

**Making sense and finding meaning: comparing  
narratives of older people with dementia and carers  
about the quality of an ordinary life**

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# **Declaration**

I declare that the thesis has been composed by myself and that it embodies the results of my own research.

Jane Marjorie Robertson, 1<sup>st</sup> July 2010

# Acknowledgements

This study is dedicated to my son Aidan who has grown up alongside the thesis. My love and thanks go to my husband Sandy who has supported me in this long endeavour.

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## **Abstract**

This research examines narratives about the quality of everyday life with dementia. The aim of the study is to compare and contrast differing perspectives about the impact of ageing and dementia upon the lives of older people with dementia. A total of 50 interviews with six older people with dementia and ten family and paid carers were conducted over a two-year period. Narrative analysis was used to examine the content and structure of their accounts to understand their perspectives on what matters most to people living with dementia. This in-depth analysis enabled an exploration of different social concepts and narrative constructions that people draw upon in making sense of their experiences of caring and living with dementia. The analysis demonstrated that older people incorporate ageing and dementia into a continuing sense of self. Positive constructions of living with dementia involve the ability to lead a meaningful life that supports pre-existing social roles and relationships and active engagement within the family and community. The emphasis is on living an ordinary life while responding to the challenges associated with cognitive impairment and social stigma. For family and paid carers, perceptions of a meaningful life depend on how the identity of the older person with dementia is positioned relative to past social roles and relationships. Positive constructions assume continuity as opposed to focusing on disruption in the person's identity and life. Carer perspectives are also influenced by how the person is perceived to conform to social standards of normality. The narratives of older people with dementia reflect their active struggle to find meaning in terms of realising their sense of self within a social world that largely defines them as different and out of the ordinary. The narratives of carers resonate with emotional difficulty, reflecting their struggle to make sense of a life that is not represented as essentially normal. These findings show that, for all, finding meaning in everyday life depends upon making sense of that life as normal and ordinary.

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# Chapter One

## Introduction to the thesis

### Introduction

Dementia is a term for a number of conditions characterised by progressive cognitive impairment, including loss of memory and communication problems. The most common of these conditions are Alzheimer's disease, vascular dementia and dementia with Lewy bodies, and age is an important risk-factor for their development. Dementia is viewed not only as the result of disease processes; it is also perceived as a collection of behavioural changes indicative of its presence (Parker 2001:331). Due to the association with personality change and unusual behaviour, dementia is often considered to be particularly challenging for others (Bond 1992:397). Indeed, it is one of the most stigmatised conditions of older age (Graham et al. 2003), often rated as a state worse than death (Patrick et al. 1994). However, despite the pervading social stigma and negative social attitudes surrounding dementia, studies of subjective perspectives have shown that the perceived quality of life among people with dementia is generally relatively good (e.g. Cahill et al. 2004; Katsuno 2005; Tester et al. 2003).

There are approximately 71,000 people with a diagnosis of dementia in Scotland in 2010, and this number is expected to rise to 127,000 by 2031 (Alzheimer Scotland 2010). Almost two thirds of people with dementia in Scotland live within the community (Care Commission 2010). Dementia was declared a national priority by the Scottish Government in 2008 (The Scottish Government 2008), and has been placed at the centre of European Union health programmes (The European Commission 2009). In June 2010 the Scottish Government published a National Dementia Strategy to improve care for people living with dementia in Scotland (The Scottish Government 2010).

In countries like Scotland, where dementia is primarily understood as a disease, family members are often called 'carers' or 'caregivers'. Care is constructed as both normal for family and as requiring formal additional support (Henderson and Forbat 2002). The care of people with dementia therefore falls to two main groups of people: unpaid family carers and paid care workers (Innes 2009:54). In addition to family and paid carers, neighbours and friends may play an important role in supporting older people in the community (Nocon and Pearson 2000). As Fine and Glendinning (2005:617) assert, care is a complex social concept that is "both an ideal and a daily reality". They argue that although the literature generally separates 'care' and 'dependency' to segregate the worlds of those providing and receiving care, 'care' should be recognised as a widespread and ordinary aspect of social relationships in which we are all implicated.

At present, there is no prevention or cure for the conditions subsumed under the term dementia. In the absence of a cure, maintaining or improving quality of life has become an overarching principle of care. The concept of quality of life has correspondingly dominated much of the research literature on dementia in recent years. An initial interest in observational and proxy reporting of the quality of life of the person with dementia has developed into subsequent attention to the direct reports of people with dementia about what matters most in their lives. This shift in perspective has revealed differences in what people with dementia and their carers believe are important in the life of the person living with dementia. However, the meanings of these differences have not been established.

In this thesis I compare the perspectives of older people with dementia and their carers to explore the meanings of different understandings of quality of life. This analysis involves attending to narrative processes of meaning-making in identity and emotion work in people's accounts. As dementia is predominantly a condition of older age, I have focused this study on older people with dementia. I am particularly interested in people ageing with dementia, since conceptual frameworks of dementia are tied up in expectations of

and assumptions about older age. I have chosen to use narrative as an approach to gathering and analysing data, since it is a method suited to accessing subjective perspectives and exploring the discursive construction of meaning. It is also a methodology that takes account of the narrative construction of self and social identity, important concepts that have been largely absent from the 'quality of life' literature to date. In exploring narratives about the quality of everyday life, I have analysed conversations with older people with dementia and interviews with carers to understand the differing ways that people talk about living with dementia and caring for a person with dementia. I compare and contrast perspectives about the quality of everyday life to establish that the often difficult process of articulating understandings reflects a shared narrative struggle to make sense of experiences and find meaning in everyday life.

In this introductory chapter I present a brief context to the research study. I first provide some background about conceptual models of dementia that have informed the changing conceptualisation and investigation of quality of life, before considering the development of quality of life measures, focusing particularly on evidence for different perspectives among people with dementia and their carers. I highlight the importance of understanding the meanings of differing perspectives on quality of life, which I argue can be addressed by applying a comparative framework of narrative meaning-making that explores processes of identity and emotion work in people's accounts. I then describe how I have developed my research questions to compare and contrast perspectives on quality of life among older people with dementia and carers. In the last section of this introduction I set out the structure for the remaining chapters of the thesis.

## **Background and context for research**

### ***Making sense of ageing, dementia and the quality of life***

Being 'old' is primarily a social category (Higgs 1999:197) produced by government retirement policy and wider social processes (Townsend 1981; Walker 1981). Ageism

(Bytheway 1995) is one of the greatest social barriers faced by many older people with dementia. As Bartlett (2000:34) attests, older people with dementia face discrimination based upon negative stereotypes related to age in addition to the social stigma associated with 'mental illness'. Cultural stereotypes associated with age include powerlessness, decline, sickness, dependency and ultimately death (Dein and Huline-Dickens 1997:114). Harding and Palfrey (1997:133) argue that Western countries have turned bodies into a means of affirming identity, and those whose bodies or minds are viewed as unhealthy are stigmatised and separated from society. In this context, age itself becomes an incurable illness as the body declines and 'fails', and dementia becomes the ultimate symbolic embodiment of death since the mind is assumed to have 'gone'.

Different approaches to understanding dementia have informed different perspectives about living with the condition. Biomedical and psychosocial approaches are the main conceptual frameworks that have dominated dementia research. The biomedical model conceptualises dementia as a disease category distinct from ageing and frames the person with dementia as a person to be treated. Bond (1992:400) considers unfavourable aspects of the medicalisation of dementia, which include the medical exercise of expert and social control, and the individualisation and de-politicisation of behaviour. Parker (2001:332) describes how the biomedical model is frequently brought to mind when professionals, family carers and the general public consider dementia. However, psychosocial models have become increasingly prominent in formal approaches to care, especially with the recent growth in person-centred practice in dementia care. Psychosocial approaches emphasise the individual psychology of the person and the social psychology surrounding them. The most well-known psychosocial approach is Kitwood's (1989; 1990; 1997a) theory of the dementia experience as a dialectical interaction between neurological impairment and psychosocial processes (Finnema et al. 2000:71).

While these two approaches each have their role in understanding the experience of dementia, they have been critiqued for their individualistic orientation and their failure to represent the subjective perspective of the person with dementia (Adams 1998:615). A separate but related approach to dementia care has been called the 'care for the carer' approach (Nolan et al. 1996), which highlights the physical and emotional burden of caring for a person with dementia. It applies a theoretical framework of stress and coping methods to examine the experience of caring for someone with dementia from the perspective of the carer. This approach has similarly been critiqued for its individualistic focus, as well as its tendency to focus on burden and strain to the exclusion of positive aspects of care such as reciprocity and interdependence (Adams 1998:615).

Bond (1999) has considered how the different models of dementia lead to different meanings of the concept of quality of life. The biomedical model, with its focus on the value and potential of science to respond to illness and improve life, is concerned with a loss of 'normality' among people with dementia and the impact of the condition on carers (Bond 1999:563). This response can be linked to Oliver's (1996) 'personal tragedy theory' and the labelling of people with dementia as 'victims' or 'sufferers'. In seeking to understand the disease process in the search for a cure, biomedical approaches tend to focus on individual pathology and fail to consider the social consequences of being old and having dementia. The assumption is that deterioration in cognitive functioning is directly related to the deterioration of quality of life. As will be discussed in chapter two, this assumption is problematic, as studies have established that reduced cognitive functioning is not necessarily associated with a poorer quality of life (e.g. Banerjee et al. 2009).

Psychosocial approaches to understanding dementia are interested in the quality of the social environment in maintaining well-being and improving the care of people with dementia (e.g. Kitwood 1993; Kitwood and Bredin 1992). Bond (1999:564) argues that while psychosocial frameworks are important in recognising the self and personhood of

people with dementia, they are problematic in the specific study of quality of life. The first problem is that psychosocial approaches are concerned with the social psychological adjustment of people with dementia and their carers to the condition. They therefore continue to frame dementia as the disability and ignore the external socio-cultural context affecting people's experiences. The second difficulty is that a specific focus on social interaction undermines the personal meanings and subjective interpretations of people with dementia and their carers.

Adopting the social model of disability (Oliver 1990), Bond (1999:565) suggests that a social model of dementia is most suitable for engaging with personal meanings and subjective perspectives on quality of life. He argues that such a social model of quality of life should be concerned primarily with the personal meanings that people with dementia attach to their situation, in the context of their life experiences, as they struggle to be included as citizens. If we take as a starting-point that quality of life is an individual experience, Bond (1999:566) argues that the quality of life will be influenced by general experiences throughout life, and particular expectations about ageing and living with a chronic condition. I argue in this thesis that such a focus on meanings and subjective experiences in the context of life history is essential to understand perspectives on the quality of life of older people with dementia.

### ***Perspectives on the quality of life of older people with dementia***

The term 'quality of life' is now part of popular discourse and highly visible in media and politics, which indicates the importance of the concept in everyday life as well as in the research community (Farquhar 1995:1439). In general, the concept of quality of life in everyday language is defined as a positive ideal rather than as a neutral state. However, as Farquhar (1995:1439) maintains, the concept of quality of life should encompass both the positive and the negative aspects of life:



When we talk of someone's quality of life we are not simply talking about the good things in their lives, but the bad things too; descriptions centre on the nature of peoples' lives, and the ability to maintain or even improve the quality of their lives.

Increasing interest in the measurement of quality of life among people with dementia has reflected a changed conceptualisation of the person, as an experiencing individual rather than someone without 'personhood'. As Russell (1996:1401) asserts, understanding the person as an experiencing individual allows for a more positive interpretation of life with dementia:

An individualised approach challenges us to go beyond the narrow idea of dementia as a contraction of life to a new and more complex vision of a unique and creative world of those persons living with dementia.

Defining and assessing the quality of a person's life has been a key focus of empirical research on various chronic health conditions including cancer, stroke and diabetes. Since the early 1980s, a particular concern for measuring the impact of dementia on a person's life has generated increasing research interest in the field of geriatrics and gerontology. As most commentators now recognise that neuropathology does not solely determine the experience of dementia, there has been a move from research measuring biomedical aspects of dementia such as cognitive function and health, to research examining outcomes in general and quality of life in particular (Bamford and Bruce 2000:543). Increased attention to quality of life has also been part of the drive for 'successful' ageing that is both part of a long tradition of gerontological research (Walker 2004:661) and part of the wider policy imperative to maintain or improve health and independence (Grundy and Bowling 1999:199).

The development of quality of life measures has accompanied the broadening focus on outcome measurement for service users within health and social care (Bowling 2005:1). In line with the World Health Organisation's positive definition of health as encompassing social, psychological and physical well-being (The WHOQOL Group 1995), quality of life

measures have shifted from a negative disease-based focus to a broader and more positive concept of health (Bowling 2005:4). Bowling (2005:6) advocates incorporating social health as a dimension of quality of life. Social health can be conceptualised in terms of social support, participation and the performance of major social roles that conform to societal norms (Lerner 1973). Bowling et al. (2003) have established that the absence of such dimensions adversely affects perceptions of life quality in older people.

Accompanying this shifting conceptualisation of quality of life, methods of measurement have changed from a predominant interest in observation and proxy reporting, to greater interest in the direct perspectives of people with dementia. Some self-report studies have simultaneously assessed proxy reports to examine the extent of congruence between the perspective of the person with dementia and their carers. These studies have consistently shown that there is only modest agreement in perspectives on quality of life. Most studies examining these different perspectives have focused on technical issues of measurement. They have examined levels of cognitive functioning and carer 'burden', with limited success in explaining differences or improving the correlation of reports.

I argue for a new focus on the meanings of different perspectives on quality of life, as it may be that different perspectives reflect real differences in the interpretation of quality of life. A recent interest in the phenomenological aspect of living with dementia has revealed new dimensions of quality of life that highlight the contextual and biographical elements of life satisfaction. However, these aspects of quality of life have not been considered in a comparative framework of meaning-making among people with dementia and their carers. What is missing in the field of quality of life research is an approach that can access personal perspectives and subjective experiences in a framework that is meaningful to both older people with dementia and their carers in order to compare and contrast meaning in their accounts. I therefore adopt a narrative approach to engage with the narrative construction of meaning in people's accounts.

### ***Exploring meaning in narrative constructions of quality of life***

Adams (1998:620) argues that the ways in which people with dementia and their carers talk is an important area of study to understand the ways that dementia and care are conceptualised. He suggests that the perspectives of people with dementia, family carers and paid carers reflect their selective interpretation of situations. By focusing on personal perspectives, Ray (2007:61) depicts the narrative mode of knowledge as emphasising feelings and relationships and deriving personal or emotional truths. While the socio-cultural context constrains people's narratives, with cultural concepts and beliefs creating a framework for people's stories, within these boundaries people can actively assert their own stories (Holloway and Freshwater 2007:9). This attention to narrative agency is important in the study of meaning-making, and Baldwin (2008:225) emphasises the importance of identity, belonging and social relationships in engaging with 'narrative citizenship' among people with dementia.

Holloway and Freshwater (2007:8) describe how "when people tell their own story, they reflect on the meaning and significance of their experience, and through this construct and reconstruct their identities". It has been established in the literature that older people with dementia use stories that can act as a means of maintaining a sense of self identity and constructing valid social identities in the face of social stigma and negative stereotypes associated with dementia (Cheston 1996; Crisp 1995; Surr 2006; Sutton and Cheston 1997). Studies of paid and family care have also demonstrated that carers use discourse and narrative to develop a sense of identity and meaning in their experiences of caring, constructing storylines of how they understand the nature of dementia and cope with the task of caring (Hinton and Levkoff 1999; Holst et al. 1999; Levy et al. 2000; O'Connor 2007; Yeo et al. 2001). These studies reveal the importance of 'biographical work' (Corbin and Strauss 1988) in defining and maintaining identities as people make sense of their experiences to find meaning. However, an in-depth analysis of these

narrative processes has not yet been applied to understand different perspectives on quality of life among older people with dementia and their carers.

In developing a comparative framework of quality of life that explores the personal perspectives of older people with dementia and their carers, I take account of the ways that identities and emotions are managed within their narratives. This involves attending to stories of important events and experiences that older people with dementia and their carers use to represent their interpretation of quality of life. The intention is not to establish a factual report or objective evaluation of a person's quality of life by matching participants. Instead, the focus is to compare processes of meaning-making in the accounts of a group of older people with dementia and a group of paid and family carers.

A concern for subjective meanings in the context of life experiences provides a humanistic framework to understand the influences of ageing and dementia on people's expectations of life as an older person with dementia. In developing this framework, I have integrated relevant traditions from social gerontology and the sociology of health and illness that take account of the narrative construction of meaning. I therefore explore the accounts of older people with dementia and carers to understand the different social concepts and narrative constructions they draw upon to make sense of life with dementia. Examining the narrative construction of meaning in people's perspectives on quality of life provides the means to explore potential differences within accounts in more depth.

### ***The concept of an 'ordinary life'***

The social model of dementia attends to principles of social inclusion and citizenship among people with dementia (Baldwin 2008; Bartlett and O'Connor 2007). When considering quality of life, the disablement process is important in view of the social barriers imposed by society on older people with dementia. The philosophies underlying concepts of 'normalisation' and 'inclusion' have been debated in terms of their value in challenging oppression among marginalised groups (Culham and Nind 2003; Race et al.

2005; Yates et al. 2008). Whether or not these particular terms are useful, the desire among older people to maintain an 'ordinary' life has been ascertained in empirical research (Godfrey et al. 2004). This notion of an 'ordinary life' similarly emerged from my own analysis of the narratives of older people with dementia in this study. In framing their lives as ordinary, older people with dementia resist their devalued social status as different and out of the ordinary. Being able to frame life as ordinary and normal is an important theme that also recurs in the narratives of the carers in this study. Establishing life as ordinary in quality is fundamental for older people with dementia to find meaning in life and for carers to represent a person's life as meaningful.

### **Development of the research questions and approach**

The literature has highlighted a gap in our understanding of the meanings of different understandings of what 'quality of life' means for a person with dementia. The central aim of the thesis is therefore to understand the way that meaning is constructed in differing perspectives about the impact of ageing and dementia upon the identities and lives of older people with dementia. In exploring subjective perspectives among older people with dementia and their carers, I consider the ways that people construct meaning in their narratives. I seek to advance from a descriptive understanding of what constitutes 'quality of life', to the development of a conceptual framework that considers different meanings among older people with dementia and carers. With this aim as the basis of the thesis I developed the following research questions:

How do older people with dementia describe the experience and quality of their everyday lives?

How do carers describe the quality of life of the older people with dementia with whom they live and work?

How do older people with dementia and carers construct meaning in their different perspectives on quality of life?

In order to study processes of meaning-making, I use narrative as both a methodological and an interpretive approach. This is discussed further in chapters three and four, where I develop my conceptual and methodological approach. My focus has been on the mundane and on the difficult aspects of everyday living and caring rather than adopting a social policy or social work approach.

I take the perspective of the older person with dementia as the starting point for my study of different perspectives on quality of life. I examine everyday narratives about living with dementia to explore different perspectives about what quality of life means among a group of older people with dementia. Following a consideration of these perspectives, I consider the perspectives of a group of family and paid carers to understand the ways that they conceptualise quality of life among the older people with dementia with whom they live and work.

By exploring these narratives about everyday life experiences, I have been able to compare and contrast accounts so as to understand the meanings of different perspectives on quality of life with dementia. I pay particular attention to the ways people draw on social constructs of ageing and dementia relative to concepts of self, social identity and social status. By comparing and contrasting the accounts of older people with dementia and carers, I bring these perspectives together in a study of narrative meaning-making, to explore the commonalities and differences in their descriptions of quality of life.

### **Structure of the thesis**

In chapter one I have provided a brief context to the research study and the current state of research into the concept of quality of life. This has established a gap in the literature about the meaning of differences in perspectives among people with dementia and carers. I considered how this particular gap in the literature relates to the lack of an appropriate comparative framework and discussed the value of narrative inquiry to address this issue.

I then described how I developed my research questions in relation to the question of differing perspectives on quality of life between people with dementia and their carers.

In chapter two I consider the conceptual and methodological development of quality of life research, which through the use of different methods has revealed differences in the ways that people with dementia and their proxies evaluate quality of life. I discuss how the meanings of different perspectives remain unexplained, and I examine how a biographical and contextual approach to understanding quality of life is useful to explore the meanings of these differences in depth.

The focus of chapter three is on the subjective experience of living with dementia and caring for a person with dementia. I consider how the parallel processes of meaning-making can be understood as similar types of identity and emotion 'work', as people strive to make sense of their experiences and find meaning in their situation in life. I then argue for a narrative approach that can draw together these processes of meaning-making to conceptualise and explore differences in perspectives on quality of life among people with dementia and their carers.

The methodological approach to this study is explained in chapter four. I explain the rationale for the particular methods that I use for narrative interviewing and analysis with older people with dementia and their carers. I describe the ethical and practical details of my research design and process, before reflecting upon observations from the field in a critical appraisal of the study.

In chapters five and six I present my findings concerning the ways that older people with dementia make sense of their experiences and find meaning in their lives. In chapter five I explore the differing ways people describe their experience of dementia and ageing to make sense of their lives as an older person with dementia. This involves an examination of the ways that people relate the past to the present in narrative constructions of self and social identity over time. In chapter six I examine the ways these older people with

dementia describe the ongoing accomplishment of maintaining an ordinary life, as they narrate strategies to remain engaged in normal roles, relationships and activities.

Chapters seven and eight present my findings about the ways carers make sense of their experiences and find meaning in the lives of the older people with dementia with whom they live and work. In chapter seven I explore the construction of social status, as carers define the self and social identity of the person in the present relative to the past, and according to frameworks of normality. In chapter eight I analyse the ways that carers narrate the achievement of an ordinary life for the person with dementia. This analysis involves examining carers' narrative constructions of their role in preserving continuity and normality, and the emotional meanings entailed in this biographical work.

In chapter nine I compare and contrast the perspectives of older people with dementia and carers. I demonstrate that the way dementia and ageing are conceptualised in relation to self, social identity and social status has implications for the way that the meaning of living as an older person with dementia is constructed. For all the people in this study, finding meaning in life depends upon making sense of that life as normal and ordinary. These findings are considered in relation to the existing literature to establish the contributions of the study, its strengths and limitations, and implications for practice and further research.



# **Chapter Two**

## **Understanding different perspectives on quality of life with dementia**

### **Introduction**

This thesis aims to understand different perspectives among people with dementia and carers about what has traditionally been termed 'quality of life'. There are many meanings of quality of life, ranging from terms such as well-being and personal satisfaction, to the ability to lead a normal life (Grundy and Bowling, 1999:200). The assumptions and conceptual underpinnings of different approaches to quality of life are considered in the first section of this chapter, drawing upon research with older people and people with dementia. The second section considers the different measures and methods that have been used to investigate quality of life among people with dementia. The development of different methods has shown that there are some differences in the ways that people with dementia and their carers evaluate quality of life. In the final section of this chapter, I discuss how the meaning of these differences remains unexplained, and consider how a humanistic framework drawing on biographical and contextual understandings of quality of life is a useful approach to understand the meaning of these differences.

It should be noted at the outset of this review that the existing literature comes mostly from Western industrialised societies, and features mainly the experiences and perspectives of white older people. It is also important to note that much of the literature has framed people with dementia in relation to health and social care. From this standpoint, quality of life is often conflated with quality of care, and thus framed as an outcome measure rather than as an end in itself. By limiting lived experience to the context of services, the existence of a person is in danger of being limited to the realm of life as a service user. In this literature review I therefore endeavour to understand quality

of life from the perspective of everyday lived experience rather than as an outcome of care. I take the same approach to terminology as Killick and Allan (2001:3), to use the neutral term 'condition' in my description of dementia as more than a purely medical entity, which is implied by the use of words such as 'illness' or 'disease'. Similarly, I have chosen the phrases 'person with dementia' or 'people with dementia' as terms that do not define someone entirely in terms of their condition. I use the term 'family carer' to represent friends and family members who provide unpaid care to people with dementia. The term 'paid carer' is used to refer to care workers who are paid to provide services to people with dementia. In an effort to avoid sexist language, I use 'they', 'their' and 'them' when talking in general terms.

### **Conceptualising quality of life among older people with dementia**

As was established in the introduction, different approaches to understanding dementia have informed differing perspectives about living with the condition (Bond 1999). Early research on the quality of life of people with dementia reflected the dominance of the biomedical approach, with its focus on the single dimension of health-related quality of life. Bond (1999:566) suggests that this approach has been "rooted in the taken-for-granted assumptions of policymakers and researchers". Health-related measures are generally normative and disease-specific, informed by professional perspectives and with a focus on domains such as functional limitation (Bond 1999:568-569). These measures are aligned with the quantitative tradition of research, with its emphasis on measurement, causality, generalisation and replication. Disease-specific measures are used to assess the impact of specific conditions and associated interventions (Bowling 1995:1448). There is an inherent assumption that a decline in functional ability equates to a poorer quality of life. In terms of ageing, an assumption of declining quality of life is associated with models of older age as a time of deficiency (Schmid 1991).

Bowling (2005:2) argues that most health-related measures take “life quality as a starting point and measure deviations away from it (deteriorating health and quality of life), rather than also encompassing gradations of healthiness and good quality of life”. The difficulty in focusing purely on health status has been highlighted by Browne et al. (1994:243), who found that there was no correlation between perceived quality of life and the importance of health in a sample of older people, even when there was a significant decline in health status over the study period. While health is valued highly by older people, it is only one aspect of their quality of life (Bowling et al. 2003). Examining quality of life among people with dementia, Dabbs (1999b) has established that although physical health is important, it is of lower priority compared to social and emotional aspects of life. The equation of quality of life with physical functioning is therefore too simplistic and it is likely to underestimate the quality of life of someone with a chronic condition (Browne et al. 1994:237). Studies showing that older people report better quality of life than younger researchers expect from the conditions they have (e.g. González-Salvador et al. 2000), may be associated with pessimistic attitudes towards older people.

In line with the World Health Organisation’s (The WHOQOL Group 1995) positive definition of health as encompassing social, psychological and physical well-being, quality of life measures have shifted from a negative disease-based focus to a broader and more inclusive concept of health (Bowling 2005:4). Bowling (2005:2) contends that “a perspective which captures the positive end of the spectrum is required to create a balance and a less skewed perspective”. Bryant et al. (2001:940) have established that ‘health’ for older people means having the ability and opportunity to engage in something meaningful. Similarly, Bowling and colleagues (Bowling et al. 2003; Bowling and Gabriel 2007; Gabriel and Bowling 2004) have established areas of importance such as social integration, meaningful social contact, social relationships, reciprocity between generations, and the maintenance of social roles and activities. They have established that the absence of such aspects of life adversely affects perceptions of life quality in older

people. These findings emphasise the importance of meaningful social engagement in understanding quality of life among older people.

Most commentators now agree that a multi-dimensional approach, which includes a number of constructs or domains relevant to quality of life, is more appropriate to the measurement of quality of life (Brod et al. 1999a; Cohn and Sugar 1991; Lawton 1991; Lawton 1997; Logsdon et al. 2002; Rabins et al. 1999). Research with older people and people with dementia supports multi-dimensional models of quality of life encompassing social, physical, emotional and psychological domains (Bamford and Bruce 2000; Bowling et al. 2002; Dabbs 1999b; The WHOQOL Group 1995). Recent research suggests that it is the capability of achieving desired attributes, rather than the actual achievement of specific functions, which is most important for older people (Grewal et al. 2006). While it has been recognised that multi-dimensional measures are most appropriate when examining quality of life, there has been debate about whether these measures should be developed specifically in relation to people with dementia, or according to more general population samples of older people.

Whether developing dementia-specific or generic measures, it has generally been accepted that examining quality of life involves deconstructing the concept into component parts, rather than measuring the concept as a whole (Rogerson 1995:1375). There has consequently been a related preoccupation with the psychometric properties of measurement tools (e.g. Falk et al. 2007; Karim et al. 2008; Smith et al. 2007; Thorgrimsen et al. 2003). In their critique of life satisfaction research, Gubrium and Lynott (1983:30) argue that the focus of establishing validity depends upon a taken-for-granted orthodoxy that researchers understand what the concept entails in the reality of living. Moreover, it has been shown that individuals nominate different areas or weight universal domains differently from each other; while there may be a generic structure for quality of life, the actual content may be different for different individuals (Browne et al. 1994:236). It has

therefore been suggested by Ebrahim (1995) that the search for scientific measures should be abandoned, as the models are inappropriate to the individual and fail to capture the complexity of life.

Felce (1997:132) contends that there is “little prospect of a definitive scale or approach satisfying the quality of life research agenda”. Taking a pragmatic stance, Felce (1997:134) proposes using a ‘collective toolkit’ of indicators to address particular domains of quality of life. Similarly, Selai and Trimble (1999:109) suggest that the appropriate measure depends upon the goal of the study or the required data. Rosenberg (1995:1412) questions this pragmatic focus on epistemological problems, as opposed to a concern with ontological questions relating to the specific meaning or theoretical framework of quality of life. He argues that the translation of quality of life into psychometric components, even if incorporating multi-dimensional domains, fails to capture the inherent subjectivity of quality of life. Hendry and McVittie (2004) have also argued that an emphasis upon measurement is misplaced. They contend that quality of life is not readily measurable and should be viewed in terms of phenomenological experience, rather than fragmented into discrete components that can be operationalised.

Bond and Corner (2004) argue that the fundamental problem with traditional approaches to understanding quality of life is that they ignore the symbolic nature and meaning of life to the individual. An alternative approach to the normative study of quality of life, which has focused on the importance of subjective dimensions, has been described as ‘phenomenological’ or ‘hermeneutical’. This approach assumes that quality of life is dependent upon the individual’s interpretation and perception of what is relevant to their life (Bowling 1995:1448). From this point of view, quality of life should be defined by the individual in terms of past experience, present lifestyle, and personal hopes and ambitions for the future (O’Boyle 1997:1875). Understanding and interpretation are treated as more than epistemological means of gaining knowledge about quality of life, and as actual

ontological dimensions of human existence (Rosenberg 1995:1413). I adopt this approach to understanding quality of life by treating personal understanding and interpretation as the conceptual focus of inquiry.

A focus on interpretation and personal understanding has been promoted by Gubrium and Lynott (1983) in their review of life satisfaction measures in ageing research. They contest the value of traditional measures that ask people to think about their life as a universal and discrete entity that can be established and measured in general terms. Gubrium and Lynott (1983:31) argue for a conceptualisation of life in a contextual sense, by which a particular occasion's sense of continuity is established in comparative terms between the past and the present. This conceptualisation calls for an understanding of life quality as relative and subjective, in which temporality is a stream of experienced time rather than a linear, discrete and concrete concept. Gubrium and Lynott's (1983:34) assertion, that quality of life is articulated through the ongoing experiences of those who have it, calls for an approach that engages with subjective meanings and judgements of life in a temporal and comparative dimension:

It is not so much the facts of past life in their own right that determine one's current evaluation of life as whole as it is current social considerations that retrospectively serve to articulate both what life was and how satisfying it is said to have been.

Gubrium and Lynott (1983:36) contend that quality of life should be interpreted against a background of lived experience in which older people claim, take and abandon social roles. This more complex and fluid conceptualisation of quality of life acknowledges older people evaluating their lives in a past-oriented time frame, while also taking account of current lived experiences, and how present and future concerns relate to past experiences. As they suggest, this data is largely narrative, and so this conceptualisation of quality of life requires an approach that can capture the narrative processes of meaning-making in people's understandings of their life. This is a similar stance to the position

taken by Hughes (1990:57), who argues that biographical approaches produce the kind of data necessary to investigate the significance of the many different components of quality of life that are important to particular groups or individuals. This approach is applied in the current study to understand and compare the meanings of living with dementia among people with dementia and their carers.

Hughes (1990:53) suggests that theoretical models of quality of life should embrace how ageing as a social construct affects expectations and experiences. If extending this argument to understanding perspectives on quality of life among older people with dementia, it is clear that constructions of dementia should be considered relevant in addition to constructions of ageing. Downs (2000) has described the growing interest in the social context of dementia in relation to developments in disability studies. In relation to disability studies, Thomas (1999:68) refers to the significance of accounts of personal experiences and the personal narratives literature to understand what it means to live with disability. While traditional disability models assume that the primary focus of analysis should be at the structural level (e.g. Oliver 1990), those advocating a renewed social model (e.g. Crow 1996; Thomas 1999) make clear that the personal is political, and that personal meanings and the subjective experience of impairment are essential to fully understand the social consequences of disability.

In the field of dementia studies, a need for a focus on 'lived experience' rather than the 'observed phenomenon' has been described by Robertson (1990:430). Within critical gerontology, Moody (1988:33) has emphasised the importance of attention to interpretation and subjectivity in the study of ageing, and in particular the way that older people use narratives to organise their experience. Minkler (1996:470) similarly argues that a humanistic orientation is required to complement critical gerontology's predominantly structural concerns. Holstein and Minkler (2007:18) explain that humanistic orientations are interested in the intersection of culture and biography, asking

questions of how older people make sense of the ageing experience, and how cultural ideals shape these interpretations. In relation to disability, Kennedy and Minkler (1998:771) argue that by understanding the way that disabilities are physically based but socially constructed, we can better understand the meaning of disability within and across groups in society.

Bond (1999:565) suggests that a social model of dementia, adopting the social model of disability, should be concerned with the personal meanings that individuals attach to their life experiences. He argues that a social model should “focus on the way that people with dementia and their informal caregivers interpret their own experiences of living with dementia and the meaning that their situation has for them”. Consequently, Bond and Corner (2004) have developed a conceptual framework that recognises quality of life as subjective lived experiences that are constructed and reconstructed within the context of individual lives and life history. They contend that subjectivity, at different times and in different spaces, explains the diversity of perspectives and meanings of quality of life. They argue that quality of life is a subjective state, strongly influenced by the context in which we live and in which we establish our identities (Bond and Corner 2006:159). A focus on meanings and subjective experiences in the context of a person’s life history is therefore essential to understand different perspectives about the quality of life of people with dementia. This conceptualisation of quality of life is applied to the thesis, providing a humanistic framework to understand the influence of ageing and dementia on people’s experiences and expectations of life.

### **Investigating quality of life among older people with dementia**

Having established the value of a humanistic framework to explore different meanings of quality of life, this review turns to an examination of specific methods that have been used to research quality of life among older people with dementia. It will be shown that, in line with a shifting conceptualisation of quality of life, an initial interest in normative measures



using observation and proxy reporting, has now been complemented by increasing attention to the subjective and qualitative dimensions of quality of life reported by people with dementia. These developments in methodology have revealed differences in the evaluation of quality of life, depending upon the type of method that is used, and the person who is asked. This review will show that methods which engage with subjective perspectives provide the richest approach for exploring different meanings of quality of life, especially if the contextual element of subjective experience is taken to be a fundamental aspect of a person's quality of life.

Considering the empirical research on quality of life with dementia, the majority of measures are normative, developed by professionals, and based on their definitions and standards of what is important for someone with dementia. The legacy of reliance on 'expert' knowledge relates to assumptions about the inability of the person with dementia to deal with the cognitive demands of introspection and evaluation (Brooker 1995:146). They have commonly used proxy and observer ratings to measure behaviours taken to be indicative of quality of life. Studies focusing on objective measures are usually based on research constructs such as 'activities of daily living' and 'functional impairment' that come from biomedical models of dementia. The focus of normative measures includes observation of activity, affect and behaviour (Albert et al. 1996; Albert et al. 1997; Lawton 1994; Lawton et al. 1996; Lawton et al. 1999; Perrin 1997; Teri and Logsdon 1991; Volicer et al. 1999), and measurement of the quality of staff interaction and its impact on the person's well-being (Bredin et al. 1995; Clark and Bowling 1989; Dean et al. 1993; Fossey et al. 2002; Innes and Surr 2001; Morgan and Stewart 1997; Rabins et al. 1999; Skéa and Lindesay 1996).

These observational methods may be useful for assessing the quality of care if objective indicators are required to evaluate the outcome of service approaches and interventions. Yet the value of using these measures to assess quality of life remains questionable. While

Albert and his colleagues (Albert et al. 1996:1347) emphasise the reliability of using behaviourally-anchored measures to minimise observer bias and increase the consistency of ratings, they recognise that there is a problem with proxy reports through which information is “refracted through the lens of a caregiver’s interpretation of patient [sic] behaviour”. Firstly, it is problematic to assume that readily observable behaviours and proxy measurements offer insight into the subjective world of the person (McKee et al. 2002:748). Furthermore, assumptions about the inability to reflect on life have the potential to be disempowering for people with dementia by marginalising their perspective in defining outcomes (Bamford and Bruce 2000:544). And without any examination of subjective experiences, observational and proxy instruments may be measuring dimensions of quality of life that have no meaning for the person being considered (Russell 1996:1401). If we are engaging with quality of life as opposed to quality of care, the meaning of activity and interaction can only be known by engaging with the subjective perspective of the person with dementia.

Due to such practical and ethical objections to observational and proxy measurement, more recent studies have attempted to access the person with dementia’s perspective directly, recognising that the person’s values and interests may differ from those of their carers (Gwyther 1997). This shift in approach has accompanied an increase in research that recognises the capacity of the person with dementia to consent and make decisions. Studies about decision-making capacities have shown that people with mild to moderate cognitive impairment can respond consistently to subjective questions about choices and preferences, as well as to objective questions about demographics (Feinberg and Whitlatch 2001). The interest in the perspectives of people with dementia also reflects the World Health Organisation’s (The WHOQOL Group 1995:1405) definition of quality of life, which recognises the importance of a person’s own perception of their position in life, in the context of their culture, values, expectations and concerns.

The first group of studies to successfully elicit self-report of quality of life from a significant proportion of respondents administered structured questionnaires to people with dementia in an interview format (e.g. Brod et al. 1999b; Coen et al. 1993; Logsdon et al. 2002; Mozley et al. 1999; Novella et al. 2001; Selai et al. 2001). All these studies found that respondents with mild to moderate dementia were able to comprehend questions and respond appropriately to provide information about their subjective values. While such direct self-report appears more valid than proxy and observational methods due to its concern with subjectivity, researchers in this tradition still impose their own values on respondents by predefining the domains to be rated. Due to objections about imposing an external value framework on a person, there has been a move within this tradition to include people with dementia in the development of measures and tools (Brod et al. 1999b).

A separate group of studies has developed qualitative methodology to examine the person with dementia's phenomenological experience of quality of life. Phenomenological approaches, which focus on the subjective dimensions of quality of life, recognise the importance of the individual's personal perspective in defining what is relevant to their quality of life. These qualitative studies have tended to focus on quality of life in the context of care, generally within residential settings. Specific methods include ethnography (Cooney et al. 2009; Tester et al. 2003; Willcocks et al. 1987), unstructured conversations and interviews (Aller and Van Ess Coeling 1995; Clare et al. 2008; Dabbs 1999b; Dröes et al. 2006; Hendry and McVittie 2004; Parse 1996), focus groups (Bamford and Bruce 2000; Byrne-Davis et al. 2006), and the qualitative analysis of archived accounts and interview transcripts (Gwyther 1997). Their findings demonstrate that people with dementia can describe what is important to their lives in significant detail. They have also revealed aspects of quality of life that are missing from most normative quality of life research instruments. These include having a sense of autonomy or control,

having a sense of self and identity, being useful and having purpose in life, forming and maintaining relationships, caring for oneself and being able to help others.

Qualitative studies have revealed that the way people describe quality of life is far more complex than what is captured in quality of life instruments and assessment tools. Borglin et al. (2005) describe the way that quality of life in old age is associated with a preserved self and meaning in existence. Important aspects of life, not generally included when assessing quality of life through normative measures, involve the meaning of home, how life is viewed, thoughts about death and dying, and telling one's story. Silberfeld et al. (2002) highlight the discrepancy between normative and phenomenological research in their study examining the valued aspects of life quality among people with dementia. They compared an open-ended semi-structured interview with the content of three generic health-related quality of life instruments. Essential components of quality of life identified by the respondents were missing from all three of the instruments. This evidence, that important items are missing from measures based on the value frameworks of professionals and other proxies, confirms the importance of examining the meanings underlying different perspectives on quality of life.

Tester et al. (2003) highlight the role of continuities and discontinuities in the evaluation of life quality in older people adapting to their move to a residential home. Being connected to others, being able to maintain a sense of self and making meaning of experiences were important features of their quality of life. These themes reflect the type of contextual understanding of quality of life advocated by Gubrium and Lynott (1983) in relation to the importance of continuity and social roles in the background of lived experience. Similarly, Clare et al. (2008) have established that people's descriptions and emotional responses to their situation are grounded in a strong sense of self and identity. Hendry and McVittie (2004) examined the subjective meaning of quality of life among older people and identified four themes that represented their phenomenological

experiences: holism of experience, relativity to others, ambivalent views, and management of quality of life. These descriptions of the contextual and contingent dimensions of life resonate with the framework of quality of life articulated by Bond and Corner (2004), which focuses on subjective meanings that are influenced by the social context within which people live and establish their identities.

Gubrium (1995:70) uses the term 'narrative context' to describe the way that people's responses derive their meaning from the particular story being told - the 'it depends' quality of people's responses - in addition to the way that local cultures influence individual narratives. In his discussion of the contextual basis of interview responses, Gubrium (1995:75) highlights the importance of understanding the experiential connections and meaningful backgrounds of a person's life in answering questions about issues such as life quality. In a study of the quality of care and quality of life in a nursing home, Gubrium (1993) describes how older people make linkages with lifelong experiences, with 'horizons of meaning' arising from the pattern of narrative linkages between the past and the present. According to this framework, Gubrium and Holstein (1994:697) represent lives as narratively constructed, in other words made coherent and meaningful through 'biographical work' that links lived experiences into compelling life courses.

Jennings (1999:102) has emphasised the importance of acknowledging 'semantic agency' in understanding quality of life among people with dementia. This includes the activity of making and experiencing meaning through verbal and non-verbal communication. Jennings (1999:104) has consequently argued for the development of methods of investigating quality of life that can access these capacities. A narrative conceptualisation of quality of life fits with this interest in the activity of making and experiencing meaning. By placing quality of life in narrative perspective, the subjective experiences of older people with dementia can be contextualised within their evolving life history, to explore

the way that meaning is created in relation to connections between the present and the past. Using a narrative approach to understand the meaning of quality of life therefore offers a fruitful avenue for understanding perspectives on quality of life.

From this review of quality of life studies, it is evident that different methodological approaches to investigating quality of life have provided different conceptualisations of what is important to people living with dementia. Qualitative studies have started to engage with the lived experience of dementia, to reveal additional aspects of life quality that are missing from normative measures of quality of life. However, a narrative conceptualisation of quality of life has not yet been applied to answer the specific question of what meanings underlie different perspectives on quality of life. In the final section of this chapter, I explore existing research about different perspectives on quality of life, to consider how a narrative approach could answer the specific question of how meaning is constructed in differing perspectives on quality of life among people with dementia and their carers.

### **Comparing the perspectives of people with dementia and carers**

The comparison of normative and phenomenological methods of investigating quality of life has revealed important differences in the perspectives of people with dementia and their proxies. Objective measures by professionals and proxy reports by carers have been shown to be different from the subjective self-reports of life quality among people with dementia (Kiyak et al. 1994). The contrast between proxy and individual perspectives is important to the assessment of quality of life (Bond and Corner 2004). Qualitative studies in particular have revealed additional aspects of quality of life that are important to people with dementia that are missing from measures developed by professionals. If we conceptualise quality of life as subjective and personal, involving 'biographical work' (Gubrium and Lynott 1983) that contextualises meaning, it may be that differences in perspectives reflect real differences in the subjective interpretation and meaning of

quality of life with dementia. Cohn and Sugar (1991:46) argued 20 years ago for a new focus in quality of life research to develop a conceptual framework that takes account of differences in perspectives between people with dementia and carers. In this section, I review the evidence for quantitative and qualitative differences between how people with dementia and their carers rate quality of life, and argue for the need to focus on the way that meaning is constructed in people's accounts to develop an appropriate framework to understand these differences.

There is now an extensive body of work that consistently shows there is only modest agreement between the person with dementia and their carers when it comes to assessing the former's quality of life (Albert et al. 1996; Bamford and Bruce 2000; Cohn and Sugar 1991; Feinberg and Whitlatch 2001; Jönsson et al. 2006; Logsdon et al. 1999; Naglie et al. 2006; Ready et al. 2004; Silberfeld et al. 2002; Sloane et al. 2005). In quantitative terms, proxies generally rate quality of life lower than individuals with dementia report themselves (Carpenter et al. 2007; Edelman et al. 2005; Hoe et al. 2007; Novella et al. 2001; Sands et al. 2004; Selai et al. 2001; Siedlecki et al. 2009). Research comparing proxy ratings among paid and family carers has shown that this pattern is consistent across both groups of carers (Albert et al. 1996:1345). However, within this overall trend, there is some individual variability, with some proxies more consistent than others in their reporting (Carpenter et al. 2007). The general finding of lower reporting among carers of people with dementia is consistent with the wider literature on proxy reporting of quality of life for people living with a chronic condition (Sainfort et al. 1996; Sprangers and Aaronson 1992) and the health status of older people more generally (Magaziner et al. 1996; Magaziner et al. 1997).

One explanation for this discrepancy in ratings is that cognitive impairment causes people with dementia to over-estimate their quality of life. It has been proposed that self-report among people with dementia is unreliable due to cognitive impairment (Arlt et al. 2008;

Rabins and Black 2007; Whitehouse 1999) or poor insight and awareness (Lin Kiat Yap et al. 2008; Vogel et al. 2006). However, studies comparing the reports of people with dementia and carers have shown that people with dementia can accurately report on physical and functional health, even when their cognitive skills decline (Sands et al. 2004). It has also been established that lower cognition is not directly associated with a poorer quality of life (Banerjee et al. 2009). Moreover, comparisons with proxies have shown that discrepancies in reporting are not related to the person's cognitive performance or level of functioning (Kiyak et al. 1994). It therefore seems unlikely that discrepancies in perspective are due to the unreliability of people with dementia in reporting their quality of life.

Attention has therefore turned to carer burden as the most likely explanation for a difference in perspective. The assumption is that depression among carers is linked to a lowered evaluation of life quality (Banerjee et al. 2006; Banerjee et al. 2009; Karlawish et al. 2001; Sands et al. 2004). The lower evaluation of quality of life has been linked to factors such as perceived dependency (Hoe et al. 2006) and perceived behavioural disturbances within the person with dementia (Banerjee et al. 2006; Vogel et al. 2006). The basic premise of these studies is that the pessimism associated with dementia and ageing may negatively skew results, causing a bias that is linked to a lower evaluation of the person with dementia's quality of life (Logsdon et al. 2002; Lyons et al. 2002; Sands et al. 2004).

The main basis of this research tradition has been to examine the extent of statistical correlation between self and proxy report, with the ultimate aim of finding ways to address perceived errors in reporting that cause people to over- or under-estimate quality of life. While these comparative studies suppose quantitative errors in reporting, it may be that the differences among people with dementia and their carers reflect qualitatively different forms of meaning-making in people's accounts. As Edelman et al. (2005)



conclude, each perspective appears relatively independent and unique. It seems likely that proxies, whether family or paid carers, have a qualitatively different appraisal of quality of life than people with dementia do themselves (Banerjee et al. 2009). Logsdon and colleagues (2002:518) suggest that differences in reporting between people with dementia and their carers are likely to reflect real differences in how they perceive quality of life:

Because there is no 'gold standard' for quality of life and it is widely agreed that quality of life assessment involves subjective perceptions, the correlation between patient [sic] and caregiver reports likely reflects a real difference in the way they perceive the patient's quality of life.

