Domenico, G. (2003) 'Quality of Life and Psychosocial Issues in Ventilated Patients with Amyotrophic Lateral Sclerosis and Their Caregivers' *Journal of Pain and Symptom Management.* 26 (4) pp. 890-896.

Kraskowsky, L. H. & Finlayson, M. (2001) 'Factors affecting older adults' use of adaptive equipment: Review of the literature' *The American Journal of Occupational Therapy.* 55 (3) pp.303.

Kristjanson, L. J., Aoun, S. M. & Yates, P. (2006) 'Are supportive services meeting the needs of Australians with neurodegenerative conditions and their families?' *Journal of Palliative Care.* 22 (3) pp. 151-157.

Kristjanson, L. J., Aoun, S. M. & Oldham, L. (2006) 'Palliative care and support for people with neurodegenerative conditions and their carers' *International Journal of Palliative Nursing.* 12 (8) pp. 368-377.

Krivickas, L. S., Shockley, L. & Mitsumoto, H. (1997) 'Home care of patients with amyotrophic lateral sclerosis (ALS)' *Journal of the Neurological Sciences.* 152 pp. s82-s89.

Kübler, A., Winter, S., Ludolph, A. C., Hautzinger, M. & Birbaumer, N. (2005) 'Severity of depressive symptoms and quality of life in patients with amyotrophic lateral sclerosis' *Neurorehabilitation and Neural Repair.* 19 (3) pp. 182.

Kvale, S. (1996) *Interviews: An Introduction.* London: Sage.

Lacomblez, L., Bensimon, G., Leigh, P., Guillet, P., Powe, L., Durrleman, S., et al. (1996) 'A confirmatory dose-ranging study of riluzole in ALS' *Neurology.* 47 (6) pp. 242S.

Lane, D., Carroll, D., Ring, C., Beevers, D. G., & Lip, G. Y. H. (2002) 'The prevalence and persistence of depression and anxiety following myocardial infarction' *British Journal of Health Psychology. 7*(1), pp. 11-21.

Langridge, D. (2007) *Phenomenological Psychology: Theory, Research, and Method*. Pearson Education Ltd: Harlow.

Larkin, M., Eatough, V., Osborn, M. (2011) 'Interpretative phenomenological analysis and embodied, active, situated cognition' *Theory & Psychology.* 21 pp. 318-337.

Lavie, M. & Willig, C. (2005).'I Don't feel like melting butter: An interpretative phenomenological analysis of the experience of inorgasmia' *Psychology & Health.* 20 (1) pp. 115-128.

Lawton, J. (2000) *The Dying Process: Patients' experiences of Palliative Care*. London: Routledge.

Lazarus, R. S. & Folkman, S. (1984) *Stress, appraisal, and coping.* New York: Springer Publishing Company.

Lazarus, R.S. (1993) 'Coping theory and research: Past, present, and future' *Psychosomatic Medicine*. 55 pp. 234-247.

Leder, D. (1984) 'Medicine and the paradigms of embodiment' *Journal of Medicine and Philosophy.* 9 pp. 29-44.

Leder, D. (1990). *The Absent body*. Chicago: The University of Chicago Press.

Lee, J., Rigby, S., Burchardt, F., Thornton, E., Dougan, C. & Young, C. (2001) 'Quality of life issues in motor neurone disease: the development and validation of a coping strategies questionnaire, the MND Coping Scale' *Journal of the Neurological Sciences.* 191 (1-2) pp.79-85.

Leigh, P., Abrahams, S., Al-Chalabi, A., Ampong, M., Goldstein, L., Johnson, J., et al. (2003) 'The management of motor neurone disease' *Journal of Neurology, Neurosurgery & Psychiatry.* 74 (S4) pp. 32-47.

Levine, R. (1986) *Ethics and Regulation of Clinical Research.* Baltimore, MD: Urban & Schwarztenburg.

Levine, S. (1982) *Who dies? An investigation of conscious living and conscious dying.* New York: Anchor Books.

Li, J. T. (2000) 'Hope and the medical encounter' *Mayo Clinic Proceedings. Mayo Clinic.* 75 (7), pp. 765-767.

Lillo, P. & Hodges, J., R. (2010) 'Cognition and behaviour in motor neurone disease' *Current Opinion in Neurology.* 23 (6) pp. 638-642.

Lincoln, Y. and Guba, E. (1985) *Naturalistic Inquiry.* Newbury Park: Sage.

Lloyd, V., Gatherer, A & Kalsy, S. (2006) 'Difficulties Conducting Qualitative Interview Research With People With Expressive Language' *Qualitative Health Research.* 16 pp. 1386-1404.

Lloyd-Williams, M., Friedman, T. & Rudd, N. (2001) 'An analysis of the validity of the Hospital Anxiety and Depression scale as a screening tool in patients with advanced metastatic cancer' *Journal of Pain and Symptom Management.* 22 (6) pp. 990-996.

Lloyd-Williams, M., Dennis, M. & Taylor, F. (2004) 'A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer' *Palliative Medicine.* 18 (6) pp. 558-563.

Lo Coco, G., Lo Coco, D., Cicero, V., Oliveri, A., Lo Verso, G., Piccoli, F. & La Bella, V. (2005) 'Individual and health-related quality of life assessment in amyotrophic lateral sclerosis patients and their caregivers' *Journal of the Neurological Sciences.* 238 (1-2) pp. 11-17.

Locock, L. & Brown, J. B. (2010) 'All in the same boat? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND)' *Social Science & Medicine.* 71 (8) pp. 1498-1505.

Logan, P., Ahern, J., Gladman, J. & Lincoln, N. (1997) 'A randomized controlled trial of enhanced Social Service occupational therapy for stroke patients' *Clinical rehabilitation.* 11 (2) pp. 107-113.

Logroscino, G., Traynor, B., Hardiman, O., Chio, A., Couratier, P., Mitchell, J., Swingler, R. & Beghi, E. (2008) 'Descriptive epidemiology of amyotrophic lateral sclerosis: new evidence and unsolved issues' *Journal of Neurology, Neurosurgery & Psychiatry.* 79 (1) pp. 6-11.

Lomen-Hoerth, C. (2004) 'Characterization of amyotrophic lateral sclerosis and fronto-temporal dementia' *Dementia and Geriatric Cognitive Disorders.* 17 (4) pp. 337-341.

Lomen-Hoerth, C., Anderson, T., & Miller, B. (2002) 'The overlap of amyotrophic lateral sclerosis and fronto-temporal dementia' *Neurology.* 59 (7) pp. 1077-1079.

Lomen-Hoerth, C., Murphy, J., Langmore, S., Kramer, J., Olney, R., & Miller, B. (2003) 'Are amyotrophic lateral sclerosis patients cognitively normal?' *Neurology. 60* (7) pp. 1094.

Lou, J.S., Reeves, A., Benice, T. and Sexton, G. (2003) 'Fatigue and Depression are associated with poor quality of life in ALS' *Neurology.* 60 pp. 1527-9.

Lou, J.S., Moore, D., Gordon, R.H., Miller, R. (2010) 'Correlates of quality of life in ALS: Lessons from the minocycline study' *Amyotrophic Lateral Sclerosis*. 11 (1-2) pp. 116-121.

Love, A., Street, A., Harris, R. and Lowe, R. (2005) 'Social aspects of caring for people living with motor neurone disease: their relationships to carer well-being' *Palliative and Supportive Care.* 3 pp. 33-38.

Lowe, G. (2006) 'Health-related effects of creative and expressive writing' *Health Education.* 106 (1) pp. 60 – 70.

Lyon, M. (2003) 'Riluzole for amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND)' *Amyotrophic Lateral Sclerosis.* 4 (3) pp. 191-206.

Madii, S.R. (2006) 'Hardiness: The courage to grow from stresses' *The Journal of Positive Psychology.* 1 (3) pp. 160-168.

Madill, A., Jordan, A. and Shirley, C. (2000) 'Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies' *British Journal of Psychology.* 91 (1) pp.1-20.

Malterud, K. (2001) 'Qualitative research: standards, challenges, and guidelines' *The Lancet.* 358, (9280) pp. 483 – 488.

Martin, J. & Turnbull, J. (2001) 'Lasting impact in families after death from ALS' *ALS and Other Motor Neuron Disorders.* 2 pp. 181-187.

Matthews, E. (2006) *Merleau-Ponty: A Guide for the perplexed.* London: Continuum.

Mays, N,. & Pope, C. (2000) 'Qualitative research in healthcare: assessing quality in qualitative research' *British Medical Journal*. 320 (7226) pp. 50-52.

Matuz T., Birbaumer, B., & Hautzinger M. (2010) 'Coping with amyotrophic lateral sclerosis*' J Neurol Neurosurg Psychiatry*. 81 pp. 893-8.

McCaffery, M. (1983). *Nursing the Patient in Pain.* London: Harper and Row.

McClain, C.S., Rosenfeld, B., Breitbart, W. (2003) 'Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients' *The Lancet.* 361 pp. 1603-1607.

McDonald, E. R., Wiedenfeld, S. A., Hillel, A., & Carpenter, C. L. (1994) 'Survival in amyotrophic lateral sclerosis: The role of psychological factors' *Archives of Neurology.* 51(1) pp. 17-23.

McDonald, E. R., Hillel, A. and Wiedenfeld, S. A. (1996) 'Evaluation of the psychological status of ventilatory-supported patients with ALS/MND' *Palliative Medicine.* 10 (1) pp. 35.

McIlfatrick, S. (2007) 'Assessing palliative care needs: views of patients, informal carers and healthcare professionals' *Journal of Advanced Nursing.* 57 (1) pp. 77-86.

McLeod, J. E. & Clarke, D. M. (2007) 'A review of psychosocial aspects of motor neurone disease' *Journal of the Neurological Sciences.* 258 (1-2) pp. 4-10.

McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007) 'Feeling like a burden: Exploring the perspectives of patients at the end of life' *Social Science & Medicine*. 64 (2) pp. 417 427.

Mead, G. (1934) *Mind, Self and Society.* Chicago: University of Chicago Press.

Meininger, V. (1999) 'Getting the diagnosis right: Beyond El Escorial' *Journal of Neurology.* 26 (3) pp. III10-III12.

Mehta, M., Whyte, E., Lenze, E., Hardy, S., Roumani, Y., Subashan, P., Huang, W., & Studenski, S. (2008) 'Depressive symptoms in late life: associations with apathy, resilience and disability vary between young-old and old-old' *International Journal of Geriatric Psychiatry.* 23 (3) pp. 238–243.

Merleau-Ponty, M. (1962) *The Phenomenology of Perception.* C. Smith Trans ed. London: Routledge & Kegan Paul.

Midtgaard, J., Stelter, R., Rorth, M. & Adamsen, L. (2007) 'Regaining a sense of agency and shared self-reliance: The experience of advanced disease cancer patients participating in a multidimensional exercise intervention while undergoing chemotherapy–analysis of patient diaries' *Scandinavian Journal of Psychology.* 48 (2) pp. 181-190.

Miles, M. B. and Huberman, A. (1994) *Qualitative data analysis: An expanded sourcebook.* Thousand Oaks, CA: Sage Publications.

Milligan, C., Bingley, A. and Gatrell, A. (2005) 'Digging deep: Using diary techniques to explore the place of health and well-being amongst older people' *Social Science & Medicine.* 61 (9) pp. 1882-1892.

Mitchell, J. (2000) 'Amyotrophic lateral sclerosis: toxins and environment' *Amyotrophic Lateral Sclerosis.* 1 (4) pp. 235-250.

Mitchell, J., & Borasio, G. (2007) 'Amyotrophic lateral sclerosis' *The Lancet.* 369 (9578) pp. 2031-2041.

Mitsumoto, H. and Bene, M. D. (2000) 'Improving the quality of life for people with ALS: the challenge ahead' *Amyotrophic Lateral Sclerosis.* 1 (5) pp. 329-336.

Hiroshi Mitsumoto, H; Bromberg, M; Johnston, W; Tandan, R; Byock, I; Lyon,M, et al. (2005) 'Promoting excellence in end-of-life care in ALS' *Amyotrophic Lateral Sclerosis.* 6 (3) pp. 145-154.

Mockford, C., Jenkinson, C. & Fitzpatrick, R. (2006) 'A review: carers, MND and service provision' *Amyotrophic Lateral Sclerosis.* 7 (3) pp. 132-141.

Mockford, C., Jenkinson, C. & Fitzpatrick, R. (2009) 'Development of the Motor Neurone Disease Carer Questionnaire' *Amyotrophic Lateral Sclerosis.* 10 pp. 463-469.

Moore, M. J., Moore, P. B. and Shaw, P. J. (1998) 'Mood disturbances in motor neurone disease' *Journal of the Neurological Sciences.* 160 pp. S53-S56.

Moorey, S., & Greer, S. (1989). *Psychological therapy for patients with cancer: A new approach* Arlington, VA: American Psychiatric Press.

Moos, R.H and Schaefer, J. A. (1996) 'Coping, stress resistance, and growth: Conceptualizing adaptive functioning' In: C. Holahan., C. Moos., H. Rudolf., J. Schaefer., A. Zeidner, S. Moshe., N.S. Endler., (Eds.) *Handbook of coping: Theory, research, applications.* Oxford, England: John Wiley & Sons. , (pp. 24-43).

Morris, SM. (2001) 'Joint and Individual interviewing in the context of cancer' *Qualitative Health Research.* 11 (4) pp. 553-567.

Morrison, V., Pollard, B., Johnston, M., & McWalter, R. (2005) 'Anxiety and depression 3 years following stroke: Demographic, clinical, and psychological predictors' *Journal of Psychosomatic Research.* 59 (4) pp. 209-213.

Morse, J., Barrett, M., Mayan, M., Olsen, K., & Spiers, J. (2002) 'Verification Strategies for Establishing Validity and Reliability in Qualitative Research' *International Journal of Qualitative Methods.* 1 (2) pp. 1-19.

Morse, J. (2002) 'Interviewing the ill' In: Gubrium, J.F., & Holstein, J.A., (eds.) *Handbook of Interview Research: context and method*. Thousand Oaks, CA: Sage Publication. pp. 317-28.

Murphy, PL., Albert, SM., Weber, CM., Del Bene, ML., Rowland, LP. (2000) 'Impact on spirituality and religiousness on outcomes in patients with ALS' *Neurology.* 55 (10) pp. 1581-4.

Murphy, V., Felgoise, S., Walsh, S. & Simmons, Z. (2009) 'Problem solving skills predict quality of life and psychological morbidity in ALS caregivers' *Amyotrophic Lateral Sclerosis.* 10 pp. 147-153.

Nadin, S. & Cassell, C. (2006) 'The use of a research diary as a tool for reflexive practice. Some reflections from management research' *Qualitative Research in Accounting and Management.* 3 (3) pp. 208-217.

Neary, D., Snowden, J., & Mann, D. (2000). 'Cognitive change in motor neurone disease/amyotrophic lateral sclerosis (MND/ALS)' *Journal of the Neurological Sciences.* 180 (1-2) pp. 15-20.

Nelson, N. D., Trail, M., Van, J. N., Appel, S. H. and Lai, E. C. (2003) 'Quality of life in patients with Amyotrophic Lateral Sclerosis: perceptions, coping resources and illness characteristics' *Journal of Palliative Medicine.* 6 (3). pp 417-424.

Neudert, C., Wasner, M. and Borasio, G. (2004) 'Individual quality of life is not correlated with health-related quality of life or physical function in patients with amyotrophic lateral sclerosis' *Journal of Palliative Medicine.* 7 pp. 551-557.

Norquist, J. M., Fitzpatrick, R. and Jenkinson, C. (2004) 'Health-related quality of life in amyotrophic lateral sclerosis: determining a meaningful deterioration' *Quality of Life Research.* 13 (8) pp. 1409-1414.

Nygren, I. & Askmark, H. (2006) 'Self-reported Quality of Life in Amyotrophic Lateral Sclerosis' *Journal of Palliative Medicine.* 9 (2) pp. 304-307.

O'Brien, M. (2004) 'Healthcare professionals' knowledge of motor neurone disease' *British Journal of Neuroscience Nursing.* 13 (18) pp. 1080-1084.

O'Brien, M. R., Whitehead, B., Jack, B. A., & Mitchell, J. D. (2011) 'From symptom onset to a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND): Experiences of people with ALS/MND and family carers: a qualitative study' *Amyotrophic Lateral Sclerosis.* pp. 1-8.

Pakenham, K.I., Dadds, R.M., Terry, D.J. (1994) 'The relationships between adjustment to HIV and both social support and coping strategies' *Journal of Consulting and Clinical Psychology.* 62 pp. 1194-1203.

Pakenham, K. I. (1998) 'Coping and adjustment to Multiple Sclerosis in Care Receiver-Carer Dyads' *Family Relations*. 47 (3) pp. 269-276.

Park, C.L. (2007) 'Religiousness/spirituality and health: A meaning systems perspective' *Journal of Behavioral Medicine.* 30 (4) pp. 319-328.

Parkes, C. (2006) 'Guidelines for conducting ethical research in psychosocial issues in palliative care' *Indian Journal of Palliative Care.* 12 (1) pp. 17-21.

Pennebaker, J. W. (1997a) *Opening Up: The Healing Power of Expressing Emotion*. New York: Guilford.

Pennebaker, J. W. (1997b) 'Writing about Emotional Experiences as a Therapeutic Process' *Psychological Science.* 8 pp. 162–66.

Peveler, R., Carson, A., & Rodin, G. (2002) 'Depression in medical patients' *BMJ. 325* (7356) pp. 149.

Plahuta, J. M., McCulloch, B. J., Kasarskis, E. J., Ross, M. A., Walter, R. A. & McDonald, E. R. (2002) 'Amyotrophic lateral sclerosis and hopelessness: psychosocial factors' *Social Science & Medicine.* 55 (12) pp. 2131-2140.

Plugge, H. (1967) *Der Mensch und sein Leib.* Tubingen: Max Neimeyer.

Polit, D. F. (2009) *Data analysis & statistics for nursing research.* New York: Prentice Hall.

Pope, C. & Mays, N. (1995) 'Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research' *BMJ: British Medical Journal.* 311 (6996) 42.pp 42-45.

Quill, T. (2005) 'ALS, depression, and desire for hastened death: (how) are they related' *Neurology.* 65 (1) pp. 119-127.

Rabkin, J. G., Wagner, G. J., & Del Bene, M. (2000) 'Resilience and distress among amyotrophic lateral sclerosis patients and caregivers' *Psychosomatic Medicine.* 62 (2) pp. 271-279.

Rabkin, J., Albert, S., Del Bene, M., O'Sullivan, I., Tider, T., Rowland, L., et al. (2005) 'Prevalence of depressive disorders and change over time in late-stage ALS' *Neurology.* 65 (1) pp. 62-67

Rabkin, J. G., Albert, S. M., Rowland, L. P. & Mitsumoto, H. (2009) 'How common is depression among ALS caregivers? A longitudinal study' *Amyotrophic Lateral Sclerosis.* 10 (5-6) pp. 448-455.

Rancour, P. & Brauer, K. (2003) 'Use of letter writing as a means of integrating an altered body image: A case study' *Oncology Nursing Forum*. 30 (5) pp. 841-846.

Ray R.A & Street A.F. (2005) 'Who's there and who cares: age as an indicator of social support networks for caregivers among people living with motor neurone disease' *Health and Social Care in the Community*. 13 pp. 542-552.

Ray, R. A. & Street, A. F. (2007) 'Non-finite loss and emotional labour: family caregivers' experiences of living with motor neurone disease' *Journal of Clinical Nursing.* 16 (3a) pp. 35-43.

Ray, R. A. and Street, A. F. (2006) 'Caregiver bodywork: family members' experiences of caring for a person with motor neurone disease' *Journal of Advanced Nursing.* 56 (1) pp. 35-43.

Reed, P.G. (1991) 'Self-transcendence and mental health in oldest-old adults' *Nursing Research*. 40 (1) pp. 5-11

Reed, P.G. (2003) 'The theory of self-transcendence' In: Smith, M.J., & Liehr, P.R., (eds.) *Middle Range Theory for Nursing*. New York: Springer Publishing Company. pp.145-165.

Reid, K., Flowers, P. & Larkin, M. (2005) 'Exploring lived experience' *The Psychologist.* 18 (1) pp. 20–23.

Revenson, T. A. (2003) 'Scenes from a Marriage: Examining Support, Coping, and Gender Within the Context of Chronic Illness' In: Suls, J., & Wallston, K.A., (eds.) *Social Psychological Foundations of Health and Illness*. London: Wiley- Blackwell. pp. 530–559.

Reynolds, F. and Prior, S. (2003) 'Sticking Jewels in Your Life: Exploring Women's Strategies for Negotiating an Acceptable Quality of Life with Multiple Sclerosis' *Qualitative Health Research.* 13 (9) pp. 1225.

Ricoeur, P. (1970). *Freud and Philosophy. An Essay on Interpretation.* New Haven, CT: Yale University Press.

Ricoeur, P. (1984). *Time and Narrative, Vol 1.* [trans K. McLaughlin and D. Pellauer]. Chicago, IL: University of Chicago Press.

Ricoeur, P. (1985). *Time and Narrative, Vol 2.* [trans K. McLaughlin and D. Pellauer]. Chicago, IL: University of Chicago Press.

Ricoeur, P. (1988). *Time and Narrative, Vol, 4.* . [trans K. McLaughlin and D. Pellauer]. Chicago, IL: University of Chicago Press.

Rigby, S., Thornton, E., Tedman, S., Burchardt, F., Young, C. & Dougan, C. (1999) 'Quality of life assessment in MND: development of a social withdrawal scale' *Journal of the Neurological Sciences.* 169 (1-2) pp. 26-34.

Rio, A., Ellis, C., Shaw, C., Willey, E., Ampong, M., Wijesekera, L., Rittman, T., Leigh, P. N., Sidhu, P. S. & Al-Chalabi, A. (2010) 'Nutritional factors associated with survival following enteral tube feeding in patients with motor neurone disease' *Journal of Human Nutrition & Dietetics.* 23 (4) pp. 408-415.

Riviere, M., Meininger, V., Zeisser, P. & Munsat, T. (1998) 'An analysis of extended survival in patients with amyotrophic lateral sclerosis treated with riluzole' *Archives of Neurology.* 55 (4) pp. 526-528.

Roach, A.R., Averill, A.J., Segerstrom, S.C., Kasarski, E.J. (2009) 'The Dynamics of Quality of Life in ALS Patients and Caregivers' *Annals of Behavioral Medicine.* 37 pp. 197-206.

Robbins, R., Simmons, Z., Bremer, B., Walsh, S. and Fischer, S. (2001) 'Quality of life in ALS is maintained as physical function declines' *Neurology.* 56 (4) pp. 442.

Robinson, I. & Hunter, M. (1998) *Motor Neurone Disease.* Abingdon: Routledge.

Robinson, L., Clare, L., Evans, K. (2005) 'Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples' *Aging & Mental Health.* 9 (4) pp. 337-347.

Robson, C. (2002) *Real world research: A resource for social scientists and practitioner-researchers.* London: Wiley-Blackwell.

Rowland, J. H., & Baker, F. (2005) 'Introduction: Resilience of cancer survivors across the lifespan' *Cancer.* 104 (S11) pp. 2543-2548.

Sabat, S. R. (2002) 'Surviving Manifestations of Selfhood in Alzheimer's Disease' *Dementia.* 1 (1) pp. 25.

Sabat, S. R. & Collins, M. (1999) 'Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease' *American Journal of Alzheimer's Disease and Other Dementias.* 14 (1) pp. 11.

Sabat, S. R., Napolitano, L. & Fath, H. (2004) 'Barriers to the construction of a valued social identity: A case study of Alzheimer's disease' *American Journal of Alzheimer's Disease and Other Dementias.* 19 (3) pp. 177.

Sabat, S. R. & Harré, R. (1992) 'The construction and deconstruction of self in Alzheimer's disease' *Ageing and Society.* 12 (4) pp. 443-461.

Sandelowski, M. (1995) 'Sample size in qualitative research' *Research in Nursing and Health.* 18 pp. 179-183.

Sarbin, T. (1986). *Narrative Psychology: The storied nature of Human conduct*. New York: Praeger.

Sartre, J. (1978) *Existentialism and Humanism.* London: Methuen.

Satayana, G. cited in I.D. Yalom. (1980). *Existential Psychotherapy*. New York: Basic Books.

Schleiermacher, F. (1998). 'Hermeneutics and Criticism and Other Writings'. Cambridge: Cambridge University Press.

Scottish Government. Living and dying well: a national action plan for palliative and end-of-life in Scotland. Scottish Government, 2008. www.scotland.gov.uk/Publications/2008/10/01091608/0. [accessed 14 March 2009].

Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J. & Smith, P. (2005) 'Ethical and methodological issues in palliative care studies' *Journal of Research in Nursing.* 10 (2) pp. 169-188.

Seymour, J. & Ingleton, C. (1999) 'Ethical issues in qualitative research at the end of life' *International Journal of Palliative Nursing.* 5 pp. 65-73.

Shaw, P. J. (1999) 'Motor Neurone Disease' *BMJ.* 318 (7191) pp.1118.

Shaw, P. (2005) 'Molecular and cellular pathways of neuro-degeneration in motor neurone disease' *Journal of Neurology, Neurosurgery & Psychiatry.* 76 (8) pp. 1046.

Shotter, J. (1984) *Social accountability & Selfhood.* Blackwell: Oxford.

Shotter, J. (1995) 'In conversation: joint action, shared intentionality, and ethics' *Psychology and Theory*. 5 pp. 49- 73.

Shotton, L., Simpson, J., & Smith, M. (2007) 'The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: A qualitative investigation' *Brain Injury.* 21(8) pp. 857-869.

Simmons, Z., Bremer, B. & Robbins, R. (2000) 'Quality of life in ALS depends on factors other than strength and physical functions' *Neurology.* 55 (3) pp. 388-392.

Simmons, Z., Felgoise, S., Bremer, B., Walsh, S., Hufford, D., Bromberg, M., David, W., Forshew, D., Heiman-Patterson, T. & Lai, E. (2006) 'The ALSSQOL: balancing physical and nonphysical factors in assessing quality of life in ALS' *Neurology.* 67 (9) pp.1659.

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008) 'The brief resilience scale: Assessing the ability to bounce back' *International Journal of Behavioral Medicine.* 15(3) pp. 194-200.

Smith, J. A & Osborn, M. (2008) 'Interpretative Phenomenological Analysis' In: J. Smith (ed.) *Qualitative Psychology: A Practical Guide to Research Methods*. 2nd Edition. Thousand Oaks, CA: Sage Publications. pp. 53-80.

Smith, J.A & Osborn, M. (2007) 'Pain as an assault on the self: an interpretative phenomenological analysis of the psychological impact of chronic benign low back pain' *Psychology and Health.* 22 (5) pp. 517-34.

Smith, J. A. (2004) 'Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology' *Qualitative Research in Psychology.* 1 (1) pp. 39-54.

Smith, J. A. (1996a) 'Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology' *Psychology & Health.* 11 (2) pp. 261-271.

Smith, J.A. (1996b) 'Evolving Issues for Qualitative Psychology' In: J. Richardson (ed.) *Handbook of Qualitative Research Methods.* Leicester: BPS. pp. 189-202.

Smith, J. A., Harrè, R. & Van Langenhove, and L. (1995) Idiography and the case study In: Smith, J., Harre, R., & Van Langenhove, L., (eds.) *Rethinking Psychology.* Thousand Oaks, CA*:* Sage. pp. 59–69.

Smith, J.A. (1999) 'Towards a relational self: social engagement during pregnancy and psychological preparation for motherhood' *British Journal of Social Psychology*. 38 pp. 409-26.

Smith, P. J. A., Flowers, D. P,. &Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research.* Thousand Oaks, CA*:* Sage Publications.

Smith, J. (2011) 'Evaluating the contribution of Interpretative Phenomenological Analysis' *Health Psychology Review*. 5 (1) pp. 9-27

Sreedharan, J., Blair, I. P., Tripathi, V. B., Hu, X., Vance, C., Rogelj, B., et al. (2008) 'TDP-43 mutations in familial and sporadic amyotrophic lateral sclerosis' *Science.* 319 (5870) pp. 1668.

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Lindquist, J. H. and Tulsky, J. A. (2006) 'Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research' *Palliative Medicine.* 20 (8) pp. 745-754

Sturgeon, J. A., & Zautra, A. J. (2010) 'Resilience: A new paradigm for adaptation to chronic pain' *Current Pain and Headache Reports.* 14 (2) pp. 105-112.

Strauss, A.L., & Glaser, B.G. (1970) *Anguish*. Mill Valley, CA: Sage Publications.

Strauss, A.C., & Glaser, B.G. (eds). (1975) *Chronic Illness and the Quality of Life*. St. Louis, MO: C. V. Mosby.

Sullivan AD, Hedberg, K., Hopkins, D. (2001) 'Legalized physician-assisted suicide in Oregon, 1998-2000*' N Engl J Med.* 344 pp. 605-607.

Sutedja, N. A., Veldink, J. H., Fischer, K., Kromhout, H., Heederik, D., Huisman, M. H. B., et al. (2009). 'Exposure to chemicals and metals and risk of amyotrophic lateral sclerosis: A systematic review' *Amyotrophic Lateral Sclerosis.* 10 (5) pp. 302-309.

Swash, M. (1997) 'Health outcome and quality of life measurements in amyotrophic lateral sclerosis' *Journal of Neurology.* 244 pp. S26-S29.

Talbot, K. (2004) 'Motor Neuron Disease' *Medicine.* 32 (11) pp. 105-107.

Talbot, K., & Marsden, R. (2008) *Motor Neuron Disease.* Oxford University Press, USA.

Taylor, M. C. (2005) 'Interviewing' In. Holloway, I. (ed.) *Qualitative Research in Health care.* Berkshire, UK: Open University Press. pp. 39-55.

Taylor, S., & Bogdan, R. (1984) *Introduction to Qualitative Research Methods: the search for meanings.* 2nd Edition. New York: John Wiley.

Tedman, B., Young, C. and Williams, I. (1997) 'Assessment of depression in patients with motor neuron disease and other neurologically disabling illness' *Journal of the Neurological Sciences.* 152 pp. s75-s79.

Terry, W., Olson, L.G., Ravenscroft, P., Wilss, L., Boulton–Lewis, G. (2006) 'Hospice patients' views on research in palliative care' *Internal Medicine Journal*. 36 (7) pp. 406-413.

Thekkumpurath, P., Venkateswaran, C., Kumar, M., & Bennett, M. I. (2008) 'Screening for psychological distress in palliative care: a systematic review' *Journal of pain and symptom management.* 36 (5) pp.520-528.

Thomas, S. A., & Lincoln, N. B. (2006) 'Factors relating to depression after stroke' *British Journal of Clinical Psychology. 45*(1) pp. 49-61.

Thomas. S.P (2005) 'Through the lens of Merleau-Ponty: advancing the phenomenological approach to nursing research' *Nursing Philosophy.* 6 pp. 63–76.

Toombs, S.K (1992) 'The body in Multiple Sclerosis: a patient's perspective' In: Leder, D., (ed.) *The body in medical thought and practice.* Dordrecht: Kluwer Academic Publishers. pp.127–139.

Toombs, S.K. (2002) 'Healing and incurable illness' In: Fulford, K.W.M., Dickenson, D.L., Murray, T.H., (eds.) *Healthcare ethics and human values: an introductory text with readings and case studies.* London: Blackwell Publishers Ltd. 125-140.

Toombs, S. K. (2004) 'Living and dying with dignity: reflections on lived experience' *Journal of Palliative Care.* 20 (3) pp. 193-200.

Trail, M., Nelson, N. D., Van, J. N., Appel, S. H. & Lai, E. C. (2003) 'A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options' *Journal of the Neurological Sciences.* 209 (1-2) pp. 79-85.

Trail, M., Nelson, N.D., Van, JN., Appel, S.H., Lai, E.C. (2004) 'Major Stressors facing patients with amyotrophic lateral sclerosis (ALS): a survey to identify their concerns and to compare those of their caregivers' *ALS and other Motor Neuron Disorders.* 5 pp. 40-45.

Tuckett, A. (2005) 'Applying thematic analysis theory to practice: a researcher's experience' *Contemporary Nurse.* 19 (1/2) pp. 75.

Turner, A., Barlow, J. & Ilbery, B. (2002) 'Play hurt, live hurt. Living with and managing osteoarthritus from the perspective of ex-professional footballers' *Journal of Health Psychology.* 7 pp. 285-301.

Twigg, J. (2000) 'Carework as a form of bodywork' *Ageing and Society*. 20 pp. 389-411.

Uchino, B.N. (2006) 'Social support and health: a review of physiological processes potentially underlying links to disease outcomes' *Journal of Behavioral Medicine.* 29 (4) pp. 377-387.

Usher, K. J., & Arthur, D. (1998) 'Process consent: a model for enhancing informed consent in mental health nursing' *Journal of Advanced Nursing.* 27 (4) pp. 692-697.

Välimäki, T., Vehviläinen-Julkunen, K. & Pietilä, A. M. (2007) 'Diaries as research data in a study on family caregivers of people with Alzheimer's disease: methodological issues' *Journal of Advanced Nursing.* 59 (1) pp. 68-76.

Van Langenhove, L. (1995) 'The Theoretical Foundations of Experimental Psychology and its Alternatives' In: Smith, J., Harre, R., & Van Langenhove, L., (eds.) *Rethinking Psychology.* London: Sage. pp. 10-23.

Van Manen, M. (1997) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.* 2nd Edition. London, Ontario: Althouse Press.

Van Tejilingen, Freind, E. and Kamal, A. (2001) 'Service use and the needs of people with motor neurone disease and their carers in Scotland' *Health and Social Care in the Community.* 9 (6) pp. 397-403.

Von Eckartsberg, R. (1986) *Life-world experience: Existential-phenomenological research approaches in psychology.* Center for Advanced Research in Phenomenology, Washington, D.C: University Press of America.

Ward, C., Phillips, M., Smith, A. & Moran, M. (2003) 'Multidisciplinary approaches in progressive neurological disease: can we do better?' *British Medical Journal.* 74 (4) pp.8-12.

Warnock, M. (1970) *Existentialism.* Oxford: Oxford University Press.

Warnock, M. (1987) *Memory.* London: Faber.

Watson, M., Homewood, J., Haviland, J., & Bliss, J.M. (2005) 'Influence of psychological response on breast cancer survival: 10-year follow-up of a population-based cohort' *European Journal of Cancer.*41 (12) pp. 1710-1714.

Wenger, GC. (2002) 'Interviewing older people' In: Gubrium, J.F. & Holstein, J.A. Holstein (eds.) *Handbook of Interview Research: context and method*. Thousand Oaks, CA: Sage Publication. pp. 269-78.

White, C & Hardy, J. (2010) 'What do palliative care patients and their relatives think about research in palliative care?—a systematic review' *Supportive Care in Cancer.* 18 (8) pp. 905-911

Whitehead, L. (2004) 'Enhancing the quality of hermeneutic research: decision trail. Methodological Issues in Nursing Research' *Journal of Advanced Nursing.* 45 (5) pp. 512-518.

Wicks, P., Abrahams, S., Masi, D., Hejda-Forde, S., Leigh, P. and Goldstein, L. (2007) 'Prevalence of depression in a 12-month consecutive sample of patients with ALS' *European Journal of Neurology.* 14 (9) pp.993-1001.

Williams, M., Tederous, Donnelly, J., P, Holmlund, T. & Battaglia, M. (2008) 'ALS: Family caregiver needs and quality of life' *Amyotrophic Lateral Sclerosis.* 9 pp. 279-286.

Willig, C. (2001) *Introducing qualitative research in psychology.* Buckingham: Open University Press

Wilson, K. G., Curran, D. & McPherson, C. J. (2005) 'A burden to others: a common source of distress for the terminally ill' *Cognitive Behaviour Therapy.* 34 (2) pp. 115-123.

Woolley, J., & Ringel, S. (1997) Caregiver quality of life in ALS: Relationship between patient health status and caregiver health-related quality of life, role satisfaction and workforce participation. Paper presented at the *Proceedings of the Eighth International Symposium on Amyotrophic Lateral Sclerosis and Motor Neuron Disease,* 3–5.

Worthington, A. (1996) 'Psychological aspects of motor neurone disease: a review' *Clinical Rehabilitation.* 10 (3) pp.185.

Wyer, S., Earll, L., Joseph, S. & Harrison, J. (2001) 'Deciding whether to attend a cardiac rehabilitation programme: An interpretative phenomenological analysis' *Coronary Health Care.* 5 pp.178-188.

Wright, J. & Cheung Chung, M. (2001) 'Mastery or Mystery? Therapeutic writing: a review of the literature' *British Journal of Guidance and Counselling.* 29 pp. 277-91.

Yardley, L. (2000) 'Dilemmas in qualitative health research' *Psychology and Health.* 15 (2) pp. 215-228.

Yardley, L. (2008) Demonstrating Validity in Qualitative Psychology. In: Smith, J. (eds.) *Qualitative Psychology: A Practical Guide to Research Methods*. 2nd Edition. Thousand Oaks, CA: Sage Publications. pp. 235-251.

Yin, R. K. (2009) *Case study research: Design and methods*. Thousand Oaks, CA: Sage Publications.

Young, J.M. & McNicoll, P. (1998) 'Against All Odds: Positive Life Experiences of People with Advanced Amyotrophic Lateral Sclerosis' *Health and Social Work.* 23 (1) pp.35-43.

Loss and transcendence in couples living with MND: An Interpretative Phenomenological Analysis

Bridget Mary Ann Hanley

Degree of PhD

Edge Hill University

August 2012

Appendices

Contents Page - Appendices

Appendix 1 – Table showing demographic information of the couples participating in this study

ID	Gender	Age at Diagnosis	Disease duration (at interview)	MND type	Carer ID	Type of Interview
27	F	67	92 months	ALS Bulbar	201	Joint interview
94	M	58	6 months	ALS Limb	205	Joint interview
45	M	74	8 months	ALS Limb	202	Separate Interview
73	M	58	16 months	ALS Limb	204	Separate Interview
83	F	74	18 months	ALS Bulbar	203	Separate Interview
54	F	58	41 months	ALS Limb	207	Joint Interview
46	F	56	11 months	PLS	218	Separate Interview
6	M	79	11 months	ALS Limb	208	Joint Interview
9	M	56	11 months	ALS Limb	210	Joint Interview
86	M	52	33 months	ALS Limb	212	Joint Interview
19	F	72	18 months	PLS	213	Joint Interview
20	M	51	30 months	ALS Limb	214	Joint Interview

Key: Amyotrophic Lateral Sclerosis – limb onset/ Amyotrophic Lateral Sclerosis –bulbar onset/ Primary Lateral Sclerosis (upper motor neurones only)

Appendix 2 - Information Sheet

Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Edge Hill University

Participant Information Sheet.

Optimisation of Services for the Care of People with Motor Neurone Disease.

We would like to invite you to take part in a research study. Our study aims to assess the extent to which the changing needs of people with MND are being met by health, social and palliative care services, based on their personal experiences and perceptions, and those of their carers.
Before you decide it is important for you to understand why the study is being done and what it will involve. Please take the time to read this information carefully and talk to others about the study if you wish. Take time to decide whether or not you wish to take part.

Do I have to take part?

It is up to you to decide if you wish to take part. If you decide to take part, we will ask you to sign a consent form. However, you are free to withdraw from the study at any time, without having to give a reason. If you decide to withdraw from the study at a later date any information about you or provided by you will not be included in the study if you do not wish it to be. The standard of care that you receive will not be affected whether you do or do not decide to take part.

Why have I been invited to take part?

You have been invited to take part in this study because you have either been diagnosed with MND, or you are or have been a carer of someone diagnosed with MND.

What will happen to me if I agree to take part?

We are seeking to collect the personal stories of people affected by MND, to evaluate the quality of services provided and identify what is important for people with MND based on their own experiences. A member of the research team will interview you in a location that you feel comfortable with. In similar studies previously, interviews have taken place in the interviewees' home as this involves less disruption for study participants. The interview will last for approximately one hour and will be tape recorded if you agree.

While interviews can give us a very good picture of what has already happened, we would also like to find out how services respond to your needs in the future. A recognised way of documenting this is through keeping a diary. Therefore we would also like to ask you to keep a personal diary of your experiences, in whichever format you prefer. These could include:

Written
E-mail
Telephone
Tape recorded

Personal contact with the research team
We will ask that you complete a monthly review of your experiences, up to a maximum of twelve months. However, you do not have to keep a diary if you do not want to, you can take part in the interview only if you wish. If you would like to continue to share your experiences with us after the interview but do not wish to keep a diary, we will offer further loosely structured interviews on a 3 monthly basis for a period of up to twelve months, to record your on-going experiences. How and if you choose to participate in the study is up to you. You will receive guidance on what to include in your entries.

We are aware that keeping a diary may be difficult and that you may not wish to continue with it, please remember that you are free to withdraw from the study at any time.
We understand that by taking part in the study there could be times when you may require additional emotional and psychological support. Should this be required, we will make arrangements for this through the [(name of hospital) MND Care Centre.

What will happen after the study is finished?

We cannot promise that the study will benefit you personally, but from the information you provide you can help to ensure that the voices of people affected by MND are heard, allowing your experiences to help shape services in the future.

Will my taking part in this study be kept confidential?

Only members of this research study team will have access to your information. Once the interviews have been transcribed the tapes will be destroyed. All data will be kept in a locked cabinet within a locked room. We will endeavour to maintain confidentiality regarding any information which you give us, by anonymising the transcripts and diary entries. In reports and publications emerging from the study, no identifying features will be used. We do acknowledge that as the study will involve a relatively small number of participants, that there is a remote possibility despite these measures that some individuals might be recognised from their comments. You will be given the opportunity to remove any of your comments which you do not wish to be included.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by a Local Research Ethics Committee.

If you have any questions or would like further information please contact:

Mary O'Brien
Senior Lecturer,
Evidence-based
Practice Research Centre,
Faculty of Health,
Edge Hill University,
Ormskirk,
L39 4QP
Tel: 01695 650918
E mail: Obrienm@edgehill.ac.uk

Bridget Whitehead
Research Assistant,
Evidence-based
Practice Research Centre,
Faculty of Health,
Edge Hill University,
Ormskirk
L39 4QP
07826890667
bridget.whitehead@edgehill.ac.uk

Appendix 3 – Consent Form

Edge Hill University

Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Consent Form

Optimisation Of Services For The Care Of People With Motor Neurone Disease.

Please initial box

I confirm that I have read and understand the information sheet version 1 dated 27.07.07 for the above study. I have had the opportunity to consider the information, ask questions, and am satisfied that I have had all the information that I require.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that relevant sections of my medical or nursing notes may be looked at by members of the research team, where it is relevant to my taking part in the study. I give my permission for these individuals to have access to my records for this purpose.	☐
I agree to take part in the above study	☐

Participant Name	Date	Signature

Person taking consent	Date	Signature

1 copy for study file/1 copy for participant

Appendix 4-Ethical Approval

North Manchester Research Ethics Committee
Room 181
1st Floor
Gateway House
Piccadilly South
Manchester
M60 7LP

Telephone: 0161 237 2166
Facsimile: 0161 237 2383

05 September 2007

Professor John Douglas Mitchell
Associate Medical Director (R&D) and Consultant Neurologist
Lancashire Teaching Hospitals NHS Foundation Trust
Sharoe Green lane
Preston
PR2 9HT

Dear Professor Mitchell

Full title of study:	**Optimisation of services for the care of people with Motor Neurone Disease (MND) based on an understanding of personal experience of MND in Lancashire and South Cumbria**
REC reference number:	**07/H1006/71**

The Research Ethics Committee reviewed the above application at the meeting held on 30 August 2007.

Discussion:

The Committee felt this was a straightforward, well written application.

The Committee noted that there was no real hypothesis for the study and liked the open ended research method.

The Committee were pleased to see that the researcher had recognised that the participants' involvement in the study could be relatively difficult due to the nature of the disease. It was noted that numerous measures such as email, phone and semi structured interviews would be employed to ensure the participant could take part easily.

The Committee were impressed that there was ongoing consent for the participants as, due to the nature of the disease; participants may withdraw from the study at various times.

The Committee were pleased that 3 research members would be employed, which would reduce any potential interview bias.

The Committee liked the fact that there was input from carers on the steering committee.

The Committee felt that the researcher was sensitive to the needs of the participants.

The Committee noted that counselling support services were in place for the participants, however did feel that this should be added to the PIS along with contact details.

The Committee were pleased that the participants would be shown their interview transcripts

and could amend or remove any of the details if they were unhappy with what had been recorded.

The Committee queried whether a lone worker policy was in place.

The Committee would like the PIS to clearly state that the interviews would be recorded.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation. The Committee however would like to be reassured that a lone worker policy is in place and the counselling details and a sentence stating that the interviews will be taped are added to the PIS.

The Committee were impressed with the standard of the PIS and would like to ask the researcher whether a suitably anonymised version could be used for training purposes.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application	5.4	31 July 2007
Investigator CV	John Douglas Mitchell	18 April 2007
Protocol	3	27 July 2007
Covering Letter	Professor J D Mitchell	30 July 2007
Participant Information Sheet	1	27 July 2007
Participant Consent Form	1	27 July 2007
Email from Funder		28 March 2007

Research governance approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final research governance approval from the R&D office before commencing any research procedures.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/H1006/71	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Ken Cook
Vice-Chair

Email: stephen.tebbutt@northwest.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting

Standard approval conditions

Copy to: Mr John Wardle
Research Directorate
Royal Preston Hospital
Sharoe Green Lane
Preston PR2 9HT

North Manchester Research Ethics Committee

Attendance at Committee meeting on 30 August 2007

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Osman Abdelatti	Consultant Anaesthetist	Yes	
Mr Ken Cook	Clinical Services Manager	Yes	
Dr Valerie Edwards-Jones	Biomedical Scientist/Reader in Microbiology	Yes	
Mrs Heather Evans	Chartered Counselling Psychologist (Lay Member)	No	
Mrs Debbie Hamburger	Social Worker (Lay Member)	Yes	
Mrs Sally Hatfield	Barrister (Lay Member)	No	
Ms Philippa Jones	Pharmacist	Yes	
Rev Dr Clare McBeath	Baptist Minister / Chaplain	Yes	
Mr Rama Mohan	Consultant Orthopaedic Surgeon	Yes	
Mrs Sarah Rhodes	Medical Statistician	No	
Mrs Gillian Rimington	Paralegal (Lay Member)	No	
Dr Narveshwar Sinha	Staff Grade Ear Nose & Throat Surgeon	Yes	
Dr Andrew Ustianowski	Consultant in Infectious Diseases and Tropical Medicine	No	
Ms Julie Wray	Lecturer (Nursing) / Research Fellow	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Stephen Tebbutt	Co-ordinator

North Manchester Research Ethics Committee

Room 181
1st Floor
Gateway House
Piccadilly South
Manchester
M60 7LP

Tel: 0161 237 2166
Fax: 0161 237 2383

05 October 2007

Professor John Douglas Mitchell
Director, Preston MND Care & Research Centre
and Consultant Neurologist
Department of Neurology
Royal Preston Hospital
Sharoe Green lane
Preston PR2 9HT

Dear Professor Mitchell

Study title:	**Optimisation of services for the care of people with Motor Neurone Disease (MND) based on an understanding of personal experience of MND in Lancashire and South Cumbria**
REC reference:	**07/H1006/71**

Thank you for your letter of 19 September 2007, responding to the Committee's comments in their letter dated 05 September 2007.

The further information has been considered by the Vice-Chair and I am pleased to re-confirm the favourable ethical opinion given for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Documents received

The documents received were as follows:

Document	Version	Date
Lone Worker Policy	1	02 November 2007
Notification of a Minor Amendment		14 September 2007

Conditions of approval

The favourable opinion is given provided you comply with the standard approval conditions document sent with the favourable opinion letter dated 05 September.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for

Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/H1006/71	Please quote this number on all correspondence

Yours sincerely

Stephen Tebbutt
Committee Co-ordinator

E-mail: stephen.tebbutt@manchester.nhs.uk

Copy to: Mr John Wardle
Research Directorate
Royal Preston Hospital
Sharoe Green Lane
Preston PR2 9HT

Appendix 5-R&D Approval

Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Royal Preston Hospital
Sharoe Green Lane
Fulwood
Preston PR2 9HT

Tel 01772 522031
Fax: 01772 523184
Email: Lin.Nelson@lthtr.nhs.uk

RESEARCH AND DEVELOPMENT DIRECTORATE
Director of Research: Professor J D Mitchell, R&D Manager: Lin Nelson
PA to Prof Mitchell: Debi Fowler
Research Support Assistant: Rasi Gunasekara

Our Ref: JDM/LN

Thursday, 04 June 2009

Professor JD Mitchell
Royal Preston Hospital
Sharoe Green Lane
Preston
PR2 9HT

Dear Professor Mitchell,

R&D Ref: 1102 **MREC Ref: 07/H1006/71**
Optimisation of Services for the care of people with Motor Neurone Disease (MND) based on an understanding of personal experience of MND in Lancashire and South Cumbria.

The amendment to the above project has been reviewed by the Research Directorate at Lancashire Teaching Hospitals NHS Foundation Trust and I am pleased to inform you that no objections were raised and the amendment was approved and the study may continue as outlined in the protocol.

The following documents were received and reviewed.

- **Substantial Amendment Form 1. 2008**
- **Participant Information Sheet V1 03/04/09**
- **Consent form V1 03/04/09**
- **Study Protocol V4 13/05/09**

Please ensure that you continue to abide by the principles of the Research Governance Framework and inform the research directorate of the studies progress and any future amendments.

Yours sincerely

Mrs Lin Nelson
Research and Development Manager
cc.

Appendix 6 -Diary Instructions

Instructions for writing diaries

This diary is for you to record your experiences of living with Motor Neurone Disease. We would like you to complete this diary once every week if possible for a period of up to 12 months. You can write as little or as much as you like. You are not under any obligation to write this diary and please feel free to stop at any time if you wish.
You can decide the way you would most like to record this diary; you can either write it by hand in a journal, on a computer or by speaking into a dictaphone.

We are not concerned with how good your handwriting, grammar or spelling is. The most important thing is to describe what your life is like and how you think and feel about it.
These are examples of what might feature in your diary:

- Your physical symptoms and how they affect your daily life.
- Your emotional mood and feelings.
- The people involved in your care (carers, health professionals, social services) e.g. specialist nurse.
- Equipment and adaptations e.g. wheelchairs.
- Medication and medical interventions e.g. PEG.
- Your friends and family.

Please remember that this is a guide. We would like you to comment on anything you think will help us to understand what it is like to live with Motor Neurone Disease.
If you have any questions or would like further information please contact:

Mary O'Brien
Senior Lecturer,
Evidence-based
Practice Research Centre,
Faculty of Health, Edge Hill University,
Ormskirk,
L39 4QP PR2 9HT
Tel: 01695 650918
E mail: Obrienm@edgehill.ac.uk

Bridget Whitehead
Research Assistant
Research Directorate,
Preston Royal Hospital,
Sharoe Green Lane,
Preston

Tel: 07826890667
bridget.whitehead@edgehill.ac.uk

Appendix 7- Interview Schedule

Part A – narrative

'I am interested in learning about how you are living and coping with MND. Please begin where you like. I will listen first, I won't interrupt you. I'll take some notes so that in case I have any questions, I can ask you when you've finished telling your story.'

Part B – specific

When did you first notice any health difficulties? What was it that made you seek medical advice?

Can you describe your diagnosis experience?

Can you describe your experience of referral to other professionals and services?

How do you rate the overall co-ordination of the multi-disciplinary team? Do you feel there is adequate communication across the different services?

Can you describe your experience of equipment provision? Are you happy with the standard of service you have received?

If you have had contact with social services can you describe your experience of this e.g. adaptations or care packages?

How do you feel about your role in making decisions about your health e.g. PEG/NIVVP?

Do you feel well-informed and included in the decision-making process in terms of end of life care?

Do you feel that your emotional and psychological needs have been met?

Do you think that there are any other services you would like to receive?

Part C- generic

What was important to you before the illness and what is important to you now?

How has MND changed the way you live?

Is there anything else you would like to add?

Appendix 8-Transcripts

Interview & Journal Transcripts for case study (Jackie and Frank)

Jackie's Interview

Present: Jackie/Research Assistant/ Research Supervisor/ Frank

J: Erm… I was aware I'd got a problem with my hands. I really didn't think it was anything serious. And, I wasn't very in my head, I just really thought it was connected with my neck. It… When I couldn't use the gear very easily on the bike, I didn't think that was a problem, it was only when in September I tried to write and I couldn't that I thought perhaps I ought to go to the doctors. Erm… I think I was more concerned when we got to October/November time er… we… in the climbing club we have a working party and I end up doing the cooking for lots and lots of people and I take it across. I couldn't go for the whole weekend because of looking after my father. Er… But I always did lots of homemade soup and big casseroles and things and I'd actually got a friend staying here and she had to do all of the peeling and chopping, I couldn't do it and that was the first time that I thought 'Hmm, there… This isn't right.' And when I was at the doctors concerning my dad very soon after that I then said 'Well look, where's my appointment and started chasing it up. I actually am glad that I didn't have an earlier appointment, I'm glad there was a big cock-up in the administration department… erm… I'm actually glad that it took me quite a long time to get an appointment because I had extra time when I didn't know what was going on. And it wouldn't have made any difference if I'd seen him any earlier, it wouldn't have made a scrap of difference so I… I don't feel anger towards the cock-up, I'm quite pleased about it. But I quite clearly remember the ninth of February and being ushered in to see the consultant, not being given any time whatsoever to talk to him, having to go out into the examination room via the waiting room and having everybody else looking is diabolical. I then went back in and he made his pronouncement, threw it on a piece of paper and we came home. And when we Googled Anterior Horn Cell Disease which he'd written on his piece of paper, my world fell apart. Cos I knew what we were in for. And then I got angry. I wasn't angry I'd got MND, I'm sad I'd got MND but I was bloody angry at the way we found out. Nobody should have to go through that. When I was working, I spent a lot of time working with consultants, being there when bad news was given. I was involved in doing training sessions for other doctors about how not to do it and I think my consultant broke every rule in the book. I'm not saying it was easy for him either, it must be shit giving people bad news all the time but there are ways and means of doing it and I got it the bad way. We were then left on our own and everything that we found out afterwards was through our own efforts. I think it hit me quite forcibly because in the middle of all this I had a breast problem and had to go to the breast clinic. And when I went to the breast clinic I was treated as a human being, with dignity and informed what was happening, given follow-up appointments, I never left the breast clinic without another appointment in my hand and without information about what would happen next. And I think the fact that that happened at the same time as getting this diagnosis really fuelled my anger and I remember when I was at [hospital name] one day just going across to the out-patient department and refusing to budge until somebody somewhere told me what was going on as far as seeing the consultant was concerned, because we were just left hanging there. So I really think that people in the future need a better system. Certainly the setup at [hospital – outlying] is appalling. When we went for the subsequent appointment, somebody, a young girl who went in before me, was obviously getting dished out the dirt, I could hear every word. We saw her come out of the one room and go into the other room for examination and we saw her go back. It's not nice and it shouldn't happen. There should be rooms with inter-connecting doors, you shouldn't have to go back out into the main corridor. There should be the opportunity, when they know they're going to give you bad news, they should at least give you time afterwards. If you get bad news in the breast clinic, erm, there's a room there, they can sit you down and you can have a cup of tea, a cup of coffee and talk to a nurse. Its only common sense to make sure somebody's in a fit state to drive home afterwards and it's only courtesy to make sure that they've got a phone number or an appointment so that they know that they're not left and I feel really really strongly about that and if you don't do anything else from this interview but try and

improve that then it will have been worth doing it. After that, we did find the MND clinic helpful. It was useful to have the opportunity to see different professionals all on the same afternoon, erm, so that saved further appointments. Because I also had all the community people coming, so we had the social worker, we had the OT, we're having the physio next week. Um, every time someone comes you have to go through it all again, explain it all again and I found that really very difficult, I wanted people to know, I didn't want to have to go through it all again. So, a better way of co-ordinating services would be useful, I don't know how you'd do that, everybody works separately, everybody's in different teams and everybody has different budgets and I know that's not easy but it would have been helpful. But ….yeah, so, [MND nurse] was helpful for getting things done. [RCDA] came and got my, huh, got my anger, and she listened and all the rest of it. But even [RCDA] there were platitudes, 'Oh you're on a journey' and all that crap. Well, I don't want to be told I'm on a journey, I'm on a journey I don't want to be on. And, erm, everybody has avoided looking at the future, its all been 'Oh, take a day at a time' and just concentrate on the now and don't think about what might happen because it might not happen and everybody's different and nobody knows how they're going to be. Well, ok, everybody's different, it progresses differently in everybody but the end result is surely very similar for a lot of people and the people who deal with it know what they have to do. And I'm a person who needs to know exactly what I'm in for and how it's going to be managed because actually I'm shit-scared about the future, shit-scared about how it's all going to be and I need to know what they'll do and I need to know what my options are and that's just not being discussed at all. And even as far as ok, yeah, people we've seen have all been quite helpful within their capabilities, we, in a way, we've been left again, because, yeah, ok, we've got to see [MND nurse] again in three months' time or two months now, whenever it is. Erm, we don't know whether [RCDA] going to come and see us again, we don't know whether she 'll email us or what. I mean, I think it's always nice to know what is going to happen. Erm, I don't know, I think, that's really difficult. Um, there's a lot of people out there and a lot of people in a worse state so, but I do think, I mean the OT, the community OT actually said, she's the only person who said it, she said 'would you like to contact me when you want to or would you like me to keep in touch and see how you are?' And I said, yeah, I'd like you to do that please because if I don't need you, um, then that's fine, but I might need you and not feel like asking because when you have to find out everything for yourself, some days you just wish someone would do it for you because it's just too much to cope with. Um, as for the impact on my life well it's devastating. I spent my life looking after other people. My job was caring for people. Had three kids, got them off our hands and as soon as they'd gone off to university, we started with parents, first of all my husband's parents but my father, because his mother had died before, but his father, at least there were other people involved with that. And then we started with my parent's big time. We ended up moving them up to live round the corner to where we used to live. My husband did everything because they wouldn't, couldn't, erm… take part in that. He sorted out everything for them and watched my mother die very slowly by degrees. And then, the only way we could come up here, which we've wanted to do for… ever since we've known each other and it's never happened was to bring my dad with us. And life was getting very difficult dealing with him and his bowel problems and his waterworks and his forgetfulness and all the rest of it and we made a new year's resolution that we weren't going to do this for much longer and we would have lots and lots of respite and he would probably have to go into a home very soon because it was all going so awfully wrong and then I got my diagnosis and er… the future was taken away. So try not to be bitter and try not to be…. It's no point saying it's not fair, life's not fair, I know that only too well from all the people I dealt with. But, it's not been easy and er… We, we, we put him in a home right away and we've tried to make the most of ..and we've had some lovely holidays but we can't do what we're used to doing. If we'd, oh, I don't know, if we'd been the sort of people that went to the opera or the theatre all the time, it actually wouldn't have made much difference yet but because we were active and we liked walking then that is really difficult, but erm… we've taken up bird-watching and we're trying to be positive and some days it's easier than others to be positive. Some days you just sort of get on with it and you think well, I'm here now so let's do what we can

now and then other days, the whole thing gets a bit overwhelming and you think, well, if you're going to die, why don't you just do it and get it over with rather than having to go through the process. Erm, I'm not afraid of dying, I'm afraid of the process of dying and the way, all the things that are going to happen on the way. But no doubt we'll face it. I've got a fantastic husband who has always solved practical problems and will carry on solving practical problems for as long as he can. But I don't like what it's doing to him. And the kids, the kids are finding it difficult, erm, we've always been there for them and now we're not going to be, they're going to have to get on with it. Ok, they're adults and perhaps they should but the one who's going through a divorce, the timing of that was brilliant. I had the breast problem and the diagnosis and my son-in-law walking out all in the same week which was just about the worst time and they'd been to Relate counselling and now it's not worked so we came back from a lovely holiday to find out that that really is the end of it. And there's a little three year old child involved and it's not good. But I'm learning to let other people solve their own problems and I'm learning to let go and they will have to get on with it because my concern now is [husband] and me and erm we've done our bit for everybody else and we're going to make the most of what we can do. And that's about it really. We'll get through it because we won't have a choice. Erm, I haven't contacted the local MND association, I feel, part of me wants to contact them because I think they'll have useful information and useful contacts, part of me doesn't want to see people further down the line. Er, so we, we haven't done that one yet. Church friends are very good. Church helps. Mountaineering club friends are great, but that doesn't help me at all. Er, I'm rambling, I'm going all over the place really, and I know I am… Er… I think I've dried up.

R: Do you think you could elaborate a bit about the multi-disciplinary team in your experiences, the different professionals, say a bit more about the OTs and the specialist nurses, how you felt they, they provided care?

J:Er, the OT at the hospital was a really, really super person who was the only person that I've met who recognised what it must mean for me to have MND as a person who is active and she's the only person who tapped into that. And she did come up with various suggestions for different therapies and she gave me some equipment. But I don't have to see her again unless there's anything I think she can help with. The community OT will keep in touch and she brought lots of gadgets, spoons, pens, oh I don't know, all sorts of bits and pieces that might help so she's been a positive person as well and the fact that she's keeping in touch is nice, I don't have to make the effort to contact her but she makes the effort to contact me and I appreciate that. Er, I have to say the social worker was useless and hasn't got back… hasn't sent a summary of her assessment or anything like that which I thought she was supposed to do. But we'll get in touch with her when we need to. And I haven't met the physic yet, the community physic, the physic at the hospital was very good but wasn't able to recommend anything that I could do that wouldn't make anything better, I mean I know there's no treatment but because I try and keep swimming and because I try and still do bits of yoga and because I try and keep my body moving that was all I can do and she could 't suggest anything. I'm interested in the community physic coming because I want to discuss wheelchairs and buggies and things like that because I just see that as the way forward for getting out. I don't know if she'll be able to help, I would love somebody just to be able to give me information. It's alright, I know it's on the internet, but you can't do it all the time, you just sort of get bogged down and think I don't want this anymore, you want somebody to tell you what to do, tell you what there is, give you the information, erm, not always have to find it out for yourself. Erm, who else have we seen? [RCDA] has been helpful. She always got back to me. But even with her there… there was problem with communication… erm… at one point. Information that the consultant told her to give me didn't tie up with the information that he wrote in the letter and subsequently gave me at an appointment… erm… The MND co-ordinator was helpful erm… I'd quite like to see her again, I don't know whether she can or she will, I know she's got quite a big area. I think her job really is to probably just to make sure people get what they need and let other people provide it. She offered me counselling which at the time I refused cost it was just too strange being on the other side of the fence, I mean she was

talking about loss and grief and I've got bookshelves of books on loss and grief and its taking me a bit to get my head round being cared for instead of being the carer. Erm… who else? *(Off mike whisper – dietician?)* Oh well, the dietician. That was, that was a waste of time. The dietician gave me a pamphlet and told me to eat all the stuff I'd been trying to avoid all my life, full fat everything and lots of sweet and sticky stuff which doesn't agree with me and it was really quite funny because erm… I said I can't do full fat milk, I can't do lots and lots of dairy and I'd given it up at one point because it helped with hay fever and with allergies and things and the speech therapist joined in and said 'Well actually, that's what I agree' so they weren't even in unison on what that should be so the only useful advice actually from the dietician was to make sure you keep eating and I find that it's no good getting hungry because I get very tired. I suppose actually the most useful advice that anybody's given me is, both the OT at the hospital and the physic at the hospital explaining how you get tired because its contra to everything that you've believed in because in the past its been exercise or if you lose it, if you don't use it you lose it, well in my situation if I use it, I've used it up. And I think it was the OT because she was such a positive person, she said to me 'Save your energy for the things that you want to do, so that if you want to go for a walk, if you can manage it, even though you know you're going to be tired after it and it could take you a week to recover, if there's something you want to do, save your energy for that rather than waste it on stupid things'. So that's what I'm learning to do. And when we did a walk last week, and I was determined to get to the lighthouse to see round the corner and I knew that the next day I'd be wiped out, it didn't matter because it was a fantastic walk and we managed it slowly and with rests and I paid for it. But it was worth it. Whereas if I'd used that energy on doing the shopping or something, that wouldn't have been worth it, so little bits of advice like that have been helpful. But by and large it's been, find it out by yourself I think, to be fair. And [husband's] ingenuity at solving problems. So I've been lucky that I've got a practical bloke.

R: You talked about counselling. Do you think that there's a need for psychological support in any sense or do you feel that it's not necessary?

J:Yeah there probably is. I could probably do with it, but I've avoided it because it's a change of role for me. Erm, but it's strange because there's no solution, there's no positives so in terms of outcome, so I'm not sure, but I think it should be offered and I think it should be available to people. I mean from my own experience working I mean some people found self-help groups that we set up useful and others didn't want it and some people wanted to talk and some didn't and you just have to respect where people are at but I think it should be available.

R: How are you coping, where do you get your support at the moment?

J: Mostly through my husband which is probably not the best way to do it, cost it's putting it on him. Erm… Partly through friends, certain friends… Partly through church friends.

R: Can I ask about your thoughts for the future?

J: Don't want it. Don't want it, don't like it. But I have to do it. And I would like to know how it will be managed and what my choices are. I dread not being able to communicate. That's the worst bit I think. I can… cope with people looking after my bodily things erm… but I need to be able to communicate and if I can't communicate then I'm not quite sure about whether I'd rather or not have some sort of euthanasia by then, I don't know. But I want to talk to somebody about it, but that's not been offered yet. I mean all this assisted stuff with ventilation and tracheostomy… gastrostomy and all that is only what I 've read, nobody's broached it and whenever I've said 'what about the future?' it's always been 'Don't go there yet.' Well, I can't help it. So yes, I'm anxious about the future.

R:Do you feel there are any other areas of care missing from the service?

J: Well in an ideal world, something that was being piloted with families, with children with disabilities was 'Care co-ordination' and the idea behind that was that there was one person, who could change as needs change so it didn't always have to be the same member of the team but that there was one person who would keep in regular contact and co-ordinate everything else so that you didn't have to deal with so many people all the time. I don't know how feasible that is… It needs

money. It needs what the health service hasn't got… Time and money. But yeah, I think it would be useful. I used to find when I was dealing with people, if I rang them up, very often I would get how families were coping and what they needed but they would never have rung me up because they were too busy dealing with the situation in physical terms or they were too emotionally upset to pick up the phone. And I think actually if someone was to ring on a regular basis that would actually be quite a helpful thing to do. And my friend who's had cancer said exactly the same, that although everybody says ring us if you need us, that is quite hard to do sometimes. It's alright if you want something practical so you can ring up and say 'Please send my next lot of pills' or 'I'm having a problem with doing this, can you help me find a way of dealing with it' but if you're feeling low, if you're feeling depressed, you're not going to pick the phone up, it's just too much to do. And, er, certainly I had a long conversation with my friend who's been through a lot of cancer treatment and she found exactly the same. But er, apart from that we… we do know what's out there and we do know we can contact people. And I feel that knowing the people at the MND centre are there, they deal with people with MND so they might not have seen exactly the same situation but they've probably got more knowledge of it whereas some of the community staff perhaps don't see it very often so their experience in your particular needs might be more limited, so I suppose I'm lucky I live in an area where I can get to an MND centre. So there should be more of those.

R: You just mentioned about having to repeat your story to lots of different members of the multi-disciplinary team, do you get a sense of there being communication amongst members of the team or not?

J: I know that letters are sent. When I was at the surgery yesterday, I mean the nurse that I was seeing had got everything up on the screen so she knew, but I don't know exactly. I mean that is actually something else that would be useful, why can't I have a copy of all the letters? The consultant I worked with, with the families used to send letters to everybody in the team and he used to copy it to the parents and I know he was unusual in doing that but the parents knew exactly what was going on. Whereas when we went to see the consultant the second time and he'd got this letter there that was totally wrong, the information in that letter about me not wanting to go on the drug and about what the test results said and all the rest of it was totally, totally different from what I'd been told on the phone and from what we erm… discussed. In fact [MND nurse] had said to me, when you next go and see him, discuss going on the drug with him because it needs raising. And he'd got it written down, I think he'd probably totally got my, well I wondered if he'd got my notes mixed up with somebody else's notes. It happens, I know it happens. But if, I was, you know, he then turned the letter round to show me and I was trying to sort of take it in so I had to go to my GP then to say, 'Look, what did you write?' Well my GP 's great, she just put the screen on and we read it together. Erm, but yeah, I mean it, I think, we found dealing with the parents of kids with disabilities, the parents are as part of the team as everybody else and in a way if everybody's helping my husband and me to manage this disease, then we should be included, we are as important as the other people in the team, so that would be quite useful. But everybody who came to the house wanted to know when it started, how it started, where you're at and all the rest of it, well I know the where you're at is changing all the time but, you know, it was very hard going through it all again. And in fact, you know, we put the physio off because we were going away and that was when we decided that we would start managing the appointments instead of the appointments managing us because otherwise life would just be dictated to and time is running out as far as we're concerned and we've got to make the most of it. So I actually plucked up the courage and said to the physio 'We're not going to be here, we'll have to rearrange it' so she's coming next week. Has that answered your question?R: The other thing I just wanted to raise with you was about your children. You've mentioned that there are obviously problems there perhaps with them coming to terms with your illness. I know that there are services available for younger children when perhaps the parents develop the illness are at a younger age. What do you feel about maybe the support that might be available for older children?

