Living With MND:

An evaluation of care pathways available to adults with, and the families or carers of, adults with Motor Neurone Disease in Scotland

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MND Scotland

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1

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Main Findings

Motor Neurone Disease (MND) is a progressive condition that damages motor neurones, the cells that control voluntary muscle activity, in both the spinal cord and the brain. It can cause difficulty in walking and movement, talking, swallowing and breathing and many muscles in the body can become affected. To find out what it is like to live with MND from the perspective of those with the condition we carried out a longitudinal study in which we interviewed 40 people with MND and their partners a number of times over a two year period. We found that:

- **Control**, or more particularly the lack of it was the overarching theme that occurred throughout the interviews. People wanted to be consulted, informed and involved in decisions about their health and their social care and where this happened people were more likely to report satisfaction with the service.
- **The diagnosis of MND** is a long and protracted process, one that was for many a very distressing experience. 45% of those we spoke to took over 12 months for a diagnosis, 19% over 18 months. Participants had difficulty getting professionals to take their symptoms seriously and once they entered the neurology system many people experienced delays and often the diagnosis was not confirmed by a neurologist.
- **Physical access to hospitals** was in some cases difficult. Car parking and the location of the clinic often made it hard for people to get to a hospital appointment.
- **Health professionals** had an important role. Good professionals were those who took time to create a sense of teamwork with the person with MND and their family. This was less likely to happen with hospital consultants and where this did not people felt insecure and not listened to. There was also some evidence of poor communication between professionals and medical notes were often not shared between different professionals. Where people accessed general wards they were rarely treated well.
- **Informal carers** provided much of the social care and support for those with MND, with spouses meeting most of the need. Whilst many people were happy with this arrangement meeting the need placed a great deal of strain on the families. Many people did not want to rely on care supplied by outside agencies as they did not trust the quality or the reliability of the care and neither did they want their home overrun with people.
- **Housing adaptations and the provision of aids to daily living** were for many a great cause of stress and strain and many people felt that they were not involved in the decision making process, felt out of control and unable to influence the situation. The rapidly progressive nature of MND can exacerbate this problem.
- **Social Care** and support provided by local authorities was very heavily criticised. There were inconsistencies between services, people felt excluded from decisions made about their care and their care needs and people did not have access to the necessary information to make an informed choice about which services to access.
- **Specialist Care Nurses** (SCN) played a vital role in the care and support of those with MND. Not only do they provide help and support directly they also help to act as a champion for the family and coordinate services and service provision. This service is however under great strain and there are a significant number of people for whom this service is not working because the service was too stretched and the resources were not available to allow the SCN to meet their needs.

Contents

Executive summary

Background

Motor Neurone Disease (MND), sometimes called Amyotrophic Lateral Sclerosis (ALS) is a term applied to cover a range of different neurodegenerative syndromes all of which share a common neuropathology, in particular the progressive degeneration of motor neurones. It is a terminal condition that can cause a range of symptoms and can affect people's mobility and their swallowing, breathing and eating.

Much of the previous research into MND has been preoccupied with a focus on medical issues and the medical management of the condition including eating, home ventilation and other issues around the use of services. The voices of those with MND and their immediate family and carers have frequently been excluded as research has focused on the perspectives of health and social care professionals.

The overall aim of this project was to try and rectify this gap and to explore the experiences of those who are diagnosed with MND and their families across Scotland from their own perspective. We aimed to document their experiences and their perceptions of the diagnostic procedure, what it was like to live with MND; their views of services they accessed and the service providers; and of how living with MND affected their social relationships with family, peers and professionals. We also aimed to examine the role of the providers of care and support in shaping their experiences, to document examples of good practice and to make recommendations relevant to policy and practice.

Methods

We set out to ensure that the voices of those with MND and their family and carers were heard and that the research findings were based on their views and perceptions. We interviewed 40 people with MND and their partner or spouse a number of times over an 18 month period. We also ran a series of focus groups with people who had cared for or supported a person with MND who had died. All our research participants were recruited through MND Scotland and were

drawn from across the whole of the Scotland and included the views of people from the range of social experiences and from a variety of geographical locations.

The breadth and depth of our data meant that we were successful in meeting our overall aim, and in the results section we highlight key themes from our analyses: the diagnostic process, access to medical service and to social care, the role of the family in the provision of care and support, access to information, the role of the Specialist Care Nurse (SCN) and people's perspective on end of life. Importantly we were able to develop an understating of people's experiences across different contexts, and involving interactions with different professionals. We have been able to highlight the variations experienced by people in their treatment and in the delivery of care in addition to the contingency of professional responses, particularly the differences between SCNs and other health and social care professionals. We succeeded in gaining insight into the preferences of people with MND in the design and the delivery of care and support.

Findings

Diagnosis

Fatigue, muscle weakness, circulation problems and difficulty forming words were the most common symptoms first noted by those we spoke to. Once people started to notice these symptoms for many people the diagnosis procedure was one that was characterised by delay and by confusion. Their first task was to convince often doubting professionals that their symptoms were real and important. GPs and others often tended to dismiss their claims, suggesting that their problems were the result of a range of causes including ageing, minor strokes, diabetes, allergies and even, in more than one case, badly fitting dentures. The actual diagnostic procedure was also very traumatic and many of the participants felt that it could have been better handled. Even where MND was suspected participants often felt that they were not being seen quickly enough and that they had to fight to get access to the hospital. Confirmation of the diagnosis was also, for many, poorly handled. Many of the problems were related to poor communication between health service professionals, where one professional assumed another had already informed the patient. For example one participant described how their GP had been

informed about the diagnosis but she had failed to get in touch with their patient. Most people were not pleased with the way the diagnosis was delivered.