As would be expected, if differences in reporting reflect real differences in perspectives, it has been shown that proxies are poorest at measuring the subjective domains of quality of life (Weyerer and Schaufele 2003). An interest in the qualitative dimension of different perspectives is pertinent when studies have shown that people with dementia, family and paid carers often have different perceptions of their needs, preferences and values (Fortinsky 2001; Hancock et al. 2003; Silberfeld et al. 1996; Whitlatch 2001; Zweibel and Lydens 1990). Bamford and Bruce (2000:565) suggest that carers may have difficulty 'disentangling' their own desired outcomes from those of relevance to people with dementia. Similarly, Cohn and Sugar (1991:43) propose that people with dementia and their carers may describe quality of life differently to achieve different purposes related to their own particular roles and responsibilities. They suggest that people with dementia focus on their own morale and attitude, while carers focus on quality of life primarily in terms of care. It may also be that age affects a person's perspective on what is important, with people redefining what matters according to their life stage and capabilities. Perspectives on quality of life are therefore likely to be framed by the individual's values, interests and attitudes towards care.

Evidence of different attitudes and values influencing the reporting of quality of life has been demonstrated in some recent studies. Winzelberg et al. (2005) have found that there is a positive association between proxy reporting and attitudes to person-centred care and training, with people who adopted person-centred principles rating quality of life more positively. They suggest that this positive association could relate to whether or not carers view people with dementia as having the capacity to engage in relationships. Gerritsen et al. (2007) have established that carers in different roles focus on different quality of life domains. They found that while professionals who offered daytime activities rated being useful or giving meaning as important to people with dementia, assistants providing nursing care did not pay attention to these dimensions of life. These findings suggest that carers define quality of life within their own field of competence or expertise. Harmer and Orrell (2008) have demonstrated that people with dementia and carers have different perspectives about the basis of what makes activities meaningful. They found that people with dementia focus on their psychological and social needs, while carers focus on the maintenance of physical abilities. People therefore interpret quality of life according to their own particular concerns and social positioning.

While these recent studies move the field forward by considering the qualitative dimensions of differences in reporting, they continue either to use structured methods to explore perspectives or to focus on delimiting different domains of relevance to quality of life. The field of quality of life research still lacks an in-depth exploration of processes of meaning-making, which is necessary to develop a conceptual framework of different quality of life perspectives that appreciates the subjective and interpretative elements of people's accounts. If focusing on the contextual and biographical relevance of meanings of quality of life, this requires an approach that can access the different ways that people make sense of ageing and living with dementia. Developing a humanistic framework of quality of life among older people with dementia involves asking questions about how people make sense of the ageing experience and how they understand living with a

chronic condition, paying particular attention to the context of a person's life history and the way that cultural ideals shape interpretations. However, to date there has been little attempt to construct a sociological framework that compares the personal meanings and subjective perspectives of people with dementia and carers to explain how and why their perspectives on quality of life may differ.

Bowling and Brazier (1995:1337) have argued that the greatest problem with quality of life research is that most studies do not apply social scientific theory in their analysis. In particular, they argue that there has been little attempt to build on the rich data from qualitative studies of chronic illness and personal experiences within the sociology of health and illness. Some scholars within the sociology of health and illness highlight the social construction and definition of illness experiences (e.g. Freidson 1970; Scheff 1984). This tradition pays particular attention to the ways that concepts of self and social identity are linked to narrative constructions of living with a chronic condition. Cotrell and Schulz (1993:206) have argued for the potential of applying concepts of self and identity from the sociology of health and illness to enhance our understanding of the experience of dementia. Similarly, Bond and Corner (2001:103) have highlighted the importance of concepts of self and identity in understanding how meaning-making relates to subjective perspectives on quality of life. As they explain, the creation and recreation of meaning and identity is fundamental to an understanding of living with dementia:

... the meaning and quality of life is only meaningful through the subjective definitions of individuals ... living with dementia involves the active creation and re-creation of meaning and identity ... as part of the daily work of living with the condition.

Despite the wide-ranging conditions that have been studied in the sociology of health and illness, dementia studies remains largely marginalised from this academic tradition. Psychosocial approaches have had greatest influence within dementia studies in recent years, with interaction the main focus of study within which conceptual frameworks of

self and identity have been examined. However, as Bond (1999:564) argues, psychosocial frameworks are problematic in the specific study of quality of life among people with dementia. While a focus on social interaction is relevant for studies examining the relationship between well-being and quality of care, it is less useful for examining processes of meaning-making in respect of subjective perspectives on quality of life. As Innes (2009:145) asserts, considering the perspectives of all groups avoids the pitfall of 'taking sides', to recognise that the study of dementia involves recognising and interrogating knowledge from a range of different perspectives. Such an approach to studying the way that meaning is constructed in differing perspectives on quality of life has been largely absent, and comparisons of subjective meaning-making have not been examined directly by any quality of life research studies to date.

What is evident is a gap in our understanding of the way that meaning is constructed in different accounts of quality of life. A focus on subjective processes of meaning-making provides the greatest potential for exploring different perspectives on quality of life. A sociological framework can be applied to the study of differing perspectives on quality of life, to focus on a comparison of the ways that people with dementia and carers construct meaning in their accounts. Randall (2001:5) recognises the ability of a narrative approach to provide a common vocabulary with which to forge theoretical connections between the various fields concerned with ageing. By bringing together relevant literature from the sociology of health and illness, social gerontology and dementia studies, it is possible to develop a humanistic and critical appreciation of differing perspectives on quality of life. Linking the sociology of health and illness with a humanistic social gerontology enables a sociological appreciation of quality of life among older people with dementia. The thesis addresses the gap in the literature, by exploring and comparing the ways that people with dementia and carers construct meaning in their accounts of the quality of life with dementia.

## **Conclusion**

This chapter has examined conceptual models and methodological approaches to the study of quality of life among people with dementia. The literature review has revealed differences in the perspectives of people with dementia and carers in their reporting of quality of life. Most studies examining different perspectives have tended to focus upon explaining quantitative differences in reporting among carers and people with dementia. A few recent studies have considered the qualitative dimension of differences, yet these studies continue to use structured methods or focus on delimiting different domains of relevance to a person's quality of life. Little attention has been paid to the construction of meaning in accounts, to consider whether different perspectives reflect differing forms of meaning-making. This thesis addresses a gap in the literature by conducting an in-depth comparative exploration of processes of meaning-making in people's accounts, to explain why carers and people with dementia may represent quality of life differently.

I have argued that a humanistic focus on the question of meaning is a persuasive approach to examine different perspectives on quality of life. This includes attention to the ways that people conceptualise quality of life in a contextual sense, focusing on meanings and subjective experiences in the context of a person's life history, and embracing the way that understandings of ageing and dementia affect people's expectations. By applying a conceptual framework that considers the narrative construction of self and social identity in relation to ageing and living with dementia, this thesis develops an appreciation of quality of life that draws together relevant strands of social gerontology and the sociology of health and illness. In the following chapter I therefore review what we already know from the literature about subjective meaning-making in accounts of identity work and emotion work among people with dementia and their carers.

# **Chapter Three**

## **Engaging with subjective meaning-making**

### **Introduction**

The previous chapter has established the rationale for exploring comparative processes of meaning-making in accounts of quality of life. This chapter advances the argument by reviewing the existing literature about meaning-making to understand the different ways that people understand ageing and dementia. I first review research that focuses on subjective meanings of living with dementia, to explore the ways that people establish their identities in the context of ageing and living with a chronic condition. I then review literature that examines the meanings of ageing and dementia to carers, and the ways that carers manage their emotions and identities in caring for people with dementia. It will be shown that these parallel processes of meaning-making can be understood as types of 'biographical work', as people strive to make sense of their experiences and find meaning in their situation in life. Finally, I consider how narrative can be used to conceptualise and explore differences in perspectives on quality of life among people with dementia and their carers. This will demonstrate the value of a conceptual framework of meaning-making, in terms of drawing together the parallel literature on identity work and emotion work among people with dementia and their carers, as well as engaging with people's own sense of meaning in their subjective perspectives on quality of life.

### **Identity work in making sense of living with dementia**

The experiences of living with dementia were initially documented in autobiographical accounts of living with dementia (e.g. Davis 1993; Friel McGowin 1993; Rose 1996), before researchers became interested in the subjective perspective of people with dementia (e.g. Downs 1997; Keady 1995; Kitwood 1997b; Woods 1997). An initial interest in personal accounts was mainly framed within the context of services, clinical

experiences and research participation (e.g. Aggarwal et al. 2003; Aller and Van Ess Coeling 1995; Bahro et al. 1995; Barnett 2000; Bender and Cheston 1997; Bowes and Wilkinson 2003; Brooker and Dinshaw 1998; Cheston 1996; Cheston et al. 2000; Cohen et al. 1985; Dabbs 1999b; Keady and Nolan 1995; Mills 1997; Smith et al. 1998; Stalker et al. 1999). At the same time as research on user perspectives increased, research on the experience of living with dementia focused on the psychosocial context of relationships, with a particular interest in the self or personhood of the person with dementia in interaction (e.g. Golander and Raz 1996; Hanson 1997; Kitwood 1993; Sabat and Harré 1992). With the growing acknowledgement that people with dementia could engage meaningfully in research, an increasing number of studies began to explore subjective perspectives on the lived experience of dementia (e.g. Gillies 2000a; Harris and Sterin 1999; Holst and Hallberg 2003; Lyman 1998; Phinney 1998).

Studies of subjective perspectives have examined the ways that people with dementia make sense of their changed situation in life. Gillies (2000a) has shown that most people with dementia contextualise their experiences within normal old age, rather than understanding dementia as an illness. Similarly, Langdon et al. (2007) have found that the label of disease is often rejected by people with dementia, who prefer to talk about having memory problems or being forgetful. Gillies (2000a) has reported that, while people with dementia often play down their memory problems, they are concerned with the humiliating effects of their memory loss and the negative reactions of others. Lyman (1998) has also demonstrated that social and cultural losses outweigh the actual impairment associated with dementia. This is understandable when it has been shown that people with dementia experience social exclusion as a result of the stigma attached to their condition (Graham et al. 2003; Katsuno 2005). People with dementia are acutely aware of the negative attitudes of other people and wish to be treated as 'normally' as possible (Langdon et al. 2007). The social consequences of dementia are therefore important in people's accounts of their experiences.

Beard (2004) argues that people with dementia actively make sense of their worlds in ways that serve to preserve their sense of self. People with dementia attempt to integrate the condition into their lives, to avoid losing a sense of continuity (Steeman et al. 2006). The importance of continuity is evident in studies that have shown that people with dementia redefine what is 'normal' by either downplaying or incorporating impairment and emphasising continued 'normality' in their sense of self (e.g. Gillies 2000a; Lyman 1998; Phinney 1998). Perceptions of continuity relate to comparative processes of meaning-making. Gillies (2000a) describes how people with dementia compare their present self with what they could do in the past, and compare themselves to other people considered worse off than them. Such processes of social comparison have also been described by Lundh and Nolan (1996) in relation to older people's subjective interpretations of a 'good' quality of life, which was linked to maintaining a valued sense of self by focusing on past achievements rather than present limitations. The importance of understanding quality of life relative to processes of social comparison attests to the contextual and dynamic processes involved as people make sense of their everyday experiences (Hendry and McVittie 2004:969-970).

Assigning meaning has been established as a fundamental part of coming to terms with a diagnosis of dementia (Lingler et al. 2006; MacQuarrie 2005). The significance of meaning-making is evident in conceptual models of adjustment that examine the way that dementia is incorporated into a person's sense of self (Beard and Fox 2008; Clare et al. 2005; Gilmour and Huntington 2005; Keady et al. 2007; Ohman et al. 2008; Pearce et al. 2002; Steeman et al. 2007). Clare and colleagues (Clare 2002; Clare 2003; Clare et al. 2005) describe the process of adjustment as people attempt to achieve an ongoing balance in their lives through strategies of self-maintenance and self-adjustment. Self-maintaining responses are linked to self protection and preservation, by maintaining continuity with the prior self, normalising the situation and minimising difficulties. Self-adjusting responses are linked to confronting difficulties and integrating experiences into a



changing self concept, through 'fighting' and coming to terms with the condition (Clare et al. 2005). In the context of coping and adjusting to their condition, quality of life can be perceived as fluid, as people actively manage their identity to make sense of dementia (Bond and Corner 2004:93).

In a review of the literature surrounding the subjective needs of people with dementia, van der Roest et al. (2007) have established that the most frequently reported needs involve people being respected and accepted as they are, finding adequate strategies to cope with disabilities, and the need to come to terms with their situation. Grenier (2006) links the emotional adjustment of dealing with experiences of impairment, disability and decline with maintaining a continuous identity. Investigating the ways that older people cope with dementia, Preston et al. (2007) found that coping involves managing identity in relation to dementia, making sense of dementia, in addition to coping strategies and mechanisms. Managing identity involves axes of continuity and discontinuity between the past and present self, as a person integrates dementia into their identity, to either represent their self as able and valued or as substandard. Making sense of dementia relates to individual experiences and making sense of the condition as a whole. Coping strategies incorporate individual everyday strategies for dealing with practical issues, finding benefit from being with similar people and getting help from others. The centrality of the roles of identity and meaning in quality of life are clear.

Studies focusing on the experience of living and adjusting to dementia emphasise the centrality of identity in people's accounts. Kelly and Field (1996:245) describe how self and identity are central aspects of everyday experiences and the everyday experience of illness. Self is constantly being constructed and reconstructed, and is expressed in narrative and autobiographical accounts offered in self-presentation. Identity links self to the social structure, and is therefore public and shared. They contend that ageing and the onset of illness can create a tension between self and identity, which is related to

Goffman's work on stigma and spoiled identity (Kelly and Field 1996:246). Goffman (1968) depicts a discrepancy between 'virtual identities' imputed by others, and the individual's self conceptions based on the 'actual identities' of what they are able to do. Consequently, the negative and stigmatising labels associated with a chronic condition are tied to transformations in identity associated with Parsons' (1951) concept of the sick role. Kelly and Field (1996:247) argue that the problem of meaning is therefore another way of looking at the tension between self and social identity.

Kelly and Field (1996:248) also argue that this problem of meaning is related to a tension between continuity and change as a condition progresses. Robinson (1993:14) describes the process where, in the face of the societal story of deviance and difficulty, individuals manage living with a chronic condition by constructing and living that life as normal. This involves a balancing act, whereby problems are acknowledged, but in a way that minimises deficits and emphasises abilities. Herskovits and Mitteness (1994:336) consider how people with chronic illness need to engage in strategies to normalise their condition and reject the social significance of their impairment. This is evident in Aminzadeh et al.'s (2009) description of the normalising strategies of older people with dementia, who frame themselves as resilient in the face of the challenges they experience. This finding fits with Holstein and Cole's (1996) position that part of the identity work involved in living with a chronic condition includes creating a new story of the self that integrates the condition into the person's ongoing life history. Charmaz (1999:374) points to the importance of stories and the roles that they play in "making sense of suffering, locating self in life, and coming to terms with an altered existence". This process has been described by Brown (1995) as 'narrative reconstruction'.

The importance of narrative in the context of life history is evident in gerontological traditions that link well-being and identity development. Well-being is associated with the importance of coherence as an essential element of an integrated and satisfying life story

(Bluck and Habermas 2000; Coleman 1986; Coleman et al. 1999; Sherman 1994). Coleman et al. (1998) describe how story is used in making sense of the past and interpreting the present, with older people's sense of continuity associated with the relatedness of their recent life experiences to their whole life course. The general theme by which people have lived their lives, rather than its temporal relevance, is what appears most important in people's stories (Coleman et al. 1999:844). Taking a similar stance, Atchley (1991) argues that ageing influences the self, mostly for the good, until the onset of frailty or disability in later life, when there is a disruption in the continuity of the person's way of life. This disruption relates to the way that aspects of self that are significant in Western societies, such as competence and self-reliance, become difficult to maintain. Ray (2007:70-71) relates the need for continuity to the importance of emotions within narratives of ageing.

A growing number of studies have started to examine the narrative construction of identity in personal accounts of dementia. These studies have demonstrated that people with dementia use stories as sites for identity construction, in order to reposition themselves as active and capable people within their communication (e.g. Edvardsson and Nordvall 2007; Lenchuk and Swain 2010). Crisp (1995) has shown how narrative structure provides a means of bringing the fragments of memory together to construct an active identity, sometimes using metaphors to create meaning. She points to the importance of people with dementia being able to bring order to and make sense of the past in a way that counteracts stigma and asserts a sense of worth. As Dorenlot (2005:460) suggests, by speaking about their lives and circumstances, people with dementia are challenging negative constructions of their capacity to act. Attention to these narratives has demonstrated that, despite the losses that people with dementia experience, it is possible to reject a narrative of loss and incorporate dementia into a positive story of living (Beard et al. 2009). This narrative conceptualisation of meaning-making is helpful in framing people with dementia as active agents striving to find and communicate meaning.

Cheston (1996:579) describes the function of stories to explore the significance of experiences. Bender and Cheston (1997:521) describe how stories about the past enable people with dementia to establish identities that may be different from those allocated to them on the basis of having dementia. Cheston and Bender (2003:175) have described the importance of people being able to present the appearance of being normal, to hold onto their sense of being a worthwhile person. Similarly, Steeman et al. (2007:119) have established that people with dementia often present positive narratives about their lives to counteract “threats posed by dementia and by the person’s interactions with others”. In addition, Macquarrie (2005) has shown that people with dementia may resist their diagnosis through reminiscence about past achievements and experiences of competence. Narratives therefore need to be understood as attempts to negotiate identity within the context of the practical and social consequences of having dementia.

Sutton and Cheston (1997:160) explain that people with dementia have much to try and make sense of, particularly the sense of loss, uncertainty and threat that arise in the context of cognitive difficulties and devalued social identities. Engaging with these aspects of life points to the importance of the emotional meaning of stories beyond the immediate surface content (Sutton and Cheston 1997). In this context, Hydén and Örvulv (2009) stress the importance of paying attention to the organisation and function of talk, since temporal discontinuities in stories do not necessarily reflect disrupted identities. Bender and Cheston (Bender and Cheston 1997; Cheston and Bender 2003) emphasise the importance of understanding the emotional world of people with dementia in the context of narratives of dementia. Mills and Coleman (1994) have argued that emotional memories are essentially stories of self that give people with dementia a sense of narrative identity. Mok et al. (2007) have demonstrated that people with dementia can adopt a positive outlook in life if they are able to make sense of their condition. Coping is linked to illness attributions, as well as to emotional-focused, practical-focused and cognitive-focused strategies. As

Coleman et al. (1999:824) assert, even though control over external events may be relinquished, control over meaning remains important for older people.

While coherence and continuity have been emphasised as important aspects of identity development, some studies of chronic illness have described the difficulty of integrating illness into a coherent narrative, especially when our culture does not provide the resources for making sense of pain and illness (e.g. Becker 1999; Frank 1995). Mishler (1999:81) contends that there needs to be a place for discontinuities in developmental theories. Estes et al. (2003:152) have similarly argued that a critical analysis of identity in older people requires elements of continuity and coherence, as well as options and possibilities for change. As Hydén (1997:53) suggests, narratives have the potential to give meaning to events that have disrupted and changed a person's life. Mishler (1999:110) therefore reconceptualises coherence as a social accomplishment, through which people make sense of the contradictions and tensions in life as they communicate their narratives. This approach to the creation of meaning, and its relationship to identity, conceptualises coherence as narrative practice (Gubrium and Holstein 1998), as social action rather than disposition (Ville and Khlat 2007).

Gubrium and Holstein (2006:124) argue for viewing the ageing self in terms of the 'constructive craft' of biographical work. Understanding identity as life story highlights the importance of narrative continuity and discontinuity in perspectives on quality of life. While the narrative construction of identity and meaning has become more evident in research examining the experience of dementia, such a framework has not been applied to understand the meaning of different perspectives on quality of life. In my approach to investigating quality of life, I take the same stance as O'Boyle (1997:1875), that "individuals are active agents, involved in a continuous search for meaning and constantly striving towards the goal of self actualization". I contend that the ways in which people with dementia describe their quality of life should be explored by examining the ways that

they construct meaning relative to narrative frameworks of self and social identity. This approach can engage with the emotions, metaphors and contextual processes of meaning-making that are evident in existing studies that have explored the lived experience of dementia. I now turn to the perspectives of carers to consider some of the parallel ways in which carers make sense of ageing and dementia.

### **Emotion work in making sense of the experience of caring**

In the previous section, I discussed the importance of identity work and narrative processes of meaning-making in subjective accounts of living with dementia. In this section, I consider the relationship of socio-cultural meanings of ageing and dementia to the ways that carers represent older people with dementia and their experiences. It will be shown that, in addition to the influence of these wider discourses on people's perspectives, carers adopt particular understandings of dementia that provide explanations for their experiences and help them cope with the tasks of caring. The search for meaning is linked to the emotion work of carers, as they endeavour to make sense of the experience of caring. Studies of paid and family carers have demonstrated the importance of meaning-making, with evidence that care work is informed by what Adams (1999:51) describes as "narratively organised knowledge". I therefore explore the processes of meaning-making in carers' accounts, to understand the way carers represent their own identities in relation to caring for older people with dementia.

Featherstone and Hepworth (1990) have reflected on the way that ageing bodies and minds have been devalued and become feared in Western society. Negative cultural stereotypes associated with age include powerlessness, decline, sickness, dependency, death and an association with being conservative, inflexible and incapable of creativity (Dein and Huline-Dickens 1997:114). Harding and Palfrey (1997:133) argue that "illness, disability or growing old are biological processes mediated through discourse". They contend that socially prescribed norms take on a moral quality, to form the basis of a

definition of dementia, whereby instances of forgetfulness are synthesised into a syndrome by the medical profession (Harding and Palfrey 1997:144). Robertson (1990:436) describes how dementia is constructed as a 'fearsome disease', surrounded by images of the loss of qualities that represent humanness. Whitehouse (2007:460) describes the limiting social narrative of Alzheimer's as one of terrifying, degenerative loss. Cultural representations of dementia reveal the extent to which dementia is viewed as a personal tragedy (McColgan et al. 2000).

'Oldness' is socially constructed by older people as well as younger people, with a decline in mental acuity associated with the start of real old age (Degnen 2007). Dementia is associated not only with biological death, but also with social death in terms of a loss of social role and self identity prior to biological death (Cotrell and Schulz 1993). As Bartlett (2000:35) argues, the relationship of older people with dementia to others "is inextricably linked with social constructions of not only 'old age' but also dependency". In her discussion of the social construction of Alzheimer's disease 20 years ago, Robertson (1990:430) argued that the biomedical approach has neglected social issues including loss of role and status. This depoliticised conceptualisation of dementia and ageing, which attributes difficulties to biological processes of individual pathology, has continued to be apparent in much of the literature examining different perspectives on quality of life.

Socio-cultural representations of dementia are important in terms of whether life can be interpreted as 'good' or 'normal'. Sweeting and Gilhooly (1992:257) consider the concepts of 'being a person' and 'living a worthwhile life' with dementia from the perspective of carers. The relationship between these two concepts is considered in terms of 'social death', whereby life cannot be recognised as worthwhile "if an individual ceases to possess the characteristics that we recognise as being those of a person". Social death is associated with a person outliving their social context, as engagement with social activities diminishes, friends predecease them, and the possibility of death becomes

greater (Sweeting and Gilhooly 1992:263). From this point of view, life cannot be perceived as 'good' if it fails to meet some standard of normality (Sweeting and Gilhooly 1992:260). As a result, social death can be related to anticipatory grief in carers (Gilhooly et al. 1994). Living a 'good' life with dementia is therefore a problematic notion, for both the person with dementia and their carers, when dementia is fundamentally associated with death and decline.

The association of dementia with a loss of normality is connected with wider social discourses about competence and status in Western society. Herskovits and Mitteness (1994:331) suggest that dementia constitutes a threat to adult status due to the violation of socio-cultural values of independence, mastery, productivity and individual responsibility that are associated with 'inappropriate' activity such as disinhibited behaviour, disorganised activity and wandering. They link these values to Foucault's (1973) analysis of the ways that industrial and biomedical mandates have penetrated public perceptions of the individual body and subjective experience. Within this discourse, people with dementia are perceived to transgress norms of physical and symbolic cleanliness. These 'transgressions' have been associated with a stigmatising 'second childhood' status (Herskovits and Mitteness 1994:332) that has been observed in service settings to justify the management of behaviour (Lyman 1988). Ageing, helplessness and dependency are therefore linked together in metaphor, to justify the way that older people with dementia are perceived as experiencing a second childhood (Hockey and James 1993). The continuing persistence of the biomedical model of dementia as the normative framework of care has been reported by Ward et al. (2008:646).

In countries like the United Kingdom, where dementia is considered a disease, wider policy contexts influence the development of ideas about dementia (McCabe 2006:117). For instance, the understanding of dementia as a disease is prevalent among nurses, who frequently apply a biomedical model of dementia in their representation of older people



as dependent and disengaged from the social world (e.g. Armstrong-Esther et al. 1999; Cooper and Coleman 2001). These professional discourses are tied to the way carers define their own role in care-giving. The use of maternal metaphors in nurses' accounts supposes a nurturing role of maternal love that may be self-fulfilling in reinforcing dependency (Hägström and Norberg 1996:437; Rundqvist and Severinsson 1999:802). More recently, psychosocial models have started to influence expectations about people with dementia, with person-centred standards focusing on the personhood of the person with dementia and their relationships with other people (Edvardsson et al. 2008). While there is evidence to suggest that person-centred approaches may be improving attitudes towards older people with dementia, the perceived inability to experience and a lack of capacity for social interaction have been found to be associated with less positive attitudes in nurses (Norbergh et al. 2006:267). Particular professional discourses in health and social care therefore categorise and address older people with dementia in particular ways (Adams 1999:42).

Herskovits and Mitteness (1994:336) consider how the stigma of dementia can generalise to family carers, who may then engage in strategies to avert social transgressions by their relative. The acquired feature of this type of stigma is described as 'courtesy stigma' by Goffman (1968). The experience of stigma is complex, and some family carers avoid experiencing stigma by concealing dementia from the outside (MacRae 1999). Such strategies may also be part of a 'protective gaze' that seeks to protect the person with dementia from the judgements of others (Innes 2009:84).

These socio-cultural and professional discourses of dementia influence the way that carers understand the person with dementia and their experiences. For example, Hinton and Levkoff (1999) apply a narrative approach to understand the way that family carers draw upon cultural and personal resources to construct storylines of how they understand the nature and meaning of dementia. Different story types configure

particular moral concerns and cultural meanings of dementia. While some carers make sense of dementia as an expected part of ageing, others attribute dementia to a disease that erodes the person's identity. Yeo et al. (2001:145) suggest that these different meanings may help carers cope with the tasks of care-giving. They emphasise the importance of understanding the stories and metaphors that carers use to make sense of their struggles. The way that carers adopt particular meanings of dementia to cope with the task of caring can be related to research about ways that people with dementia adjust and make sense of their condition. Robinson (1993:19) represents people living with chronic illness and their families giving meaning to their lives and relationships by 'storying' their experiences.

Ways of making sense of the person's identity relate to the carer's own well-being, in addition to the impact of socio-cultural meanings of ageing and dementia. An association between carers' understandings of the experience of dementia and their own experiences as carers has been demonstrated in studies of narrative meaning-making. Levy et al. (2000) explored the patterns of illness attributions in carers' explanatory styles. They found that carers who focused on dementia as an internal attribute of the person experienced a higher 'burden' than those who attributed dementia to causes outside the person. Parsons (1997) has similarly concluded that the way carers make sense of dementia, and understand its impact on the person's identity and behaviour, is related to the meaning of their own experiences as carers. The function of these narrative processes of meaning-making can be linked to Kelly and Field's (1996:242) argument, that expert and lay languages of illness provide a benchmark against which to evaluate experience and provide explanations of what is happening.

Gubrium (1987:5) was amongst the first to portray the dementia experience from the perspective of carers as a form of 'biographical work'. Despite the accepted variability of dementia, paid and family carers repeatedly use developmental codes of expected declines

in behaviour to depict a stage-like model of the condition. Despite this biographical work arising from the emotional need for order, staging has been related to role strain and alienation among carers (Lyman 1988). Staging can also have consequences for the person with dementia, as even normal behaviour can begin to be interpreted in terms of disease stages (Gubrium 1987; Lyman 1989). Therefore, the emotional needs of carers can be linked to the way carers interpret the experience of dementia, which in turn has implications for the carer's own well-being. Lyman's (1988) thesis is tied to Hochschild's (1983) conceptualisation of 'emotional labour' among workers who have to manage their feelings. Studies examining the construction of care and emotional labour (Henderson and Forbat 2002; James 1989) and strategies of affective care in organisations (Lee-Treweek 1997; Lopez 2006; Lyth 1988) reveal the contradictions, emotional demands and coping mechanisms involved in this type of work.

Biographical work can therefore be understood in terms of the emotional needs of carers who are trying to make sense of their experiences. From the perspective of social work practice, Phillips et al. (2006:38) explain that care work with people with dementia is often characterised by battling negative stereotypes and dealing with an exceptionally high emotional content. Rowlings (1981:26) considers how carers working with older people may come across losses and experiences that they themselves fear for their future selves. Rowlings (1981:40) also explains that the experience of being depended upon can evoke feelings that are not dissimilar to those of the person receiving care, including anxiety and guilt about confronting suffering and death. In working with people with dementia, there is the particular difficulty of making sense of behaviour and understanding the meaning of what people are experiencing (Rowlings 1981:51).

The impact of caring on the well-being of family carers of people with dementia has been well documented within the stress and coping paradigm (e.g. Bledin et al. 1990; Burgener and Twigg 2002; Pearlin et al. 1990; Pearlin et al. 2001; Wagner et al. 1997). A related

consequence of this research tradition has been a preoccupation with the negative elements of care (Nolan et al. 2002). Although aspects of a care situation can cause difficulties, it has been shown that care-giving per se does not lead to depression and burden (Robison et al. 2009). For some people, care-giving can be spiritually fulfilling and it can be associated with personal growth, satisfaction and a good quality of life for the carer (e.g. Andrén and Elmståhl 2005; Dilworth-Anderson 2004; Netto et al. 2009; Quayhagen and Quayhagen 1996). Ayres (2000a) explains that, for some family carers, caring is an ordinary component of relationships, even though for others it results in a compromised life. Therefore, the focus of inquiry in traditional models of well-being may be problematic, as they focus on the functioning of the person with dementia, rather than the way the carer makes sense of their experience. As Hughes et al. (2002:38) explain, a burden of care is usually linked to the difficult behaviour of the person with dementia, rather than more complex issues within the care situation, such as the carer's evaluative judgements.

Saltz (2000:55) describes the struggle of giving and accepting care within a culture that emphasises youth, independence, autonomy and self-control. She reframes the model of care from decline and dependency, to a more positive model of 'generational shift' that reconceptualises how roles can change within the family. Dependence can therefore be viewed as meaningful readjustment in a reciprocal relationship, rather than as a symptom of decline due to role 'reversal'. The significance of reciprocity has been observed in studies of paid and family care-giving, in which care is conceptualised as a dynamic process of accomplishment, in the context of social roles and relationships that are embedded in biographical histories (e.g. Hellström et al. 2007; King et al. 1995; Pickard et al. 2000; Redfern et al. 2002). Farran et al. (1991) have argued for the significance of reciprocity in understanding the way people with dementia and carers can find meaning within the context of care-giving. Parsons (1997:405) describes the process of finding meaning from the perspective of carers as "a continual searching, trying to discover

meaning and ways to care". The meaning of caring is therefore far more complex than the concept of burden.

Recent research about the experiences of carers has engaged with the emotional and evaluative aspects of caring that are considered relevant in the frameworks of social work discussed above. For instance, Gillies (2000b:439) has examined family carers' awareness of losses, especially around activities and socialising, which carers understand as a gradual erosion of the person's recognisable self. Perceived disturbances in a person's behaviour and a breakdown in shared meanings appear to cause particular distress to carers (Blieszner et al. 2007; Gilhooly et al. 1994; Gillies 2000b; Spruytte et al. 2002; Wilson 1989). Negative aspects of caring include experiences of vigilance, loss, aloneness, taking away, the need for assistance, and the overstepping of normal boundaries (Parsons 1997). Askham et al. (2007) have highlighted the contradictions in family caring, such as in the tension surrounding the desire to preserve a home life and an intimate relationship, while simultaneously providing care and 'custody'. These perspectives highlight the importance of attending to meaning-making in carers' accounts of their well-being. These findings also suggest that carer perspectives on quality of life should be understood in the context of the way dementia is perceived to influence the person's sense of self and involvement in the social world.

These accounts of carer well-being can be linked to the way both family and paid carers struggle with the tension of providing formal care while maintaining close and personal relationships with older people with dementia. The importance of the search for meaning and its links to emotion work have been explored by Berg et al. (1998) in their study of the interpretative work of nurses caring for people with dementia. The affective care of older people has been linked to the use of family metaphors among paid carers (Berdes and Eckert 2007). The emotional component of such work is evident in narratives that demonstrate the intersection of public and private, where there is a conflict between

'insider' and 'outsider' roles, and the transference of maternal relationships (Gattuso and Bevan 2000). In a similar representation of the tension between formal and family roles, O'Connor (2007) has highlighted the critical contradictions in family carers' narrative constructions of their identities, as they struggle between the storylines of family member versus carer to understand and make sense of their experiences. As Askham et al. (2007) assert, managing identities is an important aspect of the care-giving experience.

Holst et al. (1999:103) explain that nurses search for meaning in their reflections on caring for people with dementia, which involves a complex process of making sense of the person's experience in a way that impacts on their own emotions and identity. For nurses who perceived their patients as being 'lost', the inability to manage the person's perceived anxiety is threatening for the nurses' own emotions and sense of identity. Holst et al. (1999:103) describe nurses creating stories that make situations understandable and meaningful for both themselves and their patients. When stories cannot be made meaningful, the lack of meaning creates difficult emotions due to the inability to mutually confirm identities. The simultaneous transition in identity for people with dementia and their family carers following diagnosis has been reported by Harris and Keady (2009), indicating the importance of the management of identities among both people with dementia and their carers.

The identity work of carers is therefore intimately connected with affirming the identity of the person with dementia. The impact of this interpretation for carer perspectives on quality of life has been established by Åberg et al. (2004), who found that continuity of the person with dementia's self was found to be important for the person's perceived life satisfaction. When the image of the former self was perceived to be in the past, life was considered less meaningful (Åberg et al. 2004:800). From this perspective, Åberg et al. (2004) showed that the main purpose of caring was framed around protecting the person's continuity of self. This finding points to the importance of constructions of self

and identity in understanding carer perspectives on quality of life, and draws parallels with the literature on narrative constructions of self and social identity among people with dementia. This potential similarity in the processes that people with dementia and their carers employ to make sense of their experiences is fundamental to this thesis, as it brings both perspectives together in similar narrative processes of meaning-making.

Ayres (2000b:431) argues that, just as the process of meaning-making among people living with a chronic condition has been conceptualised as 'biographical work', so carers are similarly engaged in 'biographical work' to make sense of the changes that the person's condition has made in their lives. This is linked to Corbin and Strauss's (1988:52) conceptualisation of the importance of 'biographical time' as people make sense of their present experiences by comparing them with the past and projecting them into the future. Just as Gubrium and Holstein (2006:124) represent the way that older people make sense of their experiences as 'biographical work', so carers can be represented as engaging in similar contextual processes of meaning-making to understand the impact of dementia on their lives. Understanding differing perspectives on quality of life involves comparing processes of meaning-making in people's accounts, to explore whether there are differences in the way people with dementia and carers make sense of their experiences.

Exploring the narrative processes of meaning-making in carers' accounts has demonstrated that people draw on cultural meanings to make sense of their experiences, and deal with the challenges and sometimes difficult emotions of caring for someone with dementia. It is clear that these meanings influence the way carers understand the impact of dementia and ageing on the person with dementia's self and social identities, which also has repercussions for their own identities as carers. The separate traditions of literature examining the meanings of living with dementia and caring for people with dementia can be viewed from a similar perspective, as people make sense of their situations in adjusting and coping with the practical and social consequences of a chronic condition. Bringing this

common approach to the question of differences in reporting of quality of life between people with dementia and their carers requires a framework that can take account of the different ways that people make sense of and find meaning in their experiences of dementia. I now turn to a consideration of how a narrative framework can be used to directly address the research question of how older people with dementia and their carers construct meaning in different perspectives on quality of life.

### **A comparative framework of narrative meaning-making**

The preceding sections of this chapter have established the conflictual meanings and contextual elements of emotion and identity work that are evident in subjective accounts of caring and living with dementia. In seeking an approach that can engage with these aspects of meaning-making, to bring them together in a framework of different perspectives on quality of life, narrative inquiry is relevant due to its concern with the way that people make sense of their experiences. In contextualising quality of life in terms of the impact of dementia on the coherence of a person's life story, narrative inquiry is relevant for understanding the subjective processes of meaning-making as people adjust to living with a chronic condition. Similarly, in understanding perspectives on quality of life among carers in terms of the emotional context of meanings of ageing and dementia, narrative inquiry is relevant for understanding the way carers manage identities as they make sense of their experiences of caring. This section therefore considers approaches to narrative inquiry that can engage with these forms of meaning-making to inform our understanding of different perspectives on quality of life.

This study engages with narrative processes of meaning to understand the meaning of different perspectives on quality of life among people with dementia and carers. Importantly, the focus is not to match carers and people with dementia to understand how their perspectives accord with each other. This absence of matching is a significant feature of the study, as much of the research comparing perspectives on quality of life has being



based around paired participants, in order to correlate the reports of people with dementia and their carers. Studies within this tradition are based on the premise that measures should be refined until they provide an objective and reliable report of a reality that should be similar from different points of view. However, this project of attaining a 'truth' is fundamentally problematic, as variations in individual perspective will necessarily produce different versions of the same reality. The current study therefore shifts attention from technical issues of measurement, to focus instead on people's efforts to construct coherent and reasonable worlds of meaning and to make sense of their experiences.

Conceptualising quality of life in a narrative framework provides a means to understand the different subjective processes that construct particular accounts of quality of life, and how these may lead to types of 'truths' in different subjective realities. I am interested in what Plummer (2001:461) describes as narrative 'truth', to access and understand the subjective world from the person's point of view, even if it does not match reality. A narrative approach is not interested in how well a story accords with experience, but with how the account is used for descriptive purposes (Atkinson 2001:124). The relevance of narrative is therefore that it provides a 'perspective' rather than a direct factual report (Cortazzi 2001:384). Instead of a preoccupation with objective validity, it is important to be aware of the function of a narrative, since it relates to the narrator's motivation and the associated structure, content and style of the account (Cortazzi 2001:388).

Understanding different perspectives on quality of life from a narrative framework therefore involves an examination of the descriptive processes through which life is constructed as meaningful. This includes attention to the types of concepts and social constructs that people draw upon to make sense of quality of life with dementia. Bury (2001) conceptualises three types of narrative about chronic conditions: 'contingent narratives' that address the beliefs about the origins of a condition and the effects in

everyday life; 'moral narratives' that provide accounts of changes between the person, condition and social identity, either establishing the moral status of the person or maintaining distance; and 'core narratives' that reveal connections between the person's experiences and deeper cultural levels of meaning about illness. My thesis therefore engages with these narrative forms of meaning-making, to understand how cultural meanings of ageing and dementia impact on constructions of identity and social status in representing the quality of a person's everyday life.

The recent growth of research examining identity work in the narratives of people with dementia has revealed the way that people make sense of the present by comparing it with the past. This narrative action can be linked to Ricoeur's (1984; 1992) analysis of narrative, which is concerned with the experience of being in the world and in time; the 'narrativity' by which people, embedded in time, give new meaning to the past, but in terms of their present circumstances. Ezzy (1998:247) considers Goffman's (1961) analysis of the 'inpatient phase' of the psychiatric patient with reference to Ricoeur's hermeneutic theory of narrative identity, and describes how the reinterpretation of the past is used in the present in constructing a self-story of lived experience. Lived experience and narrative are assumed to shape each other, as lived experience precedes narrative and narrative shapes action (Ezzy 1998:244). My thesis extends the quality of life literature by applying this type of narrative framework to perspectives on quality of life, to understand the ways that both people with dementia and carers engage in identity work in their constructions of quality of life.

Kenyon and Randall (1999:2) point to the possibility of 'restorying', depending upon the complex dynamic of personal meaning and external constraints. While it is possible to be creative in constructing a self-story (Polkinghorne 1988:15), most people adopt culturally given plots (Ezzy 1998:248). Ezzy (1998:240) describes how Goffman's (1961) work on the experience of the moral career of a psychiatric patient highlights the institutional

sources of self-narratives. It has been suggested by Becker (1994) that narratives of disrupted lives reflect the struggle to come to terms with moral ideologies of normality, and the effort to create continuity is a complex cultural process. As Ville and Khat (2007:1012) contend, “the subjective dimension of health has its roots in cultural meanings and values, which are themselves embedded in the historical context”. These arguments provide a critical perspective in which to understand the framework of narrative identity, as the narrative construction of lived experience is linked with the wider socio-cultural context (Ezzy 1998:250).

Garro and Mattingly (2000:23) consider telling stories and making sense as mediating the personal and the cultural. This is apparent in the role of cultural representations of dementia and ageing in the accounts of carers and people living with dementia. Therefore, by attending to the ways people with dementia and carers construct identity and social status in their accounts of quality of life, a narrative framework can engage with the cultural meanings of ageing and dementia that people draw on as they adopt or resist particular plots or storylines. Kleinman (1988:49) explores how chronic illness is lived and responded to, according to personal and cultural models for arranging experiences in meaningful ways:

Thus, patients [sic] order their experience of illness – what it means to them and to significant others – as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narratives are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings.

Adopting a narrative framework from this perspective involves examining the different plot lines, core metaphors and rhetorical devices in people’s accounts, to compare and contrast different representations of quality of life among carers and people with dementia. Gabriel (1998:136) emphasises the need to engage with the emotions and

meanings that establish narrative needs, as opposed to the traditional concern for objective, reliable and accurate data. This is important in the current study, given the evidence earlier in this chapter about the emotional context of identity work among people with dementia as they make sense of their experiences in the context of loss and uncertainty. Engaging with the narrative needs of carer perspectives is also important when studies have highlighted the importance of the search for meaning in the emotion work of carers as they often struggle to make sense of their experiences. By adopting a narrative approach, it is possible to bridge the divide between the literature on the experience of caring and living with dementia, to conceptualise subjectivity and meaning-making among people with dementia and carers within the same conceptual framework.

In his consideration of narrative gerontology in clinical practice, Clark (2001:206) claims that narrative reasoning is useful for acknowledging the tensions between different narratives and the conflicting value systems that underlie them. This is pertinent to the study of different perspectives on quality of life, to compare and contrast the different values underlying particular accounts. While there is a danger in focusing purely on the tensions between people with dementia and their carers, which has sometimes been apparent in the two distinct traditions of literature reviewed in this chapter, understanding the meanings of different perspectives offers the opportunity for dialogue. Moreover, by representing people with dementia and carers as attempting to make sense and find meaning in similar ways, the approach taken in this thesis brings emotional commonality to their experiences in everyday life. This avoids the binary opposition of 'care-giver'/'care-recipient' that assumes the active/passive distinction between people with dementia and carers that is often evident in research (Ray 1996:677). This is a beneficial approach for both people with dementia and carers, when their lives have often been viewed through a distorted and limiting lens, as if either having dementia or caring for a person consumes the whole identity of a person.

Due to the neglect of an underlying conceptual framework, our understanding of the ways that people construct meaning in different perspectives on quality of life has been underdeveloped. In this thesis I address the gap in the literature about differing perspectives on quality of life, by considering the narrative processes of meaning-making in accounts of people with dementia and carers. It has been demonstrated that people with dementia construct meaning in their accounts relative to narrative constructions of self and identity. Similarly, it has been shown that carers use discursive and narrative strategies to apply particular conceptual models of ageing and dementia to develop meaning in their experience of caring. Parallels can be drawn between the literature on identity work among people with dementia, and the literature on emotion work among carers, as people endeavour to make sense of their situations. Both types of narrative action can be seen as processes of biographical work as people strive to find meaning in their lives. This demonstrates the value of developing a comparative framework of narrative meaning-making to understand the meanings of different perspectives on quality of life among people with dementia and carers.

## **Conclusion**

This chapter has demonstrated the relevance of understanding the narrative construction of meaning in accounts of identity and emotion work among people with dementia and their carers. This develops the argument in chapter two, which demonstrated that a humanistic focus on the question of meaning is vital to examine different perspectives on quality of life, given the evidence for the importance of contextual and biographical elements of subjective meaning-making. Chapter three has shown that, through applying a narrative approach to understand the biographical work involved in caring and living with dementia, it is possible to bring together the perspectives of carers and older people with dementia to consider the identity and emotion work that frames different perspectives on quality of life. Understanding different perspectives on quality of life can then be reframed

as a question of understanding the different processes of narrative meaning-making in the accounts of people with dementia and carers as they make sense of their experiences.

The aim of the thesis is to understand how people construct meaning in their accounts of what quality of life means for older people with dementia. This involves attention to the concepts of self and social identity as they relate to ageing and dementia, in addition to attention to the discursive and narrative practices that people use to account for particular perspectives on quality of life. As Hatch and Wisniewski (1995:126) contend, narrative is both product and process, phenomenon and method. Narrative is therefore being used in this thesis as both a conceptual framework and as a methodological approach to understand different perspectives on quality of life. A narrative framework can be used to understand the rich detail within individual accounts of quality of life, and to compare and contrast the processes of understanding between different accounts. This approach can therefore bridge the theoretical with the personal level of experience. In chapter four I now turn to consider the specific approach and methods that have been adopted in this study to examine the narrative processes of meaning-making in people's accounts of quality of life.

# Chapter Four

## Methodological Approach

### Introduction

In chapter four I now discuss the methodological approach that I developed to understand processes of meaning-making in different perspectives on quality of life among older people with dementia and their carers. I discuss the rationale for my approach to narrative inquiry, my particular approach to narrative analysis, and some of the practical and ethical issues associated with biographical approaches in dementia studies. I then describe how I gained access to the field and negotiated consent. In the next section I illustrate the steps of data gathering and my procedures for data analysis. This is followed by a critical analysis of my methodological approach as it relates to the research questions set out in the introduction to the thesis. As this study was exploratory in nature, my discussion of data gathering and analysis integrates some reflections on the process in order to explain how I developed and adapted my methods as the research progressed.

What distinguishes my approach in this study from more traditional approaches to quality of life is my interest in understanding how people talk about their experiences and the ways that they construct meaning in their accounts. Rather than establishing some fundamental truth about their experiences, I seek to understand the particular perspective of a person and the experiences and ideas that inform this perspective. Over the course of two years I carried out a total of 50 interviews with six people with dementia and ten carers to examine their understandings of what matters most when living with dementia. My approach thus involved engaging with the everyday concerns of older people with dementia and eliciting stories from carers about important events and experiences that represent their perspectives on what matters most when living with dementia. In order to

study processes of meaning-making in people's accounts, I use narrative as both a methodological and interpretive focus, to understand the creation of meaning within differing perspectives on quality of life.

## **Research strategy**

### ***Motives for narrative inquiry***

In this study I develop a narrative approach to understand how people construct meaning in their accounts of what quality of life means for older people with dementia. The term 'narrative' covers a range of types of talk and text and, at its most abstract, it refers to knowledge structures and storied ways of knowing (Cortazzi 2001:384; Polkinghorne 1995:7). As I have found in previous research engaging with subjective perspectives on quality of life (Robertson 2002), despite attempts to structure responses to correspond to predetermined topics of interest, people often digress with lengthy narratives that initially may seem unrelated to the specific research questions I had in mind; yet these 'digressions' are often the most interesting pieces of data, revealing insightful aspects of experiences and the significance of their meanings to the person. As Riessman (2001:695) asserts, despite the careful crafting of interview questions to correspond with the topic in mind, people tend to respond with lengthy accounts or stories that resist the researcher's effort to fragment their experiences into thematic categories.

The argument that life comes to us in the form of stories (Cortazzi 2001:384; Fontana 2001:167) is therefore the basis for my interest in personal narrative. Coffey and Atkinson (1996:56) explain that narrative is a common genre through which people relate key experiences and events, particularly sensitive or difficult ones:

Precisely because it is a form of discourse that is known and used in everyday interaction, the story is an obvious way for social actors, in talking to strangers (e.g. the researcher) to retell key experiences and events ... Narratives are also a common genre from which to retell or come to terms with particularly sensitive or traumatic times and events.