J: I don't know what there is. My daughter who's a nurse had been going through a difficult time at work and when she got my diagnosis that just pushed her over the edge and she went to her GP and she got referred to occupational health and she saw a counsellor once or twice and I think that helped her. She also got in touch with her local MND person and had a long chat with them and I think she will… I… She's alright, she's recovered from all these years on nights now she's on days and she's got herself back together and I… I think she'll be alright, she's quite a strong person and I think she'll find, I think she'll find her support herself if she needs it, she also does lots of physical things and will release it in that way. My other daughter, who lives locally, who's going through the marriage breakdown has actually asked her GP for counselling. Partly because although she's breaking with the marriage breakup at the moment she doesn't know that… how she's going to be in the future and partly because she doesn't know how she's going to cope with me. So, she's on the waiting list for counselling anyway. My son, erm, has gone back to university and is doing a long architecture degree and has had to defer because he got too upset and he's quite a sensitive creature. So I don't know about him, erm, but he's ok at the moment and I don't know what there is for him really. I don't know. I don't know how he'll be. I watched my mother deteriorate and found it difficult and she was 80 when she died. Erm, 82… Yeah, 82 when she died. And watching her deteriorate and watching her go downhill I found very difficult even though she was not much older, so I don't think they're going to find this easy. But they've got each other and they're quite strong people but I don't know. I don't know. It'd be nice to think that there was somewhere that they could contact if they wanted to. I don't know.

Frank's Interview

Present: Frank/ Research Assistant/ Research Supervisor/ Jackie

F: Where do we begin? Erm. I dunno. Erm. About a year ago really. In fact it was when I bought (Jackie) a new bike. Because I'd been trying to persuade her to get a new bike. Because she had a shopping bike, where we'd go, we used to go to the mountains to walk and in Scotland, one of the easiest ways of getting in there and not having to walk on the forest road for several miles before you start on the mountains was to use a mountain bike and the shopping bike wasn't up to it so we er… So we bought one a year ago. And after using it and walking a few times she found that… Because she was using poles, I'm sure she thought it was because her hands and wrists weren't… You know… Feeling a bit numb, weren't responding properly and she couldn't use the gears with her left hand on the mountain bike very well, it was very difficult, very stiff for her to push. And this went on, on and off, for about six months until come September last year… we were on holiday and she went to write something down and she literally couldn't write with her left hand. So at that point I… All the questions about trapped nerves, cos she'd had a neck injury, sort of whiplash injury several years ago, sort of, all the comments about trapped nerves and so on… I said you've got to get to the doctors and try and sort it out. Er, so she went… And… The doctor ummed and ah-ed, I wasn't in with her at the time but unbeknownst, said well I think I'll refer you to a neurologist. Now as you know, she was… She was caring for her dad, he was living downstairs, and about October, November, he started going totally wacky, he basically was dagnosed with Parkinsons at the end of last year. And er, things were really going downhill fast, he wasn't able to get to the loo in time and so on and so forth. But the doctor saw him, put in a referral to a specialist for him and that came through and then (Jackie) started thinking 'Where's my referral to the neurologist?' And that was the first in series of sort of of disasters because it was lost, er, the neurology department hadn't got it so they put in another referral to the neurologist. And all the time, it was getting worse, you know, the left hand. And I was getting quite worried because I hadn't any clue, neither of us had any clue that it was going to be something like erm motor neurone disease. But we were thinking of other things. We thought of MS, er, I think. Erm, and I said, well it could be a tumour, you know, something like that, its growing and making things worse, it can't just be a trapped nerve because that would stay the same or perhaps get better from time to time but this was just slowly deteriorating. But we thought nothing of that, and er you know, and her dad got erm, some treatment, but there were still problems, he was still sort of being incontinent at times and he was actually taking up a fair amount

of (Jackie)'s time and we were thinking he's very soon going to have to go into a home. Anyway, we got an appointment with a neurologist eventually, in February, erm, the ninth… I can remember the date… And it was on a Saturday. And we went along to see (name of Consultant). And he basically… I'd written loads of stuff down about history and how long she'd had the problem and when it had first started. Quite a detailed page full of notes in case she wanted. And for once I actually went into the doctors with her into the consulting room and he just basically asked her a couple of questions, not very much at all about which hand was it, what was the problem. Then he took her into the room next door, so he had to go back out into the waiting room and back into another room next door to get this clinical examination. Er, and then marched her back in, started saying 'Well it isn't good news… I think its Mo… Anterior Horn Cell Disease, it might not be but I'm pretty sure its this…So, we, we, looked at each other and we hadn't heard what that was, we hadn't a clue. And he basically said, "I've got to arrange some tests. You'll get a scan and you need to do another test where we check, er, a needle test where we check the conductivity of the nerves and so on, but you'll get those in three to four weeks, cheerio, bye-bye…"And we had some details taken by the nurse and we walked out. And that was it. We thought, well, we'll have a cup of coffee and went out in (name of hospital) because this wasn't in (name of Care centre), it was in (name of hospital) where there was a sort of outpost for him. Had a cup of coffee, bought something in home… home.. British Home Stores, came back, got on the internet, went onto google, and, you know, bang… Motor Neurone Disease came up. So that was totally devastating because we were in and out there like a dose of salt. He'd used this new fangled… this funny fangled name on us, Horn Disease and well, (Jackie) immediately knew what it entailed, I mean I'd got a fair idea as well. We started looking at the websites and getting information from the websites about it. And it was totally and utterly devastating. And we didn't know what to do because there was no… nobody to call, because if you phoned (name of hospital) and his supposed secretary in (name of hospital) all you got was an answer machine and she never got back and it took us a few days and it was the fact that (Jackie) had worked in a hospital setup before… We found some information about it that a friend had sent us about it because they were actually advertising (name of Care centre) for a locum neurologist. And a friend of (Jackie)'s had actually taken this from the internet and emailed it up to us. So we went through the list of who worked in the neurology department and (Jackie) suddenly twigged that they'd got nurses there, specially trained to deal with this in the MND care department and from her experience it was the nurses who were the best people to contact about anything. So that's where we started digging up… trying to get some… you know… some answers from all about this to hurry up the appointments because those weren't three to four weeks, I mean it took a lot longer than three to four weeks for those appointments to come through. And in fact to get… to get an appointment for a scan which wasn't two months away because that came through about two weeks after we'd seen (name of Consultant) and it was going to be… not until… Oh, the end of March I think it was, it was going to be about six weeks… seven weeks because of the pressure on the scan machines. So actually trying to get a range of private scans so we could get them earlier because if it was something else like a tumour it were better to know sooner rather than later. So we paid for a scan and even that didn't work properly because erm… we got a letter for the scan and it was posted the same day as we were due to phone up and make an appointment for the scan so there were more delays there because of the things getting lost in the post and the general organisation there. The admin isn't perfect by any means. So you had the EMG and the scan and eventually… How much later was it? It was a lot later. We eventually got another… another session to talk to (name of Consultant), you know, a second consultation with him. And information had got lost on the way there in that he'd got written down somewhere that (Jackie) didn't want to go on any drugs whereas we'd discussed the idea of her going on the Rilutek even though there were some side effects, we hadn't actually made up our minds. But it was in black and white, in a letter that went from her GP that she was not wanting to go on it so again this information…

He told her that it was in… one segment or two segments of the spine. I mean we'd heard this information because (Jackie) had been talking to (name of specialist nurse), the MND nurse about

this so we actually got some information from the MND nurse and not through him. And the two didn't quite match up because he said it was in one segment because he'd seen it in one segment clinically, that's her arm but in fact the needle test, the, what's it called, EMG I think it is, actually showed it in her legs as well. So we didn't actually get a look at that report. (name) who, we didn't get very much information from him at the time, because (Jackie) was really quite cross about the fact that the doctor, her GP had been told that she'd refused this treatment. So, and she was also very cross about the fact that he'd told us that it were this anterior horn cell disease when we'd… he used a medical term that we wouldn't know. So, and then left to find out everything ourselves.

I wonder how some people go on, because, I mean, we've got good contacts, we've got her friend has got two Gps as son and daughter in law, a cousin of (Jackie)'s works for the MND association anyway. So I think we found out about 90% of the information about the disease and things through friends and people we know rather than through the actual care centre itself. So the actual finding out was pretty abysmal in the way it was done and the way (Jackie) and I were told about the thing. I have to say that (name of specialist nurse) has been helpful and especially (name of MNDA care coordinator), the MND association co-ordinator has been very helpful and always got back to us, both of them always got back to us. But the service we had from (name of hospital) was absolutely hopeless because there was… I don't think the secretary at (name of hospital) actually returned our phonecalls once. And I don't think there is a permanent secretary there, I think its someone taking on part of the work it, obviously it got too much, but it is a bit unforgiveable something like that. Erm, that really is the worst thing. I mean the help is there now, we've been to the MND clinic, we we've been to see all these specialist people. The specialist people at the care centre have been very, very good and very useful. But one of the biggest problems has been that (Jackie) and I were both very hard walkers and, I mean (Jackie), at the beginning of this year, I mean even when she got the initial diagnosis, there's a big hill up there which is two and a half thousand foot high we walked it… we walked up it one day and back down it and its about a ten mile round trip. Now she can't even walk two miles without resting up for the next two or three days. She was swimming, I mean, somebody commented in the… We were members of the spa pool because we liked swimming a lot. And we swim hard… member of the spa fitness club commented on how well she swam, you know, but now she can hardly swim two or three lengths. And we've had to solve a lot of the problems as we've gone along ourselves. I mean, it was quite… One of the things we wanted to do was actually travel as much as we could while we could. Er, but initially, that, was very difficult for two reasons, the one reason was that we'd got all these appointments to go to. And they weren't co-ordinated, you know, one would be Monday, the next one would be Thursday, and then we'd have to go to (name of Care centre) for something or to (name of hospital) for something. And the other reason was that without a specific diagnosis, and I know this is difficult with MND, without a specific diagnosis of MND, or someone who was willing to say what it was, so that we could put it down on er, in er, the travel insurance forms, insurance companies didn't want to know. You know, they were gonna charge us three hundred quid or something for a week's insurance. So we couldn't actually… We were tied by lots of different things in that way so it was really very, very frustrating that we, that nobody would actually say 'Yes, you've got MND' and even now I think that they're still using this stupid phrase that if its present in one segment its possible, if you've got it in two segments, its suspected. If its in three segments its probable, and if its in four segments, you know, you definitely have the disease. So, at least (name of specialist nurse) has, as it were, stretched the truth a little bit when it comes to things like this. Because if you're trying to claim DLA and all this stuff, you need to have the diagnosis, which is, she's been very helpful in that way. We know she's… (Jackie)'s got it, it can't be anything else, but present? I mean, the thing that (name of consultant) would stick to, that (name of consultant) would stick to is that its suspected is a joke. Yeah. So that's a real nuisance, this method of diagnosis and its stopped us going away straight away. But once we actually had fairly clear indication that it was MND, and all the other tests had come back, erm, its been easy to get insurance, so we've been away, we've been away to Madeira, and that was ok, that worked quite well. We hope we can go away again in the future, we've been to Scotland, which isn't, you know, as

adventurous, but its been a great place to go. So insurance has been a real problem, you know, sorting that out, because we wanted to travel as much as we can while we can. And its also solving all the little problems that have been a problem as well. Because we, because we were active, trying to get gadgets and things that would help, erm, the OTs, even the OTs had been very good, but even the OTs, have been unable really to come up with things that are specific to what we've been wanting to do. (Jackie)'s had a problem with her swimming, and because she couldn't grip anything, her hands just won't just bend with the water, fingers are open, she just can't swim. And she found that really frustrating because there's been quite a few months when she could have swam reasonably well but the hand problem. And we'd managed to spot something when we went up to Aron a couple of weeks ago which was one of these little paddles that slides over your fingers, its supposed to be one of these training paddles, and that's actually solved that problem. Now her legs don't work very well, so she's not swimming particularly well. But at least she can... Although she can't do the breaststroke, she can do crawl with this paddle because that works pull blood flow between your legs (?) and she can actually lift her arm out and even though it doesn't, she can't actually push or move her hand, her arm works and this paddle helps her to swim in a straight line. And we... The kids actually bought her a superb present for her birthday, it was a balloon flight. And when she looked at the details of that, you had to stand up for an hour or so, an hour, two hours while you're in the air because that's the only way you can do it, you're in a basket, you've got to stand up because there's no seats. So, she was in tears because she read this, she phoned up the place, and basically they said, well, if you can't stand up, you can't do a balloon flight. And we ended up, and I ended up actually going, digging out my climbing harness, meeting the bloke with the basket and saying 'Look, can we climb into this and show you how it might work' because one of the things we needed to make sure we could do then was to actually put her in the climbing harness, put a Caribbean (?) on it and as there are grab rails on the inside, you just clip the Caribbean on there and at any time during the flight she could once or twice rest her legs cos otherwise she wouldn't have been able to cope with it. He just sit her on the climbing harness, so sit on it, and that gave her enough rest space to do that. It'd be quite useful if there was some way of getting information like this because other people must have come across problems that were similar and, you know, like your friend turned up and you're having all this problems with standing for a long time. And she actually, her friend, has had breast cancer three times so she knows, and she's had chemotherapy and that actually wipes her out, so she'd actually bought herself a little folding out aluminium stool, with a back, which she gave to (Jackie), and that's been great because when we went to Aron, we went across to Holy Island which is a sort of Buddhist retreat on there. And its an island where you can do a couple of walks, one goes right over the top, couldn't do that, but there's one walk that went along the from one end to the other, and because we had this little chair with us, we could walk for five or ten minutes, get this up, sit down, get the binoculars out, look at the wildlife and then walk a bit further, and you actually managed it, you were still wiped out afterwards, for the next two days then, but at least you managed your walk. So again, you know, I've read lots about MND on the websites, and lots of information, and none of it gives you tips and hints like that, it'd be quite useful to have some. And the other thing is we really would like people to be upfront about what you're in for. The problem is, we both probably know too much about what its going to be like because (Jackie)'s mum was in a wheelchair and then in a nursing home for five years and we've had (Jackie)'s dad going downhill, so we actually know what its like to be an invalid, a disabled person. We also know, from (Jackie)'s work, whats... what MND was and what would happen. And when you ask about people, how's it going to develop, they say, 'well, with everybody, its different.' And even all the professionals shy away from saying, 'Right, you will have problems when you go to the toilet or you will not be able to get to the toilet, and this is how people cope with it.' You know? I want to know now, and it would be really useful to know, so we can plan, what its going to be like, how's she going to have a shit. How she's going to go and have a pee. What its going to involve, you know, cos that's the nitty gritty of what we've got to cope with. And even the OTs are... don't like treading that way. I mean, I suppose they're trying to protect us from what will happen but personally it would be

useful because I need to make, well I'm gonna be the main carer and it'd be useful to know what we need to plan for in the future so we don't make the wrong decisions. We were lucky when it came to financial decisions because (Jackie) was just about to take her pension because she was just coming up to 60. And, er, we decided, a) to take it earlier, slightly earlier and b) to take a larger lump sum. Because what is the point in having a pension if you're going to die within two years or three years or whatever. So it really is important that people are upfront with a lot of these things, right at the beginning so you can actually plan both the physical things properly and financial things because its, you know, if... We're going to try and get you an all-terrain buggy aren't we? You know, not a standard, I mean if you're getting a wheelchair you might as well get one that'll go over rough ground because one of the things we need to do because of our history in the mountains, is (Jackie) needs to go out in the fresh air. She needs to feel as if she can walk and do things and she can't do that and that's really hit her hard. Again, I mean, (name of specialist nurse) was useful pointing us in the direction of a bike shop in (name of Care centre) but we actually solved the problem ourselves in that (Jackie) was able to ride a bike for about four or five miles this holiday because I went into the bike shop up the road and bought a few extra bits of kit to put on the bike, raised the handlebars, had some flat grips on them, instead of the round ones, which made it easier to ride. The only things that give in now are her legs so she might not be able to do that much longer but it seems like all the time we're having to solve the problems ourselves. And that it would be nice if there was, you know, somewhere... somewhere where you could look up what people had done.You came across a website recently where some guy with a disabled, with his disabled wife had gone round the world and he was talking about having to solve problems, and it was... that wasn't MND, it was due to strokes and other things but er... The way he'd solved her problems was quite useful and reading that website was quite good... I haven't found anything like that on the MND website, so you know, something like that could be quite useful. That's my feelings on that thing certainly. I don't know if you want to ask me anything else...

R: You mentioned how (name of MNDA care coordinator) was useful for the MND association...

F:Yeah

R:Can I ask how she helped?

F: Erm, how did she help? She... She found out information about, well, we asked her specifically for things. I mean a) we asked her to find out information about travel insurance, which she got back to us with. We got the MND folder which was quite useful. She's put us in touch with the MND association in this area. We've not joined that of course yet, that's a big step to take. Erm, I mean she was just useful... More than anything else, she was just useful as somebody there to offload to. Its about somebody you could talk to who would listen, and you know, it was quite nice for (Jackie) to have somebody she could talk to, and would listen to her, and she came round to see us and I mean she had a load of grief I think from (Jackie) because (Jackie) was so uptight about the way she was told about the disease that you know, it was somebody who would... offload it to. She was useful to me in that in the first couple... three months... even now... (Jackie) was very very weepy. She'd cry all the time. And she got quite depressed as well. And I could talk to (name of MNDA care coordinator) about that when I visited the centre. And I was able to talk to (name of MNDA care coordinator) about that so it was quite useful from that point of view. She also knew we'd listen and I think that's what we needed as much as anything, so that you can bounce comments off them so you know that, you know, that you're not on your own through this and that somebody will listen and who if she can give you some help, will give you some help. Yeah?

R: Ok. And can I ask how its affected your life in particular?

Try an extra stone down there... Erm.. Yeah, in times of stress I drink too much, I am drinking too much. I am not exercising half as much as I would like to. Because we used to exercise together. Because of all the things... appointments and things we've had to do. So I've put on weight... Erm... Its gonna restrict me in a lot of other ways. I know that. But I'm doing... I'm happy to go along with that because its a positive decision that I want to care for (Jackie) as long as is possible in the home... So... I find it difficult, and it really is difficult, erm, its very interesting when you talk to friends, how

some people ignore the fact that (Jackie)'s got this disease, cannot cope with a problem, so they'll talk about anything except that and I find that awkward. You soon find out who you can be open to and who, you know, perhaps its not a good idea to see anymore... But particularly because most of my friends are mountaineers and quite active mountaineers, the conversation... You know, I find it difficult, in that, that's difficult with some of them, talking to them, we find it difficult meeting with them sometimes because they want to talk about where there next trip is, what their next mountain is and we know quite well that we won't be going up any mountains again unless its in a cable car or something. Er, so that's quite hard. So I don't get as much exercise, I've not got as much freedom as I would like. I feel extremely cheated, pissed off, because we've been looking after (Jackie)'s mum and dad now for ten... for the last ten years, and I mean looking after them, they have needed more and more attention as we've gone along. And I was looking forward to a period of time where (Jackie) and I might have freedom to go off and do what we wanted to do when we wanted to. Erm... And that hasn't happened. So that's a bit of a... Bummer to be honest with you...But yeah, I mean, I've got to be around for (Jackie). She needed me around emotionally for the first few months definitely. And I think its coming to the stage where I will need to be around for her, to care for her, and do things. As you know, she can't use her left hand. So cooking, even a simple meal is quite difficult, unless you just have a ready meal, you know? One of these off the shelf things, we don't like those. We eat healthily, we like to cut our own food from scratch. So peeling anything is difficult, even with the gadgets that the OTs have given us. Erm, chopping things is equally difficult. Even buttering toast can be a problem, so, you know, somebody needs to be around to do up her bra, not quite pull your knickers up yet, but, you know, we know that's going to come. So yeah, it will affect... I'm a full time carer. I'm aware of that. I think we've talked about this as well. The one thing I will need as time goes on is to take time off on a regular basis. I did get her... And her friends have been very good. About a month ago, I did a big bike ride with some friends, round ??????????????, a two day one, and (Jackie)'s best friend came up to stay. Coincidentally, at the time, we were very grateful that somebody had... erm... again another friend who... A couple we know came up to stay and we hadn't been up together and... er... and I went out for a bike ride with Tony for two days while Sue looked after... looked after (Jackie), so that is... that is a problem in that I'm not getting enough exercise from my point of view apart from when I can fit it in. We will look after each other at the same time, so that's... that's gonna have to be sorted in the future when (Jackie) needs more care.

R: And do you feel that you have support for yourself from (name of Care centre) and the community care?

F:I haven't... I'm a very independent person. Extremely independent... I like to do things myself. I would hate to be like (Jackie). I would be throwing things around the place, I know, because I would be so frustrated. And I understand how frustrated she feels with not being able to do things. I do know... I have been told, I know I could go to (name of MNDA care coordinator) and talk to her if I wanted help and support. I know there is a carer's association in (name of area). So I know that it exists out there but the likelihood of me going and using it is fairly small actually. I know a few friends I can talk to about it. Surprising sometimes who... who, you know, who your friends who you think you could talk to about it and don't turn out to be the ones who you can talk to, and those who you perhaps don't know that well who you can talk to about some of the problems. Yeah, there's help out there, I've got friends, But I'm not likely to use standard support networks there are out there I don't think unless... Well, until it gets really bad. And then I'm sure that... Certainly (name of specialist nurse), certainly (name of MNDA care coordinator) will point me in the right direction. OK? So I feel confident with the..

R: Ok... And how's it affected your family and social life?

F:Er... Well, as I say, social life. We socialise with two lots of people. I socialise mainly, along with (Jackie), with the mountaineering club. We have... We are members of a large mountaineering club... Both members... That we've been in for the last 40 years... 35, 40 years... And I've been very involved with it... And it's got a mountaineering club hut in just half an hour away which I look after. And they are like a second family to us because we haven't got brothers and sisters, we're both only

ones, which is why (Jackie)'s been looking after her dad. But, they've been very good, but the problem is because they're all active people, like going in the hills, meeting up with those tends to be at the climbing hut, they tend to go off walking and then they tend to be planning all the next expeditions. So that isn't good. (Jackie)'s... I'm not religious but (Jackie) is a member of the church, down the bottom, and she's got into a cell group with church (PHONE RINGS) And they're great... I'll leave it, it'll go onto message. And they're great, they've been really very supportive. So I think (Jackie)'s found the social life with the church really good because she can get to church. She can go to an evening cell group and she can just sit there and talk and be like the rest of them. And they came round here, we had a meal here as well. So there hasn't been any change there because of her circumstances. So at the moment, that's the difference with the groups and friends we've got. We still socialise, we went to Coniston Sunday afternoon evening to talk to them. And we went out for a meal with them, there were 24 of... 25 and we hired a room in a hotel to have this meal. And they are the sort of friends who were very good actually, and were good, but there is... The fact that we can't go walking is a problem. Family? Well, family's been very supportive. The children, by family I mean. But there have been problems there. Kids need support. They always do. And our children are no exception. Tom is trying to get through a degree, and he's finding it very difficult, he's actually deferred because of the pressures of work. (name of daughter) is trying to cope with the pressures of nursing. She's getting close to... Well, she got signed off for a couple of weeks sick. Because she's been working on nights far too long and is trapped in her job and she's finding difficulty with her job. And the other daughter, they're going through marriage breakup at the moment, so its difficult. They are all very supportive. We are going to see (name of daughter) in... from North Wales, this afternoon evening with the kids, but its... Yeah... We talk to them, we're open with them. (name of daughter)zie being a nurse knows what (Jackie)'s in for. She was actually quite happy to talk to (Jackie) about the nitty gritty because she used to work in a spinal injuries unit, so she know what its like when you're in a wheelchair and can't move and the sort of things you have to do for toileting and so on, so yeah, we've been very open with them all, we let them know right from the beginning and included them but er... But as far as ... You know, they've give as much support as they can given they've all got families and problems.

R:And erm... If I could also ask about your thoughts for the future really? How you feel about it.

F:Shit. I'm quite scared about what's going to happen. To (Jackie) and us... I don't want to lose her. I'm trying to make the most of the time that we've got and the fact that we can go out, we can meet people, we can have sex. We can cuddle each other, we sleep in the same bed, you know, all that. I know its going to end. So I don't want that at all. So I... excuse me... I try and concentrate as much as I can on the present and I try and busy myself by doing things, because I know its going to get worse. Its going to be shit at the end. I know that. We're under no illusions. Yeah.

R: Erm, I think that's all my questions, have you got anything else you'd like to add?

F: No, not really

RS: If I can just pick up on one thing that you said?

F: Yeah

RS: About the local MNDA, you said to join that would be a big step?

F: I think it would. Yeah. Do I want to go and look at people who might be further on than (Jackie)? Erm, you know, do I want to be reminded of that? I suppose I'm trying to bury my head at the moment by only trying to solve the problems quickly and easily trying to organize ourselves so we can get off on holidays as much as possible and do things. I mean, our next project is, (Jackie)'s never seen a puffin. I've actually been on the top of the Old Man of Hoy with puffins staring at me with its head on one side about two yards away. And photos of that as well, so one of the things I want to do is to take (Jackie) to… Take (Jackie) to see puffins. I want to do things and… er… make the most of life as it is. I think its only when I get into the real business of caring, and we're talking about wheelchairs and stuff like that, that I might be persuaded to go along to somewhere like that, to talk to people about it because I need to discuss it with other people. I don't know, I don't know

whether… hmm… I don't know whether it'd be very useful or not to be honest with you. I don't know. So I'm avoiding… It's avoidance. Yeah. Ok?

Journal – extract 1

February 9 2008

Jackie: A date that will stay with me. We went to (name of hospital) to see a neurologist. It was a Saturday clinic –an extra one –a waiting list initiative. We got there early for the 9.30 appointment. What a drab place- no magazines let alone old ones and nowhere to get a coffee. My turn came and in we went together. I had asked (Frank) to come in with me as I thought he might remember the answer to questions I might get asked. I was not asked anything except how old I was and when I first noticed anything was wrong. The doctor was brief and seemed in a hurry. I had to go next door to the examination room. This meant going back out into the corridor where those waiting could see. I got on the couch. He looked briefly at my arm and hand and then scraped an instrument along the bottom of my feet before telling me to go back and sit down in the other room. Then he got a piece of paper and drew a diagram. He said it was bad news and that he thought I had Anterior Horn Cell Disease. I would need an MRI scan and another test called an EMG. He would see me in 2-3 weeks. Good bye. No time to ask questions and too stunned to take this in. Then, we were ushered out quickly so the next person could be seen. Brutal was the word (Frank) used.We wandered down into (name of place) looking for a coffee shop wondering what we were in for. We got home and put the computer on and into Google went that phrase: "anterior horn cell disease." The reply came back: "synonymous with Motor Neurone Disease".I was devastated. Everything flashed through my mind at once: wheelchairs, swallowing problems, breathing problems, television news items on people with MND going to European Courts trying to get permission to end their lives with dignity, my relationship with (Frank) changing from one of equal partners to one of dependency, not being able to watch the grandchildren grow up, not having any life doing the things we wanted because already we had lost time looking after parents and now it was too late, feeling cheated and so much more. I cried and cried and cried.Then the anger set in, not that I could have this disease but in the way I had found out.A lot of my working life had been spent being with doctors giving "bad news" to parents of children with life limiting conditions or disabilities. We had done training to GPs and medical students about good practice. Now I was on the receiving end of the worst "bad practice" imaginable. How ironic!

A friend emailed me a job advert for a locum neurologist at the (name of Hospital) where my neurologist was based. This gave full details of the department and showed that the doctor I had seen was no junior. (Frank) had decided that he knew his stuff as soon as we met him and this confirmed that he was a well trained and experienced neurologist. It also reminded me that specialist nurses are always attached to specialist departments. So I rang and spoke to someone in the MND care centre. The nurse was very helpful and said that she would talk to the consultant and try to chase up the EMG which would be done at (name of place). As the MRI scan was to be done at (name of place)she could do nothing about that.

February 10 (Frank) decided to cancel his imminent Ice Climbing trip. This meant telling people why. So to prevent some people knowing and others finding out we decided to do some blanket emails. I also asked for prayer from my Christian friends. I do believe what one of them had said to me earlier, that God is in every situation. I just pray that God will help us to get through this. I sent an email to close friends:

"Just to tell you that I went to see the neurologist yesterday re my hand and he told me that he thought I had anterior horn cell disease. If you Google this like I did when I got home, it says that it's a synonym for motor neurone disease. I have to have some more tests and an MRI scan and then he will see me again. There is a slight chance it is something less awful. Don't feel very brave and struggling to cope with this but wanted you to know. I am not good on the phone at the moment."

What wonderful friends we have! Comforting emails poured in and people phoned to offer support.

February 13A lovely day walking with (name of place) up (name of mountain). Strong sunshine and lovely to be up on the tops. a superb day. With lots of laughs. It has done me the world of good and I

feel much stronger. There was a message on the phone about a scan on10th March. I will be on the case to try and bring that forward or get a cancellation. Feel very angry that the neurologist has told me so much and then left me high and dry. Whatever happens I am putting Dad into a home as he has deteriorated so much and he needs full time care, so concentrating on that. Also got lots more help for him starting next week whilst I trawl the homes. Enough is enough and coping with him will become beyond me. It has already been very difficult as his needs have been increasing.

February 14 (names of friends) visited. Lunch at (name of restaurant) and a walk by the river. A romantic Valentine meal in the evening at (name of restaurant), booked by (Frank) before all this. Determined to do something nice every day.

February 16 (Name of family) came. All the family have now been seen. We have all cried together and it is good to feel their love and support.

February 19 Totally knackered because of visitors and not sleeping and trying to sort out care home for Dad.

February 26 We are so tired. I have private MRI in (name of hospital) tomorrow afternoon and then the EMG on Thursday morning, again in (name of hospital). I do not feel angry but (Frank) does.

I feel sad, scared and yet well supported. Also, busy and worn out and hoping that when the responsibility for Dad has gone that things are a bit easier. He has had a lot of problems with his bowels and there is enough shit to deal with without his!!!!

February 28 Frank wrote an email:

"We've been contacting all our friends over the last couple of weeks so that they are told first hand of (Jackie's) news. (Jackie) has had problems with her left hand for some time. Early last year she had difficulty with some tasks but put it down to using her walking poles and relying on them too much. Also had problems with her new bike and thought her wrist was being strained. It came to a head in Sept when on holiday she could not write properly (something most people would think was the case anyway!) I eventually dragged her to the doctors to sort out the problem. Anyway referrals got lost and then after the thing got worse and we chased it up she had an appointment with a neurologist almost three weeks ago. The outcome was that he ordered some further tests but after a short consultation and a clinical diagnosis said he was fairly sure she had anterior horn cell disease – and it wasn't good news – neural – degenerative – but the tests would help to rule out other, unlikely, causes – cheerio – and out we went.

We were stunned but had never heard of it before so had a coffee and went home and googled. When we found it meant motor neuron disease we fell apart. Yesterday (Jackie) had an MRI scan in (name of hospital) and today she had an EMG test at (name of hospital) (They stick needles in arms, legs and throat and check electrical responses etc.) Have to wait to see the consultant himself again but I thought he knew his stuff and it turns out he is the chair of the dept. During the tests today there were the beginnings of similar symptoms in her right arm which the doctor noticed.

In the meantime John has been getting worse – Parkinson's – and whilst going to the day hospital and drugs have made his mobility better so he has no longer urge incontinence (wanting a pee and being unable to get there quick enough) the drugs for his crumbling spine they have been prescribing have lead to bowel problems to add to the shit we have to deal with. At least we have found him a residential home in (name of place) which appears OK and in which he takes up residence tomorrow.

We are going to see some friends in the climbing club at (name of place) on Sat/Sun so if we manage a walk and have a laugh with them (black humour is de rigour) we will cope better. Murphy is trying to gain the upper hand at the moment – after a routine breast scan several weeks ago she has to go to [(name of hospital) for further tests on Tues - !!

Totally wiped out and knackered at the moment. We will let you know when (Jackie) knows for sure but even if it is not the worst case scenario (of which we are almost sure) it will not be good. If it is all a bad dream we will have a big party!

February 29I sent an email:

"You have all been so supportive and I want to tell you where I am at. It has been a gruelling week so please excuse this blanket email. I will contact you all individually as I get the chance. It really has helped to share the nightmare with you. So thanks for that.

Today we took Dad into the care home. We spent all day sorting out his stuff and transporting it and trying to make the room as homely as possible. We had to take him to the day hospital first but it meant we could sort things out without him watching. (Frank) even found time to buy him a new TV! We left Dad trying to be brave enough to face his first night. But I think he will be OK and the staff all seemed very caring.

Wednesday evening saw us down the M6 to (name of place) for the MRI scan. That was worse than I expected. It was very claustrophobic and extremely noisy!!! Then back Thursday morning for the EMG. That was better than anticipated though they put needles in more places than I had thought would be the case!!! I didn't like the ones in the throat!!!

Today the MND nurse rang me to inform me of the discussion she had had with the consultant and to let me know what would happen next. It seems that MND is only ***diagnosed definitely*** *when it is in 4 segments. I have it in 1 segment therefore I have* ***suspected*** *MND. 2 segments means* ***possible*** *MND and 3 means* ***probable*** *MND. Given that my left hand and arm is worse than it was and I have now some symptoms in the right arm I am curious about this method of diagnosis. I have to wait for an appointment to see the neurologist in possibly 2 weeks' time. It is frustrating but I suppose I should count my blessings. The nurse did indicate that, usually the slower the initial progression, the slower the disease progresses in the long run. I am holding on to the fact that there should be some time to make the most of life without Dad to care for.*

We are going to (name of place tomorrow to try to forget it all for a couple of days."

March 2 Had a strop at (name of lake). Everyone going for walk and I knew I could not keep up. Decided to flounce off to the Lake but could not tie my boots! Cried and laughed at the situation. Then had pleasant walk round (name of place) with (Frank) and (name of friend).

March 4 Went to breast clinic today. Something had shown up on mammogram so had ultrasound. This showed **not** a cyst as the radiologist first suspected but a new problem (had cysts in past) so had a needle biopsy and will get results next Thursday. Please don't let me have cancer as well as MND.

Whilst at (name of place) I went in search of the neurologist's secretary and refused to move till someone found her for me! I was impressively assertive and very polite!!! Had a call back later to tell me that the neurologist is really booked up but they are on the case to fit me in so I can get this blood test done which will rule out (or not) multifocal motor neuropathy. I have a phone number of a very helpful person if this appt doesn't materialise in next day or so. So it's all waiting but progress is sort of being made.

Visited Dad. He is not at all well. More bowel problems and he seems now to have lost the use of his hand. I am so glad he is not my direct responsibility. The staff at the home have all been lovely and very caring and so I feel relieved.(Frank) has been venting his feelings on the garden and has nearly finished the preparation for planting the hedge!

March 7 Just as I was trying to cope with it all I had a phone call from (name of daughter) in tears to say that (name of son of law) had walked out. The lowest moment of all.

March 13 I sent an email:

"Thank you for your prayers and thoughts. They do help a great deal. I will contact you properly later but wanted you to know that I have been to the Breast Clinic today and got the results of the biopsy. It is good news! It is fibrosis and doesn't need treatment. So it is just the "suspected" MND to deal with. I see the neurologist again on 29th March to get the results of the blood test I had on Tuesday (to test for multifocal motor neuropathy – which can mimic MND)"

March 14 A lovely walk near (name of place). A beautiful Spring day. We ended up going up to (name of place) and into (name of place) and walking much further than I thought I could. I need to do this. How will I cope when it is no longer possible?

March 18 Had bad day yesterday. Church group tonight and this helps. I off load on (Frank) and he gets the brunt of it but he doesn't have an outlet for it at the moment.

We are surviving. Very up and down. We have had diversion therapy by clearing Dads rooms and ordering stuff from John Lewis online! We will able to run a B&B!!!

Not getting very far with holiday insurance at the moment so it's a good job I love Scotland! Still not made any firm plans re holidays.

March 23 Easter Sunday and it has snowed! I go to church at (name of place) and it is such a beautiful scene. Daffodils and lambs, sunshine and snow. Afterwards we go up the fields at the back of the house so I can walk in the snow. I love snow! I remember 2 years ago when it was (name of friend's) 60th and we were at (name of place) for his party. We woke up to so much snow nothing was getting in or out of (name of place) and we stayed an extra night. I had always wanted to get snowed in!!

March 25 It is (name of son's) birthday and I could not write in his card. Tears. I have always bought the cards and been the one to keep in touch with people. Another loss. A very low moment. A visit from the MND person. You are on a journey she said. I don't want to be on that journey I thought. It is all to do with grief and loss she said. Then I get cross and tell her I have lots of books about that and that it was my job, dealing with grief and loss. She offers me counselling. I refuse. I have a diploma in counselling. Doesn't she see how ironic it all is? I suppose I was a bit harsh on her. After she has gone I feel ashamed. I remember how I gave my "parents" at the Childrens Centre that piece about going to Holland instead of Italy. I wonder what mistakes I made and what unhelpful things I might have said. I remind myself that when I took early retirement they all sent cards and letters saying how helpful I had been. It mattered that they thought so. It mattered that I had made a difference. It made all the sweat and tears of my working life worthwhile.

March 29 An appointment with the neurologist. He said he had told me last time that he thought I had MND . I pointed out that he had not and that I had discovered this from googling. He said that he had told me two segments were affected and that I had refused to go on Rilutek. I was totally stunned as this was totally incorrect. (Frank) thought I was going to lose it. I told him I was fed up with all the cock ups and was not impressed with the way I had been treated.I will go to see my GP and get her to show me the report when I have calmed down and can take it in.

April 2 (Frank) has gone to (name of place) to stay with the (name of friends) and to do The (name) Round- a big bike ride-with (name of friends)and (name of friend) has come to stay with me, a visit planned long before I had my diagnosis. We talk and talk. It is so wonderful to have a friend who knows me so well and who knew me growing up.

We walked down to (name of place) and after mooching about and lunch in the (name of café) we walked back up again to the house. Then in the evening we went down to (name of restaurant) for a meal as she was treating me for my birthday. We had promised (Frank) to have a taxi back up but after the meal I felt strong enough to walk. I needed to walk whilst I still can. We discussed MND and how awful it is and cried together re my fears for what is to come. It is good to be so open and honest.

I can no longer knit so (name of friend) decided she was going to finish (name of grandson's) jumper! It somehow seemed so important to me that she did this.

April 4(Frank) sent an email:*"Saw neurologist Sat 29th. Clinically (Jackie) presents symptoms in one segment – cervical. The EMG supports this and shows denervation in the lumbar region. In other words as well as her left hand being knackered her legs are beginning to deteriorate as well. She has complained her legs aren't as strong but this has confirmed it. We went to MND clinic today. Useful: especially the OT. We appreciate everyone's thoughts and emails but it is difficult to always get straight back to you all. Please keep in touch but understand how tired (Jackie) gets. It has been a mammoth task completing filling in DLA forms today - so negative."***April 5** (name of place) working party. Facing people. Couldn't do the cooking or cleaning. Oh, to do ordinary things.**15 April** My birthday weekend was a turning point and so fantastic! They all arrived at the same time on the Friday night. (name of relatives) went to the upstairs guest room and (name of relatives) used the whole of the downstairs which we had finished in time. It really worked well and (name of relative) loved the bunk beds!On the Saturday (name of relative) came across and the "girls" went to the Spa

where we were pampered. (name of relative) and I had time to talk and I asked her about ventilation, tracheostomies, toileting etc and we hugged and wept together. It must be hard for (name of relative) knowing so much and relating it to her own mother. I really cannot bear the thought of being a burden to my children. When we got back we had cake that (name of relative) had made and I opened my presents-a balloon ride! Plus lots of silly o.a.p. things! What a lot of time and effort they had gone to in order to make it all so special. In the evening we had an adults only meal in our lovely house all sat around talking without interruptions from small people! (Name of relatives) watched DVDs in (name of relative's) bed whilst (name of relative) snored his head off in the children's bedroom! (Frank) excelled himself with a truly delicious meal with champagne and good wine and I was spoilt rotten. The next day we went up the (name of place) and had lunch at the (name of pub). It was such a lovely weekend. There was time with everyone. Then yesterday I really was 60! I had confirmation from the MND nurse that the blood test for multi focal neuropathy was negative. In other words I definitely have MND. Happy Birthday!!(Frank) and I went to (name of restaurant) at (name of place) for an evening meal a deux. We managed to enjoy it despite the tears I shed so easily. I love him so much I don't want to leave him.

April 29 Back from (name of place)! One week of rest, sunshine, swimming and good meals. (Frank) drove around this mountainous island and even got me to walk a very short Levada. We read and talked but more importantly had precious time together without the phone going or appointments or visits from people about MND. For a week I could pretend that I was my old self and not this person with MND that I have become. We had wheelchair assistance at the airport but although I hated it, it did save my energy.

May 4 How wonderful it is to have such good friends. I am really blessed with all my friends. (name of friends) have come and are sleeping downstairs. It really doesn't seem like Dad's flat any more. (name of friend) and (Frank) did a bike ride and (name of friend) took me to a craft centre at (name of place). She is so understanding having lived with cancer three times. It is twenty years since she was first diagnosed. She took me to (name of church) on Sunday and again they are such supportive people. I miss some of my (name of church's) friends but can't cope with the size and bustle of the services in the school whilst they do the alterations at the church. Saturday night we had a meal at (name of restaurant) with (name of friends). (Frank) has to cut up my food but I still manage to feed myself with my right hand. I have got very proficient with my right hand!

May 5 I did the balloon ride!We both went up from a (name of farm), over the fields, over and finally down over the lake-we even landed in the car park at (name of place)! The balloon ride was absolutely fantastic and only possible thanks to my wonderfully ingenious husband who is determined to solve all problems! When I read that I had to be able to stand for an hour I got worried as I knew I could not. I rang up to see if it was possible to sit down and was told no, so I was told I couldn't do the flight. I gave the phone to (Frank) and wept buckets. It doesn't take much for me to be a wet mess but this time I was inconsolable. My son and daughters had spent money they didn't have to give me a special present. I didn't want to let them down. (Frank) talked to (name) the pilot and then disappeared downstairs. He came back with his climbing harness and proceeded to hang me from the door! He rang (name) back and persuaded him to let me try hanging from the basket to rest my legs! We had the MND clinic in (name of place) Friday but afterwards drove to (name) barn near (name of place) to try out (Frank's) idea. (Name) said ok so it was to be the next available flight!!! (Name) was so lovely and pleased I was able to do it. We had champagne afterwards! (Name of family) followed the flight and (Name of relative) took lots of photos. It was a magical evening.

May 6 Visit to (name of daughter). We sat in the garden drinking tea and then went for lunch in a pub near a fantastic view over (name of place). It was good to have time with (name of daughter) on her own. We met two very surprised little boys from school and went with them to (name of grandson's) swimming lesson. We went on the beach for a while. What fantastic weather. I have so missed seeing the boys. This is the first time we have been to visit (name of relative) for ages as we couldn't leave Dad when he lived with us. We saw (name of relative) briefly and then went to (name

of friends) in (name of place). Again how long since we had been able to do this. How ironical that MND has freed me up to do things other people take for granted.

May 7 Birthday tea with (name of grandson). 3 today!

May 8 Visited Dad. He is so frail but seems to be aware of what is happening. Managed to get the carer to push him outside so we could sit in the sun for a while.

Then home to pack for Scotland though (Frank) does all the work these days. What a week and I am so exhausted. It is good, however, to pack so much in and it does take my mind off MND. We are racing against time.

May 9 Scotland here we come!

May 10 It is three months since that fateful day our world changed irrevocably. I am sat outside (name of cottage) on (name of place) contemplating what has happened to us. We always meant to come back to the Islands and now it's a race against time to visit a few more. My legs are getting weaker and walking in the hills or striding out anywhere is no longer an option. I wept today looking across at (name of place) knowing that I would not be able to walk the Strand as once I could have done so easily. Walking has been the activity (name of activity) and I have shared and loved, and I struggle to accept it is no longer possible.

That Saturday on 9th February will stay with us. It was such a dreadful way to find out that the trapped nerve I thought I had was the worst degenerative condition imaginable. I cried for all I had lost and would loose and for what it would do to (Frank) and me. We have had such a fantastic marriage and a wonderful relationship built on being equal partners. I did not want him to become my carer and for me to have to become so dependent. I got angry about the way we had found out and how we had to chase tests and find support and information. I still feel anger about this. Three months on, however, I am more resigned and more inclined to save my precious energy for doing special things with (Frank) or family and friends.

We have had tremendous support from friends and wonderful prayer support from many people. I am so grateful for my Christian faith. I never did say "why me Lord?" but I did ask God how he was going to get us through this.

Health professionals/Equipment

There has been support from the MND association. The Regional Care Advisor visited early on and has made contact with local services on my behalf. Yesterday an association visitor came. She was helpful and did not avoid my direct questions about the future! She lent me some books. The OT has given me various aids. She is advising re the wet room planned for the bathroom downstairs. The Physio came this week and is ordering a wheelchair. What I really dream about is an all-terrain thing that will get me out in the country but wheelchair services won't provide one of those! Finding out all these things takes time and energy. We found a "Toto Washlet" on the internet - a Japanese toilet seat that washes and dries. They are all the range over there for everyone not just disabled people, but we couldn't find any suppliers to UK. They looked much better than the special toilet the OT has mentioned.

Medication

I started taking Rilutek in the middle of April. I was not sure it was worth it as it may only buy a few extra months and can have awful side effects. However, so far, so good. We call them my "live longer" pills!! I guess three extra months of life with my family is worth every second.

Friends & Family

Friends have been great and all want to help/visit. The hardest thing is in updating them when they ring. I hate going over it all again. So I might start a blog and put this diary on it so they know where we are "at". The best thing is going out for meals as sitting round the table I feel "normal' instead of different. I can still feed myself and have got fairly adept with my right hand. I dread the day that I need to be fed or I need a gastrostomy. We love friends coming to visit as long as they muck in, which most of them do. (Frank) can't wait on everyone.

Family are good too. It must be hard for them. Roles have changed. I can no longer look after my grandson one day a week. We cannot help out in any of the ways we used to. We do talk about MND and have always been close. I do believe that they will all support each other.

(Frank) and I joined the RSPB this week. We went to (name of place)and he wheeled me to some hides. We are trying to be positive and this is an attempt to find something we can enjoy together now the hills are off limits for me. Yesterday we went to buy some new binoculars for (Frank) – an early Birthday present from me and also a spotting scope. Then (Frank) took me up (name of place), right to the top in the car. There was no one else there. It was so wonderful to be up in the hills. I could see (name of places) one way and look down into (name of place). From the other direction I could see (name of place) Our house was identifiable through the new spotting scope. I really miss a day out on the (name of place).

Today we went swimming at the Spa we belong to and they have listened to our grumbles re the disabled changing room and wanted to know what is needed so they can improve things. It felt good to be doing something useful that will benefit other people. I swam 15 lengths of the 18 metre pool which is nothing by my standards but an achievement for me now. It feels good to be "active" in any way possible and the sauna after always makes me feel good.

Also today I received confirmation that the MND association will provide me with a lap top with voice recognition software! How good is that! I just hope my voice lasts. I have begun to notice it gets "tired" with too much talking.

June 9 (Frank) said that he will find a way to connect with me until the end. He knows how scared I am of losing the ability to communicate. I seem to live in my head a lot these days. I think of things in a way I never did when life was fast and furious. Yesterday I was too tired to go to church and didn't get up till lunch time. I probably did too much swimming yesterday. I always pay for it if I do too much. The problem is that at the time I don't know if it is too much. (Name of relative) and (Name of relative) came for tea. He was entertaining and very chatty today.

I miss looking after (Name of relative) on Mondays and feel not so involved with him as I was. I must remember that I had 18 wonderful months of being a "hands on" granny! I remember when (Name of relative) was pregnant being determined to give up work and spend time with her baby. I had seen (Name of relative) quite a lot when he was born but by the time (name of relative) came I was heavily into parent care plus working, and she was working and trying to see (name of relative)who was then in (name of place). We did have (Name of relative) and (name of relative) to stay when (Name of relative) and (name of relative) went away and I did go to (name of place) to help out when (name of relative) was away. I loved making playdoh and letting the boys paint and make a mess! They were always so active and loved going to parks. I remember going to (name of place) one day as soon as it opened at 9am! I am glad that the boys have (name of relative). (name of relative) christened me "Nanna no dogs" once and it has stuck!

(Name of relative) rarely sees his other grandmother. (Frank) will have to be both granddad and Nanna to him when I have gone. I remember walks with (Name of relative) by the river, especially in Autumn with all the leaves, and on the canal path. We always had lots of sticks, flowers or leaves to take home. We used to go to the "fun factory" and he loved bouncing on the equipment. He was bored at the playgroup we tried but the sessions at the library were such fun. He loved listening to the stories and then choosing books. I was sad when I couldn't cope with that any more.

(Name of relative) said to me recently that Mummy had cried because I would go into a wheelchair one day. I said yes I would. He knows my hand doesn't work as I couldn't help with the Lego. Last time they were here I was just about to read a bedtime story when (Frank) shouted down that Shrek was on TV. Two little boys shot upstairs and we ended up curling up on the sofa eating hoola hoops and watching the film. It was a very special evening.

(name of friends) came today. It is always hard seeing someone for the first time. We wept and remembered and caught up. We are so blessed with our friends. I told her I was struggling to pray at the moment. She said "its OK. Let others pray for you". I am on her fellowship group's prayer list. It is quite humbling to realise that there people all over the country praying for me.

June 10 A Very Bad Day. The much anticipated wheelchair arrived today. Dreams of freedom and some independence smashed. It is heavy-almost 20Kg. (Frank) will certainly knacker his back lifting it in & out of the car. I tried the self propelling wheels and couldn't do it, unlike the one I used in Booths last week. Gutted. Upset. Weepy all day. Have to wait for full assessment by the Wheelchair Services but will that electric one I have been promised be any good? Worried now and how long to wait? It seems we will have to do our own research and buy something ourselves but with MND and its ever changing nature what do we buy. What can I get that gets me outside on paths not just pavements.?

The OT came as well. Lots of discussion about toilets. She, like everyone else, is a lovely well meaning person but it does feel like we have to do our own research and find out everything for ourselves. It is all so exhausting.

Last night I felt suicidal. Realisation of the situation seems to have hit home. I felt that as I was going to die, that I might as well get it over with and save everyone the hassle and anguish of the next months to come. I couldn't go to my church group and (Frank) rang to explain why.

June 10 Went to (name of place) with (Name of relative) & (Name of relative). She rang up before hand to book a wheelchair but when (Frank) fetched it, it was broken and he could not steer it. Thy found another one but that too was broken though steerable . Felt really upset about it.

Later went to a wheelchair shop in (name of place). It is bewildering all the different sorts you can get. The man was very nice but said you had to have an assessment before he would sell one. He also told us about a voucher scheme.

June 12 Tried again to ring wheelchair people. Fed up of being fobbed off. Fed up of bathrooms and wheelchairs and want to end it all now. (name of friend) from church came round with a meal for tonight and insisted that cell group were going to help us. She will ring (name of friend) re possible counselling. Cried on everyone including (name of friend), a visitor from MND assoc. She is one very perceptive lady and said I had to allow myself to be upset. (name of friend) arrived and (Frank) went off to (name of place) with (name of friend). Cried on (name of friend). Really, I am useless and pathetic.

June 13 Got a mobility scooter and hit the town!!! It is scary as there is no brake! When you let go the lever, it just stops. Going down hill you just have to have faith! (name of friend) ran along side and we made it to Quaker Tapestry. This was good therapy. We later went to the bistro for a meal. The "balloon man" happened to come in and thanked me for my letter of thanks. I make an effort now to thank anyone who is helpful and kind! (name of friend) rang and booked a counselling session. I do need to sort my head out as far as God is concerned.

June 14 More therapy from (name of friend). She is so long suffering and can take my tears. She pushed me round (name of shop) to get beer for Dad and then took me to see him. It is so hard visiting him as my voice is not strong and he is so deaf. I feel sorry for him being dumped in this care home and at the same time resentful that looking after him took away precious time I could have done things with (Frank), had I known what was coming.

Then we went up (name of place) I so miss exercise and walking and days out in the hills. I don't think I will ever get used to it. (name of friend) understands this. I need to be in the hills physically, not just as an observer, but cant.

(name of friends) came on way home. She brought me a prayer about peace. (Name of friend) and I had been talking about finding peace and she gave me a Celtic prayer about peace too. Perhaps I will find peace one day. Perhaps that is all I can hope for.

(Frank) turned up as couldn't cope any longer on the meet at (name of place). He described feeling as if he was behind a glass screen and in a different world from everyone. He had found it difficult but was glad that he faced people. He is worn out from walking and biking but at least had some exercise at last!

June 15 Father's Day. (name of friend) went. She has been very good at listening. (name of friends) called on way back from Edinburgh. (Name of relative) came for a meal on her own. I am so blessed

with family and friends, I really am. Knowing I am dying at least gives me the opportunity to tell people how much I love them.

June 16 Our house was cleaned while we went out! Anyone who knows (Frank) will realise what a milestone that was!! Letting someone else do what he could do better!!! (Name of relative) says we have to let go!! Well we went for a swim…..well, he swam and I floated. Then we went to (name of place). Sunshine. Wind on my face. Waves on the lake. Oh to walk in the hills! Mustn't keep on about it. It was a good time. We proved yet again that if you sit quietly wildlife comes to you. Today mother duck took her ten nearly fully grown, yet still fluffy, ducklings for a walk. We watched as she stood proudly as they waddled by on the lake shore. She reminded me of a teacher on playground duty! Yes, a good day.

June 22 More tears. Really tired after a busy week. Back on the sleeping pills. Rain and wind outside. More like a stormy November. (name of friends) called in for coffee.

Then spent the rest of the day trying to get to grips with new computer that MND assoc has supplied me with so I can use Dragon software ie voice recognition software. This last week has been so hard trying to get my head round so much. The visit from the wheelchair services people was exhausting. The options via the NHS are limited but we have no choice as if we went privately we could be changing machines frequently 'as my needs change'. How I hate that phrase that all the professionals use. Why cant they say 'when I deteriorate' which is the truth.

(Frank)'s visit from the carer's assoc also upset me. The assessment took more than 2 hours. I went upstairs so he could discuss his needs but it was weird hearing voices and knowing I was the cause of him having needs anyway.

In between there were nice things like a visit to (name of friend) who gave me foot massage, a visit to (name of friend) who made me feel peaceful, a meal with my church friends, a sit by (name of place) in the sun and a sit at (name of place)watching the seabirds.

And looking at the flowers. The daffodils this year were brighter than ever and lasted for ages as the early spring was so cold. Masses of yellow everywhere. I have always loved daffodils. Then Bluebells in profusion in Scotland. Really vivid blue. Even on the beaches. Rhododendrums. Big purple heads. Red azaleas. Wild orchids. When we got back home there were fields of buttercups everywhere. Now its daisies. Big daisies. All along the roadsides in clouds.

Must try and stay positive but I can't help blaming myself for what has happened however illogical that is. Perhaps counselling will help to sort my head out. Didn't go to church again. Told myself I was too tired but really I just could not cope with going.

June 23 Went to (name of friend) with (name of friend) and borrowed a mobility scooter. Yet again it felt good to get around under my own steam. Gardens were lovely and the scooter coped with woodland paths. Sun shone today and was such a contrast with the storms of the weekend. It was good to sound off at (name of friend) I am lucky to be indulged by my friends, as (Frank) puts it! He did a ride with (name of friend) and did his share of unloading.

(name of friend) has asked me what did I really want to do in the time left. It was quite a challenge to be asked this. All the answers I once would have replied seemed wrong. I used to dream of travelling the world but now I get so exhausted being driven down the motorway for an hour or two, long distance travel seems less attractive. All I really want is to have time with (Frank) and to do ordinary things, peaceful things, be in the hills or at the coast, on boats, looking at sunsets, looking at birds, or having a laugh with friends and having meals with them, or seeing my family, being with grandsons.

We put bird feeders up a few days ago and almost immediately goldfinches came. As the garden is fairly open and windy we didn't know if they would come. So we were very pleased. Today we spotted a hooded crow, greenfinches and sparrows as well. A fieldmouse came out of the wall and hoovered all the bit of seeds left by the birds. We have such a superb grandstand view from our lounge window.

Yes, (Frank) is so right. These last few days I have been so tired. I was told at the beginning that fatigue has a major part in MND. It really is making normal life impossible now.

The hydrotherapy session was quite soothing but left me shattered. The physio said I must stop thinking about exercising my body, just use the water to relax and stretch. How I miss swimming.
This last week I have had a lot of discomfort with my neck and shoulder and it is disturbing my sleep- and (Frank)'s.
I had a counselling session. It helped in that I realised how bombarded I have felt by people, appointments, emotions, physical symptoms and the unpredictability of the disease. I realised I was not weak in the way I have dealt with it all, but that what is happening to us is so huge. In some ways it reminds me of when I lost my second child when I was six months pregnant. I could do nothing about that and I can do nothing about this. What is happening to me is outside my control. My body will continue to deteriorate and I will die. There is no point in raging against it any longer. I have to accept this now.
June 28 Frank: *Perhaps we were told to live day by day because, with this disease, planning ahead is so difficult - if not impossible. The moment one problem is solved another appears. It isn't easy to plan holidays or visits, or to find ways to cope with (Jackie)'s increasing lack of use of her body and increasing fatigue.*
One week she was able to walk a couple of miles along the coast of Holy Island, the next week she was unable to walk around a supermarket. Because of her useless left hand I adapted her bike so the handlebars where higher and the grips bigger and flatter so she could peddle a few miles. Now, a few weeks later, her legs are weaker and her neck muscles tire so she cannot cycle. Ideally to solve practical issues like this it would be nice to be able to go to a warehouse and get the equipment you needed 'off the shelf' rather than having to wait for an appointment to get assessed and then wait for the equipment to be ordered etc. When she found she couldn't to walk around the supermarket it was great that there was a wheelchair available for customers. Thinking ahead and planning for the future can be very depressing: when/if (Jackie) cannot use the computer keyboard; when/if she cannot talk When/if (Jackie) cannot get upstairs; when/if she cannot wipe her own bum…….Trying to keep a positive attitude is not easy. Planning to do things in a few weeks' time which are feasible now requires thought. Will (Jackie) be able to get upstairs to the loo? – Is it going to tire her too much (and is it worth paying the price for that over the next week)? This means that we can become over cautious.
Journal – Extract 2
July 5 Jackie: I am writing this using Dragon voice recognition software. It is amazing that all I have to do is to sit and talk clearly into my microphone and the computer will do the rest! I have had one lesson so far and am now trying to put into practice what I have learnt. Hopefully, what I write will not appear too stilted! I will probably end up writing far too much as talking is easier than typing!
It is a week since I sent in the first instalment of my diary. I found it very therapeutic to write down my thoughts and feelings of dealing with motor neurone disease. Several of my friends who read my diary said it had helped them to understand my situation and my family think it is useful too and have encouraged me to continue.
In many ways I feel I have "turned a corner". I feel stronger emotionally and during the last week there have not been so many tears. I went to Church on Sunday and felt that it was a positive experience. It had been several weeks since I had been and it was good to go back. (name's) friend sent me some Bible references that she had put together. I am so touched by the thoughtfulness of this person. What she sent was really helpful and I feel more in touch with my faith than I have for a while- more at peace. I enjoyed listening to the music but found it sad that I could not sing hymns or choruses. I used to enjoy singing- must be my Welsh blood!
Then we decided that we would go to Anglesey and go to South Stack to look for puffins! I managed to find a B&B close by and so on Monday morning packed up and drove to North Wales. It was a beautifully sunny day and it was good to be beside the sea. We have been to Anglesey many times but have never really explored the coastline near Treaddur Bay. Tuesday was an extremely windy day and it was very difficult to hold the binoculars steady. We went in Ellin's Tower (RSPB) and from the viewing window there, we saw hundreds of guillemots and razorbills and even a pair of choughs.

Eventually, our patience was rewarded and we saw three puffin's swimming in the sea. We then went to the steps of the lighthouse and despite the strong winds, (Frank) managed to set up his scope and I was able to see a puffin near its burrow and to watch it walking about. It was amazing! (I know that we would have seen a lot of puffins on the Farne Islands but we didn't have enough time to go there. We only had three clear days without appointments). Nevertheless I *have* seen a puffin! It was really good to get lots of fresh air and to see the sea crashing on the rocks. We came back Wednesday morning and stopped at (name's) for lunch so that we could see her new downstairs toilet and utility room which has just been put in.

On Thursday we woke to a phone call to say that the chair was going to be delivered. We thought this was to be my wheelchair so imagine our surprise when two men delivered a recliner chair. Only the week before, I had commented to the physiotherapist that I couldn't get comfortable in any of my chairs and she did say that she would talk to the occupational therapist about this. Presumably this chair has come as a result. It is so comfortable! The back goes right down and there is leg support, all with the touch of a button! The only drawback is that we cannot get it up to the first floor living room, so it has gone in the downstairs room that used to be my father's kitchen. It is a wonderful chair for relaxing in and I am very grateful for it. Also on Thursday I went for my second hydrotherapy session. This time I used the water to stretch my muscles and to float. I can swim a little bit on my back still, but as I can only use one arm I find it difficult to go in a straight line. (Name of daughter) took me there and back which was nice as it gave (Frank) a rest from chauffeuring me about. I also got to see (Name of grandson). And then in the afternoon, I had my first lesson on using this software. The hardest thing was holding the phone for an hour while I listened to instructions. My teacher could see my computer screen. I have never had a “remote” lesson before! Isn't technology wonderful!

By Friday I was so *exhausted*.

(Name), my yoga teacher, came, as she does every fortnight. I have practised yoga for much of my adult life and when I found that I was unable to go to classes, (Name) agreed to come to the house. It is very limiting what I can do now: very gentle stretches and also some relaxation and meditation. But, it does help me a great deal and (Name) is a very special person.

It was such a sunny day! Such a contrast to the wet and windy weather we have had. So we went to the garden centre to buy some plants for the top of the wall outside the garden room. The idea is that I will have some colour to look out when I sit downstairs. It was very hot and I could not walk very far at all today. We assumed wrongly, that there would be a wheelchair to borrow. So (Frank) had to go and choose the plants while I sat and waited.

I wonder how long it will be before my electric wheelchair comes. That however, will cause another problem to solve as we will have to get a wheelchair accessible vehicle.

After the garden centre we drove out to Arneside and sat in the sun drinking Guinness and watching the seabirds on the beach. I enjoyed looking at some herons. I looked at them for a long time but they did not seem to catch anything!

Today would have been my mother’s birthday. I think of her quite a lot. For many years she was very disabled. She was very stoical and never complained about the situation she was in. I hated watching her lose all her abilities. I wonder how my son and daughters will deal with my deterioration. They are three exceptional people so they will find a way. I am so looking forward to seeing them next weekend when all the family come to stay to celebrate (Frank)'s 60th birthday.

July 6 Church - laughing and joking (though I still could not sing),

Visited Dad. I find this hard work as raising my voice is a strain and if I don’t say anything he does not initiate conversation and there is nothing to talk about. I don’t know how much he understands of my situation.

Pleasant pub meal with (Frank, family members)

July7 8am the builders came. They banged and made a lot of noise taking out the old bathroom downstairs. Then in the afternoon, I had to go and choose tiles and other fittings for the bathroom. This was quite depressing as I had to try different types of taps and shower controls and realised just

how useless my left hand and arm has become. I was exhausted from my visit to the bathroom suppliers. I am a wet mess again. The way that I cope does indeed seem to be very much connected with how tired I am.

July8 A visit from the speech therapist. We talked about my voice which is not as strong as it used to be and we talked about the various aids that exist to convert text to speech. We are also discussed how there are many people who are unable to communicate and depend on their partners to anticipate their needs. After she had gone, I felt very upset. I want to know all there is to know about the future but at the same time it is hard to think about it. I am beginning to learn to live within my physical limitations but the thought of not being able to communicate is too awful to contemplate.

July9 (Name of son) came to stay as he had an appointment in Whitehaven the next day. It was good to chat with him. Time with my son and daughters is so very precious.

July10 I enjoyed my hydrotherapy session this morning and practised swimming on my back. This is difficult as I can only use my right arm and it is nearly impossible to keep in a straight line! However, there is a lady there who swims length after length on her back using just one arm. She told me she uses her head as a rudder. I shall have to keep practising!

Then (name) called to cut our hair. I miss going to the hairdressers but it is easier now to have it cut at home.

(Name of friend) called. We talked about her father's funeral. I didn't realise it was not necessary to go to the crematorium. They had a church service only. I think I might like that as driving miles to the crematorium for 5 minutes always seems so silly.

July11 Today my voice is very weak. Yesterday I talked too much so I am trying to say very little and to drink lots of water. Years ago I went on a silent retreat which was very liberating at the time. Now I realise how precious speech is. At church group the other evening, we were studying James and discussing how easy it is to say the wrong thing and use speech destructively. How we take talking to each other for granted!

Earlier we went to buy food for the weekend as all the family are coming to celebrate (Frank)'s 60th which will be on 17th. (Frank) is having to do all the preparation himself which is not right but he does not complain. I do hate not being able to do things and it is especially hard when I feel I want to be making a special effort for his birthday. It is so frustrating sitting doing nothing and letting him do all the work.

July13 What a hectic weekend ! Yesterday morning we had minibus to pick us up and take us off to Carnforth railway station. With a coffee stop at Grange, lunch at The Prince of Wales pub at Foxfield and a tea stop at Whitehaven, we had a train ride around the Lake District! We travelled up the coast and then from Carlisle over Shap, passed the Howgills and on to Oxenholme . It was a proper old fashioned day's outing and we had a lot of laughs as well as enjoying the scenery. I was wheeled around but managed to get on and off the trains myself though some low platforms were difficult. I was grateful for my arm sling, neck collar and cushtie.It was too cold for the planned evening BBQ so we ate indoors with everyone, except (Frank), helping to produce a feast. The boys enjoyed the balloons and party poppers and the silly presents included a cap for Parker!

Today (Frank) and (name of friend) went for a bike ride while (name of daughters & grandsons) drove to Morecombe for the kite festival. (name of son and friend) stayed with me and set up a web site so I can publish this diary. It will be passworded so only those people I choose can access it. So then I spent ages inputting past entries and there is still more to do!

It is so quiet after everyone has gone and we are absolutely shattered. It will take me several days to recover but it was worth it.

It was good that there was time to talk to everyone. (Name of daughter) wanted to ask what would happen to my ashes when I died. She says that she finds it very difficult to understand all the things that might happen as the disease progresses, whereas (name of daughter), as a nurse, knows only too well what could be in store. (Name of daughter) feels that she needs a special place or a bench

or somewhere where she can come and talk to me when I am no longer here. We shed tears talking about these things but it is so important that they are faced.

Monday 14 July

(Frank) and I are so tired. The builders came at eight o'clock to do more work on the wet room. A lightweight wheelchair was delivered and the temporary one removed. The cleaners came. We heard from (names of daughter) has been successful in his application to be a tutor in a hall of residence in [(name of hospital) from September 1. This brings home the reality of their separation but there is also a relief in knowing that he will not have to pay for his own accommodation and so will be able to continue to pay the mortgage for the time being.

I went to see my father for a short while. I find it very difficult visiting him with my weak voice. I spoke to (name) the MND specialist nurse today. She told me that if my voice was affected I would begin to slur my speech. She said it is probable that my chest muscles are beginning to weaken and that this is why I feel the power going from my voice. It would also explain the hoarseness and the cough I have at times. We also discussed the pain in my shoulder. My left arm often feels very heavy and uncomfortable. I wake several times in the night because of this.

(Name) came to collect me from the home and took me out to lunch. She is a very positive person and it was good to talk to her. She told me she was still praying for healing for me. We laughed and I said that if I was healed from MND that would be a first! However, I commented that there are different forms of healing. I feel much stronger emotionally in spite of my physical problems increasing. I hated the time when I felt suicidal and so immersed in my own problems. I am interested in people again and what is going on in everyone else's lives which makes me the same nosey person I have always been! Anyway, (Name) said that she would still pray for healing. Last week she prayed for my wheelchair to arrive and the one came today and the electric one will be here by Thursday!

Tuesday 15 July

At 7 am the toilet was delivered! This is a very expensive state of the art piece of equipment called a clos-o-mat which gives the user a wash and blow dry! It is supposed to save my dignity in the future. We will see!

Once I have the electric wheelchair I will need a car to put it in so (Frank) has been researching wheelchair accessible vehicles. The cheapest option seems to be to go via Motability and get something very basic like a Renault Kangoo. Several years ago we bought one of these for my mother but she only went in it a few times and it ended up being a waste of money. At least if we go through Motability they will pay insurance, repairs etc and when it is no longer needed, (Frank) will just be able to ring them up to take it away and not have the hassle of trying to sell it.

We tried out the manual wheelchair at Holehird Gardens. If anyone has to have this disease, it is a good job its me and not (Frank)! He is so practical and capable. I wouldn't have clue how to adjust the foot rests and head support on this chair!

Wednesday 16

Frank: I'm typing this whilst I wait for (Jackie) to shower and get dressed. The morning routine which has evolved is for me to get up and get tea and bring it up to the bedroom; (Jackie) will eventually surface enough to struggle to sit up and I will rearrange the pillows so she is comfortable; I'll then go down and make some breakfast and unload the dishwasher and/or clear up. We used to have breakfast in the kitchen but this meant (Jackie) would come down the stairs in her dressing gown (it was an effort for her to get dressed in time) and then have to go back up to shower and dress. Because the stairs tire her it is easier to have breakfast in bed. Normally I usually make the bed whilst she gets in the shower. I'm listening for the shower to stop now – that is my cue to get the bath towel and drape it round her shoulders – something she cannot do without an enormous effort. It is a huge bath towel which means she just sits on another towel on the loo with her feet on the bath mat and waits for the water to be soaked up by the towels. The next step will be helping her fasten her bra and sometimes do up the trouser fastenings. She's been quite ingenious opening and using the shampoo and shower gel and so far is managing with the toothpaste although I've got to remember

not to screw the top on too tight (those pump action ones get far too stiff to use). Occasionally help with creams is wanted and then I have to put the towels back on the towel radiator.
I feel as if our life is a bit less stressful now than it was at the start of this month. (names)have made progress with the wet room and we are close to getting the floor tiled. The "super loo" is ready for them and all the other bits of kit appear to be here scattered around. The manual wheelchair has eventually arrived and hopefully they will deliver the electric one today so the visit by wheelchair services engineer and OT tomorrow will not be a waste of time! It would be nice to have a phone call telling us when these were being delivered rather than just appearing on the doorstep. Friday sees a demonstration of a WAV from (name of place)– the firm we bought an adapted vehicle from for (Jackie)'s mum. The next hassle is likely to be delays with Motability when we choose the vehicle but we must hope for the best.
I am managing to get out on my bike at least once a week for an hour or two which helps. I'm careful not to go off road at the moment as I cannot afford to have an accident. The fact that (Jackie) is feeling stronger emotionally has helped – I found it hard to cope with the suicidal lows she had. I know that she will continue to need more and more help physically. We have slept in different rooms for the last couple of nights and last night I slept through for the first time for months.