Specialist Care Nurses

The specialist care nurse (SCN) plays a vital role in the delivery of services for people with MND and their families. The tasks carried out by the SCN were many and varied and included; visits to newly diagnosed patients to offer counselling and support and to assess their needs, the provision of care and information, liaising with a range of health and social care professionals including OTs, nutritionists, physiotherapists, speech and language therapists, palliative care services, social workers and counsellors, working with and supporting other family members and acting as a first point of call for medical advice and to advise on disease progression.

Where the person with MND and their family built up a good relationship with the SCN this service worked very well and they were very well regarded and people were very complimentary about both their function and their performance. Many people looked on their SCN as more than just a professional who delivered care, describing them as a friend. Their role as a key worker and coordinator of services acting as a link between the different agencies was perhaps their most important. Our data would suggest that one of the key factors that helped in cementing the relationship between the person with MND and their family and their SCN was the opportunity to meet soon after diagnosis. Where this happened people in the main developed good, productive and helpful relationships, when it was absent people tended not have such a strong bond with their SCN. There were often good reasons why this did not happen, many of which were beyond the control of the SCN. For example there were occasions where the SCN was on secondment, was absent due to ill-health, worked part-time, the service was too stretched or even the geographical location of the family. Our findings would suggest that this is an under-resourced service that is currently being stretched to a point that at times it cannot cope with the demands being placed on it.

Access to and delivery of health and medical care

Physical access to hospitals, primary care and dentistry was for many problematic. Often car parking arrangements or the location of the clinic meant that people had to walk great distances

and the physical demands this placed on people put them off attending. People's physical limitations were rarely considered in the design or delivery of services.

Control and autonomy were key when it came to deciding what worked and what did not work in terms of the delivery of health care. Some participants spoke highly of their relationship with their GP. They described how, because he or she listened to them and worked with them and involved them in decisions about their health care they felt that they could trust them. Building a good relationship and feeling a sense of trust within that relationship was crucial to participants' feeling safe and secure in accessing health care. When health service professionals took the time to create a sense of team work people felt in control. A small but significant number did express some reservations about the work of their GP and their suitability as a provider of care. Many more participants were very critical of their hospital based consultant. They questioned the whole purpose of the hospital consultation, which were not seen as productive and they felt that they were run for the benefit of the consultant. They wanted to be actively involved in the process and be able to ask for information that was useful to them and not be passive recipients of services.

Hospital stays were also very problematic, especially where people had to stay in general wards where staff had little or no experience of working with people with MND. Non-specialist staff did not know how to handle people or how to meet their specific needs. Real concerns were voiced around Percutaneous Endoscopic Gastrostomy (PEG) feeding and not only was this a problem when people were admitted as an in-patient, many people were also discharged after a PEG was fitted with inadequate information about the technology and about how to administer food via the PEG.

Access to social care

People received a range of support in the form of social care including help with housing adaptations and the provision of aids to daily living and mobility aids, care support and personal assistance. These were all funded through a range of different mechanisms and delivered by a variety of different organisations including statutory bodies, local authorities and the voluntary sector. For care and support to work effectively it had to be provided in a timely manner and had

to take into account the potential for rapid progression that can be experienced by people with MND.   Many of those we spoke to told us that they did not know what was available or how to apply for a particular service and that they had to rely on information provided by professionals. In order to fully meet their needs many participants had to self-fund their support. People complained about the carers supplied by both the local authority and through private sector organisations, describing the services as poor and they did not trust the quality of their work and the care they provided. Accessing the appropriate care and support required was often a source of stress and frustration for participants, partly because participants did not always know from which sources to seek care combined with a lack of consistency across different service providers. Interagency cooperation was in the main poor.

It was hard to determine any pattern or single causal factor for the fairly widespread dissatisfaction with social care expressed by our participants. What worked best for families were social care professionals who came to work in partnership with those who were accessing the services, making them active in the process, and giving them some control of the situation. When decisions were taken for people without consultation the service tended not to be well received. This is not contingent on the type of job the professional does, but on their attitude and may involve working beyond their remit or considering novel solutions to problems.

Informal care and the family

MND meant that many of those we spoke to were forced to take on different roles in the family. Many felt that they could no longer provide care and support and people who had been independent now had to rely on others to help them with daily tasks. The family provided much of the support and care for people with MND, perhaps not surprising given their overall dissatisfaction with the quality of social care provided through formal channels. Providing the care themselves was the only way that they were able to ensure that the quality of the care was sufficient to meet the needs and to secure the safety of the person with MND. People also felt that by relying on informal care they could help to preserve the home as a family home rather than a site of care.

Whilst many were happy to deliver the care this solution was not without its costs, both emotionally and physically. People with MND described how they had lost any privacy and felt concerned about their own and their partner's physical safety with many feeling that neither they nor their partner had been sufficiently trained in the delivery of care and in particular manual handling. Many relatives who provided care and support suffered from physical and mental ill-health, and reports of musculo-skeletal problems and anxiety and depression were common. The physical effects of providing support combined with the normal effects of ageing and many conditions were exacerbated.