Narrative is therefore an appropriate approach due to the question of understanding how people construct meaning in different perspectives on quality of life. Fontana (2001:167) highlights Sarup's (1996) conceptualisation of narrative as two-part: the story is the 'what' and the discourse is the 'how'. In this study I therefore pay attention to both the content and structure of people's accounts. Coleman et al. (1999:840) describe how the term 'story' has connotations of interest, movement and purpose. Polkinghorne (1995:5) describes narrative configuration as a temporally organised whole, with a thematic thread or plot that takes on a narrative meaning with a particular function or outcome in mind. Stories can therefore be described as 'moral' or 'ethical' tales, as people struggle to show the different choices they have made and how they have dealt with them (Plummer 2001:403). The act of narrating is therefore an act of meaning, as people make sense of their complex situations (Ville and Khlal 2007:1004). This understanding of narrative relates to my concern for how people construct meaning in their perspectives on quality of life relative to their everyday experiences of caring and living with dementia.

Narrated experiences can be particularly useful for analysing meaning-making in situations where there is a breach between the ideal and the real (Riessman 1993:3). This is pertinent to a study about quality of life for older people with dementia, as both ageing and dementia are often considered problems affecting the ability to live a 'good' life. As Lincoln and Guba (2000:179) assert, personal experience and narrative methods capture the conflictual, emotive and problematic qualities of human experience. This is relevant to my approach to understanding the identity and emotion work that may influence different perspectives on quality of life. When exploring different perspectives, it is vital to engage directly with people's own sense of meaning-making, to understand how constructions of self and social identity relate to perceptions of change and continuity in a person's life. It is also important to engage with concepts and representations that influence personal perspectives on living with dementia, and the cultural meanings and emotions that surround caring for older people with dementia.

A concern with representational practices in this study is useful in considering the narrative function of knowledge production to understand the biographical, contextual and institutional elements brought to an interview situation (Fontana 2001:166). A narrative method can be utilised to access the cultural conventions, social context, motives and intentions that construct meaning for the narrator (Cortazzi 2001:385). This includes attention to the 'deep' understandings beyond common-sense explanations, and how these assumptions constitute a person's interests and how we understand them (Johnson 2001:106). Narrative analysis can therefore be described "as a technique that seeks to interpret the ways in which people perceive reality, make sense of their worlds, and perform social action" (Phoenix et al. 2010:3), all aspects of experience that relate to my interest in understanding the construction of meaning in people's accounts.

Hatch and Wisniewski (1995:128) maintain that it is unsatisfactory to leave narrative analysis at the level of 'untheorised' individual stories; they recognise that narratives should be interpreted and theoretical frameworks applied to illuminate the logic of individual courses of action, as well as the effects of system-wide constraints. They distinguish narrative research from other types of qualitative inquiry in terms of: (1) a focus on the individual and the contextually situated nature of individual experience; (2) the personal or collaborative nature of the research; (3) a practical orientation to bridge micro and macro levels of explanation; (4) an emphasis on subjectivity. Narrative research therefore fits the approach taken to quality of life in this thesis, with its interest in the contextual and biographical elements of subjective perspectives, and my intention to develop a sociological framework to understand the meanings of different perspectives.

Like Mishler (1986:105), I consider narrative analysis to be particularly well suited to the interview method. In this study I have used 'unstructured' interviewing, in contrast to structured or semi-structured interviews, where there is a degree of formality to the wording, and in the former case also the order of questions. Unstructured interviewing

allows respondents to use their own way of defining the social world (Fielding and Thomas 2001:142). The value of this approach is in engaging with the respondent's own meanings, rather than imposing the researcher's own value framework at the outset of the research, something that has been apparent in previous quality of life research.

Accessing 'deep' understandings to provide depth of analysis is therefore important in adopting an unstructured approach to interviewing. Bond (1999:569) suggests that 'private' voices are likely to emerge only after intensive qualitative interviewing in which an emancipated relationship between researcher and participants is developed; this can be compared with survey techniques, which are likely to evoke a 'public' voice of people taking part in research. Cortazzi (2001:390) suggests that the interview is more authentic, in terms of ownership and voice, if the interview style is conversational as opposed to a controlled 'question and answer' format, and I therefore adopt this more flexible approach in the study. As Kvale (1996:4) suggests, the interview route may take unexpected turns, as the researcher follows the particular interests and disclosures of respondents. It should be noted, however, that a lack of boundaries has ethical implications, which are discussed further in the critical appraisal of the study.

By focusing on the accounts of personal experiences, personal narrative research is essentially a type of case-centred research. As the method requires rich data, and detailed and time-intensive analysis, this necessitates a small sample size to provide a deep and meaningful investigation of people's accounts. The approach to narrative research that I take encompasses a tradition that analyses personal narratives as extended accounts of lives that develop over the course of conversations and interviews (Riessman 2001:698). This approach enables a comparative orientation to interpreting similarities and differences among participants' accounts. The thesis therefore engages with the narratives of older people with dementia and paid and family carers to develop an understanding of the different ways that they construct meaning in their perspectives on quality of life.

### ***Narrative analysis of interview accounts***

Formal narrative analysis generally involves moving beyond the immediate data to consider how accounts and stories are socially and culturally managed (Coffey and Atkinson 1996:58). This involves an examination of the structure, meanings and motives underlying talk (Coffey and Atkinson 1996:57). Narratives commonly consist of plot, episodes, themes and characters (Plummer 2001:399). Cortazzi (2001:384) maintains that a careful analysis of the topics, content, style, context and telling of narrative data gives access to respondents' understandings. These narrative dimensions of meaning fit with a conceptualisation of quality of life as fluid and temporally constructed, as people evaluate and interpret the present relative to past experiences, and the impact that these shifting connections have for self and social identity.

While privileging the respondent's experiences, Riessman (1993:61) argues that interpretation is necessary, especially if the researcher wishes to attend to the discursive features of narratives and make theoretical propositions. Riessman (1993) develops an approach to narrative analysis, which is theoretically informed by Gee's (1991) linguistic approach to the poetic features of language, to develop different means of attending to 'deep structures' of meaning. This goes beyond searching for formal structural properties, but she suggests that structure should be unpacked to avoid the tendency to read narrative simply for content or as evidence for a priori theory (Riessman 1993:61). Becker (1999:77) explains that poetic transcription is useful to encourage critical reading and show how coherence and meaning flow from the organisation of a story in lines and stanzas. I therefore attend to these linguistic features in interview transcripts to move beyond the content of what is said and consider the way meaning is structured.

Labov's (1972; 1982) sociolinguistic approach is another formal methodological approach that has been applied by a number of researchers to the study of narratives. Labov argues that narratives have formal structural properties that can be identified and used to

interpret each segment of a narrative. Elementary units of narrative include the abstract, orientation, complication, evaluation, result and coda of a story. These units offer a perspective to reflect on the function of stories and identify key themes and issues. Coffey and Atkinson (1996:58) contend that, while it is not necessary to maintain strong claims for the pervasiveness of these elements and their sequencing, the identification of such units facilitates a more sociological kind of analysis. Similarly, while I agree that a story does not have to contain all these elements to be considered a narrative, I find this type of structural analysis useful for different individuals and for different parts of their interview accounts, as will be described in the section on methods of analysis below.

Mishler (1995:117) advocates combining different analytic strategies to develop a more comprehensive understanding of how narratives work and the 'political' work that they do. I therefore apply different types of structural analysis, to engage with the way that stories work in different ways to reveal particular ways of sense-making. I do not follow one method of representation and instead analyse stories in different ways according to what seems most fruitful to understanding a person's meaning. For instance, in some cases I apply Labov's framework to understand the particular function of a narrative. In other instances I follow Gee's approach, by paying attention to changes in pitch to structure topics, rather than attending to the function of a clause in the narrative. Coffey and Atkinson (1996:80) emphasise that a particular strength of a narrative approach is in its capacity to engage with a variety of analytical strategies that can engage with the social discourses that surround personal experiences:

There are no formulae or recipes for the 'best' way to analyze the stories we elicit and collect. Indeed, one of the strengths of thinking about our data as narrative is that this opens up the possibilities for a variety of analytical strategies. Such approaches also enable us to think beyond our data to the ways in which accounts are socially and culturally managed and constructed. That is, the analysis of narratives can provide a critical way of examining not only key actors and events, but also cultural conventions and social norms.

In working with broad storylines for the sake of analysis and the development of theory, it is important to acknowledge that people's understandings are fluid and changing, and that in focusing on narratives we should avoid fitting individuals into a 'general unifying view' that risks denying the variability and complexity of individual experience (Phoenix et al. 2010:6). This variability is evident in the work of Frank (1995), where the three thematic types of illness narratives that he defines as 'restitution', 'chaos', and 'quest' can be found in the same story. Frank (1995) also suggests that we should listen to stories that do not conform to the accepted conventions of telling a 'good' story. Such stories may not be organised chronologically, or have a defined start or endpoint, as they may represent the dislocation between past and present. Kirmayer (2000:171) describes how the fractures of narrative, with their fragmented strands and bursts of figural language, may reflect the inchoate nature of illness.

In attending to narratives, it is therefore important to examine fragmented stories that violate narrative conventions, in order to fully understand the experiences of living with a chronic condition. Becker (1999:86) argues for a conceptualisation of narrative that acknowledges poetics, dependence and diversity in our understandings of self and identity, and which in its expression reflects the ways that older people make sense of their lives. She explains that some people's lives do not stand for coherent stories that uphold the rational, autonomous and self-controlled discourse of self that is upheld as the norm in our society. Attending to stories that do not conform to standard representations of a 'good' story is therefore important in this study when engaging with the narratives of older people with dementia and their carers, as their stories are likely to reflect the discontinuities and difficult emotions surrounding dementia and dementia care.

Phoenix et al. (2010:5) explain that structural narrative analysis has not been widely used in ageing research to date, but that attending to formal structure is valuable "because the formal aspects of structure 'express' the identities, moral dilemmas, perceptions and

values of the storyteller". They argue that by understanding the types of socio-cultural narratives that people draw on in their accounts, structural analysis can engage with the constraints and opportunities people experience in their lives. I therefore take an approach that considers the structure, meanings and motives that underlie particular perspectives on quality of life, paying attention to the ways that narratives are structured, while applying a variety of analytical approaches to engage with the different forms and presentations of people's stories. In so doing, I endeavour to work within a rigorous and systematic framework of analysis, while engaging with the varieties of ways that people make sense of their experiences in relation to dementia, to avoid discounting those narratives that challenge the conventions of a 'good' story.

### ***Biographical approaches in dementia studies***

Barnett (2000:40) emphasises the value of narrative methods for working with people with dementia, as they attend to association, memory and metaphor, aspects of long-term memory that appear to remain relatively intact in dementia. Her findings indicate that people with dementia are able to talk at an emotional level about their feelings and can recount stories of past events. The durability of emotional memory and narrative identity has been documented by Mills (1997), who found that people with dementia can recall past experiences that have emotional meaning and significance, and these memories formed fragmented pieces of the people's life stories or personal narratives. Cheston (1996:598) highlights the use of metaphors and symbolism by people with dementia to communicate emotional response. The relevance of symbol and metaphor is an important feature of the narratives of older people with dementia in this study, which is considered further in the critical appraisal of the methods.

This attention to emotional memory corresponds to Hollway and Jefferson's (2000:37) concern with focusing on the emotional rather than cognitive narrative, to achieve a richer and deeper understanding of the respondent's experiences. This involves avoiding 'why'

questions that may require intellectualisation, and instead following-up responses using the respondents' own ordering and phrasing, to focus on emotional motivations as opposed to rational intentions. Eliciting a narrative in such a manner avoids too great a preoccupation with coherence, and enables the researcher to attend to contradictions, elisions and avoidances. This is an important principle for working with all participants, although Dabbs (1999a:43) suggests that it is particularly relevant in research with people with dementia, when information may not always come in an orderly sequence.

Due to the metaphoric and fragmented speech of some people with dementia, it is realistic to assume that narratives may require some degree of interpretation (Proctor 2001:374). This requires attention to the context within which meaning is created (Cheston 1996:599), and critical self-awareness is the key to good practice (Goodley 1996:345). Within the field of disability studies, Booth and Booth (1996:66) conceptualise the researcher as editor in the reconstruction of stories. Booth (1996:250) suggests that when considering interpretive strategies, the duty to 'preserve the message' remains key. Crisp (1995:137) attests to the importance of focusing on the common themes and tendencies of stories, rather than their veracity, to attend to the metaphorical and emotional dimensions of their meaning. As Goldsmith (1996:161) explains, the onus should be placed on the researcher to develop the necessary communication and listening skills to facilitate and hear the voice of the person with dementia.

Research with people with dementia (Clarke and Keady 2002:35) suggests that prolonged engagement is important to establishing a productive and ethical research relationship. Sustained contact is useful, as it enables the researcher to familiarise and adapt to the individual conversational styles of people with dementia (Reed and Payton 1998:237). Lessons on ethical practice can also be drawn from research that has engaged with people with learning difficulties. In establishing prolonged relationships with participants, care is needed to avoid intrusion and deal with potential expectations of friendship, especially if a



person is lonely (Stalker 1998:10). Careful attention should be paid to withdrawal from the field (Booth 1998:134; Cutcliffe and Ramcharan 2002:1005; Wenger 2001:275). Commitment must therefore be made to create time to engage and disengage from the field in an ethical manner (Gilbert 2004:299). Bowsher et al. (1993:877) recommend positive closure activities to demonstrate appreciation, which I describe in the section on access and fieldwork below.

As Clarke and Keady (2002:39) suggest, consent should be negotiated continually to check the limits on information available as research data, and I adopted this approach as described below. It is impossible to predict all potential dilemmas at the outset, and an 'a priori' approach is dangerous in that it suggests that all responsibilities have been fulfilled (Swain et al. 1998:33). Bartlett and Martin (2002:51) suggest that the continuous nature of qualitative research, which stresses the negotiated and relational processes between researcher and respondent, lends itself to such a continual process of consent. Pratt (2002:171) suggests that the researcher should re-establish who they are and why they are there throughout the research process. Safe practice also involves using key people, such as carers and gatekeepers, when necessary, to increase confidence in the person with dementia's consent and ensure that practice is appropriate. These key people can be used to establish how a person usually consents or withholds consent to activities and procedures (Dewing 2002:165).

While most of the literature in this area refers to the opportunities and challenges associated with engaging marginalised groups, I would argue that many of the arguments should be extended to engaging research participants more generally. For instance, Booth and Booth (1996:60) emphasise the need to use a self-developing method for people with learning difficulties, to jointly set agendas that can be refined during the interview process depending upon the particular dynamics. Similarly, King (1996:185) advocates the use of paraphrasing with older people, reflecting and summarising meaning back to participants

to communicate an empathic understanding of their thoughts. I think these are important issues for all participants in research. In this study I therefore endeavoured to treat each participant as an individual, tailoring my approach to their particular needs and individual qualities, and making arrangements flexible to acknowledge the different abilities and preferences of the people taking part in the study.

## **Access and fieldwork**

### ***Gaining access to the field***

Following the successful completion of the initial period of study for the PhD, and in accordance with required procedures at the time, ethical approval for the study was sought and gained in January 2005 from the Research and Ethics Committee in the Department of Applied Social Science, University of Stirling. Once the study was approved a local organisation that provides services for people with dementia was approached to access older people using their services, family carers known through the service, and paid carers who provided services for the organisation. I had previously carried out research for an MSc dissertation with this organisation and had established a good working relationship with key staff. I therefore met with my main contact and the service manager to gain their agreement to work with me again.

As this service is funded by three local authorities, I submitted separate research access applications to the three associated social work departments. In June 2005, following approval of the research from all three local authorities, I was given permission to formally approach potential research participants through the service. While waiting for approval to be granted I met with my main contact at the organisation on a number of occasions to discuss potential confidentiality and ethical issues, consent forms and procedures, and information for potential research participants. Consent forms and information sheets were developed and checked with the service to ensure the appropriateness and suitability of information to their clients, family carers and the carers

who worked for the service. These are attached, along with an information leaflet for project workers, in Appendices 1 to 7.

Ground rules were established at this stage for preventing harm to participants and dealing with any potential disclosures of concern. If participants showed distress during interviews I would stop the interview and only recommence if the participant wished to do so. If the person asked, or I thought it would be beneficial and the person gave permission, I would ask for a professional from the service to speak to the participant. I agreed to speak to the service manager if any person made a disclosure of abuse or mistreatment related to care within the service setting. If this was considered inappropriate due to the nature of the disclosure I agreed to contact an appropriate person within the relevant social services department. In considering the effects and consequences of my work, the statement of ethical practice created by the British Sociological Association (The British Sociological Association, 2002) guided my research.

### ***Negotiating my approach with older people with dementia***

Fieldwork was conducted with older people with dementia over 14 months from July 2005 to August 2006. I took a staggered approach to data gathering, which was adopted for two reasons. Firstly, as I planned to interview the older people with dementia over an extended period of time, it was agreed that for practical reasons ideally no more than two people would be involved in fieldwork at any one time. Secondly, the situation of many of the people using the service was changeable, and so it was not appropriate to approach people far in advance of when they would be asked to participate.

I asked the service to identify older people with dementia who they believed would be able to take part in the study. This was a convenience sample due to the small pool of potential participants. I set two criteria for participation. As a minimum level of verbal language skill is necessary to participate in narrative research, the participants had to be able to communicate verbally. The other requirement was that a potential participant had

to have the capacity to understand that they were being asked to take part in research. It is important to note that the minimum requirements for participation did not exclude people with moderate levels of memory loss and confusion. I stated to the service that I was particularly keen to access people with more than mild cognitive impairment, as this group of people with dementia had not been involved as frequently in research about subjective perspectives.

An initial approach was made to potential participants through a familiar professional who gave the person an information sheet and consent form which they discussed and completed together. If the person consented to take part I then arranged an initial meeting. Three of the participants chose to be accompanied by a familiar professional or family member at the initial meeting. The purpose of the initial meeting was to discuss any issues or questions about the research, negotiate consent, and allow the participant and me to familiarise ourselves with each other. It was stressed that the right to non-participation would be respected at any stage of the research, and that there would be no negative consequences as a result of non-participation or withdrawal from the study. Although I did not gain formal assent from relatives, they were advised by the service that their relative had agreed to take part in research. In most instances I liaised with family to arrange interview times and visits due to the extent of the person's cognitive impairment.

As I employed a process approach to consent, I established consent at the start of each interview as well as checking throughout for verbal and nonverbal cues as to whether people were happy to continue. With the exception of one person, the older people with dementia who I met could not remember my name between visits, and most appeared to have only vague recollections of familiarity when I met them on each occasion. However, this varied between people and at different times, and in between visits some people could remember that they were helping me with research, while not remembering the details of me and my visits. For people who had greater cognitive impairment, it helped to

put my research in the context of their own experiences of studying at school or college, which I did each time we met, to ensure that they had enough awareness of what I was doing to give their ongoing consent to participating in the research.

Establishing informed consent involved attention to whether the person could grasp the concept of taking part in research. For instance, one woman was identified as a potential participant, yet it became apparent that she could not hold onto the concept of being asked questions as part of a research interview, and she did not take part in the study. On the other hand, a man was initially identified as a potential participant, but his project worker was unsure whether he could give informed consent due to the extent of his cognitive impairment. However, despite his cognitive difficulties, this man was able to grasp the concept of research; when I explained that I was a student carrying out a study, he talked about an assignment that he had undertaken for a college course, making a joke about how I could only publish my work after he had published his. I felt that his comments established that he understood that he was being asked to take part in a study, and each time we met I made reference to this connection to remind him that he was taking part in research.

The service identified a total of eight participants with dementia, seven of whom arranged an initial meeting, and six of whom agreed to take part in the research following this initial meeting. In addition to the initial meetings to discuss the research and gain consent, a total of 33 interviews were carried out with six participants with dementia over a one-year period. Four women and two men took part in the research. One man was in his early sixties and lived at home with his wife. The remaining five people were in their eighties, all of whom lived alone in the community. Less than two years after conducting interviews with this group, three of these five older people were living in nursing homes. One woman withdrew part-way through the study, and her interviews are not included in the thesis: this will be discussed in the critical appraisal of the study below. Most people chose to be

interviewed in their homes, although on some occasions I would meet a person at a day care centre and we found a private space to conduct the interview. One person chose to meet at the university and we used a meeting room for the interview. The characteristics of this group of older people are summarised in Table 1 below:

**Table 1: Older people with dementia who participated in the study**

<b>Pseudonym</b>	<b>Gender</b>	<b>Approx. age</b>	<b>No. interviews</b>
<b>Cynthia</b>	Female	80s	7
<b>Ted</b>	Male	80s	7
<b>Martha</b>	Female	80s	6
<b>Rena</b>	Female	80s	6
<b>Louis</b>	Male	60s	3
<b>Dorothy</b>	Female	80s	3 (withdrew)

As interviews progressed, I introduced comments about the ending of the study and my return to university, to manage expectations of the research relationship. At the end of the fieldwork stage I gave people an appropriate token of thanks for their assistance with the research and as a way to round off the research experience. This ranged from taking people out for lunch or coffee (as ‘going out’ was described as a valued activity in the older people’s accounts), giving flowers to the woman who withdrew from the study, and giving the younger man in the group a gift voucher for a restaurant.

***Negotiating my approach with paid and family carers***

Once fieldwork with the older people with dementia was nearing completion, the service approached paid and unrelated family carers to ask if they would be willing to participate in the research. Fieldwork with carers was conducted over nine months from July 2006 to March 2007. Due to the particular demographics of age and gender in paid care work, the participants were mainly middle-aged women. While there was no formal sampling procedure, the aim was to source a range of possible experiences to reflect a potential diversity of perspectives. As was discussed in chapter three, the focus of the study is on

understanding processes of meaning-making rather than establishing an objective evaluation of a person's quality of life. The carers have therefore not been matched with the older people with dementia in this study.

The first two paid carers were initially approached after being randomly selected by the service (names were drawn from a hat). Following the selection of these first two participants, I selected three further participants more purposively to build in variety (Stake 2005:451) according to experience, gender and type of care work. If the person was interested in taking part in the research, and they gave permission for me to be given their contact details, I initially spoke to them on the telephone to explain more about the study. If the person was still interested in participating, I sent a letter with further details, information sheet and consent form. I contacted the person a week later to check if they were still favourable to taking part in the study. If they wanted to take part, we then met for an initial meeting to discuss research involvement and check consent. I applied the same process approach to consent as described above. A total of nine interviews were carried out with four women and one man. Four people chose to be interviewed at home and one person chose to be interviewed in a meeting room at their place of work. The characteristics of this group of paid carers are summarised in Table 2 below:

**Table 2: Paid carers who participated in the study \***

<b>Pseudonym</b>	<b>Gender</b>	<b>No. interviews</b>
<b>Graeme</b>	Male	2
<b>Joyce</b>	Female	2
<b>Karen</b>	Female	1
<b>Maureen</b>	Female	2
<b>Teresa</b>	Female	2

\* The paid carers in this study provided a variety of services in the community including short breaks, day care, one-to-one support and adult placement. The type of care work each person provides has not been specified in the table, as due to the small number of people providing certain types of care within the service, this could make the individual participants more identifiable and reduce the level of anonymity offered to those who agreed to take part in the study.

In parallel to the recruitment of paid carers, I met a group of family carers who provided unpaid care to a friend or relative with dementia. The sampling for this group was purposive. I requested a mixture of men and women, in addition to a variety of familial relationships. The service identified potential participants unrelated to the participants with dementia, and a known professional from the service approached the person to establish their initial interest in taking part in the research. Once this was established, and the person gave permission for me to be given their contact details, I contacted them to establish further interest. If the person was still favourable to taking part I sent further details, an information sheet and consent form. I contacted them again a week later. If the person agreed to take part in the study, I met them for an initial meeting to provide further information and gain formal consent. Five participants were identified with different familial relationships: a husband, a wife, a son, a daughter, and a friend. All agreed to take part in the study. A total of nine interviews were conducted. All the family carers chose to be interviewed at home. The characteristics of this group of family carers are summarised in Table 3 below:

**Table 3: Family carers who participated in the study**

<b>Pseudonym</b>	<b>Gender</b>	<b>Relationship</b>	<b>No. interviews</b>
<b>Irene</b>	Female	Wife	2
<b>Duncan</b>	Male	Husband	1
<b>George</b>	Male	Friend	2
<b>Robert</b>	Male	Son	2
<b>Cathy</b>	Female	Daughter	2

At the end of the fieldwork stage I gave family carers flowers or gift vouchers for a restaurant as a token of thanks for their assistance with the research. Due to contractual terms, the service requested that I did not give paid carers gifts or vouchers for their assistance.



### ***Methods of data gathering with older people with dementia***

Although I started this research with a topic guide of loose questions, I quickly changed this approach, due to its lack of value in drawing out responses about what really mattered in people's lives. For older people with dementia, direct questions did not seem helpful in eliciting their understandings about quality of life, compared to a more free-flowing format that followed the person's concerns and experiences in life. While these accounts appeared very 'ordinary' in terms of everyday activities and relationships, a lot of interesting information was revealed about what is important to someone with dementia, the types of social barriers they encounter, and negotiation involved within the care situation. I therefore used a conversational approach with participants (Foley and Valenzuela 2005:223) to elicit stories about specific events and experiences that were important to them, and engage with their particular perspective about what makes their life feel good or not so good.

My approach with most of the older people with dementia therefore involved a mixture of active listening and a conversational style of interview. As many of the participants' accounts were often fragmented and metaphoric, I met four of the participants between six and seven times to build a picture of their concerns, which developed across interviews until no new information emerged. One participant was interviewed three times before she withdrew from the study. The value of repeat interviews was in allowing me to make connections between comments, and to understand how people were engaging in rich meaning-making, even if they sometimes jumped back and forth between ideas. Repeat interviews were also helpful in enabling me to be more certain of the significance of metaphoric talk, by being able to look across interviews at similar descriptions or themes and establish their meaning in different contexts.

One participant did not like this conversational style of interviewing. Several features distinguished this man that might have affected his preferred interviewing style. He was

relatively younger than the other participants, his language was more literal rather than metaphoric in quality, and he had previous experience of research interviews. I adopted a more formal style of narrative interviewing similar to what is described below for carers. Three interviews were sufficient with this participant to reach the point where no new information was emerging. This interview process was therefore different to the more gradual and evolving process with the other people with dementia. It was also different in terms of location; whereas the other people chose to be interviewed at home, or occasionally in a service setting, this participant preferred to be interviewed at the university where I studied. This experience suggests that different participants require different forms of approach or involvement in research.

#### ***Methods of data gathering with paid and family carers***

For carers, a 'free association' narrative technique was used, based on the biographical-narrative-interpretive method originally developed by Rosenthal (1993). I had attended a training course on this biography-based methodology and found it a useful way to engage with people's explanatory frameworks rather than asking direct 'why' questions or using a more structured approach. By eliciting lived experiences and narrative events, and letting participants explain on their own terms what is important, my intention was to engage with their particular concerns to examine the structures and discourses surrounding their talk, and so understand what frames their particular perspectives on quality of life. The focus is therefore on the person's systems of relevance, and eliciting narratives of past experience rather than only explicit statements of present or remembered 'positions'; this method engages with people's conscious concerns and unconscious presuppositions to elicit explicit and implicit perspectives (Wengraf 2010:43-44).

The first interview commenced with an open question that asked the person to describe what is important to their friend, relative or clients with dementia (see Appendix 8 for details of the wording and interview format), which is based on a questioning technique

for eliciting narratives developed from Rosenthal's (1993) method by Wengraf (2001). I did not interrupt for as long as it took for the person to tell their "story", which ranged in duration from five to 40 minutes, to avoid breaking their pattern of explanation. Relevant points were then followed up in the same order as presented in this story. A second semi-structured interview provided another opportunity to ask further questions or follow-up areas of interest based on what had been said in the first interview. The focus of this method is on generating responses from 'narrative pointed', as opposed to 'narrative permitting', questions to elicit the participants' stories about specific events and experiences that are important to them. Detailed stories of important events and experiences were particularly helpful to reveal thoughts and feelings that are often difficult to articulate in abstract terms and in direct question-and-answer formats.

### ***Recording and transcription of conversations and interviews***

With the consent of respondents, interviews were tape-recorded. Consenting to have interviews recorded was a prerequisite condition of taking part in the research, as the analysis required detailed verbatim transcription and examination of the language used. While this decision may have excluded people who chose not to take part for this reason, I was not aware of this being an issue for potential participants. A digital recording device was used to maximise the quality of sound recording, which was necessary for detailed linguistic analysis, such as listening for changes in pitch. A tape cassette recorder was additionally used as a back-up device; it was also useful as a visual prompt for the older people with dementia to remind them that they were taking part in research and that their conversations were being recorded.

All interviews were transcribed word for word, including my asides such as 'mhm', 'uh-huh' and 'yeah'. I transcribed interviews with four of the older people. For expediency, interviews with the other two older people, and all the interviews with carers, were transcribed by a professional transcriber approved by the Department of Applied Social

Science, University of Stirling, who worked within specific terms of acceptance set up by the Department (see Appendix 9). Following the initial transcription, I listened to the digital files to develop detailed structural analysis of relevant sections and updated these sections of transcription with linguistic cues and non-lexical markers such as pauses and laughs (see Appendix 10). Digital files, audio tape cassettes, electronic files and paper documents have been stored securely in compliance with the Data Protection Act (1998).

For the sake of anonymity, the names of the participants have been replaced by pseudonyms. Information that would easily identify individuals has been omitted, as have identifiers of any service settings that are mentioned. Certain biographical details of individuals have also been changed when necessary to further assure anonymity. Due to this deliberate 'muddying up' of personal circumstances, I have not presented case summaries and demographics for the individual participants. While I have endeavoured to reflect the richness and complexities of people's lives in the analysis, I have avoided describing the particularities of their living situations that would reveal their identities. While making changes to maintain anonymity, I have taken care not to remove or modify details in ways that would change the analytical message. I am also mindful that participants have willingly given their permission to take part in the study and share their experiences with a wider audience. So, while ensuring anonymity and confidentiality, the analysis retains the essence of the participants' stories, to ensure that their experiences and concerns are heard.

### **Methods of narrative analysis**

In this section I describe the general process and stages of analysis that I used to move from the raw data to my general conclusions. To support the general points that I make here, an example of the process of narrative analysis is detailed in Appendix 10 to show how I moved from the verbatim transcript to a detailed consideration of the linguistic and formal structural properties of a narrative. The text has been marked-up and crafted into a

particular structure to elucidate the relationship between the data, commentary and conclusions. This example illustrates how the nature of the data requires unpicking or 'crafting' to understand the significance of what is said from the narrator's perspective. As Riessman (1990:116) asserts, narrative work 'lays bare' the interpretive work as a person evaluates an experience in the process of its telling.

### ***Analysis of the accounts of older people with dementia***

I carried out my initial analysis alongside data gathering and transcription. This involved a broad analysis of older people's concerns about their quality of life. I produced summary documents of what stood out as important to each individual in their everyday life as the interviews progressed. These summaries were based on reading the transcripts for key themes, narrative elements and interesting text that related to the research questions. As my first reading of the transcripts seemed to generate a particularly negative interpretation of people's quality of life, I re-read transcripts adopting a different position, looking for the positives in people's accounts, to ensure that I was not automatically reading for themes that I had first identified. I also tried to be aware of potential assumptions that might affect my perspective as a younger woman in my thirties, which is discussed further in my appraisal of the study below.

Following this initial analysis of older people's accounts, particularly salient points in the text were unpicked to move from 'surface' to 'deep' levels of meaning. This involved more detailed structural narrative analysis of interesting narrative sequences or important segments of text (Riessman 2001). First interviews were chosen for this in-depth analysis, in addition to key segments of text in later interviews. While I may not have established the same rapport with participants in the first interview as in later interviews, I chose to explore people's meanings and sense-making at a point when I would have had less impact on their explanatory frameworks. In reading the transcripts I looked for 'bounded narratives', identifying sections of accounts that were bounded by particular phrases to

identify the start and end of talk about a particular topic or theme. I also paid particular attention to stories of specific events and experiences, and to parts of the interview where language appeared confusing or the person's meaning was unclear.

I adapted Gee's (1991) linguistic framework of narrative analysis, which is based on the poetic or prosodic structures of talk, to examine the 'deep structures' of meaning in people's accounts. Gee's approach is based on attending to spontaneous pauses in the structure of stories, as they mark the significance of critical points in a story. Analysis is based on listening to subtle changes in pitch and intonation to arrange narratives into idea units, lines and stanzas. This involves listening to pitch glides (the rise or fall in relation to normal base pitch) to signal the focus of a sentence with new or asserted information. The narrative is parsed into units consisting of lines (a single sequence of words comprising an 'idea unit') that form stanzas (groups of lines with similar content that are separated by pauses and shifts in pitch). This process is useful for examining the relationship between form and meaning.

In some cases I applied Labov's (1972; 1982) structural analysis, to ensure that I was not reading the narratives purely for content or a priori theory. This involved reducing core narratives to skeleton plots by interpreting the function of each segment of the narrative. Labov's approach is based on what he describes as elementary structural units in narrative structure, as indicated below:

*Formal narrative properties: Function of narrative elements of story:*

Abstract	summary of the substance of the narrative
Orientation	time, place, situation, participants
Complicating action	sequence of events
Evaluation	significance and meaning of action, attitude of the narrator
Resolution	what finally happened

Coda

returns the perspective to the present

This formal framework was useful for examining the structural properties of temporally ordered narrative clauses that have a clear beginning, middle and end. Paying attention to the evaluation clause was particularly helpful in attending to the values and meanings through which a person interprets their experience. As Riessman (1993:20) asserts, the evaluation clause can be understood as the 'soul' of a narrative, as it tells us how a person wants to be understood and what their main point is.

Attending to formal structural properties makes patterns and forms of meaning explicit, and so constrains the possibilities for interpretation. However, while Labov's description of structural units is useful, my analysis suggested that these units were not universal or elementary features of all narratives. I therefore looked at different ways of examining the structure of narratives, such as attending to the patterning of psychological subjects to understand the meaning of what was being said from different points of view. Where there was ambiguity or the potential for competing interpretations, I looked for evidence to support my speculations from other parts of the interview. Connections across interviews also strengthened the significance of particular themes and ideas that emerged from specific narratives. For some participants the main ideas flowed in and out of various stories, and in these instances my role has been in crafting a more succinct version of their concerns. In order to reduce the risk of abstracting too far in successive redrafts, I would read over excerpts from the transcripts to 'moderate' my analysis.

The analysis of repeat interviews was important to focus on the overall coherence of what participants were telling me about their lives. The depth of analysis produced from this process was useful to generate a real sense of the person's life, and to understand the contextual and biographical elements of their narratives as they compared the present with the past. Each person's narrative had an individual shape, which had to be understood to understand the individual's particular perspective on life. I went through

this process of writing the detail to understand a person's perspective fully, before moving to a more general position that condensed the detail and looked for underlying patterns in the data. These 'stories' of living with dementia are summarised under the section headings in chapters five and six. While the specifics of individual stories varied, I found there were overarching patterns in the narrative structure of people's talk.

In order to move back out from the 'deep' layers of the detailed narrative analysis, and so compare and contrast perspectives on quality of life between the older people with dementia, I wrote a succession of analytical papers that looked at processes of meaning-making across accounts. I therefore moved back to a more surface-level approach, looking for cross-cutting themes that emerged from the content and descriptive processes in the older people's accounts. I integrated the detailed narrative data with the general emerging themes from the first readings that were summarised at the start of the analytical process. In order to work with a large amount of detailed narrative data, I carried out this process with the first three participants in the study. I then used the headings that emerged from this paper to compare and contrast these perspectives about living with dementia with the remaining two participants to generate an overview position.

### ***Analysis of the accounts of paid and family carers***

Once I had completed this process for the older people in the study, I analysed the transcripts of paid and family carers. I initially looked within each participant's account for themes or ways of talking about quality of life. I then carried out structural narrative analysis of first interviews (Riessman 2001) as detailed above in the analysis of the accounts of older people with dementia. I reviewed second interviews to check whether there was any additional material that could supplement analysis from the first interviews. Second interviews were useful for developing and clarifying the person's perspective, and gaining more insight into the context of the care situation. However, as



they did not bring out any new information pertinent to the research questions, I did not carry out detailed narrative analysis with these transcripts.

Detailed narrative analysis was used to elucidate processes of meaning-making in the ways that carers make sense of their experiences of caring for people with dementia. I initially worked with a heading for each person, describing and summarising the overall shape of a person's narrative. Each individual's story therefore emerged from the analysis process, before I put together the carers' accounts and looked across them for similarities and differences in the ways they spoke about quality of life and caring. While the process of understanding each individual's story was useful to fully understand their perspective, listing each participant was too mechanical for a final version of the analysis. I therefore decided that it would be more appropriate to work with headings that summarised particular ways of understanding quality of life and I grouped relevant cases under each heading.

I initially grouped the analysis of carer accounts according to whether they provided paid or family care. However, as I developed my analysis, it became evident that there were not systematic differences between paid and family carers; differences in perspectives related to understandings of how dementia affected a person's self and social identity, rather than being associated with the type of care a person provided. The analysis in chapters seven and eight integrates the perspectives of paid and family carers, with accounts grouped on the basis of the way participants make sense of the older person with dementia, and the impact this construction has for understanding and supporting quality of life.

As with my analysis of the accounts of older people, my analysis with carers had to move wider to consider and compare processes of meaning-making across the accounts. This broad analysis presented different challenges from the analysis of older people's accounts. Although I had carried out fewer interviews with each individual (two at most for each participant), I had to work across ten individual cases to build a general overview picture.

This process raised a limitation of narrative analysis, namely the greater difficulty of working with larger groups while attending to the detailed structure of people's meaning-making. I wrote a series of papers based on general themes that emerged from how carers talked about working and living with someone who has dementia and what they think is important to their quality of life. This process required a balance of breadth and depth in the presentation of individual stories, focusing on general points while retaining the rich quality of the data, to lift the level of analysis from the particulars of specific accounts to a more general level of representation.

This analytical process involved pulling together the individual stories, to combine thematic concerns while keeping the integrity of individual accounts. To explore carer perspectives in chapters seven and eight, I provide a detailed account of two carers as an exemplification of their meaning-making, to make the analysis explicit, which is followed by a general discussion of other relevant carers, to arrive at an overview position and collective understanding. In the final section of chapter eight I separate out some of the individual accounts again to explore the specifics of individual perspectives and what they reveal about the ways carers understand quality of life when they struggle to make sense of a person as normal. I have structured the analysis in a way that parallels the structure of chapters five and six looking at the perspectives of older people. This has enabled me to look within and across the groups of older people and carers, to present general conclusions in chapter nine about the meaning of different perspectives on quality of life.

The main aim of the analysis has been to understand the participants' own language, and then explore its meaning in terms of concepts that can be compared across accounts, seeking to understand how different perspectives are informed by particular ideas or experiences. This sociological analysis is grounded in the narrative data, and I use quotations and narrative excerpts to illustrate my argument. Given the breadth of data, it would be impossible to provide quotes or excerpts for every argument, so I have chosen

particularly salient examples to illustrate how meaning is created in people's accounts. When talking about dementia, I use the terms that the participants have chosen to understand the condition. It should be noted that while, for the purpose of analysis, I highlight what distinguishes participants in the overall patterns of how they make sense of their experiences, accounts vary by a matter of degree, rather than in an 'either/or' way.

### **Critical appraisal of approach**

The struggle among participants to find meaning is mirrored in the methodological processes of this study, reflecting the challenges I experienced trying to draw out and make sense of individual perspectives. Many of the ideas seemed difficult for people to articulate, and so these ideas were often embedded in accounts in a way that was sometimes not straightforward to grasp. I identified with Mauthner and Doucet's (1998) description of the process of analysis as feeling messy, confusing, uncertain and uncomfortable. People's narratives mimicked how life was experienced for them; although they talked in organised ways, themes were interlinked, and the data often appeared 'messy'. The form and content of people's narratives reflected the lives they were describing, and my ability to make sense of their efforts to find meaning depended upon engaging deeply with the narrative structure of their accounts. Using a method to uncover meanings in a detailed way has therefore been an important outcome of the research.

Examining the narrative structure of accounts has therefore been helpful to analyse the issues that are of importance in perspectives on quality of life with dementia. Meaning has been built within and across cases to explore different processes of meaning-making. The evolving narrative approach enabled subtle understandings of quality of life to gradually emerge and build during the interviewing process. The value of having a case-study structure is that it shows how, for each participant, the way that they construct self and social identity relative to frameworks of normality has a direct impact on how they construct and understand an ordinary quality of life. Each account was particularly telling,

and while the specifics of a person's life situation may not be suitable for generalising, how they came to their understanding is comparable, in terms of the way quality of life is understood in relation to identity and social status.

One of the strengths of this narrative approach has been in the achievement of thick description. By first engaging with the explanatory frameworks of participants, I was able to approach the data with an open mind, letting it 'speak to me' on its own terms, before moving onto the next stage to apply a sociological framework to the analysis. A rich sense of meaning-making has emerged from the way the data has been unpicked in stages and crafted to produce the final account. Examining the linguistic structure of these narratives has been valuable to make the meaning and significance of what people are saying much clearer. It has also been helpful to move beyond some of my own assumptions. For example, from my perspective as a younger woman, I initially viewed Rena's life as poorer in quality than the other people with dementia in this study, as she talked about "just sitting". On further detailed analysis of her narratives, I came to understand that Rena's perspective on "just sitting" reflected contentment with her life, related to her ability to manage her changed situation in life. Looking at the structure of talk therefore makes the meaning and significance of what people are saying much clearer.

This depth of analysis has been helpful, especially in relation to older people with dementia, as they are often assumed to be unable to communicate their ideas in depth, when in fact they can speak very profoundly about their life situations. Perhaps the most creative and compelling accounts come from those with most significant cognitive impairment. They appeared to struggle more visibly to make sense and bring meaning to accounts of their life, using metaphors and other cues to symbolise their thoughts and feelings and to tell their stories. One man would describe the frustration he experienced in trying to remember and articulate his meaning, often using concrete cues in his immediate surroundings to try to explain abstract ideas. The research method has therefore been

effective in its ability to understand the deeper meanings of people's accounts, and at the same time challenge some of the stereotypes associated with people with dementia.

It is clear that people were often working hard to put their meaning across and be understood. Indeed, factors such as differing extents of forgetfulness or difficulty finding words affected people's responses on different days. The narratives of people with dementia therefore required more work to interpret their meaning compared to the accounts of carers, and there were some occasions when I had to accept that I could not fully understand what was meant. However, by attending to the explicit and implicit use of metaphor, and focusing on how the story of someone's life is put together over a number of conversations, it has been possible to engage with the ways that people with dementia make sense of their lives despite the challenges of cognitive impairment. While people may have had difficulty with the specifics of dates and times, they did not have difficulty articulating their feelings. The study therefore demonstrates that people with dementia are engaged in rich meaning-making, but this may be masked by communication and other difficulties associated with their condition.

Successive interviews have therefore been important to look across fragmented narratives, to build up a picture of people's concerns when stories and ideas do not progress in an orderly fashion, but jump backwards and forwards within and across accounts. While this metaphoric and non-linear way of talking is particularly evident among some of the older people with dementia in this study, to a lesser degree it is also a feature of some carers' accounts, especially when narrating particularly emotive issues or concepts that a person has difficulty articulating. A narrative approach therefore allowed people to structure knowledge in the way that they chose. While there were differences in engaging with older people and carers, there were also similarities. Providing a space to listen to validate what was being said, without judgement or preconception, seemed most helpful in drawing out people's understandings.

Varying constructions of interviews within and between participants' accounts required differing forms of analysis to examine the content and structure of accounts. Content and structure were explored by thematic and narrative analysis, which were useful for two different ways of looking at the data. For instance, the analysis of the detailed structure gave insight into *how* people talk about their quality of life, in other words the deeper structures of the narrative, whereas the analysis of themes attended to *what* types of things help to create a good quality of life. These ways of talking highlighted how achieving quality of life is an active and ongoing process of meaning-making rather than a discrete outcome or state. A surface analysis of what people say is not enough, and the deeper analysis of narrative structures was necessary to understand the meanings of different perspectives on quality of life in depth. The form of talk tells us how the participants actually understand themselves and their lives.

Despite the advantages of a narrative approach for accessing deep meanings, there is a danger associated with the intensity of disclosure that may propel people to disclose more than they might otherwise (Hey 1999:107). By avoiding setting the boundaries too tightly, there is a risk that participants may not realise in advance how much they will reveal. This appeared to happen with the participant who withdrew from the study. This woman talked about her children's concerns and difficulties, and I initially did not stop her as I did not know how these stories might relate to her own quality of life. In retrospect, it may have been better to set the boundaries more clearly, as the woman eventually disclosed information about a family event that she later regretted and subsequently withdrew from the study. I believe her withdrawal reflected a lack of comfort with the interview process, due to this disclosure and perhaps also some discomfort with the level of introspection required by my approach. This was indicated by her comment to "call it a truce" when I noted some uneasiness in her manner and asked her if she wanted to continue participating in the study. In this instance, my approach was not suitable either for this

participant or for the purpose of the research in terms of finding answers about her quality of life<sup>1</sup>.

I was aware from the outset of the potentially sensitive nature of the fieldwork. Yet my assumptions about the emotional context of interviews were often challenged. I had assumed that it might be difficult to listen to the struggles that older people with dementia faced in dealing with the practical and social consequences of their condition. However, I found these meetings enjoyable and people never became visibly upset or distressed; while participants described limitations in their lives, their narratives reflected their active identity work in terms of getting on with life, and I found it comfortable and often enjoyable to engage with such stories. I found it more difficult to engage with the narratives of carers who described the challenges of living or working with someone with dementia, as they sometimes became angry or upset when talking about the difficulties that they faced.

My personal experience reflects the tendency in the literature to focus on the vulnerability of special groups, especially the very young and very old, when everyone is vulnerable in different ways. There is also an assumption that someone becoming upset is necessarily a sign that something has gone wrong in an interview. While it is ethically wrong to push a person to disclose information that they find upsetting and would rather withhold, it is unreasonable to expect people to push down their emotions if they choose to share an upsetting experience. Nevertheless, I was aware of the sensitivity of these situations, and would check whether the person might benefit from formal support. In one instance, with the person's consent, I arranged for formal support from the service. It was telling that even though I always asked - and sometimes recommended - that a person stop or take a break if they became upset, people always wanted to carry on and tell their stories.

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<sup>1</sup> Although the participant did not appear to be distressed during our meetings, I asked the woman's project worker to speak to her to ensure that she was not troubled by the interviews, or left with any negative effects from her involvement with the research. I subsequently met the woman to reassure her about anonymity and confidentiality, confirming that I would not reveal the information that she had regretted disclosing, and thanking her for her involvement with the study.

Another issue that is often associated with older people with dementia is the issue of confidence and the potential fear they may have of getting things wrong. I found this to be more of an issue for some of the carers in the study. For instance, at the end of one interview, a paid carer revealed how she had felt nervous before I had arrived, due to previous negative experiences associated with school and job interviews. This type of relationship with formal education may not be unusual among people providing paid care work. It was also clear that the older participants, while being careful not to appear to complain directly, had much to say about what was good and not so good in their lives. Yet the information about what was not so good was more subtle, and had to be drawn out sensitively and carefully from the accounts, often requiring me to acknowledge that a situation was less than ideal before a person was comfortable to talk about it.

In the literature older people are often described as passive and having less power in interviews compared to the researcher. However, there were times when the older participants took the lead in interviews, with one person describing how he was trying to 'educate' me. At various times when we met he would say "your turn", to indicate that he wanted a rest and that I should talk about myself. Other participants would often call me 'hen' or 'dear'. On one occasion, a woman announced that she would take me for a walk to actively demonstrate the capacity she had been describing in her narrative. During this walk she 'took charge', telling me where we were to go and when we were to cross the road, at the same time as educating me about the local surroundings we were passing. These experiences indicate the importance of intergenerational dynamics in the interview context.