July 18

Jackie: It is four o'clock, Friday afternoon, and we are supposed to be going away for a week tomorrow. To say we are not organised is an understatement! (Frank) has just gone food shopping as he has told the others that he will cook the first meal. We have decided that this will be a special extra birthday meal with friends and I have told him to get some champagne!

The last couple of days have been *mad*! The builders have been in and out working on the wet room. The wheelchair was delivered, and then the engineer and OT came to set it up for me and to give me a lesson in driving it. In the middle of all this the community OT visited to check out the toilet. The house is filling up with disabled gadgets. We have two wheelchairs (one manual), one recliner chair, one stair lift, one special toilet, lots of special cutlery, various cushions, neck supports, and arm and shoulder supports, and of course this laptop with its amazing voice recognition software. I am so lucky that I now have all that I need at the moment and that such a lot of it has been provided for free.

(Name), the yoga teacher, came today and I had a lovely peaceful session while poor (Frank) was rushing round. At the moment I think he is getting a worse deal than me. He is pampering me and to some extent mollycoddling me. This means that instead of using energy doing jobs, I have energy for the nice things. However, this means that I have a lazy time of it whilst he is always busy. The poor man is worn out. It is going to be a meal out of the freezer tonight but in the morning there will be all the packing to do which this time includes dismantling the electric wheelchair to get it in the car.

At least last night we went out and had an excellent birthday meal.

I have just put the washing in as that is something I can still manage (when the sheets get washed (Frank) has to fold them). By using small baskets I can carry washing on my lap and go up and down on the stair lift to the washing machine and tumble dryer. I can no longer hang clothes on the line outside so I am not being very environmentally friendly I'm afraid.

The first thing this morning we had a visit from Gowrings and the demonstration of a Kangoo. Sat in the wheelchair in the car I felt very safe and comfortable but my vision was severely limited and I saw a lot of the road. They are converting a Fiat Doblo now but this will not be available till later in the year so we have decided to go with the Renault. Once again the unpredictability of MND means that it makes sense to have a Motability car rather than to buy one. If we were to spend a lot more on an upmarket car and then find we didn't need it we would lose a lot of money.

Also in the last couple of days I have put my diary online and e-mailed a lot of friends to give them the website and the username and password. It has been very therapeutic for me to do this and it is also such a relief to know that I will not have to keep repeating the same old things to people.

This morning a calf was born in the field at the back of us. How amazing it was watching it get to its feet. I feel so privileged to live in this house with such wonderful views of the hills. Even today when it is grey and rainy and the clouds are very low it is still lovely to watch the sky. Sometimes we get amazing sunsets.

I am really looking forward to this week away and having some laughs with old friends. I will be able to practise using my wheelchair and hopefully get about a bit. I do so hope that (Frank) will have a rest and be able to do some walking.

July 29

We have been back home for a few days now. Today is a very bad day and as the whole point of this diary is to describe, honestly, how my life is whilst dealing with MND, I have to admit that it is. I was doing quite well and feeling fairly strong until someone, without meaning to and probably without realising it, upset me by giving me what felt like a lecture into (Frank)'s needs. I don't need reminding what this is doing to (Frank) and I was heartbroken all over again. I keep beating myself up that I am ruining his life even though I know intellectually that it is not my fault that I have this disease. On reflection, it just showed me that it was easy to lose the equilibrium that I thought I had gained.

It hasn't helped that the Christmas catalogue from the MND Association arrived and flicking through it I read:

"Motor Neurone Disease is a rapidly progressive, fatal illness. It leaves people unable to walk, talk or feed themselves, but intellect usually remains unaffected. With no cure, half die within 14 months of diagnosis."

I know this is of course, but in my low state I felt upset all over again. I do try to be positive but sometimes it is hard.

We were so lucky with the weather last week and enjoyed our time away with some good friends. (Frank) managed two walks and on those days I was taken out for tea and cakes in a very picturesque setting by a loch. For me, the evenings were the best, sat around the dinner table eating lovely meals, drinking wine and enjoying the company. It was very special. At such times I felt "normal" and no different from the others. (Frank) had a rest from cooking too. The electric wheelchair had two outings but I found it quite scary and a lot harder than the mobility scooter to control. I also felt that it would tip up easily even though it is unlikely to do so. Moffat was not a good place to practise - too many kerbs.

Since coming home, I have been to visit my father on his 88th Birthday. (name of daughter) took me to town to buy a present and pushed me in the lightweight wheelchair for the first time. Then when we got to the Home, she pushed my father out into the garden. She is getting good at wheelchairs! (Frank) and I also took the power chair out and managed to get to the paper shop and back. The worst bit was crossing the road but each time we go out I get a little bit better at it and a little bit more confident.

(Frank) has been catching up on the gardening and I even managed to do a little bit by sitting on a cushion and using my good hand to pull out some of the bigger weeds. It is very frustrating not being able to help in the garden and it felt good to have done something useful.

(Name), my yoga teacher, came yesterday evening and as usual, I felt better as a result of the session with her. She is very inventive at finding different ways of moving my body. I always feel so relaxed afterwards.

It is the end of another month. I wonder how many more I will have. It is time to send my entries for July to the University. I think that although I am struggling today, July has not been a bad month. Physically there has not been a great deal of change. My left shoulder gives me quite a lot of pain and discomfort. My legs feel stiff and heavy but I still can get around the house. Emotionally, I have been more up than down. As far as services are concerned, I have all the equipment now that I need at the moment. The wet room is progressing and the Motability car has been ordered. Family and friends continue to be a great support and are very tolerant of my vicissitudes.

Frank:*All my mountaineering friends are concerned that I should look after myself: that I should go for a walk/bike ride/etc and keep fit; that I should have a break from my 'caring duties'.*
OK I'll admit it, I'm not as fit as I was, drink too much and am fatter than I was. However, I can still manage to cycle twenty miles in two hours, or walk up and down a two thousand foot mountain and spend a day gardening. Yes, I don't do as much as I used to but it's about priorities. I need to keep fit and well in order to be able to look after (Jackie) but I don't want to spend so much time doing this that I lose precious time with her. We have always been close and I know I am going to lose her. I want to enjoy her love and company as much as possible whilst we are able to talk, laugh, smile and even cry.
I don't want to sound ungrateful, because all are concerned and want to help us both through this awful time. It is good that friends keep in touch and want to help – it must be awkward for them. I know that I didn't know what to do when friends were dealing with illness. I probably said and did all the wrong things; my natural instinct would be to run away! I need to keep in touch with friends and 'be in the loop' but I still feel as though I'm on the 'other side'
I just hope everyone will understand because I can't do it any other way.

Journal Extract3

August 2 Jackie:Champagne! I never used to like the stuff but recently I have got very fond of it and now it is any excuse to have a bottle! It started when (name of friends) brought us some to celebrate the completion of the new bathroom. I remember the large bath filled with bubbles and us toasting each other with the bubbly. What fun!
Then we had a bottle to celebrate the New Year. We watched the fireworks over Kendal and made resolutions to have more respite for dad and more time for each other. (What irony!)
Our birthdays were another excuse to pop the corks, as was an extra birthday meal for (Frank) in Moffat with our friends.
Last night the excuse was our wedding anniversary -- 38 years!
We had a lovely day yesterday. (Frank) drove me to Coniston and we went to Low House so that he could change the key code. We had lunch at the Church House Inn before driving over Ulpha Fell to Wasdale. It is such a long time since I have been there and it has always been a special place for us. Without being asked a young man came up to us offering to take photograph! It was so nice of him and I started to get a bit weepy. It was the only time all day that I did, so that is an improvement! We then drove over Hardknott and Wrynose and then to Langdale. The scenery is wonderful and I am getting used to just looking at it instead of being able to be in it 'properly'.
So, today I am tired. It is hard trying to pace myself. I was exhausted after the week away and was keen to get home. The weekend was lovely and peaceful but then the builders came back on Monday and I struggled with having them here. I had a few bad days when I was very weepy. I hate being so tearful. I read somewhere that the frontal lobes are affected by this disease and that is why tears come so easily. I also have found that when I am tired I am never far away from tears. I was warned that fatigue played a big part in MND and it certainly seems to do so. The important thing therefore is to try not to get too tired. This means not overbooking and making too many plans but if I have too much time on my own I get too introspective and then the self-pity starts which I absolutely hate. I also need to have some plans otherwise I start thinking that all I have to look forward to is deterioration and death. It is so strange not to have a purpose in life. I have always been a busy person, working, bringing up a family, looking after parents etc. I know it is important 'to be' and not just 'to do' and I know it is important to live in the 'now' but it is not something I find very easy. My yoga teacher has lent me a book on Christian meditation. It is one thing to read about it and quite another to do it!
I hate it when I start feeling sorry for myself. I am so blessed. I know that I am held in prayer and this helps me a great deal. I have a wonderful husband and family, and fantastic friends. I live in a super house in a lovely part of the world. I have two friends currently dealing with cancer. I am so very lucky not to be dealing with surgery, radiotherapy or chemotherapy.

August 10th Frank:*It is now six months since the initial diagnosis. How life has changed.We have hopefully negotiated the bureaucracy of motabiity and should be getting our converted Kangoo soon. That entailed more forms to complete, a fight to get an appointment at the DSS to get them stamped, which meant a journey into town and pushing (Jackie) in her wheelchair across town (it isn't easy getting the electric wheelchair in and out of the boot!)*

The wet room is now useable – the tiling is complete and the shower, washbasin and toilet are in. It is looking good but we are still awaiting the electrician to fit a fan and connect the loo - so (Jackie) cannot give her bum a wash and blow dry yet! Then there is some joinery for Jamie (the builder) to complete and painting to be done.

Ironically we are lucky we bought this particular house with (Jackie)'s dad in mind. If we had been moving to Kendal on our own the likelihood is that the house we would have chosen would have been totally unsuitable and we would have been desperate to move. Similarly having looked after (Jackie)'s mum has taught us to try and anticipate (Jackie)'s needs, however emotionally difficult that may be. We were always responding to crisis situations with Joan. By the time we had bought the equipment she needed or done the adaptations it was almost too late and she needed something more.

All this pushing to get things done has been tiring physically as well as emotionally. (Jackie) is learning to pace herself better and we try not book too much. We are avoiding the MND clinic in [(name of hospital). When (Jackie) contacted the MND nurse about the increasing discomfort/pain she is getting in her left shoulder we didn't get much useful advice. The nurse found it unusual that this was occurring but the books we have borrowed from the MND association do indicate that it is common. As the use of muscles in the arm are lost, the shoulder is no longer held together firmly and this puts strain on the joint. Those few muscles which still work are trying to compensate and go into spasm. (Jackie) was advised to get it checked out by her own GP but all she could do was prescribe coproximol.

We have been using a shoulder brace and arm sling (courtesy of the physio), as well as cushions. In bed (Jackie) uses an extra pillow to try and support the arm. I massage the shoulder with oil when the muscle spasms are really bad and (Jackie) is now taking paracetemol all the time and the occasional naproxen. Even the choice of painkillers (Jackie) had to research herself! This does not make for a good nights sleep and I find myself migrating to a spare bed when (Jackie) is trying to get comfortable in the night.

Diversion therapy is best. We don't have a holiday to look forward to as yet but went to the cinema to see Mamma Mia last week – great escapism! (name of friend_ came up on Saturday and (Jackie) and he chatted all day. He gave me some tuition on the mac and I have been organising the photos into iphoto. Looking at all the photos has been good – We have packed a lot into life over the years.

August 15th Jackie: It is two weeks since I last wrote this diary. I just have not been able to summon the energy or inclination to do so. (Frank) did last week's entry and so now I must try to do this weeks. I have just had a phone call from an old school friend who lives in America. It was such a surprise to hear from her and in some way that has motivated me to try to update the Journal.

There have been times during the last two weeks when I have felt at peace and contented. There have been other times when I have felt despair and great sadness. I suppose I should be used to the ups and downs that seemed to be part of this disease. I think reaching six months after diagnosis was a psychological hurdle for me. This disease is not going to go away and I cannot begin to conceive how I will be in six months time any more than I could conceive how I would be now, six months after the initial diagnosis. I try not to dwell on the future and most of the time and manage to live day by day but sometimes I just cannot do it.

The last two weeks have been very busy by my current standards:

A visit from the vicar from St Catherine's at Crook which was helpful. Another friend sent me two little books of prayers which I found comforting. I found time to read my Bible, to pray and reflect. (Name of friend) called today and will take me on Sunday so I do hope I can get up in time!

Visits from friends in Staffordshire were wonderful. Helen came from Lichfield - a long way on her own in the day but it was good to talk to her. Sandra and Pam came from Burton, again for the day. It was great to see them. However it was very sad to see these friends go and wonder whether I will see them again.
(Name of son) visited also and I always find it peaceful to be with him.
(Name of daughter) visited both on her own and with Jack. It is good to spend time with my son and daughter.
Sunday lunch at (Names of friend's) was lovely - good food and time off for (Frank) too.
Then there was a doctor's appointment, the physiotherapist called, some more work was done on the wet room, and a visit to my father, a cinema trip to see Mama Mia (great fun!), the hairdresser's visit, hydrotherapy, a wonderful reflexology session and a visit to the job centre to sort out the paperwork for the Motability car.
So once again I am so very tired. What should have been a quiet couple of weeks seems to have been a very busy time. And when I get tired I get down and when I get down I get tearful. Pacing myself is not easy. Every night I get up several times as I need to change position and get uncomfortable. It is then difficult to get up in the morning. I am amazed how little I can do before feeling so weary. This week I was just too tired to go to hydrotherapy and I also couldn't find the energy to go to a cheese and wine party at a friend from church's house. I sleep better on my own as I am then not afraid of disturbing (Frank) but then I miss him dreadfully. So we usually start off together and he usually leaves to the in the spare room in the middle of the night. He looks very tired and drawn at the moment. I am so used to trying to cheer him up or make things better for him when he is down that it is difficult now that I cannot do that any more. I do worry about him. He wonders if this tiredness is all part of the MND or whether there is another reason. Sometimes I think it is all in the mind but both (name of daughter) and (Frank) have separately, commented that it is when I get tired that I get in low spirits rather than the other way round. I had tests a few years back for possible thyroid problems so maybe that needs looking at again.
I have just read what I have written and nearly deleted it all for sounding too depressing but (Frank) insists that the whole point of this diary is to be honest. There have been some good times in the last two weeks and I have enjoyed reading various novels in my green chair downstairs. The weather has been particularly bad as well. Apart from the day that (name of friend) came it has been very grey and with a lot of rain. Summer seems to have gone away. The new car is to be delivered on Monday and then maybe I will be able to get out with me electric wheelchair and get some fresh air. We have a meal at a Spanish restaurant to look forward to and also a visit from (name of friends). We would like to try and arrange another holiday but cannot decide what we can cope with.
I continue to feel well supported with everybody's prayers, thoughts, cards, e-mails and photographs. I love to hear from all my friends and to get their news and to know what they are up to. Even though I don't always get round to replying it is such a boost to hear from everyone. I am so blessed with friends and family.

August 18

Today I feel like a new woman! When I said that to (Frank) he said that he felt like a new one too but that he is stuck with me!
The reason I feel good is that I actually slept for six whole hours without waking up and I haven't done that for a very long time. Also yesterday was a really good day. Friday night was dreadful. A neighbour's alarm went off in the middle of the night and was so bad I ended up going downstairs and dozing in my green chair. Saturday I was like a zombie and although tired on Saturday night kept waking up every two hours because my shoulder was playing up. So I cannot believe I slept for so long last night without needing to move, wonderful.
I went to Church at Crook. It is so lovely and peaceful there and so different from the noisy hurly-burly of St Thomas's which I cannot always cope with. (Name of friend) took me there and back, she

is so nice and really came out of her way to fetch me. Sometimes I think I should make up my mind and just settle at one church but they are part of the same group so I don't suppose it really matters. Then at lunchtime (name of friend's) came, our old neighbours from Rolleston. They came armed with homemade goodies and vegetables from their garden. We saw a recording of their son's wedding in New Zealand and it was just like being there, we really enjoyed it. We thought that (names of friend's) were en route for Scotland but their plans had changed and so they just came and went back in the day. I am overwhelmed by the friendship that has been shown to me and (Frank) both here in Kendal, from people we haven't known very long, and from friends elsewhere. It really is worth the effort to see friends even though I am usually very tired the following day. I really resent getting tired from appointments to do with bureaucracy or prescriptions.

August 25th Frank:*A week ago Gowrings delivered our motobility WAV (Wheelchair Adapted Vehicle) which has made such a significant difference to the quality of our life. (Jackie) has regained some of the independence she has been losing and every time we go out and she can motor around, on her own, in the electric wheelchair she has a grin from ear to ear!*

Tuesday saw us in Ambleside. We parked near the Rohan shop but decided not to get the wheelchair out as pavements and kerbs didn't look easy for a trial trundle. She struggled to walk to the shop but managed to find some clothes that were easy to get on, light to wear and don't need ironing (Parker doesn't iron!)

We then stopped at Hayes garden centre. That was great – no kerbs, automatic doors, wide isles and a lift with controls at a sensible height to get to the café. We chose plants for the garden and could go off independently looking at things. (Jackie) didn't feel 'travel sick' because she couldn't anticipate which direction I would push her next. It was so easy to get the chair in and out of the car – open the tailgate, drop the ramp, attach the inertia reel safety straps and drive in – then secure the rear of the 70kg wheelchair.

Wednesday Sue came. We went to Wilf's café for lunch and afterwards (Jackie) and Sue followed the river Kent and explored the craft shops around the café. Again she was smiling at her regained freedom.

Thursday (Jackie) was tired because she hadn't had a rest in the afternoon on Wednesday but she came round in time for us to take (Name of daughter) and Jack up to the Eagle and Child for lunch and then out in the wheelchair again with them.

Friday and we were in Booths and (Jackie)<u>helped</u> me do the weekend shop.

Saturday we went to Arnside along the sea front and followed a path along the coast (until it became too rough). She could get the wheelchair into the beer garden of the Albion which overlooks the estuary (but there was't sufficient room to negotiate the chair into the pub to the disabled toilet – that was a walk!). Then a trip to Leighton Moss where the paths to the hides were just wide enough to negotiate and smooth enough not to shake her neck around too much.

It was June 4th when we saw the physio and started the process of getting the wheelchair. It has taken a lot of hassle and paperwork for (Jackie) to regain some of the independence she is losing. The need to be referred by the physio and then an assessment by wheelchair services. The long wait for that and then the chair has to be ordered together with the extras (headrest, lumbar supports etc.). Then delivered before we can have a demonstration of the WAV (which all motobility dealers are obliged to do before they can supply a vehicle). Forms to complete to order the vehicle and forms for motobility. Delays because she put her name as (Jackie) rather than (Jacqueline)! More forms to have to take down to the local DSS to have stamped…….

It has been worth the hassle and delays.

Our wet room is complete and useable but we are still waiting for the electrician to fix a more powerful extractor fan and connect up the 'wash and blow dry' bit of the superloo! (Name of daughter) said how well we had got things in place for (Jackie)'s needs – Our experience with (Jackie)'s Mum and Dad has been invaluable. I wonder how other MND sufferers and their families cope.

(Name of friends) came across from the MAM mountain biking weekend at Coniston yesterday. I went for a ride up Longsleddale with them in the afternoon whilst (Jackie) rested. They stayed for a meal with us before going back to Low House. It was good for us to see them and for me to get some exercise. It was also good that (Jackie) found that she was able to deal emotionally with us going out and leaving her. It cannot be easy accepting loss all the time. I think that the increased mobility independence she now has is a help.

August 31 Jackie:Today is not a good day! A bad night's sleep and then too late waking up to go to church. It is grey and raining yet again and very muggy. On top of that I have just spent quite a lot of time talking to my computer and doing this week's entry for the diary. And then, idiot that I am, I have pressed all the wrong buttons and lost what I wrote. So here I go again! I will not to be beaten! It has taken me all weekend to summon up the energy to do this diary and I promised (Frank) that I would do it this week. (Name of daughter) and the boys went back home on Friday morning and since then I have done absolutely nothing. It is not that they are demanding but that any effort on my part results in me needing a few days to recover.

Physically the disease is progressing but I am only aware of this when I look back and realise that I can no longer do things I once did. My voice gets very croaky if I talk too long but I can still swallow and eat normal food. In fact I have put weight on and have needed to buy bigger trousers. I have also started wearing shirts as they are easier to put on than other tops. My left hand, arm, shoulder and shoulder blade continue to bother me. I wouldn't say that I was in pain, just discomfort. It is okay in the daytime but at night it causes me problems and I find that I keep waking every couple of hours and need to move. Sometimes I am awake for quite some time trying to get comfortable. I have a physio appointment on Monday at the hospital to discuss the possibility of acupuncture. We will wait and see. My legs feel tight and stiff but I am still able to stagger about the house and can still walk across the garden to fill up the bird feeders.

Equipment-wise we seem to have everything we need at the moment. The special toilet is waiting to be commissioned by Closomat but can be used in the normal way. The wheelchair and new car have made the biggest difference. (Frank) has got the knack of putting the wheelchair in and out of the car quite quickly. I could sit in the wheelchair in the car but prefer to sit in the front passenger seat whilst able to do so. I have been to the supermarket and have been able to whizz up and down the aisles fetching different items to go in the trolley. When (name of daughter) was here we all went to Grange one afternoon and I was able to watch the boys in the park and go up to them and talk to them -- magic. I was also able to race them up the promenade and even got into top gear! Such freedom is wonderful and much appreciated. We did try to get up to Scout Scar but that was not very successful. The wheelchair will go uphill quite well and it will also go on a path that is not too gravelly, but a path that is both uphill and gravelly is not good, and it kept skidding and I didn't like the feel of that at all. It is quite sad that Scout Scar is now off limits as we used to walk up there quite often just to get some fresh air as it is so close to the house. I have noticed that when I am being pushed in the manual wheelchair but I seem invisible and no one talks to me or makes eye contact. However when I am in the power chair driving myself about, lots of people say hello. This makes such a difference as it makes me feel so much better.

Emotionally I am fairly strong and am convinced that this is because of all the prayers, e-mails, cards, letters, and thoughts of all our friends and family. Sometimes I feel I live in a twilight zone as I spend a lot of time on my own resting and reading or catching up on TV programmes with i-player. (Frank) also spends a lot of time on his own doing jobs and doing all the things that I can no longer do. So this contact with our friends and family is very important to us both in different ways. Doing the diary has been both difficult and rewarding for both of us. The irony is that by 'going public' we have retained our privacy. The fact that people do not have to either wait for us to e-mail them or telephone us to find out our situation means that we are able to keep in touch much more easily, and that phone calls and e-mails can be shorter and more meaningful.

All the visits that we have had have been fantastic. We have to try to spread these out as best we can as we know that they are tiring but they are definitely worth it. Pacing myself is so necessary as

when I get tired I also get very tearful. I have mentioned this before but it is so true. Having the grandchildren to stay was wonderful and seeing my daughters is very precious. As well as (Names). called in, having now moved up here after selling their house in Sutton Coldfield. (friends) visited. Ian is the vicar at St Mary's in Rolleston and as he and (name of friend) are such busy people it was such a privilege to have them come here. I worked as Ian's administrator for 12 months when I gave up social work and he married (Names of daughter and son in law), baptised (grandson)and did the funeral service for my mum. It was very special seeing them again and to have them pray with me.
We have spent time discussing holidays. (Frank) said he was prepared to try to go anywhere I wanted but the reality is that we now need certain facilities. We need the car and the power chair and we need separate beds so that I don't disturb him at night. We have belonged to HPB for many years and feel that they offer the best solution. Most of their sites have properties that have been specially adapted for wheelchair access and with walk-in showers. We know what we would be going to and the standard of accommodation. There are also usually leisure facilities such as a pool and although they are self catering there are on site restaurants. The reason for holidays is different now as well. Partly it is so that we can still have plans. (All our lives we are planning what we are going to do next. I have discovered why the very old spend so much time thinking about long ago. If you have no future your mind starts thinking about what has happened in the past and I have started to do this. It is a very strange feeling remembering things I thought I had forgotten). The other reason is that (Frank) needs a break from all his domestic duties - he needs meals put in front of him and a change in routine and the chance to stretch his body in the swimming pool.
The key to living with MND seems to be to keep adapting. Life is not over yet, just very different. It is not as good as it was but it is still worth living and in many ways, (Frank) and I are closer than ever.

Journal Extract 4

September 7 The benefits of writing this diary are enormous and have been in so many unforeseen ways and on many levels. Gradually, it has been given to just about everyone we know and it saves having to answer questions continually from friends who want to know how we are. Instead, if they want to know they can log on and read it. Then any phone calls or emails can be about other things than the progression of my MND. Also, we have maintained contact with so many people all who send messages which in turn support us. So by taking the risk and being open and honest, we have gained in ways we did not think of. Many of my friends have reappraised their own lives and made positive changes as a result of what is happening to us, so that again has been a positive thing. Also, if it helps anyone to understand the ever changing nature of this disease that is good and if services can be speeded up as a result that is even better! To think, I only agreed to do it in the first place as I was so angry at the way I got my diagnosis and wanted to try to prevent anyone else being treated so abysmally!
As I dictate this I am sitting in my recliner chair downstairs watching the birds on the feeders and looking at the clouds scurrying across the sky. Today there are patches of blue amongst the grey and it's actually not raining. I love the gold finches especially but wish I knew how to get rid of pigeons!
I am learning to live in ‘the now’. It is taking some practising but it is very worthwhile. In any case, the future means further deterioration and I don't want to dwell on that. So I am grateful for what I can do now and hope that it is some time before things get much worse. People tell me how well I look and when I am sitting down chatting it is difficult to imagine that there is anything wrong with me. I had a yoga session and we are concentrating on meditation and relaxation and this helps me to concentrate on the present. So does church. St Catherine’s is so peaceful and the people therevery supportive.
I had two lots of acupuncture this week. It should have been only one but the physiotherapist is on holiday next week. The results were amazing! At that time I didn't feel especially relaxed and I didn't really feel the needles. I did have a weird sensation either side of my neck but that was all. However, later, I realised I was feeling a lot brighter and when (Frank) commented on it, I knew it wasn't my imagination. The second time, the discomfort in my left arm intensified but then the next

day it felt better and again I felt energised. I have been told that acupuncture releases endorphins. Perhaps I liked it because it made me feel a little bit like I used to after exercise.
I continue to enjoy using the power chair and only wish I had had it sooner. But wheelchair services were quick by their standards but until we had the chair we could not test drive a car and then we had to wait for a car. I love going to the supermarket and helping with the shopping and this week I was able to go around Marks & Spencer's choosing lots of clothes to try on at home.
(Name of friend) took me to hydrotherapy, having missed a few weeks. I still am not sure how helpful this is to me as the effort of dressing and undressing wears me out. However this week I managed just to enjoy the water and to float and did not even try to swim at all. This is very hard for me as I used to be such a good swimmer.
I have started to contact the people that I normally only write to at Christmas as it is highly unlikely that I will be able to do Christmas cards this year. I cannot write and I cannot put cards in envelopes, and I am sure that (Frank) will not have time to do all the cards for both ourselves and for Dad, as well as look after me. I have been very humbled by the replies that I have been receiving. One friend commented that in the beginning I had written in my diary that I wondered how God would help me to get through this. She said that from reading my diary it was obvious that God was surrounding me with caring friends and family. I have always known how important friends and family are but I suddenly realised how much God was doing for me through all these people. Sometimes it takes somebody else to point out the obvious!
We have had a lot of giggles this week trying out the closomat toilet! It is very effective!
We have booked to go back to Arran in about 10 day's time. Where we stayed last time has several rooms converted for people with disabilities and we checked them out when we stayed in May. Breakfast is served till 1130, and there are three restaurants to choose from in the evening. Then at the end of October we have booked with HPB for the Trossachs. It is important now to know where we are going and not to have too far to travel. It will be a much needed rest for (Frank). We have, however, discovered some ready meals in Booths that taste home-made so (Frank) can have a break from cooking whenever he is too tired.
September 17I am sat in my hotel room on Arran as I dictate this. Outside there is a lot of low cloud and the weather is not at all inspiring so whilst (Frank) has gone to a WiFi area to collect e-mails, I have decided to update the diary.
Last week was all about managing fatigue. This seems to be an ongoing feature of MND. (Name) came from the Isle of Man to visit me. She is an old friend from university days and I haven't seen her for a very long time so it was lovely to catch up. She had wanted to come for longer but very kindly agreed to shorten her visit when (Frank) explained how easily I got tired. I was really exhausted by the end of her visit even though we had done very little except sit and chat. I did not have the energy to go to church group and the next day I did nothing at all. On Thursday I went to hydrotherapy and although I quite enjoyed floating in the warm water I was totally and utterly wiped out afterwards to such an extent that I do not feel that it is doing me any good. (Frank) wants me to stop going. Saturday was The Torchlight Carnival in Kendal and (name of daughter)zie and the children, and Tom and Ali came for the night. The children loved the pageant and enjoyed the light wands that we bought them. On Sunday, we all had lunch together and Tom did all the cooking. It was a lovely meal and (Frank) really appreciated having a meal put in front of him. Again, after everybody had left, I needed to rest.
When (Name of grandson) visited last time the new toilet had been installed but not commissioned. He had asked what the silver tube was in the toilet bowl. So I told him and explained that the tube would come out and squirt water to wash the bottom of anybody sat on the toilet, and that then a dryer would be turned on afterwards. (Name of grandson) just looked at me for a moment and then said ' don't be so silly Nanna ' ! So this weekend, (name of grandson) remembered the new toilet and wanted to know if he could try it out. (Frank) let him sit on it but the problem was he was so light and his bottom wasn't big enough! This meant that the water was squirted everywhere. Both he and (Frank) got very wet and there was great hilarity!

On Monday I was very upset to get a phone call from the hospital to say that the physiotherapist was off sick and that my acupuncture was cancelled for the following day. I had been really looking forward to another acupuncture treatment because it had been so helpful. However, it meant we could change the ferry booking and get to Arran earlier on Tuesday.

In January we went to Lanzarote for a week and took hand luggage only. What a difference now! Our car was packed with two wheelchairs, a big bag of pillows and cushions, shoulder supports, and a bag containing my towelling robe in case I wanted to try and use the sauna. The boot was nearly full before we started with clothes, books and computers. We took our time driving up to Ardrossan and had a couple of stops. We took the manual wheelchair in the lift on the ferry and I coped with the ferry journey of one hour very well. The hotel is quite close to the ferry terminal but I was very glad to finally arrive and flopped on the bed exhausted. I am not sure that I could cope with air travel any more as it would be about four hours of just getting to the airport and hanging about at the airport before the fight started. Then there would be the time of the flight plus any driving time the other end. It would make for a very long day with no opportunity to rest. In any case, holidays are now more about (Frank) getting a rest, having all his meals put in front of him, having someone else make the beds and tidy the room and having a change of scenery. I hope the next few days will achieve this.

September 22nd. Arran was a good break. The skies were grey most of the time but it was dry and we were able to get out every day. We did two wheelchair walks. One day we took the coast path which meandered through the golf course, around the dunes, over some streams and through overgrown paths. We certainly went to places that the wheelchair services would probably not approve of! It was good fun, great to be beside the sea and in the fresh air. Another day we had coffee and cake with (Name) and his wife. We had bought some of (name's) pictures and he had invited us to his home. They were a very interesting couple who made us very welcome.

The swimming pool at the hotel had problems with the heating which meant it was warmer than usual, so when (Frank) tried it he found it a bit too warm swimming and thought I might like it. So he wheeled me in, wrapped in my towelling robe, and helped me into the pool. I floated on my back for a while and then he towed me up and down -- magic! I then staggered into the sauna which was very enjoyable. Afterwards, I did not feel tired as I do following hydrotherapy so we are wondering if it is a combination of the very warm changing rooms plus the hassle of trying to get dressed that makes me so tired when I go there. We might try using the same method to see if it is any better before I give it up altogether.

(Frank) enjoyed having a rest and the meals -- breakfasts were very good and the evening meals splendid. Our bedroom was on the ground floor and breakfast was served upstairs. I could access this by going in the lift in my wheelchair and then by using Stannah lift to get up a short flight of five steps and which was operated by the restaurant staff. On the last morning the Stannah wasn't working. It was quite entertaining being stranded waiting for the engineer to come and try to mend the lift. Other hotel guests stopped to chat, offer advice, assistance and to lend me newspapers to read whilst I was waiting. In the end I went back downstairs and we had room service.

The ferry journey back was frustrating for me. The sun was shining but I could only access the enclosed passenger deck. I used to really love being outside on ferries feeling the wind. Another loss. I shall soon have to face up to moving downstairs to sleep.

I use my wheelchair all the time and it gives me such great freedom. I went to church at Crook on Sunday morning and took the wheelchair for the first time. I felt a bit conspicuous and tried to hide at the back but was persuaded to move alongside some friends right in the middle of the aisle. I felt a bit like the Queen on the throne!

I have just had acupuncture and had a few more needles this time. I certainly have slept a lot better since starting it -- long may it continue!

Sunday September 28

What a glorious day today! After the extremely wet summer the last week of dry and often sunny weather has been very welcome. Today was especially warm with blue skies, white fluffy clouds and

the beginning of autumn colours creeping into the landscape. I missed church. After a busy few days and a bad night's sleep I was very late getting up this morning. I was tired but determined to make the most of the weather so we took a picnic and headed out. First of all we parked by Helsington church and I trundled around in my wheelchair enjoying the wind on my face and the feeling of warmth from the sun. The views across the fells were fantastic. In my spirit I was walking high up, with my boots on, and my rucksack on my back. I was striding out along mountain paths, clambering up rocks, crossing streams and arriving breathless on the summit. However, in my body, I was just making the most of what I am able to do. My uncomplaining husband never once mentioned that he wished he was elsewhere.

Yesterday he took me to Coniston to meet some friends but first drove up to the Walna Scar Road so that I could get the feel of being in the hills. The path is too rocky for my wheelchair and I couldn't go very far but it was so brilliant to be there and to see the bracken turning the hillsides brown and orange in the sunshine. After a fish and chip supper at the pub Janet brought me home and (Frank) went to the committee meeting -- his first for many months. It is good that he feels able to start to get involved again.

Also this last week, I have been to the dentist, visited dad, had a yoga relaxation session, had a meal with some friends at their house and met Jack from his new nursery. One day, we drove over to Keswick and I was able to trundle my wheelchair on a path around the lake for a short distance. I don't know what I'd do without the wheelchair and I am so grateful that I can get out into such beautiful countryside so quickly and easily.

I continue to receive letters and e-mails from friends. At church group on Tuesday evening we were talking about blessings and I know I keep saying it but I really do feel very blessed. Given my limitations I feel I live a very full life. As long as I have a rest and pace myself, I manage to do something every day.

But of course all of this is only possible because of (Frank) and all that he does for me. He really has given up his life for me.

Tuesday 30 September

Yesterday, after visiting my father, I went for my fourth session of acupuncture. It really does seem to be helping me and I feel so much better.

It is the end of another month and time to send the September diary to the researcher. It always makes me aware of the passage of time.

Today I went to the MND clinic but instead of going to [(name of hospital) I went to St John's Hospice at [(name of hospital). The specialist nurses are doing clinics both at St John's Hospice and at St Mary's Hospice in Ulverston. As we live halfway between the two I can go to either. Next time the plan is for me to go to Ulverston. This way I can get to visit both hospices which will be useful for the future!

St John's is a purpose-built hospice and has a new day unit which has just been opened. It was a peaceful place and the grounds were pleasant, with lovely lawns, flower beds and lots of trees. I didn't mind in the least going there and won't mind going in there in the future.

When I came back from my church group feeling quite positive, I found (Frank) quite depressed. Going to the MND appointment had not been at all helpful for him.

On the way, in the car, I had filled in a questionnaire about my abilities and that had really started him thinking of all the changes since I had last gone to a clinic.

Seeing a new nurse had been difficult because of having to go through everything again. It was the first time I had to do this for a very long time and yet again I realised how much the Journal has helped me in this respect. (Frank) had also found it difficult going to the hospice. As I have spent my working life in a medical setting and nearly went to work in the hospice once, I felt comfortable there. I have always believed that the hospice movement is so worthwhile and have always thought that if I cannot die at home I would be happy to die in a hospice. I really do not want to die in hospital and unless it is absolutely necessary.

We try and live from day to day and we do not avoid talking about the future and we have been quite good at certainly planning for physical needs. The problem with appointments is that they force you to think about these matters then and there and not necessarily when you want to do so.
In many ways the appointments seem a waste of time as all that is happening is that my deterioration is being monitored but I do know that if we weren't offered any appointments we would probably feel neglected! So really, it is a no-win situation.
We came away with some positives however, in that we were told that a special bed could be available very quickly when I need it. We were also offered complimentary therapies at the hospice. This was for both of us which was nice. (Frank) needs a treat too.
I suppose I am luckier than (Frank) in that I have faith to sustain me. I want to end with a quote from a little book of Celtic prayers by David Adam:
"The joy of prayer is in learning to rejoice in and rest in the presence, the peace and the power of our God. If we don't seek to do this, we must be caught up in the madness of the world. We will end up being weak-spirited and unable to cope if real troubles come."
Frank: *(Name of daughter) said she found the diary useful to her, especially the bits I write. Mother and daughter have always been able to talk – it's a woman thing! I suppose I've opened up more in this diary than I could ever do face to face – that's a Man thing!*
It's been useful for me to be grumpy about things which don't work, take a long time to get or are bureaucratic nonsense, but it has also been therapeutic to talk about the effect it is having on me. Besides which, it will save a fortune in counselling!
(Jackie) doesn't get upset as often as she did, but when she was talking to the physio about swimming tears started. Even I, who am helping (Jackie) all the time, was shocked when the Physio was checking out the mobility in her left arm. He was asking her to raise it as high as she could, and move it out to the side etc. I could see her willing it but it only moved a cm or two – the only way she lifted it was to use her other hand. In Arran at the end of May we bought a swimming aid to go on her hand so that when she swam crawl the water didn't go through her fingers which she was unable to hold together. Now she cannot swim at all.
It really is important to be confident that the facilities we go to are 'disabled friendly'. I went back to the Spa we joined in Bowness today after dropping (Jackie) off at Crook church. The new pool and Spa facilities were completed in 2007 so you would expect, in view of the disability discrimination act, for it to be easy for (Jackie) to access and use. Not so! The Spa is accessed through the Hotel main entrance – two steps and a revolving door. To get in one has to ask the doorman to fold the revolving door and put a ramp over the steps. The ramp, however come very close to the edge of the pavement – and there isn't a ramped curb of course. (Jackie) would have to first ask the doorman to put the ramp over the curb – then she have to manoeuvre to one side whilst it was moved to the door – then a turn that would take one set of wheels very close to the edge of the pavement before a ninety degree turn to get on the ramp! After that we would be inside the building and, given the present weather, pretty wet. The problems don't stop there. There are some sufficiently wide corridors to the back of the hotel to the lift down to the Spa. We couldn't use the lift in the entrance as the lift doors aren't wide enough. The new lift to the Spa has wide enough doors and is big enough to accommodate the electric wheelchair but if (Jackie) is negotiating it on her own (I have doubts if I could get in as well) she will have to ensure she is facing the right way to use the controls – which will have to be on her right. Next problem is the door into the Spa – How does a person in a wheelchair open a heavy, extra wide, fire door with only one weak arm – and use that arm to manoeuvre the chair?
It isn't that (Jackie) wants to use the facilities of the pool (too cold), sauna or steam room – This is where the only disabled loo in the whole building is – unless of course it is being used for family changing – in which case (Jackie) would have to cross her legs and hope!
We tried using the disabled/family changing room a couple of months ago: No chair for her to sit on whilst getting dressed/undressed; no mirror; no hair dryer (which was perhaps as well because the shower head would rotate under the pressure of the water and soak everything!)

I think all architects and planners ought to be strapped into a wheelchair for a fortnight as part of their training!

I found it all very depressing. I was hoping the Spa was something we might still share, even if (Jackie) just sat in the lounge reading the papers or having a coffee overlooking Windermere. The Spa is something that we joined together and we enjoyed swimming and relaxing together. Instead it brought it home to me that (Jackie) wasn't the only one who has to cope with constant loss.

The only problem I had was that (Jackie) saw another one of the three MND nurses – someone else to get to know and explain things to. I suppose we may have to deal with whoever is available if we need help so it might be useful in the long run. Talking about what (Jackie) was (and wasn't) able to do highlighted the disease's progress. We are aware of that but this time when she blew into a machine her lung function registered 98% instead of 120%. At least staying fit and swimming whilst she could means that she has started off at a high level.

Journal Extract 5

October 6 Jackie: Today is the birthday of my eldest daughter (Name of daughter). We took her out to lunch and it was very pleasant! Another sunny day! How I do love autumn.

The problem with lovely sunny autumnal weather is that it makes me want to get out and tramp the hills. I thought I had got used to not being able to do this but yesterday in the Langdale Valley I found myself getting quite upset just looking at the hills and not being to get into them. It is quite a hassle trying to find places in the countryside that are wheelchair accessible. One of the reasons I used to like walking in the hills was that I could get away from the madding crowd. Now I am stuck in a wheelchair it seems that the only places that I can get to are visitors centres and the like which tend to be very busy places. We did have a really good wheelchair walk however, last Friday, when we went all the way round Tarn Hows. Last year they redid the paths to make them accessible. We have been waiting for good weather when it was not the school holidays or the weekend so that we could avoid the crowds. It was a beautiful day.

Another hassle, being disabled, is connected with accommodation and going away. We have been invited to a wedding blessing next month and we thought it would be nice to go to. However, having a daytrip is too exhausting. The best way is to pace myself and therefore we decided we would have a hotel stop overnight. We could take our time getting there and then I could have a rest and then I would be able to cope with the following day. (I would probably get home very tired so would have to make sure that there was nothing in the diary for a couple of days afterwards). So then I started to try and find a suitable hotel. It was amazing! Most of them did not have ground floor rooms and even those that did and said they were "disabled", in fact had showers over the bath. When I explained that I need a shower to walk into, one hotel said that they had rooms upstairs with wet rooms but further enquiry showed that there was no lift to get up to them!

Going out to cafes is just the same. I have to check where the toilet is and whether the dining room is upstairs and if so whether there is a lift. The other day when Jack and (Name of daughter) came we decided to go out for tea and cakes. Sizergh Barn has just put in a new lift for wheelchair users and also disabled toilets, so we went to try them out. Success!

My cousin and her husband came on Saturday and stayed the night. They were very helpful in various ways including helping me sort out the family tree. They have also gone home with envelopes and stamps and letters to print off to various friends and relatives that we are rarely in contact with and also to my father's friends. This is a huge help as I can no longer deal with correspondence. She came with me to visit my father on Saturday afternoon and then on Sunday we had lunch out before they went back. It was lovely to see them but yet again I found myself very tired afterwards. I think I make an effort, without realising it, to chat and to catch up because I really enjoy it. I just forget that it does make me tired. They commented how well I looked. Most people say this and when I'm sat at the dining table, chatting away, it is easy to forget that I have a problem. She I will be able to deal with. Hurray!

We are off to Northumberland tomorrow for a few days in a hotel. (Frank) is ready to be pampered again! No beds to make! No meals to cook! No food shopping! No washing up! Just me to help with dressing, undressing and general sorting out!

October 13 Frank: *(Jackie) had been talking about getting to the top of a mountain over the last week or so – getting a helicopter ride or being carried up on a sedan chair. Well this is the best I could do! - read on.*

Last week we spent a few nights in Northumberland thanks to Jill who found and checked out a suitable B&B. We left Tuesday and even though I did all the packing (Jackie) was tired from just getting up and getting organized.

We had scenic, if wet and windy, drive to Hexham stopping briefly to struggle with the wind into a café at Hartshead Top. It is important for (Jackie) to have food at regular intervals - they did great wholemeal toast! We stopped for soup at Jills but (Jackie) crumpled after a couple of hours and we left to get to the B&B. (Jackie) needed to lie down and doze for an hour to recover.

Our visit to Kielder was great. The facilities and lakeside path are suitable for a wheelchair and we did 2-3 miles of the available 17! The autumn colours were glorious. At Kielder village was a forest drive. Only 4 by 4's and other suitable vehicles – that had to include us of course! We stopped at the highest point, Blakehope Nick (1500ft) and got out to admire the view – brilliant. On the other side of the forest was Carter Bar viewpoint on the border. Here I got the chariot out and we bought a hot dog and tea at a mobile café - with views of the Cheviot and surrounding hills. Back at Wark (our B&B) another rest and doze for (Jackie). A good, if somewhat tiring day.

The following day we visited Alnwick where we parked at the Gardens and had a snack. Then off to Lindisfarne. By the time we got there (Jackie) was on a low and needed food. The Pub we approached first had steps, the hotel we tried had a step – they said they had a ramp but someone had stolen it! Third time lucky we found a nice tea shop with level access. We felt it was all a bit tacky. Our experience of trying to get in for food wasn't good - perhaps we should have tried the mobile chip shop outside the entrance to the castle!

We went home via the scenic route along Hadrian's wall. Awful weather again but we called in at Vindolanda. They couldn't have been more helpful with access. Didn't charge (Jackie) and gave us a pass to go and park right outside the museum. Well worth the detour and although the excavations would not be accessible, the museum was. We both found the artefacts absolutely fascinating – in particular the writing tablets which gave such an insight into everyday life at the fort.

Sunday was busy. I took (Jackie) to church as, with using her wheelchair now, she cannot get lifts any more. Afterwards Kevin and Sarah called in. I could see (Jackie) drooping and her voice was going so they left and after a late lunch (Jackie) had a snooze again so she would have the energy to cope with (Name of daughter), Jack and, unexpectedly Tom.

Monday (Jackie) had another session of acupunture and then off to the garden centre for lunch and to buy some bulbs. (Jackie) used to enjoy gardening because it was a way of getting out and having some fresh air even if we didn't go for a walk. I suppose the garden centre is a substitute. At least access is not a problem.

27th October Jackie:We are on holiday in the Trossachs. Yes another holiday! But then why not? After all, the time for holidays must be running out. In fact the one regret of my life is that I have not travelled more widely. After university I thought of doing VSO but then I met (Frank) and didn't pursue it. After we married we had no money to go far - a social worker and a teacher don't earn the sort of money to travel the world especially when there are three children and a mortgage. Still, it didn't bother me as I thought that when I was 60 and drew my pension I would have a lump sum and have a gap year late. I was going to make up for lost time. I didn't reckon on getting MND! Anyway I digress.So we are at HPB at Tigh Mor on Loch Achray in the Trossachs. I am sitting in the apartment looking at the light fading behind the hill. It has been a glorious autumn day. We have seen overflowing lochs, bursting rivers, tumbling streams, gushing waterfalls, glowing forests and remote mountains. The colours have been glorious reds, yellows, browns, russets, golds, oranges and green. The mountain tops have been capped with white snow brilliant against the blue sky. The

sun has shone all day. We drove over a pass, via Ben Lawers visitor centre, over 2000 ft high, and through Glen Lyon, and then back again. There was hardly any traffic and just miles and miles of stunning scenery. I have never been to Scotland in the autumn before. It is such a different, wonderful experience. We had lunch at the Kenmore hotel overlooking the River Tay with the mountains in the distance. We had afternoon tea in a cafe overlooking Loch Venachar. It has all been so beautiful.

We travelled up in glorious sunshine on Friday but the storm arrived at the same time as we did! All Friday night and Saturday, till teatime, it rained and the wind howled. In the late afternoon we went out down to the loch and couldn't believe how much the lake was overflowing. On Sunday we drove over to Aberfoyle and then down to Loch Katrine driving through floods. Boathouses were submerged along the shore of Loch Ard and the dry stone wall, separating the lake from the road, was under the water. At the David Marsh visitor centre I trundled around one of the Forest rails to the waterfall which was spectacular after all the rain.

In the evening, after I'd had a rest, we went for a meal at the on-site bistro. It was quite a novel experience driving my wheelchair in the dark.

It is the end of another month and time to send the diary to the researcher again. I always feel this calls for an update.

Physically, I am aware of the disease progressing. My legs are weaker and I cannot stand for very long. I stagger about the house but I really have to concentrate to walk. I can still do stairs but only once a day and it's getting harder. The muscles in my calves are quite wasted. My left arm is totally useless and very heavy. In bed I have to lift it every time I want to move. My right hand and arm is getting weaker but I can still use it and can still feed myself. My food has to be cut up into small pieces. I need a lot of help dressing and undressing and I get very tired with the effort of it. I still manage to stand in the shower but need to sit down afterwards. I do more and more sitting down. My facial muscles are affected a little bit and I have a lopsided smile. I feel numb around my mouth and it takes me longer to chew my food. I am also aware that I am beginning to slur my words sometimes. When I cry I feel my mouth being pulled downwards. It feels as if it is dragging and I cannot control it. It is very strange becoming aware of all these changes and not being able to anything at all about it. I don't like thinking of what is to come.

Family and friends continue to be a great source of support. We are grateful for everybody's offers of help, cards, letters, e-mails and telephone calls, and visits. Family life is different. Roles are changing. I can no longer help anyone. I miss playing with the grandchildren, babysitting etc. (Frank) no longer has the time or energy to help the family out with practical tasks. My daughter now helps me to go to hydrotherapy. I am grateful to the people who ring up and offer to come and see me and don't give up on me when I say, " no, I'm too tired" or "no I'm going away".

Professionals ring me from time to time to see if there is anything we need. I am grateful for their continued availability. I am glad that we faced the future and got the wet room sorted as I am now ready to use it. We have just about got all that we need at the moment. We know who to go to for what and most of the people that we deal with are very helpful or try to be.

Emotionally I am fairly strong most of the time. But we have found that it is the emotional impact of this disease that has had the biggest effect on both (Frank) and me. In the immediate months after diagnosis we were both on a rollercoaster of emotions. The shock of what we were dealing with was a big one. It took a lot out of us and took a long time for us to get to grips with it. I shed a lot of tears especially when tired. With a lot of prayer and support from friends and family, we pulled ourselves round and started to cope. I managed to get to a stage of acceptance and peace. Then I discovered this was not a constant state of being. The longer it goes on the more I realise how much there is to accept. Neither of us have "normal" lives. The change has been huge. Coming to terms with one stage is fine but then we know the next stage is only round the corner. The secret is living in the present and not worrying about what will come. Most of the time we can do that but sometimes it is not possible.

Like last week. On Sunday a week ago, I spent the day in tears. Again I think it started because I was tired. However, I also have to admit to struggling with feelings of envy. Several friends are about to embark on trips to New Zealand and Australia. I have always wanted to go to New Zealand since I read a book as a child. I am glad for my friends but once again I had to face the limitations of my situation, and self-pity crept in. The thing is it brought back all the longings that I have struggled to accept. It is hard not to be able to plan for the long term. It is painful not to be able to babysit or look after the grandchildren or help out my adult children in any practical way. I wish I could to all the ordinary things that as I used to do automatically. I hate getting tearful as it doesn't help and upsets (Frank) who tries so hard to help me. This was the first time I have been so low for a very long time. Counting my blessings helps and then I feel ashamed because there are so many people in the world who are hungry, homeless, without love or support, or in war zones or dealing with unimaginable horrors on a daily basis. (Frank) worries about me, I worry about him and all that he has to do. There has been a lot of media coverage about assisted suicide. It is hard to make a decision about such matters. Sometimes counting my blessings and resting in the God is easy but other times it is much harder but it is the only way.

A week on and I feel so much better. It did not help that (Frank) was busy trying to sort out downstairs and having finished the painting had started moving furniture. The reality of having to move downstairs struck me very forcibly and upset me more than I wanted to I acknowledge. It is another emotional hurdle though practically it makes a lot of sense.

Then on top of this, my daughter learned that her husband had lied to her and had after all been seeing another woman for many months. She was very hurt and upset. I found it all very difficult and wept a lot of tears.

But it is *never* right to wallow in self-pity.

So back to the present. The forecast is for more cold weather and possible snow showers. Whatever comes, today has been fantastic. We've just had a glass of champagne to celebrate!

30 October Another beautiful day! How blessed we have been this week with gorgeous autumn weather. A meal out tonight at the bistro and then tomorrow morning we head back home. I wasn't overly excited about coming away this week but I knew that (Frank) was keen to do is so. However, it has been a really brilliant week in every way. The weather has been fantastic, the scenery is stunning, and the apartment so very suitable and comfortable and also with lovely views.

On Tuesday although it was bitterly cold out of the sun, the sun shone all day. We took the wheelchair on its longest walk yet. (Frank) rode his bike while I trundled on the path that goes alongside Loch Katrine. I went to where the battery lights on my wheelchair showed halfway and then I trundled back again. There was snow on the hills in the distance, the sky was blue against the oranges and browns and yellows of the trees. I found it so exhilarating to be outside in the fresh air for so long. We took a flask and some snacks and sat looking at the lake. It was so quiet and peaceful. We reckon that I did about 10 miles. The battery on the wheelchair is supposed to last for 15 miles but it could be that the warning light showed early because of the cold. It was the best wheelchair walk I have ever done!

Wednesday was dry but dull and we had a lazy morning. In the afternoon we went to the pool which was warm enough for me to get in. (Frank) towed me up and down and then I enjoyed floating whilst he had a swim. I was able to get in the sauna which I really enjoyed as it has been a long time since I've been able to do that. It was good to be able to access the pool even though the corridor to get there was a bit narrow.

Today we drove to Balqhuidder along Loch Voil and to the end of Loch Doine. I trundled down a track towards a farm and we sat and watched buzzards circling up above. Again the autumn colours were glorious. We treated ourselves to lunch in a hotel overlooking Loch Voil and now I am back in the apartment watching an amazing sun set over Ben Venue.

What a wonderful week!

Journal extract 6

November 6 Jackie:We have been back almost a week. What a busy time! As soon as we got home (Frank) started to get himself organised for the working party at Low House and (Name of daughter) came to spend Friday night with me. (Name of grandson) was spending the weekend with his father). We are all very upset by the lies that (Name of son in law) has told -- it is so very hard to deal with. On Saturday a close friend came to help me so that (Frank) would feel able to stay in Coniston. I was very upset to learn that she has a recurrence of the cancer that she has fought so many times. We talked and she took me out, cooked me a lovely meal and it was a very precious time. On Monday, another glorious day, (Frank) and I met some friends at Wilfs café on their way back from Coniston. It was good to see (name of friends) and to thank them for the work they put into helping (Frank) organise the working party. After lunch, (name of friends) accompanied (Frank) and me on a wheelchair trundle towards Kentmere. The weather was too good to waste and I felt I was on an MAM walk for the first time for ages! On Tuesday I visited my father. He has not been at all well and had several falls whilst we were away. He was very sleepy and not his usual self. After that we met (name of grandson) from nursery and took him out for lunch whilst (name of daughter) had a meeting and later on he came to tea. Then the church group met here.

So by Wednesday I was well and truly exhausted. I got up very late and went to bed very early. I shed some tears as I always do when I'm tired but they were not tears of self-pity this time but tears of sadness. I am so sad about my friend as I feel she has had enough to deal with in the past. I am sad about my daughter and the situation she is coping with. I am sad about my father having to be in the home. I am sad that I may die before him and the difficulties that may cause. I am sad because other friends seem to be having difficult times. I am always sad thinking about leaving (Frank) on his own.

Despite the sadness this week, however, there have been happy moments -- a lovely bouquet of flowers and chocolates from a friend, more letters, cards and phone calls, the meals my friend cooked me, the time spent with my daughter, a phone call to my other daughter, the opportunity to be with my grandson, the surprise visit from (family) on their way to a wedding party, being with my church group, shopping in town for new bedding and blinds for the downstairs bedroom, curling up on the sofa next to (Frank) watching TV. I spend more time reading books than watching TV. However, I do like Autumn Watch as I enjoy seeing the films about the Farne Islands and Mull. I enjoy Stephen Fry's programme on America and have been watching the US presidential election. What historic times we live in.

So we carry on. It is now nine months since my diagnosis. Life is still worth living and we are living it as fully as we can. I try not to dwell on the future: the present is the only thing any of us have got. The present is okay -- no, the present is actually very good.

November 14

I spend a lot of time reading. This is nothing new as I have loved reading since I was a small child. Then it was Enid Blyton's, Noel Streatfeild's, "The True Books About" and so on. I was always at the library. Then I had a teacher who banned Enid Blyton's and made us read books on the ' Hundred Best books for children ' list. What favour she did me! Reading has been for escape, information, and for pure pleasure. Friends are lending me all sorts of books -- about the Lake District, Christian books, Chick Lit, Booker prizes -anything. I have only read three books however, by people with MND. The first one I read years ago about a young woman with very small children. The second one was lent to me by my local MND visitor written by a Swedish television presenter who had the disease when she was 50. I decided not to read any more as really the disease develops so differently with everybody. I am more interested in how people cope with the disease. Then, recently, I heard of the new book called ' My Donkey Body ' by Michael Wenham who is an Anglican vicar not that much younger than me. A friend had sent me an article about this book from the Church Times and another friend has sent me a flyer about it. So I bought it. I sat and read the book the other day in one go and found it hugely reassuring. Here is a man, a Christian, who is experiencing such a lot the same feelings and emotions as I am. He puts it more eloquently of course! This is a book I am really glad I have read. He talks about how he had always been ' a doer '

and how he had to learn just ' to be '. He also learnt that he was still valued for just being himself even though he couldn't do anything for people. He talks about the pain of seeing his wife doing all the jobs which they used to share, he talks about disability and society's attitude to it. He talks about so much more and it was helpful for me to read it. It may be one of those few books that I read for a second time. Initially, as a Christian, I felt I should be able to cope and didn't allow myself to get upset without feeling guilty. My counselling session helped with that but this book has helped even more. So once again I'm grateful to my friends who pointed me in the direction of the book.

My smile is getting more lopsided, I take longer chewing my food and I am conscious that my speech slurs if I talk too long or get too excited! My right hand is getting weaker and although I can still use it there are little things that I cannot do any more such as press the button on my perfume. Sitting up in bed is getting more difficult also.

This week I have been busy dealing with my father's affairs. When we realised I was the only executor for his will and consulted a solicitor, she said he would have to change his will in order to appoint more executors. This entailed a lengthy session with him trying to explain that I could very well die before him. Because of his Parkinson's he shows no emotion and it is very difficult to know what is feeling. I found it quite upsetting trying to talk to him about it all. However, when the solicitor visited him yesterday, she was very nice and the business got done more easily than I had anticipated.

Also this week we have been having the outside of the house painted (or rather treated). This has meant the doorbell going early in the morning and poor (Frank) having to get up and sort things out. Not that the weather has been very good for outside work. Also on Wednesday the sun shone all day. Our policy is now, as far as possible, to make the most of every sunny day -- so we did! We went to Kentmere for a wheelchair trundle. I put my walking socks on and my boots - to keep my feet warm but it made me feel I was getting ready for a walk! We packed a picnic and put my rucksack on the back of the wheelchair! We did a circuit of about 4 or 5 miles with wonderful scenery and nobody else about. How lucky we are to live near such wonderful countryside. I thought living in Kendal would be good because it was near the Lakes but didn't realise how much fantastic countryside was on the doorstep. I always feel better for some fresh air. I went quite fast in the wheelchair so (Frank) has some good exercise too! I never stop being thankful for my wheelchair -- it has made such a difference to my life.

Sunday was a good day too. I went back to St Thomas's Church the first time for ages and it was the first time there in my chair. Some friends were waiting for me and everybody made it very easy. It was a lovely service and good to be back there. It is good that we have different types of churches and different types of services. Sometimes we need different things and in any case everyone is different. (family) came to tea and afterwards we had fireworks. It was pouring with rain and (Frank), with his head torch on, and under a big umbrella, lit the fireworks and it was great fun.

Tomorrow, we go to Rolleston and on Sunday will attend St Mary's Church for the wedding blessing for (friends). I am so looking forward to it and seeing old friends. It is good to have things to look forward to. We have got some tickets for the Kendal Mountain Festival and also for all the family to go to the pantomime at Christmas. One thing about being in a wheelchair, you get to sit in the front row!

23 November. The weekend in Rolleston was brilliant. We travelled down Saturday and arrived in the afternoon having had lunch in a very old pub on the Buxton to Ashbourne Road. We drove through the Peak District for old time’s sake but it was very misty and gloomy so we didn't see very much. When we got to the hotel we found they had given us a room with a shower above the bath. After all my phoning round to get the right facilities I was a bit miffed but it ended okay as they managed to find another room with a walk-in shower! It is a good job that I can still stand however, as the shower had an enclosure which prevented anyone in a wheelchair transferring to the shower seat. Anyway, I had a long rest on the bed and then we went to have a meal with(friends) at their house. They had invited (friends) so that we could see them also. He had finished his chemotherapy only a few days before. We all hope and pray that it is has been successful. The following morning,

we had a leisurely start before calling in for coffee at (name of friends). After that we went to the church for the wedding blessing. It was so lovely to be back in St Mary's. It is such a beautiful church and I found being there very emotional. Apart from being the church I had attended for so many years, it is where (names of family) were married, where (name of grandson) was christened and where my mother had her funeral service. The blessing service was very special and I had to concentrate hard not to cry. Now I am losing some of my facial muscles it is difficult for me to cry quietly and I certainly didn't want to make a terrible noise and spoil it for (name of friends)! The meal afterwards at the Dovecliff hotel was really good. We hadn't anticipated a sit down three course meal. It was a very long day but it was very good to see so many old friends. By the time we got home I was well and truly exhausted and went straight to bed! I think it took me till Thursday to recover but it was well worth it.

This weekend has been the Kendal Mountain Festival. On Friday we went to a talk and slide show by Doug Scott at the Brewery Arts Centre. Waiting to go in we found ourselves bumping into (name of friend), who used to be one of the GPs at Tutbury and for whom (name of daughter) used to babysit. It turns out that she is doing voluntary work in Nepal with the charity that Doug has founded and she is involved in training nurses. What an amazing surprise! Then on Saturday we went to another talk and slide show, this time at the town hall to hear Andy Cave. Having read his book I was interested to meet him and afterwards bought his new book and went to queue for the book signing – wheelchairs are also useful for queue-jumping! All of a sudden (names) says hello. He is the son of (names) who we saw last weekend and who lives in Northumberland. Another surprise! And then someone else says hello and it is (name), an occupational therapist, I used to work with at the Children's Centre. I am quite overwhelmed by it all. We then went for a coffee with (names) who were also at the lecture.

Also this week, I heard from an old schoolfriend who has known me since I was five years old. She was full of comments and reminders of people and things not thought about for years. Amazing! I met up with church friends, who are so supportive. I had flowers from Judy in America and lots more e-mails. (name) sent me earrings she had made which I had commissioned.

So today, I did not get to church but stayed in bed late. I read a book of Celtic prayers by David Adam that I had just bought. I find his books speak to me.

We woke up to a sprinkling of snow and (Frank) got up early and walked down to the Brewery arts Centre. He had an all-day film pass. It is the first time he has left me for so long. He was to indulge himself with a day's worth of climbing and mountain films. (name of daughter) came later with (name of grandson). She helped me shower, dress and she got my lunch. Tomorrow we welcome some friends from Dronfield days. We haven't seen (names) for a very long time.This diary entry has therefore been all about friends! My friends are so important to me and a real blessing. You have all supported (Frank) and myself in so many different ways during the last months

Nov 27

Thoughts from Anglesey. It is winter now. The trees are bare with branches stark and black against the clear blue sky. Autumn colours are long gone except for those still clinging to a few determined branches. Burnished brown bracken carpets cliff tops. I smell the sea, feel the energising wind, hear the screeching gulls, watch the dazzling winter sun shimmering on the waves. Taste the salt in the breeze.

I look longingly at the beaches I used to walk along, paddling in the surf; watching the waves racing and foaming white. I lift my eyes to the hills wistfully thinking of climbs done with panting breath. Snowdon's hills covered in snow are shrouded in clouds and ominous gloom. Anglesey is bathed in sunshine.

A trip to visit family. Good food to enjoy, rich wine to taste. Wheelchair trundles give me the movement I crave. Children's chatter to enjoy. Precious time with those I love.

Tears in the night. Speech is deteriorating. My right hand is weakening. I have been a chatterbox all my life but this will soon change. Dictating into Dragon is more difficult. I try to envisage being trapped in my body unable to communicate. My love comforts me. But this is hard for him as well.

But I can still breathe, see, hear, taste and feel. I can think and pray. I can love, dream and hope. I am still me.I am more than my body. I am. I must live for now and trust God with the future.

Journal extract 7

December 3 Jackie**:** I have just lost the whole of today's entry! This is really hard as talking into dragon is more difficult now and it makes more mistakes because my diction is not so clear. Windows was installing new updates and so shut the computer down without saving everything. So here goes again!

We are back home after a good week away. The weather was sunny and we could get out and sit by the sea. We saw (name of daughter) on her own which was really special and we were able to take her for a birthday lunch. (name of family) joined us for the weekend and so on Saturday we all met up in Llandudno and I raced (name of grandson) on his bike along the promenade. He can go twice as fast as my wheelchair! (Name of grandson) on his go-kart peddled like mad and could go as fast as me! On Sunday (name of family) was able to join us and we had an enjoyable meal all together.

The journey back was horrid. We went through every sort of bad wintry weather imaginable but luckily did not get held up in the jams on the motorway that the weather caused later on. What a contrast today! I sit in my picture window looking at the snowy landscape. After the frost last night, the snow is sparkling in the sunshine and the hills look so inviting. I watch the robins, blackbirds and goldfinches on the feeders. Before we went away (Frank) somehow manhandled the green recliner chair up the stairs, getting it passed the stairlift. Needless to say, he did this while I was not there as he knew I would have tried to stop him from doing so because of the chairs weight. However it is wonderful to have it upstairs in the living room.

We have collected the blinds for the downstairs bedroom. So this week the plan is to swap the beds around and start sleeping downstairs. We really need to live on two levels instead of three. It will be much easier for (Frank) and I know I have to do it. We have been talking about doing it for quite a while and although we have used downstairs I have put off moving there completely. However I know it is now time. I am struggling so much more with everything. Getting up the stairs to bed last night was hard work. We will soon need extra help as I need a lot of help now with showering and dressing. My good hand is much weaker and losing power. I shall miss the king-size bed with its comfortable Vi sprung mattress but this is too big and heavy to get downstairs. Anyway it won't be long before I need a special bed as I find it extremely difficult to sit up in bed.

It was lovely to come home to more messages. I do enjoy everyone's e-mails. It is getting harder using the computer and I have to choose whether I reply to e-mails, do the diary or some other computer work I want to do.

December 14(Frank) said he wanted to do the next entry but he has been so busy that I have decided to start rambling into dragon.

I have found the last week or so difficult emotionally and lots of tears have been shed. (Though we do still manage to laugh as well).

We have moved downstairs and the arrangement works quite well. It is certainly easier for (Frank) and I haven't had to struggle to walk upstairs to the top floor at all since. So I use the Stannah to come upstairs to the middle floor in the daytime and sit in my recliner chair.

My speech is deteriorating and slurs a great deal. It is worse in company when I try to speak normally. I went St Thomas's Church last Sunday and today and talked to a few people I hadn't seen for a long time and found my voice giving up on me. We went to the church group Christmas meal one evening and as the evening wore on my voice got worse and worse until I end up talking gobbledygook. Talking into dragon is more difficult as well. I have to talk more slowly and more quietly and have frequent rests. The speech therapist visited and has talked about aids called light writers. She also discussed PEG feeding with me. I know it has to be faced but it was all rather depressing especially as this week there has been a lot on the news about assisted suicide and there was a programme, which I did not see, about a man with MND choosing to die and being filmed doing so. Death is such a taboo subject so it is perhaps good the debate is being raised. I really value life as a gift from God but I could, and still can, always see both sides of every coin and all the shades

of grey in all the big questions. There are many circumstances where answers are not straightforward, and judgemental comments unhelpful. No one ever knows what it is like to be in any situation until it happens to them. (Frank) and I have had emotional discussions about the future but we operate much better on a day-to-day basis. My main concern is not to wear [Frank] out. I can see that there could be pressure to end one's life simply to spare relatives the pain.

December 28 Frank:*I certainly do not want (Jackie) to feel any pressure in this respect. My love for her gets stronger and even though these last few weeks have not been easy and although there have been many tears we have still found lots of things to enjoy and laugh about.*

(Jackie)'s problems with chewing and the first signs of difficulties swallowing mean that I have to be careful what food I cook. She finds scrambled egg with smoked salmon more palatable than egg and bacon – I can live with that! I am buying more ready meals to make it easier as I need to help her much more with personal things. I have also got to be careful not to offer drinks in heavy pot mugs or fill them right up. It has to be the small china ones as her right hand is now very weak. We had a treat last weekend when friends in Kendal brought a three course meal up to our house in a rucksack! - we all sat and ate this very tasty paella and drank lots of wine.

(Jackie) made quite an entry and exit when we went to Jack's nativity performance. Getting into the school was a task as disabled access was right around the opposite side of the building (surprise, surprise!) but once we had negotiated what felt like a labyrinth of corridors we found that the place she had been allocated was in the middle of the front row. It would not have been fair to those behind if (Jackie) had parked her wheelchair there as it would block those behind from seeing. She insisted on going at the end of the row and so needed moving etc. It pays not to be self-conscious! – it is quite common to have silence descend on a room whilst this goes on.

We parked her chariot next to a piano sized keyboard and managed not to prevent others seeing. However not content with rearranging the chairs on her way in (Jackie), on her way out, had somehow managed, unknowingly, to get the power lead of the keyboard caught in the chair and almost left a swathe of destruction as she dragged the keyboard through the seating!