People's ability to have an active social life was also very greatly affected and many of those we spoke to lived very isolated lives, often rarely getting out of the house and then only to visit the hospital or hospice. For many even relatively simple mundane activities such as calling round to a friend's house for a coffee became difficult, mainly due to access issues. The requirement to provide care and support often meant that social activities were curtailed for the partner as well as for the person with MND. The need for short breaks, where both partners get time away from each other was something that all people talked about.

Access to Information

Prior to developing MND very few people had heard of MND or had much understanding of it as a condition. Many were aware of public figures with MND but they had little understanding about the disease, its effects or its prognosis. This meant that at the start of their journey people had a great need for information, a need that was not satisfied by their consultant during the diagnosis procedure. SCNs were seen by many as the most trusted information source. Many people turned to the Internet and whilst this allowed people to access information at their own pace it is uncontrolled and people were often made aware of the future consequences of having MND in harsh and uncompromising detail. MND Scotland's website and their fact sheets were considered good by those who used them but many could not use the site, mainly because they did not have access to the Internet. There was also some concern that the website was focussed more on fundraising than on information delivery and some of the fact sheets were of little practical use. The Support Groups, often run by people who have lost someone through MND,

were considered useful by some but many thought that they were too dominated by past carers. Although all those we spoke to were aware of them less than a quarter had actually used them.

LITERATURE AND RESEARCH DESIGN

Introduction

Motor Neurone Disease (MND), sometimes called Amyotrophic Lateral Sclerosis (ALS) is a term applied to cover a range of different neurodegenerative syndromes all of which share a common neuropathology, in particular the progressive degeneration of motor neurones. There are four common forms of onset:

Primary Lateral Sclerosis (PLS),

Progressive Muscular Atrophy (PMA)

Amyotrophic Lateral Sclerosis (ALS)

Bulbar Palsy

The symptoms people experience vary according to the mode of onset. Bulbar onset affects breathing and eating whilst PLS, PMA and ALS, often grouped together and termed spinal onset, affect the upper and lower limbs and walking and movement. Most people experience a combination of both spinal and bulbar symptoms.

It is a terminal condition affecting about 1 in 50,000 people and there are approximately 5,000 people in the UK living with the condition (Heywood et al 2012). Standardised incidence in Scotland is 2.4 per 100,000 (Forbes et al 2007) rising to 7.3 per 100,000 in people aged 80 and over (Forbes et al 2004). These figures suggest that incidence in Scotland is greater than in many other countries (Forbes et al 2007). Age-specific incidence increases sharply as people age, reaching a peak in the seventh decade, although the incidence in the very elderly is uncertain and it is less common in people under 50 (*Ibid*). Although the condition is very rare the effect it has on the population is very large with one report suggesting that for every person affected by MND another 14 close family or friends are affected (MND Association of Victoria 2008).

It is a condition that affects more men than women and in the majority of cases there is no known aetiology, although there is emerging evidence to suggest that there is a genetic link in between 5% and 10% of cases (Shaw 2005). Whilst there is no known cure, recent research has pointed to the potential survival benefit of a small number of therapies including non-invasive ventilation and Riluzole, a drug now licensed for the ALS form of MND and recommended by NICE guidelines (Heywood et al 2012).

MND causes motor weakness often starting with fairly minor symptoms like a drop foot (increasing the risk of tripping) or slurred speech. New symptoms emerge every few weeks or months depending on the individual and many adults with MND will experience motor weakness to the extent that they can no longer turn in bed, cough, breathe, eat, talk, walk or hold themselves upright in a chair. The historian Tony Judt described the condition as "progressive imprisonment without parole" (2011: 15).

There are a range of co-morbidities associated with the condition and MND can affect cognitive skills and mental health. Although there is some evidence to suggest that the use of oxygen and side effects of certain drugs proscribed to counter spasms and to manage pain can leave individuals in an 'altered state', psychiatric symptoms are often an inherent part of MND and are not usually the result of secondary phenomena or a side effect of living with a disabling or terminal disease (Lilo et al 2011). Research has linked MND with depression, dementia, and apathy, lack of motivation, sleep disturbances, fatigue and psychosis (*Ibid*).

The onset of symptoms and the progression of the disease can be rapid or slow. An individual prognosis is hard to predict and in Scotland the medical survival time is 25 months (Scottish Government 2010) and the survival time is lower than that found in many other developed countries (del Augila 2003). The most common cause of death is usually respiratory failure and people with bulbar onset tend to survive for less time than those with other forms of the condition. These figures are however variable and some people do not survive 6 months post diagnosis, whilst others survive up to 5 years and sometimes beyond.

Much of the previous research on motor neurone disease has focussed on the medical aspects associated with the condition, how the disease progresses and how the disease can best be managed. In their recently published systematic review of qualitative research with people with MND Sakellariou et al (2013) emphasize the point that we only have limited knowledge of how people live their lives with MND. In recent years there have been a small number of studies which have sought to explore how motor neurone disease is experienced from the perspective of those with the condition and their family and carers. Studies in England by Brown (2003), Hugel et al (2006) Hughes et al (2006) and Brown et al (2008) have documented the lived experience of those with MND and the care and support that those with the condition and their carers receive. These have been relatively small scale studies.