I am therefore aware of my role in the interview process and the way that meanings have been co-constructed throughout. However, I have chosen to foreground the participants rather than write my own role into the analysis chapters, as it would make the thesis too unwieldy to integrate this with the multiple perspectives of the different participants that



I am already representing in the analysis. I take a similar position to Bornat (1993) in my desire to have the stories of the research participants dominate the analysis. While the participants' narratives in my study are crafted and excerpted to bring out their meanings, I want the richness and complexity of their stories to dominate, and so I have avoided academic references in the analysis chapters. I have had to integrate my own commentary in order to condense the details, and distinguish and draw out patterns of meaning-making across accounts. However, while adding my own interpretations, the analysis chapters are grounded in the meanings and perspectives of the people whose narratives I am representing.

## **Conclusion**

In this chapter I have linked my interest in subjective meaning-making with a methodological approach that engages with the form and content of people's talk. I have described how I engaged with older people's subjective experiences of everyday life using detailed narrative analysis to understand the ways that they find meaning in life. I also described my approach to eliciting carers' perspectives on quality of life to understand the ways that they make sense of working or living with older people with dementia. The purpose has been to engage with narrative processes of meaning-making to compare and contrast different perspectives on quality of life among older people with dementia and carers and so develop an in-depth understanding of the meaning of these differences.

The thesis now turns to the analysis of the participants' perspectives. I start first with the perspectives of older people with dementia in chapters five and six, before considering the perspectives of carers in chapters seven and eight. In the presentation of narratives within the analysis chapters, I adopt a mixture of approaches to illustrate the participants' meanings. As I discuss further below, not all people spoke in the same way, which may relate to different expectations of the interview, a person's preferred style of speech, or different emotional states. The older people and carers who struggled to represent their

stories due to the difficulty of cognitive impairment or the emotional significance of their accounts tended to provide richer and more detailed stories of particular events and experiences. Therefore, for most of the participants, a narrative excerpt accompanies my summary of their perspective. I explain in the analysis where this is not appropriate due to the style of narrative and when another form of presentation is used.

In the narrative excerpts I have smoothed out the vernacular to make local dialect easier to understand. With this exception, words have not been changed. I have removed most of the markings that were added to the transcription, as I want the structure of the stanza format to stand out in explaining the meaning of what has been said. I have deleted my asides and short non-lexical markers (mhm, uh-huh, yeah), and some of the participants' repetitions and false starts have been removed to make the presentation clearer when this does not affect the meaning of what is said. As detailed in the data analysis section, and the example in Appendix 10, I have structured most excerpts into stanzas, and given each stanza a title according to my summary of the main message in each segment of text. Square brackets have been used to identify when words have been removed for anonymity or to indicate something happening during the interview that affects the narrative, for instance an interruption or a person losing their train of thought. Round brackets are used to identify distinctive pauses or expressions, which have been retained to give a sense of the quality of people's talk.

## **Chapter Five**

# **The construction of self and social identity in the narratives of older people with dementia**

### **Introduction**

This chapter examines the ways that five older people with dementia use narrative to define their sense of self and social identity in conversations about everyday life. Narrative analysis is applied to explore how descriptions of particular events and experiences are used to define past and present social roles and relationships, and to represent past and present involvement and capabilities. As was discussed in chapters two and three, ageing and dementia are potential threats to self and social identity, either as a result of ageism and the social stigma associated with dementia, or due to the internal uncertainty that can arise from cognitive impairment. The ways that older people with dementia discuss and often struggle with these aspects of their self and social identity are important features of their accounts that are explored in the analysis. For some of the participants, the consequences of ageing feature most strongly in their accounts. For others, the impact of dementia is more fundamental to their narratives. The analysis will demonstrate that the way a person interprets their present social location relative to past circumstances, and the resulting status they afford their position in the social world, is significant in understanding how they make sense of their experiences as an older person with dementia.

The overarching theme of each person's account is summarised in the section headings for each participant. These themes represent how the older people with dementia relate 'then' to 'now' in comparisons of the past and present to evaluate their current situation relative to earlier times in their lives. A continuum of representations is presented, beginning with Cynthia, who feels her life is "finished up" due to her marginalised social

position as an older woman who has lost her valued place in the family and community. The next section considers the experiences of Ted, who believes the best part of his life is in the past, due to his lack of involvement in the present. The situation of Martha is then examined to understand the way she has reframed her social position in her focus to keep the appearance of being normal and counteract perceived threats to her reputation. In the following section, consideration is given to the way Rena defines her experiences relative to understandings of reciprocity and generational exchange, to interpret her life in older age as continuing to be based around the same values and meanings that framed her life in younger days, although requiring a new interpretation of her stage in life and what this means for family relationships. Finally, the case of Louis is presented to demonstrate the way that experiences of living with dementia can be reframed positively, to represent how he has moved on from the past to create a new sense of self and social identity that brings renewed purpose and meaning to life.

### **Cynthia: 'being over the hill and finished up'**

Cynthia is an older woman in her eighties. She is a widow who has raised a number of children and grandchildren and who worked in paid employment until her sixties. Cynthia's personal biography and life history is important in presenting herself to others. The importance of family, work, age and change were continually highlighted at the beginning of our conversations, as well as throughout Cynthia's narratives of particular events and experiences, indicating the centrality of these themes in her life. Cynthia describes how her family moved due to changes in work opportunities, and stresses that these changes had to be made because work "finished up". This same phrase "finished up" was often used by Cynthia to describe her current situation in life more broadly, suggesting a link between changing circumstances and a deteriorating quality of life. This evaluation of her life is related to an important tension in Cynthia's narratives about family life. Family is vitally important: "Well, it's just been family that's been important".

However, while Cynthia values the importance of family in her life, she feels her role within the family has been diminished.

Cynthia's narrative of how her life has gone downhill comprises a critical comparison of her past and present situation. Following a brief description of her past, Cynthia moves into the landscape of her recent life, describing the "ups" and "downs" as she has moved from "up there" to "down here". Close analysis of the narrative suggests that Cynthia's description of the physical location of her homes represents her changing social status from the past to the present. Changing physical location is being used as a metaphor to represent changing social location. An emphasis on "up" refers to earlier stages of Cynthia's life when she could take part in social activities like dancing. Such activities have now been "stopped", which Cynthia relates to being too old. The point where she is now, "here", is related to being "down". Importantly, rather than seeing the cessation of activities as a result of personal limitations, Cynthia perceives this restriction as being imposed by others: "they stopped it". The use of such comparison throughout this narrative suggests that being "higher" is a metaphor for the good things of the past, in direct comparison to Cynthia's less satisfactory situation in the present.

In addition to a comparison of past and present life stages, Cynthia talks about some being higher than others. This metaphoric talk about position may reflect the comparative social status between herself as an older person and others who are younger. Such a contrast is made when Cynthia compares her own restricted life with that of her daughter. In the final part of the narrative, Cynthia directly compares herself as "down here" with her daughter "up there". At another point in our conversation, Cynthia describes how her daughter is "up the top, right at the very top ... so you just, sort of change with one another". Cynthia's place in her family is shifting, and she appears to understand this change as her daughter taking the valued social role from her. On several occasions when we met, Cynthia described being "vexed" to have given away the place that her daughter has taken,

because she liked it better. Cynthia's social identity is diminished in relative terms and this is affecting her quality of life. She views her life as going downhill and concludes that she has now had enough. There is too great a disjuncture between her past and present. With the use of words such as "higher", the comparison between past and present can be seen as more than a description. It is an evaluation of Cynthia's past and present life situation in terms of social location.

Cynthia's sense of value and status therefore relates to having an active role within the family, which she feels she has had to relinquish to the next generation. Cynthia often told me how, once her own daughter had grown up and had children, she made way for the growing family by moving out of her house and "down" to the house where she is currently staying. At various times during our conversations, Cynthia describes how difficult it was to have her daughter looking after her, especially when she used to be the one looking after the family. Cynthia also expresses sadness at no longer having a husband. She feels she has lost the important roles of mother and wife, and she has consequently been marginalised from valued activities associated with looking after a home and family. Cynthia expresses a discrepancy between what she wants to do and what she is allowed to do, with comparison being made between her own situation and that of her daughter who is actively involved in looking after the home and family. Cynthia's language contrasts what she "did" in the past, with what her daughter "does" now. Cynthia interprets these changes in her situation as having lost status in the family as a result of changing social roles.

The process of comparing her present circumstances with what she had done and achieved in the past is therefore critical to how Cynthia understands her quality of life. Cynthia's sense of self is framed as continuous and unchanging, despite the emphasis upon changes in her place within the family and wider community. She still understands herself as "a worker", a person who is willing and able to contribute to her family and community.

People viewed positively by Cynthia are described as “great workers” or “a worker like me”. Working, contributing and being active are therefore important to Cynthia’s everyday life. She emphasises her dislike of sitting, and finds being framed by others as unproductive and dependent problematic for her sense of self as a capable and active woman. Cynthia represents the greatest impediment to her quality of life as the restricted social identities that are available, due to being treated by others as no longer useful or competent, and so being stopped from doing things despite feeling that she is capable.

Marginalisation from family life and the associated loss of status are related to Cynthia’s ultimate evaluation of everything having stopped now. The themes of social restriction and social isolation were repeated throughout Cynthia’s conversations with me. Cynthia relates her earlier life to being able to take part in social activities, and this theme recurs in other narratives in which she describes her earlier life as a time when she worked hard in paid employment, in the community and in the home. Her narratives of the present are full of frustration and resentment at the restrictions she feels are imposed by others. Being older is associated with marginalisation and being perceived as lacking in competence by other people. In the following narrative, Cynthia evaluates how her life has gone downhill and that everything has stopped in her life. It is not just the dancing that has stopped, as was recounted in the narrative above, “it’s all stopped now”:

***Narrative: my life has gone downhill - it’s all stopped now***

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***Stanza 1 (Abstract: I live down here while they’re up there)***

And, eh, I stay here

While [my daughter] is up the top, higher

And this is where I live

For I gave the place to them

And I came down here

But that's a while ago

But [my granddaughter] always comes down, to see me

And [my daughter] was in here today

***Stanza 2 (Orientation: I gave away the top bit to my daughter)***

[Jane: And how do you like it down here?]

Well, I've just got used to it because (long pause)

I left her with the place at the top

Because I didn't like the bairns<sup>2</sup> coming down, onto the road (low pitch)

And that's how I came down here

I gave away the top bit

And I felt, once I gave it away, I'd given it away

***Stanza 3 (Complicating action: I can still walk and do things but I get a row)***

But I can still walk

And do things

And then if it's windows

I get a row for touching the windows

[My daughter] will say, "I'll do it!"

But she comes in and does things for me (low pitch)

But I did do my windows, too

***Stanza 4 (Evaluation: walking, dancing, "it's all" stopped now)***

So, and then, you can walk, to the town, along and down

But I don't like going to the town now, I'd rather go to [different town] (low pitch)

[Why's that?]

---

<sup>2</sup> children



I don't know (pause) I just always ...

There was dancing in [town] and things like that, for a while

But it's all stopped now

And then, my son, he's married, and they live up that area

***Stanza 5 (Coda: that's all I can tell you)***

So I think that's about all I could tell you

The process of change as her life has gone downhill is described as having given away the higher position in the family. The fifth stanza is very brief, although from the structure of the narrative you would expect to hear how the story is resolved. Cynthia explains "that's about all I could tell you". This phrase suggests that these issues have not been resolved, with Cynthia constantly repeating the theme of being restricted across our conversations. The difficulty in finding a resolution to her situation may be due to the discrepancy between how Cynthia sees herself and how she believes other people perceive her. Representing herself as a person who works and can do a good job is important for Cynthia's sense of self.

Cynthia often reflects upon her previous active involvement in community work and paid employment. Yet, with sadness, she explains how she no longer feels needed, that other people think she is "too old", and people find her memory loss problematic, despite her describing it as "just forgetting". While Cynthia sometimes rationalises not being involved as having done her share in the past, most times she describes how she is no longer invited despite wanting to be involved. She frequently uses the phrase "being finished up" in relation to her family and community roles, and this can be contrasted to her ongoing concern with being capable of doing activities such as walking, dancing and housework. Feeling capable but being restricted by others is a recurring theme in Cynthia's narratives, as Cynthia contrasts her own sense of self with how others perceive her.

Narratives of ageing and dementia are interrelated in Cynthia's evaluation of her restricted life. Cynthia often struggles to talk about her memory difficulties, and the topic of dementia was conspicuous by its absence during our initial conversations. When Cynthia does talk about memory difficulties, she relates these to ageing, and compares herself to me as someone who is younger and therefore untroubled by memory loss. When Cynthia makes reference to her memory, sentences often end in the middle, with words unarticulated and stories seemingly disrupted. While this may be purely due to her cognitive difficulties, it may be that what Cynthia terms as being "lost", refers to her situation in life more generally, which is emotionally difficult to articulate. The consequences of dementia are both personal and social. Cynthia describes her brain not being what it used to be and not being so good at things since losing her memory. She talks about having to be careful that people do not think she is "off her head", which suggests a concern for social stigma and the impact on her reputation. Therefore, Cynthia's comparison of past and present life stages, and the resulting changes in her situation, are influenced by her understanding of the way that dementia has affected her later life.

In summary, ageing is tied heavily into a negative evaluation of life, as Cynthia comments on how "when you are older, life is not very good". Within this evaluation of ageing, dementia features as an aspect of later life that can impair memory and influence how others perceive a person. For Cynthia, the best part of her life is relegated to the past, and she does not talk about the future in her narratives. What was a good life appears to have become unbearably difficult, which she perceives as being constrained and controlled in how she is able to participate and contribute. Cynthia frames her quality of life in terms of the way she believes other people view her, as "being over the hill, and finished up", which she contrasts to her actual abilities. She has lost her sense of purpose in life and tells me with emphasis: "I've lived too bloody long, that's what wrong". Being unable to find meaning in the present, it is not possible for Cynthia to look to the future, and so Cynthia's

narratives do not look forward, but rather centre on the negative evaluation of present circumstances relative to the positive associations of the past. Cynthia's strategy of keeping moving and working to stay engaged in valued activities that support her sense of self will be explored in chapter six.

### **Ted: 'living in history and faltering in the past'**

Ted is an older man in his eighties. He is a widower, and he has children and grandchildren who live near him. He worked in local industry until his sixties. For Ted, locating himself in the present relative to his past life history is of primary importance in how he experiences his life. The phrase "living in history" is a significant representation of Ted's life, as these were the first words that he used when I asked him what was important in his life. Ted often recounted stories of past achievements and provided me with information surrounding his family history. A sense of pride and accomplishment in his past was evident when he showed me memorabilia relating to his voluntary work within the community. Ted showed me what he described as "records from the past", which were old correspondence, pictures and mementos. He described keeping things that had memories for him. Ted also repeatedly showed me his photograph album, talking about his attachment to his family and friends in the photographs. Reminiscing on the past, and reflecting on its significance, is an important feature of Ted's life that brings him satisfaction and enjoyment.

While looking back to earlier memories can be enjoyable, Ted's interpretation of living in history also reveals the negative aspects associated with the focus on reminiscence in his life. Ted explains the problematic process of "going back a wee bit, into the areas, and frowning (pause) there's an awful lot of things that falter in the past". Ted associates faltering in the past with his cognitive impairment and a lack of involvement in the present. The past and present are described by Ted as "two situations". Ted uses a song to compare a situation that was "at home", and a situation where someone has "now landed".

“At home” is described as his situation in the past, in which Ted had an active role in the community. Ted’s current situation, where he has “now landed”, is tied to his dementia, which he describes as his “situation health-wise”. Ted uses metaphor to describe limited and limiting perspectives associated with having dementia. Dementia appears to have affected his perspective in life, with Ted describing his view as limited, which can be related to his description of “faltering in the past”. Dementia therefore has a significant impact on how Ted understands his quality of life.

Dementia is framed in Ted’s narratives as a barrier to his involvement in the present. He compares the blocked and restricted vision of someone with dementia, to those without dementia who have not only a vision for today, but a vision for tomorrow. Dementia is portrayed as blocking the potential to look forward into the future and deal with change. The limitations associated with cognitive impairment are described in the following narrative. Ted compares himself to ordinary people whose perspectives are not limited by dementia, and he explains how people with dementia are less able to deal with changing situations because of the confusion that their dementia causes. However, surrounding this narrative of the limitations of cognitive impairment, Ted starts by describing the potential for people with dementia to do things if their mind stays alert, and his narrative ends on the possibility of people being able to do things if they can concentrate. Despite the restrictions that dementia causes, the potential to remain involved is still there:

***Narrative: dealing with the restrictions of cognitive impairment***

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***Stanza 1 (Abstract: it’s possible to do things if your mind is alert)***

It’s surprising (pause)

things that you’re capable of doing

if your mind is alert

you can mind a certain amount

and then it stops

[And does that change from day to day?]

***Stanza 2 (Orientation: ordinary people have the capacity to be mentally alert)***

It changes from day and day in as much as (pause)

the people round about (pause)

they have (pause) vision for today

and a different vision for tomorrow

and so on (pause)

***Stanza 2 (Complicating action: the capacity of people with dementia is more limited)***

The person who, is ill (pause)

has as much (pause) as they can see

and their vision, is held

by the things they can see

and appreciate

***Stanza 3 (people with dementia are used to dealing with more restricted situations)***

So, round about them (pause)

is a situation where

for them it doesn't change

If it doesn't change

they're repeating what they did yesterday

***Stanza 4 (people with dementia are limited in their ability to deal with change)***

So, if (pause) the scene

if the scene has changed

by (pause) other things being implanted

into the (pause) scene (pause)

they can go so far

***Stanza 5 (people with dementia become confused if things change too much)***

And then they are sort of blocked

because they haven't done that

they haven't, been involved in that bit

they might get confused

***Stanza 6 (Evaluation: people with dementia can deal with change if they concentrate)***

But, eh (pause)

if, they concentrate

on what's going on, eh

they'll be able to do

because, they'll know

***Stanza 7 (Resolution: by concentrating people with dementia can manage change)***

They'll know right away

and they'll be able to, kind of

thought in mind with the change

[telephone interrupts and loses train of thought]

I'm getting lost now (laughs)

In addition to the impact of cognitive impairment in limiting his personal perspective, Ted describes the social repercussions of his cognitive difficulties, specifically the different ways that he now associates with people as a result of his condition. There is reference to social stigma in the way that other people may interpret his difficulties, when Ted explains: "If I'm sitting here talking, to somebody who was local, they'd be saying, 'That's a

nutcase!” When I asked why he says that, Ted replies: “Because they wouldn’t know all that you’re getting to know”. Therefore, if people do not understand Ted’s situation, he feels that they are likely to judge him adversely. Ted is self-conscious of the way his mind is working, which he describes as jumping back and forth between ideas and experiences that are connected with each other. Explaining these associations is important, as Ted believes that people who do not fully understand these connections will think he is speaking nonsense, and during our conversations Ted frequently asked me whether I had “learned anything there”.

Ted described himself when we first met as “the oldest member of the family”, yet the stories he narrates are mostly of times when he was “a fit young man”, and representations of being strong, fit, capable and active resonate throughout Ted’s accounts. This dichotomy represents a problematic tension in Ted’s narratives. It is clear that maintaining a sense of self from past times is important for finding meaning in the present, yet this is complicated by the reality of not being involved in activities that support Ted’s idea of himself as being active and capable. Ted’s sense of self is strongly connected to his occupational background, and he repeatedly showed me mementoes relating to his previous paid and voluntary work when he was a younger working man. In direct comparison, Ted’s accounts of the present emphasise his lack of activity in the social world around him and the lack of capacity fully to make the right connections in his mind. Due to his lack of involvement and participation in the present, Ted compares his past life of activity to his present life of sitting.

In addition to asserting a strong sense of self as a working man, Ted presents his social identity as a valued and knowledgeable member of his community. Achievement and social status are themes that recur in his accounts. Being informed is an important theme, which Ted considers was a feature of his earlier life. He describes how he enjoyed “finding things out” and jokes that he was “a bit of a gossip”. The personal and the social are linked

in terms of the resulting knowledge that he gained within the community. Like other aspects of his life, Ted compares now and then. He now needs to rely on his daughter to “keep him right” and keep him aware of what is going in his local area. He also refers to his son being well regarded by people of social standing. The close proximity of these remarks in his narrative suggests that these ideas are linked in his thinking. Ted is now neither well informed nor has social standing in the community. This diminished social status can be compared to Ted’s stories of past events and experiences in which he was valued and held in high esteem by others.

The different ways of representing the present compared to the past illustrates how Ted’s involvement in everyday life has changed. For instance, Ted is no longer actively involved in gardening, but he enjoys looking at photographs of his garden at a previous house. His perspective has shifted from being involved to watching, and Ted reflects on how time drags now that he is older. This sense of time dragging is related to how he is not “involved” in life either mentally or physically. It also links his situation to one of ageing more generally. Ted tells me stories of “situations” in the past that highlight his active involvement in particular events and experiences. There is a juxtaposition of the youthfulness and “involvement” described in these stories, alongside the disenfranchisement of his life in older age as a person who is no longer involved. Ted’s language signifies loss, as his involvement in activities that he values is described in the past tense. Losing the struggle to stay involved characterises a large part of Ted’s current experiences, both in terms of cognitive capacity as well as being socially engaged.

While dementia is the most important factor in Ted’s evaluation of his life, ageing is therefore implicated within the context of no longer being involved. Ageing is understood by Ted as a process rather than a fixed status in his description: “age wise, I’m getting older”. Ted does not think of himself as either young or old, but as moving somewhere in between. Ted makes a distinction between the opportunities that he has as an older man,



compared to the ones I have as a younger woman. When we discussed making use of a calendar, Ted commented: “But the point is, I’m getting older. You’re young, you can do something with it”. Ageing is a frame within which Ted understands his situation as one of reflection rather than action. When he describes his difficulty in recalling people’s names as a result of dementia, he again compares himself with me in terms of age: “I mean, you’re young”. Ted’s sense of self is therefore affected by how he relates himself to others in terms of ageing.

To summarise, the phrase “living in history” represents how Ted characterises his personal cognitive challenges and his restricted social involvement within the community. As he sang in a song to me, his life is about the past: “And there we stood talking of days that were gone”. As Ted constructs his present life as “living in history” and “faltering in the past”, so his struggle and purpose has become to try to keep in the present. He describes this process of keeping in the present as “keeping in this world and not being lost”. This description of “getting lost” is similar to Cynthia’s use of the term “lost” in the metaphoric context of physical and social location. Ted’s quality of life is similarly related to his social position in the wider community. For Ted, his life has had value and significance in the past, but in the present this sense of purpose has diminished. This may explain why Ted’s narratives are focused on the past and rarely mention the future. In the next chapter, I explore how Ted emphasises the importance of support from other people to build his confidence in keeping involved in the present.

### **Martha: ‘keeping normal and not letting it beat you’**

Martha is in her eighties and lives alone. She has a son and grandchildren who have moved away to another part of the country. Martha’s younger sister lives nearby, and they spend a large proportion of their time together. Reciprocity is an important feature of this relationship. Martha emphasises the ways that she and her sister work together in each other’s homes. She also represents her role as a caring one in helping to look after her

sister who experiences poor health. Whereas Cynthia describes a loss of important social roles in the family, Martha relates stories about the past and present that emphasise her caring role in an unchanging way. Supporting other people has been a feature throughout Martha's life, and she narrates accounts of her role in caring for her family and neighbours. Martha describes how the role of helping other people is in her nature and that she is an "ordinary person, helping people". Helping others is an enduring aspect of Martha's life that is placed in the context of being an ordinary person. Continuity between the past and present, in terms of her perceived role in the family, is helping Martha to maintain an ongoing sense of worth and value as an ordinary person.

The normality of looking after her own and sister's homes is a significant aspect of Martha's description of her involvement in family life. When I ask Martha how she would describe herself, Martha talks about doing "normal things", like "normal shopping" and "normal housework". By describing her involvement in normal activities, Martha is defining herself as normal, which links being and doing. Martha believes that others frame her as disabled, but she rejects this status: "I'm not disabled" she responds angrily in a story about a neighbour who asks her how she is feeling, which Martha mimics in a patronising tone. Martha also contrasts herself as being in a different situation from her sister who is disabled. Similarly, while Martha places importance on her membership of a day care group for people with dementia, she distinguishes herself from other members who are "worse" than her. Like Ted and Cynthia, Martha emphasises her continuing ability to help other people within the context of a mutual support group. Martha is emphasising that she is not disabled, and this status of being normal is linked to her practical and emotional capabilities.

Martha does acknowledge her memory difficulties, but she construes them in a different way to how she believes other people understand them. Martha describes her impairment as "just forgetting" or a "weakness" related to ageing, and she challenges other people's

understanding of dementia as either a disease or an infection. Martha explains how she is in good health, “not ill in body”, and that she has just taken “this short of memory”. Martha understands forgetfulness as something that happens with age, and compares this with how other people construct memory problems as something more fundamentally problematic to a person’s identity. This contrast is suggested in Martha’s narrative about how some people she knew used to forget, but they would all laugh and put it down to ageing; yet she says when it happened to her, people changed their way with her, as if she has an unbalanced state of mind. Therefore, while Martha accepts that she has a problem with her memory, she does not accept that there is something wrong with herself in terms of either physical or mental health. While Martha is successful in her ability to construct a narrative that emphasises continuity in her sense of self as an ordinary person in the context of home, she is less able to frame herself as normal in the context of the ways that other people perceive her.

A concern for social stigma is reflected in Martha’s narratives about how those with weaknesses may be perceived as different from other people. Martha often recounted stories of how other people were badly treated by those around them. When recounting one particularly detailed account of a neighbour who had a stroke, Martha changes to the personal pronoun: “And I’ll say, ‘Oh, I’m just the same as I was, only I’m forgetful’”. This change in reference suggests that Martha is using stories of other people to express the difficulties she faces herself in dealing with perceived threats to her social identity. Martha is trying to resist a spoiled identity, but the sense of stigma is so great that she articulates most of her narratives in terms of other people. When Martha does speak of her own direct experience, she describes telling people to speak to her the way they have always spoken to her, and not to treat her as if she is stupid. Martha emphasises that she is still the same person as before, and that she does not want to be treated as someone different, as an idiot: “I’m still me. It’s just I forget sometimes. So, I ain’t no idiot”. Being perceived as foolish as a result of her forgetfulness is therefore a fundamental concern for Martha.

Keeping the same as before is a recurring and prominent theme in Martha's narratives about her sense of self and social identity. Martha does not wish her dementia to define her. Martha's narratives are mainly concerned with rejecting a spoiled identity and asserting her social status as an ordinary or normal person. She often spoke about other people demeaning her, but she could not explicitly say the way they named her: "Of course, somebody will slip, they'll say, 'Do you not know, Martha was ... (long silence)'" . In this instance dementia cannot be named with direct reference to herself. This concern for other people to see her in the same way as before is represented in the following narrative in which Martha emphasises how she is the same person as before. Martha is stating that there is no change in her identity and that the only difference is in her forgetfulness. She talks about people shunning her as if she had an infectious disease, which is linked to her concern with other people being fearful about her dementia, due to their belief that she is either mentally or physically ill. Martha makes an emphatic demand that people should treat her the same way as they always did, that she is still the same person. In the following narrative Martha structures her account with alternating stanzas of how other people understand her condition and stigmatise her, and how she resists their beliefs and responds to their stigmatising actions:

***Narrative: I'm the person you always knew, I'm not doo-lally<sup>3</sup>***

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***Stanza 1 (What other people think: people shun you as if you have an infection)***

You'll get people

And you say anything to them

And oh, I've got something!

They seem to kind of shun you

As if it was an infection you had

---

<sup>3</sup> mad

***Stanza 2 (How I respond: but you've not got a disease)***

Because it's not a disease you've got

Not an infection, any kind

So, if they can't take you now (pause)

that's that

No, I, I don't, eh (pause)

***Stanza 3 (How other people act towards me: people are patronising to me)***

They'll say to you, someone will come by

And they'll say, "Oh, how are you?" (in dragging mock sympathetic voice)

And I'll say, "Oh, I'm just the same as I was

only I'm forgetful" [in bright, cheery voice]

I says, "I'm not ill in body"

***Stanza 4 (How I respond to them: talk to me the way you've always done)***

"You don't mean that Martha"

I says, "Well, talk to me the way you always spoke to me"

It's only that, I'll forget

I says, "I've no germs or nothing about me"

"Aye, that's right" (meekly)

***Stanza 5 (How I want others to act: treat me normally)***

So now, this woman particularly

She'll always say, "Are you going down the town, Martha?"

I'll say, "No, I'm just going down to [supermarket]"

I says, "Where are you going?"

"I'm just going down to [supermarket]"

“Come on,” she says, “I’ll get you down”

I says, “Fair enough”

And talk away normal

***Stanza 6 (How I don’t want others to perceive me: some people think I’m stupid)***

But some folk think you’re stupid

It’s like (pause) an infection

They’ll say, “Oh!”

***Stanza 7 (How I want to be perceived: I’m the same person, it’s only that I forget)***

I’ll say, “Look! I’m me!”

I’m the person you always knew

The only difference is I forget

That’s all

I’m not doo-lally!

Martha describes old friends passing her by without speaking, and gives an example of someone only being forgetful, but their neighbour not having any time for them. Martha feels that “there are not many good friends going about now”. This is similar to Cynthia’s evaluation of her social situation. Martha likens the reaction of people to memory problems, to the reaction of people to someone whose money has gone; their friends drift away and she describes these former friends as Judases who come into money and go to a “higher” class. Using money as a metaphor for social status, Martha is talking about how she is treated and perceived by others. Like Cynthia’s metaphoric description of changing physical location, moving from up there to down here, Martha is describing a loss of social status and separation from others. Her aim is to try to keep “the same” and not let dementia beat her. Martha’s narrative is constructed as a struggle to avoid being seen as different from before. She frames the main difficulties in her life around the repercussions

of being perceived as different in status from other people, and the detrimental impact that this has for her reputation.

A concern for maintaining her reputation relates to the importance of maintaining a sense of normality and ordinariness. Martha stresses that you have “to keep your appearance and the position that you’re in, to keep normal”. Normal activities are emphasised as important in the effort to keep the appearance of being normal. While Martha can construct such a positive sense of self in narratives about her home life, this can be contrasted with narratives about her social life outside the home. Narratives about events and experiences outside the home are spoken with a tone of anger, resentment and frustration. Like Cynthia, there is a sense of rejection and social isolation within the community. Martha’s social identity and reputation are represented as spoiled in her descriptions of membership of community groups such as her church. She describes a shift from the outside world to the home environment as needing her own space: “I let them slide quietly (pause) I just stopped going, and I got into my house (pause) I just felt I need my own space”.

In summary, Martha is managing to frame aspects of her life positively, but these are confined to her home life and the relationship with her sister in this context. The project of keeping normal, and its relationship to keeping things homely, will be considered further in chapter six, to explore how managing the loss of social status is fundamental to how Martha continues to find meaning in life.

### **Rena: ‘being older but feeling just the same’**

Rena is in her eighties and lives on her own. She has not married and does not have children. She regularly sees her siblings and their children, who live locally. Rena worked in paid employment until her sixties, and her working role is a strong feature of her identity. Like the other older people with dementia in this study, continuity with her past is important in how Rena perceives her life. In several narratives, Rena contrasts how her

life is now with how it used to be before. She discusses how she used to be busy with things at an earlier stage in her life, and compares her present situation of relative inactivity with her niece who is very busy. However, Rena does not represent this change in her situation as harmful to her place in her family, which can be compared to Cynthia, who relates a changing life stage to diminished social roles. She describes how she now receives practical support from her family, but she interprets this as her family reciprocating the financial support she gave to them when she was younger and in employment. She also emphasises how she continues to contribute by giving pocket-money to her niece's grandchildren. Rena emphasises continuity in her social roles and relationships within the family, with a particular emphasis upon reciprocity between generations, and she is able to find continued meaning from having a valued place within her family.

Rena understands her current situation in life relative to ageing and she constructs her sense of self in a way that emphasises continuity. She tells me that she is the same person as she always was. Although she describes herself as "not young", Rena does not feel "old". Like Ted, Rena describes herself as "getting older". Rena distinguishes "being" older and "feeling" older. She is aware that others perceive her as very old and that they cannot believe she was "ever" young. When asked if she feels different being older, she says "just the same". This sense of herself as a person is distinguished from what she feels she is able to do physically. Whereas 'being' is associated with 'doing' for Cynthia and Martha, they are separate for Rena, and so she evaluates her life differently from Cynthia and Martha. Rena contrasts a younger person who "sits on his backside" with herself and contemporaries who have "worked all our life". This suggests an evaluation that, having worked at a younger stage, it is now appropriate to rest and enjoy the rewards of earlier employment. This attitude is represented in Rena's narratives of having worked for a pension that provides money in her retirement. Rena also describes having supported her family financially in the past, and relating this to why they provide practical support in her



later years now that she has limited mobility. Interpreting the way that ageing influences her circumstances while not undermining her sense of self is important in the way Rena makes sense of her situation.

By emphasising continued social status within the family and among her peers, Rena is able to construct her life in a positive way. Rena describes the day care centre she attends as “a place for us”, but she defines “us” not as older people, nor people with cognitive impairment, but as “the girls I went to school with”. This representation suggests continuity in her sense of social identity, and a sense of community with other people who she has grown up with. This can be distinguished from the sense of social isolation represented in Cynthia’s and Martha’s narratives. As well as identifying the people who attend the day care centre as being the same age as her, Rena also describes them as being the same in terms of not being able to walk well and needing to be taken out. Rather than describing herself as different from others in a fundamental sense of identity or degree of normality, Rena is identifying herself as similar to others within her generation who need assistance with their mobility. Despite the emphasis upon continuity, Rena also reflects on how her life has changed in respect of ageing, as most of her contemporaries have died. There are occasions when Rena reflects on death as being inevitable, of her being near the end, and how she and her siblings are living to a good old age. This emphasis on the present is important. Rena mentions that in the future she may need to go into a nursing home permanently. Therefore, both continuity with the past, and a new perspective associated with the future, are important in how Rena makes sense of her life.

Older age is therefore associated with inactivity and immobility, but not with ill-health. Good health is important to Rena and she tells me her life would be worse if she were ill. Rena distinguishes her memory problems from ill-health, and therefore she does not place her cognitive difficulties within the context of either mental or physical decline. When asked about her memory problems, Rena jokes that she does forget sometimes, but she

explains that she does not forget the important things such as the names of her family, her money or her meals. Rena describes her memory as “not bad” and associates her forgetfulness with ageing. Rena is emphasising a change in mobility and restrictions associated with physical capacity, rather than the types of changes in mental capacity and social involvement that are emphasised by Cynthia, Martha and Ted. Consequently, Rena’s memory problems do not appear to worry her unduly, and she did not raise her memory problems in our conversations, only responding to my questions about memory. If there is a concern, it is of a future time when she might not recognise the members of her family. Rena describes accepting things as they come, and this reflects her approach to ageing and dealing with memory difficulties. Memory problems are not constructed as fundamentally problematic for Rena’s sense of self, as she continues to remember those things in her life that give it meaning and purpose. Rena frames her forgetfulness in the context of ageing and distinguishes this from being ill, as indicated in the following narrative:

***Narrative: My memory problems don’t bother me***

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***Stanza 1 (Abstract: how my memory problems affect me)***

[Do your memory difficulties affect how you feel?]

***Stanza 2 (Orientation: sometimes I forget things)***

Oh aye

sometimes I forget things

and things like that

***Stanza 3 (Complicating action: I get things done for me)***

But it doesn’t bother me

I mean it’s not important

I mean, I get my meals and things

I don’t forget my meals and things

I've not got that to sort of attend to

That's all, done for me

***Stanza 4 (Evaluation: it would be worse if I was ill)***

No, my memory's not bad

I don't think much of it

It's no worse than anybody else's (laughing)

Oh dear

It's the worst of getting old

It could be worse, I could be ill

Or I could be lying in a bed in the hospital

***Stanza 5 (Resolution/coda: I don't have to worry)***

So I don't have to bother

about that sort of thing

Rena is maintaining her sense of capability in the way she makes sense of her life. This can be compared to Cynthia, Ted and Martha, who struggle with constructing themselves as capable or normal, whether due to the ways others restrict them, the limitations of cognitive impairment, or the social stigma attached to having dementia. Rena describes being capable in so far as she is able to look after her own personal care, and this capacity is framed as important in being able to stay at home. Personal care is distinguished from practical support with housework and cooking, and continuity is emphasised in the way that Rena recalls how she never had an interest in cooking and housework. Although Rena presents herself as capable and competent, there is evidence that she is aware that others might not perceive her in quite the same way. She comments that, while she is often asked whether she would like to move into residential care, she wants to stay in her own home. Rena is therefore aware that she might need to go into residential care eventually, and

that others may wish her to do this sooner than she wishes. However, Rena is content with her life in the present, and this is reflected in her uncomplicated narratives, which are generally spoken in the present-tense and without a great deal of metaphoric talk.

While Rena's narratives generally emphasise continuity and contentment, one particular break with the past reveals sadness and disappointment. This disruption involves Rena's changing involvement with the church, which was a prominent feature of her earlier life. Due to her mobility problems, Rena is no longer able to attend church. She recalls in vivid detail an occasion as a child when she walked to church with her father. This is set in stark contrast to the present. Despite continued financial contributions to her church, Rena comments on how the minister never visits, and she rarely has visits from other members of the church. The lack of support and sense of isolation from the church community creates a disjuncture for Rena. Rena's story emphasises a split from the past when she could go to church, and her current situation where she has to rely on others to come for her and this does not happen. The sense of reciprocity that is an important feature of her family life is absent in the church community, and so Rena cannot find meaning in her changed situation within the context of the church.

In summary, Rena constructs herself as a capable person who still holds a valued place in her family. Rena's references to the past are used to emphasise continuity in her relationships with her family and friends, specifically the role of reciprocity and intergenerational exchange within the family that has been a feature throughout her life. With her focus on the present as containing meaningful connections with the past, Rena's narratives are different from Cynthia's and Ted's narratives with their focus on broken connections between the past and present. However, Rena understands these connections, not in terms of keeping normal by keeping the same social roles within the family like Martha, but in terms of evolving social roles that make sense within the context of ordinary ageing. While Rena understands her life as meaningful in terms of sustained

reciprocity and shared values, she also recognises and accepts change in her life, but interprets this change as part of the ordinary life course where social roles change between generations. Consequently, Rena is able to evaluate her current life situation positively, by incorporating dementia into ordinary forgetfulness associated with ageing. Rena is therefore redefining her life in the context of ordinary ageing to find continued meaning in the present.

### **Louis: 'getting over it and getting on with it'**

Louis is in his sixties and lives with his wife. He has children and grandchildren who live near him. He worked into his late fifties until he stopped working following a diagnosis of dementia. Louis understands his life as being separated into two stages, before and after the diagnosis of dementia. In response to my first question: "So can you tell me about what's most important in your life?" Louis asks me "Do you want prior, before dementia?" Beginning with a description of his work, Louis defines himself in an active sense in the first person, presenting himself as a skilled, respected and capable man. His life before dementia is defined by his work identity. He then relates a series of incidents that precipitated a formal diagnosis of dementia. Whereas the first part of Louis's narrative represents how he was in control of his work and business, the second part of his account represents life as out of control. Dementia is defined as something tragic, which Louis believes was brought on from being a workaholic. This is a different interpretation from the other people with dementia in this study, who being in their eighties are almost a generation older than Louis, and who associate their memory problems with ageing rather than as being brought on by a specific incident or reason.

For Louis, dementia is understood as a medical problem with his brain, which is associated with getting mixed up and losing track. Causing problems for others is another theme that Louis narrates within his stories. Louis describes putting his family through hell with his aggressive mood swings, before going back to acting "as normal" as if nothing

had happened. Louis's narrative illustrates the way that he makes sense of his condition. Louis understands dementia as an illness that has taken time to "get the level and all that balanced out". The use of medication to help achieve equilibrium is described in detail, and Louis talks about his experiences of trying to successfully control his condition with medication. In this sense, dementia is a challenge, but one that he takes positively, as it is something that he believes can be managed. Louis emphasises stabilising his condition and learning to live with the challenges, which he describes in the following quote as it "all balancing out". I have presented this excerpt as a quote, as it seemed the most appropriate form for this stretch of talk, which is based on broad description. Indeed, most of Louis's narratives did not involve the same level of rich stories as the other older people, which may relate to his argument being well-rehearsed in his mutual support group:

And I'm now stabilised. But there are a lot of funny sides to it. It's not all down. I mean, it's not dramatic, I mean, there's life, beyond dementia. I mean, dementia's not the end of the world. I mean, if there is life, there's a lot of life after dementia. I mean when you're diagnosed with it, dementia, it's only a matter of grabbing the bull by the horns, take life as it is, and get on with it. Face the music, and get on with it. Learn to live with it, and get on with it (pause). It all balances itself out. It's how you approach it, it's how you approach it and get on with it. I, I had a lot of fun and laughs and sides to it.

Following his early understanding of dementia as something tragic, Louis's narrative moves from a time when he was not able to believe he was "a nut", a term which reflects the fear and stigma surrounding dementia, to getting treatment and reconciling his dementia as not being so terrible. This comparison emphasises the importance for Louis of coming to terms with his condition. Louis stresses that there is a lot of life after dementia, and this is a phrase that recurs throughout his narratives. How the condition is approached is what matters, and Louis places its impact within the control of the individual. The way that Louis makes sense of his condition allows him to evaluate his life positively. He rejects the association between dementia and social death, by telling me

that people with dementia are living with their condition, not dying from it. In the following quote Louis accepts the presence of such social stigma but rejects having to accept it personally in his life:

Well, I don't let them see that (pause) me (pause) in that in me. But it used to be, no, but, eh (pause) it's (pause) it's still there. It is still there. The stigma's still there but I (pause) not so much with me but (pause) I've seen it happening, eh (pause) but I don't allow it. I just don't allow it. I mean (pause) eh (pause) dementia is an illness, not a (pause) a disease. I mean, eh (pause) it's well (pause) wait a minute, I'm trying to find the right words here (long pause) we're living with dementia; we're not dead with dementia.

Louis focuses on leading a normal life, but he describes this in a different way to Martha. Rather than resisting the idea that he has dementia in order to define himself as normal, Louis believes that he can still live an ordinary life despite having dementia: "You can live as normal a life as you want to. Okay, you might not be 100%, you'll not be the full shilling, but you can be 11 pence of it." Louis describes a process of acceptance in coming to terms with dementia and the changes that have occurred in his life as a result of the condition. "Getting over it and getting on with it" is how Louis describes coping with his diagnosis. This acceptance has involved coming to terms with the loss of important aspects of his life before dementia, like working and driving. While there is loss and change in his life, Louis describes making sense of his situation to find new meaning by helping other people: "I took the bull by the horns, got over it, I learned what was wrong with me, tackled it, know how to assist other people now".

Like the other people with dementia in this study, helping other people is a fundamental aspect of life. In addition to the significance of helping other people, Louis finds meaning from being part of a collective. Being able to have a valued social identity is associated with this positive interpretation of living with dementia. Louis represents people with dementia in positive terms, as people who are sincere, only having good words to say, and

only helping if they can. In this quote Louis interprets belonging to this group as positive, and reframes other people as having something wrong with them:

I've never met so much loving people (pause) loving in respect of the people who've got the diagnosis of dementia (pause) because they've got to support and help one another (pause) [My friend's] favourite quote is: 'I used to think I was daft. Until I joined [the group], and now it's everyone else is daft, you know'.

Rather than emphasising his sense of self as unchanging, Louis frames his self as changed by dementia, but in a way that is affirming due to the positive qualities he attaches to other people who have the condition. Being part of a group of people with dementia brings new meaning to Louis's life. Like Martha, Louis focuses on being seen as a person, rather than focusing on the disease, which he believes can happen due to the social stigma surrounding dementia. This is described in response to a question that paraphrases an earlier comment that he made:

[And what do you think that's all about, people speaking down to you when you've got dementia?]

It's not a matter of speaking down to you (pause) they don't realise you're a person (pause) you're not a disease (pause) you're a person with a disease (pause) a lot of folk don't realise there's still a certain amount of stigma out there (pause) although it's getting highlighted more and more (pause) there is still a lot of certain stigma.

While Louis recounts personal struggles associated with dementia like the other older people with dementia in the study, he reconciles these difficulties as a prejudice inherent in other people. Despite denying having personal experience of discrimination, Louis relates examples of how he retaliates if people are awkward or rude in public to him. Resisting social stigma is a recurring feature of his narratives. For instance, Louis recounts a story of dealing with stigma, and compares the responses of those who do not understand, with people who treat him with compassion and understanding of his difficulties. Louis is locating the problem with the other person, who does not understand



his difficulties, rather than within himself. Moreover, rather than focusing like Martha on how he can manage his appearance to deal with these challenges, Louis focuses on changing other people's prejudicial attitudes towards dementia. Louis is resisting discrimination by explaining that, while social stigma is present, he does not allow it to affect him.

This rejection of discrimination at the personal level suggests that Louis understands the challenges of dementia as a wider social problem. Therefore, rather than focusing on a personal struggle to assert his status as a normal person, Louis focuses on the need for collective action to reject the stigma associated with dementia. This interpretation is suggested in Louis's narrative about an incident when he was part of a group that challenged a magazine for publishing what he describes as a "ridiculous portrayal" of a man with dementia. Like Martha, Louis is resisting the threat to identity posed by the stigma of dementia. However, rather than focusing resistance at the personal level, he is finding meaning by fighting a wider cause for people with dementia as a group, and identifying positively with this group of people with dementia, rather than rejecting the status of having dementia.

The overall pattern of Louis's account is about moving forward, initially in his own personal life to manage his condition medically, as well as in wider social terms as part of a collective group of people with dementia. Whereas Ted is struggling to make sense of his current situation, and describes himself as faltering in the past, Louis is describing how he can live positively in his present life and look forward to the future. Rather than focusing upon broken connections with his past life as a working man, Louis is focusing upon new connections in his collective work with other people with dementia, and being able to have an active role in this context. Having a future is made possible by the emphasis on living with dementia, and the affirming associations of being part of a collective group of people with positive attributes. Unlike Ted, who no longer feels involved, Louis feels

engaged with a new group of people with whom he can identify. He has moved on from his past to find new meaning in the present. As will be discussed further in chapter six, Louis's narrative entails a process of adjustment, which relates to assimilating dementia into his life in a way that enables him to construct his life as meaningful.

It should be noted that Louis's narratives are very different from the other people with dementia in this study. As has been noted above, Louis does not relate his dementia to ageing, and this is likely to be due to the early onset of his dementia, which was related to specific neurological events. Louis's narratives are well formed, and are likely to have been well rehearsed through his role in a mutual support group, making presentations about the impact of dementia on his life. It is important to note that Louis is in his sixties and so he is from a younger generation compared to the other people with dementia in this study who are in their eighties. His particular narrative may relate to different opportunities and services that he has been able to access as a relatively younger person with dementia. As will be discussed in chapters seven and eight, carers define older and younger people with dementia differently, and therefore it is likely that services for younger people will be set up differently. Louis may also have a different outlook, as he is part of the "baby boomer" generation, with different life experiences and different expectations from those born before the Second World War. It is a useful reminder that being older and having dementia is not necessarily a commonality.