Having left the top floor has made life easier but was a big step psychologically. The ground floor is quite cosy and the wet room works a treat. We have the added advantage of a single <u>and</u> double bed in the bedroom – we can have a cuddle if we want but if one of us is restless I don't have to go in another room.

We have the Christmas tree up and the turkey is ordered. Our open plan lounge is now much cosier after we invested in a dimplex electric stove. We are really looking forward to seeing the family at Christmas.

Yesterday we went to the panto 'Christmas Carol' at the Brewery in Kendal – all the family! Thought we might not make it but in the end got there, all enjoyed it and the meal together at Pizza Express afterwards. (name of daughter) and [(name of grandson) managed an impromptu appearance half way through the "ghost of Christmas past" when a desperate toilet visit was needed. This caused some ad lib comments from the actors and laughter from the audience as they rushed across the front of the auditorium from one side to the other (and back again later!!)

It had been a difficult run up to seeing the family. What with Jack poorly before his nativity play and (Name of daughter) with flu just after, (name of daughter) and the boys with colds the week before Christmas and then just a couple of days before Tom and Ali came on Christmas Eve, I started with an infected root filling and ended up on a weeks dose of penicillin. To cap it all I have hardly been able to walk because I have pulled a muscle in my back – probably from completing rearranging the bedrooms. It was a toss-up at the panto who should use the wheel chair as (Jackie) could probably stagger further than me! I even considered using the manual wheelchair at one point but my pride wouldn't let me. I might be willing to share some of my inner feelings, even though I'm a man, but using a wheelchair unless I <u>really</u> needed to was a step too far!

It has been a bittersweet time for all of us. (Jackie) is physically much worse and is finding being unable to talk clearly very difficult. Emotions are difficult for her to control and then her speech becomes unintelligible. There have been a lot of tears this festive season. Talking last night we both

acknowledged that we knew in our hearts that this was our last Christmas together. (Jackie) is not looking forward to heralding in the New Year. We will need to get help in on a regular basis. (Jackie) will need to have the op for the PEG soon, if we decide to do it – she is finding eating and swallowing very difficult. Communication is getting slower and more tedious. Her right hand is weaker and legs are now not strong enough for her to get up from a chair.

Services have been very good with the provision of equipment: software from 'Abilitynet' which will hopefully give her a 'voice' (when we have time to load and install it and learn yet another piece of technology); an amplifier from the speech therapist so she can be heard by her dad when she visits (yet to be tried as he had a chest infection before Christmas so (Jackie) was told it was wise to avoid him); a shower chair and various bits of kit from the OT which always arrive quickly and include a mattress raiser.

The one piece of equipment which (Jackie) really does not want to have is a 'hospital bed' (she calls it her death bed). The OT suggested a mattress raiser instead. This is a device which fits under the top of the bed, between the mattress and the base, and has a electric lever which lifts the top few feet of the bed. Because (Jackie) cannot get herself out of bed in the night (I am having to help) we thought this would be a good interim way of delaying the 'profiling bed' arriving. Unfortunately it tends to slide her down the bed instead or to lift the pillows as well and they end up falling on her! On the second day of using it she ended up with her feet hanging out of the foot of the bed and in danger of sliding the whole way out. (Name of daughter) suggested a trap door at the bottom of the bed with strategically suspended knickers and trousers etc as per Wallace and Grommet!

We saw several friends we had not met for a long time just before Christmas. It was good to see and talk to them but just emphasised how much our world has changed. I went next door for mince pies and mulled wine on Christmas eve and found the talk between our neighbours about the respective weight of turkeys and who was coming for dinner a different world.

So tomorrow I have a list of phone calls to make to get some physio for me and more help for us to cope with all these changes.

One good thing before Christmas was a visit to the RSPB at Leighton Moss to stock up on bird food. We went out to the bird feeding station in the drizzle and no-one else was there so (Jackie) discovered that the hide had a boxed in wheelchair hole just below an observation slot which allowed her to comfortably watch the birds feeding for a long time. We saw a Siskin and Nuthatch, which we have never seen in our garden. Full marks to the RSPB.

Jackie: Also, earlier this week, I asked the physiotherapist to call in. She is great and, of all the professional people I see, the one I can relate to most easily. I wanted her advice as I am finding it difficult sitting up and getting out of bed. I thought she might have some information about buying a special bed. She suggested a hospital bed (which could be provided) and so she sent the district nurse to discuss this.

It is so strange sitting around when I would normally be rushing about doing Christmas preparations. I still find it hard watching (Frank) doing all the work and not being able to help. I no longer manage to get out to the washing machine in the garage so that is something else he has taken on. (Name of daughter) is poorly at the moment with a bad cold and feeling rough. It hurts that I cannot help with (name of grandson) as I would normally have done. Christmas time is an emotional time anyway. We went to see (name of grandson) in his nativity play earlier in the week. It was lovely to be there but I had to force myself not to think that it would be my last.

Journal extract 8

January A New Year

We started last year with great plans. We were going to get a lot more care for my father so that we could have time together and also with family and friends. Things worked out so differently from what we intended. However we did make the most of 2008. Despite the problems, we intend to enjoy as much as possible in 2009.

However, I have to admit I have found the last few weeks difficult. I had achieved a certain inner peace, an acceptance of what is, but Christmas threw me and I struggled with my emotions. I was

managing reasonably until [(name of grandson) said “I miss you Nanna”. I told (Frank) what he had said and heard him mutter ”so do I”. I lost it then and was overwhelmed with sadness for all that was and all that will never be. I shed many tears. I have read in a book about MND that the frontal lobe of the brain is affected and that is why I cry so easily. Instead of just having a sad thought I end up weeping. It is very awkward because often I cry when I do not want to and it is not the sort of crying that makes me feel better. I make horrible noises and I feel worse. (Frank) and (Name of daughter) know to chivvy me out of it but other people can easily be embarrassed.

Although the disease continues at the same rate throughout its course, there are times when it feels as if there are big changes and this is one of those. Muscles compensate for others, which have stopped working, but eventually there just are insufficient left to carry out particular movements.

My voice has changed a great deal. Conversation is difficult. I now have to speak very quietly and slowly and without emotion in order to use Dragon. Normal conversation is impossible. I find this very hard to cope with. I have always been a chatterbox! Using the telephone is not easy. (Frank) is able to understand me but when I visited my father the other day it was hopeless. My voice also makes me sound miserable even though I am not.

I am much more wobbly when I stagger about the house. When I go to the toilet I struggle to pull up my pants and trousers and usually end up needing help. One night earlier this week when I got up to go to the toilet I managed to fall. This is the first time this has happened and luckily I got away with only a bruised knee.

My good hand is weaker. I no longer have the pressure to switch the table lamp on. Using my mobile phone is tricky too.

Eating is becoming more laborious. More and more I am eating softer food like scrambled egg, thick homemade soup, porridge etc. Chewing takes ages. My food goes cold before I am halfway through a meal. I have to be careful with drinks and find them difficult to swallow at times. Also I cannot hold a heavy cup. Sometimes I use a straw. It is not all gloom however as (Frank) now gets all the crusts!! For 40 years I have always pinched the end crusts from loaves of bread. He seems to enjoy getting them now! The other day he cut his dinner into small pieces, as well as mine, by mistake!

I now have a special bed. It is an improvement on the mattress elevator. Sleeping is still a bit of a problem as I can get stuck in one position and cannot move out of it. We have been very lucky with equipment. Everything has come very quickly.

Family and friends continue to support us. Sue came to stay for New Year which was really good as she stopped us being miserable! She is so soothing to be with and helped (Frank) a lot despite fact that she has her own health problems. We even managed to stay up to welcome in the New Year.

(Frank) had physio which helped quite a lot. He has some exercises to do. His back is not right but better than it was.

I am not surprised that he had trouble. He spends so much time looking after me and doing all the jobs, that he does not have time to look after himself. We had another meeting on Monday with the social worker and district nurse. It was weird to be assessed re my care/health needs. I hope we will soon get some help. (Frank) is such a source of strength to me. He never ever complains about all he has to do. We get less and less done now in a day. Because we are awake in the night we usually end up going back to sleep and then not waking up till late - often nine o'clock. It takes at least two hours to get me breakfasted, showered and dressed. By the time (Frank) has made the beds, put the washing in, etc it is lunchtime. The day disappears with neither of us achieving anything very much at all. It must be very frustrating for him.

I am going out less and haven’t made it to church for a few weeks, which I miss. When we do go out it is often afternoon before we are organised. What I like best is to be driven through the hills and by the lakes, to gaze at the stunning scenery which surrounds us. Today we went to Coniston so (Frank) could programme in some codes at Low House. We met (Name of daughter) and Jack by the lake and had lunch in the Yewdale. I could get the wheelchair in but could not access the toilet so there is no way I could go to the Dinner in a few weeks time. I had already decided I would not go as the difficulties of talking and eating in a large gathering are too great, but today convinced me not to

try. (Name of daughter) has offered to “babysit” me so (Frank) can go. Still, today was magical: snow powdered fells, iced over streams, frozen tarns. We drove over the Struggle coming back and the sky was pastel shades of blue, grey and pink shafted with gold. All was still, silent, chilled; an iron landscape.

Journal Extract 9

January12 Frank: ‘Diamonds are made under great pressure. I’m alone in the house writing this. I’ve just made myself a meal and eaten it alone. It is very strange to be on my own with time to think and reflect. Usually these moments occur in the middle of the night when I’m awake and go to sit down in the small lounge we have downstairs. There are all sorts of thoughts and feelings going around my head: anxiety, fear, sadness and anger at the cruel twist of fate that has dealt us this.

The title quote is on a mural I read each day as I go down the stairs to visit (Jackie) in the [name of hospital]. It brings tears to my eyes each time – I don’t know why. She is on the post op ward after surgery to remove a blood clot which formed between skull and brain. An acute subdural haematoma. When we could see her after the emergency operation on Saturday evening she looked like one of those shock pictures you may have seen on the drink-drive campaign posters. The right side of her head was shaved where they had cut a large flap of skin to remove a piece of her skull. There were two drains and a monitoring probe into her head, various tubes into hands and arms to measure blood pressure and give fluids etc. But at least she was aware of us, and able to nod acknowledgments almost imperceptibly – the first time for nearly ten hours.

Now she looks as though she has been in a fight. Her face is swollen with the first signs of bruising. Her right eye is puffed up. The comment “you look well” she gets from many visitors no longer applies! Her awareness and responses are much the same. Thinking of how tiring just doing simple things was, and how long it took her to recover from doing too much, We are all aware that recovery is going to be very slow and very hard.

Tuesday last week (Jackie) started to feel that her insides weren’t quite right and also complained of a slight headache. We thought she may have caught a bug. The symptoms came and went. Thursday she was quite bright in the late afternoon when (name of friends) popped in on their way to Low House. By Friday afternoon her headache was bad and she went to change lie down. Resting appeared to help and by tea time had decided to get up and come upstairs for a meal. I’d helped her into a sitting position on the bed and just left her for a second or two to get a fleece when she went dizzy and fell banging her head. What followed then was the start of a nightmare. I got (Name of daughter) to come over to help (Jack was with Dave), (Jackie) started to be sick so we called the emergency doctor, We knew (Jackie) did not want to go into hospital and still believed she had somehow caught a winter vomiting bug. It took hours for the doctor to arrive. She tried an anti-sickness injection to be followed by some liquid painkiller first because of (Jackie)’s reluctance to go the hospital. This appeared to work but when she threw up again we called the emergency doctor again to get her into hospital. More waiting then a suggestion we called an ambulance to go to casualty! – at which I started to assert myself and she was finally admitted to the Medical Assessment Unit in [(name of hospital) at two am Saturday morning. Form filling and bureaucracy and by four she had seen the doctor who put in a needle for a drip – which was eventually set up at about five thirty. Then a long wait punctuated by us bodily lifting (Jackie) onto a commode. She was able to let us know she needed a loo but was not able to talk and was now not able to help at all. Her jaws were clamped tight and her right arm held tight against her chest with her hand in a fist. Eventually in the morning a doctor did his rounds and decide a ct scan was needed which was done within the hour.

I had sent (Name of daughter) home to sleep shortly after we had got (Jackie) into her room in the MAU but had texted her just after ten when the doctor decided on the scan. She arrived in time for the news of the scan and when I was asked to make decisions about doing the operation.

At the time that felt like a huge responsibility and I asked to know chances of success with (Jackie) having MND. Phone calls were made to the surgeon in [(name of hospital) and a wait whilst he

completed an op and got back. However there really was only one choice I could make and that was to go ahead. Not to do so was not an option.

(Jackie) went down to the operating theatre in [(name of hospital) where a team of medics got her anaesthetised and ready for the operation. She then went on her way to [(name of hospital) in an ambulance. No room for either of us in the ambulance with two medics and all the gear. Tom was on his way to [(name of hospital) so we went back to Kendal knowing that there was nothing we could do in the meantime. I showered and changed after nearly two days without sleep and threw some clothes for (Jackie) and myself in a bag. We had eventually contacted (name of daughter) and she was preparing to board a train to [(name of hospital). A few hurried calls were made. (Name of daughter) booked a double room in a travel lodge near the Hospital and we then began the forty five minute drive to [(name of hospital) and met Tom at about half seven. He collected (name of daughter) from the station and we all sat in the waiting room and waited and waited. We were told the operation was successful but couldn't see her for a time whilst they sorted her out.

When we were confronted with the sight of her I think (name of daughter) was the only one who wasn't shocked. She knew what to expect and had seen it before. However this time it was her own mum. (Jackie) responded to us. She was confused and had no recollection of what had happened or where she was. By small nods and slight shakes of her head we knew she could hear us. (name of daughter) was allowed to stay that night. I was happy because (Jackie) has been having trouble swallowing etc. (name of daughter) was able to inform a medic who was not getting the reflex on her left arm why this was the case! (Name of daughter) and I caught up with some sleep at the Ibis and Tom went home. We were all there again in the morning and I talked to the nursing staff again, explaining (Jackie)'s condition. I also saw the consultant on his morning round and could explain about her speech as she was not talking. I picked up that monitor and drain in her head would be staying in for a while as although the readings were in the normal range they were high in that range.

Through Sunday and Monday we took it in turns to rest or visit. I did not go in on Monday morning so I could make some phone calls but (Name of daughters) visited. The children have been close and a great support to each other and me. However (Jackie) was not making progress. She was not as responsive with us and the nurse was observing a gradual deterioration on the coma scale. I was needed back in [(name of hospital) urgently.

To be continued – (Jackie) not making good progress

Going back to [(name of hospital) – 4pm Monday

January 13

Waiting

You know something is serious when you are invited into a room with the doctor and nurse. (Name of daughter) and (name of daughter) joined us. Tom was on his way. Before we went in they gave (Jackie) 200ml of mannitol through the drip to try and reduce cranial swelling if there was any. (Jackie)'s level of consciousness was falling on the coma scale. The blood clot was small and should not have produced the reaction (Jackie) had. It may have contributed but was not the main cause. Something else had to be at work but scans did not show any other physical cause. They had exhausted their medical repertoire. All we could do was to wait.

There was a discussion about putting in a feed tube (i.e. through the nose), which (Jackie) had refused before. We then went to the canteen for a family conference and to take in what had been said. When we saw (Jackie) later the mannitol had had an effect. She responded to us – still no words but recognised me when the nurse opened her eye to check. We told her about the feed tube and what had been said and I am sure she took in everything. (Name of daughter) found a bible and read a psalm to her and she was clearly moved by that. When we left I said I wanted to see the feed tube in on Tuesday and she nodded. I felt I had got (Jackie) back. Today (name of daughter) and I visited this morning. (Jackie)'s eye is less swollen and the feed tube is in so she is getting the first nourishment for four days. She is not as responsive as last night and her neck is puffy again. The nurse said she was responding to instructions to move her arm or legs.

The MND nurse had called in yesterday. This had not happened to any of her patients before. Trust (Jackie) to be different!
Looking back over the last eleven months I'm glad we tackled the mnd head on. Everything that was needed we had in time. I know lots of people wanted me to keep walking and cycling but I am so glad I spent as much time as I could with (Jackie). Whatever the outcome of this episode life for (Jackie) will be severely limited now. Even if time heals this problem the mnd is still marching on taking its toll.
I will attempt to update this journal as soon as things change. It helps me and I know there are a lot of you out there who care about (Jackie) – thanks for your support
January 14 Do not resuscitate. I had a call on my mobile yesterday evening just as I was getting ready to go back to [(name of hospital). A (name), the surgeon I spoke to after (Jackie) came out of the operation. He must have been trying to tidy up his paperwork because the essence of his call was that the operation wasn't the success they had hoped for – (Jackie) wouldn't get any better – and could he write her off – i.e. could he put 'do not resuscitate' on her notes.
At least the surgeon we had spoken to the night before had attended the lectures, and put into practice what the text books say about giving bad news. This one needed a refresher course!
I had already confronted this question and already made a decision. In my heart I believed that there was hope that (Jackie) would improve and, whilst not recovering to where she was, would at least be in this world. In my head I know that this is as good as it can get. I'm sure she can hear and understand we are with her. She responds to touch – I managed to relax her right arm and hand last night, which had been tense and drawn into her chest. However it can only go down from here. (Jackie) has battled against the effects of this disease and we have made the most of a limited life. She said she was not ready to die yet, before all this happened, but I have to be realistic and do not want her to endure yet more trauma. He medical notes will now say 'do not resuscitate'.
This morning the nurse said she is no longer responding to commands to move her limbs. She is in a side ward on her own which is more private. The monitoring lines are off - just the nasal feeding tube, catheter and a line for fluids into her groin. This last one will be removed today as fluids can be given down the nasal tube.
We are now trying to see the MND nurse to try and fix up a bed in a hospice. The nursing staff have been excellent in their care but it would be better for (Jackie) and us if she could be moved.
I'm finding all of this very difficult. Sitting by a bedside is not my thing.
January 15
Not Coming Home
They have got (Jackie) a place at St John's hospice, Just north of [(name of hospital), and I will be travelling with her in the ambulance tomorrow morning.
(Jackie) was sick again this morning. She doesn't appear to be absorbing any of the nutrients which are going in via the nasal gastric tube. Those have been stopped to prevent any further vomiting and risk of inhaling the vomit. That may have already happened so some oxygen is been given. She is been given fluids only.
(name of daughter), (name of grandsons) visited this afternoon. We counted the staples in her head – thirty six I think. If we shaved the left side of her head to match she would make a good punk, especially with traces of blood clotted in the hair on top of her head.
No response to us being there. I'm so glad they have a place at St John's. The care has been excellent in [(name of hospital) but they cannot give her the same attention she will receive in a hospice.
Many thanks for the emails and text I receive I'm sorry I cannot reply to you all.
Jan 16 St John's. (Jackie) eventually got to the Hospice today. Although the ambulance was booked for between ten and eleven it did not arrive until ten past one. My daughter (name of daughter) (the nurse) expected that to happen! It is a very peaceful place compared to the hustle and bustle of the [(name of hospital) Royal. (Jackie) was comfortable on the journey and I was able to travel with her. She has been settled in and the staff are excellent. It is a lovely place and where (Jackie) said she wanted to be at the end.The whole family are here – at least for the weekend. It is good to have

them around. Though it means that, with [(name of grandson) and (name of grandsonr) staying there, (Name of daughter) isn't getting those quiet moments she relied upon. When all three grandchildren are together they go bonkers!

January 18 After the Storm. I'm looking out of the study window at Ill Bell – the last mountain she walked up. It is covered by a sprinkling of snow which fell during the storm last night. From time to time the sun breaks through the clouds and lights up it, or the surrounding mountains, like a jewel.The weather over the last week has been abysmal. I've travelled the M6 and A6 in fog, rain and wind with hardly a glimpse of the sun. Today however the weather, on the journey back from the hospice, was bright and clear with the verges and fields showing just a hint of snow or frost and the hills standing out clearly in the sunlight.It was the end of the storm for (Jackie) this morning. I stayed at the hospice overnight. I grabbed a few hours sleep in their visitor's bedroom in between sitting at her bedside. She was working hard to breathe all night – but otherwise relaxed and comfortable. As the morning came the breathing became slower and slower – until it eventually stopped. She died at eight o'clock on Sunday, January 18, 2009.

Interview Transcripts (12 couples)

ID 6 & ID208 (Joint Interview)

Present: Individual with MND/ Spouse/ Research Assistant

I: When I was six I got polio, in early 1990 I realised I was having muscle wastage in my right leg, in 1998 I was diagnosed with recurring polio or PPS, post polio symptoms ….Later in the year in 2005 I had a pace maker fitted.

S: In May that was

I: I declined physically from then, up till then I only had a slight limp in the right leg I walked up to 1000 miles a year, walking I had no problem with mobility then since January last year I've been in a push chair and I kept falling, and originally I could get up but then I found I couldn't get up without being lifted and that's the situation now, my condition is deteriorating, my speech is getting worse, my arm is getting, strength is going, I have difficulty in lifting it, I can move the arm there but I can't lift it any further, I can manage to get the food into my mouth but its not easy, So that's my story,

R: Well, can I just ask about the, when you were being diagnosed, how did you feel the process was? Did you feel it went ok?

I:Well, the process last year was the same as polio, everything was alright, the thing I wasn't happy about personally was the injection of the dye into my back and that was done in (place), I had difficulty cause number one, to get me from the chair onto the table is not easy, I can't lay on my left hand side, cause the can't lift me with that arm, I have a surgical pin in my left shoulder. Well, anyway, it went very well and I had no problems.

S: That was the lumbar puncture wasn't it?

I: The mylogram,

S: Oh the mylogram, yeah, sorry,

I: And er, that was, it went fine, I have no problem with anything that has happened since or before, bearing in mind the best thing that ever happened in my life was the National Health Service. My arm was in 1934 and it was 1948 when the health service came in and the transformation was a miracle and I have been very surprised at the way people have treated in hospital, when I went in to have the pacemaker fitted, the first time for twenty years so I am have no problem at all with the services or with what we were provided, …but all the other treatment has been at (name of Place) and it's been wonderful.

S: On the day that (name of consultant) diagnosed we had an extensive interview, there were a lot of services that day and the multidisciplinary team which lasted about five hours, was first class and all the times we have had to go to [(name of hospital) the services have been excellent and (name of patient), all along has said how appreciative we have been of everything, both at (name of places), the occupational therapist and all the services for equipment and care have been excellent.

R:Great, so do you have a lot of contact with lots of professionals in the team?

S:Yes we have them call here once a month, Speech therapist. And (name of specialist nurse), Oh yes (name of the specialist nurse) has been a couple of times and (name) the speech therapist she comes once a month and we've had a lot of care equipment, the first thing was the care bed, the first thing was the district nurses, when (name of patient) first needed help the district nurses they alerted the services because he needed the bed and without the bed he couldn't manage at all, it's a care bed from hospital.
R: So the district nurse organised that?
S: Yes, they did, the nurses did as a team
R: Great,
I: So I have no problem at all
R:Do you get a sense that they all communicate well as a team?
I:Yes.
S: When (name of patient) was having the problems before he was fully immobile, he walked with a Zimmer and he kept falling and we had to call the paramedics eleven times in the year because of his disability having only one arm, if he slipped he would fall flat and I couldn't pick him up, so,
I: But I can't walk at all now, I can't stand.
S:He has to be lifted out of bed,
I:That's Zimmer is just (inaudible)
R: So that was given to you by the OT?
S:Yes, because he used that for a year and that's how his mobility was decreasing
I: Without they given me that lift, to lift me up, to transfer me from the bed to the chair or the commode or the bed, without the lift I don't know, I couldn't move.
R: So do you feel that the equipment has been delivered and supplied on a timely basis, like, when you've needed it, you've not had to wait at all?
I: The only worry to me is that lift, has no back up, if that lift stops working, I can't move,
S: We'd have to have the paramedics to come in to lift him, either to get him out of bed or into his chair,
I: She couldn't do it and neither could my daughter who is my other carer.
R: And have you spoken to people about that?
I: Yes, I have discussed it with (name of specialist nurse) and she said, well it's a bit vague and that's my long term worry, apart from that everything is alright,
R: That's good, and have you had much contact with social services in terms of funding benefits, for equipment and adaptations for has that been alright?
I: We get an attenders' allowance and we get a reduction in rates apart from that nothing
S: They have sent some vouchers for respite care but up to now because (name of patient) has been so ill we've not used them at all and we have got a list of nursing homes but we haven't availed of the services because at the moment I don't want to leave him at all and it would mean him going into a nursing home if I wanted a day off or anything our daughter puts him to bed at night and she is on call 24 hours a day.
I: And showers me three times a week,
S: Puts him to bed at night, gardening, shopping,
I: She takes me shopping, if I need to go anywhere she takes me, I used to drive but the car we had wasn't adapted for my needs and (name of daughter) is now driving my car but she doesn't live here, she lives not far away.
R: OK. Do you feel you get the support from outside services or do you feel there is too much put on family members?
S: Well, if (name of patient)'s ability diminishes anymore, we shall need to call on social services because up to now we have managed.
R: How do you feel about that?
S: Well, if he can't stand on the lift, I've not asked the question yet, of what the next stage is if he can't be lifted and transferred from there into his wheelchair and or into his bed

I: They have said, there is a different lift. But it takes two people to do it and having a lift through the roof. And I'm not sure that the beams could take, so we are keeping are fingers crossed and hoping that does not happen.
R: Sure,
I: Any questions?
R: Can you tell me how MND has affected your daily life, what changes have it made, and that kind of thing?
I:It has completely changed my life from walking 500 to 1000 miles a year
S: He did fell walking and walking holidays and all sorts,
I: To being sat in this chair, completely, I have to be dressed, undressed, washed, lifted on and off the commode, everything, completely changed.
S: He can just wash his face that's all. Nothing else.
R: How does that make you feel?
I: I am not in any pain, I am, I've come to terms with it, I can't do anything about it , I've got a wonderful wife, I am 80 years old, ninety percent of my peers are dead. Absolutely, well looked after and that's it, comfortable.
S: Unfortunately, can I just chip in that he would be able to go out more, we've had provided an electric wheel chair, which is excellent but it is not easy to get him into it. We were hoping with the warm weather that we would be able to go a little bit further but we haven't managed to go o go very far in it he's been out about four times in it but previously here the weather has been a bit too, the wind has been too cold, so because of his present condition it was too cold for him to go out.
R: You're scared of him getting a cold?
S: Well, we can't risk him getting a chest infection, and we are keeping our fingers crossed that that doesn't happen.
R: Can I ask how it's affected your life as well?
S: well, it's completely changed both our lives, yes because we were quite active and socialised erm quite well; we liked dancing and visiting the local conservative club (laughs) and also out and apart, walking from (place name) to place name, about four times a week, when the weather was good until (name of patient)s mobility decreased, the year before he started having walking difficulties, he was walking with a stick but we still used to walk four or five times a week if the weather was warm enough along the promenade (to place names) have a coffee and walk back which was about three miles in total, didn't we? And in between we used to have a caravan in the Lakes, we used to go up to the lakes quite often, or other places, didn't we? Scotland and all over the place and abroad at times, since my father became older and ill, we had to curtail our holidays, and then (name of patient) started being ill a month before my father died, with being ill quite a lot over the previous three years but before that we used to go abroad a lot on the continent and for ten years and he used to go oh for ten more years he used go once a week hiking with his friends walking on the canals latterly cause course his friends were getting a bit older and having knee problems and things like that, (name of patient) didn't have problems like that.(Lists canals/walks he has walked) .They have walked on the (names of places) all in stages.
R: Oh lovely
S:Just spent a day over a time that's over the last few years.
R: What do you find now do you keep yourself occupied?
I: Watch television, listen to cassettes, Radio, read, and that s about it. I can't do anything else, there's not many things you can do with one arm
R: Has it affected your social life, do you find?
S: Completely yes, cause we used to love dancing, especially the waltz and quick step, dancing at (name of place)
R: Oh great!
S: (Name of place) all that and he was a good swimmer as well, Yeah and er cyclist
I: That's in the old days, cyclist in the old days.

S: Very busy, very active
I: So I can't grumble
S: His speech has only been affected over the last weeks, he spoke quite clearly before but his speech has got more difficult.
R: Has the speech therapist been able to offer you much with that?
S: It has been a help but there is nothing they can do, but they have been very helpful. (name) helps greatly cause she also monitors how he's swallowing and she has also brought various cups and aids for him to drink because he now has to drink through a straw and he has to have all his drinks thickened, so erm, one problem he has is with he gets phlegm in his throat which he has difficulty in removing, it makes him cough a lot. But apart from that he seems to be managing well
S: Any questions?
R: Can I ask about, how do you feel about information, do you feel that if you have a problem do you feel you know where to go for it? And do you feel well informed about decisions that you have to make?
I: Well, social services, I know that if I need any assistance I have to contact them, and the if there are any problems with any of the equipment I have to ring (name) to the occupational therapists or the relative, if there is anything broken down, there is the repair store, or the place where they supply the equipment from, so I am ok about that.
R: So you feel confident you know where to go for things, well informed?
S: We don't avail ourselves, we haven't been to age concern, whether the have any facilities like coffee mornings because of leaving (name of patient) we haven't availed myself or anything like that.
R: Do you have any contact with the MNDA?
S: Yes we have a newsletter but up to now (name of patient) has not felt up to going to any of the meetings,
I: But (name) has been here,
S: Yes (name) he's the chairman, and he has visited (patient) he is the palliative care visitor and he's been to see (name of patient) two or three times.
I: Yes, and they gave us a donation of over £1000 for the bathroom
S: Yes to turn it into a shower room and it's beautiful
R: So you feel very positive about the association?
I: Oh yeah,
S: Oh yes because the shower we couldn't obviously manage without a shower, previously well for two years we had a bath seat, we managed, we had a bath and social services had provided a seat which (name of patient) sat on and we turned it and I lifted his legs into the bath but when his health deteriorated and he needed a lift, and we needed to be able to when he went into a wheel chair we had to get him into the bathroom and we had to have all the facilities and so we had that changed in January and that's been fine since then
R: So you've not had any problems?
I: No,
S: And er, we were very grateful to the MNDA because we didn't realise that this would be available so that was wonderful of them
R: So you feel you get all the support you need from the services?
S: Yes if (name of patient) is feeling ok to go the meeting we have to ring (name) and he will arrange a suitable taxi for him but we haven't been yet.
R: Do you feel that is something you might do, in the future?
S: Again that's the weather and he hasn't been well on the days of the meeting and you have to let them know a couple of days before the meeting as well.
R: So if I was to say to you have a blank piece of paper and you make the services better in anyway, is there anything that you think that's missing or that could be improved in anyway?
I: I can't think of anything,

S: Because we haven't availed ourselves of any services, that unknown quantity at the moment
R: Can I ask about your feelings of the future and how you feel about it?
I: Well, I'm not looking forward to it but as I say there is nothing I can do about it so I just have to sit here and wait. I, from what I can gather my condition is going to get steadily worse and there is nothing I can do about it, so I'm not looking forward to I and I hope it comes quick for her sake, not mine, but erm, I just go out on a Friday morning to a social group, my daughter looks after (name of patient) on that day but I haven't attempted to go anywhere else?
R: So you find it quite hard to do things for yourself, find time for yourself?
S: Well, I do handicrafts so in the evenings, when I've finally finished attending to things I manage to sit down for an hour or so to do that erm before bedtime so, (laughs)
R: Relaxation for you then?
S: But as er, obviously as you can tell it has completely altered our lifestyle, in 2000 I retired several years ago, 2001 when I was seventy but our lives have changed completely.
R: That's all my questions have you anything you'd like to add?
I: We've been very grateful for everything that's been done up till now, no grumbles at all in fact it has amazed me and when I think back to my parents and my grandparents, you know, how the hell they managed I've no idea, you know it must have been terrible for them, and erm but er, that was it, you know, in those days, that was it, no NHS. Another thing, we do live in a bungalow and its easy to get round, otherwise, people with staircases, I haven't been upstairs for two years. So that's it,
S: Just before we do, I do apologise, we're due to see (Respiration Consultant), we didn't mention we do go to the Dr (name) in July at the chest clinic. It's the chest clinic and er I think he also monitors and he has got an interest in MND and we not seen him since January as (name of patient) was unwell the last time so we look forward to seeing him,
R: So do you feel that has been a good service as well?
S: Yes, well unfortunately its been delayed cause the day he should have gone (name of patient) was unwell, there's been a delay a couple of times
R: So there is quite a long wait in between?
S: Yes,
R: It's just a routine Check-up ?
S: Because the fact he's not had a chest infection, we've not exposed him to anything that could cause him either, we haven't not been in large group of people ever since cause obviously we want to guard against that, if we can, so everything that doesn't cause his illness to deteriorate unnecessarily, we have guarded against
R: Great, that's been really useful, its been nice to hear some very positive comments as well.

ID 9 & ID208 (Joint Interview)

Present: Individual with MND/ Spouse/Research Assistant

I: Well, about eighteen it'll be eighteen month ago I were having problem with my right foot, er I used to walk down to the street, I had an operation on my back, which affected my left leg and started having trouble with my right leg, it started getting more and more so I couldn't walk, they thought it, it was actually something to with the operation on my back, so they sent me for scans, to (Name of care centre), couldn't find anything wrong with it, er after about three scans, er the doctor at (Name of care centre) sent me to Mr er, Mr (Name of consultant) at (Name of care centre), to do some tests on me, he had said did you mind, I said no, no I had no problems so they did some tests on me and he told me he thought it was motor neurone disease, but he wouldn't confirm it till later on, it wasn't actually confirmed on the 21st December last year and basically that's actually how I found out how I had it, er since then I've ended up obviously in a wheelchair, and I can hardly use my hands now, er my breathing. my diaphragm and my lungs are affected about it, and erm that's basically where I am up to now, I'm just, now I can't walk at all or anything, so that's how I found out about it,
R: And how did you feel that the diagnosis process was? Did you feel you got enough support at the time?

I: Yeah, well, yeah, pretty happy with that, I mean, well, yeah, (Name of specialist nurse) comes out to see me quite a lot
S: At the initial, It were a shock, finding out, about it, I did try and make it easier because I knew because of the fasciculations, when they were doing the tests on him, I could see what were going on, because I have a neurone problem myself, I have CMT so I knew a little about it anyway, and I could see all the muscle twitching and everything going on, and er I kinda knew, you know
R: So you know even before?
S: Well I had a good idea, lets say, so when we went back to be told for it to be confirmed I was quite prepared anyway for it, I don't think you knew, properly, what the implications of it were, No they explained it all and everything, well it comes as a shock obviously but you just get on with don't you, like its,And they said like you've got probably between two and five years,
I: But they weren't sure about that
S: They weren't sure because they didn't know how long he had had it,
I: Because of my back problem four year ago
S: Because the spinal injury he had, could have masked a lot. So it could have started just after his spinal injury, we just don't know,
R: So did you see a GP first of all, was it?
I: With my leg yeah, I went and told her I was walking outside of my foot and it was getting harder and harder we had to go distances that I was finding reasonably easy, and she said it could be your back we are not sure, we will send you back to (Name of consultant) at (Name of care centre), they did, well obviously he sent me for scans and everything and he said I just can't find anything (Name of patient) at all so he referred me to Mr (Name of consultant) and he said do you mind and I said no, not at all, lets get it sorted one way or another,
R: Did you feel the process of diagnosis was ok or did you feel it took too long?
I: No, I've no problems with that, it was obviously more serious than I thought because they kept me in, didn't they? So, I've no problems
S: And then just after Christmas you started hallucinating and dropping like this and hallucinating and I kept thinking 'well is this normal? Is this what I'm supposed to expect?' Nobody had told me what, and erm anyway eventually I rang (Name of specialist nurse), the motor neurone nurse at (Name of care centre) and I said 'I don't know what's wrong with him, he just doesn't seem right, he's falling asleep all the time, he's hallucinating', and I said 'he's terrified because these visions that he is having they are right in front of him', pictures were coming in off walls, and nightmares, terrible, and er so she had a word with the neurologist and rang back and said can you get him in for five o'clock, this is at four o' clock in the afternoon, had to get him for (Name of care centre) for five, that's where they found out his, he had no oxygen in blood, his diaphragm wasn't working, so it went from there he had to go to (Name of hospital) for a ventilator, Just on your nose you see, but since I have got this machine, I've been…
S: The hallucinations have stopped.
I: The hallucinations have stopped, obviously, but I am sleeping better but I think obviously I'm going to need it more and more, during the day I don't use it that much do I, if I am up, when I've eaten but (name of MND nurse) was saying that's pressure of the food on the diaphragm, stops you breathing proper, like days like today if I get wrapped up and go out I don't need it at all, when its breezy its superb for me, really good for me, but as I said you have good days and bad days, Saturday I had a terrible day, hadn't I? Really bad,
S: I thought his end was
I: Really poor day, Couldn't breathe, Since then? I find out this week, I can't , I use to be able to stand up off my bed or off my commode and shuffle around a bit but now just this week my hands have gone, and I've no power to move myself anyway, so I'm just in the sling now, so my carers are coming along and sling me about but we have a good laugh, I must say we do I think if you keep the funny side of it you know but its, most of the time you only think about it when you are sat on your

own, with pictures of my grandkids and I think I'll miss them and they will miss me hopefully, you just get on with it, see what happens, you have a laugh, we carry on, we are alright.
S: At the beginning, It were hard work at the beginning, It were awful because of the shock of it and then the anger, why? because he has never done anything wrong to anybody, why should he have to, it's a horrible thing and then its frustration because you can't do this, one day he can do it and then next day he can't and the amount of effort it took for me to look after him on my own, I did it for nine months and I just couldn't cope anymore, so we had to get help in, hadn't we? So now carers come four times a day,
I: They are brilliant
S: Better for him because they know what they are doing, how to move him and everything and a lot better for me, so I can be more me rather than nurse (Name of spouse), do you know what I mean?
R: Yeah, so do you think that has made a difference?
I: A lot, a lot of difference
S: A heck of a difference
R: How did you become involved with the carers was that social services?
S: That were a complete breakdown, I couldn't move him off the commode one night at midnight and er I had to send for my son in law, who had to physically pick him up and put him on his bed and everything I just
I: We sent for a doctor didn't we?
S: I just couldn't, I was up, because he was having a bad time with his bowels as well, I were up night, days, just exhausted, absolutely exhausted,
R: So you were just coping on your own, before?
I: We sent for a doctor, need to get me out, or something else we talked about getting me to the hospice, is that what you want? No, no, but if I don't it's going to kill (Name of spouse), she's hardly off her feet you know, and she got a meeting didn't she with care, and er district nurses, social services and they all come down, and that's where it all came from there,
S: And the Care package was worked out there and it was implemented the same day as well,
I: The same day yeah,
R: So you are quite happy with that?
I: Oh, brilliant yeah, but I can alter it anytime I want, like today, normally, what I usually do, is they come, half nine till ten in morning, get me up dress me shave me, wash me help me brush my teeth, blah, blah, then they come at dinner time, half past one till half past two then they come six till half past but today, they are going to come at four o'clock because I usually, what I used to do when I couldn't get out my chair was I used to go and lie on my bed at four o'clock just to have a rest on well if have to wait till six, Ill be away this chair is that uncomfortable so (Name of paid carer) come this morning to have a talk to me and said if I send them at four o'clock? And I said it will be better and then I have got from four o'clock then till nine o'clock at night just to rest basically and then they come and wash me, get me ready for bed then, its superb, yeah that's better for me, in winter months, like in summer months if I am still here hopefully, I might have to change it again because I can get out after tea when its warm you see, but during the winter after four o'clock its cold and dark, I said get me into bed, I can watch my football or whatever then, its, cause I am not going to go out,
R: So you feel it's quite flexible?
I: Yeah I have no problem
S: Oh they are excellent, them girls are excellent, the manager, she comes down checks up on him, at least once a week ,at least once week the manager of the home comes down,
I: They come down, in the afternoon, didn't they? on Monday or Tuesday, just to get me onto my bed I felt really terrible, so we just rung them up and there were two carers here within five, ten minutes, and they got me off my chair onto my bed, no problem, they are absolutely brilliant,
S: Cannot fault that care home, at all

I: Thing is though, they are funny as well, they have all got a sense of humour, last night in that room, you would have thought it was Monty Python's Flying circus,
S: Because one of the girls is black, right and he said to her 'I am going to buy a bag of jelly babies and bite all the heads off black ones, and I said to her and I'll give you the white ones you can bite all the legs off
I: She was laid on bed on top me, she had her hands stuck down my underpants, at the back trying to pull my underpants up, she's laid across me laughing, couldn't get up and I'm laid on the bed and I'm 'get off my machine, I am choking' and this other carer was up against the wall laughing it was like Monty python, we have some right good fun with them, but we have become friends with them haven't we (Name of spouse)?
S: It's not all, I can't live like that, and (Name of patient)r can't live like that,
I: No chance, I couldn't have somebody coming in that's boring
S: Occasionally, if I am hoovering I just burst into tears and I have to fight it back, you know but then I do, I get a grip on myself, I have a good talk to myself if he sees me crying he says get out because you will start me off, get out, you know and that's how it is, so whatever happens I want it the easiest way for him whichever way it is meant to be I want it the easiest way for him.
R: So did you think at the beginning you wanted to stay at home?
I: Yeah
R: So this is the ideal situation for you?
I: Yes I definitely wanted to stay at home
S: Well its easier all round because family can,
I: We can get people round at night, during the night we have had people in when (Name of spouse) was struggling to sleep, one part of the care package was somebody coming from the hospice was it the hospice? And somebody came from Marie Curie was it?
S: Hospice at home, it is,
I: They sent nursing at night, if I needed the commode she would help me onto the commode I didn't have to ring for (Name of spouse), but during the night, I have not needed the commode for a long time now, it's all controlled
S: Everything has changed, it's all changed now, I sleep properly
I:Even though I am worse its better, for us,
R: Because you have got the support you need?
S: Oh, tons of support, district nurses ring every Thursday, they come up pretty regularly,
I: They come up, when if I send for them, if they are going past, they just nip in, and say I am here,
S: I mean last Saturday morning when you're catheter were blocked, I just rang and they came and put the catheter in,
I: They were here, within ten minutes, ten minutes, they are good
R: And you feel if you need to ring anyone you can do?
S: I ring (Name of specialist nurse) if I think, there is something I don't understand, or is this normal, because I don't actually, I have never actually been told what will happen,
I: But they don't know, they can't tell you,
S: Its not that they won't volunteer the information they can't, because he has started different to what most people do, most people their voice goes, you lose the power of speech, the speech therapist,
I: Well, I had a peg put in, to feed me, but they don't think I am ever going to use it, but if I hadn't ever had it put in, and it had have gone, I would have been to weak to operate on, so it was just precautionary you see,
R: Was that because of your breathing?
I:It affects your swallowing, MND you sometimes ,so if it had affected my breathing and I didn't have this I would have starved basically, that's what they tell you, so I had to have this in case it did affect it, but they don't think its going to affect it, but its there just in case,

S: But the speech therapist, came from (place) and she said I don't think it will, I think if it will be anything it will be the diaphragm, with most people it's the last thing to go but with (Name of patient) it seemed to be the first, a long with his legs which were already weak from his spinal injury,
R: Do you think the carers have good experience and knowledge of the disease?
I: Well (name of MNDA Care co-ordinator) came and gave them all a talk, she actually came to the care home and they all attended it, well they all came and said, they were all upset when they come here, they were all crying
S: They were crying because they had already got to know him, when (name) was telling it she was saying Mr B there were no names mentioned but they knew who Mr B was, one or two of them had to leave the course, they were that upset, but they all appreciated the course, they said it was really good and the way she put it to them was excellent, really good. She was saying to them I didn't come here to upset anyone, but you need to know this is what is going to happen you know, and then they know what they are dealing with, you see, I think they are having another one next week for them on death and bereavement, aren't they?
I: Death and bereavement, they are having lots of courses regularly on different things, I mean, if I have done a good thing there its worth knowing,
S:They are very good I must say and she, (name of manager) tries to get them on as many courses as she can, particularly if they are relevant to that carer, you know because (Name of patient) has kind of set carers as much as possible and all of them have been on that course,
R: So you feel that you build up a relationship with your carers?
I: I have just texted one of them, she is in hospital, I've just texted her to see is she is alright, not supposed to but we do,
R: That's nice, to build a rapport with them,
I: She comes on Tuesdays for me to take me out for three hours but if its raining I'll stop in and she will take (Name of spouse) out to the shops or whatever she took her for a full day the other day.
S: We have built a really good relationship up with (name of carer), haven't we?
I: She is really good, really, really, actually I was down and out till she come, I was just didn't bother I didn't want to know, well, she come and she said 'well you can, don't think you are going to be getting a soft touch with me', and I thought that's what I want, you know, and since then, laugh we have some good times, she takes me out every Friday for a pint, yeah, she shoved me out of the wheel chair last Monday, she's not been right since I fell out of the wheelchair,
S: She's been ill since, hasn't she? We've been distraught, it's weren't her fault, it's that, (looks at chair) it's useless
I: The wheelchair buckled
S: We are waiting for an electric one coming from er, wherever it is, it's not in the country yet,
I: Germany
S: I thought it might be,
I: But it's an electric once, so in the morning when my carers have been and gone, I can, they have put these doors in here and a ramp down back, and they've got me ramp for the back door, I can get out down street on my own then, I can still talk, I can still do everything else I just can't walk you know,
S: That's the only fault I have is the waiting times, for equipment sometimes
I: Most of the time it's alright
S: Yeah, the things like the slings and hoists there fine but something like the wheelchair, its not even due into the country until the end of month, and its three weeks since he were here, you know what I mean, so its going to be like, it would be, I know, they are going to have it by the end of the week and then its to go to their engineers
I: And then it's to go to their engineers at their company and make sure that it is British standard to and all that and they are hoping that I will have it by the end of next week,

S:Because eight week if we had waited and (name of social worker) hadn't pushed, it would have been something like eight weeks, which eight weeks is a long time when you have motor neurone disease.
I: It is when you are stuck in the house, its like today I could have got wrapped up and gone out, this morning, you know I've got waterproofs and everything I mean obviously I wouldn't go out now, (laughs) its raining out but I'd have been out that fresh air helps me a lot, you know, but I can't go out on my own, I do have an electric scooter but I can't get off it now, because its too old for me, I went out on it Friday, they got me back and I stood up and I had to sit on the floor and fortunately my son was here and him and (name of carer) picked me up and put me into this and then lifted me out of this onto my bed but it is just impossible now to get anywhere without that sling, I was talking to (name of Manager) Well, (name) I can't see anything happening now unless you use a sling she said don't worry about it, she said are you happy with it, yes I have no problem, whiz me where you want,
S: But I can't use it; I physically don't have the power you see
I: She hasn't the power to shove it you see,
S: Because my muscles are wasted in my arms and legs, my bodies fine, the CMT only affects your arms and legs, your swallowing a bit, you're narrow oesophagus,
R: How do you manage when the carers aren't here?
I:Well what we do, they said they would be here shortly, they are here now, so basically do it when carers are here, they will just see to my needs now, just do it when the carers are here, (name of Wife) has nothing to do,
S: If I have to I ring (names of sons) they are both big strapping lads, (name of son) has the same disease as me, so him and me don't make a good team together, (Name of sons) together can move him but (name of son) and me we can't but I can't move him, I have stood behind you, I can't even support his wait, do you know what I mean? Not for want of trying, believe me, tried all sorts but we have been told if ever he needs to be moved or anything like that and I am on my own, and there is nobody here to help, we just ring the home and they will send somebody down asap, to move him in the hoist, what time do you close?
I: Half ten, that's the last call. They finish at half ten.
S: Yes but there is somebody on call 24 hours, that mobile number you can ring that anytime.
I:I have never really,Once I am on bed I am ok, once I am laid on my bed, carers have gone, I am alright then.
S: Once we got the care package sorted out, I feel like a new woman, honestly it has made a hell of difference, they are superb, they are brilliant them girls up there, and l lads as well and manager as well, she does, I mean I can't say for other people but for (Name of patient) she does make an effort, yeah definitely.
R: Can I ask about the ventilator, did you feel that went well, did you feel you got enough information about it?
I: Yes, when I were there, they were very impressed at how quick I learned how to use it. They, basically, they take you in and train you how to use it, because it just fits on your nose and you can't breathe through your mouth, so what they did, when I got there, they laid me on the bed, they took the oxygen off me they said it was no good for me the oxygen, er they took it off me, and then she said right sit up in bed but what you'll have to do is go to sleep, so we'll put this mask on you and just breathe in through your nose and try and go to sleep, well I mean I hadn't bed for it was days and I was absolutely shattered, so they put this mask on me and went to sleep and when I woke up three hours later they said fine, you're not going to stop five days, say another day and we will send you home with it, she said I've never known anyone take to it like that and I said well I am only done what you have asked me, its in there the machine if you want to have a look at it, and after that I came home, yeah I am fine with it. No problem,
R: You're fine using it?

I: They give you some, its like a nostril, you know the oxygen l thing that fits up your nose, its like that but it is air tight on your nostrils and I couldn't work them, it kept, my nose kept breaking out in blisters, so they sent me a proper mask (interruption) which fits here like that and that's more comfortable for me, a lot better, so they come up and they ring me every month, they ask me if all the equipment is ok, if the machine does go funny, sometimes there is a, like a valve inside and if it goes funny and when I breathe the machine won't breathe and when I don't breathe the machine will breathe, so its like a bit complicated to say the least you know, its but if I ring them, somebody will be here within an hour with a new calibrated machine.
R: Who do you ring?
I:(Name of hospital), and all they do, they ring for an engineer for the company that supplies them, he goes to (Name of hospital), gets the machine that is already calibrated for me, fetches it and swaps it but I have a spare one under my bed that's calibrated, the only problem I have at the moment is they have sent me a battery and they have asked me to just put the battery on the machine and run the machine off the battery, so last week they rung up and I said well how do I plug it in, the batteries charging, she said there is a blue lead, so yesterday I said to (Name of spouse) we are going to have to find this blue, anyway there is no lead there so I am going to have to ring them and ask them to come and either they will have to fetch me a blue lead or show me where this blue lead is, there is that much stuff under bed, but that's just in case there is a power cut, but I am going to have to sort it, sooner rather than later, I mean if there is a power cut, if its during the day I am not bothered, but if its at night I just wouldn't be able to go to sleep there is no chance I'd be able to go to sleep I would just have to sit up all night in my chair, but other than that every body has been brilliant, absolutely brilliant and I went back to (Name of hospital) to have the peg putting in, I had it done at (Name of hospital) because I am on this machine, so the machine had to come with me to (Name of hospital) because when they operated me I had to be on this machine because I can't breathe, being laid down I can't breathe so then they had to teach me how to breathe with my mouth open while they did the operation I said a lot of teaching going on here for an old fella,
R: Do you feel you have the right amount of information for that?
I: Brilliant, yeah, no problem at all, anything I want to know I can either ring (Name of specialist nurse), (Name of hospital), my own doctor, anything, doctor has told me don't ever come down to the surgery, just ring me I'll come up,
(Interruption)
R:In terms of how you are affecting your day to day life, do you feel there have been a lot of changes?
I: Well, yeah it made a lot of difference when I had the operation on my back, which is four years ago, they said I would never walk again but I did so obviously, I never worked again when I had my back operation so what I used to do, get up in the morning, walk down the street meet my mates at the bookies, whatever, come back, but I could walk a bit then but obviously other than that the only thing its affected is me getting up in the morning and getting dressed but when this other wheelchair comes I'll basically be back to what I was doing then, its just I will be in a chair rather than walking, hopefully I'll be able to get, I mean when I had my scooter, I bought my scooter didn't I (name of wife)? and it didn't affect my life all that much really, apart from the fact that
S: It made your life brilliant for twelve months, that scooter has been brilliant for twelve months but he cannot use it anymore
I: I can't use it anymore, so hopefully when I get this new wheelchair that will take over from what that did for me, you know so, I mean what I say now might sound a bit strange to you but I like going round cemetery, I have a lot of relatives there and I go and have a talk to them,
S: Its flat ground and its beautiful in there
I: Its flat ground, and its beautiful cemetery, the sun shining, its peaceful and its, I used to go down on my scooter, get down
S: We take the grandchildren down
I: My carers take me down now if the weathers right,

S: They're safe, you're not watching roads all the time or anything, they can run and
I: My carers take me down regularly, just take me down, I sit there they sit with me, they have relatives in there and I have relatives in,
S: But it's sunny, its always sunny somewhere in there it's lovely,
I: It's really nice, but the thing is when I get my electric wheelchair I don't have to wait for my carers if I want to go, you know if they say it might rain this afternoon but it will nice this morning, I can get out, you know,
R: So you can be a bit more independent,
I: Exactly, other than that, my carer who is in hospital at the moment and there is a lad coming down to take me for pint, in the pub like, my mates come, proper mates come visiting, so called mates
S: He has some very good friends
I: There were two yesterday and they were both on crotches
(Wife talks)
I: My carers when they take me down the street say is there anybody you don't know, I have lived here all my life you see, apart from the young ones I know a lot of them
R: So you feel you have a lot of social support?
I: Oh yeah,
S: And family, the family are brilliant
I: Up to me er getting motor neurone, my mate used to come every Saturday, he would take me to the football, come up, get in car we are away, off to football, cricket anywhere but obviously with weather as well, the only thing that has a big bearing on you is the weather, if it's cold and wet I can't go out, because if I get a cold that's it, I'm snookered.
R: You have to be a bit careful
S: Well, he has had chest infections, six months ago he had one and that was bad enough but if he was to get one now,
I: Well, they sent me some, I've got some tablets, didn't I? For emergency, they said if you start coughing take these straight away,
S: We have anti-biotics all the time in case and there is a nebuliser under the bed and all that stuff,
I: but if the weather is being clement I won't go out, just no way, I won't go out, I have found a taxi firm that does wheelchairs as well in (place) so if its raining and I need to go anywhere, I can ring them and they can throw me in the back of there and its not too bad, cheap,
(Interruption)
I: Other than that I wouldn't say it's the wheelchair or owt like that that's making me life, it's the weather more than anything
S: Are you out of breath?
I: A bit
S: Take it slowly then..See I am used to him so I can tell
I: No it's just,
R: If you are feeling tired we can stop,
I: No I am not tired, I am alright honestly
R: So is the wheel chair the only thing you are waiting for?
I:That's the only issue that we have at the moment because I can't push that, I am at a disadvantage because I am disabled myself, do you know what I mean? I cannot push it, I cannot move that wheelchair, I am bad enough with the baby in the pram but if he had his electric ones I would be able to go with him
S: We used to go with the electrical one didn't we?
R: All other equipment has been ok?
I: Everything else, yeah, we have always struggled with the wheelchair.
(Interruption)
R: Would you say there is any sort of, area of care that you think isn't available that you would like to see that is missing?

I: We have been offered,
S: We have had to turn some down, haven't we?Because he is not in the hospice, but the hospice have said to me you can come up and you can have a massage or your hair done or whatever, but its (name of place) and its quite a way from here, you know, I would have to go by bus and I don't really want to leave him anyway for that length of time, I have think I have only once in last twelve months been out for six hours,
I: (Name of carer) took you, didn't she?
S: Only once in twelve months,
I: You never did go out much
S: I have always been very homely, I like sit down at night, warm, TV on, (conversation continues not relevant) I have always been a very homely person, my family, my home, I don't have a lot, I only have one really good friend, that's just the way I am,
R: Do you feel supported?
S: I am happy, honestly
I: We were just talking about it last night, somebody asked about support, it's just been that good, it's untrue
S: It's been fantastic for us, the GPs, the district nurses,
I: The only people we haven't seen is the social workers
S: I don't want them, I haven't a lot time for social workers anyway, they are all for useless, no good,
R: Have you had much to do with them in terms of benefits, adaptations or anything?
I: To be honest they changed mine without even telling me
S: The social worker left and we didn't even know,
I:Never even told us, this woman turned up, they had a meeting here, there were district nurses, care workers, (Name of MNDA care co-ordinator) come, didn't she? And this woman come walking in, whose this?
S: A stand in
I: A stand in social worker cause my social worker was on holiday, and I said 'well, where's my social worker?' Well nobody knew her name, did they? When we rung up nobody could pronounce her name (name) why can't you pronounce that?
S: But to be honest, I mean, (name of previous social worker) were alright, he were, he were alright.
I: I have niece that is a social worker
S: But to be honest if I didn't see one again it wouldn't bother me, I must be honest
R: You have not felt you needed to have much contact with them?
S: Well, I mean she sat there and never said a word anyway, never said a word and then she said when your social worker comes back of holiday she will get in touch with you
I: They were only sending me fourteen weeks, stamps, yellow voucher things and I was entitled to forty two,
S: If we need anything up and above the care package we use these vouchers, give them (name of carer) and she sends them off and its extra care for you… I have stopped doing even that now, I can't be bothered with that, you wouldn't believe the forms I've filled in, I'll tell you, you wouldn't believe it, the forms for the care home, forms about the care home from the government, forms about research forms about hospitals, you name it I have filled a form in for it, benefits, GP, how's your GP? We have just been treat excellent, I can't fault anything at all except the length of time we have to wait for wheelchairs, that's the only issue I have,
I: I was housebound, I couldn't get in and out the house as well, they come and put a, we had a window there, they put them doors in for me,
R: Who did that sorry?
S: The council,
I: I couldn't get out the house, because of all the steps leading out front and they said don't worry about that, we will take you out, put you those doors in
S: Means tested us to see how much we had to pay, a vast sum of £32,

I: £32 it costs us for them
S: And four thousand pounds to put it in,
I: And a ramp and everything
S: Council did that, social services, the council and they've ramped it, so you just go straight out, right down and out the back gate
R: That's brilliant
I: Because getting out was a work of art, oh it were a work of art, (Name of spouse) would sometimes,
S: Do you remember when you banged your chin on your frame?
I: Because when the door were there either I had to go out the back kitchen and there was a step there, step there, or (Name of spouse) had to drive it round the front and there were step there, step there, step there, step there, so there were like steps and I thought I can't, no, it just, and it got to where I was getting back on the scooter, parking up and couldn't get back into the house, I said 'what's the point of going out if I can't get back in?' so
R: So that's made a real difference?
I: Oh yeah, yeah
R: Do you feel these things are happening at the right time?
I:I think we waited about a month didn't we (Name of spouse)? for that, from start
S: It was recommended to be done in January, but it weren't actually done till July, but they had no funding for it anyway, but as soon as they had the funding I think we were first on the list,
R: Do you normally have occupational therapy come in?
S: (Name) is OT
I: Name comes, yeah, the speech therapy rings me up to see if I am ok, she said you know where I am if you feel like you are deteriorating or anything, just ring me and I will there right away, I said well, to be honest there is only my gob which is working proper. There is nowt else that is working properly,
R: Occupational therapy do you ring them or do they ring you?
S: What physio? No, no physio,
I: I don't have physio
S: It's pointless,
I: They said it was pointless,
S: You can't make muscles that are dying work, you cannot make them work if they won't work, I know that cause they tried it with me and they cannot make it work if they won't work but she is fantastic, (name), she has done everything I have asked her,
R: That's the OT, is it? She rings here or do you ring her?
S: She usually comes
I: She will bob in if she is passing, if she is in the area whatever, she will bob in. quickly, you know, she is not here for hours, everything alright? you know, (Name of spouse), (Name of patient)r you ok?, anything you need? Well, if you think of anything ring me and er, we will sort it.
S: Well she brought that ramp, to the room didn't she? Because outside the back door, it goes into the back was a bit
I: It was like a bit ropey,
S: Any chance of a ramp (name of OT)? Ay, yeah, I'll fetch it and she brought it, put it there and then she sent a joiner to put a piece of wood on it so it wouldn't move about, no problem, absolutely brilliant
R: So you can't find faults with anything then?
I: I can't fault anybody.
S: They call the national health but I still think we have the best health service,
I: I can't call anything me.
R: That's great, that's good, when it works it really works.

I: I think a lot of people find faults with owt, I could find faults but I can't see the point, they are that small and minor,
S: I mean the biggest fault we had was the spinal injury, that should have been picked up long before, they sent him to the gymn instead of doing scans on his back and , he had a disc out which was stuck into spinal cord.
I: So doctor sent me to the gymn (laughs) just got over that and we found out about the neurone.
S: The spinal injury is what paralysed his bladder and his bowel
I:Well you've got people who 'I'd sue', they close rank, you know, they close ranks like that you get nowhere, and I couldn't do with hassle, he didn't need the hassle he had been through enough, mistakes happen,
S: Course they do, everyone makes mistakes, we're all human
I: Mistakes happen, get on with it, deal with it, live what you've got, left well
R: Is that both your attitudes?
I: Actually, if I hadn't got this motor neurone disease, I was getting on better than thought really didn't I (Name of spouse)? Cause they said I wouldn't walk after the operation, didn't they and I thought I was doing so well for that 12 months 18 months after,
S: You were on crutches weren't you, you were doing great
I: I was walking down street, on my walking stick I know I am suffering and its painful, and stuff like that but at least I can get out, and then the other came along and well they said I am not going get old here, yeah but its no good bearing grudges or owt like that, it doesn't change things, I am still sat here, so, as I said there are a lot of people in the cemetery who would swap places with me, so, but other than that,
R: You tend to try to live for today?
I: Oh yeah definitely you don't give up on it, do you? You don't give up on it. I mean it's like they say you might have two years, you might have five years, (Name of specialist nurse) says with your attitude you might live ten years, a lot of people give up
S: (Name of specialist nurse) says they have had people who you know that's it they are not going to survive this you know, and then they rally round and there are others where you think they are going to be here for twenty years yet and then they just go in their sleep, you know, she said it's very, very difficult, you cannot predict anything with it, and that's what I want for (Name of patient) I just want him to go to sleep and
I: We want it to happen here don't we? We don't want to go to hospital.
S: I want him to be at home,
I: They have told me I have no more hospital appointments, have I? They just ring me up you have an appointment for such a thing and we have cancelled it for you, When they took me to (Name of hospital), I was just, it were just, I could walk when I went in but I come out couldn't, I was just drained, absolutely drained, just, I was absolutely just shattered
S: No he is not going anywhere. He has a preferred place of care, there is no resuscitation or anything,
I: I don't want that
S: If he gets pneumonia or anything just let it take its course, because I can't, and I agree with him and I would be exactly the same, I cannot see the point of bringing anybody back to suffer more, this is enough, this is enough, no more, I don't want him,
I: Well what they basically they told you was if I have a heart attack,
S: I'll just cradle him
I: I'll end up in bed all time not be able to get out of it and on a ventilator,
S: If he collapsed I'd just cradle him, just let it pass and let him go peacefully, I'm not having all that bang bang, bring him back, do you know what I mean?
I: What would happen I would only get a week or two more than likely anyway, I just think it would be the start of a long chain of suffering

S: Same with pneumonia, just stop all the drugs and everything, just please let him go peacefully, because bringing him back won't make a, what a couple of weeks it certainly won't be a two or three years.
R: Is this stuff what you talk about openly with each other?
I: Yeah sorted out the funeral and anything
R: In terms of the future you have thought about it?
I: Grandkids and all, well, apart from my two baby ones obviously, kids have come to accept, well apart from (name of daughter)
S: What our kids? I think our (name of son) will be the worse,
I: Could be, yeah he is very quiet
S: He is very deep, very, very deep, is (name of son) he comes here every night
I: He comes here every night, and he has his own family and
S: He comes here every night
I: So it has affected him
(Patient talks to cat)
R: Do you feel there is support for all your children, although they are grown up?
I: Well (name of care co-ordinator) brought them all in the house didn't she? She asked them all to come and explained it all to them what was wrong, everything but our (name of daughter) keeps in touch with (care co-ordinator) quite a bit, doesn't she?
S: She is very emotional anyway she has a boy who has NF1, neuro-fibre metosis, so he is not well either, I'd don't know how we have come to have had all these neurone defects, honestly (conversation continues irrelevant)
I: I think it is helping them with me along with me, personally, my personal opinion is that the jobs they do, they see a bad side things, they see me like this at least they know I am being cared for , I think it helps them
S: and (name of son) is trained up to use all this equipment in here, yeah he's trained up for that
I: But I don't think he would be able to shove that hoist because he is like his mum you see, because the care workers, with it being on carpet you see, it's hard to shove it
S: I said that last night, have we to take carpet up? He said 'mum, no mum, we would have to move the bed, lift the bed, lift the,'
I:The thing is, the only time they are moving me is from a chair here onto my bed, so actually shoving it from where it is at the back of the bed its empty till get into here so the only part, they are picking me up there turning it there and dropping me on my bed, its no big deal, I'm not taking my carpet up for that.
S: He hasn't been upstairs for months now have you? he can't bath now
I: We had a brand new chair lift put in and everything that they put in for us
R: That was social services again?
I: Yeah
S: He couldn't get on it, we only used it for about three weeks didn't we? I felt really bad about that, you know
I: Well like (name of OT) said, you don't know, you don't know what's going to happen, I might have been using for twelve months, five years, you don't know.
(carer talks)
I:It was a brilliant stair lift and all
(carer talks)
I: They had all this gear in the bathroom and all for the care workers, they brought all this gear for the care workers it was like a teddy bears picnic you couldn't get in the bathroom,
S: Dodging this, under that, over that
I: I was looking at what to move first to get into bath
S: I was not sorry in that respect
I: It was dangerous really,

S: It was dangerous in the bathroom
I: There was that much in it, it was really,
S: Stooping stools, toilet frames, bath seats, hoists, it ain't that big, it ain't that big,
I: it got to dangerous side,
S: it got to silly point didn't it, it were silly.
I: I mean if someone wanted a bath you had to take bath seat, electric bath seat which was appreciative for me, you know when I needed it, but
R: Who made that decision to think no more?
I:Well I couldn't get on the stair lift, so I just when the carers were coming to take me for a bath I'd say its pointless taking me up because I am struggling more and more, so I said can we sort something out so I am just having a bath on my bed?
S: You nearly drowned didn't you?
I: Yeah, I slid off chair, I got off, fortunately (Name of paid carer) is a big lass, she is a strong girl, and she kept me above water really, I was going under, I thought oh god, she shouted for (name), didn't she?
S: Pull plug out right away first drain water
I: Thing was she was holding me, so pulling plug out and holding me, so I thought I can't be doing with this, I'd sooner be dirty than like this, but anyway then they decided we will wash you downstairs, and so they just took it out then but when they did come to bath they were superb with me, absolutely superb
S: It's just not practical,
I: No its not
S: and it just exhausts you, doesn't it? It were exhausting.
I: The last time I had a bath I had to come down and I was on my machine for four hours, it drained me, I'd sooner not be drained I'd sooner just be clean and washed down,
I: Would you like a drink?
R: No I am fine, thank you, thanks very much I thinks that everything
S: We have tried to cover everything, I mean even the personal thing like the funeral and stuff like that there is nothing we can do about it, fighting, banging, screaming shouting, striking not going to make any difference, we talked about it and we just take each day as it comes, I just pray to god that it takes him one night peacefully and he doesn't have to go right to the bitter end
I: I don't want it to be a year or two yet,
S: No we don't but
I: There are a few more horses to run and few more fights to be done.
S: I won't be able to bear the suffering, you see, I won't be able to bear it, I don't know about him but I know I won't be able to.
I: I don't want to be in pain, I don't think anyone wants to be in pain, do they like, I can cope with being thrown about,
S: Quality of life, to me quality of life is more important than quantity,
I: Yeah, oh definitely, I think if you can still talk to people and you still have got your marbles, from there down, if that goes, I mean well you know, you can still cope with that, you know as long as you have your marbles and you can still communicate,
S: Its good if you have got people you obviously, have a good family.
I: Yeah, if I can talk to my grandkids, if I am sat in chair, it doesn't make any difference.
S: We do have some fun as well, because some of the situations, I mean if you were to see him being hoisted in the sling, we do have a laugh about it, you can't live like that, just all sad and depressed all the time, you have got to make the most of what you have got while you have got it, you know and then deal with it when you haven't got it.
R: Have you always been like that, that's always been your outlook on life?
I: Oh yeah definitely,

S: I am exactly the same and in fact I have told my kids if I ever start with Alzheimer's or dementia, you get me in a home, don't think for one minute that you will be able to cope with me, because you won't, book me in a home because I probably won't know who you are or where I am or anything but don't try and take that on yourself, I've told them, I've told them straightforward, I am not all, I am not life at any price, no I am not, I don't, it sounds like, I don't want to die, don't get me wrong, do you know what I mean?
I: It's something you have to talk about
S: To me if there is no quality, there is no life
(Research assistant speaks)
I: It's a pity you didn't come to see us before actually if you had see us before the care, and what you are seeing now, before the care home, I would not have bothered if I had died, I'll be honest, I was up to here (makes gesture) I was just up to there, I wouldn't get out my bed and then they sent (Name of paid carer) along,
S: And I was just on my knees, me, absolutely, you cannot do it on your own,
I: No it's impossible
S: You cannot do it on your own, with all the will in the world, with all the heart you have, I couldn't have done it, I did it for nine months and I thought I did it damn well.
I: I think even you have that negative thing even when they have been here once or twice, it was a little bit easier that, but the more they come, the easier it gets, the easier it gets and then you think why didn't I do this 6 months ago, twelve months ago?
S: Its asking for the help, it's hard because I have always been very independent anyway to me working and bringing four children up was a doddle, well it wasn't a doddle but it was just something you did, you got on with it and you did it, and that's how it had always been because I lost my mother when I was seventeen, do you know what I mean? So I had no, my family are over in (name of place) I have had to cope, you know, and that's how its always been,
I: I think a lot of people are reluctant to accept.. A lot of people have too much pride, and to be honest well and to be honest, its just, (Name of paid carer) that come, her father in law, (name) he is waiting for a liver transplant, he has had chromes disease all his life, they have told him if he doesn't get one for Christmas he could die, so (Name of paid carer) has been saying to her father in law, 'why don't you ask for care?', 'I don't want no bugger helping me', I thought and I said to her he doesn't know what he is missing does he? get him round to my house I'll tell him you know because his wife is a nurse at (name of hospital), she has given her job up for the time being, well not given up but taken this leave to care for him, all the pressure is on her now, so instead of going to work and relaxing and doing her ordinary job she has got this twenty four seven, of caring for him, whereas it may sound selfish, well how do you put it? it is selfish him to me him saying I don't want care, well if someone had said to me I would have agreed with him,
S:It either happened or he would have had to gone away, I was at collapsing point, I was definitely at collapsing point and I wish now that I asked right at the beginning.
I: They were all here that day and they were sat here and I was gobsmacked me, all these people they can do this, that for us, and it is going to start tomorrow, I thought 'why didn't we do it before?'
S: I wasn't aware that all that was available.
R: Really?
S: This will sound really racist, I am not racist, I promise you I am not, if you are ethnic minority they send people out to translate and tell you all that you are entitled to, if you are indigenous to, you know, they expect you to already know it, they don't do that, they don't send people out and they don't send out anything.
R: You mean in terms of social services, you think they could have, you weren't aware..?
S: It weren't social services that told us what we could get,
R: Right so how did you find out?
I: It was my daughter rung up, no it were me, I asked for a doctor to find out about sending me to hospice, and she came and said 'do you want to?' and I said 'no I don't', I was lay on bed in there

and I said 'if you don't get me out of this house one of us is going to die and I said 'I don't care if it is me, to be honest', and she said 'Well, a hospice isn't the answer' and I said well 'What is the answer?' She wrote down a couple of things and my daughter got on the phone and rang all these people up. They had the meeting the day, a couple of days after it wasn't long was it? and they were all sat in this room, here where we are now, couldn't move in this room for female bodies, I was sat in corner saying nothing, you know, and when they left everything was so different.
S: At that point we were both depressed, I was just exhausted, I weren't getting, probably getting two hour sleep a day,
I: No sleep at all. None whatsoever
S: It was alright for (Name of patient), it weren't but he didn't have to do anything, I still had to run a home, do the washing and believe me there is plenty of that and make meals, and look, and have grandchildren, be a mother and do everything, you know, I was completely on my knees.
I: I think that is the only fault that we can honestly say, is the information that's actually thrown at you, if you will, you know, you have to go out and find out what is available and then you have to get into a drastic position though to get to that point, but that's the only thing I can say.
S: But if you are Asian, Chinese
I: They explain it all to you
S: Whatever, they send somebody out, and then they will interpret and tell them what they are entitled to and everything
I: It's not straight forward, the information, quite complicated.
S: Oh no we have been means tested and everything, they came last week and means tested us, we are fifty odd p over the poverty line, I think they said
I: Fifty eight, I said it is about eight point seven p, is sixty per cent of fifty odd pence,
S: So we will not bother then, because they were on about charging us for care and stuff like that, if you start charging us he will be in hospital, Alcoholics can stop drinking, drug addicts can stop taking drugs, women with five kids from five different blokes can stop lying on their backs, I've said there isn't a man on this earth who can stop my husband from dying, but you are all for them, you are falling over yourself to stop parents beating their kids up and one thing, they shouldn't have them, if they can't look after them, they shouldn't have them. A drug addict shouldn't get more money, more money than him because he takes drugs. He's worked, I said my four children, me and my husband to this tax year just gone have paid one hundred and fifty years of tax and insurance to this country please don't tell me that I have to pay x amount of money, when I know that Fred koporplosky is coming in to this country from Poland or Romania or wherever, and you are like this doling it all out, and he's paid it in, I've paid it in, they haven't I am not bitter about it, people might think I am, I just think it has gone mad, its gone completely mad, you know…She said to me 'calm down (name of carer), you don't know what, It tell you now, I am not paying anything, I am not paying anything, he will go in hospital and I tell you it will cost you a damn site more for him to be in hospital than it will for me to look after him at home.
R: So they did agree to pay for it?
I: Yeah
R: Do you think you have to fight to that then?
S: I wouldn't say you have to fight for it but you have to explain yourself very thoroughly and I think if you don't do that they will take advantage of you.