All of these studies describe the emotional trauma associated with the condition. Research in the area describes how living with the condition produces uncertainty and as a consequence people prefer to live in the "here and now" rather than think about the future (Sakellariou et al 2013). Brown (2003) for example documents what she calls the 'existential shock' of the diagnosis and the impact that has on both those with MND and on their families and their friends. Hughes et al (2006) comment on how the rapid physical deterioration associated with the condition can affect both the emotional and physical wellbeing of the individual and their family and how these two combine and make coping with the condition very difficult. As the condition progresses people start to lose touch with their friends and stop their usual social activities (Brott 2007). However people also want to be in control of their life and to be involved in decisions about their care and support and about their opportunities (King et al 2009). People want to be enabled to be in charge and to maintain their sense of self and self identity. Hugel et al (2006) describe the isolation experienced by people with MND and their families and Lockwood and Brown (2008) have looked at the role of peer support groups for people with MND.

Problems in the delivery of care and support are also often highlighted. The move to primary care as the main deliverer of support, whilst welcome in some areas can create difficulty in the case of MND. Brown et al (2005) link the poor service provision to a lack of knowledge in health and social care providers. For example although General Practitioners (GP) will invariably

be involved in the care of MND patients, often they have little or no prior experience of working with people with MND and many have not come across people with the condition before and may lack adequate experience and knowledge of this rare condition (Oppenheimer 1993, Robinson & Hunter 1998, Van Teijlingen et al 2001). A general practice with 10,000 patients is likely only to encounter a case of MND every two to three years (Shaw 1999) and an individual GP can expect to see one patient in their career (Levvy 2000). The provision of good care and support is, the literature suggests, critical during the early and late stages of the condition (Sakellariou et al 2013)

Care and support for people with MND is, or should be directed by or through a specialist neurologist or other dedicated agency provided by an outside source such as MND Scotland. They run a service to co-ordinate and manage the care and help to fill the gap in service provision. MND Scotland fund a team of MND Specialist Care Nurses (SCN) to provide such a service.

According to MND Scotland the roll of this service is to:

- Act as an expert source of advice to support the activities of all health and social care professionals
- Act as an expert resource to patients and carers; involving appropriate health and social care professionals in response to changing needs
- Link with other service providers
- Advise on probable disease progression to aid assessment of needs for the carer as well as the formulation of advance/anticipatory care plans.

The limited previous research in this area, such as the studies cited above, are all based in England and there has been little work in Scotland. There is also no available research on the services MND Scotland funds, in particular its SCN service. In addition they are also all relatively small; Brown (2003) for example interviewed six families and the study by Hughes et al (2006) is based on nine families. Given that there is now a significant difference in the way

that care and support are delivered between Scotland and England a study is needed that can explore how people with MND in Scotland experience the care they receive in the hospital, in the community and how they manage their pathway through care as they transfer from one service to another and how their views change over time.

The literature points to a number of key issues including the provision of care and support, an area that is very important as there is evidence from Ireland to suggest that the way care is delivered can dramatically improve survival (Traynor et al 2003). For example, the way health and medical professionals interact with people with MND and their families: the provision of information; the role and the place of palliative care; and how and when palliative care services should intervene and become involved with people with MND.   In the next section we review some of the pre-existing literature.

Health Service Care for people with MND

Guidance for the design and delivery of health and social care for people with MND are governed by the Clinical Standards for Neurological Health Services (NHS=QIS 2009). These standards were introduced in 2009 following a review implemented by NHS Quality Improvement Scotland in 2005 into services for people with neurological conditions in Scotland. This review found that there was a great deal of variability in the standard of the care offered to people with neurological conditions and expressed concern at the low priority accorded to services for this group. It also found that waiting times for appointments were often too long, there was a lack of communication between different agencies involved in the delivery of care and services, inpatient care was criticized and there was a shortage of specialist care nurses. A steering group was set up to develop general clinical standards for care and these were published in 2009. The clinical standards are aimed at improving general and specific health provision for people with neurological conditions and to ensure good access to social care services and improve the experience of patients, they also aim to improve general management of the condition.

There are three specific standards relating to MND;

- Standard 11 Access to specialist motor neurone services
- Standard 12 Diagnosis of motor neurone disease
- Standard 13 Ongoing management of motor neurone disease.

Each of these standards is composed of a number of essential criteria. The essential criteria for Standard 11 are that people with suspected MND must be referred to a neurologist and those with confirmed MND must have access to a specialist MND service. This service must be multi-disciplinary in nature and have links to therapists, palliative care, gastronomy, respiratory services and social services

The essential criteria for standard 12 are that people with MND have access to investigations within 20 days of request and that any diagnosis is confirmed and conveyed by a neurologist. The standard also stipulates that patient review after tests occurs within 15 days and that a regional care specialist contacts a patient within 2 days of diagnosis and people are offered contact details of support services.

The essential criteria for standard 13 are for people with MND and their family and carers to be a offered wide range of support at all stages of their journey and for ongoing and continual needs assessment at all stages to both those with the condition and their family and that an identified individual has responsibility for coordinating care at all times.

This study did not aim to evaluate either the effectiveness of these standards or how far or how they have been rolled out and implemented across the country. The standards were not introduced until after the research had started and most of the participants that we talked to were diagnosed before 2009, however they are included here as reference is made to them throughout the text and in the conclusions and they provide a useful framework for discussion.