## **Conclusion**

The accounts of five older people with dementia have been considered to explore the way that each person constructs their self and social identity in their descriptions of everyday life. A continuum of representations has established the varying ways that these older people compare the past with the present, to interpret and evaluate their experiences of ageing and living with dementia. Whereas Cynthia and Ted define themselves in terms of what they have lost from the past, Martha defines herself in terms of being the same as

before, albeit within a more limited social context than in the past, while Rena and Louis redefine their sense of self and social identity within the respective contexts of ageing and dementia. These differences in definition appear to be reflected in the narrative structure of their accounts; the narratives of Cynthia, Ted and Martha are more lyrical, repetitive and full of metaphor, reflecting their struggle to find meaning, while the accounts of Rena and Louis are more linear and straightforward to read. Although their stories are different in terms of the details of their lives, their narratives share a common feature in the way that they represent their self and social identity relative to their social position in society. All the older people in this study strive to represent themselves in ways that emphasise their status as ordinary human beings who continue to have a valued place in the social world. The extent to which each individual can continue to represent themselves as an ordinary person is significant for how they make sense of their changing situation relative to ageing and dementia.

Constructions of self and social identity are related to valued social roles in the community, especially paid and voluntary work for those people who were involved in work outside the home, and care-giving and home-making for those who worked at home to support their family. For instance, Martha's perspective of retaining an important role in her family can be contrasted with Cynthia, who no longer feels able to contribute due to her marginalised social position as an older woman. While Rena can make sense of her place in her family and community relative to understandings of generational exchange, Martha can only construct a valued social status within the context of home and homely environments, due to her concern for her status being diminished within the wider community. While recognising the importance of family relationships, Ted and Louis place greater emphasis upon their social roles outside the family. While Ted describes the struggle to stay involved in his community, Louis has found new opportunities to engage with a new community and adopt a positive social identity. The relevance of continuity is

in being able to define self and social identity in ways that maintain a person's sense of status in the social world.

The extent to which older people with dementia define themselves in ways that reflect their desired social status influences the temporal focus within their narratives. Cynthia and Ted focus on maintaining associations with the past, and so their struggle to maintain a sense of normality is represented in metaphoric descriptions of how their social position has changed from the past. Martha similarly strives to maintain important connections from the past, and while she is able to represent her valued social status within the home and among other people with dementia, she struggles to reconcile her sense of self with being perceived as abnormal by people in the wider community. Rena and Louis can continue to make sense of their situations in ways that uphold their sense of being ordinary people involved in the wider social world. While making connections with the past in terms of continuity in important values and relationships, Rena focuses on the present and the way that she can interpret her changed position in a way that does not undermine her social status. Louis focuses on new associations that afford a changed but positive social status, and so an important feature of his narratives is looking forward to the future. The different accounts can be contrasted in terms of whether a person can look forwards in their narratives, which is associated with whether they perceive themselves as retaining a valued place in the social world, or whether they view their social status as diminished.

Despite having differing perspectives on the impact of ageing and dementia on their lives, each person is representing how they are trying to be the same as before in terms of being an ordinary or normal person. For the purposes of analysis accounts have therefore been represented within overarching themes of positive or negative constructions of being an older person with dementia. All the accounts reflect a struggle at some level to reconcile ageing and dementia with a person's enduring or evolving sense of self and social identity.

However, Louis's evaluation of "getting over it and getting on with it", as he constructs a new and valued identity as part of a group of people with dementia, is more positive than Cynthia's evaluation of "being over the hill and finished up", as she struggles to make sense of her diminished social status. Nevertheless, these narrative constructions are not absolute. There are moments when Cynthia's narratives reflect positively on her capabilities, such as her ability to still dance and move, while there are times when Louis reflects on the loss of important social roles, such as owning his business. Therefore, while people's accounts are fluid rather than fixed, they can be viewed in terms of general storylines that reflect a particular perspective on their situation in life.

## **Chapter Six**

# **Perspectives on the quality of an ordinary life in the narratives of older people with dementia**

### **Introduction**

In chapter five I explored the ways that older people with dementia construct their self and social identity to make sense of their experiences relative to ageing and dementia. In chapter six I reflect on the ways that these narrative constructions of self and social identity relate to different evaluations of living with dementia. The creative process of meaning-making involves images and metaphors of movement as people describe their attempts to engage actively within the social world. This movement reflects the momentum and energy involved in maintaining an ordinary life in a society that largely stigmatises being older and having dementia. The analysis will demonstrate that, even when life is viewed negatively, all the older people with dementia in this study describe active strategies as they respond to challenges to their perceived sense of self and social identity. Responding to these challenges involves personal strategies to maintain involvement in everyday life, as well as engaging the support of significant others to help them sustain important connections and associations. It is evident that the way each person makes sense of their self and social identity has implications for the extent to which they can find meaning in life. In this way, quality of life is about being able to realise a preferred sense of self and social identity to maintain involvement in everyday life.

Adopting the same scheme as in the previous chapter, the overarching theme of a person's approach to life is summarised in the section headings below. Cynthia describes trying to keep moving and working to stay involved in valued social activities, and Ted similarly represents trying to keep the movement in thought and action. Their approaches to

keeping mentally and socially involved in everyday life reflect their sense of being less involved in the present compared to the past, and having to work hard to maintain valued connections and capacities. Martha's approach of moving and working to maintain normality reflects her preoccupation with maintaining her reputation and keeping the appearance of being normal despite having dementia. The resulting strategy is to withdraw from outside social situations that challenge her sense of being normal to find meaning in the context of home. Rena's focus is on being contented with her current situation now that her life has changed, and this contentment involves continuing to be socially engaged with her family and friends. With a focus on finding new meaning in life, Louis describes living with dementia as continuing to live a normal life, and he represents the potential to look towards the future in continuing to find meaning in his life.

### **Cynthia: 'trying to keep moving and working'**

Having "a good life" is described by Cynthia as having "worked for it". This is similar to Rena's evaluation of her current position. However, while Rena represents her changed situation in a positive manner, Cynthia represents her changing life in a negative way. Cynthia believes she is being stopped from doing things by others, but she does not want to stop working at things she enjoys and give her life meaning. There is an implicit suggestion in many of Cynthia's narratives that she can resist her situation through activity, that she will keep doing things despite other people trying to stop her. Cynthia's narratives are full of activity statements alongside her description of memory problems, suggesting that she is trying to focus on her capabilities in dealing with her difficulties in life. Cynthia is responding to the perceived challenges in her life by keeping herself moving. By focusing on what she can do physically, for instance walking, Cynthia is attempting to resist others' evaluation of her restricted capabilities. Cynthia presents herself throughout her narratives as someone who in a practical sense is still active and capable.

In the following narrative, Cynthia describes this tension between being physically able to do things, but being prevented from doing so by others. The good times, when she was “a lucky person”, are located in the past and compared with the present:

***Narrative: I've been a lucky person to be able to do things***

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***Stanza 1 (Abstract: I'm lucky to be able to do things at my age)***

I'm lucky at eighty-odds, to be able to do things

[Yes. What kind of things do you do?]

***Stanza 2 (Orientation: I'm getting too old to do things)***

Well, I used to go to the dancing

I went to dancing

[My daughter] goes to line dancing now

This is a new thing

that I've never been at

I say, I'd better not go

I'm getting too old, for these kind of things

***Stanza 3 (Complicating action: I can do things but my daughter gets angry)***

But I think I could do it

But, no, I can walk the roads a bit ...

And [my daughter] gets angry at me

for, she thinks I'm, getting away too much

I go up to (pause) where am I? [loses track of what saying]

***Stanza 4 (I've a younger sister who never goes out)***

I've a sister who lives at [town]

And she's younger than me



And I go up and see her

but, she's never out the door

[My daughter] goes

and does things for her too

***Stanza 5 (Evaluation: my daughter does my work but I don't need her to do this)***

But I, I don't need anybody to do my work

[My daughter] will do things for me

But I can still (pause)

And she gives me a row when I start to do windows

She says, "Mother, stop doing that!"

I think she thinks (pause) because (pause) I'm old

***Stanza 6 (Resolution: I finished up working but I'm still able to work)***

I started (smiling as looks at memento from work)

I finished up working at [workplace]

I worked at [workplace]

And I came to [town of work] (pause)

Now, that's a long time ago

That was me finished working

***Stanza 7 (Coda: I've been a lucky person)***

And I'm still working yet

to a certain extent

So, I've been a lucky person

Within this narrative, Cynthia links the past with being actively involved in activities she enjoyed such as dancing. Being older is linked to a lack of involvement in such activities.

This narrative illustrates how Cynthia evaluates her life in terms of the extent to which she can do things, which she relates to what others allow her to do, rather than to her ability to do things. Being and doing are therefore connected, as being a lucky person is related to being able to do things. However, this connection is perceived to be broken due to the restrictions that are imposed by others on what Cynthia is allowed to do. The contradiction of being physically able to do things but not being allowed to do them is a difficult challenge for Cynthia to reconcile. Yet, the narrative concludes with a description of the present, in which Cynthia describes being lucky to “still” be working “to a certain extent”. Cynthia’s evaluation is not absolute and she is resisting being defined as totally finished up. Her sense of self is still strong despite her restricted social circumstances.

Being capable but restricted is therefore one of the dominant themes in Cynthia’s narratives, and consequently one of the main purposes of her narratives seems to be her resistance to being perceived as unproductive or dependent. By constructing herself in an active way, Cynthia is trying to resist the limitations and constraints that she believes others impose on her. Cynthia repeatedly tells me that she can do things, but that she gets into trouble for doing them. Cynthia wants to be walking, but tells me that people think she is “off her head” to want to do this. She explains: “And they don’t realise that I’m capable”. Cynthia demonstrated how she was still able to walk by announcing one day that she was taking me for a walk, so she could prove to me that she was still capable: “I’ve not to go out myself, so they say. You’ll know if I’m able to do it or not. You know how much I can walk if I want”. With great frustration, Cynthia explains how others restrict her freedom and disapprove of her walking, which she perceives as them treating her as if she is stupid, and contrasts with the ease with which she can do this activity: “And it’s so easy to go for a walk. And I get a row when I go for a walk. I think they think (pause) I’ll say, ‘I know, I’m getting on in years, but I’m not stupid’”. Therefore, the contradiction in Cynthia’s life is in being unable to achieve what she believes she is capable of doing, and so her narratives are generally imbued with disappointment and sadness.

While Cynthia sometimes resists understanding her life as completely restricted, at other times there is a sense of resignation to her situation, and Cynthia talks about having to accept change and learn to deal with her changed position. Having to “live with it” is how Cynthia evaluates her current situation. Cynthia reasons that a lack of freedom relates to being older, and she compares her situation of sitting in the house with her daughter who goes out: “[My daughter] can go different places. She’s younger. And, eh, well, I say, I’ve had my life. But see, I just sit in the house, because I’m eighty odds.” Cynthia also comments on not having anybody her age, and describes having to sit and wait for visitors in order to fill her time. Related to a dislike for where she lives is her sense of social isolation from her neighbours, who she describes as unfriendly and avoiding her. Cynthia feels marginalised within her family and from the wider community. Sitting is described as “hellish”, in terms of being physically inactive, as well as being socially isolated.

Despite framing her life as having to sit around, Cynthia compares herself favourably to people who sit about and do nothing. She constructs herself as fit and active, as someone who likes to get out to try and move, and contrasts herself with others of her generation who have let themselves go or who “just sit”. This comparison reveals the contradiction that despite having to sit about, Cynthia does not define herself as somebody who sits about and does nothing. A good day is described by Cynthia as feeling like walking, putting her shoes on, and going for a walk, which reveals how activity and freedom are central to her life. Yet nearly all of Cynthia’s descriptions of her current situation are described in terms of how her life is curtailed, how she wants to go walking but she is not allowed to go out. Cynthia’s evaluation of her life is that: “I’m wanting to do something, and I know I can’t. And I’ve just got to sit”. Therefore, despite a positive construction of her personal capabilities, Cynthia is not happy with her life due to her lack of involvement, and on a number of occasions she tells me she has lived too long.

When asked explicitly about her quality of life, Cynthia comments on how her life has changed after recounting the jobs she used to have. Cynthia's work has finished, and consequently her valued role as 'a worker' is no longer available. Cynthia wants to be a productive worker and contributing family member, yet her work has finished and she is now the one being taken care of by her daughter. This reversal of roles creates problems for Cynthia's ability to evaluate her life positively, as she is no longer able to find a valued place in work or in her family. After reflecting on her grandchildren growing-up, Cynthia's last comment on tape sums up the sense of change in her life: "Och aye, life just changes very quickly". This notion of life changing is reflected in comments about how the town where she lived has changed, and how she has become fed up with the town. However, despite the negative evaluation of change, Cynthia describes how "I just sort of keep my life going, back and forward". This description represents the sense of movement and continuity that Cynthia is trying to achieve in her life. The central theme of keeping moving or involved reflects Cynthia's focus on how she "loved to be working".

In responding to the challenge of no longer being framed as "a worker", Cynthia finds opportunities where she can to construct herself as continuing to contribute and be active. In the context of the day care centre that she attends, Cynthia focuses on being able to work, help and dance. Supporting others is a recurring feature of Cynthia's description of her time spent at this centre. Cynthia avoids representing herself as a service 'user' and instead positions herself as someone who works there. She describes "helping out", "doing what's needed" and that she likes to be "doing a good job". This sense of activity and productivity gives Cynthia a sense of meaning and purpose that reflects her sense of self and social identity as a worker. This evaluation of helping out at the day care centre is linked by Cynthia to what she did in the past, and what she would ideally be doing in terms of going walking. Cynthia is essentially telling me how she finds meaning in her life by using an opportunity to feel useful in a pragmatic way. She may be restricted in terms

of not being allowed to walk, which as indicated earlier was her idea of a good day, so she makes use of the opportunity to keep moving.

The accomplishment of activities that represent Cynthia's sense of self is represented in a narrative where Cynthia expresses delight at finding a rare opportunity to dance at the day care centre. She tells me how she has danced all her life, and how she used to "get" dancing. The use of 'get' highlights the way others are implicated in this activity, in influencing whether or not she can take part. There is an emphasis on continuity in her desires and wishes, of wanting to dance, but a disruption in what she can actually achieve, which is framed relative to what she is allowed to do by others. The suggestion of different perspectives between herself and other people is indicated in her description of how others were laughing at her dancing, and how she could not wait to tell her daughter that she was dancing, as if her capability of dancing was a surprise to them. At this point in her narrative, Cynthia brings in the theme of learning to be confident to dance again. While she describes memory problems being something that was difficult for her in the past – she lost her memory, but got it back - Cynthia needs to have confidence in the present primarily because of the way she believes she is framed by others.

Cynthia believes she has been a lucky person to be able to do things, to keep going, to move, to walk, to be agile. Being a lucky person is therefore framed in the past tense while references to what she can do are framed in the present. Despite being concerned with activities having stopped, movement features heavily in Cynthia's narratives: "As long as I get moving, that's all I want". Cynthia tells me how she would "go melancholy" if she was sitting doing nothing and feels lucky that she can move. Cynthia is trying to maintain momentum in her life, despite all the changes to her circumstances. This is evident in Cynthia's descriptions of attending the day care centre. Whereas Rena describes attending a centre as a social opportunity to meet her contemporaries, Cynthia frames it as a place to make a contribution and feel useful. Even though the desired outcome of attending a

day care centre is different for these two women, what makes each of them feel good is continuing to be associated with people and places in ways that represent their sense of self and social identity.

### **Ted: 'keeping the movement in thought and action'**

Ted's perspective on life is that he is no longer actively involved in doing things; instead, he is focused on observing what is going on around him. Despite a general sense of not being involved in current activities, Ted finds opportunities when they arise to feel as if he is contributing, and describes his role in supporting people with dementia in a mutual support group. Ted evaluates dementia as problematic for his life, and identifies the need for solutions at both a personal and social level. Ted describes how dealing with dementia involves processes of trying to remember and retain information, as well as the importance of the actions of others, who can support people with dementia to give them confidence in their abilities. Therefore, while Ted believes the best part of his life is in the past, he represents the potential for his life to be improved with the support of other people to help him manage dementia.

Similarly to Cynthia, the concept of movement is a feature that permeates Ted's narratives. At one point he discusses the possibility of "creating speed and making things happen", which he links to having confidence. Ted is speaking about his life being "controlled" by the speed within him. This suggests that Ted is referring to how his dementia slows him down, and consequently affects what he can do and how he interacts with others. While Cynthia understands her restricted situation being caused by others preventing her from doing things, in other words external constraints, Ted considers his constraints to be inner ones caused by cognitive impairment. For Ted, being involved in a situation entails a creative process, and so being an ordinary person involves having the ability to create one's own experiences. He compares this creativity to the situation where a person is being controlled.

Dementia is significantly affecting Ted's confidence in himself and in his ability to do things. In a metaphorical narrative about getting birds to have confidence to come to a feeder box while a human being is around, Ted describes the importance of other people having patience and instilling confidence, for a person to overcome the obstacle of their natural wariness about being approached. Ted suggests that families become used to the awkwardness of their relative with dementia not being clear in what they are saying or doing. He compares this with strangers who are not used to dealing with the unusual things that people with dementia do, which Ted describes as not normal. Ted then tells me the importance of being amongst a community which can understand people becoming confused. This highlights the relationship between the ways that other people treat him in his everyday life and his ability to have confidence.

Ted describes his need to have confidence through the help of those around him. Keeping the movement in thought and action, through involving and supporting a person, is how Ted thinks a nurse should help someone with dementia. He describes the attitude of carers being fundamental to this support, and Ted compares it to the way an adult looks after a child, like a mother-figure, while nevertheless emphasising that people with dementia should not be treated as children. This evaluation reflects the balance of needing support but still being perceived as a capable adult, and Ted refers to the possibility of feeling trapped if this balance is not right. From Ted's perspective, having support and assistance from a patient person can enable a person, but it also has the potential to curtail freedom and obstruct the person. Metaphor is used to describe how others can help him and others like him with cognitive limitations, but Ted also highlights how others can obstruct and restrict a person's freedom. Ted's narratives therefore represent the potential for others to either support or limit him.

Ted relates the idea of "keeping the movement" to the way that a family can help a person to feel "involved" within familiar surroundings. He relates a story of a relative who "kept

her sanity” by being looked after this way. Ted also relates a story about how he was involved with volunteer work visiting patients at a local hospital when he was a young man. He concludes this narrative by arguing about how he realised that people who were not capable of taking things in on their own, were capable of understanding if someone was there to help them. Ted stresses the need for a balance between not making activities too complicated, while not making things so simplistic as to be demeaning to the person. Ted is stressing the need for support to enhance his ability to achieve what he wants to do in his life. He can keep going if he receives the right type of support from others who are nurturing and caring without treating him like a child.

Having confidence is what Ted believes is essential to his quality of life, and this is related to others supporting him to have this self-confidence. In the following narrative, Ted alternates stanzas about himself and other people, representing the relationship between the two in building confidence in his abilities:

***Narrative: being perceived as an adult and being able to do things depends on other people recognising me and what I can do***

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***Stanza 1 (Me: it's difficult to look back and believe I could do certain things)***

Aye, flying an aeroplane

Quite low down

And (pause) you look back on it

You say, I didn't do that, you know (laughing)

I didn't do that (laughs)

***Stanza 2 (Others: other adults can give me confidence in what I can do)***

And, eh (pause)

You've got adults round about

Who give you confidence



in what you can do (long pause)

I just forgot it (laughs)

***Stanza 3 (Me: I have to imagine that I can do things)***

It's a case of (long pause)

if you could think

See the view that you've got out there, with the flowers

If you could imagine

you're in an area

close to that

***Stanza 4 (Others: my limitations have consequences for other people)***

And you're controlled

with the speed, that you have

and what you can do in that area

otherwise you would be creating hell

for everybody else round about

***Stanza 5 (Me: I wonder how I was able to do certain things)***

No, the thing was

when I looked back myself

on certain things

I wonder how I was able

to do certain things

***Stanza 6 (Us: we can all do things if we have confidence)***

And then I realise

that you or I, can do a variety of things

if we've got confidence

if what you're doing (pause)

is limited in, what the outcome is

Aye, you're doing things

that you know, have I seen?

***Stanza 7 (Others: people need to see my actions for them to be noticed)***

But the point

if these things were done

without a human-being being there

they'd never be noticed

***Stanza 8 (Us: being with another person makes things possible)***

If they're done with a human being there

the human being is actually creating speed

that the thing has happened in

therefore they can be accepted

by another human being

that's being possible

Ted associates confidence with having courage and being capable. This links back to the importance of narratives of his earlier involvement in paid and voluntary work in which he describes himself as a courageous and successful campaigner. Like the other older people with dementia in this study, Ted links being with doing. Ted is describing the social construction of identity in terms of only being a person if others recognise him as actively being involved. Feelings of being capable in the present are tied to his ability and confidence in singing, which allows him to be articulate, creative and expressive in a way that he finds difficult in conversation. Singing enables Ted to "keep in this world" and by

so doing this brings him back to feeling involved in the present. This was reflected in our conversations, when Ted sometimes became confused with what he was saying, so then used song to get his point across to me. While Ted's narratives tell of the times that he was physically involved as a younger person, he now focuses on the importance of being "mentally involved" in the world around him to maintain his social connections.

Ted believes that people with dementia need to be kept involved both mentally and socially to avoid becoming "lost". This situation of being lost because of dementia is also associated with being "not normal". On one occasion, Ted wondered aloud how he was able to achieve many of the things that he did in the past, and he asked me whether I could ever imagine him doing these things. He then went on to tell me how anyone – "you or I" – can do a variety of things if they have confidence. Having confidence is therefore related to being engaged in everyday life as an ordinary person. With his emphasis on the possibility of others engendering understanding and confidence, there is hope within Ted's story. While he is "faltering" in the past, Ted has not yet completely faltered. There is the potential for his situation to improve, although this is dependent on the reactions of other people who can either help or hinder him. Whereas Cynthia perceives her life as "finished up", Ted's life is only "faltering", and his life still has worth if he can keep the momentum of being involved in the present.

### **Martha: 'moving and working to maintain normality'**

Martha emphasises the importance of keeping normal by keeping her appearance, which she understands as acting normally rather than acting as if she is stupid. Martha uses metaphor in a story about people losing money to illustrate how a person's social status can be affected if they let themselves go below a certain level. By keeping the appearance of not having dementia, Martha may either be trying to resist the associated social stigma, or creating a defence mechanism to protect her from being abnormal in her own eyes. Martha's resolution to her predicament is to keep within the home and focus on working

there alongside her sister. Martha stresses how she and her sister are always together and that they “work into one another’s hands”. She explains that she and her sister “manage well” and that they do not need other people. The importance of continuity in the relationship is emphasised, as Martha explains that they are always together and that they always did go together. It is significant that the capacity to manage well is framed within their ability to do normal things together. Therefore, keeping normal by doing normal things is how Martha contextualises her life within the home.

Martha attempts to maintain her normality by constructing a social environment that enables her to engage mentally and socially in ways that support her sense of self as an ordinary person. Martha describes the value of “homely” environments: namely her own home, her sister’s home and day care settings that provide support for other people with dementia. Attending services for people with dementia helps Martha to achieve a sense of normality, as she describes how the people at day care are “just ordinary people”, “treat her like family”, and “work away in with her”. She talks about the different people going to the centre as “all in the same boat”. As has been described before, Martha uses the metaphor of having and losing money to represent the change in social status that arises from having dementia. In referring to other people with dementia, she describes how “irrespective of money, they are all persons”. This sense of commonality in status is important to Martha.

Martha is seeking a social space that is comfortable for her. She describes mixing with people, but not getting too friendly, because she has seen too many people hurt. Suspicion and distrust feature heavily in Martha’s accounts. “Keeping it inside the family” is a phrase that Martha uses on several occasions. This is contrasted with existing social groups and associations that she has “fallen away” or “drifted away” from. She describes these groups as becoming too big and serious, rather than being intimate and “homely” like they were in the past. For example, bingo is described as becoming “overpowered”, which may

represent the way that Martha feels in large or unfamiliar groups of people due to her memory difficulties. She describes being “alright if I’m in company where someone can keep the conversation going”, and being able to join a group if there are not too many people there. This evaluation suggests that outside activities and events may have become too overwhelming for Martha, and keeping things “homely” is a coping strategy.

Instead of being involved with outside activities, Martha describes how she “got into her house” since developing memory problems. In framing her life around the home, Martha focuses on the importance of the relationship with her sister, to the exclusion of outsiders. From Martha’s perspective, it is important “not to bring in people” due to the dangers of neighbourhood gossip. Martha warns against outside involvement as she narrates a story from her sister’s childhood, when Martha told her: “if there’s anything private you want to know, ask me, don’t ask an [out]sider”. There is a related concern with “nosy” people and giving out too much information. Therefore, keeping things inside the family is perceived as the best strategy, and this continuing philosophy is apparent from the way that Martha has gradually withdrawn from outside activities to concentrate on her home life, with the exception of the “homely” day care centre in which she feels safe and valued. Martha is able to define her life as having value and worth within the context of home, and so she seeks to avoid bringing other people into her home due to the perceived threat of gossip.

The reliance on her sister is related in part to a feeling of rejection by others due to the stigma of dementia. Telling me about an exchange with her sister, who Martha describes as experiencing prejudice due to her physical disability, Martha asks: “How does it feel getting rejected?”, to which her sister replies: “Ah well, that’s right, we have our own ways”. Responding to other people’s reactions to her condition occupies a significant part of Martha’s narratives. Often Martha uses examples of other people experiencing stigma and oppression. Occasionally she describes her own experience directly in terms of the way people shun you as if “it” (dementia) was an infection. Martha describes “snubbing”

people if they make an issue out of her forgetfulness, and she follows this comment by saying she does not mix a lot. These comments link the social stigma of dementia with Martha's strategy of withdrawing from wider social life. In response to a question about what makes her feel happy in her life, Martha replies: "keeping going and not letting people annoy me". Martha is keeping busy within the home to maintain her normality and resist the spoiled identity of dementia. To keep going equates to maintaining an ordinary life by removing threats to her sense of self and social identity.

In the following narrative Martha explains the strategy for withdrawing from wider social life to maintain a sense of normality, using her sister as an example:

***Narrative: I don't like mixing because people say stupid things***

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***Stanza 1 (Abstract: the embarrassment of social stigma)***

But she was a wee bit kind of embarrassed

going out with it

at the beginning with it

Because you get a lot of people saying, "Oh!"

You get a lot of people that can be very catty

***Stanza 2 (Orientation: I don't like going out)***

Because if they see [my sister] maybe walking and, eh (pause)

She likes going to a club

where I don't go to these things

but [my sister] likes going

***Stanza 3 (Complicating action: people are stupid)***

And she has her own company that she goes with

I mean they'll say, "Aye, she can go out and enjoy herself"

But I says, "That's nothing to do with her legs"

People are so stupid at times

they don't stop to think

***Stanza 4 (anybody could be disabled)***

And I mind one day

I had said to this person

I says, "Look! You're not off the face of the earth

You don't know

You could go to the end of that street

and be knocked down and made a cripple"

I says, "Use that (pointing to head)

before opening your mouth"

***Stanza 5 (people should think before they speak)***

So after that, she says (pause) eh

"It's right what you say doing this"

I says, "Yeah, you should always stop

to think before you speak"

So that was it

we never fell out

or anything like that, you know?

***Stanza 6 (Evaluation: I've got no time for these kind of people)***

But just (pause)

some folk they think because they're whole and hearty

that nothing can happen to them

And then when they do take an illness or a wee cough

they're looking for everybody to look after them

You see?

They're that thick

And that's how I've got no time for these kind of people

***Stanza 7 (Resolution: I avoid gossip and get on with my own business)***

I get on with my own business

I see to my sister and that

I'm not one for people running in and out of my house

I speak to, I've got good neighbours and that

But I'm not one for (pause) because there's too many carry-stories

***Stanza 8 (Coda: I don't mix with other people)***

So I don't bother

I speak to them

and I go shopping and that,

but I'm not one for sitting in other people's houses

In coping with her condition, Martha likes to “keep on the move”, referring to how she does not “brood over “it”. Martha emphasises how she does not “sit down to it”, but keeps doing things when she forgets. There is an association between being active in body and active in mind. Martha has got a routine that helps her when she forgets, which is going and doing something else until she remembers, and then going back to finish what she had originally been doing. Martha explains that she is content if she can keep going and keep her mind ticking over. She says that so far she has not “gone astray”, which suggests that this is a primary concern. She also uses humour as part of this strategy, and describes how “working it off herself” enables her to laugh rather than cry about her situation. She also



explains that she feels less upset if she forgets something in the home, as she knows that she will eventually come upon it again. Just as keeping things homely is a coping strategy to deal with perceived threats to her reputation, so being at home provides a secure environment in which Martha can cope with her memory problems. Home is therefore a sanctuary in which to deal with the challenges of cognitive impairment.

Like Cynthia and Ted, activity is a solution to Martha's memory problems. Martha explains that the "worst thing you can do is sit down and let a thing beat you". Martha deals with forgetting by "working it off me", and she describes how she "doesn't sit down to it". Martha emphasises her own motivation to work compared to those who "sit back". Sitting is evaluated negatively and Martha describes resting as "an illness". Martha connects sitting with being socially isolated and her mind drifting. Activity is therefore connected with keeping engaged socially and mentally, which is evident in Martha's evaluation that by attending the day care centre she does not have time to sit. Similarly, undertaking everyday activities like shopping and cleaning are used in Martha's narratives to establish that she is an active person. Being on the move is linked to Martha's sense of self: "that's just me". This description is framed with the context of being the same as before, as Martha tells me that she has always been on the move, no matter her age. Keeping moving is therefore linked to being an ordinary person and so maintaining an ordinary life.

Sitting is also evaluated negatively in terms of creating the opportunity for gossip. Martha's concern about social stigma is reflected in a narrative about how she does not like people coming in and out of her house. She talks about "not being one for sitting", as this suggests that a person does not have anything to do, and so fills their time with gossip. Martha distinguishes enjoying company from having her house used as "a sitting place" or "for collaborating". Instead, she describes how she "gets on with her own business" and helps her sister, who she believes is depressed and needs to be motivated to keep busy. Martha likes to "keep check" on her sister if there is anybody visiting. This

sense of “keeping watching” means that Martha is always alert for people threatening her reputation. When walking outside, Martha comments on how she walks beside her sister and “keeps moving”, to avoid her sister gossiping and giving information to other people. Martha claims to have too much to do, with no time for gossiping, so she just walks away. In addition to dealing with cognitive impairment, keeping moving is a strategy to resist threats to her reputation. Martha has metaphorically and literally moved into her home to avoid the risks of social stigma.

Keeping normal is fundamental in maintaining Martha’s quality of life. The narrative construction of ‘being’ and ‘doing’ are linked in Martha’s narratives about being a normal person, as she relates the importance of doing normal things to keeping normal. The project of keeping normal is an active accomplishment of involvement in normal activities that maintain Martha’s sense of self and social identity. While dealing with social stigma is tied to maintaining appearance and social status, Martha’s narratives about dealing with cognitive impairment are tied to activity and routines. Both types of action are framed within the social context of home, as a place where Martha can maintain ordinary social roles and relationships, and as a space where she can safely manage her memory difficulties without fear of stigma. While Martha achieves a sense of being “the same” in narratives about her home life and “homely” environments, this is not something that she realises in narratives about the wider social world. With the potential threat of social stigma, Martha now constructs outsiders and outside environments as threatening, and instead constructs her life as meaningful within the context of home. By withdrawing from the wider social world, and finding meaning within the context of homely environments, Martha is able to keep going in her attempts to maintain an ordinary life.

### **Rena: ‘being happy and comfortable just sitting’**

Rena describes herself as someone who is “just sitting”. Although sitting is evaluated by Cynthia and Martha as something to be resisted, Rena evaluates sitting as acceptable. The

main change in Rena's situation is related to physical activity, which does not impinge on her continuing sense of self. Like Cynthia, Rena compares herself to younger women in her family who now do the things she used to do. However, Rena is content to accept that she is at a different stage of life, which does not require the same level of physical activity as was required when younger. She describes being "past that stage", but this is not evaluated negatively, instead less activity is interpreted as appropriate to her stage of life. Similarly, whereas sitting is constructed negatively by Cynthia, Ted and Martha as a representation of their lack of involvement in the social world, sitting is constructed by Rena as something appropriate to her life stage that for the most part does not affect her engagement with others. Rena describes a change in perspective now she is older. However, unlike Ted's interpretation of his changed perspective as limited and limiting, Rena's viewpoint is that she can "sit and watch" and therefore still be involved. A change in situation is therefore incorporated into Rena's view of the ordinary life course, and there is no sense that her perspective is limited as a result of this change

Rena has limited mobility and she describes how "I make myself comfortable when I'm sitting so much". Her use of the active construction of "sitting" is related to activities associated with sitting, which are also described in the active tense, for instance "looking all round about me". Rena gives purpose to her situation of "just sitting" by explaining that she can read and talk to people. Sitting is constructed as something positive, such as when Rena describes the opportunity to go out to a day care centre to sit with others and have company. She tells me she can "sit with them", "sit and play" social games, and because she can "sit and watch" she explains that she is "never weary". Rena is able to use sitting as an opportunity for social engagement. Sitting is also constructed as something that other people do, so Rena is framing her sitting as ordinary: "We just sit and enjoy that". This contentment with her present life is represented in the way that Rena distinguishes herself from those who are depressed. She talks about how she is happy and not depressed because she can sit and read the paper and know what's going on. Rena has

mobility problems, but her lack of physical activity is not presented as an issue. There is a sense of contentment and acceptability of sitting as part of being engaged in everyday life. Rena's contentment is indicated in the following narrative where she evaluates just sitting. I start this narrative by asking Rena how she usually spends her time:

***Narrative: I'm happy just sitting***

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***Stanza 1 (Abstract: how I spend my time)***

[Can you talk about how you usually spend your time?]

***Stanza 2 (Orientation: I'm sitting here looking around)***

Well, I mean, I'm in here [nursing home on respite break]

I'm just sitting

looking all round about me, y'know

***Stanza 3 (Complicating action: I'm not able to walk about)***

And when I'm at home, I don't do anything

because I'm not able to walk

I mean, in my home I can't walk about

***Stanza 4 (people come in and do my work)***

There's always somebody comes in

and makes, and does anything

well does my work

***Stanza 5 (people bring me my meals)***

And then she, eh, sorry, I don't

I get meals on wheels

and I enjoy them

***Stanza 6 (people take me out)***

And when I'm in the house  
they take me to the [day care centre]  
And I go up there and I get a meal  
And I pay for the afternoon

***Stanza 7 (Evaluation: I'm never fed up)***

Yes, I'm never wearied  
I mean some folk don't want to do these kind of things  
but I'm not sitting in the house when I can be up there

***Stanza 8 (Resolution: I enjoy myself)***

I enjoy (pause)  
and, I mean, when the weather's not good  
I can play cards and everything  
and bingo, and things like that

***Stanza 9 (Coda: I enjoy my life)***

Oh aye, I enjoy it

What matters most to Rena is going out to be in company, and she is happy to rely on others for support to do this. Being in the house alone is associated with a certain level of monotony, but this is countered with having support to be taken out to mix with other people. Despite talking about "sitting here", Rena says: "I'm not kept in, I'm always out". Rena expresses satisfaction with this situation. She also refers to her regular involvement with her family, and describes being happy that they are always "out and in". There is no sense of restricted social engagement in Rena's accounts. For Rena, physical activity and physical work is less important than keeping socially involved. This is related to a different stage of her life: "I've seen the day when I had to run here, there and everywhere, but I'm past that stage". Social involvement is therefore distinguished from physical

activity, and being sociable is an important aspect of Rena's involvement in everyday life. Because of her perception that she can stay socially involved while sitting, Rena is happy "just sitting".

Being socially involved is linked to Rena's sense of being capable. Without this, there is the risk of feeling or being perceived as stupid. Sitting can be active in terms of interacting with other people and this social aspect seems key to resisting being thought of as stupid. Rena comments on how some people would not like to go out to a day care centre and be brought food and drinks, but she says that these people will eventually be glad of being able to go. There is awareness of the sense of stigma in going to "a place like this", but Rena cautions that other people will be glad of the opportunity to get out when they are older. While there is a sense of confinement in the home, it is an acceptable situation that can be managed by relying on support from family and formal services to go out to meet other people. Rena explains that a person's means of getting about is what they "get used to". There is a sense of balance, that life is good enough if support is taken to overcome limitations such as mobility problems. She says there is no point "moaning and groaning".

Rena is happy to accept support from others, due to the way she interprets this support as an exchange across generations. She also depicts herself as someone who is still able to contribute to her family by giving pocket money to the children. Rena stresses the fact that she has been contributing to her family from early in life, and that she has worked hard and is deserving of her pension. Contributing is an important and enduring aspect of her identity: "I always give. I've always done it". In addition to this focus on continuity, Rena interprets family support as a normal part of ageing, especially when they have been helped by the older person earlier in their life. Rena is both emphasising continuity and dealing with change, by representing support as a part of reciprocal and ordinary family exchange. Paying for formal services is also talked about in a mutually beneficial way, as Rena asserts that the people she pays need the money. She has worked all her life, and the

implication is that she does not need to work anymore, as she has earned her dues. This can be contrasted with Martha and Cynthia who want to be working still. Rena feels she is at a different stage in life and is content to be receiving the rewards of her earlier working life.

While Rena distinguishes physical and social activity in terms of her engagement with the social world, she frames being able to stay at home as needing to accept practical support from other people. In order to stay in her house she needs help with cleaning and cooking but she is willing to accept this help. This is in contrast to Martha's and Cynthia's perspective of wanting to take care of their homes. This attitude may relate to previous social roles, as housekeeping was not an important part of Rena's earlier life, in the way it was for Martha and Cynthia. Rena is keeping her independence in terms of staying at home, by allowing others to support her in the things she cannot do physically in the house. Rena describes not having to "bother" with housework and day-to-day finances, which suggests a sense of relief. Similarly, while she is glad to have the financial independence of her own pension, she is happy to have someone else to look after it. Rena tells a story about how she was never interested or good at housework, and that she is not a house-proud person. She is framing her current situation in a way that suggests continuity with the past. Yet, the way she talks also reflects her view of her current stage in life being different from before. Rena focuses on being retired and having her pension, and associates retirement with her lack of involvement in work within the home.

Rena frequently stresses that she is not neglected, and tells me how she gets more attention from her extended family than other people with children. The way Rena describes her brother reflects her own attitude of contentment to her life: "He'll never be rich, but he's not poor". Her life is defined as a compromise, but one with which she is content. Rena talks about the compromises involved in accepting that she has to make what she can out of her life, now that she is limited due to her lack of mobility. She

considers herself fortunate to get out of the house for a little while, compared to those who have to stay in their house because they have nobody to take them. Rena believes that others might not think much of going to day care, but for her it is about “getting out” from the isolation of being alone. Unlike Cynthia, who resents the restrictions associated with family care, Rena is glad of the support she receives, as it means she can stay in her own home while still being able to get out into company. Rena is aware that her situation may change in the future, as she comments on being able to do certain things “at the moment”, and how there could be a time when she might have to move into a residential care home. However, she is content to deal with the present and not worry too much about the future: “I just accept everything as it comes”. Rena can find meaning from her continued social involvement in the outside world, due to her ability to understand her life as mutual exchange across generations to emphasise interdependence within the family.

### **Louis: ‘moving forwards to live a normal life’**

Louis describes the early years after a diagnosis of dementia as very difficult. He describes being socially withdrawn until he was “drawn out” by a paid carer who helped him to adjust to his condition. Louis describes his passivity and lack of involvement at this time in relation to sitting: “I used to sit like a vegetable. I used to sit and look at four walls, not interested”. This time in his life is associated with being mentally confused between the past and the present. Louis goes on to describe how “we’ve pulled through it”. He is referring here to the support of his family to bring him through this period in his life, and he represents this difficult time as in the past. Like the other older people with dementia in this study, support from others is represented as important in the process of adjustment to living with dementia. Louis represents this support in terms of family, formal services and mutual support from other people with dementia.

Being surrounded by other people with dementia is viewed as important, because they are “on the same level”, and “there’s nobody higher or any lower than you”. Like Martha,



Louis's reference to this commonality of status suggests that being surrounded by people in a similar position is helpful. Having support from a person who does not look down on you is what Louis believes is important: "I just don't like being spoken down to. I've got dementia. I'm not daft. I'm not a child". This is similar to Ted's description of receiving support from other people without being infantilised. Louis tells a story about a time when he 'threw out' a carer because she spoke down to him, but he accepted another carer who spoke to him with respect and understanding. Like Ted, support is constructed positively if it involves people accepting him, encouraging him and helping him gain confidence. Louis describes his family as his "backbone", in terms of accompanying him through the process of acceptance and recovery. This support is what Louis believes has helped him to "come out the other side", to find something positive from "the tragic".

Louis's new stage of his life is represented as active, spoken in the present tense, in contrast to his previous passivity and focus on the past. For Louis, living with dementia is associated with activity and engagement: "There's life after dementia. Dementia's only an illness, you know. Life with dementia, that's what I'm doing". Louis is emphasising personal agency in dealing with dementia. In contrast to Martha's focus on keeping the appearance of being a normal person, Louis focuses on living a normal life. Rather than concentrating on achieving a normal status, Louis's narratives assume this status as given, as he is defining himself in the same way as ordinary people. While Martha outwardly rejects having something wrong with her mind or body, Louis understands dementia as an illness. By doing so, he is able to frame a normal life as something within his control: "You can live as normal a life as anybody if you want to". This statement suggests that Louis feels in control of his life, which is not so apparent in the narratives of the other older people with dementia in this study. Rather than focusing on strategies to keep the appearance of being normal, Louis is focusing on how to demonstrate to others that having dementia does not negate having a normal life.

While the other older people with dementia focus on the importance of continuity, whether in terms of social roles, relationships or valued activities from the past, Louis's narratives are different in that he reframes his involvement in life as different in quality from the time before he had dementia. Louis talks about missing his work, and discusses his sadness at not being able to do some of things he used to do, such as driving, but he has found new meaning by redefining his social role and becoming involved in new activities. He describes "battling" institutions about issues relating to dementia. Louis is fighting for social justice in his new community in the same way that Ted used to campaign in his old community. Their engagement within the wider community can therefore be contrasted to explain why Ted falters in the past and Louis can look forward to the future. Louis's statement that "there is an awful lot of life that goes on after dementia" is a direct contrast to Ted's perspective of no longer being involved. Being able to look forward depends upon having a sense of purpose and active engagement within the wider social world.

Louis is finding new meaning and purpose through supporting others, by sharing what he describes as "the reality" of what it is like to have dementia. While Cynthia, Ted and Martha find opportunities to support other people in the context of day care and support groups, these occasions are infrequent or transitory. By framing dementia as something tragic that he has overcome, Louis is using the 'survivor' story to bring a positive quality to his experience of having dementia. This positive evaluation of living with dementia is apparent in his language, as he talks in the present and future tense, in ways that suggests hope and possibility. Whereas the other older people with dementia focus on a restriction of activity to differing degrees, whether physical or social, Louis describes the numerous activities he is involved in around his work as part of a mutual support group. Louis is contributing within this new community and he is able to construct a valued social role in this new space.

From his involvement with the mutual support group, Louis describes how he has never met so many happy, friendly, loving, affectionate and honest people since he had dementia from “ordinary walks of life”. Louis represents people with dementia in this positive way and then contrasts them to other people he meets at conferences who need “converted”. He reframes people with dementia as having nothing wrong with them, by framing people who do not understand dementia as having something wrong with them. Louis describes how he is “taking on” the academics who are researching dementia. He narrates a story of subverting an academic event to dispel the social stigma associated with dementia. Like Martha, Louis describes telling people off for “speaking down” to him. However, while Martha withdraws from social situations that are threatening to her sense of self, Louis is using the opportunity of being part of a collective endeavour to actively engage with stigma to tackle it directly.

For Louis, moving forward to find meaning in life is related to engaging with others to support them in their experience of living with dementia, as represented in the following quote:

and once you've helped yourself (pause) if you're willing to (pause) and able to (pause) you try and go out (pause) and help others (pause) and that's what my aim is (pause) and I think I've achieved (pause) quite a bit of it (pause) so far

From this part of Louis's narrative, it is clear that he has moved from helping himself to helping others, and this sense of purpose is related to being positive about the place of dementia in his life. Like the way Ted explains how he is trying to educate me about his experience of living with dementia, Louis is demonstrating how he is educating people at a wider level so that they understand “the reality” of living with dementia. His message, which helps him to continue to find meaning in his life, is that people are living with dementia and not dying from it. Louis finds benefit from being part of a collective group, and this experience is important because Louis can be actively involved in creating something, which he can grow and gain confidence from. This represents the potential for

new meaning. Louis is finding fulfilment, which can be contrasted with Cynthia who feels finished up. His sense of self is expanding and developing, to incorporate dementia into his identity in a positive way, and he defines this experience of finding meaning as personal growth. Like the other older people with dementia in the study, finding meaning in life is associated with living an ordinary life.

## **Conclusion**

The cases of five older people with dementia have been considered to explore the way each realises their preferred sense of self and social identity in everyday life. A continuum of representations has established the varying ways that these older people construct their ability to stay involved in life and so maintain their status as an ordinary person. Cynthia describes her efforts to try to keep involved in her social world, and in being unable to keep involved in social activities that reflect her sense of self and social identity, she focuses on working to staying physically involved in her social world. Ted represents his efforts to keep mentally and socially involved in the present, and links this to the need for support from other people to gain confidence in his capacity. Martha portrays herself as staying involved within the home and homely settings, but this is contrasted with her inability to stay involved in the wider social world due to the difficulty of maintaining the appearance of normality in this context. Rena describes her contentment in being able to remain involved, albeit in a different way now that she is older. In being able to represent his social world as changed but still normal, Louis is able to subvert the tragic story of dementia, to incorporate dementia into his new identity and find continued meaning in living with the condition. These narratives of ageing and living with dementia reflect the ways that people evaluate the quality of their lives in terms of the ability to lead an ordinary life despite the challenges associated with cognitive impairment and social stigma. This representation of the narrative processes of meaning-making moves forward

our understanding of quality of life as a contextual and relative process through which people with dementia make sense of their lives.

The older people's narratives about everyday life reflect their connections with significant people and valued activities that represent their sense of self and social identity. In the comparison of past and present situations, themes that recur in people's narratives include being useful, productive, valued and included. This process of interpretation is associated with the ways that people understand their social roles and relationships and how they evaluate their personal competences and capacities. In general terms, positive constructions of living with dementia involve the ability to lead a meaningful life, which either supports valued pre-existing social roles and relationships, or introduces new associations that bring a renewed sense of meaning in people's lives. In less positive constructions, where narratives emphasise a rupture between the past and present, without the potential for renewed meaning, people are less able to make sense of their lives in ways that can be represented as essentially meaningful. Older people's narratives are essentially about keeping mentally and socially engaged in the present, to either maintain existing connections from the past, or to develop new associations that offer the potential for renewed meaning in life. Where a person loses momentum this causes a disruption in their ability to find meaning in their life, while more positive interpretations of living involve narratives that reflect an ongoing and continuing engagement with everyday life.

An in-depth exploration of the structure and content of these narratives has established the key theme of engagement that cuts across the different accounts. Movement is a recurring feature of people's narratives as they 'work' to maintain their preferred sense of self and social identity through active involvement in everyday life. There is a sense of effort in keeping engaged, whether in thought or action, to find continuing meaning in what they are doing. Having a sense of purpose, contributing and feeling capable are all

aspects of this involvement. Being a useful member of their family and community is a fundamental aspect of all the participants' lives. The contribution to family and community may be reframed in comparison to earlier life stages, but the importance of having a valid and respected social role is vital to a sense of well-being. Positive constructions of living with dementia involve maintaining a sense of normality that reflects existing associations within the family and wider community. Finding meaning in everyday life can also involve creating new connections that enable a person to maintain the perspective of living an ordinary life. When people no longer feel involved or connected with people or activities that have been important in the past this has a negative impact on their sense of self and social identity. A restricted capacity to stay involved is associated with a conflict between self and social identity and the consequent ability to lead an ordinary life. What unifies the different narratives of the older people with dementia in this study is the central function of finding meaning in everyday life through their involvement with the social world.