ID83

Present: Individual with MND & Research Assistant

R: First of all, you could tell me a bit about yourself, first of all, like what work you used to, what interests you have, those things just to generally introduce yourself really.
I: I worked for social services, I belonged to Scotland, Edinburgh, and I've always dealt with children, looked after children.
R:Oh right.
I: Er, I've started at being a nanny, is this you want to know?

R:Yeah, that's fine.
I: And then blind school, deaf school and disabled children and then I, then I went into children's homes and eventually I was officer in charge up in Scotland in children's homes and then I came down here and carried on with my career and then after I retired when I was 52, this is my second marriage, my first husband died in 92, I have one son, he also works with community justice, I have two grandchildren, and two step grandchildren, when I , then I met (name of spouse), 6 years, 7 years ago and he was a widower and we remarried last year.
R: Right, that's lovely.
I: Am I doing alright?
R: Yes you're fine. So I am wondering if you could tell me a bit about any symptoms you started to have.
I: Well, I didn't know there was this problem. I used to get quite upset because of these, I call them little sores up my nose and I would go to the doctor and the doctor would give me cream but it wasn't really helping and about a year and half ago, I knew there was something but if you said to me what's wrong I couldn't tell you, I couldn't explain, then I, it was Dr (name) referred to me this, with this problem with my nose, and it was Mr (name) at (name of hospital) that said he might have to refer me to someone else but didn't say who and eventually I got an appointment through the post, I think it was (name's) assistant and then from there it was Dr (name). I know I am different, I know there is something but I keep on thinking that I'll get better because I am a type of person that will fight, I forgot to mention in 1974 I had Hodgekins disease, in 74 and I erm had my spleen out at (name of hospital) and (name of hospital) but everything has been fine since er, so it was Dr (name) that saw me and he said he would, I would be having a visit from (name) he is a special nurse and he did come and then they started me on Riluzole in January 2007 now since then I have seen (Name of specialist nurse) about six times erm I can contact him if I need to, I see the speech therapy, she comes here, every three months to see how I am managing with my meals and my swallowing, I have sometimes difficulty, it all depends what I am eating but (name of spouse)'s a good cook and he liquidises a lot of my stuff otherwise I am inclined to chop it up, can we stop there for a minute or two?
R: Yeah, sure, that's fine, shall I ask you a question? Yes, erm, I was just thinking about the diagnosis process and erm how did you feel it went, did you feel it met your needs?
I: Sorry dear?
R:The diagnosis process how did you feel?
I: When (name) told me? Well, I just went, I just freezed, even though I didn't know about motor neurone but (name of spouse) had a friend and he died in 1992 with motor neurone disease but (name of spouse), he just mentioned that died and that was it so its not like. You hear a lot about Cancer and things like that so I am afraid when (Dr) did say I just freezed, I didn't take it in really.
R:It was a shock?
I:It was shock. Well, so from there it wasn't that long before (name) came to see me and he was very good and he tested me, my arms, the usual ? and breathing out and this type of thing but erm I have noticed that when I am speaking to someone or speaking to someone on the phone, I am not alert, usually when you are speaking, you just take it for granted, but I've noticed I'm having to think.
R: Right, to concentrate?
I: To concentrate before saying it, which does give me, at the end I feel tired, I get tired
R: Do you, how did, like you said it was shock for you at first, after that period, did you find that you told people about it?
I:No, I didn't say anything, in fact I didn't mention anything, in fact, I didn't mention to my son, although he is forty five,
R: Right,
I: I've always tried to protect, which I suppose every mother would but with Peter being in the type of work he is in erm it was (name of spouse) that said have you told Peter yet? In front of Peter so I had to say to him er,

R: What was the reaction?
I: Well I think he had a bit of a shock for a minute and he was asking like people coming a few people explained the usual about how it will deteriorate, but I am shutting that off, I'm … alright?
R: Yes, it's fine. So you just think that's your way of coping?
I: Yes, I've got a file, that (name of specialist nurse) gave me, and I should really read it,
R: Well, its up to you really.
I: And I keep on saying I will but up to now I haven't.
(whispers to interviewer if ok)
R:Ok, that's fine, don't worry, so
(coughs)
R:Have a break. Are you ok to carry on, if you want to stop at any time just let me know. So how would you say that the disease impacts on your daily life, how do you think things have changed?
I: Well, I cannot do housework and I've been the type of person who everything has to be right so that irritates me, my grand daughters very good she comes and does my hovering and dusting, my bathroom, I do shake, not all the time but I do shake I can't understand that in the sense of why because its nothing to do with, well it maybe something to do with motor neurone, I m feeling I am still working, I have a wheel chair, I think I have used it twice, I have, we call it a buggy, its four wheels with a seat on it so I can push along, I prefer using that because once we start using the wheel chair, even ?, I feel my legs a wee bit weak I don't want to rely on the wheel chair all the time, I may one day but not at the present, my legs sometimes, they ache even in the house, and there has been an odd time that I felt my legs go a way from me and that doesn't happen all the time but it does quite often,
R: You feel that if you can still walk you want to carry on?
I:Yes, (name of spouse) does my feet, well we've just had a wet room, just these last two weeks and that's a great difference because I am more independent even though (name of spouse) has to wash my back, wash my feet, dry, my feet and my back, there is sometimes, like a hook for my bra, things like that, this shoulder aches and I have noticed this seems down more than my other shoulder I don't know if that is motor neurone, or if, I have arthritis as well, I forgot to mention from my, right down my spine, I have it in my knees as well so I keep on thinking there is a lot of aches, my shoulder and that whether it is arthritis or if it is motor neurone, can we stop? : Coughs, I hope, this will sound terrible.
R: No, it's fine, honestly.
I: Will people understand?
R: Yeah, well, I type it up afterwards so, I type it up
I: Oh I see. So we don't
R: So I should be able to understand it, so it's fine.
I: I was a bit worried about it.
R: No its fine, your very clear actually. If it hurts in anyway or you want to stop just have a break.
I: Now, I don't know if I am jumping from one thing
R: No, its fine, that's what I want you to do, just to tell your story,
I: The, my tongue, is very dry and I take tablets for that but I was up at the doctors yesterday (name) and he has given me a liquid which we will get today, because the chemist didn't have it.
R: Oh right, so that helps?
I: I haven't used it yet, I have to use it three times a day (Dr name) says, so I hope but the front of my tongues seems very hot, and I can't put my tongue out properly.
R: So that affects your eating?
I: Yes, there are things I can't chew, if its something quite a lot of stuff, I use with my cup of tea and that softens it, things like that,
R: so that makes it a bit easier,
I: A bit easier, yes.

R:Can I ask about the services, then, so you say you've seen a speech therapist and (name of specialist nurse) but I was wondering how do you feel in general the service is in (name) and do you feel that they communicate well together and that your needs have been met?
I: Yes, I haven't, I've never known such a lot of kind people that has been there for me, I've always, if I've not been ill, well, I just carry on, yes, (name of specialist nurse) is absolutely very good, social services.
R: Has it been good has it?
I: Yes, I've had a chair lift, I've got this, (points at chair), I see (name) at the hospice.
R: Oh yes, the physio therapist.
I: I've not had physio, I can contact her , but I've not had physio, she has given me I call it a buggy, a delta or something, I do use sticks in the house and it helps me to get into the car,
R: But you've felt that if you needed something?
I: Yes, everyone has been so kind.
R: Do you feel that people are up to date with how you are?
I: Yes,
R: Informed?
I: Yes, it's just marvellous
R: And is there anything that you think, oh, erm, there is something missing from the service, that you wish you had that isn't provided, that you think they are lacking, I know you said you've got physio if you want it but feel you don't need it yet but is there anything you think I could do with that and that's not been offered.
I: No. I can't think of anything. Social services, put a step there coming in the front door and down towards the garden some steps and banisters, yes banisters, sometimes, you say stupid things, and I think I haven't got the same confidence but that could be my age.
R: Right, have you felt that then, a loss of confidence in yourself?
I: Yes, I've always been a very confident person, especially the job I've been in but I haven't got the same confidence. I'm coming up for seventy.
R: Right, you don't look it.
I: I'll be seventy in August, so it could be my age with that.
R: Do you feel it's about going outside and things, do you feel a bit more vulnerable?
I: Yes, I, (name of spouse), takes me in the car, to go shopping, a friend of mine we always went out twice a week but I can't get on the bus now so that I've lost that, I still see my friend, (name of spouse)'s dropped, picked (name of friend) up, friend and we've gone to (name of town) just the both of us and he will come and pick us up again, but I still think its not fair to (name of spouse), he does a lot more now.
R: How do you feel about that?
I: Well, I'm not a good cook, (name of spouse) is, I still do the washing, (name of spouse), quite often, if the washings been done, he'll hang it out and I want to hang it out. If its tops I can do it, if its sheets it's getting more difficult, the bedding, er
R: So he's doing a lot more round the house?
I: Yes, (name of spouse), it's only, not a year yet that we got married it was last September but er with (name of spouse), he does, I don't do much and that doesn't go down with me too well.
R: Whys that?
I:Because I've always been a type of person, that's independent, doing things, I, with the paper I find it difficult because with the arthritis, its holding the paper , and if I read it down there which I can't do, its just, it is awkward, I sometimes, quite often have a lie down, sometimes its 2 hours. I did mention to(name of specialist nurse) that quite often I go to bed and have a lie down and sleep which I do and he did ask do I sleep, do I have eight hours, I said yes, but I don't sleep the eight hours, I am in bed, so I have misled him there not meaning to .
R: No of course, so you're finding your sleeping is disturbed?

I: A bit yes. If sometimes, I don't go to bed, I feel tired I want to go to bed but I don't sleep very well at night then and I am up about four times to the toilet and that doesn't help.
R: So you feel very tired during the day?
I:So I get tired during the day, but saying that there has been times before I was diagnosed that I used to have a lie down sometimes but I certainly didn't sleep for two or three hours, I don't actually sleep for two or three hours, but I do fall sleep and I wake up and I say I'll have another ten minutes and its another hour you know what I mean,
(interruption for two minute)
R: Erm, you mentioned about friends and things and I was just wondering how it's affected your friendships and relationships in general, do you think it has impacted?
I: As I say, (name of friend) a good friend, on a Sunday evening I go to the (name) club, but I've not been the type of person for clubs but its (name of spouse) would go to the club and I've met such a lot of nice people but if (name of spouse) doesn't go or has been away for some reason or other I don't go to the club. The people up which are very nice, sits with us, they've all said you don't need to rely on (name of spouse), someone will pick you up but I don't like to, I just, I don't like to explain to them, they know what I've got but I don't like to explain to them that I've not got, I haven't got the same confidence.
R: So it's affected it in that way?
I: So it's affected it, yes
R: Erm, the other thing is about your GP, do you feel you that you have much confidence in your GP, do you feel that they've been good?
I: The one, I have now, I don't want to say too much
R:It's all anonymous, all names are taken out and nothing will identify you.
I:No, Dr (name) is absolutely marvellous which is the same practice but I see Dr (name), it may be when I did go to see a doctor, try this, try that and I just felt that I was being a nuisance, so that's why I was not one, I wasn't the type of person who would go to the doctor unless I wasn't well and I mean wasn't well. But saying that the doctor I have now that I see is absolutely marvellous, I don't know if he knows a lot about motor neurone but saying that cause there are different sections isn't it , but he gets all the information from Dr name, name of specialist nurse, I think the speech therapist.
R: and the GP you have a lot of confidence in?
I: I have, so that's a great help.
R: That's excellent.
I: I'm fine.
R: You were saying about equipment, that's been fine, there as been no delays and with social services and I don't know if you have had to make any claims,
I:No, we were going at first to have a shower put in, not the bath, take the bath out, and because I couldn't get into the bath, and it was (name of Specialist nurse) that mentioned about a wet room, now I knew we wouldn't be entitled to get any help from them because of the income but (name)?
R: From the MND association?
I: Yes, we got up to a thousand pounds towards that so
R: So you feel that they've been really good as well?
I: Excellent…I do sometimes feel sorry for (name of spouse) because I sometimes get annoyed with him, but its probably frustration that I can't do certain things, like hang out the washing, which sometimes I do, but (name of spouse) he was frightened in case, he helps to take out the washing for me but I like to carry myself..(pause and looks confused)
R: So you were saying you get annoyed sometimes?
I: Yes I get quite cross although I am a little bit better but that's what (name of spouse) thinks.
R: And then you feel sorry for him?
I: I feel sorry for him, I mean (name of spouse) is 73, and I suppose we should be enjoying life, retiring, which we do but at the same time but I feel with (name of spouse) that I am holding him

back because like, (name of spouse) is very active, with his computer upstairs and different things, his hobby with the garden, I don't do anything in the garden either, we have a man come to cut the grass, we have always had that but I would love to have been able to do things in the garden, I am not the type of person that, I'd like to have a nice garden but its only been a year, well over a year now so its getting things sorted out.
R: Do you find you go out in the garden much?
I: No, I am not the type of that never have been, if I do sit in the garden, its not for long, cause I go red, you know so I am not the type of person for the sun, and we have just had the conservatory done last January 2007 but I don't sit in there its too hot, (name of spouse) loves it so we, he has to have space as well.
R: Do you find you are able to do that?
I: Yes, but sometimes I don't like it, I, sometimes he's up in the computer room but saying that I know deep down he needs that space.
R: A break
I: A break yes. He's very good but I think he is always overprotective
R: He wants to look after you?
I: Yes, and I've not been. I've been a very independent person.
R: So you are finding that strange?
I: Yes, because, as I say I have been very independent.
R: Can I ask what things were important to you and what things are important to you now and if they have changed at all, do you think your priorities have changed at all?
I: Well I did retire under ill health with my arthritis and that I really missed and even though I am seventy I would love even just to talk children if they have problems I feel that I've had the pleasure, the children have given me pleasure even though sometimes they had problems they've been able to speak to me, even though we knew that there was times that they , I love my work and I've had a lot of children contacting me, I've also had a boy for a number of years coming to see me but he usually comes at Christmas as well, a boy and a girl but he hasn't appeared so I feel that there is something wrong and I must try and find out, I don't want him to feel because he's a lad in his thirties, but he knows how to contact me.
R: That's great, so you still feel that's very important to you now, that side of things?
I:Yes, I love to listen to children, if they have problems and there is a way round it, its surprising, there were some children that didn't say anything, But it was surprising through time they would say to me about their problems so these are the types of things that I feel, I felt good.
R: And now, what do you think is most important to you, would you say that still very important, obviously that is very important to you, but what would you say your main priority is in life?
I: Still children, I would love, I know I can't, to still deal with problem children.. to carry on with it, mm.And I don't mean every day, it was just if they had problems, for me to listen, I do miss that.
R: Erm I think I have asked all my questions, I don't know if you have anything you would like to add.
I: I can't think of anything
R: But you have been very happy with the service you have received so far?
I: Everything
R: There isn't anything that you think oh that needs to be improved?
I: No. I can't think of anything
R: Well, thank you you've been really useful in the things you've told me,

ID203

Present: Research Assistant & Spouse
S: She's always been worried for years, some nasal problems and he does prescribe her some medication for that to try and ease anything any medical symptoms
R: So if you feel there is something you tend to go to the GP first?
S: Yes,
R: Is that your first port of call, really?

S: Yes, first port
R: And how do you feel the service in (name) has been?
S: The service has been very good. I'd say excellent.
R: So you think it's met all your and her needs?
S: It's been very helpful, very understanding, obviously they have wide experience of MND and they seem to understand the problems well a deep understanding of the problems.
R: So you feel quite confident in being able to speak to them about any issues?
S: Oh, yes, yes, very confident.
R: Oh that's good.
S: The help we've had from the hospice. I wouldn't say a great deal of help but very understanding, they immediately supplied the aids for her walking, er, she can speak to (name of physio) any time she likes so overall the help has been very good. And from Social services with the stair lift and the chair,
R: So there's not been any delays or,
S: No it's been a really good service,
R: Excellent and from your point of view is there anything that you think oh I wish somebody was able to offer you this or that you feel something is missing?
S: No, can't think of anything, because they've suggested things that I wouldn't have even of thought of.
R: Ok, in terms of equipment?
S: Well, just in the case of the steps down there outside, they installed them because she will insist on hanging the washing out er and Ill let her get on with it because the more she keeps mobile er the better and she wants to do it. So if you've got the motivation to do it well do it.I don't want to stop in and prevent her from doing anything she is self motivated to do.
R: How do you feel that your life has changed since she was diagnosed with MND?
S: Well, we don't have the same meals as we used to do cause she can't swallow very well so it tends to be soft food but I like a steak and er grilled things are out but er we can accommodate that, if we go out for a meal then I can have a steak then. But otherwise I have a varied diet, I don't mind what we're eating at all.
R: And day to day, do you feel that your routines have changed?
S: Yes, well, (name) likes to go shopping as all women do, like to go to the shops. But she now cannot get on a bus, whereas Id used to take her, she'd go to places like Blackburn and [(name of hospital) and er Manchester, Blackpool, Id take her to the bus station, she'd get on a bus and then she'd ring me to pick her up to come home, on a Saturday, she'd go with a friend, that is out, cause she can't get on a bus. I'll take them within reasonable travelling distance, cause I don't want to be travelling all day Saturday but er I spose that's the only thing, we have to think when we go out anywhere access, disabled access for anything. Yeah be prepared.
R: And do you think that your social life has altered at all?
S: My social life? No, I don't think so, not really,
R: It's not really affected you?
S: Not to any extent, not that I can't handle.
R: You still feel able to go out and do things?
S: I think yeah, I go out with friends once a month that I used to work with of an evening. I usually go out every Friday evening for a couple, two hours, we go out Sunday evening.
R: Together?
S: Yes, together.
R: So you still do quite a lot together?
S: Yes, we still do, and some friends call and pick us up. So we have something of a social life. We're not cut off completely from society, I wouldn't let that happen, cause I think social skills are very important.

R: Mm, do you feel that informed about everything and kept up to date with services and getting information you need about decisions that need to be made.
S: Well, everything comes, not being used to the services, everything comes as a surprise that these are available, we have had help, yeah, well in many things, especially with mobility.
R: You feel that you can contact people?
S: Yes, if and when,
R: You don't think there's a need, there's stuff you don't know about you rather know about now.
S: Well
R: Decision making, in terms of PEG and things like that?
S: Yes, well the speech therapist has talked about it. I understand what its all about.
R: You are happy with that side of things?
S: Yes
R: That's fine., I think that's about everything unless there is something you feel you'd like to add.
S: Because my friend having MND, er had a certain, well understanding of what happens, I know every case is different. Its affected (name) with totally different symptoms to what my friend was ,
R: Right, so at the time of the diagnosis did you feel you got all the information you needed?
S: Well, it was quite a shock to hear it was MND, I wasn;t expecting to meet another person in my lifetime because it is so rare. So it was quite a shock but then you just face up to it. This is reality, I am a practical person, I face up to problems as they arise.
R: Just take each day as it comes?
S: I just deal with it, as it arises, can't do anything else.
R: A good motto, I think.
S: Yeah,
R: So you feel that you are coping fine
S: Yeah
R: and things are there
S: yeah
R: to support you if you need anything?
S: Yeah, yeah, if I find that there is some difficulty in some respect, I should probably ask (name of MNDA care co-ordinator) for some advice as to what to do. She is very supportive
R: You think the association has been really good.
S: Yeah, but until that time arises I don't look for problems because then I'd be kind of searching, no if a problem arises then I'd seek help but until that time comes no I don't need it.
R: That's great, I think that's everything, thank you.
S: Ok.
R: Yes, thanks very much

ID 19& ID 213

Present: Individual with MND/ Spouse/Researcher

S:When, we were gone, we had a motor home then and we did quite a lot of travelling in it, we were down in (name of place) and we went for a country walk and we was going through this field there was a style but it was quite high up the style, but she started then in having difficulty in getting over the styal but with a little bit of push and shove she got over it and then what the next time was and again we had been out with the motor home, down in, where were we then? not in (name of place), we were in,
I: When I hurt my arm in (name of place)
S: (name of place) we were going up a slope and there was some like steps cut into the like the hill side if you will, and she was going up first and she got part way up and she grabbed a tuft of grass to hold on but it came away in her hand did the tuft of grass and she fell over backwards, finished up nearly hanging over the side which there was quite a big drop.
I: He said stay there

S: So stop and don't move till I get there so we got there and that's when you sprained your arm or something didn't you? and erm it went on and the road, we used to, when we go out for lunch, we would go down to Burnley and we would go down on the bus and the bus we used to get it then, would stop on the road, on (name) where you were stuck, we used to get it there coming down there is a little cutting you can get through you can't drive car or you couldn't take a car those days that way, so we used to walk, coming down it is fairly steepish slope coming down as you probably noticed, and erm she kept saying to me stop running with me I am not running with you, I am trying to hold you back because the top half of her body wanted to go faster than her legs could take her, and it was then that we went to see, what do you call it, which doctor was it, anyhow, do you need the name of the doctor?
R: Was it the GP?
S: No it wasn't GP no it was the consultant, the GP referred her to the consultant
R: So you had been to see the GP first?
S: Yes, he examined her and that's when he got in touch with that surgeon from (MND Care centre) and he did an operation on your spine at the back,
I: ?
S: it was pushing on a nerve so they did this operation and it seemed alright at the beginning but it didn't make a right lot of difference and then we got referred to (name) at (MND Care centre)
I: we went private
S: went private to see him and he examined her but said she was mystery and eventually you went into (MND Care centre) Royal for some tests,
I: it were all negative
S: all negative were the tests, but we kept sort of, we had, we went at regular intervals to see him, six months weren't they, something like that, and another perhaps a couple of years nearly, where you were gradually going a bit worse and you went into (MND Care centre) again and they did, they went through the tests again and then they decided from these tests that it was primary lateral sclerosis that she had,
I: very slow
S: slow, it's a very slow progress,
I: and about eighteen months I lost my voice
S: yeah her sort of going, losing her voice, you know straining, so with all these, well they got, first of all they had you going to the physiotherapist down at Burnley and they gave her exercises to do, actually showing her what to do if she fell and how you get up easier and how I could assist her a little bit and also they then provided her with this to get around a bit, er and that went on but the physiotherapist that she saw down at Burnley, she moved on to, well she got a promotion and she moved out of town and she moved into (name of place), (name of place) way, weren't it?
I: Nobody took me over, I haven't had any physio for two years
S: And then nurse what do they call it, nurse (name), from (MND Care centre)
I: (name of specialist nurse) ,
S: And he sort of took over, (name of consultant) still sees her on a six monthly basis but the nurse he comes over to the day care place about once every three months to check on her well I'd say on her progress or her deterioration, we did get a wheel chair as well through the national I think, they gave us some money to buy a wheelchair which we have, which sometimes if you are going shopping especially with our daughters or anything they usually take you in the wheelchair, but I also then bought her one of those mobility scooters because now although we don't have a motor home because we really need a car with us for getting about, we sold the motor home and we joined with our daughter and her husband at a caravan, and they, our son in law he toes the caravan for us and we mainly now go to (names of places) somewhere where he can take the caravan and he can get there and back in a day easily and I have the scooter because (name of place) is the main place we go to because it is so flat, and she can get round quite well on the scooter and she can get out, so it's a lot better because round here it is very hilly, (name of place) is

in a valley so if you are in the centre of (name of place), whichever way you go out of (name of place) you climb a hill, so it is not really mobility scooter friendly albeit, I can, it comes to pieces and pack it in my car and go down into town and we can go round the shops in town with it so I think that's basically the history, I don't know if there is anything you want to add to that
I: No except, the OT put the handle
S: They put a handle outside, perhaps you noticed it, the
I: OT, occupational therapy
S: occupational therapy, they put that one here and they also put one, then we had a bath, but since we have had the bath taken out and we have a walk in shower now
I: but we didn't get any help
S: we didn't get any help with that, we had to pay for that,
I: and a frame round the toilet
S: oh we got a toilet frame, I don't know what you call them but one when you can sort of get your arms on you can get a grip for prising yourself up, fits round the toilet,
I: We haven't had anything else
S: What I did ask (specialist nurse) last time you saw us, was er if she falls, which she has done on occasions, it is now getting a bit more difficult, because she can't really help herself very much when she falls on the floor and er I am not really strong enough these days to lift her up, so in which case, the best thing you could do if you need assistance is to ring ambulance or the police but he also mentioned that he had one patient who had an inflatable chair but apparently, when it is deflated you can virtually can sort of roll round and shuffle onto this then inflate it and it can get you into a sitting position, so he said he would look into it to see what the availability would be then of course we are still waiting, we haven't heard anything from that,
I: Speech therapist
S: At the day centre where she goes, you get erm
I: no, speech,
S: Oh speech therapist,
I: Hasn't been for six months
S: yeah she hasn't been to see her for six months, she did come at firstbut then with going away, because in the summer time we get out as much as we can do with the caravan instead being sat in the house all day, so it seemed to drop off quite a bit but we haven't heard anything for six months, again we mentioned that to (specialist nurse) and he would look into that, also whilst she's been, this is the second session that she has had at the day care, we had a ten week well about twelve week,
I: six months
S: nearly six months, like through the winter, going one day a week to the day care and they said they would fix up some physio therapy there, I think they did it once there, didn't they, and then she had to finish they signed her off, she didn't finish voluntarily because she likes going there because it's a nice break, but er (specialist nurse) was seeing her then, would see if he could get another session ad you went for interview again and they decided they would take you for a ten week session for reflexology, and they were supposed to be going to give her physiotherapy but they haven't yet, this is at the hospice.I think that's about it
I: That's about it now.
R: So a couple of things you have mentioned, the first thing is the diagnosis process and how long it took, and also the fact that you had to go private as well.
I: We didn't have to go but we chose to go
S: Instead of going on a waiting list we wanted to see what it was,
I: We still had the motor home.
S: Yeah we still had the motor home
I: and we wanted to go abroad

S: So really it was really what you might say, pushing to the front of the queue, but following on from then it's been done on the national health, we see on (name of consultant) on the national health) we only saw him the first couple of visits when we paid to see you know,
I: It took a long time, but we knew the ?, the only thing my is my form of MND is slow and it is not normally fatal, not like (name), we had a friend (name) who had motor neurone and it went for year and then he died,
R: So you were aware of the disease before?
I: Yeah and I wondered if I had the same as Norman but I don't, its very rare it says on the computer, ??
S: She got on the internet to find out things about the disease that she has got,
I: And it said ?? and your speech but your breathing is ok and its not fatal, so I am looking that way and we have had ?? we have had good life
S: yes we have, we have had a good life.
I: Yes and the family are very aware
S: but we have decided now that we are not travelling abroad anymore,
I: Because we have been all over the world
S: Oh we certainly travelled,
(Patient and spouse talk about family for while)
R: Family is really your priority, than? Can I also ask you mentioned about the physio and the speech therapist, were you just left with no sort of contact at all and how did you feel?
I: I rang up one and they had nobody to ? do neurological physio therapy, and it was just before ? the day care, so I know I would not get in there but
R: Do you feel a bit disappointed about that?
I: Well, they promised me in time ? I would need a ? I do my exercises
S: Yeah before lunch there were exercises, that try and keep her supple,
I: And I don't know why the speech therapist,
S: You don't know why the therapist hasn't come,
R: Did she anything last time you saw her about like alternative communication, equipment to help you speaking?
I: That machine, but most people can tell people what I say, its sounds as if I am straining but
It's not painful
I: No it's not painful, I talk a lot, people don't know what I say
S: No, well, you see, you're sort of relaxed, you're sort of concentrating to you and talking a bit slow but you go back to what you used to be like talking and some of your words don't come our right, because you are not concentrating
I: I was a teacher so I am used to talking,
R: Can I ask about social services? Have you had any contact with them? In terms of adaptations to the house or benefits?
S: At the moment we haven't felt we need anything at all like that, like sort of with the occupational therapist, we get these letters through not necessarily through the occupational therapist or anything like that but saying oh you should get a new boiler and you are allowed because you are both pensioners, you're allowed you could get allowances for this, that and the other but then when it comes to ?, you fill the form in and it says oh sorry you don't qualify because we are not on anything, what's the word, we don't get any benefits, apart from you get the attendance allowance,
I: Means tested
S: Yeah we have been means tested, but we don't get anything else, like you need living allowances and er, to the house which loads of people are on but of course we don't get any of those, because we don't qualify at all, so when it came to the point of get yourself a new boiler because they are much more efficient, so I said oh right we will try and it said you don't stand much chance at all so we went ahead and did we got a new one didn't we? Same as that with the bath like we wanted to move to the bath because it was more difficult we had a shower over the bath but it was getting

more difficult to stride over and get into, stood into the bath, there was no way you could sit down because you never would have got up, so it was then that we decided to have the bath out and have a walk in shower.
I:They said there was a long waiting list and that we probably wouldn't
S: There was along waiting list we would have had to wait for two or three years and then you would not necessarily get it, so we went ahead and did it ourselves
R: How do you feel about that side of things?
S: Well I don't know we just went ahead, we thought if we can get an allowance we will get one, but otherwise its a benefit for us, we can afford it so we are going to do it, you can't take it with you they don't put pockets in shrouds, and of course as far as the family are concerned they say for goodness sake spend it don't bother about us, they can look after themselves.
R: And do you feel you are getting enough information about the disease and services can provide you?
I: (specialist nurse) is very good. But ? internet. (specialist nurse) and (consultant) very nice and he always said ask me any questions
S: Oh yes, he is a very patient with her, he wouldn't fob her off and push her out so we have no complaints at all about that side of it. Well you know we have no complaints at all apart from the physio therapy, that's the only thing.
I: And the speech therapy, I have a got a cold at the moment which is not very nice.
R: Do you have much contact with the MNDA?
I: No because the meetings were at ? and we got ? September or November
S: They are always you know its dark, I won't drive at night now,
I: So we can't go, so we wait for the summer, I would like to go but I can't.
R: You don't get the visitors or anything?
I: No, no
R: Would you like have more contact with the association?
I: I suppose it would because they could tell you what's on offer,
S: They sometimes help with equipment, and things don't they?
I:? I can get up and down sometimes I get stuck, like at three o clock this morning
S: it wasn't three o'clock this morning, oh yeah, it was
I: and we tried to get up, Out of bed, and I couldn't
R: Do you feel get enough support then from the services?
I: We have enough
S: Well when you say support from the services, it's mainly, the only people that we see as I say are erm, its mainly (specialist nurse) and we have no qualms with that, and we have no problems at all with that.
I: We haven't got a social worker.
S: No I don't think.
R: In terms of practical side things do you feel that you can manage ok?
S: So far so good, yes, that's the best thing, we've got. (points to equipment)
I: I can walk perfectly well with that.
S: It's her balance that is the problem if she has got nothing to hold onto, I think she is frightened of falling because you had done previously before using that, and at one time you were going to send that back and for some reason I can't remember now we didn't take it back, it's a good job we didn't take it back
I: You don't realise how it is going affect you long term
S: You don't know how long or how quickly things are going to progress, so whilst we can still do things, we do it, don't we?
R: Do you think there are any other areas of the service that you would like to see, is there anything that you think I don't have that?
S: Well what other areas do you think might benefit us?

R: Well lots of different things, district nurses, or things like that emotional support, psychologists or the more social sides of the services?
S: Well district nurses for a start, I think we haven't got to the stage yet where I need that sort of help, quite possibly one day in the future I might want some help in the things like that in which case, well who is the person to see? Would it be best going through (specialist nurse) the nurse or do we have to get in touch with er social services, you know, who would we…
R: Well, I think (specialist nurse) would probably be the best person to start with, it's just erm do you feel it is useful to get to know professionals earlier on or would you rather just as and when you need them, wait till then?
S: Well sort of all our questions that we have had at the moment and everything, (specialist nurse) has answered for us, I mean he has mentioned at times do you think you need anything else and we have said we are managing quite well as we are as things are at the moment it was only this problem about if she falls, and he said he was going to look into that,
I: But now I am using that.
S: Yeah, but the occasion might arise when you stumble and fall and down on the floor I can't lift you up,
R: Do you know what you would do in that situation?
S: They said you what you would have to do is ring the ambulance or the police,
R: And they come out?
S: Yeah
I:?
S: You see, it is, unfortunately there are sort of close neighbours round about who are quite friendly but they are quite elderly, they are like us, and so sort of calling on anybody, I don't feel is fair, because they might not like to refuse, but on the other hand, lets put it another way, if someone was to fall and come and ask me I would have to refuse, I couldn't but to save embarrassment, people having to say no they wouldn't that's why I wanted to know of people available, in actual fact I was asking (specialist nurse) if there was anybody say like from the hospice who could come out but as he said that's not really their, they don't do things like that, they don't go out to calls, they are more looking at inpatients and it was then that he said you would have to ring the ambulance or the police,
Researcher speaks
S: Well that's it, if you fall at night, it sort of depends when it is, like that time you fell, (name) was still at home it was early, I would say early morning before she went to work and between the two of us, we managed to get you up on your feet, in stages, get you onto sitting on a stool first, going through the stages of getting you up,
R: Is that something that worries you?
S: I feel more easy now he said ring the ambulance and they will come out, because it would be a good thing, because if she fell and did herself any damage in anyway if you broke an arm or anything like that they are then on hand to see it,
R: Do you feel in terms of emotional, do you feel you manage ok or do you fee there is any need for that?
S: I wouldn't say either of us are emotionally upset in anyway,
I: We are upbeat
S: Yeah, we are upbeat about everything
I: Whatever will be, will be, we enjoy life
S: Yeah, we do what we can while we can still do it
I: We go out for lunch
S: Oh, yeah, we can still go out for lunch, its just making sure the places we go to don't have many steps so you don't have many steps to climb up really to get in there, that's something,
I: disabled toilet
S: yeah, and disabled toilet,

R: Well I think that is all my questions, I don't know if there is anything else you would like to add
S: No. I don't think so.
I: No not at all.
(Researcher speaks)

ID20 & ID 204

Present: Individual with MND/ Spouse/ Research Assistant

I: Well, ok, right well, when (coughs) first kind of realised there was something wrong just about three years ago, round about Christmas time, I work, I used to work in a bank, so there was a lot of computer work, and I just (coughs) noticed that I couldn't get round the keyboard the same, but I didn't think that much of it at that point and then a few months later it obviously became worse and I couldn't er pick things up, so we decided at that point, to start trying find out what was wrong
S: You'd also had difficulty ripping up paper and just things like that and then I'd noticed one morning hadn't I? When we were sat up in be reading and I noticed all this fasciculation on his upper shoulders, on his shoulders there and his upper body, and then I started thinking there is something not right here, and I sent you, suggested you went to see your GP, who, do you want me to talk? Is it easier for me to talk?
I: Yeah, go on, I'll just
S: Is it ok? So you went to see your GP and he said who are you cause you never went to the GP and you came home and said he was referring me to a neurologist and sort of oh good we'll find out what the problem was and then things started, there were just little things that we started noticing you said the knife me knives weren't sharp enough, using cutlery and things like that, just fine motor things, weren't it? That weren't just right, and then I think what brought it all to a head, was when you were, went
I: Bowling
S: Yeah, crown green bowling, you'd started that the year before and you'd gone for some preseason training, and you'd gone and you'd come home and said 'I couldn't...
I: I couldn't pick the ball up
S: You couldn't pick the ball up and that then hit me like a ton of bricks and I thought shit, it's something
I: (Name of wife) has a medical background,
S: Right, and it hit me like a ton of bricks and I thought he's got Motor neurone disease,
I: But she didn't tell me
S: But I didn't tell him and it just all started, it all fell into place then, and I thought that's what it was and erm we'd got an appointment to see a neurologist in the June I think, wasn't it?
I: But it was twelve weeks off and we didn't want to wait
S: I couldn't wait that long, once you've got something you want to know don't you? It was that not knowing that drives you mad and so we arranged a private consultation
I: (Name of consultant)
S: At Easter,
I: April 12th,
S: Yeah
I: Wednesday, never forget it
S: Yes because we both went from work from separate places and we met in the car park didn't we? And went in there and from his questionings,
I: Obviously he did a thorough examination and then after that, erm whilst I was getting dressed he had a conversation with you and obviously discovered that (name of wife) had this medical background so when I sat down and he just looked at us and he said what do you think? I looked at you and because you hadn't said anything
S: I hadn't told you because you can't be sure, can you, but do you remember that one Friday when you came home from work?

I:Yeah, we had a big talk, because I was thinking I had MS and I said that to (name of consultant) and he looked at (name of wife) and she said 'No its not that its motor neurone' and he said 'yes but he couldn't be hundred per cent, so because there were more tests
S: Well you can't can you, but we knew, we knew right and in some ways that (name of consultant) I'm glad that's how, you need people to be straight with you, and that, because I knew, there is no point pretending and hiding from it, and so we've known for a long time, and even though its very hard, you know what you're dealing with don't you, so we've known what we've been dealing with right from and it is hard, there's no, I said to you its something and I think its something really horrible and it is, it is
I: No doubt about it
S: It is
I: And then they got me into hospital at (Name of Care Centre) about three weeks later and did tests and that just
S: We went on holiday first didn't we had a weeks holiday booked, I think it was may bank holiday and that was already booked so we said we're going and he said,' well go' we had a week away, didn't we to?
I: So confirmed it all in hospital and that was it
S: That were it and that's it get on with it
I: End of the world, basically
S: So it's just all downhill from then on, there is nothing good to say about it, there's nothing good to say about it, it's horrible
I: The first twelve, fifteen months weren't bad because
S: It's manageable isn't it?

I: I could still do things, I was still working, I could still drive, and basically things were pretty much the same
S: We tried to keep it normal, didn't we? For everybody else, you know, for the rest of the family
I: We've two boys, and my parents are still both alive
S: They're in their eighties but they're well, they live independently, they're very well and active and you know
I: And your parents are the same, we've got a big family,
S: I'm one of seven and Peter is one of four, so it's huge family, with nephews, nieces and everybody else so
I: So we have, we are fortunate in that, if you can be fortunate that we do have a lot of support from family and friends which does help, a lot erm. Erm, but the last what? Six months, we've seen things speed up.
S: Yeah,
I: Seem to be going downhill a lot faster in the last six months,
S: I mean the hardest part really for some quite time now is that he's no use in his
I: Upper body
S: hands and his arms so he can't do anything, can't feed himself, hasn't been able to do that in a long time, He can't wash himself, dress himself, clean his teeth, he can' t do anything, and that is but you're still able to walk and that, you're more dependant on people when you've no power in upper body, you know and one thing that, well you don't think about it much till you're actually dealing with when you see people in wheelchairs, and you think what a shame
I: It must be horrible, but its worse having no,
S: Yeah. And it's something I've never thought about cause it's not something I have never come across before
I: You can't write,
S: You can't scratch your nose, can you? Can't do anything, its thing like that
I: Computers, TV

S: You've got your gadget now for turning the television over,
I: My legs are suffering but I can still
S: He can walk with support and it's only the last couple of months you can't walk any distance, you're still walking a bit but he used to walking three or four miles
I: I still go to the gymn, been to the gymn today, so once, I have a guide, an instructor that goes round with me so once he gets me on a machine I am fine I can work away just like I've always done, so that helps me
S: You still try to maintain some normality, which is what we want
I: Which is what we think from day one is the only way to go, do things as long as you can, and when you can't do it, you find another way to try and do it, and keep going like that, just try and be positive which isn't, its a lot easier to say than it is to do, but I think we are making the best out of a bad deal but who knows? Its hard work, isn't it?
S: Its hard work and its horrible, it is, we
I: What?
S: I hate it, I just hate everything about it but you can't its happened and you have to get on with, you try not to be you know oh why us?
I: Well we said that on day one
S: Yes but it is hard, but it is hard
I: On day one obviously I was very angry, and I realised that to continue being angry wouldn't help,
S: It just destroys you, doesn't it? If you're angry all the time
I: Would make things worse so we got rid of that anger and even though its like (name of wife) says it's horrible, its nasty, but you've got to accept it, and as we said get on with whatever lifetime there is left and we do try and do that
S: Well I think, you sort of think, we're fortunate in some ways, and done a lot of travelling haven't we? Since, since you were diagnosed. But we've always been a couple that have gone out a lot, done a lot, enjoyed holidays and we've continued to do that, we went to Australia recently with the whole family which was really good, go out with the family, we go to friends, they come here, we go out for meals still, not as much, but we do, we don't letting stop us,
I: We still try and do the things that we've always done, it's just harder, and sometimes well I think is the effort that it takes to get there worth the result? Because sometimes it's just easy to not bother but again that's not the way to do it, you've still got to, push yourself to get there but it is difficult and very hard work.
S: You managed to go to Chelsea on Tuesday, big (name of place) fan, with his brother, but the worse thing about it was that he had to miss extra time and penalties because they were on a train normally, that's one down side of it isn't it? Normally you would have stayed so that were a bit of a disappointment but at least you got to Chelsea
I: You can put any words like on it, any horrible, negative words you can think of apply to this condition, restrictive is a good word, and though, when did I give up work? July was yeah
S: You were only working part time though
I: And you haven't worked for 15 months
S: July last year I finished as well but you hadn't been working before that, which
I: What?
S: Well that was, when you finished work I think was erm, that's when it starts to, other people, you're family realise oh there's something, that was a downer really for everybody,
I: A big part
S: Because they think you were working,
I: A big part of the normality disappears once you've stopped work, because obviously that's not normal, so (name of wife) gave up work to look after me,
S: I was made redundant but I think it was engineered really
I: She was matron at the (name of place) General but you were doing a bit at
S: At the wonderful (name of place),

I: She got the offer of redundancy which came at the right time really and so you took it, and here we are,
S: So, here we are who'd have thought?
I: So I don't know if I've got anything else to say, I don't like looking too far ahead in the future because well, you know what the end result is but, you don't know when its going to be, so we kind of take things I won't say a day at a time, but a week, month, we don't go,
S: No we can be up and away in a week can't we if we wanted to go anywhere or in a few days, we've not planned any summer holidays have we love? Next year? Put it that way (laughs)
I: So we are aware of what the future has in store for us and we are aware of what help and the systems that there is out there so, we will just wait for things to happen and whatever help we need at that time we'll get,
S: I think as far as services and things, obviously we've had the OT and people have come round but I think we've tried to manage it independently, as in, I mean, we're not, we wouldn't do anything foolish or dangerous but it's a case of trying to keep on keep as normal as possible and didn't really want the house turning into,
I: No, no,
S: Full of equipment that, you still manage to get up and down the stairs with help don't you? But you're fiercely independent and you want to do it your own way, don't you?
I: And long may that continue,
S: And you're also not interested are you, you won't look at anything and you don't want to join anything or go to groups to see people with,
I: No, I made that decision right at the beginning (gets cramp) no I never wanted to get involved with er people that er had or were more advanced as that would be a far as I could see a purely negative effect on me so I never wanted to do that and I certainly don't want to do it now er, (pause) we kept in touch with everybody that we need to keep in touch with,
S: Who do you mean?
I: Well like (name of specialist nurse)
S: Oh yeah you've those regular appointments haven't you, which?
I: I went to see my GP last month
S: Are you going to tell her why you went to see the GP?
I: Why, you can tell her
S: No you, he went to see the GP and he hadn't seen him for over 12 months, do you want me to why don't you tell her?
I: We went to see the GP and because he wants to die at home, and he doesn't want any intervention or anything and the GP was very supportive, he was, which I must admit that was a big weight off my shoulders was that to go to see the GP
S: What I don't want, and I have never wanted and certainly up to now is just to be kept alive for no reason so I don't want that, once I get to the point where I need to be kept alive artificially, I don't want that, no point, so I made that clear, with GP and
I: (Name of specialist nurse)
S: Well basically, what you, you don't want to have to go to hospital do you, you don't want to go near a hospital, because what did you say? It won't make you better,
I: No, there's no point,
S: I think what, we're looking for is quality of life, not quantity now, cause you're not going to live to a ripe old age, are you?
I: No
S: We know that,
I: Amongst all this carnage, is that my brain and mind still functions as normal. I struggle with it now, because my brain wants to do things but my body doesn't want to, and the worse that that gets then, it could drive me crazy being in that position and I can't say obviously because other people will see it differently

S: But its's right for you though isn't it, everybody's different aren't they?
I: Obviously I don't want to die but I know I don't want to be morbid but you know that you are going to die, you don't know when and I don't know when but its going to be sooner rather than later but I think that when that point comes I might be happy that it has come because it is very, very soul destroying, because as (name of wife) already said it is a horrid, horrid disease.
S: I think it is horrible as well for those that know you to see what it does to you (cries)
I: Yeah, I know that. But we do try very hard not to let it be dominant, you can't fight it but you don't have to give in to it. Alright? (to wife)
S: You cope with it better than be,
I: That's because I, because I can't do a lot. I mean if we are not going out its basically just get out of bed and come down here and sit here and watch TV so I've a lot time where all I can do is just think about what's happened er what may happen, what's going to happen and er, and I think I'm able to not get erm, too upset about it, (starts crying)
S: Come on. That's why we do try to have stuff planned all the time, to keep going out, going out all the time we've just had a few days down south with (name of patient's brother) that's when he went to the football match so we do try and get out and about a lot, otherwise you'd go mad sat here all day, and it is hard but most days we do try and go out, don't we? it doesn't matter if its raining or what, we're not bothered about the weather, but that's getting harder now, isn't it, harder to get you, cause its just me and you, cause its just the two of us,
I: Once you get out of the car, I can't go that far,
S: We have found ways round it; I've been on an aeroplane last couple of months just me and you, we like a challenge
I: And believe me it is a challenge and you're right we do laugh even though it is not funny or amusing, we do try and laugh and
S: But we didn't get too close to Beachy Head did we? Last week? (Laughs)
I: And say things, and the boys still take the Mick, because that's what
S: Yeah, in September we were, our two boys came to Portugal they stayed with us for five days and then they went home, and that was, we had a really good time, didn't we? we went down to the beach, they pushed you down and pulled you back up, we laughed for five days, we went to the beach during the day and out at night, they just, obviously its hard for them but you want to keep normal for them, cause we don't keep anything back from them and they are fully aware of everything and know what dad wants, which is how it should be or how we want it to be,
I: In one respect with the way this thing is with like, you eventually dying so I spose it does prepare people for that conclusion, in that its not like going out one morning and being hit with a car or going out and that's it,
S: I think that's better,
I: So you don't have that shock emotion,
S: This is horrible, this is slow torture
I: Yeah for us, but for other people
S: That's why, when it's all over I think it will harder for everybody else, they are not living it, I feel, they are living it 24 hours a day like me and you
I: I wouldn't want them to
S: No but I'm saying for everybody else, like your mum and dad, it will be really horrible when its all over, and when things get really bad they will be thinking, they won't want him to, they'll be thinking lets keep him going,
I: I might change myself,
S: But you can't stop it, can you?
I: Yeah and what's the point of delaying it, when you've no quality, I've had my life,
S: I don't know how can you be so, you haven't had your life had you?
I: I'm not getting any more, am I?

S: No, well, I feel cheated
I: Well, bound to,
S: It happens, it won't be just us, we won't be the only people
I: No, it's not the way that we planned it, Is that it?
S: Mm
R: Ok, well thanks for being so honest, you say that you want to manage things yourself but do you feel there is anything that the service could offer you to help you with the disease?
I: At the moment, for me, no
S: You've erm, you've accessed recently though haven't you, up at the hospice, that massage, that was something that you thought you'd try, that was when you went to the hospice a while ago to the physio, he had a physio at the (name of hospital) and then he changed jobs, and then the only person they could put you on to was a lady up at the hospice which you were really reluctant to go to you didn't want to go to the hospice at all but then you did go, it was awhile ago now, earlier this year, and she was really helpful, she was the lady that put us on the assistive technology place at (name of place), and they have organised this gadget for the telephone and the TV that is really good, and she mentioned about the massage and aromatherapy and you've just started a course of that, you were frightened to death
I: I don't think it serves any purpose apart from feel good factor
S: But that's important, maybe I'd be better having that, probably be more use for me, you're not really into all that stuff it's just not you, I'm surprised you are actually go
R: Has that link with the hospice having the clinic?
S: Yeah cause we go to see (name of Specialist nurse) he's doing his clinics there and I think,
I: Oh it's a lot easier
S: It's a lot easier and you decided to book in for the session, so
I: But other than that, I don't think
S: You've had contact with the speech therapist, they sent you in fact I could send it back that dysphagia cook book, it didn't do anything for you that did it
I: Like I was saying, we know what is out there, and if and when we need extra help we know who to contact … I think we've had, a lot of people have said, from a long time, going back twelve months or so, have you got any carers, which no, I know they say it all falls down to me, but I can't see any benefit in having somebody coming in everyday to help you get washed, showered, I think that would be more disruptive for us, because you know , you don't get up at 9.00 it depends on what we're doing, if you are going to the gymn and I feel I can see that I wouldn't need to give you a shower or whatever, but it wouldn't give me a chance to do much else, it would have been a bit more disruptive
If you could put all the things in the day where I need help, if you could put them all together then get somebody in to help with it but because its just little bits of things spread out over the day and night, its very difficult.
S: Yeah, you need someone to take you to the toilet, pull your trousers down, you need somebody to give you a drink, you need, you can't do anything all you can do is turn the television over with your foot, it is though, I mean we joked with that lad when he brought that thing, we said will it get him washed and dressed, no not yet, they've not developed that model yet,
I: We're still waiting for that innovation
S: But if you become totally immobile, it's impossible, I won't be able to do it, and we know that but when that comes, deal with it then
R: Can I ask if you have had contact with social services, with giving up work and things have you had any benefits?
S: Yeah, we dealt with that last year, which was an interesting experience,
I: Yeah, it wasn't easy

S: But we have sorted it all out now, with the disability living allowance and things and the, what's the other one you get? Incapacity benefit it took a lot of phone calls and then you got letters through asking for you to come for a work focused interview and things like that
I: It wasn't easy because the people who were dealing with my paperwork at social services obviously didn't know what MND is
S:Because we had conversations with somebody who said 'well when you get your old aged pension', 'mm I don't think you're is going live to get an old aged pension', and then when they were phoning him up to come for a work focussed interview erm'What sort of job do you want him to do? If he could still work he would work at the bank', so it was stuff like that but we got round it, didn't we?
I:We did but only because, we knew somebody who worked at work and pensions, she kind of came here a few times and went through the applications with us, which obviously helped because she knew what
S: The right wording
I:The words, the correct way of doing it was, and after that everything was
S: Pretty straight forward, wasn't it?
I:But from start to finish it probably took about four months
S: But it was all back dated, so that was all sorted because originally you said you weren't going to claim anything
I:I got correspondence from them just before last Christmas saying that it had been all been agreed and it was going to be back dated to when I had finished work which meant I was going to get something like two and a half thousand pounds and that was going into my bank account anyway about three weeks later, this money had not gone into my bank account so when I rang them up, and said 'where is it?' 'Oh there has been a terrible mistake, you shouldn't have got that letter', 'and oh I'm sorry'
S: There was a problem
I: I gave them all the copies of my pension statement, but they had forgotten to take that into account, so instead of getting seventy pounds a week I was getting six pounds a week because I was on a pension, but after using the friend of ours, the ways that benefits are graded I was able to go to the top grade,
S: Highest one
I: Where your pension isn't taken into account, so I suppose I am on maximum benefit,
S: So that was all sorted at the beginning of the year, to say that you weren't going to claim anything at all,
I: Because I have never claimed, I have always worked, so I am not part, well I am now but I wasn't part of the claim culture
S: Won't mention what our youngest son calls us now, anyway it was only what you are entitled to, and it was your GP who said you must put your claim in because it's your entitlement
I: And you get carers allowance,
S: As if you would work for fifty pounds a week
I: But when you add it all together it's not bad
S: That's the only experience we've had, they don't write to us to any more, they used to write to us every week
I: They used to write to us everyday, you had a pile didn't you; it must have been six inch thick!
S: Loads,
R: So it's a very complicated process?
S: Oh yes, I can understand it, there is so much benefit fraud and they have got to be seen to be doing it correctly but the system didn't seem to be joined up
I: I spoke to people in authority and they hadn't a clue what MND was,
S: But they won't do will they, they're not

I: I mean obviously I understand that they are all different departments and that they will only deal with one part of the application, but I don't know,… That's just reminded me, of erm, another, with your mortgage you know with your critical illness cover, we had two mortgages didn't we, or it was in two parts, and we got paid out on one because Motor Neurone disease was a critical disease and on the other it wasn't, so that was so frustrating you said 'I've not only have I got a critical illness, I've got the wrong one'
S: I mean, fortunately, they were only small amounts, I mean less than five thousand and that's only because over the years, we've always paid, to get it repaid as quickly as possible, there could have quite easily been 13,000 or something, and if we had been paid out at that level it would have made a big difference,
I: Its only money!
S: Its only money when you've got it, so that wasn't a good start really, the first time this illness, because of this illness we tried to claim and it wasn't what we anticipated so yeah, something to think about yeah, if you have a mortgage and you have got a critical illness
I: See what's covered, Cause I weren't.
R: The other thing there's a need an emotional support for you or your family?
I: Family, I don't think so
S: You don't know,
I: Well, as far as I am aware,
S: your mum and dad never ever discuss it with you, do they its like its not really happening, to me that is a bit of a frustration on my part it must be very hard for them to see what's happening to their youngest son, in the very early days it was as if it wasn't really happening and you know, and your mum used to say things that
I: In the early days, it was as though it wasn't happening, for twelve months or so, I was basically still the same person, wasn't I? I agree with you, but I don't think counselling would help them.
S: I mean I don't know, they just don't talk about it, they don't talk about what's happening, what's going to happen, I don't know who they talk to, they certainly don't talk to us about it, whether they talk to somebody else I don't know but then you've got your two other brothers and a sister maybe really they deal with it with your mum and dad I don't know,
I: I don't know, cause we have told them, haven't we? We have had moments,
S: We have had a talk with them about, I think your mum said once after we had been to see the specialist nurse she asked 'oh how did you go on, has he given you anything? Any new treatment or something?' and you know and then we said 'you know he is not going to get any better from this, you know there isn't' and then it was really difficult and then I couldn't say, I think you need to be honest with people I don't want them to be under any illusion, because it is going to be really, really hard for everybody, they are old but they are not stupid, but they just don't say anything,
I: Some people would say they are stupid not old, but not me
S: You said that you were very angry at the beginning, but how did you overcome that anger?
I: Very quickly, it just destroys you if you are angry all the time
S: Very quickly cause what's the point?
I: Very quickly, it just destroys you if you are angry all the time. We are very common sense types of people and straight away it became apparent that to be angry was so big a negative, that it could have destroyed everything, by being angry so basically from day one, I wanted to hit people. That first day, do you remember in that car park?
S: When we came out into the car park at (name of place)
I: After we had seen (consultant) there were people in the car park I wanted to fight them, I was that angry but after that initial reaction we decided then and then that anger wasn't the way forward, and I won't say, well I can't say that I haven't been angry since then, of course I have but very rarely and now I'm not likely to get angry cause there is nothing I can do about it, and that's it, from day one, its not a case of well if I look after myself, and keep the right thing and exercise and I can get

better, it don't really matter obviously I try and look after myself because that is what I have always done, but you are not going get better so why get angry, whose fault is it? who do I blame?
I: You just feel like, like its life isn't it? It's cheated
I: Cheated is a good word, because we've always tried to do the right thing
S: Yeah it's like you've said, you know, you're worked all your life, you never been off sick never done anything, you've always played football, kept fit, you know, we've been together since we were teenagers, (cries) had two kids, paid your mortgage, you know what I mean, and you just think, life were getting really good, weren't ones been to university, the other one is at university and we had, in 2005 we had a really fantastic year, didn't we? It was like our oldest son graduated and got a job and we had a couple of erm my brother got married, we had a good really good wedding, we went to a couple of weddings didn't we? And then it were our silver wedding, we went off to the Far East, and you know we were financially we were like, no money worries, we had two great boys and life was absolutely brilliant weren't it and we said, everything were
S: And then bang
I: You know, life was just so good and everything were great and then all that happened, and it's just been downhill all the way since
S: That were 2005 and then
I: 2005
S: Along came
I: 2006
S: 2006, and what a year that was, total opposite
I: But you just have to. You probably don't because I don't think you are old enough, but as you go through life and you have a good life now and again you, if you reflect on it, you're thinking when's the bad news going to come, everything's going along too well, and you think when's the bad news going to come? And we've had bad, bits of bad news, but nothing for quite while,
S: No but I think cause we've got a big family, there is always something going on and there's always more good stuff than bad stuff, but we can look back t that's the only way to look at it, and look back at it what we've had been good
I: And when she says we've been together, (cries) no all I was going to say, was, been together since teenagers, now that is something to be angry about
(laughs)
S: Well, (laughs) do you think you could find somebody better, someone who could put up with you?
I: Why do you think I go to the gymn?
S: I don't know
I: I am sat here with tears in my eyes but I still want to try and laugh and I hope that as long as that is the case, that I'm doing the right thing, and that's what I don't know

S: But looking back now, since you were diagnosed, its I know we think things are bad now, but I just thought they would be a lot worse than what they are, I did cause I didn't, cause you sort of think when you're diagnosed how long you are going live so really what we do, what we are still managing to do, get out and about, its pretty good considering but you just think how much longer will it go on,
I: But that's what it's all been, it's like when we go and see (Name of consultant) and its always been how's long as piece of string, you know what's going to happen what you don't know is when, its not like you know you've got cancer or where you've got six months to live or you know, so you can basically put a time limit on your life, I mean obviously I know I'm now a lot nearer the end than I was two and a half years ago, but I still don't know how near, so it is difficult, like I say we don't live day to day, but like we say we haven't booked a summer holiday,
S: It's getting harder, isn't it, it's harder, you do have times probably more than you, it overwhelms me and I hate and occasionally, I just wish it was all over

I: I have said for ages, that if I could go to bed tonight, and that's it not wake up, Id be happy, Id take that, I'd have taken that six months ago but I know it's not going to work that way, obviously it won't I think obviously, because it's happening to me, I can feel every second of the day, the end will be a big relief, even though there is no pain, no physical pain, there is mental pain, and er I'm not saying I am looking forward to the end but when it comes it will be a relief, won't it? Because what you see before you isn't me.
S: This is you, (gets photo) and that were just before, that boy on the end isn't stood on a box
I: And look and the size of him, and he is not stood on a box, that was in July 2004,
R: Oh it's a lovely photo
S: Yeah, and that's what it reduces you too, (points at husband) It's horrible
R: Is there anything you would like to add?
I: No, I am exhausted,
R: Well, thanks very much for taking part

ID27& ID201

Present: Individual with MND/ Spouse/ Research Assistant/ Research Supervisor
I: At first why, me but over time I am alright now (name) and family help.
R: That's really good. If you think back to when you first had problems, what was it that took you to the doctors?
S: I can answer that, I noticed that when she were talking to me she would never finish a sentence, but I didn't realise anything was wrong and then one day we was in town and we bumped into me my sister and nieces and one of our nieces is very outspoken and she said have you been drinking Aunty (name), you're slurring your words. I said no, she hasn't been drinking! Has she had a stroke then? No, as far as I know she's not had a stroke. No, we decided we'd go to the doctors. We went and he passed us on to the hospital is it Dr (name) and er she walked in and sat down and said hello to him and he said you've not had a stroke, just like that. So he examined her and he give us three diagnoses as to what he thought it was including motor neurone and he would like us to go to (name of hospital) for further tests, which we did and they confirmed it unfortunately. So that's how it came about, I was living with her, I didn't noticed she were slurring her words I noticed you were chopping sentences off not slurring so there you are.
R: So the diagnosis process, how was that?
S: We had three consultants at (name of hospital) and he gave it to her as soon we got there. There was no way I could stay there, and me daughter, they neither or less confirmed it but it was a couple of days,
I: Injections, injections with needles
S: Yeah, they give her that truth drug kind of thing which make you talk properly and that had no affect on her whatsoever and that's how they knew there and then
R: That was to rule out something else wasn't it?
S: Yes. That eliminated the other two. Yeah, I forgot about the injection yeah.
R: And when you given the diagnosis did you know what it meant?
S: I did it yeah, because we both fans of David Niven, weren't we? and it, he was one of the first to be diagnosed with motor neurone as it is now and highlighted, so I had a fair idea of what I was going to get but I didn't know it had various forms of it. I just thought it was one, but its not. It's taken her voice completely now, I get a grunt when I'm wanted.
R: The first thing you did was to tell people, I had disease.
S: Yeah, I told all our friends and all our neighbours. So because you know if you don't tell anybody and then someone says oh she's been in hospital and before you know it she's dying of bloody cancer or something else. So I went and told everybody what was wrong with her and we've had new neighbours over the years and I've been to see them, I've said my wife's not stuck up she can't talk and explained it to them and that's alright thank you.
R: Good thing to do really, isn't it to let people know.

S: Yeah. mm, the amazing thing has been the reaction of our eldest grandchildren or no reaction they just carry on as though she's normal, they just take it in their stride its something that happens.
R: How old are they?
S: Me eldest one is seventeen and her sister is fourteen they're the two that has grown up with (name of spouse).Since they were little, like and they've just carried on as normal as though she's alright.
R: I guess she is to them.
S: Mm, and when they first saw that box, cause they were younger then, they said come on granddad there's a 'g'mail coming (laughs)
R: Is that what they call it?
S: Yeah, a 'g' mail. When they call round I say go get your grandma's squat box cause that's what it is, I call it a squat box. But it's a very beautiful thing to have that that was we got that from the speech therapist at the (name of hospital), (name) and, er, she's been a big help to (name) she says I'm wasting my time trying to get you to talk as it would tire your muscles anyway and well we realise that, but she does other things, she comes round every three months, she comes here on her way home and she'll talk things over with Greta and suggest different things or she'll get different things for her and she's been a big help, a very big help, she got us that machine, she got us, er, what they call a conversation phone in the back room where if anyone rings up you just press a button and (Name) can hear everything that's said so I don't have to repeat anything to her and she's got her little special cups that she can drink out of where its cut away so when she's using it she's not banging it on her nose..
I: Very useful things
S:It is very useful, and there's a small one for taking medicines as well
I: I do not worry about my illness now I live for today.
R: It's a good motto to have, isn't it?Do you feel that you have all services that you need to help you live for today?
I: Yes
R: You've mentioned that you have the light writer, the squat box, you've obviously got the chair as well what other equipment have you got and how easy was it to get hold of and did you have any trouble to get hold of any of this stuff.
S: The only problem we had was with the stair lift
I: Stair
S: I had to buy it meself. When the people came from social services, went through everything, me bank statements and because I've got an occupational pension which you will have when you retire they have a different form for working out how much money and it came to a ridiculous figure of four thousand pounds and their forms wouldn't stretch to that and I thought why its based on what I'm bringing into the house, the amount of money I can have? So I went out and bought one second hand from a reputable firm and they installed it and they come and service it once a year, but I had to buy that but anything else I've, we're fine
I: MND
S: We've got a bath chair in the bath, a battery powered one,
I: MND
S: Which is a godsend , and we have a little auxillary step at the top of the stairs which goes in the bath normally or step on the outside of the bath but I use it as a stepping stone for getting her off the stair lift onto a wheel chair upstairs. Anything else I've asked for I've always got. The wheelchair is mine or (name's). I bought that cause we wanted to go on holiday and it folds up and er, I wanted one, I realised I need one upstairs and one downstairs so I've asked the OT would it be possible to have a wheelchair and they said yeah and its identical to the one I bought practically, so its ideal, it just folds up goes in the car, in the boot, folds up about this big and I asked er, she had an accident eighteen months ago, this was when she was walking with her frame but she was walking with difficulty and I used to get down on my hands and knees and just lift her feet up and move it a long,

one at a time whilst she pushed her frame and we went on alright for a while like this and then this time, she was going into the bathroom and she went forward, and with going forward I couldn't grab hold of her to hold her up, cause normally she falls backwards or sideways but this time she fell forward, never hurt, never hit anything, never caught anything and she didn't hurt herself or so we thought and then I got her up alright. She was a bit upset of course, and I got her back into the bedroom and she seemed alright and we went back to the stair lift to come downstairs and she seemed alright didn't you? But at dinner time, she wanted to go to the toilet and I got her round, I took her in the wheel chair for some reason and she stood up, she screamed and the pain in her left leg. Then it started hurting her all the time then didn't it, so I got her up to the hospital and her they x-rayed and she'd got a hair line crack in her heel, but she hadn't hit anything with her heel, she'd just fallen flat on her face virtually, without hitting anything. There is a little gap between the sink the wash basin and the bath, and her head had gone through that gap.
R: You were very lucky weren't you? (looks at individual with MND)
S: Heels, never touched anything, I don't know why it broke and from that day she's been. She did try to walk after we had taken the plaster off and she did a few steps but er then it got too much for her so she's been in the wheel chair ever since. I have the bed downstairs as well for about six weeks but when we, erm, decide we'd put the bed back upstairs and then we had a problem she couldn't go to the toilet four times a day like she used to. This was on a Saturday so I rang the local branch of the MND and within an hour they were here with a commode on a temporary loan, That would see us over the weekend I range up OT and, er, they got one organised for us and, er, when it came it had no wheels on it, it just had legs and I thought well that's no good I need to be able to move when holding and maneuvering her onto it so I rang them up, and said the OT and she came 'oh', she said, 'that's no good' so we brought, well one like we got now with wheels on, and I thought well it's a bit high so I rang up again and said 'this commode do you have it in different sizes?' I said, 'cause the one we borrowed before I had no trouble getting her on' and she said 'yeah, measure it will you?' So I did I said 'its 19 inches', 'oh she says there's a smaller one than that, 17 inch', so that came, so we've no problem, very helpful you see.
R: How do you find communication across the MDT? Do they all seem to be kept up to date with (name's) progress?
S: Yeah, I think they are, aren't they?
I: They write to each other.
S: When we see (name of Specialist nurse), every three months. We go to the hospital in (name) and she's got a note from (name) the speech therapist and when (name of SLT) comes here , she's got notes from (name of specialist nurse). So I presume (name of specialist nurse) is in touch with the surgery at (place name) and also the local branch of the motor neurone.
R: Yep, and you find that helpful?
S: Oh yeah, they all talk to one another or write to one another, whichever way, don't they?
R: It's important that everyone knows where you're up to isn't it?
S: Oh yes, oh yeah
I: I have a car seat.
S: She has a special car seat. I mentioned that to the OT people. We think there is something and we will get you some paper work. And they got me the paperwork and I looked it up, they couldn't provide it but as it happened that week, the area co-ordinator for motor neurone, a (name) and I mentioned this to her that I was having difficulty getting her into the car and I got these papers that there is such type of seat but I hadn't seen it and she goes oh we'll get you that, just like that didn't she? The next thing I know the firm's ringing up asking me what kind of a car it is and all me details and a week later the seat arrived all I had to do was fit it in! So there you go.
R: What do you feel about the voluntary sector in this case, that charity providing equipment for.
I: They've been very good to us. They are brilliant, in fact, the local chairman was round on Monday to see us , to see how we were going on cause I'd asked, er, me daughter had been complaining that I'm not asking people to see what's help is available. I .. (daughter's name) but she wouldn't have it

so to keep her quiet I got in touch with the local branch and I, me daughter thinks I may need some help and, er, radio contact and all this carry on, so the lines have been buzzing this week, with people ringing me up coming to see and so forth, the system works. So, I'm not, if they can provide me with something I could do with I'll accept it. Me daughter thinks I'm stubborn, she thinks I'm stubborn (points at spouse). But I keep fit because I'm picking her up twenty times a day and I use the same system of picking her up, I don't get back ache picking her up.
R: You have your own way of doing things?
S: I have me own way of doing things, when I stand up, she's comes up with me, its as simple as that. Well she's hanging on for dear life aren't you? (laughs) If she could talk she'd say how many points out of ten? Yeah, so, I think I can cope but I know I am getting old and sometime I will need some form of help either human or mechanical. I'm realistic to understand that.
R: Yeah, but you know where to go to get the help if you need it?
S: I know where to go, yeah, yeah,
(pause)
I: Good service all round
R: That's really good
S: The, er, you know she has to be weighed don't you?
R: No, I didn't
S: (name of specialist nurses) from (name of hospital) have a portable weighing machine, its like a wheel ramp. You just wheel the wheel chair on and she presses a button and she's electronically weighed and I just deduct the weight of the wheel chair.
I: really clever.
S: Yeah, but it takes two people to carry it.
R: Not very portable then is it?
S: So, its only semi portable then isn't it? But the idea is sound, its there in't it. I've no doubt somebody will make one lighter and so one person can carry it.
R: It's just advancing technology all the time.
S: Yeah,
R: (name of participant) can I ask you before you became ill, what things were important to you?(pause) and on top of that whats important to you now?
I: Family, family same
R: Yeah, so it was your family beforehand and its still your family now And how has MND affected you with your family?
I: We used to go on holiday together.
S: Yeah, we used to go on holidays every year together, to, er, Greek islands or Spanish islands. We went to Disney once didn't we? Yep, those were the days weren't they kid?
I: The family is there we do everything together
S: Yeah, when they come here they talk to her as normal and they're patient, They're more patient than they used to be cause they have to wait for (name) to answer them. Now, while we're out and about and doing shopping and that and we meet people, they may be looking at (name) but I'm answering them, which is a bit disconcerting for them. But that's the way it is. But my biggest problem is when I am out shopping with her is thinking like a woman, and no man in this world can do, think like a woman. (laughs) It's impossible.
R: Try as you might
S: You know what I mean?
R: Yeah,
S: They all think different to how we do so I'm having to think what would she like, what should I get, am I getting the right thing. You know.
R: So you've had to change the way you think about things.