In the next three sections we review some of the literature on care and services for people with MND. We look specifically at the impact MND has on the family and their role in the delivery of care, the relationship between people with MND and health service professionals and finally palliative care.

The impact of MND on the family and their role in the delivery of care

In their recently published document *Motor Neurone Disease; A problem solving approach* (MND Scotland 2011), in recognising the importance of the family in the role of care and support for people with MND stated:

> *Care requires a truly holistic approach to the needs of the patient and should encompass, where possible, the needs of the principal carers and close family members. As the disease progresses, the mounting series of losses to the individual impacts heavily on relationships with carers and family.* (2011: 9)

Despite the wide recognition of the importance of the family in the provision of care there has been very little previous research exploring how MND impacts on the family or on the family's role in the delivery of care and support. The limited and rather scant prior work in this area, such as that reviewed by Mockford et al (2006) and that carried out by Ray and Street (2005b, 2006) has focused on the views and perspectives of the carers or of the care professionals rather than of the people with MND themselves. It has also tended to be very medical in its approach.

Mockford et al (2006) carried out a systematic search of online and grey literature for research that examined the impact of caring for a person with MND published between 1994–2004. They examined 32 reports and concluded that providing care is a physically and mentally draining role. Carers of people with MND suffered from increased physical and mental ill-health, including high levels of anxiety and depression and often felt abandoned and isolated by professionals. They also faced economic disadvantage and MND can put families under severe financial pressure over a relatively short period of time.

In their work Ray and Street suggest that age can impact on the quality of care and care support provided and explores how this can affect a family's ability to provide social support. In carrying out their research they employed a concept termed 'ecomapping' (Ray and Street 2005b) a tool originally developed in research looking at child support networks. Their findings suggest that the families of people with MND who are aged 60 or over are more able to provide support and care compared to those aged under 60. This, they argue, is because those under 60:

> *... were grappling with critical issues outside that of immediate care giving such as, raising teenage children, balancing work and finances, caring for older parents and coping with people who gave unhelpful information" (2005a: 549).*

There is, they suggest, much less role conflict in families where the person is older. There is more of an expectation for older people to be in receipt of care and their children are often in a better position to help provide that care.

There is however very little research exploring how those with MND view the role of the family in the provision of care and support or of how MND impacts on family relationships, particularly in the context of managing the symptoms associated with the chronic illness or of managing the psycho-emotional consequences of living with a progressive terminal condition. Whilst both Mockford et al's systematic review and Ray and Street's work make some useful points, if we are to fully understand how people with MND experience their lives and their relationships and how best we can support them then we have to explore their experiences as well as those of their carers and couch those within their ongoing relationships. Any discussion on care and support has to include those with the condition themselves as well as the family.

Whilst there has only been limited work on people with MND there has been a substantial body of research that has explored informal care and support for people with other long term conditions and terminal conditions. This work has highlighted a number of issues including the effect it can have on the physical health of those providing the care and on other relatives

(Kuyper and Wester 1998). It can also have detrimental effects on people's mental health and on their ability to manage their lives (Kurts et al 2004). The demand and the emotional toll placed on the family can mean that all members of the family have to adjust their lives to help support the person with the condition (Newby 1996). People who are providing informal care need to acquire knowledge not just about the condition and its progression but also about how best to support the person with it and how to help in practical matters such as moving and handling, bathing and toileting and feeding (Bee et al, 2009; Docherty et al 2008).

Providing care and support is complicated and multifaceted (Esbensen & Thome 2010, McConigley et al 2010). The roles, responsibilities and relationships within a family can change radically as the demand for support can affect opportunities for recreational activities (Soderberger et al 2003). Family members can face social isolation and their roles in helping provide care and support can produce anxiety (Thorne et al 1988). The many roles that it demands of the carer can lead to strain and can create conflict both in terms of role and in terms of responsibility (Gordon & Perrone 2004).

It is important to point out that despite the many challenges that the provision of such care places on the individuals concerned there is a substantial body of evidence that suggests that the provision of support by relatives benefits the family members and those with the condition as well as the health and social care services (Glajchen 2004). It can be a fulfilling and rewarding experience (Miller et al 2000, Braun et al. 2007). Whilst recognising the increased levels of responsibility and emotional demand that providing such care places on individuals there is a danger that too much emphasis is placed on the burden of care and not enough on the rewards that it can afford both to the care giver and the care receiver.

The role of health and medical professionals

In their systematic review of the impact of caring for people with MND Mockford et al (2006) report that carers feel dissatisfaction when dealing with health professionals. They cite two

studies, one by Brown (2003) and one by Dawson and Krstjianson (2003) who suggest that health service professionals:

> *... lack empathy, often appear detached and business like, have little time to spend with individuals and little involvement, emotional input or hands-on experience. (2003: 38)*

Advice is needed on how to manage care needs and get training on the skills required (Lecoutorier et al 1998). Carers often felt that the compassionate and competent help, advice and support that they needed was not being provided. Mockford et al argue that this relationship is essential for the health and wellbeing of carers of people with MND. Health professionals, including general practitioners, consultants, nurses, therapists and dentists have a vital role to play in the delivery of services and support and in the provision of information and when this is well managed the emotional and physical load and strain associated with providing care can be ameliorated.