Close attention to these older people's narratives has demonstrated their efforts to make sense of their self and social identity in the face of the cognitive and social challenges associated with ageing and having dementia. Understanding the way a person evaluates their life depends upon understanding how they represent their engagement with the social world relative to their sense of self and social identity. This conceptualisation of quality of life entails an appreciation of the way people locate themselves in the social world relative to definitions of life as ordinary. Older people with dementia describe themselves in positive and active ways as they attempt to realise social identities that fit with their sense of self as an ordinary person like before. Finding meaning in everyday life is therefore a creative process, whereby people use active strategies to represent themselves as involved in ways that maintain their sense of self and social identity. This is a continual process of meaning-making, as people struggle to manage the challenges of cognitive impairment and social stigma, and so resist potential threats to their status as an

ordinary person. All the older people narrated accounts of events and experiences that reflected their struggle to stay involved in ways that reflected their sense of being an ordinary person, and the extent to which a person could maintain their sense of being ordinary was related to their perspective on their quality of life. The extent to which older people with dementia can find meaning in life therefore relates to the extent to which they can continue to represent their lives as normal or ordinary.

## **Chapter Seven**

# **The construction of a normal social status in the narratives of paid and family carers**

### **Introduction**

In chapters five and six I explored how older people with dementia derive meaning from being able to represent themselves as an ordinary person who retains a valued place in society. In the process of making sense of their experiences, their narratives reflect the struggle to represent being involved in ways that emphasise normal engagement within the family and wider community. In chapter seven I investigate the comparable ways that carers represent older people with dementia with whom they live or work. While older people with dementia reflect upon their changing social status relative to ageing and dementia, so carers understand people's position relative to the impact of ageing and dementia on self and social identity. The process of meaning-making among carers involves an emotional struggle to make sense of the person with dementia as ordinary and normal in the context of their existing social roles and relationships. The ways that carers represent the person's social position relative to earlier times, and the resulting status they afford the person in terms of being normal, is significant in understanding how they make sense of the older person with dementia.

In developing the analysis with this chapter, the cases of ten family, friends and formal carers are examined to understand the differing ways that they represent older people with dementia in their narratives. Narrative analysis is used to explore the ways that carers define the self and social identity of older people with dementia in comparative evaluations of the present relative to the past. Accounts are grouped thematically around two particular types of representations of older people with dementia: being the same person as before but losing skills and abilities, or losing their normality and no longer



being the same person as before. The differing accounts function to construct the older person with dementia, either as an ordinary person whose capacities are affected by cognitive impairment, or as someone whose self and social identity is fundamentally altered by dementia. To illustrate the way that meaning is constructed across an account, one carer is taken as an exemplar for each thematic category. The accounts of the remaining carers are used to develop the argument in a general discussion of significant themes across accounts.

### **Being the same person but losing skills and abilities**

#### ***Graeme: 'losing fitness and doing things differently'***

Graeme is a paid carer in his fifties who has supported a number of older people with dementia. Graeme's narratives are straightforward to read, progressing in a linear manner across his account. Paying attention to the linguistic features of his talk, such as emphasis and pauses, and then breaking his ideas into separate lines of text, which were grouped around a particular topic, made it easier to attend to the meaning of what was being said. Attending to the stanza structure of his general narrative was therefore useful to follow the ordering of different topics that he raised in long stretches of uninterrupted talk, rather than to interpret the formal functional properties of each narrative segment. His narrative style consisted of broad description and argumentation, which may reflect a well thought-out argument or may be related to his perceived role at work or in the interview. Due to this particular style of talking, my commentary focuses on summarising the general themes in his account rather than unpicking particular narrative excerpts.

When narrating stories about older people, Graeme focuses on the person's individuality, in terms of their qualities, personalities and interests. The condition of dementia is understood as affecting people differently, and Graeme starts his narrative by describing the people with whom he has worked as all being different. Dementia is not described as an all-encompassing condition, but as something that affects a person differently, at

different times and in relation to different external factors. Rather than homogenising experiences, Graeme emphasises differences in people's circumstances due to factors such as the extent of their family connections. Graeme considers how people with stronger family connections have a better quality of life, and so he evaluates a person's life in terms of their involvement within the social world. Rather than linking changed circumstances to a change in the person, the person's changed situation is interpreted relative to the wider social context of their life.

Ageing is an important lens through which Graeme views older people with dementia. Within the context of ageing, continuity is a feature that pervades Graeme's accounts of older people's lives. Important social connections like friendship and the church are described as ordinary and continuing aspects of a person's life. When talking about one older woman, Graeme describes her as "just a nice old person". He describes this woman as being "a local person", who has a good sense of humour and likes going out to mix with friends. This is similar to Rena's account of mixing in the company of her peers. Older people with dementia are understood in relation to their ongoing interests, as well as their life history and relationships with others. Graeme represents older people with dementia in ways that stress ongoing connections between the past and the present. The focus is on enduring characteristics, as Graeme represents older people with dementia as continuing to be active members of the community, taking part in ordinary activities. This perspective reflects the same type of language used by older people with dementia in their narratives of maintaining an ordinary life.

Graeme's narratives reflect a dichotomy between the way he understands dementia, and what colleagues have told him about how dementia affects a person. He explains that he has been told that dementia affects a person's personality, but he rejects this interpretation by evaluating the person's behaviour as representative of their personality before developing dementia. One older man is described as "being on this battle for a long

time". The way the man deals with his condition is linked to his enduring identity. Graeme focuses on the person being a strong and hardworking man all his life, and describes how he lasted a long time after becoming physically ill. While Graeme understands the man's condition to be progressing, he represents the main change as a physical deterioration in health. The man's deterioration is also linked to the death of an older woman who was very close to him: "It just seemed he went downhill after she died". The progression of his condition is therefore also attributed to the impact of the loss of important social connections. In addition to the physical impact of dementia on a person's health, a sense of well-being is associated with the person's social relationships.

Although Graeme rejects the interpretation that dementia influences a person's character, dementia is understood as having an effect on a person's mind. He describes how the condition impairs the person's mental or physical "fitness", rather than causing an inherent change in the person's identity. When negative personality traits are remarked upon, for instance a person being too forthright, these are portrayed as enduring features of the person: "I think she had been that kind of person all her life". In describing the impact of dementia, Graeme locates the difficulties in relation to what the person was doing: "She was (pause) a bit, she was demented. They were finding her on the street outside at night and different things she was doing". Difficulties associated with dementia are described as affecting capacities, such as a person no longer having much conversation. When discussing how one man became unable to talk, Graeme describes how "it just sort of gradually declined". Graeme focuses on older people with dementia doing things differently from before, rather than them being different in themselves. Graeme is representing a decline in skills rather than a fundamental change in the person. Dementia is understood as affecting the person's actions and capacities, rather than their self and social identity.

While acknowledging a loss of skills among older people with dementia, Graeme recognises the potential for people to remain involved if they are not unnecessarily restricted by others. Graeme explains that when people are labelled as having dementia, they are generally labelled as not being able to do anything for themselves. He compares this to the position of an older woman, who he describes as active and bright. Graeme explains how the woman often goes out, but that she does not have enough money to do all the things she wants to do, due to restrictions on her finances imposed by social services. Like Cynthia's narratives, the focus is on the restrictions placed by others on what she can do. Graeme distinguishes his perception of this older woman as "able", with how others treat her "as if she was just raving or ranting". Graeme believes that cognitive impairment in itself does not cause the person to be disabled: "Somebody in her position was not disabled, or out and out mentally ill or feeble". This representation of capacity is qualified by his evaluation of the woman's need for care due to practical problems at home that cause her to be a danger to herself. There is therefore reference to the real difficulties associated with dementia, without assuming that a person's life is wholly encompassed by them.

Graeme refers to people being "in the same situation" when describing the impact of dementia. This interpretation is similar to the way that Ted discusses being in different situations before and after the diagnosis of dementia. Problems or challenges in life are interpreted in relation to a person's social situation. For instance, he describes a man's reluctance to be helped with personal care in a nursing home, as being an understandable reaction to his embarrassment at young women carrying out intimate tasks. Graeme also describes people becoming bored because he is not able to take them out as much as they would like. In this context, difficulties are interpreted as a reasonable reaction to the practicalities of a person's situation, rather than as an inherent difficulty in the person's character or behaviour. When the person is represented as behaving in a way that challenges other, Graeme often represents their reaction as a natural and constructive

response to a difficult situation. This frames the person's behaviour as appropriate to their social context.

An emphasis on the person's changing situation shifts attention from an altered character to the loss of important social roles. Graeme's evaluation, that an older woman "would rather have been doing the looking after than the being cared for", recognises the importance of changed social roles in the person's quality of life. Linked to this statement is an evaluation of the woman's need to be actively involved: "She needed to be doing something, she just really had to be on the move all the time, and if for any time she had to sit and look out that window, that would be a danger sign". Graeme relates the woman's fundamental desire to be involved to the woman's assertion that "I need to do something, I need to work". This description of involvement is similar to the way that Cynthia and Martha discuss their desire to keep working and caring for other people. It also mirrors their evaluation of sitting in terms of not being involved. Graeme recognises that older people with dementia want to live in a way that reflects their ongoing sense of self, which is related to the person's need to be involved in ways that represent their desired social identities.

Despite the general representation of dementia as something affecting the person's capacities rather than their nature, Graeme struggles with his evaluation of one woman's behaviour that was difficult for him to understand. In his description of one particular situation, where this older woman is described as being unpleasant to a young child, she is represented as being nasty due to her dementia. It is a difficult issue for Graeme to deal with, represented by the way he hesitates and pauses, when trying to articulate explanations for her behaviour. On this occasion, when her behaviour is conceptualised as childish, he adopts the explanation that dementia has changed her personality. This is in contrast to other narratives that emphasise her strength of character as positive and enduring. This alternating way of characterising dementia reflects the emotional struggle

to represent a person as normal when the carer cannot make sense of the person's behaviour. This example shows that understandings of dementia are fluid and change on different occasions depending upon the extent to which the person's behaviour can be understood. Being able to make sense of behaviour is therefore linked to the carer's ability to represent the older person with dementia in a normal or ordinary way.

### ***Representing the ordinary social status of older people with dementia***

Graeme's perspective defines the older person with dementia as being the same person as before but losing their skills and abilities. This representation of the person is evident in the narratives of three other carers in this study: Karen and Joyce who are paid carers of people with dementia, and Irene who is the wife of a man who was diagnosed with dementia in his early sixties. For example, Irene starts her narrative with a description of her husband in relation to his prior occupation, focusing on activities that he used to be able to do very competently. Irene reflects on how her husband became unable to carry out the tasks necessary to maintain his employment, which she understands as a gradual process of change and deterioration in which his skills became impaired. Irene focuses on enduring features of her husband's nature, such as how "he has never forgotten his manners" despite becoming confused. The focus is upon a loss of competence rather than a change in the person's nature. Like Louis's description of the impact of dementia on his work life, Irene describes her husband's life in terms of "a time before" and "a time after" dementia. Irene is representing the impact of dementia as a loss of skills that changes a person's situation in life.

Carers who associate dementia with losing skills emphasise the enduring identity of the person. Joyce describes older people with dementia as losing short-term memory, and she interprets this loss as impairing skills. In the context of memory loss, Joyce highlights the importance of looking to the past to acknowledge a person's achievements and affirm their sense of self: "It's very affirming for them in the present, you know, that's what I've

done and, you know, I am who I am". Karen also focuses upon specific impairments in memory, language and mobility. Like Graeme's interpretation of mental and physical fitness deteriorating, Karen describes how dementia causes people to "deteriorate in their illness". Karen refers to deterioration in the brain, but this is related purely to memory: "I don't know what skill, what part of the brain goes, but it's just they can't remember". Irene also relates a process of physical deterioration as "the dementia was really getting a hold of him", evaluated in terms of what her husband was doing. In representing the physical and cognitive impairments associated with dementia, these carers are focusing on a change in a person's skills and fitness rather than their identity.

Carers who emphasise the person's enduring identity tend to represent the person's changing circumstances within the wider context of their social situation. Joyce relates a loss of skills to the significance of women losing social roles such as being a housewife. In reference to one particular woman, Joyce describes how she tried to maintain her involvement in housework to maintain her connection to the past: "[Cleaning] was obviously something she'd done all her years and it was kind of holding onto something in a way" and "holding on to the skills of the past into the present". Rather than linking current circumstances to a change in the person's nature, the person's altered situation is interpreted in relation to changed social roles that arise from a loss of skills and memory.

From the perspective of a family carer, Irene also highlights the impact of a loss of skills on social roles. Irene explains that she now has to do things for her husband that she did not do in the past, such as helping him with his personal care. Irene explains that the progression of her husband's dementia entails being involved in a different way from before. The most significant aspect of this changing involvement is represented in terms of activities that represent previously significant social roles. Changes in her husband's life are represented in terms of their relationship, such as in their shifting roles; whereas her husband was always in charge of household matters, Irene has now adopted this role.

Rather than representing the person's self as changing, Irene represents a shift in social roles. From this perspective, changing social roles are represented as changing obligations within the family. Locating dementia within the context of the person's social situation is related to the way that these carers understand the difficulties associated with losing skills and abilities.

Like Graeme, Karen talks about individuals all being different, expressing difficulty in responding to my general question about quality of life for people with dementia, with its requirement to try to tell a general story that represents a number of different individuals. In responding to this question, Karen focuses on the issue of older people losing their independence, and she emphasises the importance of carers acting in a way that does not take away a person's whole independence. Karen is emphasising the relevance of the care context in the person's changing experiences, rather than representing changes in a person's life being solely attributable to their condition. Similarly, Irene stresses the significance of her own response to her husband's situation, and she describes the change in his abilities as causing more difficulty for her than for him. The experience of dementia is therefore understood within the context of social relationships and the responses of other people to the person's situation. This is similar to the way that older people with dementia represent their position in life.

In focusing on the social context of a person's behaviour, carers are able to interpret a person's reactions as appropriate. For example, Irene attempts to understand and rationalise her husband's behaviour, to make his feelings and reactions comprehensible within their social context. She describes an experience when her husband damaged a room where he was staying for respite care, and evaluates his behaviour in terms of his distress of having nobody to talk to, "which was, to him I would have said, like a nightmare". Similarly, Karen describes a woman with dementia becoming agitated in specific situations. She understands the agitation in terms of the woman's past



experiences and emphasises how her behaviour makes sense given the circumstances. Even when situations are evaluated as strange, such as a person being unable to recognise their own photograph, Karen locates the difficulty in terms of the person's impaired cognitive capacity, rather than in relation to a sense of self. These accounts are therefore similar in their evaluation of the person's behaviour as appropriate to either their social situation or their cognitive capacity.

Even when a person's behaviour becomes difficult to understand, these carers are still able to focus on enduring connections to past places that are related to a person's actions having purpose. This is evident in the way that Irene makes sense of her husband's intentions relative to his physical movement. Good days are described in terms of times when her husband seems to know what is going on around him, his brain being active, and being aware of past associations. This is despite his memory having deteriorated very significantly. Irene describes an occasion when they visited a place that they had known in the past. She describes how her husband made movements that indicated he wanted to walk, and she wonders whether this was because he was making a mental association with the place, and remembering going for walks here in the past. The potential for awareness to endure is significant in being able to represent the person's actions positively. Consequently, there is less frustration in the way Irene reflects upon the process of trying to make sense of her husband's experiences compared to carers who describe a pervading lack of awareness and connections.

Despite Irene's focus on her husband's enduring identity, Irene's perspective does change when she describes experiences that she struggles to understand. A particular issue that Irene finds troubling is her husband's compulsive and repetitive behaviour, shredding paper into tiny pieces, or pulling plants out of the garden. She refers to this change in behaviour as "starting to do things that are not right". Irene's narrative reflects a belief that dementia is compelling her husband to be involved in unusual activity, which he

cannot resist despite it making him unhappy. However, this behaviour, which Irene interprets as strange, is represented as something that can be understood in the context of her husband's past concern with shredding personal documents. Nevertheless, Irene's ability to make sense of her husband's behaviour can be contrasted with times when he husband "sits like a zombie". On these occasions, Irene describes her husband as being "too far gone". At times when her husband's actions suggest a lack of normal involvement in the world, Irene is unable to make sense of his behaviour, and she focuses on his identity as inhuman.

Connections with the past are important among this group of carers. Joyce describes the relevance of focusing on the past to maintain connections with the present in the context of memory loss: "With older people, it's the short-term memory [that] is such a problem, [so] it's more looking into the past to help them with the present". Joyce describes how she is sometimes surprised by what the older people with dementia can do despite their short-term memory problems, such as always going for the same chairs each time they attend a day care centre. Therefore, while a loss of memory is emphasised, these carers' narratives reflect on the potential for awareness to remain. In a similar way to Graeme, Karen describes a person who is more "able" as being "fitter", which she links with getting out and keeping active. This type of construction relates people's abilities to their continued social engagement, and is similar to the ways that older people with dementia represent their continued involvement in life. In focusing on the possibility of maintaining connections between the past and present, these accounts represent the potential for older people with dementia to remain involved in their social world.

Ageing is an important factor in paid carers' representation of the person and their involvement. Joyce describes taking explicitly different approaches to working with younger and older people. Her approach to younger people involves dealing with the present and looking to the future, which is similar to the way that Louis understands his

life. This perspective can be contrasted with Joyce's approach to older people, which she understands as being about the past and reminiscence: "So it's a different perspective and different needs I would say that have to be addressed". Older people are constructed as living in the past, which is similar to the way that Ted understands his life. Joyce describes older people as being happiest with what is familiar to them and not being so sure about moving into unknown territory. Joyce's generalisation about working with older people emphasises the importance of sustaining connections with the past to maintain continuity. Her approach to care, which reflects her perspective on the impact of ageing, is to understand the person and current experiences relative to past social identities and activities.

When carers are able to focus on what remains from the past, they are able to represent people being involved in purposeful, positive and worthwhile activities. For example, Joyce describes the focus for older people as "the hard work they had done over the years". She associates this work with having a sense of purpose, and the person enjoying an activity that they have done for years. She gives the example of continuing to keep involved in housework as important to women, due to important connections from the past. Joyce is constructing the person in a similar manner to how older people with dementia represent themselves. The emphasis is upon having a sense of purpose in terms of involvement in activities that have a connection to past social roles. Nevertheless, with this focus on the importance of holding onto things from the past, discussion is focused on looking back rather than looking forward to the future. Within Joyce's narrative, there is no consideration of the potential for finding new purpose and meaning in life, and she only talks this way in terms of younger people with dementia. Therefore, while a focus on continuity can affirm a person's sense of self, it can also limit the potential to claim new identities within the context of a changed situation.

To summarise, these carers' accounts are similar in the ways that they represent the person with dementia as being the same person as they were before, but losing skills and abilities due to deteriorating physical fitness and impaired cognitive capacity. They understand dementia as affecting a person's mental and social involvement in life, in terms of the impact of cognitive impairment and the responses of other people to the person's situation. Their narratives mostly represent continuity in the person's sense of self and social identity, in the ways that carers continue to represent the person's behaviour as being meaningful and having purpose in the context of changing social situations. This interpretation is similar to the way that older people with dementia represent themselves as the same as before, in terms that emphasise their status as ordinary people who continue to have a valued place in the social world. Such an interpretation of the person's social status can be compared with the accounts of carers who focus on a change in the person's identity.

### **Losing normality and not being the same person**

#### ***Duncan: 'not appreciating her true self'***

Duncan is an older man whose wife has dementia. His style of presentation is different from Graeme's, and more similar to the older people in this study, in terms of his rich and detailed stories of specific incidents, which often relied on dramatisation to reveal the emotional significance of his experience. This style of reporting is also evident in the narratives of the other carers who represented the older person with dementia as being different from before, which suggests that the emotional content of their accounts is reflected in the form of their narratives. As for the older people in this study, I use a detailed narrative excerpt to demonstrate how the significance of his experience is revealed in the interpretive structure of his account.

Duncan focuses on how his wife is doing things differently from before. However, his narrative is different in quality from the preceding accounts, as her changed capacity is

related to a changed identity rather than a loss of fitness. Duncan is concerned with how there is not enough of interest in his wife's life, which is contrasted with the quality of her life before dementia. This understanding of her life is reflected in a narrative about how she has lost interest in activities associated with her adult life. She is described as "having little adulthood". A change in status is attributed to how she sees herself as a child rather than as an older woman. This interpretation of a childlike status is associated with an inability to fulfil the social roles of mother and wife. In her perceived regression from an adult to a child, Duncan believes his wife to have moved from the present into the past. Filial relationships, as opposed to conjugal and maternal roles, are deemed to be more important to her sense of self and social identity. This evaluation of his wife's changed perception of herself is described in the following narrative:

***Narrative: The loss of interest in adult life***

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***Stanza 1 (Abstract: there's less and less of interest)***

There seems to be less and less

of interest to my wife

***Stanza 2 (Orientation: she thinks she's a child)***

I think certainly

going back to the old days

when she was maybe a child et cetera

she obviously thinks she's still a child

If you ask my wife what age she is

she might well say she's a teenager

***Stanza 3 (Complicating action: she doesn't think she's got a family)***

Apparently, on most occasions

she's not married as such

and she's got no family  
there's no children  
The children just now  
can be probably brothers or cousins  
and I can be an uncle or whatever  
usually an elderly person  
rather than somebody of her own age group

***Stanza 5 (Evaluation: she's interested in stories of childhood)***

As I say she is interested  
when you recount some of these stories  
that she has already told you  
when she was a child you know  
such as going into her aunt's  
and getting a piece dipped into mince type o' thing  
and various bits and pieces  
when she ran about with her cousins and so forth

***Stanza 6 (Coda, no resolution: she's got no family)***

Apparently, on most occasions  
she's not married as such  
and she's got no family  
there's no children

Duncan believes that his wife sees herself as a young girl, represented in a narrative about how she does not appreciate her reflection in the mirror as being her true self. In Duncan's statement that his wife "is certainly not a granny", he is suggesting that his wife no longer

has an accurate perception of her place in the family. Duncan believes that there is a blurring of the person she was then with the person she is now, and the two identities have become confused and hard to disentangle. While representing her sense of self as confused, Duncan still believes that at some level his wife appreciates she is older, as he says that she is evasive about her age and concerned about being laughed at when she interacts with young children. Duncan represents a variation in her awareness, and that her sense of self sometimes changes to incorporate a connection with her children, even if she never seems to comprehend who her grandchildren are. This perspective represents a shifting understanding of his wife that depends upon her awareness at any given time.

Related to this representation of his wife's distorted sense of self, Duncan interprets her life as lacking purpose. Duncan talks about her enjoying certain activities at the time, but he explains that any pleasure either does not endure or is limited in quality: "She seems to get a *degree* of pleasure". This interpretation of limited enjoyment is linked to his wife's inability to engage purposefully in worthwhile activities or retain any memory of her experiences. For instance, "getting out" is something that she enjoys, but this is described as "just wandering", reflecting a lack of purpose in the activity. While his wife enjoys meeting her friends, Duncan explains that there is no lasting pleasure, as she is unable to remember the experience. Similarly, Duncan explains that while his wife enjoys some types of television programmes, she only partially recognises faces and does not remember anything of the content. His conclusion is that she "does not follow it at all". Duncan's overall evaluation is that "there's not really much point, it's just a case of looking at some movement". The difficulty in making sense of his wife's experiences is apparent in Duncan's evaluation of her involvement as essentially meaningless.

After depicting his wife's current limited involvement in life, Duncan describes earlier times in her life when she took pleasure from activities such as knitting. The representation of a disrupted or dislocated connection to her true self is evident in the

way Duncan compares how his wife used to knit clothes for her grandchildren, with how she now makes clothes so small that they would fit a doll. Duncan also represents his wife's social engagement as inappropriate. He narrates stories of occasions when he has had to restrain her from speaking to children who she does not know. Rather than interacting with these children like a grandmother, Duncan believes that his wife must perceive these children as her contemporaries. These instances are compared with her lack of interest in her grandchildren of the same age. Duncan therefore evaluates his wife's social interactions as inappropriate, which can be understood in relation to his perspective of her perceived association with childhood and childish things. The changed situation in his wife's life is therefore linked to her behaviour as out of context in relation to valid social roles and relationships.

The perceived denial of her true self is associated with her changed involvement in adult life. Duncan describes how his wife 'switches off' in adult company or when involved with adult activities. His narratives therefore connect the childish quality of his wife's involvement with her inability to interact normally in adult situations. Duncan also relates how his wife claims to do the cooking and housework "when in fact she almost does nothing". From Duncan's perspective, there is no validity to his wife's perception of involvement in adult activities, and therefore there can be no valid connection to adult social roles. While Graeme represents the deterioration in a person's condition as a decline in their fitness, Duncan represents the deterioration as a regression in the person's identity. Rather than representing a loss of capacity, Duncan is representing a loss of social status, due to his inability to understand his wife's behaviour in the context of normal social roles and relationships. Her perceived lack of connection with adult life involves a loss of social status as a normal adult.

The significance of this loss of status as a normal adult is implicated in Duncan's evaluation of her impaired mental status and her consequent inability to do things



properly. Duncan portrays his wife as no longer confident or capable of doing things like knitting, and relates this to her inability to formulate logical thoughts. The inability to knit properly is extended to her inability to achieve anything. His wife's involvement is framed as the interplay of being affected by a brain condition and behaving like a child. Duncan narrates an example of a behaviour that he finds particularly difficult to understand, which involves his wife's habit of rubbing and picking at fabrics and materials. Duncan considers aloud whether this habit is related to having a nervous breakdown, whether it is part of a brain disorder, or whether it is a comfort like a child gets from a security blanket. These are questions rather than answers, and Duncan's confusion and frustration is evident in his distress at this time. Duncan is unable to understand what is happening in his wife's mind, and so he is unable to make sense of her behaviour as normal.

The inability to understand his wife as normal is evident in Duncan's language. Duncan talks about everything being "an extreme" to his wife, referring to how she becomes upset and annoyed at ordinary activities. For instance, Duncan describes his wife's dislike of being taken out in a wheelchair, because she finds the pavements too bumpy and the cars passing her by too fast. When describing her reactions as extreme, Duncan compares them to what "we", as ordinary people, would think in more moderate terms. When Duncan talks about her reactions being extreme "when compared to you or I", he describes his wife as like a "caged animal". In describing her incontinence, "which was very much against her normal", Duncan is expressing his inability to construct her behaviour as normal. On other occasions, he describes unusual behaviour, such as changed eating and sleeping patterns, as reflecting "the nature of the beast". His wife's perceived lack of normality is tied to her nature, which is perceived to be fundamentally affected by dementia. Not only is his wife constructed as different from others in terms of losing her adulthood, from Duncan's perspective his wife has also lost her humanity when she acts unnaturally.

From Duncan's perspective, his wife is no longer the same person as before, and so her life consequently lacks coherence and meaning. This account can be understood in relation to the way Duncan represents his wife as childlike, and how her involvement in life is portrayed as childish and meaningless. Unable to represent her behaviour as normal, Duncan is unable to understand his wife as a normal person, and so he cannot interpret her life as having worth. The perceived denial of her true self has implications for her family, whose relationships are apparently not recognised in their true context. As a result of Duncan's perception of his wife regressing to a child-like status, which does not accommodate the social roles of wife, mother and grandmother, he is unable to represent a valid or common basis for their family shared history together. He describes how "all the yesterdays were all away, there was just nothing there". The loss of his wife's sense of normality therefore extends to Duncan's perception of their life together. The impact of this identity spread will be considered further in chapter eight.

### ***Representing the spoiled social status of older people with dementia***

Duncan is unable to represent his wife as an ordinary or normal person, due to her perceived inability to appreciate her true self. This conceptualisation of a changed sense of self and social identity is reflected in the accounts of five other carers in this study. These accounts will be considered in the following discussion, to understand how carers struggle to make sense of the person with dementia, when they perceive the person's involvement in life as lacking in normality. Maureen and Teresa are paid carers working with older people with dementia. George, Robert and Cathy are family carers who support an older relative or friend with dementia. While the first group of carers in this chapter construct the identity of the person with dementia as the same as before, this second group of carers typically understand the person and their behaviour as being changed in nature due to the progression dementia.

In comparison to the way that the first group of carers understand dementia in terms of deterioration in physical fitness and cognitive capacity, the second group of carers represent dementia as a change in the person's character for the worse. This changing nature is understood by George as his friend "becoming out of character". This interpretation of a change in character is evident in Cathy's reflection on how her mother's identity is irrevocably changed: "It's not the same person, never will be again, just this complete character change". Cathy contrasts this change in character with her mother's continuing physical fitness. Robert evaluates the change in his mother as "strange" and "out of the ordinary". Teresa represents the impact of the person's changing nature for their family, explaining that it is difficult for families, as they know their relative is not the person they were before. Framed in terms of a deteriorating character, the longer-term consequences of dementia are understood in terms of grief for the carer who is losing the person with dementia.

This representation of deterioration is also evident in the paid carers' accounts of the terminal trajectory of dementia. One of Maureen's longest narratives recounts how a woman she worked with became ill and sickly. The emotive language that Maureen uses – "she spewed everywhere" - reflects the difficult feelings associated with understanding dementia as a terminal condition. The focus of this account is how Maureen experiences great difficulty in dealing with this aspect of her work, to the extent that she felt unable to attend the woman's funeral when she finally died. Teresa presents similar accounts of the deaths of older people with whom she has worked. Teresa represents the progression of this process among the older people she works with as "moving on and being in their own world". The older people in these accounts are constructed in general terms, often described as "mums" as well as "grannies", and therefore primarily understood in relation to their familial relationships rather than in terms of their individuality. These narratives represent the difficult emotions involved when lives are primarily understood in the context of death and decline.

A changed nature is related to uncharacteristic behaviour in people with dementia. For instance, Maureen emphasises the changing nature of an older man with whom she works. She describes him as becoming “nasty” and being “in a vicious mood”, a way that he never was before he had dementia. This nastiness is associated with unpleasant behaviour towards other people. Maureen describes her resentment towards this man for upsetting people at the day care service where she works, but she re-evaluates her feelings of anger towards him by considering how his personality has been changed by his dementia. The pronoun in this narrative changes from “it’s not always *his* fault” to “it’s not always *their* fault”, which suggests that Maureen is representing a change in personality as a general feature of dementia. Dementia is understood to be affecting the person’s nature and making their behaviour uncharacteristic of earlier times.

Uncharacteristic behaviour is understood in the context of a person’s life history. Like Graeme’s representation of the changing situation of people with dementia, George describes how “there is a time before dementia, and a time after dementia”. However, George’s narrative differs in his focus on the lack of continuity in his friend’s life. He provides a vivid description of his friend’s past working life, which is marked by success and competence. This can be compared to George’s evaluation of his friend’s current life, which is marked by a lack of dignity and competence. George’s stories of significant events and experiences represent behaviour that is described as “being out of character” and not making sense. George’s narrative therefore represents a fundamental change in the quality of his friend’s life, which is associated with the change in his character. A distinction between past and present is a recurring feature of George’s narrative as he struggles to represent his friend’s behaviour in the context of an enduring identity.

Disrupted social roles are a feature of a changed identity. For instance, Robert considers that his mother would be happiest if she could go back to a time when she was young: “And basically, what my mother would like most is to turn the clock back seventy years”.

From this perspective, Robert considers that his mother would be content if she was a child again, which is related to her mistaken belief that her parents are going to come and take her home. Robert returns to this theme when he discusses how his mother continually talks about her filial family, something which she never did before she had dementia. He compares the past, when his mother never talked about her family, with the present, now that she talks about her mother all the time. This behaviour is linked to her changed nature, as she is described as being very private before having dementia. Robert also describes how his mother has no interest in her grandchildren, highlighting a change in perceived roles and relationships within the family. Like Duncan, Robert considers his mother to be living in the past, with a distorted perception of family relationships.

In the context of changed social relationships, the change in a person's nature is related to a changed quality in the person's involvement with other people. Cathy relates the change in her mother's character to having a new interest in men that was never present before she had dementia. Cathy describes this as "shocking" behaviour "that was totally alien to my mother". Like Duncan's evaluation of his wife's childish interests, Cathy frames her mother's disinhibited behaviour as improper and inappropriate. Robert similarly represents his mother's behaviour as inappropriate due to her interest in seeing parents and siblings who are now dead, and her disinterest in her children's families. This can be contrasted with the other group of carers, who frame the behaviour of people with dementia as appropriate to their situation, and represent the social context or other people's responses as inappropriate. Uncharacteristic behaviour is therefore related to inappropriate interests in accounts that focus on the changed nature of the person with dementia.

The tension associated with unusual behaviour is reflected in accounts of people with dementia doing unusual things. Particularly emotive stories represent George's frustration at his friend's denial of doing what George terms as "bizarre things". At one

level, George links his friend's denial to moments of awareness, and a self-conscious concern with people making a fool of his behaviour. However, on most occasions, he cannot understand his friend's denial. Likewise, Robert uses the words "unnatural" and "cruel" to represent his mother's character at times when she is described as confused and as behaving unreasonably. Connected to her confusion, and the perceived variability in its expression, Robert frequently uses the term "strange" throughout his accounts. He compares this strangeness with his mother's occasional lucid moments, and how in those moments he feels that his mother hates living like this now. The extent to which these carers evaluate the person's behaviour as unusual and inappropriate therefore relates to the person's level of awareness.

The significance of a lack of awareness is in the difficulty carers experience in being able to understand a person's involvement in life as having meaning. For example, Teresa's first reference to dementia involves the description of a woman who has "a wee look on her face, just the lost look". Teresa describes this woman as "being in a trance" and "pottering around in her own little world". Like Duncan's interpretation of his wife's walking as wandering, Teresa describes the woman as being unable to sit down and just following her around, suggesting that the woman's activity lacks real purpose. Being lost is a common status that Teresa attributes to dementia. A commonality in status is also reflected in Maureen's evaluation that, irrespective of social class, older people with dementia are "the same and on the same level". Dementia is viewed as a homogenising factor that brings people to a similar level. Due to diminished awareness and a changed position in society, the person's changed involvement in their social world is represented as being different in quality from other adults.

The altered quality of a person's experiences is associated with a lack of normality in the person. A change in status of the person is evident in these carers' narratives, as they struggle to make sense of the person's behaviour in a way that can be interpreted as

meaningful. For instance, Cathy's defines her mother as "seeming normal, but not being the same". Similarly, Maureen understands people with dementia as "having something wrong with them". Robert understands people with dementia as "being an adult in a special category". He describes his mother as an adult in respect of her age, but he believes that she cannot be treated in the same way as other adults due to her unnatural behaviour. Like Duncan's comparison of his wife's extreme responses to the more moderate responses of ordinary people, Robert describes his mother's extreme and unreasonable reactions to situations. The status of being in a special category is directly related to unnatural behaviour that is not characteristic of normal adults. Teresa's reference to "moving on" can be viewed in the context of a person "being in another world". In this evaluation, the loss of social status is absolute, as the person no longer has a place in the social world of ordinary people.

As was noted among the first group of carers in this study, the contextual elements of people's narratives reflect fluctuating perspectives relative to different times and places. While Duncan's reference to his wife's spoiled identity is generalised to all social situations, Cathy distinguishes what her mother is like inside and outside the home. Cathy describes her mother as relating to her family in an ordinary way, and distinguishes this from the way she relates to people outside the home, which she perceives as being quite different from before. Similarly, while Cathy generally represents her mother's nature changing as a result of dementia, in the context of home she can represent character traits that are enduring, and she is able to make sense of behaviour in the context of enduring concerns. On these occasions, Cathy's evaluation is that "I can't really say it's because of the change". This position reflects the subtle and shifting perspectives of carers depending upon the particular event or experience being described, and its relationship to whether the person can be represented as being the same as before.

In summary, for this second group of carers, the impact of dementia is understood in the context of a person's social roles and relationships. The person with dementia is typically represented as deteriorating in nature and character, and carers consequently represent a loss of normality in the person's social status, as they struggle to make sense of the person's behaviour as normal. In representing a trajectory of death and decline, the paid carers' narratives reveal the difficult feelings associated with providing care for older people with dementia. While, in their struggle to make sense of their relative or friend's behaviour in the context of a loss of awareness, family carers struggle to represent the person with dementia as someone who is normal or ordinary relative to their past self and social identity. In being unable to understand the situation from the perspective of the person with dementia, their narratives tend to focus on the consequences of the person's changed nature and behaviour for the carer. In defining the older person's social status as impaired by dementia, these carers struggle to understand quality of life from the perspective of the person, which will be considered further in chapter eight.

## **Conclusion**

The narratives of ten paid and family carers have been examined to understand the ways that they construct the self and social identity of older people with dementia with whom they live and work. Accounts can be grouped thematically around two particular types of representations of the person in the present relative to the past: being the same person as before but losing skills and abilities, or losing their normality and no longer being the same person as before. The thematic split in accounts consists of whether the person is represented as *being* different from before, or whether they are *doing* things differently. Whether the person can be understood as the same or different depends upon whether their behaviour can be understood as normal and ordinary. In accounts that focus upon losing the person, carers struggle to make sense of the person's behaviour in the context of normality, and they emphasise discontinuity and disruption in the person's self and



social identity. The person's social status is therefore represented as impaired. In accounts that focus upon lost skills, carers interpret the person's behaviour as appropriate to their social situation, and they emphasise continuity and coherence in the person's self and social identity. The person's social status is consequently represented as ordinary. Making sense of the person as normal and ordinary is therefore linked to the establishment of continuity between the person of the past and the person in the present.

Like the accounts of older people with dementia, which can be distinguished by the extent to which they can continue to represent themselves as an ordinary person relative to available social roles, so the accounts of carers can be distinguished in the ways they perceive the impact of dementia on the person's sense of self and social identity. For many carers, dementia is associated with death, sickness and decline. These carers perceive a loss of the person's self as they transform in nature, with a focus on personality change and challenging behaviour in their narratives. Other carers perceive a loss of skills and fitness associated with ageing and cognitive impairment, with an associated interpretation of difficult behaviour being the product of a particular situation rather than something that is inherent in the person. When behaviour can be framed as 'appropriate', and the person is perceived to relate to others in ways that uphold pre-existing social roles and relationships, the framework of normality remains; the person can be understood as ordinary and their actions can be evaluated as making sense. When behaviour cannot be understood as appropriate to the person's social situation, a framework of normality cannot be established; the person cannot be understood as ordinary and their actions are framed as inappropriate. Being an ordinary person from the carer's perspective depends upon having a valid sense of self and social identity that affords a normal social status.

Carers' narratives have a temporal dimension that can be understood in the context of life history, and differing accounts of the person with dementia represent different appreciations of continuity between the past and the present. Some carers reflect on an

enduring and coherent quality to the person's identity in the context of ageing, while others understand a disruption, with the person regressing in nature as their dementia progresses. For some carers, when there is a lack of continuity between the present and the recent past, continuity between the present and the far past is emphasised to try to make sense of the person's behaviour. From this perspective, the person with dementia is not understood as the same as before in terms of their adult roles and relationships; they are framed as identifying and behaving in ways that link them to earlier roles and relationships in their childhood. Understandings of dementia among both groups of carers are entangled in stereotypical attitudes towards ageing; for instance, the feminisation of older age is apparent in references to older women as 'grannies', and presumptions about older people wanting to look back rather than forward can be understood within the context of pessimism about older age. Carers' perspectives about dementia are therefore framed by assumptions of older age, and the interpretation of the impact of ageing on a person's identity and involvement in life. These meanings reveal the complex ways that identity is understood as developing or shifting over time among older people with dementia.

The narrative construction of social status therefore determines the ways that carers make sense of older people with dementia. The social status of the person is affected by the carer's perception of the extent to which dementia has affected the person's self and social identity. The person can be defined as normal if self and social identity is perceived to endure over time. The ascription of a normal social status is connected to perceptions of the person's awareness of significant social roles and relationships in their life. The evaluation of normality is also associated with the extent to which the person with dementia can be constructed as behaving normally relative to social norms of behaviour in Western society. The extent to which carers represent the person as ordinary relates to how the person is framed as either different or the same as before, and as either different or the same as other ordinary people. The framework of normality does not remain when

carers cannot make sense of the person's behaviour in the context of ordinary social roles and relationships. While carers may represent specific issues particular to the people with dementia who they know, they engage in similar processes of meaning-making that contextualises the person's social status as either ordinary or impaired. In chapter eight I consider the way that these differing constructions of social status are linked to different ways of appreciating quality of life.

## **Chapter Eight**

# **Perspectives on the quality of an ordinary life in the narratives of paid and family carers**

### **Introduction**

In chapter seven I examined the ways that carers make sense of self and social identity to represent a person's social status as either ordinary or spoiled. In chapter eight I consider the way that carers' perspectives on quality of life are related to the representation of the person as either losing skills or losing their identity. Just as older people with dementia reflect upon finding meaning through their active involvement in life, so carers appreciate quality of life in the context of the person's capacity to engage in life in a meaningful way. The representation of the person's quality of life is linked to the extent to which the carer can support the person in maintaining meaningful involvement in the social world. Quality of life is evaluated in terms of the carer's ability to support the person to preserve an ordinary life. Managing behaviour and interpreting feelings are common features of the way that carers describe their focus in supporting the person with dementia. Perspectives on quality of life are therefore contextualised in terms of the perceived role of the carer and their emotional response to the challenges of caring for a person with dementia.

The accounts of the same ten carers that were examined in chapter seven are again examined to understand the differing ways that carers represent quality of life in their narratives. Accounts are grouped thematically around two particular types of representation that are linked to the themes in chapter seven. Carers who focus on a loss of skills in their understanding of dementia represent quality of life and the capacity to support it more positively. In these accounts, the emphasis is upon creating a positive environment or experience to make the person feel good, and to keep them involved in

ways that maintain skills and sustain social relationships. The assumption is that it is possible to engage with the person and strengthen skills and connections to the past, and so maintain a good quality of life for the person. Carers who understand dementia as causing a change in the person still try to support the person, but the difficulty of maintaining a sense of normality creates an emotional barrier to connecting with the person's perspective. When there is no sense of valid or shared meaning-making, this is when living with dementia is viewed negatively. In being unable to represent the person's involvement in life as meaningful, or finding the challenge of dealing with this situation as too challenging, these carers reframe quality of life from their own perspective.

### **Supporting the person to live an ordinary life**

#### ***Graeme: 'creating a positive environment for the person'***

As was described in chapter seven, Graeme focuses on a person doing things differently from before rather than being different in character. Placing dementia in this context enables Graeme to represent the experience of living and working with dementia in a positive way. Graeme describes his role as looking after someone to make their experience better. The focus is upon an overall experience rather than dealing with specific problems associated with deficits or difficulties related to dementia. This perspective acknowledges the potential for quality of life to be improved. Graeme's account of people living with dementia emphasises ordinary aspects of life, such as pastimes and friendships, and he evaluates their importance in relation to maintaining a person's happiness and contentment with life. Getting to know individual preferences is highlighted as important for supporting the person, and so Graeme does not talk in generalities of living with dementia, but frames the person's life in terms of the specifics of their past roles, relationships and interests.

While emphasising his clients' individuality and variability, a commonality in Graeme's narratives is his focus on the extent to which people are able to show strength and cope with their condition. This is portrayed in stories of events throughout people's lives. The focus is upon a person actively dealing with their condition and their loss of skills and abilities. Doing things when the person is "able" is the focus of Graeme's accounts of his involvement in caring. By focusing on keeping a person's mind active, Graeme is able to suggest solutions on a practical level, which creates a more positive and optimistic way of representing the challenges of living with dementia. This can be compared to a perspective that focuses on the death and decline of the person, where there can be no solution to a problem defined in such a way. The possibility of a person with dementia having a good life is evident in Graeme's consideration of how, for one older man he worked with, the last years of his life when he had dementia were probably this man's happiest times.

When asked what a good quality of life means for people with dementia, Graeme gives an example of a man feeling relaxed and comfortable in a homely environment. Graeme compares a homely environment with a nursing home environment, explaining that the former makes the person more relaxed, whereas the latter can make a person decline. The social context is therefore understood as affecting a person's quality of life, and Graeme narrates several stories of the change he has seen in a person when they have been moved to a positive environment. Graeme's role in supporting a good quality of life is in creating a positive environment that supports ordinary relationships and experiences. From this perspective, the ordinary quality of a person's life is related to the social environment where the person lives.

Graeme also understands the importance of home as a place in which people are able to enact valued social roles. In a narrative about an older woman whose life involved caring

for other people, there is recognition that she still wants to be doing the caring, and Graeme frames her interaction with other people with dementia in terms of this role. This construction of life with dementia is very similar to the way that the older people with dementia in this study talked about their lives. Graeme narrates stories of occasions when older people with dementia demonstrate their capacity and capability of being involved in activities that involve valued social roles. Graeme is therefore evaluating the potential for a person's experience in life to continue to be positive if their involvement in the social world is maintained. This description of social action is similar in quality to the way that people with dementia talk about their continued involvement in life.

The importance of supporting people to maintain their social connections with family and the wider community is therefore emphasised in Graeme's accounts. This is evident in narratives about supporting people to attend church, community events and visiting with their families. This is similar to older people's description of the importance of getting out for maintaining social involvement. Encouraging the person to do things and taking them out for trips are described as important aspects of Graeme's role. Support to do ordinary tasks is described, and Graeme narrates a story of an occasion when he helped a person to open up a bank account so that she could feel a sense of independence. Graeme frames his work as advocacy, and this role relates to the way he represents people with dementia as wanting to keep involved in ordinary activities and social situations.

Emphasis upon the 'situation' rather than the 'person' is important in how Graeme constructs his narratives about maintaining skills and abilities. Helping the person to hold onto skills is related to keeping the situation going as long as possible. By emphasising his role in keeping the situation going, Graeme is indicating the importance of the social context in determining the person's experiences, rather than the stability of the person's inner disposition. Graeme describes people with dementia in an active way, such as in his

description of one older woman: “She was a very active person for her age”. In addition to understanding the person as physically active, there is an emphasis on continuing mental activity: “Her mind was always active”. Being active socially is construed as something that “kept her mind going”. In representing the quality of a person’s life, Graeme is focusing on the importance of the social context in enabling the person to maintain their involvement.

Graeme’s construction of caring as a positive experience is important in understanding the way he represents quality of life. The people with dementia Graeme knows are described as enjoying having children around them, and one woman in particular is described as “looking after them [the children] well”. This suggests the people with dementia have an accurate awareness of social relationships that surround them, which can be contrasted with Duncan’s interpretation of his wife interacting with children as if they are her contemporaries. For instance, Graeme describes one woman he supports as being very fond of his grandchildren, but distinguishing them from her own. Graeme also describes the caring relationship between people with dementia and describes how they look after and depend upon one another. In his accounts, caring is framed as something that is mutually interchangeable and an ordinary aspect of living among different generations, including between people with dementia and other people. In emphasising reciprocity, Graeme is able to frame care as an ordinary part of life.

As a result of framing care as an ordinary aspect of life, and focusing on the possibility of providing a positive experience for the person with dementia, Graeme constructs his own role as a rewarding and satisfying experience. He talks about positive consequences of caring, such as being able to make new acquaintances through the people he supports. While Graeme acknowledges the demands of caring, he compares his own position as less demanding to that of a family carer, who is more emotionally attached. Graeme is stating



some level of emotional distance within his role. His account of caring does not emphasise an emotional struggle, and it is more positive about the potential for quality of life with dementia than formal carers of people with dementia who frame themselves as like family. This suggests a link between the emotional context of a carer's experiences and their appreciation of quality of life in the person with dementia.

In responding to the question of what quality of life means for older people with dementia, Graeme focuses on his own role and involvement in supporting the person. His description of caring reveals the way he understands what is important to the quality of life of people with dementia. Related to his representation of the person being the same as before, and dementia affecting fitness and skills, Graeme focuses on the importance of sustaining the person's involvement in ordinary social relationships and activities. Just as older people with dementia focus on strategies to maintain the momentum of an ordinary life, so Graeme understands his role as "keeping the situation going" by creating a positive environment in which older people with dementia can realise an ordinary life. Quality of life from this perspective involves continuing to be engaged in the social world in ways that maintain the person's ordinary or normal social status.