S: Oh my lifestyle had changed completely, oh yeah, I've learned how to cook better than I did before, I'm not just a fish and chips man anymore or beef burger lout. She's had salmon in hollandaise sauce today with broccoli.
R: Mm very nice
S: Salmon steak, not out of a packet!
R: Oh lovely!
S: Properly cooked.
R: So you've acquired skills that you perhaps didn't really know that you had?
S: Well, I thought that I could cook a bit but I've had to learn all over again, yeah
R: And how do you feel about that?
S: It doesn't bother me one bit. Somebody has to do it so I do it. We have fixed menus, we know what we're having practically week after week but I do try and vary it, tomorrow we're out shopping in the morning so we'll have a pre-cooked meal, a ready made one whatever it is, but on Friday its fish and chips. Ill even cook something on the Saturday or make something. Last Saturday I made a cheese and onion pie, roll out the pastry under direction, supervision and the dreaded finger whatever it means I've got to work out. She always points to the kitchen and there's a thousand objects in the kitchen
R: Ah but you know what you mean don't you (name)
S: She knows what she means but I don't! (laughs)
R:Would you say that you work as a team?
S: We work as a team as long as I do as I am told.
R: What sort of support have you had from your GP?
S: We rarely trouble the GP, only with normal ailments.
R: Right, why is that?
S: Why should we? Why should I bother them?
R: Is there any MND related problems.
S: Not that I am aware of, if she has a cold or whatever, we don't associate it with motor neurone
R: But if there were any MND related issues?
S: Well it hasn't cropped up yet, so I don't know, honestly don't know.
R: What I'm trying to get at is really to try and understand the level of confidence in your GP's knowledge of MND but you've not had any dealings..
S: No,
R: No,
S: Well, you know when I go to the doctors for any complaint, I sit down, they don't ask me what's wrong with me, 'how's name?' I'm the one that's bloody sick today. 'How's name?' You've not asked me, I might be dying for all they bloody care! How's name!
R: Do you find that your life revolves around (name)?
S: Of course it does, it has to do. yeah, definitely, until seven o'clock at night, well she's where she's sat now watching that for the soaps, I don't watch the soaps so Im upstairs on me computer, reading or listening to music or whatever and if she wants me she gives me call and I can hear that.
R: So that's your free time for a couple of hours?
S: Yeah, I switch off.
R: Do you have any other free time?
S: When I go to sleep.
R: Does anyone else come and sit with (name)?
S: No, only the family come at weekend cause of working of course and the kids are at school and that. They were round last night as a matter of fact and the night before, and me son was down on Sunday with his family. They just treat her as normal, The little ones want to have a go on the machine, see if they can spell their name, little Name)
I: Bird watching

S: Bird watching, I take (name) bird watching. Now she's a prisoner of her body, I had her out this morning. I had to go to the doctors and pick her prescription up, go to the chemists and then I took her for a drive down the promenade and brought her back her home. I took her out yesterday, I get her out most days cause, I do a lot of bird watching now whereas I used to do a lot of walking, across the mere and what have you, now I go round different places in the car and she loves it, she's does sat there and she takes and interest in what's going on so round (names of place) up to (name of place) you know on different days, not all on the same day and at odd times I'll take her up to(name of place), there all hotspots for bird watching you see.
R: Yeah, it's the sort of thing you can do whether you are in a wheel chair or not isn't it
S: Yes, and more she more often, I 'm always in her sight, I rarely go out of her sight when I'm bird watching so she's quite safe.
I: Hairdressers.
R: What's that?
I: I go to the hairdressers
S: Oh, she goes to the hairdressers. Not been for a while cause, er, last Friday was very bad weather, it was quite cold as well and the Friday before, but its lose arrangements with the hairdresser, I'll ring her up or she will ring up, don't bring her today it's too bad for her or I'll ring her and say yeah at the last minute. I'm keen for her to go and be in female company rather than mine all the time and she's with people that know her and they all have their own different illnesses and conditions. The hairdresser goes to Christies regular, she's had cancer in her leg and one of her customers had cancer in the face, she looks a lot better than what she did. So they're all in their like a little club, cause they are all ill.
R: So you go there to socialise.
I: Yeah, instead of taking that (points at lightwriter) I write them letters, you see.
R: So you can still interact with other people
S: Oh yeah, the thing, they expect to see her there, that's the main thing,
R: That's really good,
S: Like today, I will take her up in the wheel chair and bring her back in the wheel chair cause nice and calm.
I: (name) is very good with me
S: Oh yeah, me sons, father in law and mother in law are very good, very good friends to us oh yeah
R: So it extends outside the immediate family
I: Yes
R: And they give you help and support do they
S: Oh yes.
R: Well I've asked all my questions, is there anything else you want to ask (name)(looks at research assistant)Or is there anything else that you want to add that you think that might be useful to us?
S: Well, her condition at the moment, as you can see, she can only use her right hand and has limited use in her left hand, she can't use her legs, she can't walk, she can't stand without assistance, she can't dress herself, she can't wash herself properly, She does wash her face after a fashion so our day starts with me getting out of bed, when I'm ready, I wake up for half an hour, I'm just moving my muscles cause I'm pretty stiff, I'm just like that, getting my hips going, getting my head going, so after half and hour I'm pretty lose, go to the bathroom, get washed, get dressed and then I get (name) up off the bed, put her in the wheel chair, take her to the toilet, sit her on the toilet and I come back and have a shave in the bathroom, then I go back for her bring her back to the bed, In the meantime I've left a big bath towel on the bed I lie her on that and I wash her from head to toe. I do that everyday. Once a week she has a proper bath as we call it, I sit her in the bath, lower her down in the water, splash about all over her and that's how we go on. And I bring her downstairs for breakfast. She has her breakfast, and then she goes on the toilet and we're ready for the day, whatever its going to bring us. But we don't plan anything. We can't plan anything for any days in

advance, so anybody who wants us to go anywhere we say no, Cause we don't know what we're going to be like on that particular day .
R: So you make your decisions on each day as they come?
S: Yeah, each day as it comes, that's what we decided we were going to do. We know what we're doing tomorrow cause we always do it on a Thursday go to Tescos, whether I'm going or we're both going we won't know till about ten o clock tomorrow morning.
R: You have to be flexible really don't you?
S: Oh yes, but that's our routine, we have little routines we get her into out of the wheel chair on top of the stairs, onto the chair lift. We follow a certain routine to do that. I bring her downstairs, I take the wheelchair downstairs to her there, pick up, do a waltz, sit her down take her into the bathroom
R: So you just break up your day into these small routines?
S: Yes, she knows what to expect and I don't do anything different. If I'm going to do anything different I'll say well lets try it this way and she knows I'm going to do something either better or worse.
R: So you experiment sometimes?
S: Yes.
R: Well that was it really I've asked my questions
S: Are you happy with what we've told you?
R: Very happy.
S: Is there anything Else I can add?
R: Only if there is anything else you want to add.
S: I don't know, I'll think of something when you've gone, usually the case.In my own mind I think I'm coping alright but my children are getting worried as you'd expect them to do. So I've set the wheels in motion and (name) is part of the wheel, she rang up the other day, has anybody been in touch cause the er, well I got in touch with the branch obviously, (name), branch secretary, or contact got in touch with (name).
R: So the communication channels are working?
S: Yeah, but they'd been a breakdown somewhere but that's neither here or there and I said, no, nobody's been in touch apart from (name) who had got upset cause nobody had been in touch as well, so the two women between them were stirring things up. (laughs). I was calm and collected
I: All are good
S: Oh yeah, we are quite happy with the people we are in contact with and have to deal with.
R: You have confidence in them?
S: Oh, yes, yes, I have to have confidence but I go through everything with them because I don't just accept things, I've got to, er, would it be alright for (name of spouse)? Will I be able to use it? Will it suit me?
(Tape runs out)
R: If we think of anything, normally we go out and buy it, don't we?
S: We are working on a different method of (name of spouse) communicating with me whilst I'm upstairs or in the back garden, apart from me having a mobile but she's only got the fingers on the right hand that are in use actually so I'm working on that at the moment.

R: You can get cordless doorbells, something like that might be worth your while having. So that you could take the bell with you and (name) could just press it. I've heard of people using that sort of thing before.
S: That's a good idea, that,
R: Or baby alarms,
S: We talked over baby alarms last night with my daughter, (name) and our eldest,(name), last night as a matter of fact, they suggested a baby alarm. I said, well, the problem with a baby alarm is I don't want to listen to Coronation Street and Emmerdale farm on it.
R: There is that yes, but the cordless door bells they ..

S: Yes, I've got a cordless phone. I've got one but the battery's gone on it I've had it so long, that that make is obsolete now, so that's out of the question. Yeah, but that's a good idea. We've got the very thing, that's our alarm, but if we got another one of these and you had the button and I had this in the bedroom you pressed the button and I'd come running or sliding down the stairs, or just come down sedately like I do. It's a good idea that,
R: I haven't lost me touch.
S: I'm receptive to new ideas. There you go.

ID45 & ID202

Present: Individual with MND/ Spouse/ Research Assistant/ Research Supervisor

R: So if I just start again and say to you that I am interested in learning about how you are living and coping with MND so if you would like to begin your story wherever you feel is important to you .
I: I don't know, It started quite honestly we were told in August last year but that was the problem, and er mainly because the muscles in my legs had wasted, Its difficult to walk about, Ive got an arthritic hip and that makes it worse. We've had loads of people down from the organisation but to me quite honestly it is more like a talking shop than action, plenty of talking and no action. We were supposed to be getting a lift there back in September, October, its not there yet erm I was going to get a specialist to come and have a look at the hip… all talk. Erm so, there are only two people who have done thinks for us and that is (name) and er, the speech therapist,
S: The occupational therapist.
I: That's it.
R: What sort of things have they done for you?
I: Erm, the chairs erm and the er the diet.(pause) and that's it.
R: When did you first notice problems?
I: Oh, I suppose in actual fact it goes back a long way but I initially thought it was cramp and it got worse and worse didn't it? Er and we went to see various specialists and tests and in the end it was a little guy from (place name) who said what it was.and then it went to (name). He agreed with the diagnosis.
R: How did you feel about seeing lots of different doctors?
I: Fed up, brassed off, yes.
R: Did you feel as though there were communication problems or..?
I: No, no.
R: Why did you end up seeing so many people?
I: I've no idea, I've no idea.
R: You mentioned about your feelings of it being a talking shop, erm how would you rate the overall co-ordination of the multi-disciplinary team in your case?
I: Oh they are grand at turning up and talking yeah, laughs that 's it.
R: It's the action that missing
I: Yeah,
R: Have you had any contact with Social Services?
I: Yeah,
R: Hows that been?
I: Er, in what respect?
R: Have you had to any care package, or..?
I: Yeah attendance allowance.
R: What was you experience of claiming that?
I: Alright, yeah,
R: Fairly straight forward?
I: It was yeah,
R: Did you get any help with that?
I: Yeah,
R: Yes, she was very good (Specialist Nurse).

I: Yeah, mm
R: If I can just take you back to your diagnosis experience, erm can you elaborate on that for me at all, about how you felt at the time. About maybe what you were told.
I: He thought it was Motor Neurone Disease, I won't see you again, that was it weren;t it.
R: How did you feel about that?
I: Er, well erm strange, odd way of doing it really.
R: What would you have preferred?
I: Er, a discussion really I suppose.
R: Some more information?
I: Yeah,
R: What did you know about the illness?
I: Nothing,
R: What were told about it?
I: Nothing
R: Have you sought information since then?
I: Er, (sighs) in bits, yeah, in bits that's all.
R: Whys that?Why just in bits?
I: Er, maybe cause I don't want to know.
R: Do you feel that's your way of coping?
I: Yeah, maybe
R: Can I ask what was important for you before your illness?
I: What do you mean?
R: What things did you regard as important in your life before you became ill.
I: Work. Going out, playing golf, gardening erm,
R: What's important to you now?
I: Not a lot really, erm, er can't think really,
R: So has MND affected the way you live?
I: Well, I can't go out, er you can't go anywhere erm so I am virtually here in this area er all day every day.
R: Is there anything that you feel would help you to live with the disease better?
I: No, not that I can think of no,
R: Do you think there are any services that could be provided that could help?
I: I'm not aware of anything.
R: Not necessarily things that already exist but if I gave you a blank piece of paper to write down what you felt that your needs were.
I: Er, it would still be blank I think, erm, no,nothing, no.
R: Has there been any affect on relationships within your family?
I: No.
R: What about with friends?
I: No,
R: Your friends still treat you the same way?
I: Well, no that's not true. To a degree er, I've dropped them all really.
R: You've dropped them?
I: Yeah, yeah.
R: Why's that?
I: I don't want them coming round here feeling sorry for me, that's it.
R: Did you get the feeling that they did feel sorry for you?
I: No, no, no,
R: It was just a decision that you made?
I: Yeah

R: When you go out, I know you've said that you don't get out and about too far, but when you do go out, how do you feel that people respond to you or react to you?
I: Alright, I suppose,
R: No differently?
I: No,
R: Do you walk when you go outside?
I: Yes, I try to with a stick.
R: I suppose it can be difficult sometimes with pavements the way they are, and
I: Oh, I can't go far at all, no erm er, where do we go? We go once a week to a pub and that's it.
R: So you've changed the way that you socialise?
I: Oh, yes. Totally yes.
R: What sort of things did you do before, I know you mentioned golf.
I: Going on holiday, cruising, yeah,
R: So do you go on holiday now?
I: No,
R: Its just out to one pub,
I: mm, yeah.
R: So its had quite an impact on your lifestyle, hasn't it?
I: Oh, yes, very much so.
R: How do you feel about that?
I: I can't do anything about it, really, as far as I know, that's it and I'm stuck with it.
R: Have you developed any other interests since you became ill, to compensate?
I: Suduko,
R: Keep challenging your brain
(Laughs), no
R: Do you have any involvement with the MND association?
I; Er, no
R: Have you thought about it or not?
I: Yeah,
R: But decided against it?
I: Because I don't want to be travelling to here there and everywhere
Pause. …….
R: What sort of support do you get from your GP?
I: Er, not a lot really, do I? No,
R: Whys that?
I: I've no idea, I don't go and see him, that's for sure, no need to, erm no idea,
R: Have you ever approached him about MND?
I: Yeah, he knows, yeah
R: Is he knowledgeable about the disease?
I: No, he says so, he says not
R: So he admitted it, that he doesn't know much about it.
I: Correct, yeah
R: Erm, Do you feel that that could affect how your care is managed?
I: I wouldn't have thought so, no.
R: If you have any issues regarding your MND where would you seek your advice about it?
I: I've no idea, er , somewhere round the talking shop I suppose. Mm
R: Do you find it easy to contact?
I: Yeah, they are, aren't they, yeah
R: And you get answers to your questions?
I: Yeah, yeah,

R: Erm, well I think just about, because you've said just about the multi-disciplinary team and the professionals not doing much to help you, I was just wondering what it is you feel you would like them to be doing more?
I: Well. Its strange, the stairlift which was supposed to be organised back in September or October and we are still in minus situation.
R: And is that through OT? Occupational therapy?
I: I don't know what board its through.
R: You don't know whats causing the delay.
I: No, we had a guy who assessed the house, a guy who measured up but we're still nowhere.
S: I think originally, I've got to interrupt. I think originally they were going to go through the ceiling, it wasn't going to be a stair lift. We had somebody down and erm because my husband can only get out of this chair and in this chair and the thing was we didn't think he would get out of a stair lift seat so er stana came down here with some young lady, probably an occupational therapist, and erm so it was left at that but then my brother in laws mother who has a stair lift, she's eighty-eight we went down there for you to try it and you know I rang up and said look, my husband can get out of one of these chairs and we went out to an assessment centre at (name), and (name) took us from Occupational Therapy, she came here and took us through, didn't she (name)? She was very good, she said we that's excellent and we are just waiting for it now to be delivered which will be in a few weeks time so there is, you know, it was going to be knocked through the ceiling there but my husband said well I'm not having that you know, we just didn't think he would be able to get out of this chair because this is the problem in why we're not getting out and about because he can't walk because of his hip.
I: It's the hip that does it really, not the MND, erm and nobodys done anything about that.
S: The physio therapist at the hospital when we went to see her that was (name) did say that she would get in touch with (name's) team to see if it was possible that he could have an injection but we haven't heard anything since.
R: How long ago was that?
I: When we saw you. So we've not this is the problem, his hip.
R: It does sound like theres been some break down somewhere with communication.
I: I'm sure, yeah, I'm sure,
R: And that obviously has an impact on your quality of life.
I: Oh, yes and its just a talking shop
R: Do you feel as though you can chase these things up?
I: No!
S: Erm, can I say something here? (Name), did say that she offered my husband there and then this mechanism which could hold to walk with and then if you wanted to sit down and she said you can take it there and then, but you didn't want it did you, you said no, but on reflection I think you should have had it, because I think if only if it means just walking so far up the front where he can sit down on the stool which there is with this mechanism, I personally think that would be ideal.
R: But you didn't want that piece of equipment?
I: No, no, no
R: Why didn't you want it?Any reason?
I: Well I didn't really think it, I couldn't see myself walking down (place name) pushing that thing quite honestly,
R: Why not?
I: Er, well why not? Well cause erm I'd sooner walk with a stick or not at all than go with a thing like that.
R: Did you feel it was too bulky or.. its difficult for me to comment cause I obviously don't know the piece of equipment but
I: Like a chair
R: A bit too obvious,

I: Yeah, yeah, yeah, yeah, yeah
R: Do you have a wheel chair?
I: No
R: What would you feel about using one?
I: Well, you know we have a problem loading and unloading , my wife's got osteoporosis
S: So we've not bothered
R: Have you tried one?
I: Yeah,
R: But you found it too awkward?
I: Too heavy
R: There are some light weight ones, I don't know whether you've….
I: There not light enough are they
s: I don't know(name) when have we tried one?
I; We were told about light weights being about a kilo less than an ordinary one.
R: But you haven't actually..
I: No,
R: Do you think it might be worthwhile having a try of one?
I: Not really.
R: You don't think it would help you?
I: No because, my wife can't push the thing, lift it out and lift it down so its pointless.
S: It depends on the weight (name) because I do do a lot of lifting and moving don't I. I'm probably not supposed to do it but I do do it and I mean as far as I'm concerned it would have been one way of us getting out if you'd I mean I don't know how I'd feel with the weight of pushing whether how I'd find that, I don't know. I don't know what it would be like.
R: I think that occupational therapy might be able to help you with.
S: Yeah, I have mentioned it, quite some time ago about a light weight chair but nothing developed with that, but I did mention it, wondering what weight are they, I just don't know with my osteoporosis, I've got to go back, I don't know whats going on there do you know what I mean. Bit difficult isn't it? We're stuck aren't we (name)?We've had some good times though. All the good times make up for it and we are quite happy to be together in this house, so that's us, that's the main thing, Your happiest when you're there, in this room aren't you? That's why we've had the room done up and it's a nice room for him
I: Yeah.
R: So you don't feel that if there is anything that you want you can go to people and say,
I: No, not at all I've just said that with the wheel chair and this thing no,
R: So you feel quite frustrated with the service you've received?
I: Well, I've given up.
S: You can't sit in the conservatory, can you? I mean I know it's a bit untidy in there but er
R: You must feel very frustrated with it
I: To a degree, yes
R: Is there anything you would like to add about your experience?
I: No.
R: That's all?
S: Yes, that's it.
R: Thank you very much.

ID46

Present: Individual with MND/ Research Assistant

R: The idea of the interview is rather than me doing lots of questions and talking its more a narrative interview, so erm, its just to get your side and your experiences really of the disease and how its affected your life and how you're living and coping with it, and some people, you might want to start at the beginning of when you first noticed some symptoms and I'll make some notes maybe to ask

you any questions at the end when you've finished, if you're happy with that, is that ok? I mean I have got some questions to ask if you feel you need a bit of prompting.
I: Yes, well I probably do need a bit of prompting because there is so much isn't there and it's been three years for me since my first symptom so you know so I don't know how much is relevant.
R:Well, I guess, the bit, what you think is most relevant to you really, the idea is that I am not dictating it but you tell me what you think is most important, that you want to get across about your experiences.
I: My experiences. Well first of all I don't think it's been a good experience but then again I don't think anyone getting a diagnosis of MND could be good, erm. I got off to a very bad start with the first consultant I saw at (name of specialist centre) and I have to say that I think that the care and treatment that I got at (name of specialist centre) was unforgivable,
R: Really?
I: Yes.
R: Why was that?
I:The consultant was absolutely horrible erm and the first time I was given any indication that it was motor neurone disease, he walked into the room, I was with my daughter he didn't know who my was, and he came in and I was with a registrar and the registrar was struggling with a drug that he wanted to prescribe and he went to ask for some advice and I was just expecting him to come back in with a prescription and the next thing the consultant walked in and he just sort of said, he mentioned the doctor's name, the registrar and tells me that you're having increasing difficulty walking and he sort of said it as if he was disbelieving me and I was sat at the end of the bed and he checked my reflexes and he said to me well I think we are looking here at a diagnosis of primary lateral sclerosis, you know which you know is one of the forms of motor neurone disease with a prognosis of between four and seven years and then he said but I'm not saying you will live that long and I said 'oh shit what am I going to do?' because I had been talking about going back to work and I'd not been able to. He then said have you tried watching day time television erm and erm then I started crying, my daughter started crying, He did nothing and I said to him, this is my daughter cause I just thought even if you're not going to be nice to me you could at least be nice to my daughter and he was erm, well he didn't really do anything to help (name of daughter) and then he just said I will see you in three months and that was it. And we both were absolutely sobbing, and we left that consulting room and nobody offered us any support. And at that point my GP said, he'd previously been pretty horrible to me once when I'd been on the ward, and erm, my GP said you don't have to put up with this anymore, you know you don't need to see him ever again and he transferred me to (name of other specialist centre) where the experience was a very, very different experience, unfortunately when I got the diagnosis, the final diagnosis of motor neurone disease which took another year really cause I had to repeat the tests twice I then had to come back to (name of specialist centre) to get support from the MND team. But my whole experience of (name of specialist centre) was very poor. And I saw (name of Specialist nurse) the other day, the MND nurse and he said well was there not a nurse there when you were told this, well there should always be, we always make sure there is. Well they don't always make sure there is cause it happened to me and he said well in (name of specialist centre) you would always have a nurse there but everyone round here gets seen in (name of area) because although they don't have beds, the outpatient clinic is in (name of area), so you know, it got off to a very, very bad start and I didn't ever want to go back to (name of specialist centre), I don't ever want to go into (name of specialist centre) hospital and I find it very sad that he is still getting away with that. If you speak to the nurses, they'll say more or less, we know. I've never heard anyone defend him yet. And erm, I know that (name of specialist centre) was one of the first MND care centres in the country but erm and you might find this hard to believe but I've got a friend of a friend, whose husband died of MND and she said to me don't ever go into (name of specialist centre), I'm in touch with somebody who has MND at the moment and they've just had two awful experiences in (name of specialist centre).
R: With the diagnosis again?

I: No, with the treatment, appalling treatment. And I know somebody, who's, sitting; you've got a steering committee, haven't you? Well I've just met, did I tell you this? I met somebody and you see he said the treatment was not good, and I think it is very sad that you've got an MND care centre there but its not…
R: Meeting peoples needs?
I: No, I think we are being let down. I think it is very sad that you've got MND nurses in that hospital and people are having to put up with that sort of treatment,
R: So when you first had the diagnosis, did you know what it meant?
I:When he said I'd got primary lateral sclerosis, no, you mean, he went on to say if you are going to have MND it's a nicer form of MND and that sort of thing, But I was so shocked, We sort of knew that was always a possibility but because it had taken so long, I used to really believe that I would wake up and I would be better, cause I didn't know enough about MND and nobody had actually said to me that sometimes it would take a long time, because even when I went to (name of other specialist centre), the consultant said that anybody with MND normally what would happen they would come in, they'd give a history, he'd examine them and he would be able to make a diagnosis and they would only do the nerve conduction studies as a sort of backup. But because I presented atypically, and you might say that some of my more negative experiences are because of my atypical presentation but you know it was a bad experience.
R: How did (name of other specialist centre) compare?
I: Well, it was, the consultant at (name of other specialist centre) was in a completely different league, he was a completely different kind of person. Whereas the consultant at (name of specialist centre), like my daughter said he'd certainly not been to the lecture on breaking bad news. She said first of all, you never have someone sat on the end of the bed, my daughter's a medical student, and you never ever give people bad news without planning whereas he just came in and just came out with it. I mean he didn't even know who (name of daughter) was, so you know, erm and I find it very interesting that that person has never ever been in touch, that consultant, I mean my husband is a GP and a colleague and I mean you would have expected, I'm not saying we should have better treatment but he just said I can't believe that consultant is treating a colleagues' wife like this. I mean on another occasion when I was in (name of specialist centre) I asked if I could go on holiday as we had a holiday booked and he said no, you're seriously ill, I mean nobody had mentioned I was seriously ill and when the consultant said you're seriously ill I thought it was life threatening, and there was absolutely no reason why we couldn't have gone on that holiday. We lost all the money for that holiday because I had the symptoms and again I was crying on the ward and he just left me.
R: So you got no support?
I: No, but I didn't have a diagnosis then, well I think it shouldn't matter if you have a diagnosis or not. I mean I did have a nurse after the ward round, a nurse did come and talked to me and she was lovely and I said I'm very frightened and she said you have every reason to be and I knew when she said that it was serious. No, I used to think that tomorrow I'll wake up and it will all be a bad dream so, didn't get off to a good start.
R: No, when you got the diagnosis how did you react to that, how did you tell people?
I: Well, my GP came to tell me cause when I finally got the diagnosis at (name of other specialist centre), I was unable to go to the clinic, I think we were going away, but the consultant at (name of other specialist centre) thought it was unfair to keep me waiting and he thought that my GP probably knew me better than he did so it was actually my GP that came to tell me. But I think I knew when his secretary said he was going to come and tell me the diagnosis, I knew then, I mean we were running out of options really, they'd looked at all sorts weird and wonderful things but I'm a nurse, my husbands a doctor so I think we both knew it was going to be MND. I can't actually remember what we told people but I think we just told them we had a diagnosis of Motor Neurone Disease. Some people would know what that meant and others wouldn't. I think one of the worse things about a diagnosis of MND is that nobody can give you any hope, nobody gives you any hope and there aren't any, erm but I feel that yes there are stories of people who live with it like Stephen

Hawkings but nobody has really said anything positive to me since I had that diagnosis, I mean one of the MND nurses said you have done very well but that was in the past tense not you are doing very well and that's quite hard but I know that nowadays, well when I was trained as a nurse we weren't totally honest with people but one of the things taught as a nurse was never ever take hope away. I mean the (name of specialist centre) consultant, once when I went to see him, this was before he gave me the diagnosis of primary lateral sclerosis, and I said to him will I get better? And he said no and again that completely took hope away and I asked him will I get worse and he said I can't answer that, nobody can answer that but he never gave me any hope. I know that I have done really well, in that I have had the symptoms it will be three years this month I just felt that at that time that once you've taken all hope away it's very difficult. I think maybe I was at a disadvantage because I had looked after someone with MND and you know I knew what a terrible disease it was and perhaps its been worse for me than other people cause I knew the sort or outcomes cause nobodies talked to me about this is what may happen, but I know so I guess I don't ask those questions whereas if you didn't know you would ask those questions wouldn't you, you know whets going to happen and then they would probably say we don't know. Erm, what else do you want to talk about?

R: Maybe about your experiences of the mdt, so people like nurses, OTs?

I: Right, so then we went to the Fast track clinic and (name of consultant) gave the diagnosis. Well he formerly gave the diagnosis as Id already got it. And then I went to the MDT and I was quite excited about going to the clinic, my only problem with it was that I thought it was too much seeing all those people on one day and I thought it was a waste of time having to repeat the story to everybody, I didn't see (name of specialist nurse), I saw (name of specialist nurse) and the speech therapist well no it was the dietician cause the speech therapist wasn't there and I felt in a way you were having to repeat all of that four times and why couldn't they have all been in that room or you tell one person and they tell the others cause we went at half past twelve and we left at half past four and if fatigues one of the biggest things, it's a long time isn't it? And you know its very confusing, and my husband, my husband probably more than me feels that after that it is a complete let down and the thing that we are always going on about is that we saw the physio and she was lovely, and fantastic and then she says but I won't be seeing you again cause they don't offer a service and then the option was would you like to find private physio and she put us in touch with a private physio.

R: So you think that's something that missing?

I: I think it is appalling, I think its absolutely terrible the one thing that would make a difference to me is having physio, and I did have a community physio when I first started to have problems walking so I went to see the community physio but I've not heard from her since October but erm, and you know I need hands on, she was teaching me exercises which was fine but the time I had got to the MND clinic I couldn't do the exercises there is very little I can do on my own and I just think that to see this physio and then say but I won't be seeing you again is appalling and I mean I've not seen the OT or anybody and you know they say well its up to you to get in touch if you have any problems but sometimes you don't know what those problems are and I think the liaison, I mean apparently, I've only just found this out, that when (name of specialist nurse) comes to see me she sends copies of letters, they go to the GP they go, I mean why are they copied into the letters cause these people don't respond.

R: So you don't have any contact with them?

I: Well, I mean the OT if I phone her up, she's off sick at the moment. I feel and my husband feels that there is a lot of paper exercises going on but very little action. We are in a position to pay for private physio but it is a hundred and twenty pounds we are paying and it's a long journey, now (name of Association care co-ordinator) said she would me in touch with someone who would be willing to come to the house and this person came last week and it was just totally disastrous, she was clueless, absolutely clueless, she was actually asking what did my physio do and she brought a bed which I couldn't even get on and I asked her to help me get up from this chair and she couldn't

help me cause she was recovering from a broken leg and that's somebody who (name of Association care co-ordinator) put me in touch with.
R: This is a community physio?
I: It's someone who works privately but she was willing to come to the house cause that's what we've been looking for and (name of Association care co-ordinator)said she had found somebody.
(Phone rings- 2 min interruption)
I: So you know, again I feel let down. I'll tell you something else that I feel really let down about, well two things that I feel let down by, I've had massive problems with my electric wheel chair you know real battles and not long ago (name of specialist nurse) said she would take some of the burden off me and said she would speak to the people involved and she did and then she phoned me up with the sort of answer, and it was pathetic the answer and I sort of said that to (name of specialist nurse) and (name of specialist nurse)'s words were to me don't shoot the messenger, and I said fair enough, anyway and because she said don't shoot the messenger I felt that was a very unfair criticism because if she says she is sorting something out and she comes back with an unresolved problem, she should have picked up on that and said really (name of participant), I need to do some further work on this, so she never followed it through and in the end I ended up having to sort it all out and then when (name of specialist nurse) came to see me, and in the mean time she sent me an email in between seeing me, and when she came to see me her actual words were I didn't dare mention the wheel chair in the email. I mean what is the point of pretending of taking on some of the problems and then not even daring to mention it?
R: Crazy.
I: I asked (name of specialist nurse) about respite recently for this weekend because my husband needed to go away and originally we thought we could manage but we realised because I have deteriorated quite a lot that I couldn't So, I asked (name of specialist nurse) about respite and I asked about the hospice cause I know now that they have an interest so I emailed her and said would it be possible to have respite in the hospice, and she emailed me back and said no. So my husband said well we want to know why not. So we emailed her back and she said it's been closed for refurbishment and they've only got half the beds. And she gave me the details of another place which she said would be lovely, and I contacted this place and I was at the point of going round to visit this home that (name of specialist nurse) had recommended and when I spoke to the person who owned the home she said we don't do planned respite and (name of specialist nurse) had sent me the details. I've not heard from (name of specialist nurse) since.
R: So you think there is a lack of co-ordination?
I: I think, they start off and they don't see it through. Because I think to give people. And when I said to (name of specialist nurse) about this place in (name of specialist centre) didn't do planned respite, she said well I didn't know where we up to with it. I mean you shouldn't be giving, I've been very big with information and networking and to give duff information is worse than giving no information at all. (name of specialist nurse) suggested somewhere else and I couldn't get in there and that's the end of it and nobody has ever phoned me to find out if I got sorted this weekend.
R: So you feel that you are doing all the work really?
I: Yeah, I mean, I don't know if I am doing all the work cause people think I'm capable, people think I want control, but you know erm when people let you down you feel that you have to do it and this weekend has been a total disaster, you know its really the first time, I know I've not been ill for three years but I have had symptoms for three years and I just think that, yeah I feel that we are short changed, and I think we are short changed when you look at the service that people with cancer get, you know I've just been I know someone whose mother had breast cancer and died very young and the services that she got compared with what I get is far, far superior I mean you might think or they might think that I don't need that at the moment,
R: In what way was it different?
I: Well, she said they were always there, fantastic support, they got regular respite erm I just felt that theirs was a very positive experience, and I think I told you about the article in thumb print about

the people who got this extra mile award, there was a photograph of this wonderful team, of physios and OTS and I just feel that here, no, you know things like my OT when I asked about a stairlift said that she wouldn't recommend that I had a stair lift cause it wouldn't be financially worth it cause I probably wouldn't live that long.
R: That's dreadful
I: Well, I can also tell you somebody else with MND the OT said something similar to them two weeks ago cause he emailed and told me, and he said to her is it because of the financial implications erm she more or less well she didn't disagree with him and he knew she was agreeing with him, and we wouldn't have got financial help anyway with the stair lift but the fact that she said that to me, you know,
R: No, it's not very sensitive
I: And I said to her if I get one days use out of that stairlift it will have been of benefit. I mean it's an expensive day erm but erm, you know, I did get help from the MND association I got a thousand pounds towards it, but it cost me five thousand pounds, I mean there have been good bits, we got a chair from the association but having said that I gave them a chair in the end. Yeah I do think there are lots of gaps and now if we go to the multi-disciplinary team we go to the hospice which is lovely because travelling to (name of specialist centre) is hard work, parking at (name of specialist centre) is hard work but you don't see anybody you just see the nurses. I mean (name of specialist nurse) has seen me at home in between, she came to see me. But things like the wheel chair and the respite are not followed through, and I find that almost negligent really I just don't understand why bother to get involved if you're not going to see things through you know just a phone call to see did you get any respite sorted out, no we didn't get any respite sorted out.
R: So do you feel that people don't really contact you, you have to contact them?
I: Yes, well erm, when I saw (name of specialist nurse) she did say Ill come and see you again but like the research project with(name), I was the one who had to chase up, that had all been forgotten, I mean I signed consent forms, where are they? I had to sign them all again the other day, I asked (name of specialist nurse) where are the other consent forms that I signed oh they will be somewhere in, you know, I mean is that impressive? It's not impressive is it? and then erm (name of Association care co-ordinator)said to me, (name of Association care co-ordinator)phoned me up the other week, and I know the only reason she phoned me was cause I contacted head office because they had sent this document out and it had the incorrect email on it for (name of specialist nurse) and because I couldn't get a response I phoned head office, I think I caused a bit of trouble and (name of Association care co-ordinator)phoned me up and (Name of MNDA Care co-ordinator)'s words were why does everything go wrong with you (name of participant)? You know does that make me feel any better? And the truth is I know that it isn't that everything goes wrong with just me it goes wrong with lots of other people but perhaps I'm in a position to vocalise it erm, you know I'd love to speak to somebody whose got a positive experience but you know (name) whose husband died said don't ever go into (name of specialist centre), and I've managed, in the early days erm when I had massive problems over my bladder, nobody listened to me, and the answer was people with MND don't have bladder problems and yet I was really, really struggling with toileting, now why weren't people listening to what I was saying?
R: How did you manage with that in the end?
I: Well, in the end my back went and you know I couldn't transfer for three days so a decision had to be made for a catheter to be put in and recently I went into hospital to have a superpubic catheter put in and its been absolutely wonderful but I just feel angry that nobody listened to me, and their answer is well people with MND don't have bladder problems but then I've got this high degree of spasticity which I think is sort of atypical and why didn't somebody say perhaps person is really having bladder problems but it was just sort of dismissed that no people with MND don't have bladder problems and I have to say I think having this catheter in has been the best thing that has happened to me because its just made a massive, massive difference. I mean perhaps I am unfortunate, I don't know, yeah, I feel quite let down, and you know this physio thing well obviously

I need to (name of specialist nurse) and (name of Association care co-ordinator)about it, I'm going to my private physio tomorrow and I mean my private physio is very good and she's happy to see me and take my money off me .But even she agrees, that you know, I'm not saying that this is what she is saying, its what we're saying together, I think that (name of specialist nurse) told me or somebody told me there are currently 17 people in the (name of area) with MND now how much would it cost to provide a reasonable service to those people cause as I see it at the moment they are spending a lot of money and I am not actually sure what they are doing. Erm, you know and not everyone has a high degree of spasticity so probably you know not all seventeen of us would need the same sort of input that I need, I just think that there should be a better service.
R: If you want it, it should be available?
I: Yeah, you know people who get cancer treatment get a fantastic amount of money spent on drugs, I know I'm on riluzole but compared to the treatments that some people are having, I mean I've got a friend at the moment whose pct is deciding to spend 48,000 pounds a year on his treatment and I am asking for one hours physio once a week, and I know its very difficult to compare different areas and you know it is a postcard lottery but I've spoken to two people who think in different areas who feel that the service I'm getting is inferior to what I'd getting where they are and I think because we've got specialist nurses and I know this cause I've been a specialist nurse, that once you've got them specialist nurses involved other people get less involved, I mean once upon a time you'd have a really good district nurses involved but she thinks you've got the specialist nurses coming and I'm not sure you know what liaison there is I mean I did ask about, (name of Association care co-ordinator)said they have these multi-disciplinary team meetings where you know she meets up with physios and she meets up locally here with a physio and I asked my community physio what feedback she gets form this person who goes to (Name of MNDA Care co-ordinator)'s meetings and there wasn't an answer well there couldn't have been an answer as nothings happening
R: So you feel there is a lack of co-ordination with the services?
I: I think so yeah.
R: Not joined up thinking?
I: Definitely not.
R: Can I ask you about issues with equipment?
I: Well I've had massive, massive issues with the electric wheel chair, massive, I think that firm who are responsible for the wheel chairs are just well I wouldn't pay them in,. I wouldn't even speak to them if I was, I mean they took my wheel chair off me at Christmas and I was without it for six weeks, it faulted again, they came unannounced and that's part of the contract that they have to let you know when their coming, so you end up with a card saying we came and you were out. They then came and there was a part they brought was broken cause nobody had checked it and I can't remember how long I waited then again for it to come , I mean again they say with MND that electric wheel chairs are a priority and I mean I did get it fairly quickly but you know again the after service is absolutely appalling so (name of specialist nurse) tries to get involved and then she says don't shoot the messenger and then she says I didn't even dare mention the wheel chair, I think that's absolutely pathetic, for a specialist nurse, she should have been on that phone a week later saying (name of participant) have you got that wheel chair sorted out? Erm, yeah, everything I've got I've actually had to suggest the MND chair, I got given chair privately and it wasn't quite suitable and I mention ed it to (name of Association care co-ordinator)and she did get me a chair from the association and (Name of MNDA Care co-ordinator)'s answer was can she not put a foot stool under her legs, how can I put a foot stool under my legs? So (Name of MNDA Care co-ordinator)'s answer was well can you not put a foot stool under your legs. Well someone else can put a foot stool, but I actually wanted to get into that chair myself and even if somebody puts the foot stool there, because it s a riser and recliner I can't do it cause there's a foot stool there. What other equipment yeah I've asked for everything. I sometimes wonder if ignorance is bliss and if I was sort of lying there helpless then people would come running I don't know.

R: So you don't find that the OT recommends things or?
I: I think my OT is rubbish, she went off sick and we jumped for joy cause we actually got something that she said wasn't possible, her colleague got me something and again does she actually speak to (name of specialist nurse) ? Does she speak to the OTs at the hospital? I mean I don't see the point of having OTs at the hospital and OTs here I don't understand how it works.
R: So you don't have much confidence with the community team?
I: I think the OT service is rubbish, and I've had things delivered here and you're not supposed to use them and I've had them here been three weeks and nobody's been in touch and they shout at you if use them. my GP recommended that I have a monkey pole, now it was just a suggestion of his, as I was in bed and I was really, really struggling and he said would a monkey pole not help so I asked the Ot for a monkey pole and she said oh we don't do monkey poles anymore cause they are really frowned upon under health and safety anyway a monkey pole came but nobody showed me how it works , it was in the garage for I don't know how long cause I said to my husband we can't use that till somebody's shown me anyway we did use it and then when I went to my private physio and telling her about new problems Id got with my arms and her reaction was like I'm not really sure you should be using a monkey pole. Now you know where was the OT then the Physio then, I mean fortunately she was bale to teach me an exercise that was able to minimise the problems I was creating by using muscles that I hadn't been using before. So you ask for a monkey pole, you get a monkey pole, but was that the right piece of equipment that I needed? Erm, don't know.
R: The other thing is if you think if there are any other areas of service you think might be missing from (name of specialist centre) or the community in terms of emotional support or do you think there is a need for that?
I: I mean I was very fortunate as my GP organised counselling for me and I had a superb counsellor and sadly he's left now and in all fairness (name of Association care co-ordinator)did offer to pay for me but I don't want to got there again I mean my counsellor was superb and I probably got one of the best counsellors in the areas he was fantastic, I did get him twice, and I had to ask for that and it had to go to a special pct for the funding arrangements, I did get it and its very difficult to say but the only reason I think I got it was because of something that happened to my husband at the time cause its difficult this did I tell you that my husband was stabbed? Well, the day they agreed to the funding was the day he was stabbed. I mean they were at the surgery in the morning all running round and in then that afternoon my counsellor got a phone call saying we've agreed to funding for (name of participant). And I'm absolutely convinced I said to him do you normally get phone calls and he said never it normally comes by email.
R: Do you feel that the counselling useful though?
I:Yes for me it was useful and I thought that the counselling was very useful but think it has to be good counselling and in all fairness (name of Association care co-ordinator)has agreed to pay for six sessions with somebody but you know, if it is anything like the physio she recommended, you know and in all fairness she did say this lady is going to see two other people with MND erm you know perhaps it worked for them but I mean when I got the cheque book out she said no I can't take that from you cause I don't think I've actually done you any good and I couldn't wait for her to get out of the house so I haven't spoken to (name of Association care co-ordinator)about that partly cause my husband has said he wants to wait and see if (name of Association care co-ordinator)asks how did you get on because again he has this feeling that people don't see things through.
R: Do you get that impression with the MND association as well?
I: Well that is the MND association isn't it? I mean I don't go to any of the local meetings cause I have worked with some of these people and I have said to (name of Association care co-ordinator)that I just don't want to go there. I have started emailing this gentleman who lives in the area who has MND who is a friend of my daughters and I have to say it has been very, very distressing. Because he told me about tow of things that have happened to him at (name of specialist centre) and I think there is a general feeling now amongst family and friends that I shouldn't really be emailing him as I'm just hearing about all these negative experiences so I don't

want to go to and my husband certainly doesn't want to go. I think in terms of financial support I've just had to pay five thousand two hundred and something pounds for a new car seat and (Name of MNDA Care co-ordinator)'s said just send the invoice and they will help out but I think just writing cheques is very easy you know I think it should be more that, I'd rather they sorted out the respite this weekend than left us to our own devices. I know I've got a social worker and I asked my social worker to recommend respite and the home she recommended was one that is full of older people and I actually told her that my cousin died there and died there because he got pneumonia and they didn't phone. I mean could you expect me to go there? I mean my mum who is 87 and can do very little said there is no way you are going in (name of home), They failed to diagnose he got pneumonia and he died there. So erm, I don't know what other people do about respite, perhaps other people, I just know that my husband is at breaking point. We've got the new deal for carers, individualised budgets; nobody's ever spoken to me about that. You know I never got any advice about benefits; I had to sort that out myself. I don't know who would have done that I mean certainly the MND, (name of Association care co-ordinator) said she had no experience when I asked she said I've very little experience of benefits.

R: The social worker didn't help in that area?

I: No, no I mean arm, I had to tell my OT, I found out that you could get a reduction in your council tax for having a room like this; my OT didn't even know that. She said I don't get involved in that and (Name of MNDA Care co-ordinator)'s said she didn't know.

R: So you feel you have to keep finding things out for yourself?

I: Yeah, and you know I wonder how many other people don't find out.

R: Can I ask how you feel your everyday life has been affected and the life of your husband?

I: Oh it's just devastating. I mean it's just our lives compared to what our life was like before I just can't even bear to think about it. I mean access is a massive, massive problem and that society's fault, yeah you know, I mean flying we tried to fly and that didn't work out very well. It just impacts on everything, what my daughter said was something has been stolen from us that affects everybody and will never, ever get back. You can't be spontaneous, you know spontaneity is completely gone, because everything has to be planned erm you know my husbands working part time he was working full time until last year and I don't know how he was doing it and now he's working part time. But I would say that he's he looks forward to going to work whereas previously he couldn't wait to retire and that's quite hard and one night a week he has well again I'm being let down over that now what I've got is a group of friends who come for two hours one night a week and a carer who puts me to bed and one night a week he goes out and that's horrible, I hate it and he sorts of hates it because he'd much rather we were going out together. I'm too tired in the evenings to go out and really its because we're great theatre goers and there is no point going to the theatre if you can't concentrate on the play, erm We were great walkers and we had a time share that we can go no longer go to cause its no longer accessible, my daughters got a flat that I can't get into, my son's got a house I can't get into that, I can't get into my mum's house. Erm, I've only really got one friend whose hose I can get into without ramps. I loved cooking yeah, you know, everything I loved has gone, I loved shopping. I do go shopping but its not the same shopping from my wheel chair, yeah it impacts on everything the only thing I would say is about something like this is that you do really, really find out who your true friends are and that does give you something's very special that perhaps you didn't know you had before. But apart form that it's horrid. There's very little that I look forward to, I try to but so many thing s go wrong it s almost if I look forward to something's now I'm always worried about, you know, what happens if my catheter bag bypasses. the super pubic catheter doesn't come with a guarantee you know and if it bypasses just before you're going out its massive, you know, we've just bought this car seat for five thousand tow hundred pounds it failed the other day we were stuck in a car park for over an hour we had absolutely no idea how we were going to get home. Sat in the car park at the (name of shopping centre). Nightmarish.

What else? I think community care. The sort of standard of care which you get with a package of care is very, very poor. I think the majority of carers are geared up to going in to older people erm and you know well in my notes you know every morning we get (name of participant) seems fine.
R: You don't think they know much about the disease?
I: No, they don't know anything, My carer was asked would she like to take somebody on who got MND erm this is what she tells me and then she went to the chemist, she's got a chemist who is very good who has a computer there and she found out about mnd and that's it and when she says things like, but I have to say I have MND, no understanding. I think its very difficult because they are very poorly paid, their unsupervised, you know I've had massive arguments with them about confidentiality which they've partially addressed, but yeah, you wouldn't want these people coming in and getting you up in the morning. I absolutely hate them.
R: You don't have any trust in them really?
I: I think my personal carer tries really, really hard. And she does often do I would say above and beyond but I would still say that they're not trained to cope with something as complex as MND I mean writing every morning (name of participant) seems fine, nothing else required. I mean a friend of mine wants me to write and article for the times or the telegraph called '(name of participant) seems fine, nothing else required' she's a doctor. Because she thinks it would make fantastic reading.
R:It's actually something that a lot of people have brought up in interviews; it seems to be a common problem. It seems to be big issue.
I: Community care? They're rubbish, and yet they are very poorly paid, and we have to listen to that. I mean do I really want to listen to that? I've not had a pay rise in two years, petrol has gone up, should I have to listen to that every morning? I've had an argument with my carer this morning and it was apparent she had been discussing my son with her husband so I told her that I didn't like that and she was saying well I was saying nice things about him. I said you shouldn't have even been talking about him, she said well he doesn't know where he lives. I said he does know where he lives because you told me that your husband brought you round the night before you started working here to check out where I live. She said well he doesn't know him, I said you shouldn't have even been talking about him, should she?
I mean if she had said I've been to a clients house and the son is absolutely amazing that is one thing, but her words I've been telling (name of carer's husband) how wonderful (name of son) is. Now both (names of children) find the carers coming in the morning very intrusive. Particularly when one morning (name of carer) went into her bedroom and switched her light off and told me she had switched (name of daughter's) light off and she was saving me electricity. Now would you have liked that at 24?
R: Not really.
I: That's how intrusive it really is. Now everyday she asks me what are we doing today. Well, you know it's absolutely none of your business cause you feel like your home is totally invaded and I suppose we were quite private people before and now we feel very exposed. Now I don't mind, I'm sort of living with the exposure but I don't think my children should have to, I think its bad enough for them already but then to have that sort of invasion is not what they need is it?
R: Do you feel that they get support from anywhere your children?
I: Well, no we try and support each other. Erm, no they've been offered support.
R: Do you think there is a need for that?
I: Well, I think it would be nice if it was offered. I mean my son certainly wouldn't take up the offer I think (name of daughter) would have done but she lives in a different area. Erm, I asked Ann to find out about respite in (name of city) but she never did. Because I think it would have been nice to have stayed in (city) and name of husband could have stayed with my daughter. She said well I am meeting up with a colleague from (name of area) tomorrow Ill get back to you; she never got back to me. I mean suspect there isn't an answer but I think it would have been nice it people get back to you.

R: So you feel that you're left dangling a lot of the time?
I: Yeah, I don't feel that they see things through. I mean I've no idea but I can't believe that they're that busy. I might be wrong but I'd like to be convinced that they're really run of their feet. I mean I make it very easy for them, they don't even have to speak to me they can email but when (name of specialist nurse) says I didn't even dare mention the wheelchair in the email. You know, I mean how big is she?
R: Erm, I think probably my last question is your thoughts for the future and your priorities now.
I:Well, I think it's very frightening and you hope that when things are really bad this team are going to come up with something but I haven't got a lot of faith in them nobody's told me about what they will do. I mean I did say to (name of Association care co-ordinator)I don't know what (name of specialist nurse) does because we've never been told, I mean we're told they're specialist nurses but why didn't they give us we get some information about this is what we do and this is not what we do. Erm because I don't know. I mean I was a specialist nurse and I made it very clear to people this is what I did and this is what I will do and this is not, and these are things I can't do. I don't know what they'll do so I'm very frightened about the future. I have got a fantastic GP and he comes and visits regularly and I know I am very lucky to get that visit. But he's never seen a case of MND before erm so he's there for me and he there when it comes to medication and when I say to him I am frightened about the future he'll say well lets talk about what you are frightened about well I spose the next thing I'm suppose I'm frightened about is that I'm able to transfer and then that will go and I will be in a hoist and then obviously you worry about speech and swallowing and that is massive an the guy that I am emailing has lost his speech and he's had to be peg fed and that's really worrying and I was going to write a living will but I've decided with my GP now that there's no point really it'll if I wrote a living will now you might want to change your mind, cause this guy decided he wasn't going to be peg fed and then his family have put pressure on him to have a peg put in, so yeah I think my other biggest worry is if anything else happens to my husbands' health I mean his back is really, really bad at the moment and if his back goes then I've really had it. I mean I spose lots of people don't have husbands do they, there must be people on their own with MND and I can't imagine what that must be like, but its what you're used to and I spose I cam from, you know prior to being ill I was one of the luckiest people, I don't want to say the luckiest people but I was in a very fortunate position, cause I was very fit and well, I had a lovely job, I've got a husband who I absolutely adore, I've got two wonderful children. You know, I was looking forward to this fantastic retirement that we had planned so much and all that's just been taken away and even my husband says he can't bear now when people you know in his job, now when people come in and tell him say we're going to Spain next week and then we're going to New Zealand to see the grandchildren. You know, last week it was half term, all, we've got lots of friends who are teachers and my sister works in school and everybody was doing something that was absolutely fantastic you know, its very hard, sometimes I can't bear to look at people walking down the street. Just when I see people walking I just want to say to them just don't ever take it for granted. I just had no idea, I had no understanding and that's perhaps what wrong with everybody else that until you lose your mobility it's very difficult to understand how that impacts. You know, people see me with a walking frame well my friends do and they see me sat here and they go away and they say oh (name) you seem fantastic look really, really well, and they see you with a walking frame but what they don't understand is that when you are holding onto that walking frame you can't do anything else, I can't open a drawer, I can't get any of my clothes out of the wardrobe, erm you know, erm, yeah the future. One of the things that I think about, one of the unfortunate things with this illness is that you don't get a day off. I mean I know somebody whose currently got terminal breast cancer and she's had some really good periods, she's had some rotten periods and I would say her rotten periods are far worse than me, than mine when she's not been able to lift her head off the pillow and she's been vomiting but in between they've had holidays abroad, you know she went on a walking holiday. I've got a friend with non-Hodgkin's lymphoma and she says when she was having chemotherapy you know she says she was really off her perch but in between, but with MND you never get a day off and in fact all you get is a

deterioration and I can measure the deterioration weekly, other people won't notice it but every week I notice there's something else that I can't do that I could do last week. I mean one on the problems now is eating at night I can't cut up food at night almost to the point I've got two big events on in July and I'm almost worrying about what will be on the menu cause if it something that needs cutting up I'm not going to be able to and I find that quite hard. So..

R: Do you feel you are getting the information that you need for the decisions that you need to make?

I: Erm, do I feel that I get information? I spose no, because nobody's talking about, when I ask them about the swallowing and the speech they say well don't go there, you know we are not going there yet. So then I just think well just blank that out. No because Id really rather see action now, I think its worrying when you think about the future, you know a bit like the respite, Id like to see some action now. If (name of specialist nurse) had said the hospital will have finished its refurbishments whenever and then we maybe able to plan some, so getting back to the respite, she gave me somewhere else for the respite, fully booked.

R: So you're back to square one?

I: How can you not have planned respite? I mean the lady at (name of home) said well you can ring up nearer the time but my husband needed to go away and make plans well he had to go away and you can't just ring up a few days before cause you need to put things in place and we did put things in place but we put it all in place ourselves and as it happens it was disastrous. I feel let down over that and I feel that I've let (name of husband down). I mean its bad enough for him to have to cope with but then when there aren't even services to support you. I mean (name of Association care co-ordinator)said she would like to meet him for a coffee, He said the last thing he feels like doing is talking to (name of Association care co-ordinator)about MND, if he wants to go out he doesn't want to go and talk to (name of Association care co-ordinator)about MND he is absolutely sick of it he is absolutely sick of the word MND. If he wants to go out he wants to meet his friends. She says I think it would do him good, she hasn't got a clue. I mean she actually suggested that he went on a training day for health professionals, She thought it would do him good, I mean in all fairness if he is a carer of someone with MND does he want to go on a training day for health professionals? It would be absolutely cruel wouldn't it I mean he would be in a completely different position to the people in that room and if they're talking some of the CRAP that they talk does he want to be in a room with health professionals and that's how strongly he feels about it. He says they've no idea and I don't know who it was who said they are passionate about MND it was either (name of specialist nurse) or (name of association care-cordinator), and the other day he said he would like to see their definition of passionate cause he hasn't yet seen any passion, now you know we might think we are being hypercritical and I feel saddened that I've worked for the nhs and social care for thirty years and (name of husband) has I think we both feel very, very let down by the services, and to say that it is a specialist centre I think it has a long way to go. I'm not saying it's totally their fault but somehow and perhaps they are working and I'm sure that (name of Association care co-ordinator) does work very hard at promoting MND but she has a long way to go. It must be very hard for you sat there.

R: No you've said a lot of useful and interesting things and it's been really good. I don't know if you have anything you'd like to add.

I: No I just feel that sometimes I think they're too many people involved and you get information overload but it's not information I want its action. You know I'm just not very sure I don't if I've just got unrealistic expectations. My GP says I've got unrealistic expectations this is the NHS for you.

R: Sadly that s part of it,

I: They must be spending a lot of money on that team. A lot of money and I know that MND is not as well funded as cancer and it makes me very angry that, its not high profile and I know cause of the numbers its not high profile like breast cancer and it angers me so much cause like every magazine you read, you know its about breast cancer which is funny because I always thought Id get breast cancer, only because my grandmother died of breast cancer, my paternal grandmother which doesn't necessarily put me at risk but she died at 52, I just feel that cancer gets such a high profile

and everything is about breast cancer and that's fantastic and I've got friends who have breast cancer but like my husband says it needs somebody really high profile tog et MND like a member of the royal family,
R: Some celebrity.
I: Well, we've had celebrities haven't we? You know, and I worked for Leonard Cheshire and he died of it and did you know Jill Tweedy she was a really fantastic journalist in the Guardian and she committed suicide and I can understand where that came from, I used to have the article that she wrote but I lost it, I used to use it as a teaching thing for Leonard Cheshire you know I can sort of understand why she did that because the future must have been so frightening. I am now at the point where I don't want to continue like this and the only reason I do is for the children, I just feel its an existence and I know some people say well it's a nice existence and it's a lot nicer than some people's but…
R: It doesn't help does it?
I: No, and I think that you know watching your husband and your children, I mean my son has been absolutely amazing, but Id don't thing he should have been put through that because the services couldn't support us over the weekend and (name of carer) who is my private carer put a lot of extra hours in and my son, but people say things like well your family should be there. No I don't think 27 year old boys should have to do what he had to do this weekend, and it puts him in a very unhappy place, he's already in a very unhappy place because he sees his mum deteriorate and for him to cope as well with personal care. It shouldn't be necessary, not when we've got specialist centres.
R: Thanks, it's been really useful.

ID218

Present: Spouse/Research Assistant

S: So right first symptoms were probably the summer of 2005, and we had been, we had gone to, we had got a time share in the lake district, because we like walking and we had just gone up as usual, and we were doing a walk that we had done before, and the ground is very uneven and there is lots of sort of muddy areas and you have to sort of move from stone to stone to sort of, you know to avoid getting wet, (Name of patient) was just taking an age to do it, and I thought, god what is the matter with her today, she had to use the walking poles that we had, and erm I mean it was eight mile walk, and we completed it, but looking back on it that was probably the first time I noticed anything wrong, she didn't have the same agility and ability to walk over rough terrain, we completed the walk and went to the pub and everything and came back, and I didn't think anything else about it because she seemed to be alright, and then she was tripping up a bit, she had been wearing some shoes without backs, so I said put your feet up, its those stupid shoes, stop wearing them that was in the summer and then we did another walk in October with the children that was quite a strenuous walk, and she had fallen once or twice or stumbled once or twice on that walk and it had obviously been heavy going for her, and then we were taking my daughter back to university, and we dropped (Name of patient) off at the lights, the traffic lights had stopped, so we dropped her off, because she wanted to catch the bus into the centre of town to do some shopping and when I saw her walking across the traffic lights I thought, god, there is definitely something wrong here, she had been going to the gymn in the meantime because she thought it was because her legs were week, and one thing and another so I examined her and there was something wrong, she had got increased tone in her legs and weakness, and erm, so I arranged for one of my colleagues to refer her to one of the local neurologists, who examined her and said yes you know, there is definitely something wrong, and likeliest explanation, is that you have perhaps got a tumour in your spine that is pressing on your spinal cord you will need to come into hospital, so that was obviously a big blow, you know, we went through a couple of admissions to hospital and various investigations they didn't find really anything, they did scans and one thing and another, they didn't seem to find anything, then they sent her for a some EMG studies, and it was, funnily enough it was the lady in one of the beds opposite she was a right know-all, and she said to (Name of patient), 'oh you know the reason why they are sending you for that, they think you have motor neurone disease', well that

was the first time it had actually entered my head that but it sort of spooked me, and when I thought about it I thought yeah, it could be Motor neurone disease, and then that was sort of inconclusive, and we had a holiday booked to go to Cyprus at that time when (Name of patient) was in hospital, and she said to the consultant you know we have got this holiday coming up in a few months, well in a few weeks, I think it was, five weeks, six weeks or something like that, he said 'oh you can't possibly go on holiday you are seriously ill, and I think that was the first time it really hit (Name of patient), that and the woman in the bed opposite saying they think you have got motor neurone disease, and at that point nobody said anything and on the ward round where that had happened where he had said that no you can't possibly go you are seriously ill, it was on a ward round where there were lots of other doctors and things , and she started crying and he just waltzed off, she had thought I am sure he will come back and see me at the end and perhaps expand on that a little bit, but no he didn't he just went off the ward, and she was still crying and one of the nurses came up and said are you alright and she said no, I am really worried and she said 'well you have every reason to be worried', and it was just left like that really, then we you know, we saw him in out patients and he arranged some more investigations, repeated the EMG studies and they were still inconclusive, and then we had another appointment to go back and he said well nothing shown up and that's good news because whatever it is isn't revealing itself, so count that as good news, so your hopes were sort of a bit up and a bit down, it could be this, it could be that, its not definitely that, there was a long period, it must have been about twelve months or more when we had considerable uncertainty, and then it was just around (Name of patient)'s birthday, I was at work and I was stabbed, I was stabbed by a patient at work, and you know, we had to have the police and everything, that was on the Friday and on the following Monday, (Name of patient) had an appointment at the hospital to see the neurologist I had to go to the police station for some photographs of my injuries, because they were going to prosecute the lady that stabbed me so I couldn't go to out patients and (Name of patient) went with (Name of daughter) that's our daughter, and it was handled really badly, I think, more or less the registrar saw her and said you know, 'how's your walking?' and she said 'well it's a bit worse', he said 'oh I will just go and have a word with the consultant' and the consultant came in and said fairly bluntly I think, without asking who (Name of daughter) was, you know, just this young girl in the room with (Name of patient) I think 'well I think, we are probably looking at primary lateral sclerosis, that's motor neurone disease, you might live five to seven years and you know, we will just keep and eye on you' and that was it, and we were absolutely appalled with the way the news was broken, and at that point we decided that you know, we had had enough of that particular person, that particular consultant and because it wasn't absolutely clear, we decided we would go to the neurology centre at (Name of place), so we went to (Name of other specialist centre), and the consultant there was probably much more understanding and handled it better, repeated the studies, again it wasn't conclusive, he repeated them a second time and then it was conclusive and we got the diagnosis, so it was a fairly long, prolonged drawn out period of uncertainty and worry really, at that point (Name of patient) was able to walk with assistance with a stick, and what have you, then obviously in the intervening period, the mobility has deteriorated, I mean she can't walk anymore, she can't get out of her chair, and erm, we have to have carers in the house, and now its affecting her upper limbs, and she can't write, she can't use a computer the same, she can't feed herself now because she is so weak she can't lift her arms up, and she has had various adaptations, and we are having various technology, adaptations to things like bed control, the computer, there is machine coming which is going to help with the feeding, the whole thing is absolutely ghastly, I mean it is just terrible, its terrible because at the end of all this, you just know that there isn't any, there is no hope, there is no sort of period of remission like there is multiple sclerosis, there is relapse and remission, so you get a bit of time off sort of thing, but with this there isn't, when all this at first began, I actually thought myself it might be MS now looking back on it I would give anything for it MS and it not motor neurone disease, because it just feels all the time that you are just battling against this constant deterioration, and you know it doesn't matter what you do and how much you battle, ultimately there isn't, there is nothing, there is no future

really, so from the point of view of the caring side of things, I mean we have got a care agency that comes in the mornings to get (Name of patient) up and they come in one night a week to put her to bed and they come one Saturday morning in four to get her up but the rest of the time its me, it is really hard work, I think, its hard work, physically its demanding, emotionally its demanding, and I am still working part time, yeah I do find it hard going, I think you feel fairly isolated, and you feel fairly lonely in it really, I mean I do get support from the family, I mean the kids you can't expect them to come home all the time, but they do come home and they are helpful and (Name of patient)'s sister is helpful, but I do find it pretty hard going, and I think the other thing as well is the number of people involved in the case, (Name of patient) worked out there was about thirty five people she was in contact with, there is various social workers, the local social worker seems to change pretty regularly, because if you don't ring them up and make contact, they automatically seem to discharge you and then you are reallocated, this is on the basis that social workers get bogged down with one particular person so they sort of try and rotate it, but it means that every time, if you have not been in contact for say I think its two months or three months and then you ring them up, you are allocated to someone else who then you have to go through the whole story right from the beginning, so that's a big problem, so there is the social worker, there's our GP, there's the district nurses, there's the motor neurone disease nurse, the nurse from the hospice, the occupational therapist, private physiotherapist, there's the physiotherapist from the NHS, who else is there? the lady from technology, the speech therapist, the guy that made the splints for the legs, another chap that has come from some advanced technology system, people who deliver the hospital beds, the people who sort out inco pads as I said I think it was about thirty five and it is difficult keeping tabs on that really, so I mean it is the hardest job I have ever done, I'll tell you, so do you want to prompt me a bit? I don't think the services are integrated, that's the other thing, I mean the Motor neurone disease nurse, I was under the impression she would have more of a role, trying to integrate and help smooth the passage, and make things run smoother for the patient, and I am not sure that that happens, one of the other things is, just going back to the diagnosis, after we had been diagnosed at (Name of place), we knew that we would need probably support from the MND nurses, so they suggested going back to (Name of place), to (Name of specialist centre) rather, to see the consultant at (Name of specialist centre), that was interested, particularly in MND so he saw us really as a formality I think just to sort of say this is the diagnosis, so he did that, he saw (Name of patient), he examined her, he had looked at the results from (Name of place), and at that first visit, the first time we ever went to (Name of specialist centre) to see the neurologist, he said at the end of that consultation 'well I won't be seeing you again', and then we saw an occupational therapist and a speech therapist, both of them, no sorry a physiotherapist and a speech therapist, both of them said 'right, well, you won't be seeing us again either', this is a specialist clinic for people with Motor neurone disease, area with, hospital with special interest, its one of the things that if you go on the web site about it, it is a designated centre, so you get the impression that all they are really interested in is nailing the diagnosis and then referring you off somewhere else and not having any ongoing contact apart from the Motor Neurone Disease nurse, so I think that's a fairly, I felt very disappointed by that, because there was not sort of this is a specialist centre and there is going to be a specialist input, all we are going to do is refer you for speech therapy locally, we are not going arrange any physiotherapy because there isn't any, in fact the physio therapist at (Name of specialist centre) suggested we pay for private neuro physio which we do, but there will be lots of people that can't afford to do that, so there is no specialist neuro physio service for people with motor neurone disease, and you would think that a centre like (Name of specialist centre), if it is a specialist centre with a special interest in research you would think, or you would hope that they would have some special expertise that could be tapped into from the point of view of physio and there isn't.
(Researcher speaks)
S: I don't think at any point anybody has, certainly not discussed with me, I think (name) the motor neurone disease nurse, might have answered one of (Name of patient)'s questions, because she said, she told me she had asked her how was she likely to die, but nobody has ever discussed the

progress of the disease, how it might affect you in the future or what is likely to happen in the future, nobody has ever said that if somebody has come to see (Name of patient) and she has said this is a bit weak, she has said that is probably the motor neurone disease, they have never sort of said, right at the beginning, I am not sure if that is a good or a bad thing, I am not sure if you knew if you had that information right at the beginning it would necessarily be such a good idea, it would be a downer, I think the general public, I think the general public know what motor neurone disease is, do you I mean we knew because (Name of patient)'s a nurse, you know what I do, we knew but I don't think anybody discussed it formally, so there was very little information, it was taken as a given that you knew what was going to happen and I know dying and mode of dying, and what's likely to happen is something that bothers you know it (Name of patient) a lot, especially as she becomes more disabled and she can't use her hands, we have another contact who is a lot worse that (Name of patient), who has motor neurone disease and we get emails from him and we know what he is going through, and the prospect of all of that is awful really awful, so the simple answer is no I don't think it was ever formally discussed

Researcher speaks

S:I think there is a need for information but it is probably is the sort of thing that needs to be drip fed, because obviously if you have just had a diagnosis like that, I don't think you necessarily want to know the very worst scenario right at the beginning, I am not sure, we had or I had a very good thing sent from the MND association, I think that was a booklet specifically for GPs and that was excellent I thought it was excellent, because it was how the primary care team could work and co-ordinate and what to expect and one thing and another, I think that was good but I don't know, I think (Name of patient) had some information from them as well but nobody that we have actually come into contact with have given a lot of information, I think that side of it was good from the association not the magazine, the actual specific literature that they sent out and they have a website which is, I've looked on that and I think that was reasonable well about discussing diagnosis, and they have a little bit about research and stuff like that , I mean that's another thing when we were there, the first time when we went to that clinic in (Name of specialist centre), we saw a research nurse, that said you know would you be interested in taking part in research, have your blood taken and all this type of thing and we said yeah, you know (Name of patient)'s done work for her Msc, you know we are both university educated, we are very happy to do that, and I think it was months, and months, months and months nothing had happened, there was no contact, and we rang up about it and nobody seemed to know anything about it, I think finally, one of the other MND nurses came got in touch, you should this should have been followed up, and it hasn't been, you know, we will come and take blood and they did do that, but it wasn't impressive that side of it and if it is a specialist centre, you would think that there would be more emphasis on that type of thing.