A good and productive relationship between health professionals and those with MND and their families is a key requirement for good care. Brown (2003) describes how people with MND and their carers wanted to be "valued and treated as 'being human'" (p215). She argues that proactive 'patient' involvement in decisions about care and about disease management is essential for good health care for people with MND. There is a substantial body of evidence to support this assertion and the BMA Patient Liaison Group (2007) have reported that where people are treated as partners by health professionals and are offered informed choice and active engagement in decisions about their health care and health management their outcomes improve.

For this to happen it is important that the relationships between people with MND and their families and health professionals are given space and support to develop and that as they develop they emphasise personal involvement and choice in health care ("no decisions about me without me" Department of Health 2010). They are about building relationships where agendas and collaborative decisions are made and people with the condition and their family are supported

and encouraged to set their own goals and they have an active role to play in the decision making process (Health Foundation 2008).

Palliative Care and Motor Neurone Disease

Palliative care, in the UK at least, is most commonly associated with people with terminal cancer and up to 95% of those receiving long-stay hospice care or daily home hospice care have cancer (Addington-Hall & Field 1999). Palliative care is a necessary provision for patients with non-malignant life-limiting diseases such as MND; Oliver (2002) argues that for people with MND palliative care should start at the time of diagnosis and palliative care throughout the disease process is crucial to the management of the condition. This care should be provided throughout the illness trajectory and not just confined to the later stages and Dawson and Kristjainson (2003) point to the advantages offered by the palliative care model for people with MND and their families. Coventry et al (2005) in their systematic review of palliative care for older people with non-malignant terminal conditions, argue that there is mounting evidence that suggests that there is a high level of unmet need. There is for example poor provision of services for symptom control, a lack of choice offered at end of life, open communication with health care professionals is rare, and psychosocial and family support are lacking; all services which are necessary for people in this group (Coventry et al 2005, Franks et al 2000,Skillbeck et al 1998). Various reasons have been put forward to explain why palliative care services have been limited in their extension to these non-cancer groups. These include arguments around the feasibility of funding for specialist palliation and, perhaps most importantly for people with MND an inability or a reluctance of medical health professionals to track a trajectory of progression, predict the time of death or 'palliative status' for people with such conditions (Coventry et al 2005, Addington-Hall &Field 1999). This is an area that is very difficult and with MND determining a prognosis is often impossible:

> *Compared with cancer, determining prognosis is more complicated in life threatening,*
> *non-malignant disease. Most of these diseases have 'entry–re-entry' death*
> *trajectories, involving episodic, acute exacerbations, frequent hospitalisation,*

stabilisation and steady decline, making determination of palliative status and referral to hospice care more problematic.

(Coventry et al: 2005: 219)

Franks et al (2005) lay out a number of criteria for determining palliative care needs for a non-malignant terminal condition; MND falls directly within these criteria. People with MND require symptom relief and support particularly due to the rapid progression of MND. They experience psychological distress and anxiety, feelings that are felt both by the person with MND and their families (Field & Addington-Hall 1999, 1273, Mcarthy et al 1996, O'Brien et al 1992). Palliative care can draw on a multidisciplinary team to help in the delivery of services. It can provide symptom management, comfort and care to both the person with MND and their carers and family. By providing a holistic approach it is able to help to ameliorate the distress and impact of a devastating illness such as MND and can improve the quality of life (Reid 2012). By working with those who provide care and support to people with MND it can also assist with grief and loss as well as provide bereavement support for those affected.

Considerations around equity are particularly salient for people with MND where in numerous avenues in their lives they experience a loss of control and choice over their general health care and social care. Extending palliation to non-malignant terminal groups is a matter of equity; palliative care is founded on the basis that every person has the right to know what their fate is (Field & Addington-Hall 1999), thus for people with MND to have this same right and equity around dying it is imperative that effective palliative care be an option for them. The philosophy of contemporary palliative care has extended to include the control of symptoms and the psychological and 'spiritual' wellbeing of individuals (Field & Addington-Hall 1999:, 1273).

This chapter has outlined the key literature. The next chapter will begin reviewing the research aims and objectives of this project before discussing the methods employed.

METHOD

Research Aims and Objectives

The overall aim of this project was to explore the experiences of those who are diagnosed with MND and their families from their own perspective. We aimed to document their experiences and their perceptions of the diagnostic procedure, what it was like to live with MND; their views of services they accessed and the service providers; and of how living with MND affected their social relationships with family, peers and professionals. We also aimed to examine the role of the providers of care and support in shaping their experiences, to document examples of good practice and to make recommendations relevant to policy and practice.

Empirical Objectives:

The research aims highlighted above were met through the following *Empirical Objectives:*

1. Experience: our research began at the level of the individual and his or her family and through their views to document how they experienced the diagnosis of MND and the symptoms associated with the condition, how they described it, what it meant to them, how it impacted on their relationships and how having both the symptoms associated with MND and the care and support they received impacted on their sense of wellbeing.

2. Organization: the research detailed how the forms, structures and activities of the services they access, in particular the health and social care service but also the services provided by MND Scotland impacted on their lives. We also explored how people with MND negotiated their way through the various care pathways and the ways in which organisation affected the experience of living with MND.

3. Sector: through direct comparisons between how different sectors and organisations within those sectors are experienced by those with MND we will be able to not only

contribute to the debates on the 'effectiveness' of the various approaches to working with people with MND and their families but also detail the characteristics and influences of various national policies on tackling the problems associated with MND and through this make recommendations relevant to policy and practice so as to enhance the well being of people with MND.