### ***Keeping the person engaged in the social world***

Graeme's way of appreciating quality of life in the context of continued social engagement is apparent in the accounts of Joyce, Karen and Irene, carers who represent the person with dementia as being affected by changed skills, rather than a changed identity. Graeme's focus on the extent to which people are able to continue to show strength and cope with their condition, is evident in Joyce's and Karen's accounts of older people with dementia continuing to actively engage in life. "Being able" is how Karen describes most of the older people with whom she works. Karen emphasises what people are able to do, and questions being asked to do tasks that she believes the person is still able to do

themselves. Karen is emphasising ongoing capacity, and describes situations where a person has been able to demonstrate their continued competence. By constructing the person with dementia as a person who loses fitness and abilities, Karen is able to construct her role in a way that emphasises helping people to deal with the practicalities of their situation. Supporting the person in this way is linked to maintaining independence, dignity and privacy.

Understandings of ageing are important in these carers' appreciation of quality of life. Perspectives of ageing involve both positive and negative interpretations of its influence on a person's life. For instance, Karen describes working with people who are ageing, and so she contextualises care as part of the ordinary life course, remarking on how she might need similar support when she is older. On the other hand, working with older people is sometimes construed as negative, something from which she needs relief, and Karen explains that she has to work with younger people too, because otherwise she would become depressed. Joyce also understands life history work in the context of ordinary ageing. However, the importance of looking back, rather than looking forward, is attributed to a particular perspective of older people. And in framing her role as a facilitator, Joyce describes the importance of taking more of a lead with older people to help them open up, which can be compared to the importance of empowerment and ownership that she relates to working with younger people.

With an understanding of dementia as affecting skills, activity is a focus of Joyce's approach to holding onto past skills. Activities are based upon past skills that have been part of a person's daily routine. By keeping things going in day care, the intention is to keep skills going for longer at home. Mental stimulation and social interaction are an important part of Joyce's work. Similarly, having company and being active are what Karen understands as having most impact on an older person's quality of life. Irene

describes supporting her husband by taking him places or doing things with him that provide opportunities to raise his awareness. A good day is described as a day when his brain is active and he is able to feel, which is similar to the ways that Graeme and Joyce represent maintaining involvement in terms of keeping a person's mind active and exploring feelings. These carers are emphasising the importance of remaining mentally and socially engaged in the present in ways that support ordinary living. This description of continuing engagement is similar to the ways that older people talk about keeping socially involved and keeping moving.

Continuity is also important in the context of physical involvement when communication is more difficult. For instance, despite sadness at the difficulties her husband is experiencing, Irene can continue to represent moments of her husband life as meaningful. She interprets her husband getting up and swaying as representing his love of dancing. She also associates a continued desire and intention to do things like walk, evident in her description of her husband having an awareness that he should be walking, even when he has difficulty in doing so. Irene can represent aspects of her husband's life as meaningful in relation to connections with the past and her belief that he still wants to be involved. She can therefore continue to find meaning in his life despite the difficulties associated with his cognitive impairment. Quality of life from Irene's perspective involves her husband continuing to have moments of awareness that represent his inclination to continue to be physically involved in the world.

Creating a positive homely environment is an important aspect of Graeme's description of his role to support people with dementia to have a good quality of life. Joyce describes a similar philosophy in relation to day care, in terms of bringing older people with dementia into a home situation, rather than an institutional set-up. Within this context, Joyce describes the importance of goals of care that include safety, security and comfort. Joyce's

role is constructed as making the setting warm, welcoming and accepting in order to keep people emotionally safe. With a focus on her role as facilitator, Joyce focuses on creating a relaxing environment to support the person. Irene also defines her role in emotional terms, representing the importance of calming her husband. This is related to specific activities that relax him, such as bathing or listening to music. The social environment is perceived by these carers as an important background for the person's experiences, and so a positive social environment is interpreted as important for quality of life.

Joyce focuses upon the importance of group cohesion, highlighting the value of creating a social environment that encourages mutual support and friendship. For instance, she narrates a story about one older woman who looked after a man in her group whose condition was declining. This is similar to the accounts of older people in their descriptions of the value of meeting and supporting people in similar circumstances. The main aim of day care is described by Joyce as having a good day out with friends in a familiar and homely setting. This places people's relationships within the context of an ordinary friendship. Karen also focuses her care around social connections, either taking people out, or providing company in their own homes. Karen views listening as an important aspect of her care, and her accounts of sharing stories with older people suggest a sense of inter-generational exchange and mutual interest in each other's lives. Like Graeme's emphasis on maintaining family and social involvement, Joyce and Karen understand the importance of social engagement within the context of available social networks.

The emotional adjustment of older people is important in these carers' narratives. Joyce describes how "there is a lot to come to terms with" when living with dementia. Joyce emphasises the importance of making people feel special, valued and important as individuals. This is in the context of the potential danger posed of feeling like "a nobody"

or being “a burden” and “not being good to anybody”. The need for affirmation is therefore related to the way others may devalue people with dementia. Joyce is expressing her awareness of the social stigma surrounding people with dementia and its consequences for the person’s quality of life. Joyce feels that quality of life does not depend on what can be remembered, but whether positive feelings stay and linger. In focusing on feelings, enhancing self-esteem and self-confidence is viewed as important. This can be related to the narratives of older people with dementia, who similarly talk about their ways of coping and the need to have confidence to do things.

Within a focus on people’s feelings, life stories are viewed as potentially healing, which suggests that Joyce recognises the person in the context of enduring and coherent emotions. In using reminiscence to look to the past and explore feelings, Joyce is emphasising enduring connections between the present and the past. The focus in reminiscence is on sharing memories and stories, described as both happy times and sad times. This construction of good and bad experiences is similar to the way people with dementia talk about their lives, recognising the balance of emotions that is a part of ordinary living. In understanding difficult emotions, Joyce frames loss within the context of the person’s own feelings about the effect of a loss of skills on their quality of life. This can be compared with carers who represent loss in terms of the person’s identity, and who consequently frame the impact of loss in terms of their own quality of life as carers.

Emotions are also important in relation to carers’ own direct relationship with the person with dementia. In the context of family relationships, Linda’s perspective that her husband still has some residual awareness of their bond is important in being able to continue to meaning in his life. Linda explains that, while on the surface her husband does not seem to recognise her as his wife, there is still a deep emotional connection between them. This is represented in Irene’s description of how her husband will say to her “you are me”, and he

will give her arm a small squeeze, which he does not do with anyone else. Irene reflects on this bond between them: "He knows there's a process between us". In being able to focus on such moments of awareness, Irene can still represent a connection to her husband at these times, and so maintain an element of shared meaning in their lives. Despite the change in their situation, Irene still represents her husband in a way that emphasises their continuing relationship and feelings for one another.

For paid carers, the way they represent their relationship with people with dementia is significant to the emotional context of their narratives. For instance, Joyce distinguishes her formal relationships with clients as different in quality from relationships with her own family. Like Graeme, Joyce is representing emotional boundaries in her role as a paid carer. Karen also represents a boundary in her relationships, describing how she becomes upset when a person dies, but explaining that she can put this in the context of being something that she does not like about her job. Karen rationalises that she cannot take her job home with her, and that consequently she has "to get on with it". Like Joyce, Karen describes the people she works with as "clients", rather than as friends or family, and she describes having a different perspective from a person's family. Karen is framing herself in a professional relationship, and this enables her to deal with the emotional challenges of her work.

In considering carers' perspectives on quality of life, it is therefore important to understand attitudes towards dementia and ageing in terms of their own emotions. In being able to retain some emotional distance, these paid carers are able to view a person's situation from more than one perspective. For instance, Karen represents tensions between the perspectives of people with dementia, their families and paid carers. Rather than viewing difficult situations as linked to the individual behaviour of the person with dementia, they are understood in relation to differing interests and actions among related

parties. Joyce describes an occasion when she protected other members of the day care group from seeing another woman who was sick. Compared to Maureen's account in chapter seven about her distress at dealing with sickness, Joyce's concern is not interpreted in terms of her own emotions, but in terms of the effect on other people who she feels could be upset. In understanding her role as a facilitator, Joyce frames her goal as helping people to have the best quality of life that they can in the context of a service philosophy: "I think [the goals of the service] came together to help them get the best quality of life as they could do". This professional frame of reference enables Joyce to focus on her role of making people feel emotionally safe.

Paid carers in this group are also similar in the way that they understand the difficulties of dealing with cognitive and physical limitations from the perspective of both the person providing and receiving care: "It's quite hard for me, and it's quite hard for them". Care is represented as "hard work", and this is a phrase that is repeated throughout Karen's account. In a story of a particularly challenging experience, Karen describes both herself and her client becoming agitated. Agitation is understood as a response to a difficult situation, rather than as an inherent quality of the person, and it is represented as something that Karen experiences in a similar way to the older person. Karen discusses the practical steps she takes to deal with these kinds of situations, and her resolution to this narrative involves pragmatism: "You've just got to get on with it the best you can". Difficulties associated with care are related to the difficulty of the situation rather than the person, and the emphasis is upon coping and moving on from the challenges associated with care.

While these narratives focus upon quality of life from the perspective of providing care, they still represent similar themes to what is evident in the narratives of older people with dementia. In framing the person with dementia in ordinary terms, particularly in respect

of continued emotional and social connections, carers are able to construct the person's life as having meaning. Empathy is an important aspect of these accounts, which is related to the carer's capacity to continue to connect with the older person's perspective in ways that emphasise normal feelings and reactions. In characterising her support, Joyce represents "keeping things going by exploring feelings", while Irene describes support for her husband as "doing things because of your feelings for the person". While the challenges involved in caring are acknowledged in these accounts, the focus is on maintaining practical and emotional support for the person, which is evident in Karen's description of "getting on with it to support abilities". With the recognition that feelings and awareness can endure, carers are able to take the perspective of the person with dementia in evaluating their quality of life, and focus on the impact of the social environment in its capacity to support the person.

### **Coping with the difficulty of maintaining normality**

#### ***Duncan: 'working out how to treat the person'***

Duncan's wife is defined as someone who cannot achieve things. When describing the strange quality of her involvement in activities, Duncan explains that it is difficult to work out what his wife is really trying to achieve, which he represents as extremely frustrating. Although she has difficulty with physical tasks such as eating, using her hands, and walking, Duncan believes that her physical capacity remains, but that it cannot be used properly possibly because of a problem with a mental aspect of her brain. He goes on to describe how his wife struggles with weight loss, which he associates with her strange eating habits, and relates the potential for weight gain as in his hands alone, due to her total lack of awareness. Therefore, because she is understood to be incapable of achieving things on her own, Duncan constructs his wife's ability to accomplish anything as dependent upon his actions. The focus of this particular narrative changes to his own needs, and how he is struggling to cope with her difficulties. The loss and suffering that is



represented as pervading his wife's life is also encompassing his own quality of life due to his wife's total dependence on him.

Duncan's perspective on the quality of his wife's life is framed in the context of the loss of her sense of self as an adult and as a wife, mother and grandmother. This changed identity is related to a change in the quality of his wife's experiences. Duncan describes how she no longer gets any pleasure from the activities she used to enjoy, due to the changed quality of her connection to them, such as Duncan's description of her knitting that was discussed in chapter seven. His wife is also perceived as wanting to go back to see her mother, who has been dead for decades, representing the distorted quality of her connections to significant others. Pleasures in her life are perceived as momentary and fleeting, and her involvement is represented as imagined, strange or purposeless. For example, Duncan describes his wife as extremely restless and links this with her "awful" idea about materials, which is associated with how she compulsively rubs fabrics and asks to go to the shop to buy new materials. Following this description, Duncan repeats the statement: "But I don't know what she's thinking about". The confusion of his wife's state of mind is related to his own confused perspective about what she is thinking.

Duncan connects the view that his wife gets little pleasure out of the things she used to enjoy, with how "it gets harder and harder and more difficult to please her". There is a sense of bewilderment and frustration about discerning what his wife needs and wants. Duncan uses rhetorical questions of what he thinks she might want to reflect his belief that her needs are unknowable. Therefore, his wife's changed involvement in life is represented in terms of Duncan's difficulty in understanding and responding to her needs. However, although Duncan describes being unsure of what his wife needs, he explains the importance of reassurance for his wife. Duncan believes that she really wants reassurance from her mother, but as she is not there, his wife consequently seeks reassurance from

him. This reassurance is linked to a dependence on Duncan that he describes as “not wanting to let me out of her sight”, and which he evaluates as preventing him from getting on with what needs to be done in the house. Duncan explains that, as his wife sleeps a lot, he finds it easier to let her lie in bed, so that he can have time to himself to do things. This suggests that while some of his wife’s needs are understandable, their consequences are interpreted in terms of their impact on his own life, which is viewed as detrimental.

A need for reassurance is also interpreted in terms of the changed meaning of their relationship. Providing reassurance is an aspect of their relationship that Duncan describes as enduring from before. However, despite representing this continuity, their relationship is understood in the context of a changed connection in their bond. This interpretation is suggested in the way Duncan sets up a comparison between the present and the past in his narrative. Duncan explains that, whereas he now holds his wife’s hand because she stumbles, he compares this to her previous reluctance to hold hands in public. Duncan perceives this change in behaviour in terms of his wife’s need for security rather than affection. Duncan comments on how others joke about them being “the young lovers” when they are seen holding hands. This interpretation reflects the paradox that, while on the surface there is more physical closeness than before, he perceives the deeper connection with his wife to be lost. Duncan believes that his wife views him as an uncle or father-figure, rather than as a husband, and he describes her as really looking for reassurance from her mother. Therefore, in the context of a change in the quality of his wife’s identity, Duncan also interprets their relationship as changed in quality.

In terms of the impact of his wife’s dementia, a recurring feature of Duncan’s narrative is how social activities have either “fallen by the wayside” or been stopped by him. This is explicitly related to concerns about spoiling other people’s activities, but close attention to his narrative suggest that it his own difficulty of dealing with other people’s attention to

his wife and her difficulties. Duncan is concerned about the fuss and mess surrounding what his wife does, and describes how people know that “there’s something not quite right”. The following narrative indicates how his shame about her condition has resulted in their changed social involvement:

***Narrative: The difficulty of dealing with something being wrong***

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***Stanza 1 (Orientation: we used to go for lunch with friends)***

We did go for lunch  
on a Thursday with our friends

***Stanza 2 (Complicating action: I was having to pay too much attention to my wife)***

Again it got to the stage  
I was possibly wasting the lunch  
for my friends  
by paying too much attention  
to my wife you know  
and keeping, trying to keep her right  
and keeping her fingers out of her dinner  
and things like this

***Stanza 3 (too much attention was being paid by other people)***

So that kind of fell by the wayside.  
but we went to [café] quite a lot  
for coffees  
and two or three of the assistants in the café  
would go out of their way to bring her extra wee biscuits

made a fuss of her

but again too much notice

was being brought to bear upon her

***Stanza 4 (Evaluation: it was emphasising there was something wrong with her)***

And folk were starting to stare at her you know

why are you getting extra biscuits et cetera

and it was emphasising

I thought in their minds

there was something wrong with her

***Stanza 5 (Resolution: we still go for coffees but we need to be discreet)***

So that, we still go for coffees

but I tend to be more choosy

about where we go

maybe a wee bit more discreet

you know

we can sit

without having too much attention paid to us

***Stanza 6 (I've got to make sure she does things properly)***

And it's bad enough, you know

I've got to try and get her to be seated properly

or close to the table et cetera

so that she doesn't spill anything and you know,

take away the saucer

and things like that

and folk do notice these things

***Stanza 7 (Coda: it's not appropriate)***

And as I say

I don't really think it's appropriate

Duncan talks in the plural – “we”, “our”, “a couple” – which shows how their lives are interlinked and how he perceives his own quality of life being adversely affected by his wife's behaviour. In starting this narrative by talking about what they used to do, the comparison between the past and the present is clear. Duncan is concerned about emphasising that there is something wrong with her mind, and so he has withdrawn from the usual group with which they socialised. The stigma of his wife's spoiled identity is understood as requiring him to be discrete and make sure that his wife does things properly, and so Duncan has to be more careful where they go out, so that other people pay them less attention. Following this resolution, Duncan describes how they have had to stop their holidays, and that their lives have had to be curtailed. This loss is a recurring feature of Duncan's accounts of his wife's life in terms of how their social activities have been restricted.

Duncan's narrative highlights the importance of his wife behaving appropriately. His evaluation of their situation is that his wife's inappropriate behaviour creates the need for people to go out of their way to help her. A lack of normality is linked to her focus of attention, which Duncan describes as an interest in children rather than adults. The perceived lack of engagement in adult life is evident in Duncan's description of how she has little input in conversations, loses interest, and cannot keep track of what people are saying. When they are in company with friends, Duncan describes having to stay close so that he can keep an eye on her and make sure she does not make too much mess. This is

similar to his perception of his role in the narrative above. As a result of his wife's perceived regression to being a child, Duncan's role is represented as custodial, how a parent might watch over a child to make sure they do not behave badly.

This representation of his wife's identity poses a fundamental challenge in Duncan's narrative. A recurring question he poses is how he should treat his wife. He debates aloud whether or not his wife would get more pleasure from being treated like a child, such as being given rewards for good behaviour. Duncan therefore struggles to find a way to relate to his wife in a way that is meaningful. Duncan also struggles to deal with his perception that his wife wants her mother for reassurance. He is uncertain of how to deal with his wife's requests to visit her mother, as he is concerned that explaining that her mother is dead will distress her, yet he has to provide explanations for why he cannot take her. When his wife's fundamental desire for reassurance cannot be met, as it relates to someone who is no longer alive, the meaningfulness of her wishes is questionable. The inability to find a solution to this problem causes Duncan distress. With his wife's fundamental desire perceived as impossible to fulfil, Duncan is unable to represent anything positive about his wife's quality of life.

The period of time that Duncan's wife has had dementia is described as one of suffering: "She's been suffering from this". Dementia is related to his wife forgetting the "good memories" of their life together. With the loss of shared meaning, Duncan's overall story is about the loss for their relationship. The sense of strangeness and pointlessness of his wife's thoughts and behaviour is related to a sense of normal meaning-making having gone. Unlike the previous group of carers who can empathise with the perspective of the person with dementia, Duncan is unable to understand and identify with his wife's perspective, as he perceives it to have no basis in reality, due to her perceived sense of herself as a child and no longer an adult. His perception of a faulty awareness is therefore

fundamental to Duncan's account. Duncan understands his wife's quality of life in the context of her changed relationships to himself and others. The quality of his wife's life is therefore represented in terms of its strangeness and lack of meaning. In being unable to understand his wife's perspective, Duncan switches focus to represent his own quality of life in terms of his difficulty coping with the lack of shared meaning in their lives.

***Coping with the challenge of a lack of normality***

Duncan is unable to make sense of his wife's perspective, due to her perceived inability to appreciate her true self. With the absence of shared meaning-making, he focuses on his own emotional response in adjusting to the difficulty of trying to work out how to treat her. The emotional difficulty of dealing with such challenges is evident in the accounts of Teresa and Maureen, paid carers, and George, Cathy and Robert, family carers who support their friend and mothers with dementia. They represent the older person's identity as being altered by their condition and no longer being normal in the context of ordinary social roles and relationships. In the context of this lack of normality, these carers focus on their own agency in trying to maintain a sense of normality in the person's life. Due to the contradiction that is inherent in this strategy, these accounts represent the unfeasibility of maintaining an ordinary quality of life, and focus on the impact of the person's changed nature on the carer's own quality of life. The perspectives of these carers represent the emotional costs of coping with a lack of normality. Due to the particular content of their narratives, I will consider each carer separately, to demonstrate that even when challenges are represented differently, the narrative processes of meaning-making are similar in quality.

**Maureen: 'coping with trying to maintain a sense of normality'**

Maureen understands people with dementia as wanting to be treated as if they are normal, despite believing that the person has something wrong with them due to the

impact of dementia on their nature. In endeavouring to treat people as normal, Maureen's care is constructed as "just try[ing] to keep everything as normal as you can with them". The emphasis on *trying*, with *them*, indicates that the status of doing so with this group of people is questionable. The tension in trying to keep a sense of normality to a person's day is represented as an emotional struggle for Maureen that is expressed throughout her narratives. Maureen's difficulty in resolving the issue is evident in a story about her response to a woman with dementia who feels upset about being patronised by someone who thinks she is "daft": "Well, what can you say?" Like Duncan's use of rhetorical questions, Maureen is posing this question in a way that reflects the impossibility of knowing how to respond. This attitude can be linked to the questionable value of trying to create a sense of normality.

The tension in Maureen's account is related to the way she frames the older people she works with as friends. Maureen describes how "you're trying to keep a *sense* of normality to their day, and not make it that's a (pause) day care centre, it is just visiting a pal, and that's how we try to go along". This emphasis on 'we' is often used when describing her approach, which suggests she is describing the service philosophy which frames her work. The qualification of keeping a *sense* of normality reflects the contradiction of framing a day care service as "visiting with a pal". This sense of treating people as if they are normal is reinforced when Maureen describes people coming "for a chat like you're coming to a friend's house for a visit". Maureen describes this approach as "that's how we always tend to look on it". The emphasis upon looking at it this way indicates that the reality is different. This contradiction in her role is represented in Maureen's explanation that "you're working, but you're not working", which reflects the tensions in providing paid care while trying to emulate friendship.



Within accounts of activities at day care, Maureen describes people helping with activities such as meal preparation and shopping. Although these are framed as ordinary activities, Maureen represents the emotional cost of helping people to “make the best of their day”, which she interprets as keeping a sense of normality. Maureen describes herself as “emotionally shattered” at the end of each day. Her narratives about the emotional challenge of dealing with sickness and death are concluded by phrases that try to resolve her own feelings. Maureen talks about trying to do a good job, but being devastated by the fact that people die, which can be understood in the context of her representation of dementia as a progressive process of decline and death. In struggling to deal with the emotions involved in the perceived contradictions of her role, Maureen interprets quality of life in the context of her own efforts of trying to maintain normality when a person’s life is disrupted by dementia.

**Teresa: ‘dealing with the difficulty of becoming attached’**

Teresa describes how she tries to give the people she cares for everything they need, in terms of making the person feel as if it is their own home. The perceived importance of the environment is therefore different in quality from the perspective of carers who emphasise the significance of maintaining skills for continued independence and involvement in valued social roles. While Teresa acknowledges a need to encourage people’s independence, she describes this as difficult from her perspective of wanting to do things for the person. She finds it difficult just letting people sit and chat amongst each other, as she feels that she is not stimulating them. Teresa describes making a difference in a person’s life by indulging and pampering them. While describing these aspects of care, the focus is on Teresa’s personal involvement and attachment to the person. Showing patience and love are therefore described as important qualities of this care. This can be contrasted with Karen’s emphasis on letting people do things for themselves, and the emotional distance she creates in her accounts, while retaining empathy for the person’s

situation. Teresa is therefore describing quality of life in terms of the quality of her care, and the person's own agency is not included in this perspective.

The way that Teresa understands her relationship to the older people she cares for is significant for understanding her perspective of care. For Teresa, care is associated with looking after a person like she would look after her mother. She likens her position to that of families and represents the older people with dementia as becoming part of her family, as extra "grannies" for her grandchild. This association with familial relationships is related to her close attachment, as is suggested in the use of personal possessive pronouns when describing her clients. In describing why a woman came to visit her mother, Teresa comments: "It was *my* lady's birthday". Teresa's narratives represent the way she has come to replace family connections that have been lost for the older person. This loss of connections is tied to the emotional difficulty of families being able to retain a relationship with the person when they are not the same as before: "They just don't know what to do, they don't know what to say you know, it's not their Gran, so it's very, very hard". Rather than focusing on maintaining the person's existing social connections, Teresa is representing the importance of her own role in fulfilling this need.

In understanding dementia as diminishing a person's identity, and representing quality of life from the perspective of care, Teresa's account focuses on the meaning of loss from the carer's perspective. This difficulty is evident in Teresa's description of guilt among families when a person with dementia "moves on" and has to be placed into institutional care. Families are depicted as struggling with the situation and Teresa describes her sympathy for them. Moving on is understood as happening once the person reaches an "advanced stage" when they are "in their own world". In framing the person's emotional existence as separate, Teresa's evaluates the situation in terms of her own emotions: "It's very hard when they move on". Stories about challenges, for instance in dealing with

hallucinations, are framed from her perspective as a carer and the impact it has had on her life. Particularly emotive and vivid stories deal with the theme of death and the difficulty of being attached to people who will eventually “move on” into their own world. Teresa is using individual stories to build an overall account of the burden of emotional attachment for the carers of older people with dementia. As the person is understood to have become socially dead, the difficulty of their situation is represented in terms of the carer’s own quality of life.

**George: ‘not having enough time for oneself’**

Keeping his friend at home is important for George, and he describes different ways he has tried to avert risk and keep his friend’s house safe. George’s perspective of vigilance is important in trying to keep the situation going. George’s narratives reflect the amount of time and energy that this involves, establishing the impact of dependency on his own quality of life. Like Duncan, George represents the difficulty of dependence, as his friend increasingly relies on him for support. His friend is described as doing less and less for himself. Consequently, when summing up what is most important in his friend’s life, George says that this involves keeping him fed, comfortable and interested, and basically trying to let him lead as normal a life as possible. George is therefore representing all the things he must do for his friend to lead his life in as normal a way as possible. Like Teresa and Duncan, George’s perspective on quality of life is presented in terms of his own instrumental role in doing things for the person. In this account, agency has been shifted from the person with dementia to the carer.

After the diagnosis of dementia, George emphasises the change as their friendship “moves on”. Paralleling a development of out of character behaviour is a description of the ever-increasing demands of caring and George’s attempts to manage a lack of time. An important aspect of George’s role in caring is understood as reassuring his friend.

However, George explains that it is difficult to spend a lot of time with his friend, as his character and behaviour have become too difficult. The stories within George's narratives build up a momentum of inevitability that represents a downward spiral of deterioration and decline to ultimately represent a care situation that is no longer tenable. There is a sense of overwhelming dependence that is similar to Duncan's description of his wife constantly needing to be beside him for reassurance. Like Duncan, George switches focus in his narrative to evaluate his own quality of life.

George evaluates his friend's quality of life in terms of its sense of normality. George explains how he has to try to let his friend live a normal life, yet whether this is possible is construed as questionable, and ultimately his condition cannot be constructed as normal: "[I have to] try and let him lead a life as normal as possible, which is difficult because what's normal for somebody in [my friend's] condition". This is a similar position to Maureen's evaluation of her role in trying to retain the person's normality. In trying to let his friend lead as normal a life as possible, George is not having enough time for himself. Quality time is also described as important to his friend, yet to give him this George represents how his own quality of life must suffer. The quality of their lives is represented as intertwined. George can no longer focus on continuing to maintain the normality of his friend's situation, as to do so negates his own capacity to realise a good quality of life.

**Robert: 'figuring out how to make the person happy'**

In Robert's evaluation that his mother has moved to a special category, he is representing her social status as diminished. This diminished status is equated to a diminished quality of life, and Robert recounts events and experiences that highlight his mother's anguish and distress. This status of being in a special category is related to his mother's behaviour as being "totally unnatural to her", and his evaluation that it would be kinder to tranquillise her to make her calmer and avoid putting her through the distress he thinks

she feels. Robert believes giving his mother a tranquiliser would enable her to interact with other people, which he believes would make her happier on the surface. Making his mother happier on the surface can be compared to his uncertainty about what she feels at a deep level. Robert's account suggests that most of time he can no longer connect with his mother at a deeper level to make sense of her perspective.

His mother's confusion is emphasised in descriptions about how sometimes she realises she is in hospital, while at other times she thinks she is at home and there are strangers in the house, and yet other times she thinks that she is being imprisoned. Robert's evaluation is: "So it's very difficult to pinpoint just what exactly would make her happy all of the time". It is easier for him to see when she is *less* happy, which is in hospital, and so he concludes that she is happier at home. Robert states that while he considers that keeping her at home for as long as possible would make her happy, he has no way of knowing if this is right, and he stresses it is only his *belief* that she would rather be at home. The struggle for Robert is in trying to figure out what makes his mother happy when he cannot make sense of her perspective. He cannot access her own sense of meaning-making directly, and this creates an uncertainty about what makes her happy: "It's so difficult, to know what really makes her happy, because she can't tell you".

The emphasis is upon the difficulty for his mother of living in the present, and this relates to Robert belief's that his mother would rather be living in the past. There is a sense of hopelessness and despair in Robert's evaluation that there is nothing that anyone can do to help her cope with this feeling. Despite a need to discover what would make his mother happy, the apparent disparity between what his mother wants and what she actually does makes this an impossible task. With the perception that what the person wants is not what they enjoy, the onus is placed on the carer to try to figure out and decide what the person actually does need. Robert explains that *keeping* his mother at home for as long as

possible is very important. The use of 'keeping' emphasises his family's instrumentality in keeping this situation going rather than through her individual agency. In perceiving his mother as living in the past, Robert is unable to represent a perspective that involves an appreciation of her life in the future beyond what his family can do to keep her at home.

The overall theme of Robert's account is of being unable to make sense of his mother's meaning-making. There is a concern for getting at the truth, finding out what is really happening, and what she really wants. Associated with this difficulty in making sense of her situation is the variability in his mother's behaviour and level of awareness: "So again it's the fact that everything varies with her from hour to hour ... there is no single rule that you can use". Robert describes feeling "stuck" and therefore that "those caring for [people with dementia] have to have some solution to the problems". In this context, the problem of finding meaning is constructed as a task for the carer. When Robert describes his mother's potential for enjoyment, he frames this in the past tense. Other than still dressing well, religion is perceived as the only thing that still brings her comfort. In comparison to Graeme, who highlights the importance of church for continued social engagement, Robert relates the importance of a spiritual connection to the need for reassurance in his mother's life due to its lack of meaning.

**Cathy: 'coping with the context of a change in personality'**

Cathy's construction of her mother's quality of life depends upon the context of her accounts. On occasions when her mother's identity is perceived to endure, Cathy describes setting up housework that helps her mother feel that she is still useful and capable. She compares her way of supporting her mother with the rest of her family who do things for her. Cathy also talks about finding activities to suit her mother's ability or disability. This perspective takes account of strengths as well as limitations. In comparing past and present activities, while opportunities seem more restrictive than before, Cathy talks

about what they hope to do in the future together. The potential to look forward is an aspect of this narrative that is absent from most other carers who represent the older person as different in character to before. In representing the potential to be involved in ordinary activities, Cathy can represent her mother's life to be meaningful.

This narrative can be contrasted with more frequent references to the occasions when Cathy understands her mother as having a complete personality change. Cathy talks about how it is like staying with a stranger, something which is difficult for her to accept. The impact of living with this strangeness is therefore interpreted from her own perspective. She explains that coping with her mother becoming different from before is the hardest thing to cope with. Like Robert, variability is also described as being particularly difficult to cope with, and Cathy expands on how she does not know how her mother is going to be when she wakes up on any given day, whether she will be ranting or being "just quite normal". This different focus on Cathy's own quality of life reflects the way that the perception of uncharacteristic and unusual behaviour makes it difficult for carers to appreciate the person's own perspective on quality of life.

Despite Cathy's attempts to support her mother, one of the main difficulties that she describes is trying to make her mother understand and accept that she cannot do certain things. Cathy describes it as her mother's mind not being able to understand that she cannot do certain things or think ahead to the implications. She describes the frustration of not being able to explain and discuss the things that her mother will not accept. Cathy's perception is that there is no answer to this problem. Other issues include her mother not having a concept of time and the stress and pressure of having to deal with this. The way that this is constructed in Cathy's accounts represents her mother as not appreciating time and this is associated with her repetitive behaviour. The pressure for Cathy is of having to

live with this continuously. Her mother's meaning-making is portrayed as problematic in this context and this is associated with behaviour that does not make sense.

Like the narratives of other family carers, the lives of Cathy and her mother are represented as intertwined. As a result of this interdependence the extent to which Cathy has had to change her own life to care for her mother is described. The difficulty that is expressed in different stories is the way that Cathy cannot explain things to her mother because she does not understand. Part of the problem is represented by her mother's denial of having dementia, which is similar to George's description of part of the problem in making sense of his friend's responses. The lack of shared meaning-making from the perceived change in her mother's personality is making it difficult for Cathy to represent either her mother's or her own life positively. In the context of her mother's identity having changed, Cathy has difficulty representing their lives positively: "It takes a long, long while to accept it. It's not the same person, never will be again. That's the other thing. Things can only get worse, is the other way to look at it". With a sense of the person being fundamentally changed, it is difficult to look forward and represent the potential for a meaningful life.

## **Conclusion**

In chapter eight I have shown that perspectives on quality of life are contextualised in terms of the perceived role of the carer and their emotional response to caring for a person with dementia. Perspectives on quality of life are embedded in the ways that carers talk about relating to the people with dementia with whom they live or work. An ordinary and therefore meaningful life involves constructing the person as actively and productively engaged in the social world, which includes fulfilling the social roles that are expected of the person in the context of their life history. When a person's life cannot be understood within this framework of normality, or it becomes too difficult to continue



providing a level of care that is necessary to maintain this position, carers switch their perspective to focus on the impact of dementia on their own quality of life. With a sense of meaning having gone, the focus in these narratives switches from the person with dementia to the carer's personal struggle to find meaning in caring for the person with dementia. The emotional difficulty associated with the carer's inability to make sense of the person with dementia impacts on the extent to which the carer can represent the person's life as meaningful. This indicates how the feelings and emotions of carers are bound up in the way that they can construct meaning in the lives of people with dementia.

Carers who can construct the person with dementia as the same person as before, but as affected by a loss of skills, represent living with dementia as dealing with the disruption caused by cognitive impairment and the restrictions imposed by a disabling society. In these narratives, the evaluation of a person's quality of life is linked to the extent to which the carer can support the person in creating a positive environment that helps them to maintain skills and abilities associated with everyday life. Their accounts reflect the active strategies of maintaining the momentum of an ordinary life that are similar to the descriptions of activity and involvement within the narratives of older people with dementia. In comparison, for carers who construct the person as losing normality and not being the same as before, the representation of uncharacteristic behaviour and loss of awareness affects the potential to perceive quality of life as meaningful. The perceived change in the person is evaluated in terms of the context of a deteriorating care situation, in which carers represent the increasing dependence of the person and the carer's increasing agency in keeping the situation going. These carers' narratives reflect their attempts to maintain an ordinary life for the person and adjust to the person's impaired engagement in the social world. The focus of these narratives switches to the carer's effort to find meaning in the situation and deal with the impact of the lack of normality for their own lives.

Carers' appreciation of quality of life among people with dementia involves them being able to make sense of a person's situation to find meaning in life. Carers who understand the person with dementia as losing skills and abilities represent quality of life in a similar way to older people themselves. Both groups focus on the person's continued capacity to remain involved in the social world, with support to hold onto skills and maintain a social environment that can uphold ordinary roles and relationships. This perspective on quality of life can be contrasted with carers who understand the person with dementia as losing their identity. Because these carers are unable to make sense of the person's behaviour as normal and ordinary, the evaluative elements of their narratives typically represent the impact of particular experiences from their own perspective. With the perceived loss of the person, these carers focus on the carer's own emotional struggle to make sense and find meaning in the situation. By paying attention to the narrative processes of meaning-making in people's accounts, this study has developed a framework of quality of life that pays attention to the identity and emotion work of people with dementia and their carers. The thesis has therefore addressed the gap in the literature about the meaning of different perspectives by exploring the ways that people with dementia and carers construct meaning in their accounts to understand the quality of life with dementia.

Differences in perspective relate to the extent that people can make sense of a person's situation in life relative to a framework of normality. Differing accounts among older people with dementia can be contrasted in terms of whether they perceive themselves as retaining a valued place in the social world, or whether they view their social status as diminished. Differing accounts among carers can similarly be contrasted in terms of whether they perceive the person as having a valid sense of self and social identity that affords a normal social status. The important difference between the accounts of older people with dementia and some of the carers in this study relates to the potential to find meaning in life. All the older people with dementia in this study construct themselves as

having the potential to be purposely engaged in the social world given the right support and attitudes of others. However, only some carers are able to represent the person with dementia as having the potential to be actively involved in life in a meaningful way. The perception of uncharacteristic and unusual behaviour makes it difficult for carers to appreciate the person's own perspective on quality of life. This is related to their emotional difficulty in making sense of the person as normal in this context. Being able to engage with the perspective of the person with dementia relates to being able to construct the person as having a normal social status. Different perspectives on quality of life therefore relate to whether carers can represent the potential for life with dementia to be meaningful.

# Chapter Nine

## Discussion and conclusions

### **Introduction**

The aim of this study was to understand the meanings of different perspectives on quality of life among older people with dementia and carers. This has involved a comparative framework of narrative meaning-making to understand the similarities and differences between people with dementia and carers in the ways that they make sense of quality of life. This concluding chapter discusses the key findings from the analysis in chapters five to eight, and relates the conclusions to the literature review in chapters two and three, and the three research questions set out in chapter one. I discuss the contribution that the study has made to understanding perspectives on quality of life among older people with dementia and perspectives on quality of life among paid and family carers. I then consider how a narrative framework has answered the question of how different meanings of quality of life have been constructed among the two groups. I conclude by considering the value of the narrative approach taken in this study to advance a comparative framework of quality of life, and the implications of the findings for how we relate to older people with dementia and for future research in this area.

### **The construction of meaning in different perspectives on quality of life**

#### ***Perspectives on the quality of everyday life among older people with dementia***

Understanding the narrative processes that people use to make sense of self and social identity has revealed a deeper understanding of subjective perspectives on quality of life among older people with dementia. The way that a person makes sense of their self and social identity is closely associated with the way that they evaluate their current life circumstances. In their narrative accounts, comparisons are made between the past and

the present, and the primary focus is upon how a person can live their life in the present in a way that reflects valued social roles and relationships from the past. The process of meaning-making is relevant to the person's perceived life stage and how they make sense of their experience of dementia. The person's appreciation of their life is demonstrated to be fluid and evolving, as they move backwards and forwards over time to define their self and social identity in the social world.

The creative process of meaning-making involves images and metaphors of movement as people describe their attempts to engage actively within the social world. This movement reflects the energy involved in maintaining an ordinary life in a society that stigmatises ageing and dementia. This biographical work involves people defining and locating their self and social identity to represent their social position in life as normal and ordinary. The relevance of continuity is in being able to define self and social identity in ways that maintain a person's sense of status in the social world. The extent to which people can achieve this task in a meaningful way affects their evaluation of the quality of their everyday life. The narratives of older people with dementia involve active identity and emotion work as they endeavour to make sense of their experiences and deal with the practical and social consequences of ageing and dementia.

The findings from this study support previous research that links quality of life to the way a person is able to engage meaningfully with the social world (Bryant et al. 2001). As Grewal et al. (2006) assert, it is the capability of achieving desired attributes, rather than the actual achievement of specific functions, which is most important for older people. As has been established in the literature that was discussed in chapter two, the social and emotional aspects of life are most pertinent in older people's accounts. Similarly, the social consequences of memory loss are most important to people's evaluation of their social status. Dimensions of life that are important for the older people in this study are similar

to what has been established in other qualitative studies. These include feeling capable and valued, being useful and having purpose in life, forming and maintaining relationships, caring for themselves and being able to help others.

Like Tester et al. (2003), the current study highlights the importance of continuities and discontinuities in the evaluation of quality of life. In dealing with discontinuities, there is evidence that people redefine what is 'normal' by emphasising continued 'normality' in their sense of self. In this context, the older people in this study focus on their ability to engage in valued social roles in the family and wider community in order to represent their sense of self and social identity as ordinary. The importance of the preservation of a sense of self and social identity has been established in the large body of work among people with 'early stage' or 'high-functioning' dementia that was considered in chapter two. The current study therefore extends this literature through its inclusion of older people who would be described as at a 'moderate stage' of dementia due to their increased level of cognitive impairment.

While the current study supports the literature about the importance of preserving a sense of self and social identity, it establishes some differences in the ways people find meaning in terms of 'protecting' their self from dementia or 'incorporating' dementia into their sense of self. Clare (2003) represents the process of adjustment to dementia as either self-maintaining, which is associated with normalising strategies, or self-adjusting, which is associated with coming to terms with a condition. These processes are reported to be associated with a person's level of awareness, with the assumption that coming to terms with a condition is linked to better awareness, which is consequently considered to be a more adaptive response to dealing with dementia. However, in the current study, in the case of Rena and Louis, both processes were associated with a positive sense of self and social identity, and consequently a good subjective quality of life.

For the older people in this study, quality of life is not associated with whether the person integrates dementia into their sense of self, or protects their self by representing dementia as a normal part of ageing. Quality of life depends upon whether the person is able to make sense of their experiences in ways which enable them to continue to be represented as normal and ordinary within their social context. For Louis, this involves rejecting a 'narrative of loss' (Beard et al. 2009), and incorporating dementia into a positive story of living. For Rena, it involve perceptions of intergenerational exchange, which reframes dependency as 'generational shift' (Saltz 2000) in the context of normal ageing. In holding onto a sense of social status, Rena and Louis are both able to represent positive narratives of living with dementia, although they attribute different meanings to their condition. This study therefore supports the position taken by Estes et al. (2003:152), that a critical analysis of identity in older people requires elements of continuity and coherence, as well as options and possibilities for change.

The association of quality of life with different processes of adjustment can be integrated with the literature on identity in the context of ageing and chronic illness. The association of self-adjusting processes with a good quality of life supports Hydén's (1997:53) position that narratives have the potential to give meaning to events that have disrupted and changed a person's life. However, most of the older people in this study contextualised their experiences relative to ageing and used normalising strategies to frame themselves as resilient, which supports the findings of other studies that have examined subjective experience among older people with dementia (Aminzadeh et al. 2009; Gillies 2000a; Langdon et al. 2007). Representing a continuous identity is important for most of the older people in the study, supporting coherence as a significant element of an integrated and satisfying life story for most older people (Bluck and Habermas 2000; Coleman 1986; Coleman et al. 1999; Sherman 1994).

The process of meaning-making in people's accounts involves the construction of self and social identity relative to the person's life history. Coleman et al. (1998) describe how story is used in making sense of the past and interpreting the present, with older people's sense of continuity associated with the relatedness of their recent life experiences to their whole life course. This has been evident in the current study, where the older people reflected on the past and considered their quality of life relative to ongoing themes in their lives. This finding supports Gubrium's (1993) description of older people's 'horizons of meaning', which arise from the pattern of narrative linkages between the past and the present.

Gubrium and Lynott (1983) have argued for the importance of understanding quality of life in a contextual sense, where continuity is established in comparative terms between the past and the present. This contextual dimension of the meaning of quality of life has been demonstrated in this study, where older people establish continuity in the context of important social roles, by comparing their present situation in life with previous life circumstances. Evidence for the importance of the contextual dimension of quality of life resonates with the quality of life framework articulated by Bond and Corner (2004), which focuses on how subjective meanings are influenced by the social context within which people live and establish their identities.

This study has therefore established that older people with dementia use stories as sites for asserting and maintaining their identities. As has been established in the literature review in chapter three, older people with dementia position themselves as active and capable within their narratives and within their communication. Steeman et al. (2007:119) have established that people with dementia often present positive narratives about their lives to counteract "threats posed by dementia and their interactions with others". Macquarrie (2005) and Gillies (2000a) have similarly shown that people with



dementia resist their diagnosis through reminiscence about past achievements and experiences of competence. These comparative processes were particularly evident in the accounts of Cynthia, Ted and Martha, who represented their devalued social identities in the context of ageing and dementia.

To summarise, older people with dementia use images of movement to describe their agency and action in terms of participating in the social world and dealing with the personal and social challenges associated with their condition. The accomplishment of an ordinary life involves looking backwards to sustain continuity with the past and looking forwards to maintain momentum and keep going. This impulse for action drives the narratives within individual accounts of living with dementia. This narrative motion illustrates that identities are not static but variably achieved or lost depending upon particular contexts and relationships. Whether meaning can be found depends upon whether life can be represented as ordinary. The accomplishment of this status depends upon the perceived distance between a person's sense of self and desired social identities. Finding meaning therefore depends upon maintaining connections with valued roles and relationships from the past or establishing new roles and relationships that bring a new sense of purpose to life. The narrative accomplishment of an ordinary life involves making sense of self and social identity as ordinary and finding meaning from active involvement in everyday life.

### ***Perspectives on quality of life among carers of older people with dementia***

This study has developed a narrative appreciation of perspectives on quality of life among the carers of older people with dementia. It has established that a carer's evaluation of quality of life is related to the way that they make sense of the older person's social status as normal and ordinary. The achievement of a valued social status is associated with whether the person is perceived to be the same as before or whether their identity is

understood to be fundamentally altered by dementia. The extent to which a person's self and social identity can be represented as enduring is associated with how carers interpret the person's awareness and behaviour as either normal or out of the ordinary. This interpretation is related to meanings of ageing and dementia, and whether the person's actions can be contextualised as appropriate to their social situation or representative of a disrupted identity. In a similar way to older people with dementia who reflect upon their changing social status relative to ageing and dementia, so carers understand the person's position in life relative to the impact of ageing and dementia on their self and social identity.

Significantly for a comparative framework of quality of life, carers' accounts can be understood as similar to those of older people with dementia in their concern with the social aspects of a person's life, particularly in relation to the importance of social roles and social status. An ordinary and therefore meaningful life involves constructing the person as actively and productively engaged in the social world, which includes fulfilling the social roles that are expected of the person in the context of their life history. This indicates that carers have similar perceptions of what is important to the quality of life of the person with dementia. Their understanding of what is necessary for a good quality of life is not fundamentally different to the person with dementia. This is important, given the evidence of differences in reporting of quality of life that was established in chapter two, which might indicate that older people with dementia and their carers focus on different aspects of a person's life.

Differences in perspectives on quality of life are contextualised in the identity and emotion work of the carer, and whether they can engage with the perspective of the person with dementia. By applying narrative analysis to understand processes of meaning-making, it has been possible to examine how cultural meanings of ageing and dementia impact on

constructions of identity and social status in representing the quality of a person's life. The extent to which carers can engage with the person's perspective depends upon their emotional response to the care situation, which is linked to their understanding of the meaning of dementia, the associated impact of the condition on the person's identity, and the related interpretation of the consequences of the person's behaviour for their situation in everyday life. This reflects the integration of what Bury (2001) describes as 'core', 'moral' and 'contingent' narratives.

The impact of 'core' narratives is evident in the way carers draw on cultural meanings of dementia in their accounts. This finding can be related to existing literature on the study of 'illness attributions' among carers of people with dementia. Hinton and Levkoff (1999) established that while some carers make sense of dementia as memory loss, others attribute dementia to the erosion of a person's identity. This dichotomy is evident in the current study, and can be linked to whether a person's condition is perceived as normal or abnormal. The important distinction in relation to people's accounts is therefore whether dementia is perceived as affecting a person's skills or their identity, the 'contingent' narrative. A relationship between 'illness attributions' and the perceived consequences of dementia is particularly clear in the accounts of paid carers. Those who understand dementia as an ordinary part of ageing represent the person as losing skills and abilities, whereas those who understand dementia in terms of a disease process that diminishes a person's self perceive the condition as changing the person's identity. Carers are therefore drawing on particular social constructions of dementia and ageing to make sense of the impact of the condition on a person.

While these ways of making sense of dementia are tied up in understandings of processes of normal ageing and abnormal disease, understanding dementia as a disease process and attributing its impact to the loss of identity are not synonymous. It is therefore important

to acknowledge that it is a focus on the erosion of identity that is the fundamental barrier to perceiving life as normal. As has been identified in the National Dementia Strategy (The Scottish Government 2010), the diagnosis of dementia is an important priority for improving care, and the focus of this thesis is that an ordinary life with dementia can be possible, rather than discounting the real existence of cognitive impairment.