R: Alongside that, do you think there is a need for emotional support or support with training obviously there is a lot of use with equipment and things like that?

S: I think the occupational therapist, although we got off to a bit of a rocky start with her, you know, when she first came, we were thinking of buying a stair lift, because (Name of patient) was walking at that time and she was finding it difficult going up and downstairs, she said 'well you won't get your moneys worth out of that', you know, ' we are not funding that and you won't get your moneys worth', which is a pretty depressing thing for somebody to tell you, and in fact we have had our moneys worth out of it, but after that rocky start she has been pretty good, and if (Name of patient) has rung up and said she is having difficulty with this, that or the other, she has come a long, she's assessed her, and for instance you know, we have got this hoist frame thing that we have got , we have got two of them, one upstairs and one downstairs, and she has shown us how to use it and she has shown the carers how to use it, so that was good she has also arranged for this firm that erm manufacture the equipment to help feeding, she arranged for them to come and give a demonstration for (Name of patient) to try it out and then said she would try and get funding, and has got funding, and has got the equipment and in fact it has been in the garage now for two weeks

waiting for someone to come and assemble it and put it into action, so I think the OT has been fairly good, we've recently had a physiotherapist organised, you know an NHS physio therapist who has been excellent, but obviously she can't come that often because she's, I think the unit is understaffed and they haven't got enough staff to sort of see everybody with neurological problems in the area, but she has been excellent as well, and our private neuro physio she is excellent, so those three have been really, really good, we have got a lot of reservations about the care agency but erm, I mean the one thing about that is it is the same person that comes all the time, which is quite good but she is of limited ability really I think for instance this morning (Name of patient) has been having lots of trouble with her catheter, and yesterday, she has got a superpubic catheter, yesterday the district nurses came, because over the last, it has got to be changed every sort of eight weeks, but over the last week, over the weekend it bypassed practically everyday, so she was wet through, so we spoke to the district nurses and they came yesterday and changed it, and then this morning after I had gone to work, I get up in the morning, give her her breakfast and everything, sit on the edge of her bed and give her her breakfast, then I put her back to bed because I leave quite early and the carer doesn't come till later on, and then after I had left, the catheter bypassed and it bypassed three times , so the bed was absolutely wet through and the carer really can't sort of thing out, she got (Name of patient) out of bed and bathed her but she didn't really sort of take the sheets off the bed and all that sort of thing, so we have got some reservations about her initiative really, I suppose a lot of these care agencies don't pay a lot of money, and you know if you pay peanuts you get monkeys really, so it is the quality of carers, I mean the fact she turns up, she knows the routine, there is continuity from that point of view but she lacks initiative, and erm, I think the training is not all it might be.

R: Do you think her knowledge of MND..?

S: Well it was totally non-existent when she came, I don't really thinks she understands, because she said to (Name of patient), things like 'oh try, try and move your leg, it is mind over matter' and things like that, which is not what you want to hear really, so no I don't think her training is particularly good and her knowledge is non-existentreally.

R: Was it easy to set up the care package in the first place?

S: Yeah, (Name of patient) spoke to the social worker and explained the situation, they came a long and there was an assessment done and it did sort of happen reasonably quickly that and was done fairly quickly that, and since then we have increased the amount because originally, yeah we have increased it because it was just five mornings a week and then we have had, an extra coming at four o'clock on a Tuesday, because I work late on a Tuesday so the same carer comes at four o'clock on a tuesday afternoon to put her to bed so I can get her up when I get back from work, and the one Saturday morning, a month she comes and also they have arranged for her to come to put her to bed on a Thursday night so I can go out if I want but the last couple of months (Name of patient) hasn't been that well, so I haven't gone so it has been increased slightly since then, yeah.

R: In terms of respite has that been difficult?

S: Well, respite is a really big problem, because we spoke to the MND nurse about this and she suggested somewhere in (Name of specialist centre) which sounded really good, and erm we rang up and they said 'oh yes we do take people for respite but it depends whether we have a bed, so the best thing to do is to ring up a week in advance and if we have a bed you can have it', but I couldn't book a holiday to he off chance there might be a bed or there might not be a bed and if there wasn't a bed what would happen, so that's really been hopeless, absolutely hopeless. I think that is a big area, I think (Name of hospice) at one time were supposed to be having some designated beds they weren't taken up, you know people didn't take it up but I suspect that's because people didn't know about it, I have actually got a patient with an elderly relative and she was telling me she wanted to go to her daughters wedding and she didn't know till two days before that she had definitely got a place for her mum to go before she went to (Name of place), for which is just useless, useless so respite is an area which needs to be looked at I think, especially for people

with a chronic condition like this, its poor, very poor so we have never found anywhere that will guarantee a bed for a specific week in advance.
R: Do you feel you get support emotionally from the services?
S: You mean has anyone ever said, no, is the answer to that I think right from the very first time we had contact with the organiser, the MND organiser she said how are you and that was it basically, I don't think I am particularly good at opening up though, and I would hate to go to some local, sort of meeting of MND carers and you know, sort of sit there moaning, that's not, you know that isn't going to be helpful to me, and we have never got involved in the local group for a variety of reasons, (Name of patient) didn't want to because she didn't want to go there and see people that were worse than her or hear horror stories to make her even more apprehensive, and I didn't really want to go and get involved with people that might be patients you know, so that was difficult, so no I don't get any emotional support, I get it, I mean the kids, particularly my daughter she is good, and my son practically, from the point of view of coming home because he is only in (Name of place) he comes home a lot of weekends and he gives sort of practical help, you know, he will sort of go and do bits of shopping and cook meals, he is very good and my daughter she is good but she is a lot further away, I mean she comes home when she can so from that point of view, yes, I get some support from them, but its difficult from a certain extent I feel that I have got a balancing act because I don't want to give up work, I only work part time, when (Name of patient) got the diagnosis I initially reduced from five days of week to four, and then as things have progressed I reduced to half time, so I just work all day Monday, Wednesday morning and part of Tuesday so that is half time, and that has been great doing that and I love going to work because I get friendship, you know I have known my colleagues a long time, I find I really like going to work because it stops me thinking about Motor neurone disease and I get quite a bit of emotional support from them if I want it but I don't talk about it a lot at work because I don't want to end up being a MND carer bore, so I don't talk to people a lot about it because they don't want to hear it all the time, and if people ask have you had a nice weekend, well, I am just non-committal about it, because most of the weekends, well all the weekends and the time I am not at work its just domestic duties and caring, there isn't anything else, we used to go walking a lot, we used to like go to the cinema and the theatre although we occasionally go to the theatre its not a relaxing it can't be a relaxing spontaneous event, because there is such planning that has to go into it, about getting the seats, where you are going to park, is the catheter going to be alright, all the things you have got to take, so its not the same, and I get fed up of thinking about Motor Neurone Disease because you live it, eat it breathe it and everyday it is in front of you and you can see it is getting worse and I think I remember saying this to you last time, one of the things I really look forward to is being asleep, at least if you are asleep you don't have to think about it.
R: So is that's your kind of way of relaxation, is working?
S: I suppose it is, yeah, I suppose it is, I've always liked my job, I probably like it out of proportion now, because I do actually like going to work, because you know, there is reception staff, there is a bit of, you know what it is like at work, you have jokes and things to talk about, banter that a good word, gossip, so from that point of view I do like it and (Name of patient) misses that about not being at work there isn't any of that.
R: So it has affected your social life?

S:This? I don't have a social life full stop, I mean we are supposed to be, we have been invited to a sixtieth birthday party this weekend, just round the corner, the people are having a marquee in the garden, it should be accessible but, (Name of patient) will meet a lot of people there that she hasn't seen for a long time, she feels uncomfortable about being in the wheelchair, about difficulty eating in a public place because she can't lift her glass up so she has to have a straw, she can't lift food up, and the worry about the catheter, so going out jointly, its very, you are on edge the whole time, if you go out to something like that and as far as going out, and as I say occasionally we have been to the theatre, but it is very infrequent, I mean I don't have a social life full stop, friends from

work will say do you want to go out for a drink, would you like to meet us for a drink, and I have to say well maybe on Thursday, we have a carer that comes and puts (Name of patient) to bed, ok shall we fix it up for this Thursday or whatever Thursday and then something will crop up, like (Name of patient) won't feel well, or the catheter wont be working or something will happen , and you know, so I end up not going and in the end its just easier to say I cant go rather than keep having to explaining it, in the end if you are not working at a friendship you tend to lose your friends a little bit because you can't get involved in the things that you would previously have been involved in with them, so I think you end up more isolated in a way,

R: I think just going back about the MDT team, how do you see it works together really and do you feel there is good communication between all the different agencies?

S: Well, I know the MND nurse writes to the GP when she has been she will send a letter to him and I know that she has helped (Name of patient) or helped with appointments for the sort of splints for the legs and the assistive technology, but I think some of the time it has been fairly, I think there has been some delays, especially with the assisted technology, so she has done that, I don't think the OT writes to the GP, the nurse from the hospice, the palliative care nurse, she has been very good, she comes and sees (Name of patient), she comes when she says she will, she keeps her finger on the pulse, she will phone up and find out how things are, and erm she has been good, because (Name of patient) has had a lot of problems with pain in her legs, and they really have tried a lot of different things, and they have actually brought the consultant from the hospice here to the house to visit (Name of patient) to discuss other options, so they have been really good, they have probably been better than the MND nurses really, because when (Name of patient) first mentioned pain to them they said 'it's not a feature of MND, not a feature' and that was more or less it, I think they spoke to the consultant at (Name of specialist centre) who said oh try this, try that, but there wasn't a lot of interest in it really, whereas the palliative care team locally have been pretty good,

R: What have they been able to do?

S: Well they have tried different types of medications and they have actually arranged acupuncture, and I think they have got it a bit better under control, so yeah they were good and when we, (Name of patient) spoke to them about it, they said they had several referrals from people with MND and pain is a feature, so makes you wonder, I think another thing there is no feedback on any research that is going on, I don't think, there was recently something about the use of lithium with MND, never heard anything much about that, it would be nice to know sort of what is going on really.

R: But yeah I think the palliative care team has been good.

S: So do you think having that link with the hospice has been good?

R: I think, we went to the hospice for some aromatherapy, (Name of patient) did, that was organised by the MND nurse, but and she referred us to the palliative care nurse because of the pain, that has that has been good, they have been good, and I think that there will be a possibility that (Name of patient) might go in there for some, for a short say, at some stage in the future, I think she would be happy about that now, having met the team,

R: Do you think that is a good way of doing it to meet them earlier on?

S: Definitely, definitely, so that is a success, that bit.

R: Just going back to social services as well, have you had any issues with adaptations or benefits, or things like that?

S: We have done all, any adaptations that would have been done, we did ourselves, we paid for ourselves, because we had an en-suite upstairs and we have that altered into a wet room so we paid for that ourselves, and we also had the stair lifts put in, so they didn't need to get involved with alterations and adaptations really, as far as benefits are concerned (Name of patient) because used to work in social services and health she knew about benefits, so she had applied for disability living allowance, and that went through without any involvement of any social worker,

R: So that has been quite straight forward?

S: Yes, and we got a blue badge and we have just had it renewed, they sent a form saying she would have to have passport sized photos, and she would have to sign on the back , and everything, of

course its difficult getting those photos, you can't go into one of those booths if you can't transfer from a wheel chair, so in the end we got round it by getting our niece to sort of print some off the computer that she had some old photos of (Name of patient) and I wrote a letter saying she wasn't able to do that, and they sorted that out pretty quickly even though we hadn't followed the rules, so that was alright, the only issue with social services, is this business of you don't build up a relationship with a social worker, because it seems if you are not constantly in contact with them, which as a responsible adult, you know, you are trying to sort things out ourselves we are not always running to people, you know we are trying to be independent and use our own initiative, we are not always running and ringing them up but if you don't do that you get allocated to somebody else, and they'll perhaps, they will maybe speak to you once on the phone and that's it and then you have to go through the rigmarole all again,
R: So quite hands off really?
S: Yeah I think so, its like well we will deal with this and if you don't contact us within so many days your off, onto somebody else so I don't think that's so good, not for this type of condition anyway, you don't build up any relationship they don't really know what's going on.
R: No consistency then?
S: None at all.
R: I think one of the things you mentioned was that although you have a lot of medical knowledge, you felt there wasn't enough explanation of who does what?
S: I know what an occupational therapist is but if you as an ordinary lay person, what would you think an Occupational Therapist does? Something to do with, at the work place, you wouldn't know who was responsible for what and there is often a blurring as to who does what, for instance you know, physiotherapists might supply you with walking aids initially, but then later on it might be an occupational therapist that does things like sort out your lifting frame, so I think that side of it, who does what, organises this particular service, that particular service for a lay person, must be so confusing, I mean if they are dealing with OTs, physios, social services, benefits, I just I don't know how they do it, I mean we are pretty ofay with it so it is not such a big problem, but I could see it being a huge problem for somebody that didn't know anything about it.
R: And do you feel that you and (Name of patient) have had do a lot of chasing up things really?
S: Yeah well (Name of patient) has done a lot of it. Fighting really, definitely we had a lot of trouble with the electrical wheelchair to start of with, you know getting it, because it kept faulting, people having to come back and take it away and then they didn't know, we would ring up to see where it was and they said well 'Its still at your house isn't it?' 'No its not. You have got it.' So that wasn't that impressive, so there has to be a lot of phoning up, and you feel sometimes, that there is nobody on your side and you are battling on your own, I can see that really (interruption) I just feel that it needs somebody maybe that is going to co-ordinate the whole like the conductor in an orchestra, because there are so many different bits that impinge on the carer and the patient, that you know (Name of patient) is articulate and she has sorted a lot out because she is able to speak and she has been able to use the phone until latterly, you know recently, and she has been able to sort that out and because she has had jobs in health and social services, she has been able to navigate the system, but if you couldn't, spose you were social class five, I am not being derogatory about it but if you have limited understanding of the system, it would just be a total nightmare, I don't know how you would get anything done, really.
R: You don't think there is one person you can go to sort it out for you?
S: There isn't, definitely not, there isn't, no, not if you have got all these people involved, you know all this technology, speech therapy, OT, physio, social worker, social services, benefits, transport, mobility, motability, you know all that sort of thing, its just shocking, I don't know how you would do it, I really don't.
R: I think, you have mentioned the MND association, have you found them useful in any other ways?
S: Apart from the information? I have to say that the local branch has contributed towards, they sent us some money at Christmas, that was a nice Christmas present for (Name of patient), and that was

unasked for, and they have also contributed some money towards, I think was it the stair lift? And I mean that is fantastic, if I had more time I would do some fundraising but I just haven't got the time, er for them, but I do think that has been good, that is the local branch and as I say that the information that we have had you know for GPs and I think the information booklet they sent initially for (Name of patient) was pretty good, one of things I don't like and this is just the personal thing, was the, if you read thumbprint there are all these sort of stories that I suppose are intended to be uplifting, its all this business of our journey and living with MND it makes it sound all happy clappy and you know wonderful and its crap basically and I hate that part of it, I suppose it is because, I don't know if it is because they are tying to buoy people up or boost them, but it has just opposite effect on me I am afraid, they all raving Christians, and its all wonderful and you know, we are battling with this and fighting bravely, and its just crap, it is, I think so, I hate that side of it, I mean (Name of patient) did see an article there was a lady that had written in, I don't know if it was in the letters page, and she had been talking about pain in her legs similar to (Name of patient) had and she said that her GP or somebody had prescribed something which had made it much, much better, and (Name of patient) actually rang the thumbprint magazine, and I think somebody from MND contacted the lady that had sent the letter and she emailed (Name of patient) with the details of what it was and in fact it was something that (Name of patient) was already having, but I thought that was good, I thought that was pretty impressive the way they had done that, I think it is such a shame that it doesn't have a bigger profile really, because I think it would get a lot more funding then, wouldn't it?

R: Yeah definitely, compared to cancer,

S: You mention breast cancer particularly and people are there,

R: Yeah, hot topic.

S: Yeah, and yet really with, I am not sort of minimising it, but often the prognosis in general now, since I started training, I qualified in 1974, well I mean breast cancer in 1974 the treatments were pretty basic, there has been such advances now, people live for, good healthy lives for twenty five or thirty years if not be completely cured, I mean that it is wonderful, but I think there is room for a bit of extra money to go to MND.

R: And do you feel socially the MND association have helped in anyway?

S: Well I don't get involved in the social events for the reasons I have explained really, and (Name of patient) doesn't want to, and I don't want to sort of, If I am going out, if was going out for a treat, my idea would not be to talk to a lot of people who either have MND or who are looking after people with MND or swapping stories about how awful it is and crying into their beer, I just couldn't stand it, so that isn't the sort of thing I would do I realise there are a lot of nice people who are involved in MND but its just not one of the things I would want to do, I think there are some diseases that have self help groups, that are probably pretty good, but maybe they are not involved or perhaps there isn't such a desperate prognosis attached to it, perhaps that's what makes the difference, like you know say down syndrome support, Ilestomy?? Association and stuff like that, you have got it, it's a problem but it ain't going to carry you off, sort of thing, so maybe that is slightly different, but I think with something like this where you go along, who are either in advanced stages or they are looking after somebody in the advanced stages even worse they have lost their partner and they want to tell you all about that, I think that is not on, I don't want that, and in fact the neurologist, said, be very careful about getting in that type of group because it may not be any help at this stage be of any help, I mean we had already decided that I think, and I would agree with him, I think it is not necessary such a good idea.

R: Do you feel there is a need for emotional psychological support maybe at the time of diagnosis?

S: You mean for the person with the diagnosis?

R: Well either, carer or the person

S: (Name of patient) did have, her GP organised some counselling, that was at the time when the diagnosis wasn't very clear, (Name of patient) had great difficulty coming to terms with deteriorating, failing independence, and having to give up work and having an unknown diagnoses,

so she had quite a lot of sessions of counselling which were very useful, she found them very useful, so I think that, because it is a very major thing in your life, coming to terms with a disease, which it is bad enough coming to terms with a disease which would cause you permanent disability but coming to terms with a disease that's going to cause continuing, worsening disability and ultimate death, in a not very nice way, where you know mentally you are ok but you have got absolutely, are totally imprisoned in your own body and you can't do anything and you are dependent on everybody, coming to terms with some diagnosis like that is earth shattering isn't it, and yes, I think support there for the person with the diagnosis is very important, erm and now, yes I wish I had access to something like that because I don't have anybody to talk to . I mentioned I talk to the children but I feel that I am doing this balancing act where, I don't want to burden them too much with it all, do you understand what I mean? I mean, I don't want them when they are on the phone, I don't want to be recounting a daily list of woes and everything that has gone wrong, so I, I don't want to moan to them and I don't want to moan to them about things that have gone wrong, or how I feel and that I have had a really crap day and I feel absolutely lousy and I don't want to moan to them, so I don't talk to them like that very often, and I don't talk to, I mean I will say to (Name of patient) that I am absolutely pissed off today with this catheter and blah, blah, you know, I mean on Friday, for instance, I will give you an example, last Friday, we had some friends that stayed the whole of last week, at some cottages round the corner, they come fairly regularly and they are pretty helpful, and we had been for the day and we had been out for lunch which is you know, quite a major expedition, and we had had a nice time and we came back and in the car on the way back the catheter bypassed, so (Name of patient) was totally wet through, the car seat was wet through, and you know, you have got to get (Name of patient) out of the car, get her changed, washed then she decided she wanted to go to bed, then you have got to clean the car seat, and all of that, we had a real ding- dong row about everything when I said I am absolutely sick to death of this, you know, and (Name of patient) was going call, to get the social workers to call a case conference, and all the rest of it, and of course I calmed down when I thought about it, and I mean I just needed to vent my anger really and she was the only person there and I felt lousy after I had done, because it is horrid, she is in a very vulnerable position I felt a heel after doing it, she you can't have somebody hanging around in case you want to shoot your mouth off, can you really?

R: But, you don't feel there is much of an outlet really, for you?

S: I mean I have some friends that I talk to, and, but I don't think they really understand, I don't know, you don't understand until you are actually doing it, so and its, you know, if you have been at work, and then you come home and the first thing you open the door and its my catheter has bypassed and this is wrong, that's wrong the others wrong, and you have got get in, sort that out, make tea, clear up, serve tea, clear up afterwards, and then its time to go to bed and then its sort of all that business, getting (Name of patient) comfortable in bed in the right position, putting the catheter bags on and everything, and you know, its, if (Name of patient) has had a bad day she will perhaps cry then and that's a bad time, and then I just feel by that time at night if she is really upset and crying, I just haven't anything left, I just feel totally rung out, I can't cope with that then, and I get a bit brusque about it then, its not quite pull yourself together, I don't mean it like that, but I do get a bit brusque about it, its just really draining, you just don't have a lot left then, bed time, so that is why I look forward to going to sleep.

R: I think my last question, is just about you thoughts for the future and what you see are your priorities at the moment?

S: Right, my big worry is that I will have a health problem, is probably one of my biggest worry, because if I have a health problem and I can't look after (Name of patient) I don't know what will happen, so that is the thing that I really worry about, you know if I had, you know supposing I had a heart attack or I if I was in an accident or if I had my leg in plaster or my arm in plaster, I don't know what I would do really, but if I had something really life threatening or if I died, it would just, it would put a lot of responsibility on the children, and you know, I suppose if I was dead I just wouldn't be here to worry about it but I do worry about that now so that is my main worry, health, so I mean I

try to eat healthily I don't get chance to do a lot of exercise, I mean if (Name of son) is home at the weekends, I will usually walk for the paper on Saturdays and Sundays, but other than that I don't really get chance to do anything and I used to walk a lot, erm so that is the main worry really, and the other worry, is that I don't want it to affect the kids really, I mean I know they are grown up now but I mean, it's a worry for them and it upsets them and it you know, it upsets (Name of patient) that she will probably won't be here to see either of them get married, and she will probably not be here to see either of them have children and all those things you just assume, you know you get to a time in your life, when you know, you have worked hard and you have educated the kids and they are alright and you have a bit of extra time to yourself do all the things you would like to do and you can't do that now, so, I think it is crap really, erm, so yeah that is really the only thing I worry about my health.

R: What do you feel are your priorities at the moment?

S: Priorities?

R: What you feel is important to you right now?

S: In what way?

R: Well, in terms of your life, I guess.

S: Well I feel, I know this sounds horrid, I just feel I am treading water really and running to keep up with everything that has to be done, my priorities, I don't really think, sometimes I think long term, what will it be like when (Name of patient) dies, if I am still alive and (Name of patient) dies, what will it be like, so sometimes spend I spend a bit of time thinking that, and I can't imagine what ti would be like, I just can't imagine it ever happening, you might, you know you can picture yourself, you might picture yourself being married or having children, well I can't picture myself as a widower, so sometimes I think I wonder if that means I am going to die, and then the shit would really hit the fan, so I mean, I don't think too far in advance, I don't have anything much, there isn't anything, I don't look forward to anything except for being asleep, that's awful I know, I look forward to reading, I mean I usually read before I go to sleep at night so I look forward to reading and there have been maybe a couple of programmes on the telly but I don't actually have long term to look forward to, so I just take each day as it comes and its mostly my priorities are about, keeping the house looking nice, making sure we have the correct shopping in, everything sorted out as far as (Name of care) is concerned, and things are in place so that when the carers come in they can do their job and going to work, so basically my priority is keeping going, that's the only priority I have.

R: So I think if there, was any one thing or any things in particular that could really help you with your situation, is there anything?

S: Yes, I think if you had good quality, bookable respite, that would make it so much better because, you could then, you could actually then, have some time away, just a break, I am not talking about, just a week, a weeks break, where you could go away and do what you wanted and relax, and know that the looking after was good quality you are not going to come back to a situation where (Name of patient) is fifteen times worse than before she went in and they haven't done this, they haven't done that and they haven't done the other, if they just had good quality respite, that would improve things no end, and I think perhaps a counselling service, a talking service, talking to somebody who knew what they were on about, at my stage now would probably be a good idea, yeah, because to a certain extent now, I am not frightened, but I mean I know there has been a vast deterioration in the last three months and I keep thinking you know, what's it going to be like in the next three months and the three months after that, erm, I don't know how I will cope, I will cope but I don't know how I will cope, and I am worried, and at work they have said if things get really bad, you can take some extended time off you can do that and come back when things have stabilised but I want to keep going at work, because I like work, so my priorities are keeping going and keeping everything ticking over, and not burdening my children too much they are just building their careers and I don't want it to impinge on them too much,

R: I think that is everything, I don't know if you feel that there is anything we have missed out?

S: I don't think so. I could probably go on all day yacking all day about it now that I think about it.

R: I think there are a lot of pointers there as to how the service can be improved.
S: It's not that I am being critical, unless you get the feedback nothing will ever change.
(Researcher continues)
S: I certainly think the respite, I used to think I could go on without having a break at all, but er I mean we had a week away, last summer, when (Name of patient)'s mobility was a lot better, and taking the car we went to a disabled, an adapted cottage, which was adapted, but you know the beds weren't right and we had to take so much equipment with us, and there was obviously no carer there so everyday I was, you know I was doing the getting up as well as putting to bed, and it wasn't a holiday, I mean it was alright, my daughter went with us and she was a help, and it was nice, I mean we saw her and got out a bit, but just to go away and not have to think catheters, bowels, leg bags, night bags, you know, inco pads, this that and the other, washing, ironing, shopping, cleaning, cooking, all the rest of it, just a week would be a fantastic, you would not want to come back would you, that's the problem, give them a taste of freedom and then they'll be off. I don't mean that, you know what I mean don't you.
R: It just must put a strain on your relationship as well with no break at all.
S: I think that sometimes, I find it particularly when I finish work now, I don't go back to work till Monday, so we have got Thursday, Friday, Saturday, Sunday, and if there are no visitors, and you know there is nothing much else happening then you are just on each others nerves all the time, and (Name of patient), she can't do anything so every time she wants something she has to shout and I have to go and do it and I don't honestly think I have, because sometimes she will be on the phone upstairs talking to friends or watching the television what she wants to watch up there, and I will be watching something I have recorded down here, and I don't think I have watched a television programme through completely, from beginning to end without interruptions for months, it's a good job I have got it recorded, I have got three episodes of have I got news for you for a bout three weeks which I have not had chance to see and a couple of episodes of ER, what's the other thing, I watch Mad Men, so that sort of thing, I think oh bloody hell just let me watch this all the way through and that makes me irritable.
R: So having a break would make a difference
S: Having a break would be lovely, I think that is something that is definitely necessary,
R: Thanks very much.

ID 54 & ID 207

Present: Individual with MND/ Spouse/ Research Assistant – spouse speaks for wife who has speech difficulties

Researcher speaks
S: The first time when it all started or we believe it all started was going up to my son's one day August? August 2004, in August 2004, we were going up to my granddaughters first birthday, second birthday, I'll get it right, who lives in (name of place) we had just set off, we were going up (name of road) and you opened the car window, and I saw you fumbling about and you said I can't press the switch to put the window back up and that lasted for thirty seconds to a minute, all the time was it ? no because you found it you put the window up after a while it might have seemed a long while it was only thirty seconds to a minute because I said put your window up and you said I can't press the switch and then I was about to put it up with my switch you said oh I have got it again, and that seemed to be the start of it, you said you had no feelings in your fingers, no movement in your fingers, you couldn't press the switch and on that day everything else seemed alright didn't it?
R: No? All at once my fingers felt funny, your fingers felt funny all that day did they? And then that continued for a long while and we thought it was a trapped nerve,
S: I went to the doctors, this was later on we went to the doctors, no I said to the doctor, I went to the doctor straight away he thought is was a trapped nerve and then it persisted and carried on and we were sent to, we were sent then to (name of consultant) at (name of hospital) and that's when, in February, in January, that was in January, and then he checked you over and then he said he would like to see you in (name of care centre), to put you on a certain machine, I don't know what

the machine and that's when he said it was this motor nerve, in your left arm or in your left neck or whatever it was, your arm I know but some diagram that I saw said it was your ? but anyway wherever it was and er then after that (name of consultant) said my legs were ok when they put you on the machine it was on your left arm, then you had a spell of falling, sorry? I fell over in the garage, you tripped over, and then you had a few spells of falling and then you broke your arm, didn't you? Not, I'm listening I had a fall on the bags, they tripped you up in the garage, and you fell down and you had a series of falls after that then you broke your tivia, humorous and you broke that didn't you? And they couldn't plaster that because it was in apposition where they couldn't put plasters on And then I had two frozen shoulders after that, and the other arm I had, have psoriasis, the psoriasis causes a lot of arthritis, and that's how it all started from nothing really, I always worked hard, always on the go didn't you, doing more jobs than you should be doing, came from nothing, no apparent reason, a man in the hospital said I were a very? A very strong lady oh ay you were as a strong, you were as strong as a man.

R: Could you tell me about the time of the diagnosis what happened then?

S: They took you into hospital, didn't you, you had to stay in overnight, when I went to (name of consultant), (in place) he said straight away that there were in my, in your neck, there is four nerves, but he did explain everything to you didn't he, I think and then you went into (name of care centre) overnight, he said there were cells, it were the cells, one in your neck, a cell, and that was why there was no power in your arm, he said that I am too go to hospital to have my, to be checked all over, he did explain everything to you, he was very, very good wasn't he, and then he said, have I heard of MND and you said yes, he said sometimes it is, my arm, your left arm, your right arm was ok, no, a bit, a bit in your right arm and your legs were ok, they put you on a special machine didn't they, for sending the, the brain transmits messages down but they weren't coming back, am I right saying that? Nerve Conduction that's it and the man said I were very, very, he said you was a very brave lady after you had done the test on that conduction machine, because it is not nice that machine it, you didn't bother about it did you? I said why am I like this? He said sometimes it is overworked muscles and two other things, they said they don't know exactly what was causing it, I have always been active and your brains second to none isn't it, memory is absolutely brilliant, it is

R: What was your reaction to your diagnosis?

S: When I heard (name of consultant) say MN, I, you thought oh, no, (cries) it was a shock, ay. And then you said, to my doctor, (name), she said it is, I am sure that I will be able to cope, cause you will have to put up with it like you have had to put up with psoriasis all your life, something you will have to put up with and you said alright, and then she said that it sometimes it can sometimes, I, I, sometimes I, will not be able to move, move your arms, and my your voice, it has affected your voice, oh no, not straight away, no, I am able to talk, (laughs). We have always wondered why, you always tend to wonder why, why me, you were strong, yeah always been strong, I am, you are strong now, yeah,

R: Can you tell me how MND has affected you life?

S: It has affected it a hell of a lot hasn't it, I mean at the beginning we used to get about a little bit, we used to be able to get you in the car, but we have not been out now for a long, long while, I mean we used to be always out somewhere everyday but now everything seems to have ceased, we are just wondering about from the bedroom to here, you just can just nip out to do a bit of shopping, ten minutes to quarter of an hour and back again, I go in the car, I am not able to get into the car because I slipped a disc so I had to have an operation on my back, hadn't I? So I am unable now to lift you and pick you up, so it has altered our life dramatically, hasn't it? To virtually stopping, confined to two rooms basically, bedroom and kitchen, sometimes, we can get into on a nice day and just go and sit in the garden and that's as far as we get, I always been a lot of you used to do a lot of needle work, always being active doing something, she couldn't sit still in her chair, she used to do a lot of needle work as well and now everything has come to a halt, and when I want to read a book, I have not able to turn pages over, we always say you are happiest, I know there is always

someone worse, she always keep saying that there is think of somebody else before yourself all the time don't you?
R: Can you tell me about your experiences of the multi-disciplinary team?
S: They are very good, aren't they, they come and keep you checked up and come and take your bloods, how often do they come? You mean with the nurses?
R: Well allied professionals like the physio, Speech therapist, occupational therapist, how they all work together.
S: Yeah, they do, in actual fact they are all coming again this week for some reason, we have not seen them for a while, especially the occupational therapist no sorry the physio only comes every blue moon, she shows us some exercises to do, we will leave you to it, if we need her, (name of specialist nurse), she comes every three months to take your bloods which she always does, religiously, every six months, three months at the beginning now it has gone to six months, last year I were not able to, you wasn't able to move your legs, no but this last few months you been able to move your legs a bit and lift them up and stretch them out. Last year you weren't able to move them at all, that's why I do the exercises everyday, yeah she does her exercises everyday, I mean when we need people we have rung them, and they have turned up and done something, haven't they? But I wouldn't say they come on a regular basis anybody, apart from the specialist nurse she comes every six months, but we don't need them that we know off.
R: Do you feel that the approach where you contact them if you need anything works better for you?
S: Yeah, I think we, us personally prefer it that way than to keep being mithered, I mean there is one thing we don't want to be doing or (name of patient) doesn't want to be doing is to be mithered everyday, that's the only thing it works a treat for us, if we need them just give them a shout, yeah
R: What about provision of equipment, have you had any issues with that?
S: No, everything has been provided straight away, yeah they have always been very good, if something has gone wrong, like one of the batteries burst for the hoist, for your bed hoist and they were here within the hour, always been very good with delivering equipment
R: When things have been suggested, do you feel that they are appropriate?
S: I, in the, that day when they said I have got to have, oh they suggested putting a hoist in the front room, so she could sit in one of the lounge chairs, but you didn't want that did you and they did try and press it with you slightly but you didn't want that did you, you said you would prefer to sit in here than go in the front room, you reckon that they were too fussy, did you? You reckoned they were too fussy. I don't know I think it was just the thought of having another hoist in the front room which put you off, for some reason, I said in the daytime I am happy in here, plus in winter time especially this is the warmest room in the house and we don't need central heating and it is nice and warm that helps you doesn't it, they are very, very good have been very, very good, at giving us things up to now, they do suggest things that you don't want that you won't have, she is a very proud lady aren't you, I you're alright, I would like to have a bath, you would like to have a bath, the only thing she does miss is having a bath, you reckon, if I had a bath chair, but that is the only thing you miss having a bath, I mean the carers come in the morning and give you a good wash but as you say it is not the same as having a bath, is it? No. I were, alright, at the beginning it was alright they supplied us with a chair that rotated into the bath, and we used to get you in there to give you a shower but now you are not strong enough to sit up straight enough, no not that chair, I am lift me, I can't lift you up, bit of a man handling job to lift you up onto the chair, (name of carer) is one of the carers that comes, he said he will put outside if its raining, I like (name of carer) he is very very good with you. He is a nurse as well so he is very good with you, he has been away for three months, on his holidays so
R: When you were getting your care package set up were there any issues then?
S: No, (name), that's the social worker, she did all that and she was very, very good wasn't she, there no problems there, about setting the package up, she said I am the, someone, I am the one that matters, you are the one that matters, yeah, yeah we had no problems with setting that up at all, no
R: Do you feel that the care that's provided is adequate for your needs?

S: Yeah, yeah, for what we need, we used to have them, one, two, four times a day, two hours in the morning, an hour at dinner, an hour at tea and an hour at night, that was when I had to go for an operation on my back since then my back has recovered a lot so we have stopped them in the day time, they only used to come and toilet her, now I can manage her on the hoist, because I have no bending and lifting but I can't put her to bed, so we have stopped them during the daytime,
R: But have you found it was relatively straight forward easy to change?
S: Yeah,
R: If you needed to increase it, it was increased without any problem.
S: Yeah, that's right, it was, alright, yeah no problems from that side of it,
R: Are there any areas of care that might be missing, thinking about emotional, psychological support,
S: No, no, we are really happy everyday together, I mean there is only us two together so there is nobody to fall out apart from ourselves and we don't do that, sometimes I have, you have a cry every now and then, but I think well we have always been on our own haven't we, I think one of the reasons why we stopped them coming at dinner and tea time, I know they only came for toileting and most of the time they were only here five or ten minutes, they were supposed to be here an hour but they were never here an hour, but we always thought that our house was not our own, because as soon as they had been and gone, we tried to do something but we felt we had to stop, because these were coming again another few hours after, we wanted our house back, didn't we? We just felt it wasn't our own home anymore there were that many people traipsing in and out, I, you were not able to have, you couldn't go on the toilet proper for people who keep mithering you, that was, you have to keep telling them to come out, if (name of patient) went on the toilet they kept going in, they were always going 'have you done?', they were just in a rush to get in and out, I had to keep telling them to leave here alone, you don't want someone stood over you when you are on the toilet, I don't know, it didn't feel right did it when people kept coming, we were much happier when we stopped it, we liked being on our own didn't we, our (name of son) and our (name of son), one of my sons lives in () and the other lives in (place) they come pretty regularly, he's just gone back on Saturday after being down for a week when I was ill, at the first our (name of son) went to the doctors, he went to see doctors to find out what it was all about, I think a lot of people don't know what MN, I mean I know it might be a little bit unfair, I think I'm speaking just, half of these carers that come they are not carers, they don't know what they are doing, alright, I know I shouldn't be saying they are alright for giving people their meals full stop, because I am certain none of these people know what MN is, the way I watch them and the way they work they just have no idea, they think they are just mauling about with a normal person, they do not know how to handle you, no, they don't know how to manage you at all, they are all alright now, well some of them are, aren't they? Two or three of them are, (name of carer) is alright, (name of carer) is alright, yeah,
R: How do you feel about the others though?
S: No, I'm just saying, There again basically, I think, the soon as I was better with my back and my physio was finished and they said I could start doing it again, there were certain people and they were in here, they used to toilet you, they would come in here at half past five and by twenty to six they were gone, that's how rough and how quick they handled (name of patient),
R: How do you feel about that?
S: I used to keep telling them, it used to get my rag up, I used to have an argument, well I wouldn't say an argument I had to shout at them, it makes your blood boil when you see the things they are doing and they just don't know what it is and how to treat people and to start throwing you about as if you are a little old lady, and things like that, that's just how they seemed to treat you, they are just ignorant of the fact, they just don't know how to treat you,
(stops to wipe mouth)
R: Sometimes they never they were, always rushing, always rushing ay, that is the fact with all these carers, I think they just want to come in and get out, I think it is a nation wide problem that, nobody

stays the length of time they should do, do they? If I were able to talk they wouldn't do it, I know you would shout at them
R: Do you think because you can't talk that's part of it?
S: If I were alright, I would tell them off. It is not right, no, I know, sometimes, they do not want to, listen, sometimes they don't listen, but we put up with them and manage don't we? If I do not have (name of carer) and (name of carer), I would not have any of them, no there is only a couple of them that do know what MN is, and they treat you right, (names) they, is having, on a course, oh yeah, one of the carers, said that, (name) whose business it is said that she is putting them on a MN nursing course or whatever, but as I say there are that many news ones coming and they are always leaving and new ones coming, I can't see how that's going to work, there is a lady, oh there is another lady who they look after, a new client she has got motor neurone disease, (somebody in name of place) so I think that is now we have got two clients they will send them on a course, whether that materialises I don't know, personally I don't think it does. I don't think it will.
R: Can you tell me about your thoughts for the future, what your concerns are?
S: I have no concerns really, I always, I were always a, b, c, d, e, f, g, you are always organised, you seem to be organising things a bit more, I always organised I you want everything meaning house wise well we are both agreed, I think the fact is that we have both got use we have made our own little world in these two rooms, haven't we? And we just accept, what we are doing every day. I sometimes wonder if I were on your own, I am not going in a home, whatever happens you don't want to go to a homes, you don't like the thought of homes, never have done, (patient cries) we manage alright everyday we both sit here together and we enjoy ourselves, our (name of son) says I will?Tell (name of researcher), that I do not think they have a helped with my saliva, oh yeah, saliva is a big problem at the moment, you reckon, that is the worst thing about it, we have tried everything in the book with it, nothing seems to work with it, all the time, your mouth always full of saliva, they, said if we just put you on some eye drops to put into your mouth, to try and sometimes they work, not doing that at the moment, (name of specialist nurse) the motor neurone nurse, said if them don't work you can try there is another thing you could try just forgot what she said and after that there is botox, most likely cure it into the salivary glands, I would not you would like that done, something that I have got to, not to, what no, I would like I have got to not to I have not to put in my mouth all them drops all that time she does not like them drops all that time because they are not doing anything are they and they hurt your throat, they tend to hurt her throat make her throat sting, make her throat smart, but I think up to now the worst part about it is your saliva it is nonstop, I have, I am very e, m, ab? Embarrassed about it, yeah,
R: Can I just take you back what support you got at that time?
S: We didn't get any did we? When you come out of hospital, (name of specialist nurse) came a few weeks after, wasn't it? A few weeks after and explained to you
R: How did you feel in that time in between getting your diagnosis and seeing her?
S: I didn't know much about it, you knew more about because when we used to live in (place name) one of our neighbours had motor neurone disease, I didn't know the gentleman very much well only to speak to but you used to go across at odd times with your friend to see him, which is how you knew all about it but I didn't know I must admit, I have always known, I myself didn't know anything about it till they explained to us what it was, when I come home from hospital, no, no-one said anything, no-one said anything, only (name of specialist nurse) came to tell us all bout it, she explained it alright didn't she? She said I have, I have AN, any? (name of specialist nurse) says my were h, o, n, anterior horn's disease she called it, yeah, I sometimes wonder what is the difference. They drew us a little diagram or something didn't she and why it is basically called horn disease, is it because, was it the way its junctions off, on my neck there is four, that's what I say the ways it junctions off, which way it shoots, when I on that on that machine, the man on the machine in (name of care centre) were very tall, was he? Very tall man was he? He said when my legs alright, he said very good, he was a big man was he? Was he?

R: Is there finally anything else that you would like to add that you think might be useful for people with the disease in your experience?
S: Is there anything you can think of? I would ask for have exercise, you reckon exercise helps your legs and your arms, yeah, it's a very difficult thing to think of, isn't it? You reckon that it is like having Alzheimers, no, it is like having arthritis, right you mean your joints, you can't move your joints, the pain? I have no pain, it is just I have only got pain with psoriaris and arthritis and psoriasis, I have although, I have had it a long while, I am always ached, you have always ached, I think basically the main thing is to have company all the time and never to be left alone, isn't it? That's how we get along, if I go shopping I only go to the top of the road and I am back within ten minutes, I think basically you need company all the time I think that takes a lot off it, if I do not have had no, spell it for me. If you had no partner, saliva, if I had no saliva I would not think, need any, you would not need anyone, no you would not need, to always have in someone to wipe your mouth, yes saliva upsets you, that's the main thing, if you just got your saliva right you would be happy wouldn't, like I say I think the main thing is having company, it helps the days go by and you do need somebody to talk to, tell (name of researcher) sometimes I always go N, E, R, nervous, if somebody is coming,
R: Thank you very much for telling us your story, I know it is a big effort for you.
S: I am, my, her, I have always my hair, hair done? You always have your hair done and your nails done,
R: Well thank you very much for that.

ID 73

Present: Individual with MND/ Research Assistant/ Research Supervisor

I: I'd prefer you not to be here (name of wife) if you don't mind. I asked for that one of the most difficult aspects to this is that (name of wife) lost her brother to motor neurone disease six years ago so obviously it upsets me even more to think that I am putting her through it twice. Er, its very very upsetting aspect in fact it's the most upsetting aspect for me to cause pain, its terrible however er six years ago we lost my brother in law to motor neurone disease and my wife took it very hard. I didn't go and see him cause I preferred to stop at home and give my wife support she needed and I knew if I started to go in Id get upset so whilst it may appear selfish I can't cope with things like that but through that I was able to give (name of wife) support during his illness and afterwards, but coming to myself and my experience I don't know the times I get confused over the times but about three years ago I fell and broke two ribs, at home and punctured a lung I was off work for about four months, I went back to work but I noticed myself having difficulties opening doors with keys and er sometimes missing the space between the doorways and bumping into the door, Id been at work after getting better, after being at work three months, I had a ?? and slipped on material and broke my ankle. That badly affected my balance I didn't 364ea(name of daughter)e that breaking a bone could affect your balance but the physiotherapist told me that if you broke your ankle that was the worst bone you could break in your body to affect your balance, so I was struggling balance wise and I just was struggling to get back, I was doing physio, I'd gone to the gym again, I was really trying hard to get fit again, but whilst I was going to the gymn everything was continually getting stronger but my arms were weakening, so I went to the doctor and he sent me to see (name of doctor) he told me there was a possibility of something quite serious and because (my brother in law) had died of it I already knew I had got it. It was a shock to have it confirmed, I asked (name of doctor) is it MND and he said well, yeah, I think it might be. I had a week in (name of centre) hospital, they confirmed it and five or six months later here we are, the support we've had from all the medical staff, the doctor, ot, mnd (name of centre) it all been wonderful, first rate, but its not something Id recommend.
R: If I just take you back to the time of your diagnosis, you've described going to the gymn, trying to get back,
I: Yes which at the time I thought was all down to my broken ankle.
R: Did you discuss those problems with anybody at that time?

I: The Physio, just the physio and he had me doing a lot of balance exercises, as well as working on my ankle. He had me doing balance exercises, because it had been a works accident the works insurance payed for me to see a private physio, prior to that I had been going to a national health physio and that's all they did, but apart from him I wasn't seeing anybody.
R: So what was it that took you back to the GP?
I: Weakness in my arms, going to gymn, everything getting stronger and feeling better apart from my arms, at first I thought it was down to general inactivity, I obviously couldn't lift anything really because of broken ribs but after four months recuperating and getting better from broken ribs, I expected to be weak and I was, going back to work was difficult but I felt better, and then I broke my ankle and I don't know I think I had a pot on for six weeks, it just became more pronounced, so I started going to the gymn but no amount of exercise would help and they were just getting weaker and eventually that was when I went back to see my doctor and he sent me to see a neurologist,
R: Straight away?
I: Yes, more or less,
R: You told me about what happened when you were given your diagnosis and that you were pretty sure you knew what it was, had you talked about that with anyone, had you spoken to your wife?
I: Yes, I kept saying, (name of wife); I'm frightened it's MND, and she kept saying, oh don't be silly, don't be daft. It won't be and I sort of denied it, thinking along on lines, not even my wife can be that unlucky, she has been, so prior to that no I'd not discussed it with anybody.
R: How did you go about telling people about the diagnosis?
I: Just came out and told them, apart from (name of wife), I have two daughters, and I just wanted to tell them straight away just to get it done with, I can't be doing with faffing, if something needs saying I want it said, prefer to have things out in the open, told them, very, very difficult because I think it is 5 or 7 % hereditary and what with it being in (name of wife's side and my side), it may apply to them and grandchildren so very difficult but it has to be done, I'm not very good at this I'm sorry.
R: You're doing fine; don't worry about it at all.
I: So tell me how having MND has affected your day to day life.
R: Its totally devastated my life, I used to fly fish, fly fishing and shooting were my hobbies, got rid of them, sold my guns, broke my heart, fishing equipment that I can't bring my self to do anything with, I can't play with my grandchild, and that's the one thing that upsets me, talking about grandchildren, cause I always wanted a little boy, I had two daughters, beautiful, lovely girls, but I've got a grandson now so I can buy cars, railway sets, toys, boys toys I'm not, I can't be a proper granddad, I can't play so that really upsets me, in the day to day living with the disease, I don't get emotional, I'm going to swear, I think well shit happens and I've been lucky up till now, so I don't complain, I don't think, I try to make light of it for family's sake, but I have nothing left of my life, Its, I've only been out the house twice since Christmas to the MND clinic, my choice, I don't want to go, I've no energy, I can't do anything, so frustrated, and yet my brain is 100 per cent so it notes every day all the deterioration, and notes it , what I've seen happen is that there is a plateau and then something will worsen quite dramatically, whether its strength in my arms, or twitches in my arms and legs or tongues and then after a week it comes back but always weaker, always weaker, er but Id don't live, its not my life I'm living now, I know it is it not the life I lived previously its devastated, I've never been poorly before, the only good thing, is whilst I broke my ribs, and was getting better, and then my ankle, I've been able to spend more time with my grandson, then I would have done if I hadn't broken my ankle so now I look back and count that as a blessing, so you have to make the bests of it , but after sitting in this chair for eight to ten hours, I'm exhausted, I go to bed the highlight of my day is seeing my grandchildren but that's a painful thing cause I can't do anything with them so I just look forward to tow tins of lager at tea time. That's it.
R: What about your computer?
I: I've always been interested in computers so I've always been a game freak, Friday night prior to getting poorly, Friday night was my game freak night, I used to get a bottle of wine and play a game

on Friday night and that's how I had my accident. I'd been playing our game for so long, I stood up not sure if I went dizzy but my legs had gone dead and I fell onto the back of a chair and that's as I said, earlier, I had friend s who I email, I go on internet a lot, but I just play strategy games, I used to read three books a week but I can't even read the paper cause my arms are so weak so I get the audio books off there, and listen to them in bed of an evening, cause I prefer reading to watching television, I always have, I've never been a great television watcher, so I listen to them and fall asleep I spend ages night after night finding where Id got to, but it passes time,

R: Do you do anything else on the internet?

I: Er, well no, I don't; research MND I keep away, I don't read anything I don't want to know, I shop, buy toys for (name of grandson), tend to spoil him a bit,

R: When you say you keep in touch with people, is that people you've known a long time, or have you made new friendships on the internet?

I: Oh yes. I've made new friends,

R: And are these people with MND?

I: No. I know people who are recovering from surgery, not because I go to places that are about that but obviously from a wider circle of people who go to soft ware forums, there are obviously people who are poorly, we don't make a big thing of it, other than to say, its my time and this is what happened, so plenty of support if you need I just think there is so much pain and devastation in people's life its embarrassing to bring your own into it, if they ask, Ill tell them but no I don't want to be a bleeding heart, and that's it.

R: What about friends from work, people you've known throughout your life?

I: No, I had a friend who moved away, I was best man for and he was best man for me, we keep in touch by email and some of the ladies from work still text me but people don't visit, I wouldn't have done either, I hated seeing people struggling, so I didn't visit and I understand why they don't want to so apart from my daughters there is only a couple of people that I see, but to be honest, after talking my mouth gets very tired and I have to stop, its very draining anyway, so no I've no social life left.

R: Can you tell me how the MND is affecting your wife's life? From your perspective how its affecting her life.

I: She's become a full time carer, my wife is a chatty person, and because I'm not she needs to get out and get rid of this chat, she needs to be talking to people. Not about our circumstances but just to chat, so I like her to get out, so apart from like from going shopping, or out with my daughters she found it very difficult to tell people without crying, I don't know with people knowing she doesn't have to tell them anymore, or she's sort of used to the situation, less upset, but she doesn't go out now as much because she's worried about me, the most frightening aspect of MND is the thought of it like going on for years, like some people do, and I just don't want to do that, Id prefer to just get it over with let everybody else get on with their life without having me as a burden,

R: You mentioned about the care that you've received and some of the services, can you elaborate on that in anyway.

I: When (name of wife)s brother had MND, I can remember (name of wife) saying that his wife had said that their seemed to be passed from pillar to post when experiencing a problem but from what I've gathered they always seemed to be fighting for assistance and information and they always seemed to be passed from pillar to post but we've not found that at all from coming out of (name of centre), I thought (name of centre) the staff were wonderful, the nurses are just so kind and caring , and since I've come home its just without asking the OT nurse comes, the dietician, speech therapist, the MND people are all wonderful, my doctors wonderful, its so reassuring to have that back up to know its there and they are such lovely people. I hate getting emotional; I don't like talking about myself. So it's wonderful.

R: Do you feel the services are well co-ordinated?

I: Oh yes, its as if they are mind readers, I can't believe the services are as good throughout the country but in (name of centre) and (name of area), the departments involved with MND are first rate and they are such lovely ladies.
R: And do you feel that they are knowledgeable about the condition?
I: Yes,
R: I suppose that helps.
I: Well obviously some are more knowledgeable than others I think the only comment that Ill make is that I was asked well your not in pain are you? Well, you're not in pain but your bodies dying around you so it's still not good but apart from that perhaps that person has had a refresher course, but no, everybody is so knowledgeable and so kind and caring.
R: Are there any areas of care that you feel might be missing, particularly in terms of psychological and emotional support?
I: No, (name of wife) goes down to the hospice for relaxation classes, she has her feet massaged and I've been told that I'm welcome to go but I don't want to go and she goes to a carers group at the hospice which she has found helpful er I don't I've read it so it must be true that MND causes sort of wild mood swings and makes you more emotional, I can't say I've noticed that but you know talking about my grandson makes me cry, thinking about it, I don't know, I never had er, I've never been involved, I don't know what there is there to miss so I don't miss it.
R: Well you've said you don't like particularly talking about yourself and your condition, well do you feel that talking about it now is helping in anyway?
I: No,
R: It isn't
I: No.
R: That's sort of thing you might get
I: No, I don't like it, I'm doing this in case it helps, not because I enjoy it, I don't enjoy it.
R: Can you tell me about the decision making about your care? About any equipment your received any interventions that there have been. Do you feel fully involved?
I: Oh, yeah, the ot nurse is outstanding. I've got a hand rail, at the top of the stairs, I've got use of a push up chair, I don't use it as yet, the biggest and most upsetting aspect of it was, I knew it was in my mouth, and I sort of made my mind up that when I couldn't eat any more I was going to take to my bed and die, I thought that was the fast way out, my biggest fear was being a burden but then I was told about a PEG and that was, I've decided I'll probably will go and get a peg fitted but I don't want to, I don't really want to prolong my life, I don't want to do anything that prolongs my life any more, cause I'm not, I don't want sympathy, I'm not feeling sorry for myself buts its not much of a life that I want to prolong, and I know everyday its going to get worse so if I could go in my sleep tonight, that would be champion, a couple of beers first, jobs a goodn. But no, I've forgotten the question.
R: Well, you've said you decided to have the PEG even though you don't really want it, so why make the decision to have it.
I: Er, its eventually (name of wife)s going to end up feeding me which is even more for me to do, choking becomes a problem which I don't fancy choking to death and it just seems in the long run the best course to follow, I think, I was told that starving yourself to death is a horrible death, but the alternatives aren't very pleasant, choking to death, dying cause you can't breathe, so I thought maybe starvation was the quickest, I know it's a long lingering way to go but it may well bring about the end soonest and then I found out its not surgery its down your throat job, so don't fancy that so I'm putting it off as long as I can.(laughs)
R: But do you feel you are getting enough information about it and then the choice is yours as to what you do?
I: Yes,
R: Do you feel that suggestions, about interventions or equipment are made at an appropriate so you have time to think about it?

I: This isn't criticism but the first time we met the OT nurse, we found that a little bit overpowering. The house, is quite rightly, the house is quite unsuitable for a disabled person we wouldn't be able to have a stair lift and then she started talking about French windows and a lift, we'd been here twelve months, (name of wife) retired just about the time I were diagnosed so , we were going to do the house up quietly ourselves and now its not gonna be but we found that very tiring at first cause we were still in shock and knowing that you've got this dreadful disease, and then suddenly to think, we'd just had a new bathroom fitted, I found that very difficult to cope with, I don't think Id been diagnosed at that point but I knew 99% what it was, and to start having the house bashed up about me I didn't want that. That was tiring, but apart from that, just things they have to ask or things that people think you should know they tell you. I just can't fault any of it.
R: And if you have a question, you feel you can ask someone?
I: And if they don't have the answer, they find out straight away and come back to me. I had a lot of problems, I think I had an infection in my mouth, and the dietician lady came out and when she went away and I think it was the following day she'd been asking friends and colleagues and she phoned up with advice so you know that demonstrates to me that having been visited and gone, you're out of mind, but she went back and tried to find out, its wonderful,
R: You sort of touched on this a little bit, but I wonder if you can sort of tell me your thoughts for the future?
I: Its so frightening, its terrifying, I've always been an active person, physically fit, mentally fit, the thoughts of being totally immobile are terrifying, I don't even want to go there, Id prefer not to experience it.
R: Is there anything you think that could be done to help you with this?
I: Yeah, somebody just give me a load of tablets, yeah,
R: And then just finally, what's your priority at this stage our life?
I: Not to cause anymore distress than I already have to my family, I'm dodgy on my feet, I've had one or two near falls, I have fallen since I was washing my face and fell backwards into the bath and obviously (name of wife) was terrified, I don't want to cause her anymore frights than I already have, so if I can quietly shuttle off this mortal coil that will do for me. Just quietly drift off.

ID204

Present: Spouse/ Research Assistant/ Research Supervisor

S: Well, I suppose it all started erm before the diagnosis of MND when [husband] had fallen in March of 2006 and broke some ribs and punctured a lung and then he got well from that so I told… and then he went on to break his ankle at work in a work accident and he tried so hard to get well from that, going to physiotherapy and in June er, it became apparent that it was the top half of his body that was weakening but it was his ankle that he'd hurt and we couldn't sort of connect the two. We talked about it that… because he wasn't working he wasn't using his arms the same and erm that was where perhaps his weakness was coming in. The physiotherapist at the gym, not the physiotherapist at the gym but one of the people at the gym who was helping him with weight lifting said to him "I think there's something a bit more to it than than breaking your ankle, erm, I'm concerned."
S: So [husband] had been going backwards and forwards to the doctor, to his own GP, to get, erm, a sick note for work and also just asking general questions and so this wouldn't then lead to about February 2007 and [husband] had trouble picking up [grandson], our grandson who would then be 3, and he said to me, "I'm really struggling picking up [grandson], I can't understand why its, why its my arms that are hurting when its my ankle." Somebody had said to him "Oh, well, when you sprain your ankle, it can affect different parts of you, your nervous system and so on," and we put it down to that. But then [husband] started to say "I think I've got what your [brother]'s got."
S: I have… I think you've heard about my brother who also had MND and I said, "No, God, surely not." He then started looking on the Internet and then he said "there's something wrong [spouse], there's something wrong, more than a broken ankle." So when we went up to see his GP, I went with him and he said, GP said to [husband], I think we're going to have to look into this further, its

taking you a long while to get well from a broken ankle, there's something more, so he said I'd like you to go and see a neurologist and make an appointment for you and that we went to see a GP in August and we then saw the neurologist in September at [local hospital] and they did some tests on [husband] and had him walking about and pushing various parts of his body and looking in his mouth and then he sat us down and he said 'This is something serious' and so [husband] said to him 'Are you talking Motor Neurone Disease?' and he said 'yes, how did you know' so then we explained that my brother died from it and the neurologist was like quiet for a minute and then I said "No blood relative of [husband]'s, my blood relative." So he just said 'Oh that is, that is cruel, that is, um, really cruel, but I'd like you to come into [regional centre] and have some tests."

S: So, [husband] went in in October 2007 and had MND confirmed and erm… even though we'd we'd talked about it and I can't say got our heads round it because I just thought, no it can't, not twice in, in the family. When er… we came home, well, we got back from [regional centre] when he'd had the tests done and had him in for a week and we were sort of silent driving on the way home and erm… then it it sort of hit us and I… I don't think we knew what to say to each other really, it was just of case of 'Oh this is real, bummer isn't it, you know.' (LAUGH) to happen and erm er I suppose I was, I were devastated obviously. [husband] had been in such good spirits and erm I er as we'd just moved here as well and er wanted to and I'd just retired and so it was going to be, [husband]'s a little younger than me so it was going to be he'd work til 60 and then we'd go off travelling and do all the things you hadn't been able to do, so it was like 'Wham' and erm, initially we were off our food, we didn't want to eat, [husband] didn't want to eat, well I certainly didn't want to eat… erm… but then gradually over a time we've… it's getting into a routine. Your life prior to retiring had been a routine, you go into work, coming home, doing abc.

S: And since, I don't know when it would be, perhaps before Christmas, before Christmas, we started eating a bit better. And once [husband] was eating, then I, then I would eat as well and and I want to, to make things for him. He'd had a, he's had a problem with his mouth and erm that put him off food, he didn't he didn't, everything tasted unpleasant so I was trying to encourage him with food that I knew he liked, but er, no he didn't want to eat it.

S: And the services have been absolutely wonderful. Absolutely wonderful. Initially when people were coming, er, because it was very, I mean it's still raw now but very raw then, and erm, people were coming saying 'Well have you thought about doing this and have you thought about doing that and have you thought about moving house and erm I'll bring someone else… I'll get someone else to come to see how they can alter the house for you to make it easier for you for [husband] and it was like 'Boom boom boom boom boom' all in your face and even though it had to be done it was, we were just so exhausted and when these people were going we we'd both fall asleep erm, but, once again routine has set in, the people are the same, they come in, they're ringing once a month or they come in once a er month and it, you build up a rapport with them, they get to know you and erm they are just outstanding, they are really outstanding people and erm and I think I've just, this is how its gonna be now and we're just gonna make the best of it.

S: It erm still affects me about my brother and… sorry… and it will though [husband] didn't go and see him I used to go, and I'd come back a wreck so [husband] would be there to pick me up and he would listen to me and so he got the idea of what… what was going on. And er… my my brother kept in good spirits and that saying better the devil you know, well I'm not so sure. Er, I found it very hard going into the hospice building because that was the last place I saw him alive, but, I'd been going there regularly for pampering sessions and I got to know the people there and I'd also gone to a carer's group which has been going monthly, this'll be the fourth one next week. And I've got speaking with another lady whose husband has MND and she and her husband knew my brother and this man was diagnosed 15 years ago and told he had two and a half years to live and he's still here. And so well people keep saying well everybody's different and even when the neurologist sort of gave [husband] 12 months erm we just take things a day at a time and erm… and that is where we're at at the moment.

S: Erm, the children, er, [daughter] was… was home when my brother was ill and she would go and see him and our youngest daughter was away at uni at the time and she found it very difficult… Er, my brother used to be an IT and maths teacher and er so he had along with her dad and her uncle had… had got this love of computers and erm… she would write to him but she couldn't go and see him and erm I was anxious, still am anxious, and probably will cope with things but they just hear [INAUDIBLE] and she comes to see her dad when she can which is quite often and er people have just been so lovely and the lovelier they are the more I cry and that's about it at the moment.
R: Can I ask how its affected your life day-to-day?
S: Well, I suppose, when did I retire, last, I retired in July last year and obviously I'm… I'm a carer now for [husband] so er… I haven't let it… It doesn't get me down… I just get on with it er… I don't… I don't feel sorry for myself but I feel sorry for [husband] because he's had to stop doing a lot of things that he did. And we don't go out now, we didn't go out a lot before but he doesn't want to go out but I can still go out, erm, locally, our friends and er, I know I can go and visit them, whenever I want to and with having [daughter], she's still on maternity leave and she pops in as much as here yesterday and she's come today, so, it, I would say I've swapped my working routine of, I… I was a teacher as well… of caring for young children and now I'm caring for [husband]. Er, it has just stopped perhaps going further afield, going on holiday because he doesn't want to go, now that doesn't affect me, it doesn't bother me at all, because as I say I'm happy doing things at home, potter about in the little garden, and out in the back garden, pot plants so I've just got that routine now of caring for him and that will be till… Him upstairs has any other ideas for him…er, yeah it is, it's a routine, I cope better with a routine, knowing that this week and at the end of every month I go up to the hospice, I've been going for reflexology, the course has finished but I know I can go back if I need to and so, I'm not I'm not doing my paperwork, like I used to have a lot of paperwork to do, so its its, I'm more relaxed in a way because I can sit with [husband], he does go to bed very early and er but I know if he's in bed, as I say, I can go out and visit friends erm… so not.. not that great a change.
S: You know, it's a routine that I'm happy with in my head. I know now I get up in the mornings, stir round my porridge and such and get [husband]'s tablets, I do the fire so I'm having to do the jobs and that… And I know it, it affects [husband] cos he was the man of the house and did the jobs and the fire in there, that was his pride and joy but he's trained me up well (LAUGH) and says well done, its still… still in when we get up in the morning. So its its remains, like waiting for things to happen, you're wondering what's going to happen next and er… [husband] will say 'Oh my arms have felt weak today' and we both say 'Well never mind, well go and have a good rest and maybe tomorrow will be a better day.' So, er…
R: So not too many changes?
S: No, no, no. And like yesterday, when [daughter] came, we walked up to town with the children and because I worked locally, I still see like a lot of mums, I saw four or five mums yesterday, and they all wanted to stop and have a chat and some of the children are in their twenties and some are still 6 and 7 so erm… I get conversation and erm friendship from them and it is a friendly place to live so its erm… and even though we haven't been here long and the neighbours have changed, we all chat to one another, and the neighbours know that [husband] has er… an illness and er… they come and say 'How's he doing today?' so its, there's that support and I know if I needed… if he fell or anything… I know next door, I'd only have to shout over the wall. Where we lived before, erm, we were, it was, quite lonely and we didn't, we lived in a semi and we knew the girl who lived next door but the other people round about… you just didn't see them. Cos there was like big gaps between the three of us, so, in a way I feel God wanted us to move here, this was always in our plan to move house, to downsize so we didn't have the garden to do and all the decorating and the big rooms and such, so thank God that we did move and even though [husband] wasn't able to help much because of his broken ribs (LAUGHS).

S: I feel comfortable, we both feel comfortable here and we don't want to move and er, I say we'd… this is why we haven't done anything in here because this hopefully will be his bedroom when the time comes.
R: So you're saying you feel supported in the environment around you?
S: Absolutely.
R: Do you honestly feel that you get support away from the services?
S: Absolutely. First class. 100%. I can't praise them enough. Even the pharmacist at the local chemist… erm… she was suggesting things to do and I said 'You're being nice, stop it I'm crying' she said 'It's alright, its alright' and the er assistants in the chemists once said 'Do you, do you have to pay for these… erm… medication…' I said I don't know. 'Here, have a form, you can see whether you need to or not and we do deliver, we do deliver medication cos the drinks [husband] has are quite heavy and no-one will bring them for you. You know, and it's just that backup, I do think how fortunate we are that people are like that in Lancashire. They are, very friendly, yeah.
S: The man next door but one, he hasn't been here long and er… he came to me about a fortnight ago saying 'Your husband's not well is he, I'm gonna get my mum to come here and she's not well, we need a stair lift and what else' so I was like sort of suggesting things to him as well… so er… yeah, even though you're not in each other's' homes, you know that there's somebody there if you need them which is…
R:You find that really helps?
S: Definitely. Definitely, and also talking about it. About [husband]'s illness because I feel that more people that know about it is a good thing and its amazing how many people there are suffering from Motor Neurone Disease… I'd heard of it before my brother, I'd had it through David Niven and such and then my brother started with it and then its just carried on so er… It is one of those illnesses which I feel really needs looking at and er… The more that can be done, the more it out in the open it is… and I know [husband] was erm… we used to try and have a walk up town every day and when he was unsteady [oh, excuse me…] he said people will think I'm drunk and erm I said it doesn't matter does it really… so er… he was aware of what others were thinking about him… erm… but as I say he doesn't want to go out now… er at the moment. He will do what he wants to do when he's ready to do it., and its no good my saying 'Oh go on [husband], its lovely and I'll take you out in the car for a ride,' he won't go and er… as I say he might do, I don't know, but its up to him… and I… I'm led by him and his illness and as I say its no good my suggesting things.
R: So in terms of like [(name of hospital) and the multi-disciplinary team, are there any areas you… think erm…work better than others or do you think are particularly good or do you think are any problems with in any areas or…
S: I… I feel… that they are a team. I think its been… I don't know, but I feel its been led from [regional centre] and the MND nurses there and the people who they deal with in this area, the occupational therapist, and the speech therapist, the dietician, um, I really do feel it, I mean I know that in my job it was important that we worked as a team and I do feel that if people work as a team, discuss things, erm, pros and cons of things, and… and… and n like us, the carer and the patient be invited to join in as well to bring this out into the open is how people will learn from it and erm hopefully make it better for whoever needs that support. Now, we have a friend whose daughter has MS and she… she's in this area but hasn't had that support and er… whether we've been fortunate, I don't know. Whether, er… the group that we have got, really are a team, I… I don't know the workings of the other people who do the same jobs in the area but the team that we have got is wonderful. Absolutely wonderful. And you know, we know, that they are at the end of a phone. They all say that. Don't worry. If you need it, if you're worried, just ask.
S: Might seem a simple question… erm… to somebody, but if its important to you, worrying you, do please ring, because we can maybe let you sleep tonight whereas if you worried about it, you won't do. And, I just think its excellent. You hear bad things of the NHS but I couldn't speak highly enough of them.