The empirical objectives were developed into a series of research questions. In designing our research tools and developing our research agenda we worked closely with MND Scotland to produce the broad analytical schema. Six major themes were identified: Perceptions & Meanings; Participation; Expertise; Resources; Institutional Factors; and Best Practice. See appendix 1 for the full list of associated research questions.

In designing this study and in choosing the appropriate research methods we adopted a research methodology designed to ensure that the voices of those with MND and their family and carers were heard and that the research findings were based on their views and perceptions. We employed a variety of qualitative methods throughout the course of this research to capture both the range and the depth of experiences. We carried out focus groups, in-depth interviews and participant observation with a range of informants including those with MND themselves, their immediate family and carers and those charged with providing professional care.

We sought to collect our data from as broad a range of people as possible and, with the help of the MND Scotland, recruited people diagnosed with MND from across the whole of the country and included the views of people from the range of social experiences. We have represented diversity in terms of gender, sexuality, socio-economic status and age. Appendix 2 provides an anonymised overview of our participants.

Ethics

This research was approved by the University of Glasgow's Ethics Panel and in carrying out this research we have been guided by the University's Code of Ethics

(http://www.psy.gla.ac.uk/~simon/ETHICS/BPSethics.pdf). All research participants were given a written information sheet describing the objectives of the research and were informed of all aspects of the research. They were all asked to sign consent forms prior to the start of the research and it was made clear to all participants that they had the right to withdraw at any point during the research process. Where families were re-visited for a further interview issues around consent were renegotiated and new consent forms were completed.

We were, at all times, conscious of the very sensitive nature of this research. We were aware that our interviews had the potential to both cause upset and to potentially harm research participants and we took great care in the way that we talked to and worked with all those we spoke to.

Confidentiality

The findings presented in this report draw almost entirely upon the information provided by people with Motor Neurone Disease or their families. We wanted to encourage all of our research participants to feel that they could speak freely and to this end we gave assurances that, when using their comments or their quotes or when describing their experiences, we would make sure that neither they nor anybody they were speaking about, either in terms of their family members or any of the health and social care workers they might refer to could be identified. Throughout the report participants are therefore given pseudonyms and we have also tried to 'anonymise' any health or social care professionals or groups or networks as appropriate.

In this sort of work however there is always the danger that an identity might become apparent to an individual reader through his or her prior knowledge of individuals, groups, professionals, service providers or networks. It is strictly not our intention to name and shame.

The Study

We adopted a two-pronged strategy in designing our research protocol. In stage one we carried out a series of focus groups (or in some cases one to one interviews) with partners or other a

familial carer who had recently cared for a person with MND who had died. Participants for these focus groups were recruited with the help of MND Scotland who sent out a letter to the relevant sector of their membership asking for volunteers to contact us directly. We spoke to 22 people during this stage of the research, the aim of which was to sensitise us to on-going issues and to allow us to develop a broad understanding of the key issues faced by people with MND and their families. A topic guide for the focus groups can be found in Appendix 3.

For the second stage of the study we initially worked with the SCNs to contact families that they thought would be amenable however this was not a successful strategy. After negotiating with MND Scotland, they agreed to send out a letter to people with MND asking for volunteers. The letter detailed the proposed research, outlined its aims and objectives, explained what taking part in the research would entail and contained our contact details. We also visited a number of support groups where we explained in detail about the proposed research. In both cases if people were interested they were asked to contact us directly at which point we again outlined the research and explained the research process.   By adopting this method of recruitment we were able to ensure that MND Scotland were not aware of who agreed to be part of the research and who did not.

In total we recruited 43 people with MND to act as our key informants though 3 withdrew prior to interview. This sample represents approximately 10% of those living with MND in Scotland.

Eight participants showed classic signs of bulbar onset where the only symptoms up to diagnosis were related to speech or swallowing. Nineteen participants showed the classic symptoms associated with spinal onset, in particular muscle weakness or twitching in their limb muscles. The remaining participants showed a combination of bulbar and spinal symptoms.

We interviewed each key informant and their family members up to 4 times over the course of the study. By adopting this longitudinal approach to the research we were able to document how their views and experiences changed over time. This longitudinal strategy has not, as far as our

extensive review of the literature revealed, been used before to explore the impact of MND on people and their families.

This sample of 40 people allowed for an in-depth study of the experiences of this group. All those we spoke to were interviewed in their own homes and we documented their experiences as the disease progressed. Most of the interviews were joint interviews with their husband, wife or (adult) child and in a number of cases where the participant had little or no spoken communication the partner answered most of the questions. We were however careful to ensure that the person with MND was included in the interview and all questions were directed to him or her. Some participants communicated through pen and paper or used equipment such as a light reader. No one was excluded because they faced barriers to communication; interviews just took longer to accommodate their needs.

Thirty-eight participants were taped and transcribed for subsequent analysis (one person emailed their responses and another chose not to be recorded but permitted note taking). The interviews were supplemented by informal contacts and we also spoke to immediate family members and carers. The informants and their family members were active participants in the research process shaping both the content and the direction of the research as they identified practices, events and processes that were important to them.