This process of meaning-making is relevant to the carer's perspective on quality of life in terms of the 'moral' narrative of how they understand dementia to affect the person's social status as an ordinary person. This process of meaning-making among carers involves making sense of the person with dementia as ordinary and normal in the context of their existing social roles and relationships. The importance of standards of normality in accounts of dementia has been reported by Sweeting and Gilhooly (1997). Herskovits and Mitteness (1994:331) theorise that a loss of social status is associated with the perception of 'inappropriate behaviour', and this has been established in the current study among carers who perceived dementia to have eroded the person's identity. Herskovits and Mitteness (1994) and Lyman (1988) link the perception of inappropriate behaviour to ideas of a second childhood and dependency. This way of understanding social status was also evident in the study, particularly among family carers who commented on how their relative was regressing to an earlier self and demonstrating childish behaviour.

In comparison to carers who focus on the loss of normality and regression of the person with dementia, carers who emphasise processes of normal ageing focus on the person being the same as before but losing skills and abilities. They therefore represent the person in the context of their ongoing life history, and focus on continuity and coherence in a similar way to the older people with dementia in this study. Carers who can construct the person with dementia as the same person as before, but as affected by a loss of skills, represent living with dementia as dealing with the disruption caused by cognitive

impairment and the restrictions imposed by a disabling society. Making sense of the person as normal and ordinary is linked to the establishment of continuity between the person of the past and the person in the present. These carers focus on the person's continuing meaningful involvement in life and the potential to remain involved in the social world given the right support and encouragement. This representation of continuing engagement reflects what older people in the study say contributes to a good quality of life. This evidence supports the finding by Åberg et al. (2004) that continuity of the person with dementia's self is important among carers for the person's perceived life satisfaction.

Whereas carers who understand identity as enduring understand dementia as a loss of skills and fitness, carers who understand dementia as associated with a loss of normality adopt cultural meanings of dementia that are associated with disease, decline, dependency, sickness and death. These representations are reflected in the literature discussed in chapter three. As has been established by Gilhooly et al. (1994), accounts that emphasise social death are related to anticipatory grief, and therefore these carers focus on the loss of the person within their accounts. Existing literature has established that perceived disturbances in the person's behaviour and a breakdown in shared meanings cause particular distress to carers (Blieszner et al. 2007; Gilhooly et al. 1994; Gillies 2000b; Spruytte et al. 2002; Wilson 1989). The current study similarly establishes that the anticipatory grief associated with the perceived loss of the person is associated with a sense of disturbed behaviour and a perception that shared meaning-making has gone. It is this aspect of meaning-making that is particularly significant for understanding a differential perspective on quality of life.

An important finding from the current study is therefore that anticipatory grief is related to a different perspective on quality of life. When there is no sense of valid or shared

meaning-making, this is when carers are unable to share the person's perspective. When carers are unable to represent a person's involvement in life as meaningful, due to a loss of normality that is associated with inappropriate behaviour and a lack of awareness, they reframe quality of life from their own perspective. The difficulty of maintaining a sense of normality creates an emotional barrier to connecting with the person's perspective. The meaning of this different perspective relates to the way that the carer focuses on their own emotional response to the situation. The carer's efforts to find meaning can therefore be understood in terms of their own attempts to make sense of a difficult care situation. This finding is important for this thesis, as it brings a new appreciation to the meaning of different perspectives on quality of life among older people with dementia and carers.

The meaning of a different perspective can be understood in the context of evidence from the literature that represents processes of emotion work among carers (Henderson and Forbat 2002; Hochschild 2003; Lee-Treweek 1997; Lopez 2006; Lyth 1988; Lyth 1989). Holst et al. (1999) have established that a lack of meaning creates difficult emotions due to the inability to mutually confirm identities. As was evident in this thesis, carers represent a difficulty in understanding the perspectives of older people with dementia when they cannot represent the person as having a normal identity. This is related to the perception that the person no longer appreciates their true self or their relationships with significant others. Levy et al. (2000) explored the patterns of 'illness attributions' in carers' explanatory styles, and found that carers who focus on dementia as an internal attribute of the person experience a higher 'burden' than those who attributed dementia to causes outside the person. This finding resonates with the current study, as carers who understood a person's identity as eroded by dementia described a higher level of emotional distress in their accounts in representing the impact of dementia on their own situation. The thesis has therefore established an important link between the emotion and identity work of carers in their perspectives on quality of life.

The meaning of dementia and ageing, and its influence on how carers represent their role in supporting the person with dementia, is important in understanding the context of perspectives on quality of life. Carers who focus on a loss of skills describe their capacity to support quality of life. In these accounts, the emphasis is upon creating a positive environment or experience to make the person feel good, and to keep them involved in ways that maintain skills and sustain social relationships. The assumption is that it is possible to engage with the person and strengthen skills and connections to the past, and so maintain a good quality of life for the person. While acknowledging their sometimes difficult emotions, these carers describe supporting the person's feelings in order to maintain their quality of life, and they are able to maintain some emotional distance in their accounts. When carers focus on a loss of identity, this has repercussions for their emotional response to the challenges associated with dealing with a loss of normality in the person. While carers who understand dementia as eroding identity still try to support the person, in framing the person as dependent and incapable they focus on their own role in maintaining the person's situation. In representing a lack of normality in the situation and their relationship with the person, these carers focus on devising ways of coping with a sense of meaning having gone.

The link between emotion and identity work in perspectives on quality of life therefore relates to the carer's perceived role in the person's life, in addition to the way they represent the identity of the person with dementia. This finding connects perspectives on quality of life to the literature on identity work among carers. The impact of care on identities has been established by O'Connor (2007) and Askham et al. (2007), who highlight the critical contradictions in family care associated with the struggle between the identity of family member versus carer, and the tension surrounding the desire to preserve a home life and an intimate relationship while providing care and 'custody'. This was evident in the accounts of family carers who focused on the eroded identity of the

person in this study. Similarly, tensions with paid care have been demonstrated in the literature, with the affective care of older people linked to the use of family metaphors among paid carers (Berdes and Eckert 2007; Häggström and Norberg 1996; Rundqvist and Severinsson 1999). The difficulty of this construction of paid care was evident in the accounts of paid carers who emphasised their emotional attachment to their clients as friends, 'mums' or 'grannies' while also representing the person's altered identity as out of the ordinary.

### ***A comparative framework of meaning in accounts of quality of life***

The evidence that, for all, finding meaning in life depends upon making sense of that life as normal and ordinary is a key finding of the research. The struggle to make sense of life is apparent in the accounts of older people with dementia, paid and family carers. The narratives of older people reflect their struggle to find meaning in terms of realising their sense of self within a social world that largely defines them as different and out of the ordinary. The narratives of carers reflect their struggle to find meaning in terms of representing lives that are disrupted by the processes of ageing and dementia in terms of a loss of skills or identities. Finding meaning in life relates to establishing coherence and continuity of self and social identity, and maintaining the capacity to engage in activities and situations that represent ordinary social roles and relationships. This establishes the parallel processes of emotion and identity work that is evident among older people with dementia and their carers.

In the face of the challenges associated with ageing and dementia, this identity work involves strategies to keep going and maintain an ordinary involvement in life. For older people with dementia, when there is a breach between self and social identity, because of difficulty sustaining involvement in ways that reflect their sense of self due to diminished cognitive capacity or disabling social environments, this is when people struggle to find



meaning. For carers, when there is a breach in the status of the person as normal and ordinary, due to a perceived disruption in the person's identity, this is when they struggle to find meaning. The thesis therefore extends the literature by developing a narrative framework that explains the meanings of perspectives on quality of life among older people with dementia and their carers as similar processes of comparative meaning-making.

The emotional struggle of finding meaning is evident in the accounts of both older people with dementia and their carers. While focusing on meaning-making in everyday life, this process is paradoxically complex as people struggle to define what is 'normal' and 'ordinary' and relate this to the life that is being described. This narrative practice relates specifically to the life history of the person with dementia and more generally to the socio-cultural expectations held about older people with dementia. Finding meaning involves making sense to oneself and to others. In positive constructions of living with dementia the emphasis is on the extent to which a sense of continuity can be accomplished or a new sense of purpose can be achieved. In less positive constructions of living the emphasis is on disruption, discontinuity and the failure to maintain a sense of purpose. These perceptions of self, identity and social status are not static but fluctuate within accounts as people struggle to understand and define particular events and experiences.

Exploring the narrative processes of meaning-making in carers' accounts has demonstrated that people draw on cultural meanings to make sense of their experiences, and deal with the challenges and sometimes difficult emotions of caring for someone with dementia. It is clear that these meanings influence the way carers understand the impact of dementia and ageing on the person with dementia's self and social identity, which also has repercussions for their own identities as carers. The separate traditions of literature examining the meanings of living with dementia and caring for people with dementia can

be viewed from a similar point of view, as people make sense of their situations in living and coping with the practical and social consequences of a chronic condition. This similarity in the processes that older people with dementia and carers employ to make sense of their experiences is fundamental to this thesis, as it brings both perspectives together in similar narrative processes of meaning-making, which is a novel approach to understanding perspectives on quality of life among the two groups.

The use of a narrative methodology that engages with subjective meaning-making has therefore established that older people with dementia and their carers engage in similar processes of meaning-making. Like the perspectives of older people with dementia, carers' perspectives represent a comparative and contextual appreciation of the person's current situation in life as it relates to past circumstances. This is a new finding, which extends the literature on quality of life research. By engaging with individual accounts among groups of older people with dementia and groups of family and paid carers, rather than focusing on matched dyads or triads, it has been possible to move from a concern with trying to establish the objective evaluation of a person's quality of life, to appreciate the subjective and representational processes that are associated with different perspectives on quality of life. In so doing, a narrative approach has produced thick description and a depth of analysis that has enabled the study to understand the ways that older people with dementia and carers construct meaning in their accounts of quality of life.

This thesis has therefore engaged with different perspectives on quality of life by considering the narrative processes of meaning-making in people's accounts. This approach can be contrasted with studies that have examined correlations in reporting between matched pairs, which are based on the premise that either people with dementia over-estimate their quality of life due to poor insight and awareness, or that their carers under-estimate the person's quality of life due to their sense of subjective burden and

strain. The current study extends the literature by shifting the focus, from a concern with how levels of carer satisfaction or burden are associated with accurate reports of quality of life, to an interest in the identity and emotion work that constructs meaning in carers' accounts. This has established that carers engage in similar processes of meaning-making to older people with dementia.

Similar perspectives on quality of life to those that older people with dementia report are evident in the accounts of carers who emphasise the enduring identity of the person with dementia. Different perspectives are evident in the accounts of carers who emphasise the eroded identity of the person with dementia. Differences in perspective therefore relate to whether or not carers can represent the person's status as ordinary in a way that allows them to appreciate a sense of shared meaning-making. In this way the awareness of the person with dementia and the emotional response of the carer are linked. However, the meaning of this difference relates to the identity and emotion work of carers in their attempts to find meaning in life when they make sense of a person as losing their normality. This brings a new appreciation to the meaning of different perspectives on quality of life.

### **Strengths and limitations of a narrative approach**

The narrative approach taken in this study has enabled detailed exploration of the ways that older people with dementia and carers talk about quality of life. By engaging with narrative meaning-making to understand the older person's subjective perspective, it has been possible to appreciate how a person understands quality of life relative to their ongoing sense of self and social identity, even when speech is fragmented and metaphoric. Talking about living life in a particular way and being a particular kind of person is an active and ongoing accomplishment, which attention to narrative structure reveals more clearly than content analysis on its own. Similarly, by attending to narrative processes of

meaning-making among carers, it has been possible to engage with complex and difficult-to-articulate issues that relate to the emotion work associated with caring for an older person with dementia. A comparative framework has therefore enabled me to engage with complex but similar processes of meaning-making within and across the two groups.

A narrative framework has therefore developed an interest in meaning-making at both an interpretive and methodological level; as a methodological approach it has elicited narrative processes of meaning-making to make different perspectives on quality of life more understandable, while at the same time providing a conceptual framework to explain how people make sense of their experiences relative to particular narrative constructions of self and social identity that are linked to concepts of ageing and dementia. This approach has therefore developed an appreciation of quality of life that has linked my theoretical perspective with the personal level of experience, by eliciting everyday experiences and concerns about caring and living with dementia, and exploring the significance of personal perspectives from the standpoint of relevant traditions within social gerontology and the sociology of health and illness.

By adopting a narrative methodology that engages with the metaphoric and emotional elements of talk, this study has been able to engage with the perspectives of older people with significant cognitive impairment, some of whom had been described by others as 'confused' and 'talking in riddles'. The research approach has established that, even when experiencing a level of cognitive impairment that affects the conventions of 'ordinary' conversation, older people with dementia are engaged in rich meaning-making that communicates important messages about how they wish to continue living an ordinary life. This study therefore confirms the importance of continuing to engage with older people with dementia in ways that acknowledge a valid and valued sense of self and social identity, even when a person might talk in ways that do not at first make sense to

someone else. Additionally, the study adds to current research by representing the active ways that older people with dementia continue to make sense of experiences in life even when cognitive impairment makes communication more difficult.

The metaphoric narratives in which older people struggled to represent life as meaningful are therefore partly related to the impaired communication and cognitive skills associated with dementia. However, carers who were struggling with the challenges of caring for someone whose sense of meaning-making seemed obscure tended to use rich, descriptive and sometimes metaphoric language, suggesting that the emotional significance of their accounts may explain the use of metaphor in articulating complex ideas or experiences. Taking a narrative approach to understand how meanings of quality of life have been constructed has enabled an appreciation of different perspectives on quality of life that represents older people with dementia and their carers as active agents striving to find meaning. The methodological approach taken in this thesis has contributed to narrative studies more generally, by taking account of the way that people's stories may differ in form and style, utilising a flexible approach to eliciting and analysing their narratives.

As indicated above, the emotional context of the narrative approach taken in this study has been important, and narrative interviewing provided a space in which people could set their own pace and explore their feelings and emotions about caring and living with dementia. While most people appeared to value having an opportunity to talk about issues of importance in their lives, the potential risk of this unstructured process was in a person disclosing feelings that they might later regret, as was evident for the older woman who withdrew from the study. While the method has generally been useful to answer the research questions posed in this study, its use has involved negotiating difficult feelings and emotions for some people. It was also apparent that the method had its limits for some participants, as not everyone talked in a way that made detailed narrative analysis

significantly more illuminating than traditional thematic analysis for exposing patterns of meaning in their accounts. This seemed most apparent when people were expressing well-rehearsed ideas or engaging in broad description of their experiences.

Despite these limitations, the benefits of thick description that have come from the use of detailed narrative analysis have made this approach worthwhile to understand the construction of meaning in different perspectives on quality of life. A humanistic framework has been valuable to demonstrate that 'quality of life' is not a collection of discrete components or 'domains' that make life feel good; instead, it is a dimension of meaning that is associated with having worth and being able to represent life as ordinary. The overall strength of a narrative approach has been in providing a rich and deep appreciation of the ways that older people with dementia and carers understand quality of life in the context of their life history and subjective everyday experiences. The accounts in this study can be understood as types of 'biographical work', as people strive to make sense of their experiences and find meaning in their situation in life. In drawing together the literature on identity work and emotion work among older people with dementia and their carers, as well as engaging with people's own sense of meaning in their subjective perspectives on quality of life, narrative has provided a useful conceptual framework for understanding the construction of meaning in people's accounts.

### **Implications for relating to people with dementia and further research**

There are some key messages from this exploratory study that may be useful for helping carers to relate to older people with dementia. While the sample size is small, which therefore limits the possibility of generalisation from the findings, the study raises some important issues that are relevant for those providing care. Within this discussion, I acknowledge that it may be difficult, if not unrealistic, to expect people to stand back from the personal dynamics of their ongoing relationships and their usual ways of relating to

each other, in order to approach communication and analyse meaning-making in the same way I have been able to do in this research study. However, there are some important messages about helping people to make sense of everyday life, which require a particular attitude or skill that may seem basic, but which is in fact difficult to accomplish.

The findings of this study emphasise the significance of supporting older people with dementia by strengthening their potential to engage meaningfully in the social world, according to their understandings of valued social roles that are important in their lives. This involves paying attention to the context of an older person's life history and aspects of communication like metaphoric talk, to understand past experiences and background meanings that are important in framing a person's concerns in the present. Understanding what is important from the person's own perspective is therefore important in providing care that promotes meaningful social engagement and so supports ordinary ways of life.

While family rather than formal care relationships were most central in older people's accounts, there was evidence that where family can no longer uphold valued social roles and relationships for an older person with dementia, formal care situations can become social spaces where opportunities can be used to help people feel useful, be productive and take part in life within the wider community. While acknowledging the valuable place of reminiscence in attending to important experiences and meanings from the past, it is also useful to recognise the potential for older people with dementia to be involved in the type of purposeful and forward-looking activities that they describe in the accounts that I have analysed. This includes people taking a role in helping others, emphasising the importance of valuing the capacity for continued mutual support among older people with dementia.

The value of helping others highlights the potential for formal care to provide meaningful social environments to support older people with dementia. This aspect of care provision

seems most helpful to older people with dementia when activities support ordinary social roles and relationships. For older women in this study, continued engagement in social roles associated with the home was most important, while for older men the loss of work roles seemed most significant in their accounts. This may reflect different gender roles in these generations, suggesting that older men and women may require different aspects of support from formal care to help them to find meaning in everyday life. In their descriptions of valued aspects of formal care, all the older people in this study emphasised the significance of activities that promoted their ordinary engagement in the family and community. This highlights the fundamental significance of actively supporting continued social engagement that is based on the person's life history.

In considering the impact of care on carers, personal and organisational approaches that emphasise close familial relationships may have particular emotional consequences for paid carers. The service philosophy ("a home from home") and the culture of the service ("a big extended family") of the paid carers in this study created a difficult tension for those who tried to treat their clients like friends or family. Emulating friendship created some contradictions in paid carers' perceived roles, especially in relation to maintaining some level of emotional distance from a client's situation. This suggests that some paid carers may require support to deal with the affective elements of their care, especially to find ways to build shared meaning-making with older people with dementia. Similarly, many family carers expressed distress and anguish at their difficulty engaging with the meanings of their relatives and friends. These findings highlight the importance of support for carers in dealing with the challenges and tensions associated with providing care.

The finding that people with dementia can communicate feeling very effectively is an important message from this study, and it has established that being able to make sense of experiences is important to the quality of life of older people with dementia. Equally, the



study has highlighted the emotional dimension of carers' meaning-making, demonstrating that making sense of experiences is important to their own quality of life. This mutuality highlights the value of strengthening the capacity of paid and family carers to make sense of communication, in order to improve their own well-being as well as that of their relative, friend or client. Some of the skills that carers require in order to do this may need to be developed, and people may not have time to explore meaning-making in great depth. However, a key message that can be taken from the study is that how people view the consequences of ageing and dementia is associated with how they appreciate a person's quality of life and how they consequently respond to the person.

A focus on improving perceptions that an ordinary life with dementia is possible would be valuable in developing positive approaches to dementia care. Further research would therefore be useful to develop practical strategies and techniques to help older people with dementia and their carers make sense of everyday life more effectively. The current study reinforces person-centred approaches to dementia care, but develops an appreciation of relating to older people with dementia that moves beyond philosophies of formal care provision, to consider how people can be supported more broadly to continue to lead an ordinary life. An area of importance for future research is therefore the relationship between particular values and attitudes held about older people and people with dementia, and the ways that people perceive the consequences of ageing and dementia for maintaining an ordinary quality of life.

Further research could engage with how less helpful attitudes can be overcome, potentially considering the influence of different types of training, service provision and care environments on how carers understand quality of life and relate to older people with dementia. Whilst not underestimating the challenges, time and resources that would be required for this, and also acknowledging how far dementia care has come in the last

two decades, it is important to revisit the fundamental question of social attitudes in the context of the difficult issues that continue to be faced by people receiving and providing care. One particular issue that may be pertinent in the context of promoting positive attitudes towards older people with dementia is how to help paid carers understand the biographical context of a person's life, especially when there are cultural differences between the older person and their paid carers. This is important when particular socio-cultural values and attitudes are likely to shape the ethical practice of carers.

The finding that there was not a fundamental distinction between how paid and family carers make sense of the quality of life of older people with dementia highlights the value of approaching research from these perspectives together, to understand more fully how the viewpoints and beliefs of family and paid carers interact and intersect with each other. This may be especially pertinent in the current socio-economic climate, with the increased likelihood of cuts in paid care services and the associated need for an increased reliance on friends and family to provide care to older people in the community. In addition to this area of research, supporting people more generally to engage with narrative processes of meaning-making may enable older people with dementia and their carers to make greater sense of everyday life. By finding practical techniques to attend more closely to the ways that older people with dementia communicate what is important to their quality of life, it should be possible to improve carers' understandings of what is valued by a person in the context of their life history and ongoing social relationships.

### **Conclusions and key contributions**

This study has addressed a gap in the literature with an in-depth exploration of the narrative construction of meaning, to make sense of different perspectives on the quality of life with dementia. A comparative framework of narrative meaning-making has been developed by comparing and contrasting processes of identity and emotion work within

and across groups of older people with dementia and carers. This conceptual framework has involved attention to the construction of self, social identity and social status relative to the meanings of ageing and dementia in the context of people's everyday experiences. This is an approach that extends the literature by taking account of the biographical and contextual elements of different perspectives on quality of life.

A focus on meanings, emotions and identities develops an appreciation of quality of life as a creative process that involves being able to find value in and from lives. By exploring the narrative constructions that people draw upon to make sense of life as an older person with dementia, the thesis has established that differing perspectives on quality of life relate to different ways of constructing a person's identity in relation to the impact of dementia on their status as normal and ordinary. Interpreted in this way, having a 'good' quality of life is the accomplishment of being engaged in the social world in ways that represent a person's ongoing sense of self and social identity.

The thesis has explained the basis for differing perspectives on quality of life in terms of narrative processes of meaning-making. Different perspectives are not associated with a general difference in forms of meaning-making among older people with dementia and carers. Both groups engage in similar processes of identity work to represent how a person's self and social identity is perceived to endure over time. Similarly, both groups engage in processes of emotion work to represent the strategies they use to deal with the challenges of ageing and living with a chronic condition or how they cope with the challenges associated with caring for an older person with dementia. However, the way that social status is achieved in older people's narratives or ascribed in carers' accounts affects the extent to which life can be viewed as meaningful. For both groups, finding meaning in everyday life depends upon making sense of that life as normal and ordinary.

The meaning of different perspectives on quality of life therefore relates to whether the quality of a person's life can be understood as ordinary. Older people with dementia, and carers who represent the enduring identity of the older person with dementia, focus on the importance of maintaining the momentum of an ordinary life, by continuing to be involved in the social world in ways that uphold existing social roles and relationships or offer new valued social roles and relationships. In contrast, carers who represent dementia as eroding a person's identity centre on their own means of maintaining a normal life in the context of providing care to a person who is perceived to be losing their normality. In being unable to focus on maintaining an ordinary or worthwhile life, these carers focus on how they can maintain their relationship to the person and devise strategies to manage the associated emotional labour that is linked to a sense of meaning-making having gone. This can be compared to the strategies that are maintained by older people with dementia, who are still engaged in rich meaning-making, although this may be masked by communicative and other difficulties associated with their condition. The strategies of these older people with dementia reflect how they are dealing with cognitive impairment and dealing with others' assumptions of a loss of identity. It is the meaning of having a valued social identity that is relevant to these different subjective perspectives on quality of life.

A key theoretical contribution made by the study has been in establishing a new way of understanding quality of life that explores how self and social identities are constructed and how care work is described and understood in people's narratives of everyday life. An important aspect of this analysis is that carers are distinguished by their way of representing the older person with dementia, rather than their status as a paid or family carer, which is a different approach to the traditional separation of paid and family caring in the literature. Case-centred narrative research has been used to develop understanding at a far deeper level than previous studies examining different perspectives on quality of

life. This has involved engaging with the richness and complexity of people's lives that are reflected in their accounts. The study has therefore also contributed on a methodological level by developing an approach that is helpful to understand what is happening in the lives of older people with dementia and their carers. This has involved listening on people's own terms about what 'quality of life' means for them and using narrative analysis to distil the meaning of what is said. People's lives are muddled and complicated and, in reflecting on the process of engaging with people's subjective perspectives on life, the research task has mirrored the messiness of people's lives as I grappled to establish meaning in their narratives and construct my own story of what was 'going on' in their lives. The study has importantly demonstrated that, even when communication is restricted by significant cognitive impairment, people with dementia are engaged in rich and creative processes of meaning-making that attest to their desire to continue to live an ordinary life and be perceived as ordinary people.

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## **Appendices**

- Appendix 1: Information sheet for older people
- Appendix 2: Information sheet for family carers
- Appendix 3: Information sheet for paid carers
- Appendix 4: Information leaflet for project workers
- Appendix 5: Consent form for older people
- Appendix 6: Consent form for family carers
- Appendix 7: Consent form for paid carers
- Appendix 8: Interview format for carers
- Appendix 9: Terms of acceptance for work
- Appendix 10: Narrative excerpt

# **Appendix 1**

## **Information sheet for older people**

**(with details of service and local authorities obscured)**



If you are interested in taking part in the study please read through the consent form with your project worker.



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
APPLIED SOCIAL SCIENCE

Jane Robertson, PhD Student



If you would like to take part please sign your name at the bottom of the consent form.

If you do not want to take part, you do not have to say why. This will not affect any help that you are receiving.

**THANK YOU FOR READING THIS LEAFLET**

**What makes life feel good  
when you are older and  
have memory difficulties?**

Information Leaflet

This leaflet is about a new research study by Jane Robertson at Stirling University.

Jane will be talking to older people with memory difficulties and carers who look after older people with memory difficulties.

She wants to find out what makes life feel good and what makes life feel less good when you are older and have memory difficulties.

This study may not help you directly but it may help older people like you in the future.

If you take part in the study Jane will visit you a few times at a place of your choice to talk to you about your life.

When the study is over Jane will write a report. She will give you a short copy of this report.

Your name will not be used in the report. This will help to make sure that information about you is kept private.

If you would like to ask any questions you can phone Jane on 01786 466308 or your project worker can arrange for you to meet her.

## **Appendix 2**

### **Information sheet for family carers**

**(with details of service and local authorities obscured)**

## Findings

The findings will be used to write a thesis for a PhD in Social Work / Dementia Studies at the University of Stirling. A summary of findings will be presented to project staff at the [REDACTED]. The research may also be shared by publishing articles and papers. If this is done your name will not be used and you will receive a copy of any published material.

## What can I do if I would like to find out more?

If you want to ask more about the study or you would like to take part please contact Jane Robertson at the University of Stirling or [REDACTED] at the [REDACTED]. For further information from someone not involved in the study please contact Louise McCabe. They will be very happy to answer any questions that you have. Asking more questions does not mean that you are agreeing to take part.

**Address:** Jane Robertson  
Department of Applied Social Science  
University of Stirling  
Stirling FK9 4LA

**Telephone:** (01786) 466308 (answer machine)

**E-mail:** j.m.robertson@stir.ac.uk

Alternatively please contact [REDACTED], [REDACTED] on [REDACTED] or Louise McCabe, University of Stirling on (01786) 466317 for further information.

Please remember that your decision to take part or not to take part will not affect the services or support your friend or relative receives at the [REDACTED] or elsewhere.

**THANK YOU FOR READING THIS INFORMATION**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
APPLIED SOCIAL SCIENCE

## Understanding 'quality of life' in dementia care

A research study by  
Jane Robertson



Postgraduate Research Student  
Department of Applied Social Science  
University of Stirling

**INFORMATION SHEET**

### **The study**

Jane Robertson, a postgraduate research student in the Department of Applied Social Science at the University of Stirling, is conducting a research study examining 'quality of life' in dementia care. Jane is interested in understanding what makes life feel good or less good when you are older and have memory difficulties. The purpose of the study is to understand why people view these things in certain ways. This will include comparing the views of older people with memory difficulties and caregivers. Permission to carry out the study has been granted by [REDACTED] Social Work Service, [REDACTED] Social Work Service and [REDACTED] Social Work Service.

### **Who will take part in the study?**

Jane has asked the [REDACTED] to identify clients, caregivers and service providers who they believe *might* be interested and able to take part in the study. You have been given this information sheet as you have been identified as someone who *may* be interested in taking part in the study. However, you do not have to take part, and you do not have to say why you do not want to take part. This information sheet is to help you decide whether you want to take part.

### **Will taking part be useful?**

Taking part in this study might not be of direct benefit to you. However, sharing your views and opinions means that other people will have greater insight into caregivers' understandings of quality of life for people with dementia. Hopefully the study will also help future services to provide good quality care so that older people with memory difficulties can achieve the things they want from life.

### **What does 'taking part' mean?**

Taking part means that Jane will come and talk to you about what you think is important for your friend's or relative's quality of life. With your agreement she will use a small tape machine to record the conversation. Jane would like to come and meet you two or three times. Interviews may last from 30 minutes to an hour and a half and this will be up to you.

### **How can I stop taking part?**

Jane will ask each time you meet if you still want to take part. You can stop taking part at any time. You can also choose not to answer any questions. You do not have to give a reason why. Leaving the study or not wanting to take part in the study will not affect any care or services that your friend or relative receives at the [REDACTED] or elsewhere.

### **Privacy**

Anything you tell Jane will be kept anonymous. Your name and personal details will not be used. Any information collected will be kept securely in a locked filing cabinet or computer. Each person will be given an alternative name so their real name is not kept with the information. Any tapes will be destroyed after the study is completed.

### **If I am interested how can I take part?**

If you are interested in taking part in the study after reading this information sheet you can either speak to Jane directly or contact [REDACTED] at the [REDACTED]. Jane will discuss any questions you have and if you would like to take part in the study she will arrange to meet with you at a time and place of your choice. To find out more from someone who is not involved in the study you can contact Louise McCabe, who is a Lecturer in Dementia Studies in the Department of Applied Social Science at the University of Stirling. Contact details are overleaf.

## **Appendix 3**

### **Information sheet for paid carers**

**(with details of service and local authorities obscured)**

## Findings

The findings will be used to write a thesis for a PhD in Social Work / Dementia Studies at the University of Stirling. A summary of findings will be presented to project staff at the [REDACTED]. The research may also be shared by publishing articles and papers. If this is done your name will not be used and you will receive a copy of any published material.

## What can I do if I would like to find out more?

If you want to ask more about the study or you would like to take part please contact Jane Robertson at the University of Stirling or [REDACTED] at the [REDACTED]. For further information from someone not involved in the study please contact Louise McCabe. They will be very happy to answer any questions that you have. Asking more questions does not mean that you are agreeing to take part.

**Address:** Jane Robertson  
Department of Applied Social Science  
University of Stirling  
Stirling FK9 4LA

**Telephone:** (01786) 466308 (answer machine)

**E-mail:** j.m.robertson@stir.ac.uk

Alternatively please contact [REDACTED], [REDACTED] on [REDACTED] or Louise McCabe, University of Stirling on (01786) 466317 for further information.

Please remember that your decision to take part or not to take part will not affect your work at the [REDACTED].

**THANK YOU FOR READING THIS INFORMATION**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
APPLIED SOCIAL SCIENCE

## Understanding 'quality of life' in dementia care

A research study by  
Jane Robertson



Postgraduate Research Student  
Department of Applied Social Science  
University of Stirling

**INFORMATION SHEET**

### **The study**

Jane Robertson, a postgraduate research student in the Department of Applied Social Science at the University of Stirling, is conducting a research study examining 'quality of life' in dementia care. Jane is interested in understanding what makes life feel good or less good when you are older and have memory difficulties. The purpose of the study is to understand why people view these things in certain ways. This will include comparing the views of older people with memory difficulties and caregivers. Permission to carry out the study has been granted by [REDACTED] Social Work Service, [REDACTED] Social Work Service and [REDACTED] Social Work Service.

### **Who will take part in the study?**

Jane has asked the [REDACTED] to identify clients, caregivers and service providers who they believe *might* be interested and able to take part in the study. You have been given this information sheet as you have been identified as someone who *may* be interested in taking part in the study. However, you do not have to take part, and you do not have to say why you do not want to take part. This information sheet is to help you decide whether you want to take part.

### **Will taking part be useful?**

Taking part in this study might not be of direct benefit to you. However, sharing your views and opinions means that other people will have greater insight into service providers' understandings of quality of life for people with dementia. Hopefully the study will also help future services to provide good quality care so that older people with memory difficulties can achieve the things they want from life.

### **What does 'taking part' mean?**

Taking part means that Jane will come and talk to you about what you think is important for your client's quality of life. With your agreement she will use a small tape machine to record the conversation. Jane would like to come and meet you two or three times. Interviews may last from 30 minutes to an hour and a half and this will be up to you.

### **How can I stop taking part?**

Jane will ask each time you meet if you still want to take part. You can stop taking part at any time. You can also choose not to answer any questions. You do not have to give a reason why. Leaving the study or not wanting to take part in the study will not affect your work at the [REDACTED].

### **Privacy**

Anything you tell Jane will be kept anonymous. Your name and personal details will not be used. Any information collected will be kept securely in a locked filing cabinet or computer. Each person will be given an alternative name so their real name is not kept with the information. Any tapes will be destroyed after the study is completed.

### **If I am interested how can I take part?**

If you are interested in taking part in the study after reading this information sheet you can either contact Jane directly or speak to [REDACTED] at the [REDACTED]. Jane will discuss any questions you have and if you would like to take part in the study she will arrange to meet with you at a time and place of your choice. To find out more from someone who is not involved in the study you can contact Louise McCabe, who is a Lecturer in Dementia Studies in the Department of Applied Social Science at the University of Stirling. Contact details are overleaf.



## **Appendix 4**

### **Information leaflet for project workers**

**(with details of service and local authorities obscured)**



# **What makes life feel good when you are older and have memory difficulties?**

## **INFORMATION LEAFLET FOR PROJECT WORKERS**

### **Consent procedure:**

Please ask the person with dementia to read through the information sheet. If they find this difficult, please talk them through the different points that are presented on the sheet.

If, in the opinion of the project worker:

(A) the person with dementia understands the research study and what is being asked of them, and agrees to take part, they should be asked to complete the consent form.

(B) the person with dementia understands the nature of the research study and expresses or signals unwillingness to take part, such as showing distress or anxiety, this should be accepted as a response.

(C) the person with dementia appears willing to take part, but it is not possible to decide how much the person understands the request to take part in the study, they should be asked to complete the consent form. However, they should be advised that Jane would like to ask for their carer's agreement for them to take part. If the person is happy for Jane to do so, she will send a letter and consent form to an appropriate carer. If the person is not happy for this to happen, Jane will need to discuss this decision with the project manager to decide on any further approach.

It is important to ensure that the following points are carried out or understood by the person with dementia in order for them to give informed consent. They appear as a checklist on the consent form.

- The person has read the information sheet (or a project worker has read through it with them)
- The person knows that the study is about understanding what makes life feel good or less good when you are older and have memory difficulties – while this may not help the person directly, it may help other people who have similar difficulties in the future
- The person knows what taking part will involve - Jane will visit the person a number of times in a place of their choice to talk about their life and what is important to them
- The person knows that s/he can stop taking part at any time during the study and that s/he does not have to say why to Jane or to anyone else
- The person knows that her/his decision to take part or to stop taking part will not affect the care and support s/he receives at the [REDACTED] or at any other service
- The person agrees that Jane can use a small tape machine to record the conversations they have together
- The person agrees that Jane can write about these conversations in her university thesis and for a wider audience

Please ask the person to complete the form, if necessary helping them to do so, by circling 'YES' or 'NO' to each statement.

If the person circles 'YES' to each statement, s/he should be asked to sign and date the form. The form should then be posted to Jane in the stamped addressed envelope provided.

Thank you for your help. If you have any questions or concerns, Jane Robertson can be contacted through [REDACTED] or [REDACTED] at the [REDACTED].

## **Appendix 5**

### **Consent form for older people**



# What makes life feel good when you are older and have memory difficulties?

## CONSENT FORM

**Please circle YES or NO for each statement below:**

I have read the information sheet **YES / NO**

I know what the study is about **YES / NO**

I know what taking part will involve **YES / NO**

I know that I can stop taking part at any  
time and I do not have to say why **YES / NO**

I know that my decision to take part or  
to stop taking part will not affect the care  
that I receive here or anywhere else **YES / NO**

I agree that Jane can use a small tape  
machine to record what we talk about **YES / NO**

I agree that Jane can write about what I say **YES / NO**

Your name: \_\_\_\_\_

Your signature: \_\_\_\_\_

Today's date: \_\_\_\_\_

**Please return the form to Jane in the envelope provided.  
You do not need a stamp.**

## **Appendix 6**

### **Consent form for family carers**



## Understanding ‘quality of life’ in dementia care

### CONSENT FORM

**Please circle YES or NO for each statement below:**

I have read the information sheet **YES / NO**

I know what the study is about **YES / NO**

I know what taking part will involve **YES / NO**

I know that I can stop taking part at any  
time and I do not have to say why **YES / NO**

I know that my decision to take part or to  
stop taking part will not affect the care that my  
relative / friend receives here or anywhere else **YES / NO**

I agree that Jane can use a small tape  
machine to record what we talk about **YES / NO**

I agree that Jane can write about what I say **YES / NO**

Your name: \_\_\_\_\_

Your signature: \_\_\_\_\_

Today's date: \_\_\_\_\_

**Please return the form to Jane at the first interview.**

## **Appendix 7**

### **Consent form for paid carers**





## Understanding ‘quality of life’ in dementia care

### CONSENT FORM

**Please circle YES or NO for each statement below:**

I have read the information sheet **YES / NO**

I know what the study is about **YES / NO**

I know what taking part will involve **YES / NO**

I know that I can stop taking part at any  
time and I do not have to say why **YES / NO**

I know that my decision to take part or  
to stop taking part will not affect my work **YES / NO**

I agree that Jane can use a small tape  
machine to record what we talk about **YES / NO**

I agree that Jane can write about what I say **YES / NO**

Your name: \_\_\_\_\_

Your signature: \_\_\_\_\_

Today’s date: \_\_\_\_\_

**Please return the form to Jane at the first interview.**

## **Appendix 8**

### **Interview format for carers**

## Interview 1

Subsession 1 - carefully constructed single narrative question: life story or particular phase / aspect of life:

(a) family carers

“As you know, I’m researching what is important for people with dementia to have a good quality of life. I’m interested in your experience of living with [relative or friend’s name] who has dementia. So, can you please tell me about how you have developed your ideas of what matters most to your [relative or friend’s name] quality of life. All those events and experiences which were important for you, personally. Begin wherever you like. Please take the time you need. I’ll listen first, I won’t interrupt. I’ll just take some notes for after you’ve finished telling me about your personal story of those experiences.”

(b) paid carers

“As you know, I’m researching what is important for people with dementia to have a good quality of life. I’m interested in your experience of working with people who have dementia. So, can you please tell me about how you have developed your ideas of what matters most to the quality of life of the people with dementia who you have worked with. All those events and experiences which were important for you, personally. Begin wherever you like. Please take the time you need. I’ll listen first, I won’t interrupt. I’ll just take some notes for after you’ve finished telling me about your personal story of those experiences.”

Subsession 2 - sticking strictly to the sequence of topics raised and to the words used, the interviewer asks for more narratives about some of the topics, being prepared to ask further questions in response to some of the answers given. In eliciting narratives of particular events and experiences the following cues are useful as prompts:

Situation, Happening, Event, Incident, Occasion, Time – Memory and Moment

- How All That Happened [and ‘Thought, Feeling, Image’ as emergency backup]

## Interview 2 (optional)

Subsession 3 – further narrative and non-narrative questions

## **Appendix 9**

### **Terms of acceptance for work**

# **TERMS OF ACCEPTANCE FOR TRANSCRIPTION WORK**

The following terms apply to all persons carrying out transcription work for the  
**Department of Applied Social Science, University of Stirling**

## **1 Confidentiality**

When carrying out transcription work for the Department I agree to abide by the Market Research Society's Code of Conduct. I will not divulge any information to a third party regarding the content of any tapes. In this way, respondents' assurance of confidentiality is maintained and the Department runs no risk of a third party gaining access to their information.

## **2 Storage**

I accept that at all times the information on the tapes remains the property of the Department. Electronic copies will be stored for a maximum of three months and then be permanently deleted. Hard copies will be sent to the commissioning member of the department or destroyed. While in my possession, tapes or digital recordings will be stored securely (i.e. where no third party can gain access to them).

## **3 Subcontracting**

I will not sub-commission or subcontract work without the commissioning member of the department's knowledge and agreement.

## **4 Exploitation of knowledge acquired**

I will not attempt to derive any gain from privileged information acquired in the course of work undertaken. I will not accept remuneration from any party in respect of this work other than as agreed with the commissioning member of the department. I will carry out all work entrusted to me with complete impartiality and shall disclose any business, financial or other interest which might affect this impartiality.

Signed..... Date.....

Print name.....

Address.....

.....

Phone Number/s.....

E mail address.....

Emergency Contact Number.....

The University of Stirling is committed to complying with the Data Protection Act 1998. For further information please see <http://www.guides.stir.ac.uk/dataprotectionguide.htm>

Please return your completed form to:

██████████, Research Secretary, Department of Applied Social Science, University of Stirling, Stirling, FK9 4LA

## **Appendix 10**

### **Narrative excerpt**

## Transcription 1

Original transcription, verbatim words, structured according to who is speaking, with long pauses inserted and names removed; (...) indicates where speech interrupted:

**Cynthia:** I'm lucky at eighty-odds, to be able to do things.

**Jane:** Yes. What kind of things do you do?

**Cynthia:** Well, I go (pauses) I used to go to the dancing, I went to dancing. [My daughter] goes to line dancing now. This is a new thing ...

**Jane:** Yes.

**Cynthia:** ... that I've never been at. I say, "I'd better not go, I'm getting too old for these kind of things." But I think I could do it.

**Jane:** Yeah.

**Cynthia:** But, eh, no, I just, I can walk the roads a bit ...

**Jane:** Uh-huh.

**Cynthia:** ... and [my daughter] gets angry at me for, eh (pauses) she thinks I'm, getting away too much. I go up to (pauses) where am I? I've a sister who lives at new town.

**Jane:** Mhm.

**Cynthia:** And she's younger than me. And I go up and see her, but, she's never out the door.

**Jane:** Right?

**Cynthia:** [My daughter] goes and does things for her too.

**Jane:** Yes. Cos she was up there, going up there this morning. [referring to conversation earlier this morning when I arrived to interview Cynthia]

**Cynthia:** Aye.

**Jane:** Uh-huh.

**Cynthia:** Mhm. But, I, I dinnae need anybody to do my work. [My daughter] will do things for me.

**Jane:** Mhm.

**Cynthia:** But I can still (pauses) And she gives me a row when I start to do windows.

**Jane:** Right.

**Cynthia:** She says, "Mother, stop doing that." I think she thinks (pauses) because (pauses) I'm old ...

**Jane:** Mhm.

**Cynthia:** ... well, I started (smiling and looking at memento), I finished up working at [workplace].

**Jane:** Mhm.

**Cynthia:** I worked at [workplace]. And I came, to, [town] (pauses). Now, that's a long time ago. That was me finished working.

**Jane:** Mhm.

**Cynthia:** And I'm still working yet ...

**Jane:** Yeah.

**Cynthia:** ... to a certain extent.

**Jane:** Uh-huh.

**Cynthia:** So, I've been a lucky person.



## Transcription 2

[Based on Gee's (1991) framework of linguistic analysis]

Adapted transcription, with my asides and short non-lexical markers (mhm, uh-huh, yeah) deleted and Cynthia's false starts and some of her repetitions removed, structured according to linguistic cues, with short pauses to separate idea units (indicated by commas), each line comprises linked idea units, changes of pitch to structure idea units into stanzas (indicated by the grouping of lines together), and words of emphasis underlined to indicate main focus of idea unit; longer pauses that were noted in the original transcript are still included:

I'm lucky at eighty-odds, to be able to do things

Yes. What kind of things do you do?

Well (pause) I used to go to the dancing, I went to dancing (said quickly)

[My daughter] goes to line dancing now, this is a new thing, that I've never been at

I say, I'd better not go, I'm getting too old, for these kind of things

But I think I could do it

But, no, I can walk the roads a bit ...

And [my daughter] gets angry at me for (pause) she thinks I'm, getting away too much

I go up to (pause) where am I? [loses track of what saying]

I've a sister who lives at new town

And she's younger than me

And I go up and see her, but, she's never out the door

[My daughter] goes and does things for her too

But I, I dinnae need anybody to do my work

[My daughter] will do things for me.

But I can still (pause)

And she gives me a row when I start to do windows

She says, "Mother, stop doing that."

I think she thinks (pauses) because (pauses) I'm old

I started (smiling and looking at memento), I finished up working at [workplace]

I worked at [workplace]

And I came to [town of workplace] (pause)

Now, that's a long time ago

That was me finished working

And I'm still working yet, to a certain extent

So, I've been a lucky person

### Transcription 3

[Based on Labov's (1972; 1982) framework of formal structural properties

Adapted transcription, examining the parsed stanzas for formal functional properties, with my summary of the abstract, orientation, complicating action, evaluation, resolution and coda; emphasis removed and idea units split into lines to make presentation of the meaning clearer; stanzas given titles according to my summary of the main message in each segment of text

#### **Narrative: I've been a lucky person to be able to do things**

##### **Stanza 1 (*Abstract: I'm lucky to be able to do things at my age*)**

I'm lucky at eighty-odds, to be able to do things

[Yes. What kind of things do you do?]

##### **Stanza 2 (*Orientation: I'm getting too old to do things*)**

But I think I could do it

Well, I used to go to the dancing

I went to dancing

[My daughter] goes to line dancing now

This is a new thing

that I've never been at

I say, I'd better not go

I'm getting too old, for these kind of things

**Stanza 3 (*Complicating action: I can do things but my daughter gets angry*)**

But I think I could do it

But, no, I can walk the roads a bit ...

And [my daughter] gets angry at me

for, she thinks I'm, getting away too much

I go up to (pause) where am I? [loses track of what saying]

**Stanza 4 (*Complicating action: I've a younger sister who never goes out*)**

I've a sister who lives at [town]

And she's younger than me

And I go up and see her

but, she's never out the door

[My daughter] goes

and does things for her too

**Stanza 5 (*Evaluation: my daughter does my work but I don't need her to do this*)**

But I, I don't need anybody to do my work

[My daughter] will do things for me \*\*

But I can still (pause)

And she gives me a row when I start to do windows

She says, "Mother, stop doing that!"

I think she thinks (pause) because (pause) I'm old

**Stanza 6 (*Resolution: I finished up working but I'm still able to work*)**

I started (smiling as looks at memento from work)

I finished up working at [workplace]

I worked at [workplace]

And I came to [town of work] (pause)

Now, that's a long time ago

That was me finished working

**Stanza 7 (*Coda: I'm been a lucky person*)**

And I'm still working yet

to a certain extent

So, I've been a lucky person

\*\* By examining the formal structural properties of this narrative, the meaning of what Cynthia is saying becomes clearer. Cynthia says, "But I, I don't need anybody to do my work. [My daughter] will do things for me." Reading purely for content, based on the first transcript, Cynthia could be meaning that she does not need help outside the family because she has her daughter to help her with work. However, put in the context of the sentences following this, which are said in the same pitch to indicate that they are part of the same narrative segment, it becomes clearer that Cynthia is explaining that she is not allowed to do housework despite being capable. When she says she does not need anybody to do her work this includes her daughter, who Cynthia perceives to be restricting her from doing things.

Put in the wider context of the whole narrative, which is bounded by the phrase 'I'm lucky/I've been lucky', Cynthia can be understood as asserting her opinion that she is lucky to be capable of working, but she is actually finished up working due to the restrictions placed on her by others. She is comparing the past with the present in this narrative, in comparing her home life with her retirement from employment, to make sense of her current situation and express this to me. In terms of her capabilities, she is also comparing herself to her sister, making a social comparison with a peer who she considers to be worse off than herself, in order to strengthen her assertion that she is capable. In talking about being too old, Cynthia is also evaluating her life in terms of her age, making comparisons with her daughter and what she can do. This narrative ends in the past tense to indicate that Cynthia was lucky in the past. However, she also says that she is still working to a certain extent, so she does not see her situation as absolute and this indicates the potential for her life to be different.