R: That's great. Erm, and in terms of like, social services and things like that, have you, I don't know if you've had to come across that yet, but is that area…
S: Yeah, is that with the handrails?
R: … equipment…
S: Yeah, yes…
R: … care package…
S: I know this [riser recliner chair] has come from… erm… the MND through the Red Cross… erm, but the occupational therapist is a mover and shaker and er… she really is and she sorted out the handrail, and the door and also a rail at the top of the stairs… and the man who came to fit those, well he was just great as well. Absolutely wonderful. So friendly, respectful, cleaned up after himself. Yeah, excellent.
R: Erm… so, maybe the next thing is about… your ideas of erm… you were saying before you were a bit scared and anxious about what happens next really… and erm, how do you cope with that and what are your feelings for the future really?
S: Right, well. One of the things, I'm going for the reflexology. [Reflexologist], a lady who worked magic with my feet. She was asking me how I'd benefited from it and I said, when I'm having my down moments, I said I revisit my time with you. And it is, I said, as you say to me, you come here and this is your hour. This is you that we are pampering. And I said, it helps me to take myself back there and I can feel her massaging my feet and I close my eyes and er… perhaps after five or ten minutes then I come back again. And then I'm also a person who thinks there's always somebody worse off than you… I give myself a shake, go and make a cup of tea and I… I just, we get through it a day at a time.
S: I'm not, I mean I know through my brother what he was like at the end… and erm… I'm not saying I blank it out but… I can't blank it out… but I just feel the care that we are getting, that [husband] is getting, erm… will just help us through and [husband] as I say has just been so positive erm… we try and laugh about something every day, however simple, or something on the television or something we say to one another, we just try and smile about something every day and erm… I just, I feel what will be will be.
S: Erm, yeah, so, no, its making the best of what time you've got left and we've a friend whose husband had a heart attack in the night next to her in bed, they didn't get a chance to say goodbye and I said at least we're getting a chance to put our house in order and say goodbye…
R: What do you think your priority now is at this moment?
S: Be strong… Be strong for [husband]…[INAUDIBLE…] caring for him… I've known him for 42 years and … those vows that we made… to look after one another… are very strong… so that is.. I think that is my job, I call it a job, its what I want to do and what I need to do, so it's to make [husband] as comfortable as possible… Ok, I feel like clouting him… from time to time… as he no doubt does with me but its erm… I keep going back to it, it's a day at a time and… things will crop up, like I say there's somebody at the end of the phone if we can't sort it out, if I can't sort it out, [daughter] can't or [son in law], my son in law can't sort it out… There is somebody there who… will… try their damdest for us… So… I can't really see past a day at a time. I can't say we'll be, off to Turkey this summer for a holiday, but there you go… I wanted to go to Crete… Majorca… that is obviously, I mean no doubt it could be made possible but he doesn't want to go and do it so I respect his wishes… and I'm not saying… I don't feel bitter about that at all… I don't feel bitter about it at all, cos, you just take on board what life throws at you, get on with it… Next question!
R: I think I've asked all my questions, I don't know if (name of research supervisor) has anything else to ask?
S: No I haven't got anything else to ask
ID86&212
Present: Individual with MND/ Spouse/Research Assistant
(Researcher speaks)

I: It started a few years ago, didn't it? I had two dvts in a short period of time, and after the second dvt, I was having problems with my right leg and I just presumed it was taking more pressure cause the dvts were both in the left leg and I just presumed that was what was happening, so I had left it for about six months and then visited me GP and he sent me for physio,
S: Pains in the knee wasn't it?
I: I got a lot of pain in the knee, you see, so they sent me to physio and I had about six months of physio and she said look there is nothing I can do for you, so it was a case of going back to the GP, but I also have the Myotonic dystrophy gene, so they didn't know whether it was the Myotonic, so I did, I went to referral through to (Name of Care Centre) because I had already received (Name of Consultant) for the Myotonic and erm they did some nerve conduit tests, but for the first tests there was nothing sort of showing up as such, so (Name of Consultant) did a second test and after the second test they decided that they thought there was something to do with the motor nerve, and that was in November and they wrote back in the January and said it was the motor neurone and so then everything sort of (Name of Specialist Nurse) Jones came into see us at the same time, it was about five, four or five came to see us?
S: Something like that, yeah
I: and erm it went from there we started going to clinics at (Name of Care Centre), and then they got the I went to the clinic at (Name of Care Centre) for the physio, and everything for the, they moved out to (Name of Place) services,
S: You went through disablement part as well for your dropped foot, and your splint
I: originally they thought it was a dropped foot the orthopaedics at (Name of Care Centre) said it was a dropped foot and then they said oh its not, you know so I went to disablement and to there as well and was given a foot splint to help it, to stop me from tripping up because I just trip up over nothing and eventually,
S: You went to the orthopaedics as well didn't you?
I: That was what I just
S: Oh did you?
I: Yeah, yeah, and it was the tripping up that really got to me, because at first it was only a little bit but then it was quite regular, so that was another thing that brought it up as well and then we have been seeing (Name of Specialist Nurse) every three months at (Name of Place)?
S: Yeah,
I: but then the disability centre at (Name of Care Centre) they have provided me with a wheel chair, and now they have provided me with a motorised wheel chair because it is just a gradual process, but they said it's the ALS the one that I have, so it's a long term one, we've had the local physio in from the hospital haven't we? Been to physio, if I need her I just have to phone her and she comes down, I have had the local speech therapist in as well, the same again if I need her I just phone her and she will call and we have been give an OT, the first OT I was given I only saw her once and then she was transferred to (name of place), so we've been given a social services OT now which we've seen quite a bit just lately, cause we have been trying to get alterations done to the house, which has been a very difficult process, because we wanted er, originally they said they would put a stair lift in, but we were looking at the long term process of it and I wouldn't be able to transfer from a wheel chair to a stair lift, so we said we would like the through floor lift if possible and we needed a step lift outside they couldn't ramp it, because there wasn't the length in the back to ramp it so we needed a step lift outside and we also needed the bathroom floor sorting as there are two steps down to the bathroom, so we started February,
S: Well it was January when we saw (Name of Specialist Nurse) wasn't it?
I: Yes we saw (Name of Specialist Nurse) in January and he said start the process because he said it was better to have it all done now than wait till I need it, and then it be taking a while so we started in January 08 the process and now its November 08, I am still waiting!
S: So what's the hold up with that?

I: It's all been the position of the lift in the middle room and the position of the lift where it went upstairs and the bathroom,
S: And just knowing what we want, rather than just accepting what the town hall and social services want to give us, because I have got experience of in other peoples' houses with these through floor lifts and step lifts so I had a bit of knowledge beforehand and I spoke to people and they have given me their experiences so we took that on board and looked at what we need and this is where we have come to, we didn't seem to be going anywhere, and we were bringing other people in, the local MP her PA and she sent a letter to the top of adult social services care and then just came down the line all the meetings were cancelled and they come back couple, a month later, didn't we? Started revising things, things have slowly moved on but not quickly and there was a bone of contention of, erm how much we have to pay, because of our ages, we are under sixty and we are over eighteen, and I work, we have to pay first ten thousand pounds was the first figure that come out, and we just looked and laughed, we still got to pay four thousand, nine hundred and ninety five pound which I still think is wrong but don't thing can't get away from it now, and they are dropping off the paper work this afternoon for us to sign, but we have told them to leave it cause we want to look at it and go through first, and sort it next week and we have another meeting next week and hopefully move on.
I: So do you feel you have had to fight to that?
S: Very much,
I: Definitely, there is a lot of people would give up, erm I spoke to various people, people who used to work in social services, and the finance side of it and they have told me what they have seen and how they've felt and they've got out and I have also worked for the disability association in (Name of Place) and asked them their views, and there was one particular incident, I think there was three, four different people with different agendas, within seven or eight people in the house and (Name of Patient) just broke down and from then we have moved all the meetings to the disability centre, somewhere neutral, (Name of MND Care Co-ordinator) has come and she's put her point, (Name) who runs the disability centre, she has lived in a wheel chair for over twenty years, so these people who think they know what's best for us, have got to go, have got to prove to (Name) that what they think is best is the right for a person that's actually living in a wheelchair and the two don't mix, they can't convince her that what they say is right because she knows what they saying is wrong, and for one instance they wanted to put a shower room in the spare bedroom, and they drew the shower room up and I took it to (Name) and said is this a disability shower room? And she said no, they have just dotted things where it was easier for them, so, I had a fair idea where of should it go but I wasn't 100% certain, that's why I went to see (Name) we are fortunate because of the experience I've got and the people we can go to, to find out advice, another particular instance when we were going through the chair, the OT had phoned (Name of Care Centre) up and asked for an electric powered indoor and outdoor chair, said it was an eighteen month waiting list, I think we waited a month and didn't hear anything so I phoned up and got the relevant person, and said about the chair and she said again eighteen months and I said well talking to (Name of Specialist Nurse) with it being MND it shouldn't take that long oh specialist case, we will phone you back in a couple of days for an appointment we got that within a month, no couple of week, and then within five week the chair was delivered, the OT was saying they won't deliver the chair because we haven't got ramps, access to our house in or out for the chair, they could do the front. We didn't want the front from the security issue, we wanted the back and when the lads came to look at the house they said they could have ramped it, anyway they weren't bothered, that they could get the wheelchair in and out and they came and delivered it,
I: That's good,
S: Its good but the OTs don't really understand what wheelchair services are doing in (Name of Care Centre) and what they can do and what they can't do, they are talking to them from what I see, from what they want and if it doesn't fit their box then you can't have it but when you bring these people in they see different things and say no, we don't have a problem,

I: But it was also the fact that she hadn't put down that I had Motor neurone disease, if she had put that down they would have known, so that to me is a fault on her behalf by not stating what sort of disease the person has when they order the powered chair.
R: So you think there is a problem of people not really talking to each other and communicating well?
S: Yeah and stating what the issue is right from day one, whether it is Motor Neurone, MS, Parkinson's, Huntington's whatever the disease and those little things do make a difference to the people on the other end of the phone, because totally believe that they with the best will in the world, can't understand every disease, but as soon as you mention the disease, then it will click into a various box with them to pass that onto the right people, but frustrating yes and can understand how people do give up and end up with equipment that is totally unsuitable for them and will never ever use, the amount of houses I've been in and altered stair cases for their stair lifts, and five months later I've gone back to redo the stairs because the people can't use the stair lift , its just a short term option, and £1500 it's a quick fix for them but it isn't for the people that have got to use it, and this is what we didn't want, its gonna be a long term thing so we wanted to get it right first time around, the guy in the town hall who deals with the grants, he wanted to knock walls down and make it all open plan so we can get the wheel chairs in and out, because (Name of MND Care Co-ordinator) was saying there was a bigger wheelchair that she possibly might need, no guarantee, might need, and that's they wanted, virtually wreck your house for something that she might never need, but I also understand it from their point of view, they have got one lot of money and try and do it all in one go, but just to me it just doesn't work that way, shouldn't work that way.
I: Well you try and keep your house as your home and they're coming in saying 'we'll take this wall down, you don't need that bedroom, that's a big landing', you know so you've lost a complete bedroom which you do use, cause I use it as a work room, and like the middle room, we wanted the lift in the alcove, 'oh no you can't have it in the alcove it had to go here', and so you've lost a small room there, and in the winter it is the warmest room in the house, as we have a wood-burner in , we do use this room, but we would like this room kept like this, but in the lift in the corner so we can still use it as a room, 'oh no that can't be done', and you think well we've had the measurements, we've had the lift people in ourselves to get advice off them, rather than just go by their say so and they say 'oh no, no it can't be done, it has to be done this way' and you find it very frustrating that you've been told it can be done and they say it can't be done, and even when they eventually agreed to have it in the corner they turned round and said, you might be able to have it there because you might need a bigger lift because your wheelchair might be wider than a normal lift you might have to have a wider lift, but when you check the measurements your wheel chair is not as wide as the lift, so every time there is a solution, you get a letter to follow saying it can't be done
R: So you feel that people aren't listening to you?
S: Well that instance when they were all in the house the last time, they weren't talking to us they were talking about us, as though we weren't here, I think it was what? Three and a half hours, nothing had been resolved, didn't have any dates, any timescales, 'oh well we will bring someone else in, we will bring someone else' in to have a look, it was as if we were just going round in circles, and it goes back to the lad who works at social services, in the finance he said they will wear down and hope that you give in, or the other case is, because motor neurone disease, because it is an individualists disease, people have got a short term lifespan that you will die before they have to foot the bill for it, and the other side of the coin is they brought anchor staying put in, they brought their lads round to have a look at the bathroom and see what they could do with it, at the early stages they were talking putting another lift step lift in there, and they were talking of lifting the bathroom, at one stage I think it was about seven grand I was up there with this lad from anchor and one of social services, and she turned round and said well it could come down to cost as against time of life if they are going to put say seven thousand pounds worth into a bathroom or thirty thousand pounds worth into a house and you have only got a short space of time left, they won't do it, I didn't say anything but I just left that to one side to come out at a relevant time

R: So you feel really let down then I imagine with the social services?
I: With that side of it, yes
S: I've said this to (Name of Specialist Nurse) and to a few other people, the OT, I don't like her, I just don't trust her, pure and simply I think she is not used to dealing with people of our ages, and people who do have a little bit a knowledge she turned round when we were talking about the chair over the phone, the people that deal with it in (Name of Care Centre) are the best people to advise you, well, I tend to disagree on that, abled body people who think they know what is best for disabled people are wrong, its disabled people who use it, that will give you the best advice as to what the abled bodied people should be doing, looking and thinking and she has never broached that subject again, so, but she seems to better now, there doesn't seem to be this conflict, whether it is because a lot of the issues are sorted out I don't know but when we talking about the bathroom, they were talking about putting a seat on, a fold up seat so (name) could sit and have a shower well that's alright for the immediate moment, but long term she is going to need a shower chair, she might not need it, but it is there when she is going to need it, oh alright then it takes about three weeks order you tell me when you want it, as soon as we get the ok for the bathroom, you order it and then its there when its done, its just frustrating,
R: So do you think they don't have knowledge of MND, enough? Do you think that's a problem?
I: She has a little bit of knowledge as she is very keen on MND and learning about it. But as (Name of Spouse) says I think it to do with the age of people
R: That they are used to deal with older clients?
I: They have older clients, who are over sixty
S: They don't have the time that we have had to get things in place before we actually need it,
I: They have symptoms for when they have a shorter life they just accept what they can take just for that period but when you've been told it's a longer one and you know what you want and as I say you still want your house to look like your home,
R: And that your needs will change over time as well,
I: Yeah, that's it, and I can think about the times when I can't move, and I need the help and the house is done, so we are looking at the long term not the short term, and I mean like now cause I have got the wheel chair, if I want to go out, (Name of Spouse) has to put it in the garage, I have to try and get to the garage to go out if I am on my own, they don't tell you things you can get do they?
S: No, there is no information coming in regards of er things to help, as in pointers, go down, phone these people and they will help you with this, phone these people and they will help you with that, the lady that come in from Anchor in their brief they can help you with support for this and that and the other but nobody has come in and sat down but by the same token, we haven't actually phoned them cause they keep saying we can do this for you, we can do that for you, so if they are saying that they can do this, we can do this, then why aren't they coming? Rather than us going to them but also on the other side of the coin I do appreciate and understand that if somebody is in their sixties and they go into hospital and they find out they have MND and what have you and they need things changing before they can come back home then that is a different scenario and that's probably where they are more geared to getting things done straight away as what they want as a short term kit, but that doesn't work in our case and the town hall to me, seem to have a one sized fits all, which is doesn't.
R: What do you think would help you both in this situation?
S: Well hopefully we are just about through the situation,
I: I don't know, I honestly don't know what the answer is.
S: I think to a certain extent, the people who are in charge of it at the town hall, don't really understand a lot of the diseases, so this is why they come in with just right, this, this and this, without listening to the person that's got the disease and what happens to them, as it goes through the system and that way if they don't understand a lot of diseases they don't really know what the person needs in the long term, which I know they are only council workers but if they are dealing with this sort of thing they should have some sort of knowledge of what's happening.

There is various branch organisations, for the various diseases that are around so why can't they tap in to them, and use their information and their knowledge because most of these people have actually been through this scenario, they have been through it all and they are on their own because their partners have died from it, so again its going back to, the people, the best people for the knowledge are the ones who have been there and again I understand that they only have a certain amount of money to spend but an individualist disease doesn't go by the cost, I've got this disease but I can only, it's a disease that only spends twenty thousand pounds instead of fifty thousand pounds well if you need the stuff for fifty thousand pounds then surely that's what you need, why should you only get thirty and if you can't afford the other twenty thousand what do you do and the first words from the OT when she walked through the door 'have you not thought of moving?' To save them money.

I: She said 'This is a difficult house to change. You'd be better of going for a bungalow.' I said, 'well, I am five minutes from town, both my daughters live down the street so I there my back up if I need them, if they're not in, their husbands are in, so I have got back up there, because we are so close to town I have friends visiting me here, if we went to a bungalow, they are all on the outskirts of town, I wouldn't see anybody, which would make it a very lonely day for me, whereas its nice to see people that call in that are close by.

R: And it's your home!

I: That's it we've built it up all these years, and sort of said when we bought the house we said it would be fine for us when we retire even though it's a big house it will still be fine because we're so close to the amenities, Yeah, so we have got the town, we have got a lovely park that we go for walks in; we have got the shops close by if you can't get into town so why move to somewhere where you wouldn't be happy, so they don't look it at that way either.

R: You think they are not really looking at you as a person, they are just thinking about money and cost saving?

S: You're just a case number, unfortunately, which everyone is this day and age, but there has also got to be a little bit more to it than that I would think

R: More humanity?

S: I would think so.

I: Its like the (DFG form?) that we applied for, its means tested, because (Name of Spouse) works it goes off his wages, but I am the one with the disease, it should go off me not him, you know it should be the person with the disease that its affecting, that can't work, not the partner in the house, it just seems unfair, and yet these people where the partner doesn't work and they are on the social and all that, they just get it, and we have worked just the same, and not claimed anything, just worked, get the house nice and had a couple of holidays and that, it just doesn't seem fair, Its just has it been hard work this year hasn't it?

S: It has.

R: You have enough problems with just coping with the disease without all these as well.

S: That doesn't bother me as long as they listen to what you are saying or you have an input and they do take notice and don't we've listened to you say now you just go away, we will deal with it, we deal with it all the time and we know best. I've got a little bit of knowledge of that cause I work for myself, because I go into people houses and doing jobs for people, I've got to listen to them so I do what they want, and I get paid, these people get paid regardless of what they do works or not, they are not accountable in that respect.

I: We have had good support from the MND association haven't we? And we have had good support from (name) which is the MP's personal assistant in (name of Place) and she says 'right no that is not acceptable and basically you need this', so we have had her backing with a lot of it, but the other people seem come and expect that what they say goes.

R: How did you get involved with the MP?

I: She's a friend. She just lives locally you see so we know her through that, well we weren't getting anywhere, where do we go from here? Who can help to get things moving? So you spoke to Jane

didn't you? And she said 'right we will help you to get it moving because the length of time its going is not acceptable for someone who is ill'. So that's why they got involved in it, and it helped in the beginning didn't it?
S: Yes it did yeah, and I think it helped with the wheelchair, as you can see its got a higher back, its got side support , it came with a head rest and a lot of them are extras, so (Name of Patient) has got the wheelchair over and above what the OT would have got for her,
R: It would have been just a normal wheelchair, wouldn't it? Same as a,
S: An assisted wheelchair.
I: No, The assisted wheelchair, the back only goes to the handle, so that's higher, when the head rests on it just comes in the right place, when that just happens you, its needed, so we feel that's helped to get it all in one go instead of phoning for extra bits.
R: In terms of other equipment, with the OT has that been timely or?
I: Erm, I have two perching stools, and that's it, isn't it?
S: A pick up.
I:One of those pick up handle things if I drop anything.
S: And a long shoe horn,
I: I can't work that, (laughs) she gave it me sock assist but I can't work that either,
S: Which a lot of people can't
I: Because, when it's on your feet, your feet don't go in the right direction, to put the sock on
S: It depends on your disability with the sock assister as to whether it will work or not, because (Name of Patient) can't lift her foot up and push her foot down to go in, it doesn't work,
I: It doesn't work, My foot doesn't move you see, so
R: So it isn't much help?
I: So it's a case of before (Name of Spouse) going to work getting up so he can put my socks on for me. That's all I have had off them, that's all I've needed.
R: How do you feel about the future then if you have had all these problems up to now are you worried about or as time goes on?
S: No, not worried cause we will just go down the same the route, just go back and get (Name) involved again and start talking to other people, it shouldn't be the exception, we are having to do this, what should be the norm is people just should phone up and should be able to do it, but as go you further down the line, the disease is going to be work and so there are going to be more pressures and really we don't want that, but hopefully because we have been down this route, but with various people down the line or working with them, that it will be as soon as our name comes up, well hopefully, not saying it will but hopefully, they might act straight away, I don't know, we haven't or (Name of Patient) hasn't been assigned a social worker, now obviously she doesn't need it just yet but in one respect it would have been nice to have had a social worker appointed, like the physio or speech therapist where you've made some sort of contact, and she could just phone up 'is there anything you need?' , 'do you need?' you don't need them to come out, but as long as there is somebody there that you've met while you are in a good state of health and mind, that you can deal with and talk to, you know then on the other end of the phone who it is rather than your disease has gone so far down the line and emotionally, you will be wondering who is going to come through the door next.
R: You are a bit more vulnerable then, aren't you?
I: Yes because I don't phone the physio or speech therapist they tend to phone me, is there anything you need are we doing alright?
R: Do you find that works?
I: Yes I do, because I mean had a problem with swallowing a while back, so (Name of Speech therapist) came out and discussed it with me and after she left I thought 'oh', she thought I might have had a, have a reaction to something now my bodies changing and I've always had coffee black and then it makes you think, and I thought it does happen when I've had a coffee, so I put milk in it

and I don't choke anymore, so it just gives you the ideas, so you can think about, what is happening and what you've had at the time it happens.
R: And you feel that having that contact earlier on makes a difference?
I: I know if (Name of speech therapist) is coming, I know whose coming, I know who I am talking to on the phone, you've got a face you can put with a name, its when you haven't got a face to put with the name, you find it difficult to talk that person, so yes, so yeah, I mean its like seeing (Name of Specialist Nurse) all the time, you know who you are going to see, I mean you know what you are going for and you know what he's going to do, but you know its not going to be a different person all time, so that makes you more relaxed, than it would if it were, well for me personally, than if I didn't know who I was going to see.
R: How do you feel about the Hospices and having the visits there?
I: I don't mind, I don't mind one bit.
R: Has that helped with travel and things?
I: It has yes
R: Yes it has.
I: It's helps a lot. I am in (Name of Care Centre) in January, so (Name of Specialist Nurse) said he will see me at (Name of Care Centre), I said it will give someone else here that appointment time if they needed it. It seems silly doing two appointments one in (Name of Place) and one in (Name of Care Centre) when both could be done together.
R: In terms of the services at (Name of Care Centre), I mean taking you back to the diagnosis stage did you feel it took too long, did you feel it was a rather drawn out process?
I: Well as I say, because they were looking at the myotonic side they were looking for the motor neurone side, they had to decide themselves which the disease actually was when they did the tests so it did take a little bit longer, but I understood why, because the myotonic is a neurological disease as well, so it must have been difficult for them to diagnose which it was that was actually happening, so I understood the period of time it took.
R: Did you feel you got support from the team following the diagnosis?
I:The initial, when they said the motor nerve was damaged, no because that was all we got and then it was time to go,
R: So they didn't tell you what it was?
S: Not at that particular stage and we waited three months and when we went back, we had a list of questions, and it was something we had worked between us, and then when (Name of Specialist Nurse) had come in to see us, and the various, we saw (Name of Consultant) again first and his two understudies, I think it was and then (Name of Specialist Nurse) came in, (Name of Specialist Nurse) then took us into another room, and was starting to explain it to us and when he was asking if we had any questions and because with strangers (Name of Patient)s not too good at saying what she feels and what she wants to say , I was just asking the questions and he looked at me and then he looked at (Name of Patient) as if to say well, you're person with the disease it should be you, but then once he realised and understood, that wasn't a problem then, he has been good hasn't he, in that respect?
I: Oh yeah, yes he has
S: and from, the care from their point of view, just picking a phone up and asking a question, if they can't answer it there and then, nine times out of ten they do get back to you within four hours, and if they can't they will tell you it will be a day or two days, which is brilliant but that first initial consultation with (Name of Consultant), but talking to people, the first time you come into contact with him, a lot of people don't like him, because he is, he's on a different level I understand that because I have worked for the nuclear physicist and what have you and they do work on different levels, they don't seem to be able to bridge from the top to the bottom and that possibly is just the breakdown with it , because nobody, well some people might know of the initial diseases, whether it's the same for the cancer sufferers when they're first told, I don't know how they deal with it
R: So you feel it wasn't very sympathetic, the way it

S: The second consultation was, but as I say it was just when he said the motor nerve was damaged, and then you go away and come home and think, motor nerve, motor neurone,
R: So you were thinking?
S: Yes its them first thoughts, and you think, well if they think if that why don't they say It could be but then it would upset people too much,
R: So you think that is why he didn't say?
I: I don't know, I don't know
S: Well which is worse upsetting somebody there or letting them go away and the distance we've got, for three months and not having a contact, alright tell them and say look, if you need to ask any questions, here is the telephone number there, they've got the backup, they've got the team there, whether the team knew of us, before we went back, I don't know I don't think it did,
I: It didn't help because I actually worked in a pharmacy, and I was dispensing medication, so I had the medical books to look at in work, you know and you look at these things and you read them and think, is it them? After you've thought about it and you've read it, them symptoms are similar symptoms to what I've got, and is it that? So probably that hasn't helped, didn't help me those first initial months before it was definitely diagnosed, a lot of it is part and parcel isn't it but you just think,
R: There are diagnosis guidelines and I think it does not sound like he was really following them,
S: When we come back, and people had asked us how it had gone on and we told them, 'well didn't you ask any questions?' I said twenty four, forty eight hours after you've been told, yes, you start thinking, but when somebody tells you something, because normally I am fairly good at picking things up straight away and asking a question, but even that shocked me so I just wasn't even thinking any further than what he said.
I: Well. We had friends with us, didn't we as well?
S: Not the first time when (Name of Consultant) told us, we were just on our own.
I: Oh I thought they were there, then.
S: No it was when we went back because I think we were there for three and a half, four hours, that particular time,
I: So ever since we have been told properly the second time, its been good because they have drip fed us information, they don't try and give you all the informational at once, and you don't take it in or you miss bits, so we have been having they give you bits of information
R: Do you like it that way, do you feel that they are giving you the right amount at the right time?
I:Yes, yeah as I say if you have a question, you phone, well (Name of Spouse) phones up and gets the answer but when we have had meetings, we have had questions and we've had answers, haven't we? We've had the information as we have gone a long, I think if they told you all at once, because you are in shock of what you have been told, you wouldn't take a lot of it in, cause I think your mind would turn off to what their saying to you,
S: and sort of shut down really, Its like they have said that, well, (Name of Patient)'s is the ALS and it's the long term one and they are talking ten, fifteen, twenty years and you keep hearing this, and you keep reading the magazines, and people are dying, are diagnosed in the, they have died within the fourteen months, twenty , twenty four months, and you're thinking, if there are all these people dying, and they're saying this, the two don't match up, and its an individualist disease, and its good in one respect when you do go to (Name of Care Centre), whether it is for the MND or the Myotonic with (Name of Patient), you don't always see the professor and you don't always see the same understudy, you see a different one, there was one time we walked in or (Name of Patient) was walking down with her sticks, there was an Irish consultant, he had done a lot over in Ireland but with the (name of clinic) and he was asking (Name of Patient) about her MND and how long she had had it, and blah, blah, blah, and he said well if it had been a quick one, you wouldn't have walked as far as you have now, and it was oh, now what they are saying is right, but it just took somebody else from a different aspect it was the first time he had seen (Name of Patient), probably read her notes and then fine, and what they do say is right, because sometimes when you do phone

up and ask a question, 'oh well its not that easy to answer that question because it is an individualist disease and it goes down different routes for different people', 'fine, ok then', but there must be parallels that they can go by because where do they get their basis for their research?
I:Well Its like we get the thumbprint don't we from the MND association, and there's peoples stories in that, and once I started reading that I felt happier, some had had it for a lot of years some didn't but you could read it, yeah, this, that and the leg and all that and fourteen years down the line, they are still, still going, maybe in a wheelchair but they are still, so I found that the actual reading about it, of somebody's story does help, whether anyone else does I don't know,
S: Plus you went on the internet to have a look at the motor neurone, didn't you? I totally think they give you a worse case scenario on there, from a legality point of view, that did upset you didn't it, what you read,
I: I have never done on it again,
R: Right, because you feel, they tell you too much?
I: Well, they tell you a short term version of it, they say they twelve, fourteen months they reckon, don't they? And that's the ones they don't tell you they don't tell you about the long term one.
S: Because you are giving somebody with the short term false hope, they can't do that, that's why I say they give you a worse case scenario from a legality point of view. And is it the same for your area, like is it the same for people in (Name of Place), as it is for the same as people down south because they have different environments, and there are, different things that come into your whole life structure, I don't know,
I:Well, It was like we were talking to our friend (name) that's in the association, and she is a visitor and she said there's are a lot of people that they don't know has it, because initially when you are first diagnosed, you don't want anything to do with them but once you get involved with them, it is a lot better, because they can help and direct you, but if you don't get involved with them, you're on your own, I mean at first I said I couldn't cope with the association, I don't want to know and all this, and we were going to (Name of Care Centre) to visit (Name of Specialist Nurse) and (Name of MND Care Co-ordinator) was actually in the clinic, so (Name of Specialist Nurse) said 'Well (Name of MND Care Co-ordinator)'s in the clinic would you like to meet her?', and I'm sort of thinking 'No not really, it's a new person', and then I said 'go on then, but it doesn't mean I have to do anything about it', and after meeting her and talking to her, we did go to the association, didn't we?, so I can understand people's fears of not going to them because I had that fear, but now I'm glad I did
R: How would you say they've helped you?
I:They purchased a scooter for me, when I didn't have the wheelchair to get around they are just back up if we need them, aren't they? You know, because the visitors they have had somebody in the family that's had the disease, and maybe died, so they want to be involved so they have a knowledge of what's, what's going on,
S: They like have the everyday knowledge, don't they, of how you cope with it, medical knowledge, that is a different issue again and this where (Name of MND Care Co-ordinator) comes in, because with (Name of MND Care Co-ordinator) working on ward 17, she has got that knowledge,
R: She's got both sides, hasn't she?
S: You can talk to her and she will tell you, er this was one of the first questions we asked, when we were first told and I phoned up, I think I was talking to Pauline at the time, we said 'if we ask a question, will be told the truth, I don't want to be told a half truth or well, you no, that won't happen and then so far down the line it will happen, I d like to know, , she said no, we will always tell you the truth, which is fine, I know that some people don't want to be told that, they want to put it in a cupboard and forget about it, and it must be hard for them to be able to decide which people can cope with the information, and deal with it the best and how far do you go?
I:But I think you have to have that information at the end of the day of what's going to happen, I don't think you know that you can 'Well I am going home, I'm forgetting about it, I'm just going to my appointments when they phone for me', I think you've got to know some information of what's happening,

R: Then you can make decisions can't you?
I:That's it, I mean especially for the ones who have families at home still, I mean we are lucky as both our daughters are married aren't they? But we have grandchildren come down, the youngest is six, and she is very good, helping and doing things, you know, if she see you trying to get something, 'I'll get that for you', I think you have got to sort of take it down to their level, where I used to go the park with her and stuff like that, when she was off school, but while I didn't have a wheel chair I can't do that so she used to do baking with me and things like that so she can see I think people need to understand, just because you have got it you can still make adaptations, to do things with people that you did things with before.
R: So how do you feel it has affected your day to day life, do you feel you are bale to carry on and do things?
I:Hoovering and dusting, well I can dust if I hold on to something at the same time, (laughs) I can walk around the house as long as I can get hold of something, if I can't get hold of anything I won't be able to do it, I can't stand at the sink to prepare meals, erm I can't do bedrooms, the everyday part of it is sort of slipping away, but I do what I can, if I have a good day I can l do a lot of things I can still fill the washing machine up, I can still sit on my perching stool and do the ironing, things like that, if I am tired, I will lay down here and have a sleep, I don't push, push myself to the extent where I lose days afterwards, so I just cope as each day comes, if I get up and I'm tired when I get up I don't, I'll sit and read, do some sewing things like that, I make cards and I do patchwork quilting, so that keeps me occupied, knowing I can't do anything else but I know can do this, I can sit here and do this, I am doing something not sitting here thinking what's the point of me being here when I can't do anything.
R: That's really important isn't it?
I: Yes, that's it, so we are coping between us.I spend more time with the kids than probably I would have done previously cause I would have been busy working and doing things so I've made more time to spend time with them, we've done more things together so in some ways there is a positive side to it.
S: And this is part of the problem the town hall don't understand why you need to keep your rooms as you need them, because (Name of Patient) goes cold all the time, if you make a house like this open plan, you will never ever keep it warm, so if you're cold, you are not going to do anything because you don't want to move and if do move, if you are cold you're limbs aren't as strong, could cause more problems.
I: I used to have a craft room on the very top, which is, cause its three storey, when they said we were going to get a lift in, I said to (Name of Spouse) well what was the back bedroom which my granddaughter stays in I can turn that into my craft room, put my sewing machine out in there, have some draws with my cards and everything in, stuff like that but then when they wanted to make it into a landing, I thought where am I going to put all my things? To me it felt like they were taking it away, because you would have nowhere else to put it, especially as they were going to take the whole back sitting room as well and you think well, that's my life line, that keeps me going, something's do affect more than others but now they are doing it as we originally wanted it, we can turn that back bedroom into a craft room, I can leave my sewing machine up and that cause I can't carry it to put on the table, so its adapting things round adaptations, isn't it?
R: Do you feel that your emotional needs are supported as well, where do get support for that?
S: Other people find it hard don't they? I don't think they understand the emotional side of the disease, she can be talking and suddenly she will just fill up and they don't know why.
I: And then they panic. I did it on Saturday to my brother, we were supposed to be going to his daughter's wedding, but (Name of Spouse) wasn't very well, so I phoned him to say 'we won't be at the day do, see how (Name of Spouse) goes but we might be at the evening do', about half way through the sentence and I went, put (Name of Spouse) on, he was panicking, 'what's up with her? What's wrong?', 'Nothings wrong, its just the way it goes sometimes,' I have a friend, and at first she tended to mollycottle me, and she was here all the time and (Name of Spouse) had to speak to

her and say (Name of Patient) is still (Name of Patient), there's no difference but she knows, if she thinks I've had a hard time she will come with flowers, I know you've not been so good and I can tell by your face, and she will bring us a bunch of flowers but other than its just (Name of Spouse) cause he understands, it's difficult to get other people to understand that's it's just the day I am going through, so.
R: Do you think there is any need for a service within the health for that side of things or do you think it is not necessary?
S: It's part of the disease, I would have thought there is something up and running, again if it is I wouldn't know where to go to find out, but then again I suppose each case is different and it will affect different people at different times
I: I think its with all the barriers we've had that's made it worse, if we hadn't had so many barriers it would have been better than it was, because I can be emotional anyhow before it happened, it was just my nature so,
S: Because pressure brings different problems, in different ways, and different things trigger it.
R: People cope in different ways
I: Yes
R: Do you think some sort of counselling would be useful?
I: Personally I couldn't talk to anyone about it, so again that's individual, I just get on with it in my own way, because after you had spoken to (name of brother) put the phone down, ten minutes later I was fine, so you just deal with when it comes and when it goes, that's it, its gone.
S: No doubt the counsellors would be sympathetic, but to be open to them I think it would take a long time for certain people to build that trust to be able to tell you how they feel to a virtual stranger, even though they do understand and they have been trained for it, it still wouldn't be easy, I don't think
S: I think that side of it, you still class it as your problem, not as somebody else's and that they wouldn't understand even if they would but you just feel that you just get on with that side of it. This is where, sometimes you are better off speaking to people in the branch, because they have been there and done it, unfortunately life is an experience, once you have been through something you have lot more understanding of somebody else.
R: In terms of other services, do you feel there is anything else that is missing?
I: I feel at the moment that its all being, people are doing what they can, I don't,
S: I don't know because the disease hasn't progressed that far or fast, if it had progressed that fast a lot of other people would have come into play a lot sooner erm, so it's a case of wait and see I think
I: I think that's a case of now isn't it? Because I am struggling with house work, we have discussed it only this week do I get somebody in to help, but if you want somebody in to help, who do you see? You don't, who do you contact for that type of thing? You don't know.
S: This is where the social worker would have been useful. Yes, you would have that contact initially, then, when you are ready, you think about, you pick the phone up and said we are thinking of this, we are thinking of that and then she would possibly have had an answer, or come round and sit and talk, sounds like you need this, you need that and bring the various people in, and see then because the first person who walks through the door isn't necessarily going to be the right person and that brings another set of problems and kicks off another set of emotions.
R: So, just to be able to have some options at this point so you can think them through and decide for the best? At the moment you don't feel you have got any information?
I: No, not that side of, it, like if you didn't leave lunch for me, and I couldn't do it ,you hear of people who they come in and make lunch for them and you think, you don't know the people but you've heard them spoke of, where do you go, you know, to contact them? I think its contacts down the line, isn't it? As things progress and you need more things, its contacts of where you find them.
S: Locally as well not just kind of, national offices.
I: That's it, because the OT's for the equipment but who's for the other side of it? Which is the thing, I mean, I suppose If you are an old person, you have a friend who is getting things like that, but when

you haven't retired and you haven't got friends that age or you might have friends that age but they can do things themselves,
S: Or busy working.
I: They don't know who, they can't put you in contact with anyone because they don't know anything either, so I think for the younger side, that sort of thing is more difficult to find out.
R: Do you think (Name of Specialist Nurse) could help you with this?
I: I don't know, for me (Name of Specialist Nurse) is the medical side, I know you shouldn't put people in boxes but that's he deals with the illness not,
S: He could probably tell you the name of the people of the group that you need to get in touch with in (Name of Place), and then they would probably be able to facilitate the right group that you would need to talk to, I don't know
R: It's a long process then isn't it?
S: Yes
I: It's like I had to fill some forms out the other week, because I am concerned if I was at higher rate of care component our contribution would drop and why wasn't I in the higher rate of care component? I said I don't know I filled in the forms originally and got the middle rate but trying to find someone that would help you, to fill the forms in,
S: Because she struggles to get out, and the services that help you they're struggling because they are oversubscribed if you will.
I: so you just do it yourself, and
R: and struggle,
I: Yes, and they say things on the phone and what to they actually mean by that?
R: They are not easy forms either are they?
S: That's a difference between gaining finance and losing finance,
I: The daft thing about it is, that citizen advice in (Name of Place) don't do home visits, but you phone Citizens advice in (Name of Place) and they will do home visits in (Name of Place),
S: Ten miles away.
I: And you think how does that work? How can they do it and they can't? The only reason knew that they did home visits was because my daughter is a nurse at the hospital and she said we had someone from citizens advice from (Name of Place) today, how did that happen don't; know but I got the number for you because I knew you were after someone to help you fill forms in, well its too late because I have done it now and sent it off.
R: But if you had known that, that would have been really useful, so it's that sort of information that you don't really have?
I: No, so that's just an instance, so the information side of thing does really let people down I think, because well, you have never filled these forms in before and you look at them and think well what do they want?
R: How do I do that?
I: That's it
S: And of course all these places are open during the day, they are not open in the night time so for me to find out the information, I have to stop work to phone them which means I am not getting paid which means your finances drop, and that then triggers a whole set of other problems
R: So its extra pressure on you then, isn't it?
I: Yes, I think the partners must have a lot of pressure, whether it is a male or female partner depending on who has got the problem because they are trying to help but they don't know where to go either, there is no back up advice for them, or if there is, it's during the day
S: Again whether this comes down to a branch organisation or whether it comes down a social services organisation, for drip feeding you that sort of information again, you can only absorb a certain amount, you don't want to accept everybody in your house at the time that every body is coming, because you do need different peoples

at different occasions and because this is the first time you have gone down this, it's a learning curve, no doubt this is part of this study to try and understand the various problems and take out some of the problems to

R: Make it easier?

S: Yes if life is any easier, (laughs)

R: I think that's all my questions have you anything else you'd like to add?

S: No that's it so far.

R: Thanks very much.

ID 94 &ID205

Present: individual with MND/ spouse/ research assistant/ research supervisor

I: I had some logs fall on me, and 2 or 3 days later I noticed I was walking with a foot drop, I thought it was the logs, I thought I had trapped a nerve as I turned around to stop the logs falling on my brother who had a heart attack at that time. And I went to a physiotherapist who noticed that the muscles in my calf had gone, but that's not unusual in the country because people on horses opening gates, crash the knee and the calf goes, so I wasn't desperately worried. But she spoke to my doctor, my doctor sent me to…we owned a hotel at the time.. and told me to go to a private consultancy, where I went to. This guy…..was an….. he insisted I pay him before I saw him, he sent me for all the various tests, lumbar punch, EMG tests all those things. And then just before Christmas he said that I was going to loose my legs and arms. I was extremely shocked at the manner in which he said it, so I called to (wife) who was waiting outside. She came in, she got very upset, didn't you? And we drove back. Now I didn't believe it at this time, because I was just walking with a limp, I eventually ended up walking with 2 sticks, with 1 stick rather, then it went to 2 sticks. We managed to sell the hotel and we moved into a small house in [place name] which was very small, and I then had difficulty getting upstairs.We then went for a second opinion to a place in [place name], and saw a surgeon there, who said it was most probably motor neurone. So this was 6-9 months later. The EMG test said that I hadn't deteriorated from the first test, so again we were a little anxious. We managed to sell the hotel and move permanently into the other house but I couldn't get up the stairs, with the result that we had to put the bed downstairs. Having negotiated to buy this house at that time, because it had the space to move the wheelchair, we moved over here. At that time I was walking with 2 sticks and at that time I slept downstairs in the bedroom with my wife and at that point I found that I couldn't breathe when I lay down , I just couldn't breathe. So I used to sit in the chair in here because I felt I could breathe better. At that point I had difficulty breathing. Had we gone to the MND society at that point?

S: No we hadn't

I: I had extreme difficulty breathing, I had hallucinations, and I had vertigo. And I used to shout in the middle of the night and I didn't speak during the day. But in the middle of the night I be screaming again and screaming for my wife and ringing through to her telling her to sell the boat that we had or whatever else, and we didn't have a boat, lots of things. And then the hallucinations came in and with the vertigo it was horrendous…

S: ….started the pills?

I: At that time I hadn't started the pills. Anyway I had 1 night that I was particularly wild about the hallucination and I fell out of the chair and [spouse] had to get the paramedics around and lifted me back. Shortly after that… before that sorry, we'd been to see [neurologist] about this time of these hallucinations and he said that he would see me again in a couple of weeks. I spoke to [MND nurse] and another doctor who said you don't look like you've got it because I was talking normally and my breathing was OK. And then I came home and had these massive hallucinations and they were getting so severe that the doctor came round, my breathing was very bad, so then the what do you call them…they deal with cancer.. the Macmillan nurse came around and I said it was desperately bad and I had really heavy breathing. [wife] mentioned that we'd been to the MND clinic and at that time they spoke to [Sp nurse] that they needed to get me in. It was for one day's investigation and I said I didn't want to go. Eventually they got the ambulance to take me and when we arrived at [place

name] hospital, I collapsed. This is where [wife] will have to come in.. I remember waking up in [place name] hospital with a NIPPY machine and I was breathing with that. I was breathing OK and they decided to take the NIPPV off me.. Dr [respiratory physician] was dealing with it at that time and they said they'd leave me for a period, they left me for about 3-4 days, I was bed ridden at this time..at the end of 4 days I just collapsed again because I hadn't had the NIPPV involvement. At that time they then sent me down to check my diaphragm on the ultrasound. and they said my diaphragm had gone, so came back and I had difficulty breathing and then I collapsed totally. [wife] was called out from here. My son who is at boarding school was called out at 2 in the morning and came round. When [wife] saw me. I was ashen. The registrar eventually put the NIPPV on me at full belt and left me for 2 or 3 days and I eventually came around again.

I: At that point I was in hospital for 6 weeks predominantly because I was in hospital in [(name of hospital) and I live in Cumbria and Cumbria would not take a care package for me. So there was negotiations about a care package going backwards and forwards all the time… eventually it was decided that instead of coming home, I wanted to come home, ..they decided to move me to Cumbria to Westmoreland general hospital where I stayed for 2-3 weeks. At that point they said that I was worthy of care, full time care. Then came the problem, they couldn't find the carers.. a big problem. Eventually we got one carer came and said OK we'll do you. They were girls who would come and put me to bed, but with the care thing I would be going to bed at 7 o clock at night and then I wouldn't get up til 11 o clock in the morning, as a consequence I was on that machine all the time. That machine is meant to take over the breathing for me, erm… and so the consequence was that I was on that machine for 16 hours straight away….. we went down to Manchester to the lung centre and the doctor asked how long I was on the machine and I said 16 hour a day most probably more. At that point he refused, he said you're too reliant on the machine if they put me under a general anaesthetic they couldn't guarantee to get me out of it to put a PEG in, so I said fine, if you can't do it. So we came back and we spoke to [mnd nurse] who said that most people get food through the nose if that is the case. We argued about the care for a long time. The problem about Cumbria is that its demographic shows that there is a lot of elderly folk who've moved here and there's not enough care for anybody here. With the result that they approached 2 carers who previously had their own caring business with the result that they have taken me over and they care for me from... I go to bed about 9.30 and I get up at 8.

I: So I'm on that less time and I don't use it any more than that. The doctor.. is a young doctor and very very interested in MND and I 'm the first case of MND he's had, so I got [mnd nurse] down to see them. When I was in the hospital at Cumbria most of the doctors came down to see me because they hadn't seen someone with MND, and the same at [(name of hospital), some doctors came down to see me who'd never seen someone with MND.

I:Now the doctor has looked after me he comes around fairly regular and I have the district nurses come around every day, I stopped them yesterday, but they come around every day to check up on me.

I: And the service from the medical side is excellent. That's all I can say. Because I was in [(name of hospital) I saw the lady {OT] who came down and chatted with me and she got me this machine which is good and its very much a case of being in the right place at the right time.

S: Did you want to know about his lifestyle ? looking for a reason…….[distant comments by wife not picked up]

I: I used to be a merchant banker and worked long hours yes… I don't drink particularly, I've never smoked.. I've had a very fit ordinary life, I ran a hotel for many years, 14 years, and I did drink then.. perhaps too much….

[Comments by wife not picked up]

I:Part of that included flying out to the far east.. and eastern Europe and places like that and I've had injections for all the various.. you know.. typhoid and things like that.. that's about it.. more work ..

Just going back to the start of this…muscles going on all the time…[comments not picked up].Fasciculation were seen on the stomach more than the leg , but then the leg really started to go,

fasciculations on the leg and the stomach .. it went down this leg and now it's coming up this arm… what the doctor in [(name of hospital) said was that I would had 3-4 months to live and did I want to live a life where there would be hoists and all the rest of it …. [wife] said to come home and my son said to come home.
[break in recording]
I: There is a hospice that I was going to go to before going to the Cumbria hospital and the hospice, [MND nurse] knows it because she goes there.. but we felt that there was politic background behind it, they said that they couldn't take me because they said they didn't understand the machine and if it broke down all the rest of it. Had I gone to the hospice…….The hospice didn't want to take me because they couldn't see an out. The problem was getting carers in the area. Now MND is fairly big. In Barrow, Ulverston and around this area we know 5 people that have died from it and it's incredible the number of people who 've got it
R: Did you know of them before you were diagnosed with it?
I: No. well you become aware of MND when you are diagnosed with MND. We went into the jeweller's in Ambleside and there was an MND box. You don't see any of them anywhere. We chatted to the bloke and his dad had died with it. We were trying to sell the hotel and it was problematic.. so, one of the things in the Lake District there's talk about local housing, so we were trying to sell the hotel, nobody was buying it, so we thought we'll change it into a house. It was a big hotel, 14 bedrooms, we would change it into a house. Now the planners all said 'no you can't because it's got to be done in [inaudible] for locals and [wife] got on the phone desperate one day saying to the planners ' we've got to get out of this house this hotel my husband's ill he's got MND' and the phone went dead at the other end and the bloke said to her 'I understand my dad died of MND'[inaudible] changed into a house. At that time the national trust made an offer we accepted and we moved in here and we were invited to a house warming party [wife] went , I didn't, she mentioned I had MND and was in a wheelchair and couldn't go, and a bloke came over to her and said 'sorry about that, my wife died of it'. So in the space of …..
I: We have been here in the Lake District for fourteen years [inaudible] … environmental… and you think to yourself if I had stayed down south this wouldn't have happened…. Why I have I got it. You always try to pin point the reasons… why I haven't got it as opposed to him. Always lived in a fairly rural area….[inaudible] ..Scotland's got quite a bit of it
I: Going back to care, I mean because I was in [regional centre] [inaudible] … quite depressed [OT] a very nice thoughtful lady. Because I was there for a long time we spent a lot of time together and she spoke to her opposite number in Cumbria and suddenly the next day hoists were moved in, hospital beds and equipment.. just like that. Now was that because I knew [OT] or would that have happened to anybody else? I just don't know. Is it because I was in the hospital and got to know people in the hospital. [mnd nurse] would come down every day and I got to know her, she's been very helpful, she's been round.[inaudible]…..sometimes people don't want to see the deterioration in other people…. And so they hide themselves away, we found strange ….. there's not even a chat room, I chat to people in America, PALS, they're open about it by being open they're getting more known…they lobby about it…problem with the charity…. Improved enormously since you've had it…when we first looked at the MNDA's website it was about 2 pages long and now it's massive and that's been helpful, well not helpful, yes helpful
[talking by wife not picked up clearly]
S: Caring is going to be a problem anywhere. Particularly in the lake district there's not enough young people that want to go into it, there's' lots of Poles and Philipino that will come and do care but there's a mass of elderly and infirm people in the Lakes that need that care, it's not specific to MND.
I: Since I've had MND 2 people who've been doing my caring are rough, if I can say that.. but it's convenient for the times they do. But during this time they've had 4 phone calls from Barrow hospital for people with MND to care for them. And it's growing. When I speak to people and they say it goes in cycles and I wish I wasn't in a cycle, but I think your in the peak of a cycle in the lake

district. With the adverse situation [inaudible] … similarly if I'd been in a small house …I mean it's an integral part of me is the lift thing because I can't walk and to get a hoist for a 15 stone bloke in the house we were at, you just couldn't do it. Similarly I've got a downstairs room that I can go to, we've got a wet room that I can go in and be showered. And that's because we've been able to do it. In a lot of cases people are not able to do it and how are you suppose to look after them? Its a big problem. The hospice can only take 8 people so they look for an exit if they are MND people because the term of life in indeterminable, if somebody's got cancer it's more determinable …it's a very awkward situation, very awkward situation. In [regional centre] we knew all the nurses, I got kisses from all the nurses, but the nurses were saying if I lived there then when they had finished their shift they would come and care for me , that was great in [place name], but it's not great out here.

R: I suppose it's a problem with the lake district anyway, the distances, you've got large distances to travel?

I: Massive distances.. there's somebody very ill on the other side of Hawkshead, the other side of the lake , over the forest and down the other side and people won't travel from here to Hawkshead, they say it's too far and too long. The person in Hawkshead, I don't know what's wrong with them, they are seriously ill, and they can't get carers. The whole of the DN service has changed drastically to a rapid response, to a long term care and to general nursing and that's had its own problems. From a nursing side, so much so, that the nurses are visiting every day, I've appreciated what they say about being under pressure, they haven't said it so much, … but I told them not to visit every day to ring, and they said OK, they've accepted that.

I: It's one of these diseases where you are involved with the consultant for a short time. Once they have seen the patient, and you are diagnosed, then they don't see you, you are very much on your own. You've got the support networks around you with regard to the local area, the GP and everything, but they can't find a cure for this disease so its just 'sorry, on your way' it just seems so clinical really. It's as if they are spending all their time trying to find a cure, getting nowhere and in the meantime there's people sitting waiting around for something to happen, You are in God's waiting room aren't you?

S: There was this issue this morning about stem cell research, people want to feel that there's some hope, and you know we seem ot be getting this either by looking at the internet, which [patient] looks at all the time, or news about stem cell research . we would like to think about some hope and be given this information, you know, when something comes along.

I: From looking at the MND website it looks as if…. it looks like its .. I mean the MND Association are awash with cash, I think that's the case because they ask for people to do research. It's not a sexy disease , so you don't get the people doing research they've got the money to give them to do the research, right, I [inaudible] Now the diaphragm helps you breath, that {NIV} breathes for me at 18 breaths a minute and the diaphragm acts as a pump, so why can't you have electrodes on the diaphragm to push it up on the 18 a minute thing to exhale the air…it's simple enough, well practically simple enough, but nobody looks at that aspect because people don't die of MND of breathing. But if you look at the box that they {MNDA} have given me it says that 90% of people will die of respiratory problems and respiratory problems mean the lungs…… madness..

S: [inaudible] drop foot type scenario where they've got this…..[inaudible] like an electrode that goes in your leg and stimulates the nerve and move the part that ….. [inaudible] so if they can do it from the knee down to get people to move this part , do this action, ……

I:If you've got Parkinson's disease and you're shaking all the time, they can drill into your head and put an electrode in,….. [inaudible] but what the hell's happening in MND?

S: Think the problem is the research is done by the consultants, the neurologists, who are experts in the field, and it's so closed shop that you don't get to know what's going on. You feel as if they are doing nothing.

I: The other thing.. the big bloke, the brainy bloke, spent all his time looking for black holes ….he had MND, Stephen Hawking.. why did he spend all his time looking for black holes when he could have been solving this problem? He could have done, couldn't he and he's had it for many years …no it's a

difficult one…I tried to work with the MND society. I got this…[NIPPV] this is fresh air, (mostly gas and air) it was introduced for scorers, because if you've got this you don't snore, so I spoke to the MND society, the press people, and I found that these weren't given through …
S: No it was sleep apnoea.. they get it from the NHS free, but the MND society are having to pay for these through the PCT.
I: So why does somebody who smokes get it free and we have to go through the PCT. So we spoke to them and I wrote a letter to the papers but it didn't get published because it had MND in it. But I notice now when the thing for stem cells was discussed through what's it… on various programmes on the TV they always talk about Alzheimer 's and something else…Parkinson's, but on the politics show it went Alzheimers and motor neurone disease and it did it on the news and that was the first time I'd heard it
S: and suddenly on the TV there was a woman from Shippley who was 7th generation of motor neuron and she was terrified about her kids getting it…. why don't they push it more[inaudible from wife]
I: If the MND soc is awash with cash and they can't get the PhDs to do research then the next best thing is to do an advertisement…Christ you advertise for dogs and cats you advertise for people who are blind you advertise for whatever else….and it creates awareness. You advertise for people in India who can't get water, you raise awareness. If you create the awareness, you'll get the PhDs going forward, because they'll see it. Most people don't know about it unless they know someone who's got it, you've got to widen knowledge of it and there's a negativeness.
S: Lot of ethical problems…they have to get over those hurdles ….human embryo research….. this week [inaudible]
I: That's another thing, you've opened… stem cell surgery is the main pointer… finding not a cure, yes a cure, quick fix, so everybody that's, not just me, anybody with problems with the spine, stem cell is the research. Yet we vote for MPs and they vote on the basis of their religious feelings, Christ they are representing members it's obscene that something as critical as that is used on a vote by a parliamentary thing on what he thinks. You have Opik who says his father died of it so he'll vote for it. Ok it got through but what if it hadn't got through? A bloody nightmare. But who was lobbying? was the MNDA lobbying the MPs?
[inaudible]
I: That's what you need, if you start hearing about it and reading about it, you will get people who leave university who can't get a job as a PhD, when we were down south, our gardener had a PhD… that can't get jobs, finding it sexy to come into MND, that's the way you get through it, You don't get it by doing bloody big web sites saying if you' re a PhD come and we'll give you the money….it's ludicrous, you throw some of that money into something else
S: It's just getting through the day to day problems…
I: No they have this thing about John's journey and they put it on the tube stations. And they did a great big thing about it… But the problem with that is that it doesn't suit everybody to know about it…..
[cross talking]
S: No, but they've got to get used to the word MND.
I: When I was a banker we went to a thing in Telford. We went to see, this was a long time before I had it, NIPPY machines, we went to see the factory where they made NIPPY machines. And we went around and looked at NIPPY machines and everything else. I saw them and I went away and though no more about them. Because nippy machines were sold to us about emphysema only, they didn't mention motor neurone at all. Now, that's an early stage where they should be talking .. emphysema, motor neurone. You have got to get it into normal language. Cancer used to be…
S: [Wife talking about her mother and emphysema] – some of the symptoms my mother copes with are similar to yours….[goes on to discuss her mother's condition]
I: I'm in the right age group of 50-60, but you get people like that John's journey and you get other people that are younger, what are the effects, they say 7 in 100,000 is the normal take up, 5 in

100,00 or 2 in 100,000 is the number of people that have it that are diagnosed with it, well if I'm in [(name of hospital) hospital or a Cumbrian hospital where doctors haven't seen it

S: Some of them never see it in the whole if their career..

I: So how many people are misdiagnosed? what are the real figures? How are the real figures taken up? how many old people are now in a wheelchair, can't walk by doctors just saying they are elderly? But have MND. Well it's got to become sexy. And use the money to do it.

R: Can I take you back to when you were given your diagnosis? Can you tell me more about the circumstances, about how you were told and what you reaction was etc..

I: I've told you there was the [doctor] who was at [place name] at the [hospital] in [place name] and he took me in, sent me for the various things in the NHS hospitals, and then in November, didn't have all the results back but he told me, quite clearly, nothing else, that I had anterior horn cell disease and I was going to loose both my legs and my arms. He drew me a little picture of bubbles….

[inaudible]

I: He didn't say what MND was, he didn't suggest I go to [MND centre]

R: There's no easy way of telling someone is there?

I: No, but he should have sent me to [MND centre], and got me to know the MND people and things like that,

R: But you went as a private patient, you weren't on the NHS…

I: Notwithstanding that fact I should have gone to [MND centre]. [……] He should have done more, I just think it was very hard to see…… when he drew the picture of what was wrong, but in fairness to him he saw what was wrong…But the way he told us was shocking, and the shocking aspect of it was there was no encouragement to research it there was no encouragement to go to a hospital and get, which I didn't agree with, riluzole, or whatever it's called, there was no awareness of it there was no…..

S: [inaudible] When you tell somebody that they have got anterior horn cell disease, the first thing they will do is go home and look it up on the internet and that's how you find these things out. And in fairness to him, we all don't want to hear bad news.

I: we've got the internet… I asked if he had anybody else with it and he said yes he had seen somebody with a hand which was going

R: and your experience with [doctor for 2nd opinion] which was 6 months later,

I: Dr [second opinion] was not good, because he called me the doctor's name,

S: He got your name wrong..

I: He got me name wrong, he looked in my eyes, he banged me with a hammer, he saw me walking, and said yes you've got MND.

I: If I go privately to hospital for cancer, I'd get all the papers for cancer. All the various help groups

I: There's negatives though but even so with… when I went to [centre name for 2nd opinion], we both came out of there shocked again. It took time. It was when I went to see a proper bloke [specialist centre]… that's when I felt as if I was being looked at properly, he took me…., Specialist nurse was with us and she explained what was going on and how it did even though we knew because we had been through it before, it was all explained to you and if it's explained to you at that point of contact, we came out and we had Sp Nurse on the phone, she comes out every 3 months.. now with the other bloke, the other 2 blokes, there was nobody. Alright I was private..

R: You felt that you should have had that follow up?

I: We should have had a follow up, certainly. It was very much, we've told you bad news and lets leave it. We went 6 months later for another test

S: It's hard to just stop doing everything…

I: But we went to the other place 6 months later when we should have gone to that one, and got the other opinion, because at that point we still thought it was ….. because it was only in one leg

S: You've still got the bills coming in , you've still got your family, we were still working.. and we were still doing all that for 2 ½ …while he has been like this, we were still running the business…you can't just say stop the business because there are financial things to deal with, it wasn't just the illness it

was everything else around it we had financial things to sort out….. planning.. it takes time to do so yes we didn' t pursue it straight away because we hadn't the time..
I: There's another thing, I had MND, I knew I had MND at this point and we went to a ….[struggles for name] guy who puts straps on you and he said as I was walking like a bird, knock kneed , so he put a strap on me to help me to walk properly…Well I got in the car and as I got out of the car, it held me and I couldn't stand so I collapsed outside. We lived in a terraced house, and one of the people who lived in the end house was the mother of the charge nurse who comes round here. But I stood on it and collapsed and we had to take my trousers off in the middle of the street and undo this thing
S: What you need to understand is that you need to lock your knee to take your weight [inaudible] bend your knee and the bracket supports you…
I: That was the one that really killed us home, because after that point I couldn't get upstairs
S: No that really knocked you for 6 ….. because in order to get out of the care, he needed to lock his knee, so that it held the weight of his body, but once you bend your knee the whole weight of you goes on your knees and you can't support your body after that.
R: You have told me about some of your interactions with the MDT , you have mentioned about the OT and the fact that you got some equipment quickly, you have also mentioned about the DNs coming in, and the care package …. Do you feel that there is good communication between the team?
I: Yes. I would say so. On that side of the lake it was one doctor only, no district nurses or anything else. On this side there's a centre for district nurses and a partnership of doctors so I'm discussed at their meeting, the nurses keep full records of you when they come here, the doctor is seriously interested, he's brought students around, and asked me to explain everything, so that part of it is OK. If we talk to the doctor about anything he'll get something to me straight away. That side of it is OK. The care side, there's a need for more carers, but that's I think with the area
S: [inaudible from wife]… how many people are in our lives … the other care company had 6 girls a day … found that quite hard to deal with at first
R: You did?
S: I did. I found it very hard. [husband] was more involved with it than I was ….
R: Do you find that the girls who come, are they the same ones each time?
S: No. they were a group of girls that would come, one time. Now I get 2 people that are the same. They are a married couple so we get the marriage rifts and all sorts of things.
R: Which do you prefer?
I: I prefer getting up early and going to bed late. The first group were carers who were interested, they would massage my legs. When I came out of [hospital] my legs were locked because I'd been in bed for,…..because of the problems in [hospital name]and more particularly in [local hospital]. If I got out of bed in [hospital name] In [hospital] if I was out of bed, it would be for a long time because they needed to get the lift to put me back to bed and so I didn't get up and so my legs would lock.
S: The carers recognise that and were very sympathetic and they exercised it…
R: Do you think that there are any areas of care that are missing? Along the lines maybe of emotional support?
I: The DNs are always asking how I'm going to die, and it gets a bit tedious. I'm fed up of people telling me I'm going to die, you know, I'm going to die.. everybody dies, but that's an issue. Yes we've had help, we've been offered counselling to our son whose still at school. [wife] has had help from the carers society, they've been round. We've had a little old dear whose part of the MNDA, who comes around and is charming.. I can't argue about it, but again is it because I've been in hospital, is it because I've got the OT, because I've got [Sp Nurse], you know
S: [inaudible from wife] ….One of the nurses talked about [son] and asked if he was coping, but I think he's alright, I just don't think that he needs it….
I: He will when I croak…

S: You don't know what goes on in their heads, he has looked at the internet for motor neurone, he knows a lot about it, He is a level headed kid, he weekly boards so is away from the everyday…… it's for them to judge whether we need it or not, they do ask us enough times…[inaudible]
I: The hospice send a masseuse over and they do [wife] as well, that's good. The nurses from the hospice that came to see me in the outreach, they're good they ring me every so often to check that I'm OK.. So I think there's enough people.
S: For me sometimes too many
I:It is good, the support you get, but I say it again, we are fortunate to have a house like this, right next to the doctor's surgery. If we had been out in(place name) or somewhere like that, would it be the same? And if you didn't have the money?
S: I agree….we are very fortunate, but we've worked hard for it. We couldn't have stayed in (place name) where we were, it was just impossible and that's what other people must be having problems with… living in very cramped conditions with the family around them, I imagine it is very, very difficult. Just to have the wheelchair and the hoist over his bed, and we've had the shower room done out[inaudible] …..we are lucky to be able to do that, not everyone is
I: So that makes it civilised
S: It makes living normal, we still do the things we would normally do. The thing that [patient] finds very frustrating, is when we first started with this, we didn't have this ramp outside, we had the ramp built, again it was £250 and not everyone can afford to just throw £250 at that…
I: I'm sure that social services would do it, the OT lady has offered to get us big chairs for massaging, everything that comes along said that she could get things…
S: [inaudible] the thing [patient] finds frustrating is not being able to get out now, you know being able to get out for the day
I: We looked at getting a car, where you can put a wheelchair in the back of it, you can't rent them, or if you do, you have to lease them for 5 years, well if my prognosis is less than 5 years then what is the point of leasing it that's why I've never taken one. So let's but one I thought, if I buy one for say £20,000, I said to the company will you buy it back when I croak for say 15K or 14K? 'No we wouldn't buy it back'. So then I rang the MNDA, could I donate it to you? And they said 'No', because they all get this allowance that enables them to buy a car for themselves and they'd rather buy a car in the early stages, but I said what about the later stages and they said 'no' because at that time they would have to maintain it and things like that.
S: There are no outlets..
I: There are taxis that come around that will take a wheelchair, so I might use them
R: Can you tell me about your experiences of decision making regarding your care?
S: Equipment comes very quickly, it's been over quick [inaudible] issue about the chair…….
I: Care is a big issue. Because as I say we have the early morning late get up which was [inaudible] …there isn't the choice of carers around here. And they don't seem to understand that if I'm on the machine that I have to have the machine on when I lie down and if I become reliant on the machine that's going to damage my lungs so caring is one of the issues, the type of care, the level of care. Because I have 2 people that have come out of care, they are man and wife, they tell us that one was a barman and one a chef they fell into this caring business, it's nice money, the national health pays £700 a week for me to be cared for so it's good money for doing what they do, but as I get weaker I can help by getting myself about, by getting myself onto the commode, by helping them to get the thing underneath me by lifting up, eventually I won't be able to and it's how that care will be able to respond to that. I don't think they will have the patience nor the capacity, so that care I think will have to go and we'll have to go back to the other one. That's a worry in my mind about caring that will come on. Erm what else..type of hoists, nobody has explained types of hoists to me. The type of hoist I've got, if I have a shower in the morning, erm..I'm wet on the commode and they have to drag the hoist underneath me which causes scrapes on my backside which have their own problems, whatever it is. That's going to be an issue in the future. It's going to be an issue in the future.

S: We had problems with the cushion in this thing didn't we? We got the wheelchair but there were no leg raisers on the wheelchair and I think leg raising is a great thing especially with water retention, if you can lift them up, it helps in a big way, it wasn't brought with the headrest, so we've had them put latterly.
I: Similarly they gave me a very firm base
S: Like sitting on concrete..
I: It magnified the sore I had. This cushion is like lots of little air triangles which has been bloody excellent.… it's been excellent.[inaudible] from the moment they brought it it has been excellent …trying to get off that spot, even though it was a high risk cushion, it was like concrete, but this one is absolutely brilliant.
S: So those things we've been fortunate, we raised the roof with the bloke didn't we, and he came back the next day, he turned up with everything we wanted. Because we were able to shout. We had the confidence to be able to shout. That instance, most certainly, the fact that we shouted, we got it.
S: He came out with the headrest but without the leg supports or the cushion… .
I: But again, I've got to say that's us here, doing what we're doing. Its going to be difficult for somebody else … we can shout that [OT] knows us, that his boss, and really put jip into it, whereas somebody else that hasn't been to hospital, and [Sp nurse] said people with MND don't come to hospital, it's not one of those diseases where they come to hospital they are left in the situation for as long as they can be and then they are suppose to go into a hospice . But it's something, there's a big problem in the area, a very big problem in this area. I'm sure it's every other area.
S: I think the start of this, when [patient] started to go down hill in January, or perhaps earlier than that, we felt we'd been given a diagnosis and then we were on our own. We were quite gob smacked about it. What do we do now? Where do we go now from here? There's nowhere to go, you felt very lonely and very on your own and yet you knew there were other people out there with this condition and I would say that the time this has all come together is when [husband] went to see [MND specialist], then everything, all the support network came around then…

Appendix 9. Table.3: Table demonstrating themes extracted from the journal and interview data of one couple

Super-ordinate Themes	**Ordinate Themes**
1. Altered Body	Awareness of the body Alienation of the body Entrapped embodiment Self in physical world
2. Diminishing Self	Loss of social purpose and participation Burden and guilt Social marginalisation and diminished relationships Adaptation Equipment and self
3. Altered Temporality	Awareness of time Loss of expected future time
4. Transcending Embodiment	Dyadic self Social and familial self Convergence of time Spiritual self Authentic being Diary

Appendix 10:Table 4: Table demonstrating themes extracted from the interview data

Super-ordinate Themes	Ordinate Themes	Recurrency
5. Altered body	Awareness of the body	ID6
		ID9
		ID19
	Alienation of the body	ID20
		ID45
		ID46
	Entrapped embodiment	ID 54
		ID73
		ID83
		ID86
	Physical self in the world	ID94
		ID201
		ID203
		ID204
		ID205
		ID208
		ID213
		ID214
		ID218
6. Diminishing self	Loss of social purpose and participation	ID6
		ID9
	Burden and guilt	ID19
		ID20
	Social marginalisation and diminished	ID45
	relationships	ID46
		ID54

	Adaptation Equipment and self	ID73 ID83 ID 86 ID94 ID201 ID203 ID204 ID205 ID207 ID208 ID210 ID213 ID214 ID218
7. Altered temporality	Awareness of time Loss of expected future time	ID6 ID9 ID19 ID20 ID45 ID46 ID83 ID94 ID201 ID204 ID205 ID210 ID214 ID218

8. Transcending embodiment	Dyadic self	ID9
		ID19
		ID20
		ID27
		ID46
	Social and family self	ID54
		ID83
		ID86
		ID94
		ID201
		ID203
	Convergence of time	ID204
		ID205
		ID208
		ID207
		ID210
		ID212
		ID214
		ID218

Key: patient IDs 6-94/ Carer IDs 201 -218