Interview Schedules and Topic Guides

Through these various methods described above we were able to develop a picture of the various aspects of people with MND's experiences, balancing their and their families' subjective experiences with an understanding of the wider social contexts. We explored their experiences of healthcare; of the diagnosis process their experiences about hospital and community services and their needs, fears and concerns and how these changed over time. We focused in particular on their own views about their care pathway and how they and their family members negotiated their way through the services. All our interviews were flexibly designed to allow for the incorporation of insights from on-going analysis. The topic guide was not a tightly structured set

of questions, but a list of topics that we wanted to cover. The wording of the questions and the order in which they were asked were altered in the course of the interview, depending on the responses that the participant gave to earlier questions. In this way the topics could be covered in any order and a manner that was in keeping with the flow of the interview. In essence the topic guide was used as a checklist to ensure that the interview covered all the desired areas (Lofland and Lofland 1995). As the studies progressed the topic guides were altered in response to previous answers. In this way the topic guide was both theoretically and empirically informed.

The topic guide for the second and third round interviews were derived from themes that emerged from the data obtained in the first round. Areas covered included mental health, emotional wellbeing, feelings, quality of life and access to services. The interviews themselves all went very smoothly. All the informants made us feel very welcome and in most cases, it was easy to get the informants to talk. Some informants were more verbal than others and the majority of interviews lasted for between 60 and 120 minutes. The multi-interview format allowed a greater rapport to be developed between the research team and the participants. A quantum of the interviews is found in table 1.

Analysis

All the interviews were transcribed and checked for accuracy and then uploaded into Nvivo9, qualitative data analysis software. The interviews were analysed using standard qualitative methods and an inductive comparative analysis of the data was carried out (Silverman 2010). The transcripts were read and coded and themes and topics of particular importance to individual participants were identified. The categories evolved as more and more transcripts were analysed. By using this coding system we were able to identify patterns, breaking the data down into manageable units and regrouping this data as emergent themes (Atkinson 1992).

It is to the actual analysis of the data that this report now moves. The data are presented under 7 main themes that emerged from this analysis of the data. Each theme has its own chapter:

Diagnosis; Specialist Care Nurses; Access to Medical Care; Access to Social Care; Family and Friends; Access to Information and End of Life.

Table 1 Quantum of recordings and transcripts generated by interviews

	QUANTUM OF INTERVIEWS
Number of participants	- 73 people involved in direct interviews* - 40 families - 81 separate interviews - 22 people involved in 5 focus groups** - 5 professionals consulted to give context to MND
Number of recording hours	- 112.5 hours
Shortest interview time	- 29 minutes, 58 seconds
Longest interview time	-3 hours, 15 minutes
Average	-Time of interview – 77minutes - Number of Pages – 19 pages -Words in transcripts – 9374 words
Total number of pages of transcripts	- 1718 pages
Shortest transcript	- 4777 words, 10 pages
Longest transcript	- 22, 450 words, 37 pages***

* Either with the person with MND, or their relative

**Focus groups ranged from one to one interviews (where participants could not physically come to a focus group) up to a focus group of 5 people

(Focus groups took place over 4 major cities across Scotland, where travel costs were provided, to make it more accessible to a diverse range of people with MND)

***1 Family did not want to be recorded and 1 family responded only by email therefore those participants feature in the 'Number of Participants' cell, but are not represented by the rest of the data in the table

***It is also important to note that a small number of participants experienced difficulty talking (due to the impact of MND), where others did not; this is reflected in the quantity of data that they provided but not in the quality, meaning or context which was immeasurable.

THE TRIAL OF DIAGNOSIS

Introduction

In this chapter we present an overview of how the research participants described the onset of MND. We document the early symptoms of the condition; the triggers that made the participants seek treatment and their pathway through the diagnostic process. All of these are presented from the perspective of the patients and their families.

The section opens with a discussion around the time taken for diagnosis and the journey. The data was thematically analysed to aid understanding of care pathways in Scotland. The data collected in this paper was generated using a general code of 'diagnoses'. As the coding continued, sub-categories were identified and form the sub-headings of the Findings section.

Findings

Sample

Most of the data presented in this section are drawn from the first interview. Although all of the 40 participants with MND interviewed are included, 7 did not talk in enough detail about their experiences of the diagnostic procedure in order to map their progress. Eight participants showed classic signs of bulbar onset where the only symptoms up to diagnosis were related to speech or swallowing. Nineteen participants showed the classic symptoms associated with spinal onset, in particular muscle weakness or twitching in their limb muscles. Six participants showed a combination of bulbar and spinal symptoms prior to their first visit to a GP.

Table 2 shows the length in time from the first visit to a GP, to a diagnosis of MND. The gap between GP and diagnosis did not exceed 24 months. Whilst some informants had difficulty discerning exactly how early symptoms started before first visiting their GP the data suggest that this varied greatly across our sample. Thirteen first reported symptoms to their GP immediately,

10 within 3 months of noticing symptoms, 3 waited up to 6 months, 3 up to 12 months and 2 just over 1 year. Advice from others, painful symptoms or restricting symptoms were most likely to trigger an early visit to a GP.

Time to Diagnosis

Table 2: Months taken from first GP visit to a diagnosis of MND

Months from initial GP visit	0-6	6-12	12-18	18+	Total
Bulbar onset	1	4	1	2	8
Spinal onset	7	3	5	4	19
Combination of Bulbar & Spinal symptoms	1	2	3	0	6
Total	9	9	9	6	33

Whilst the sample size is too small to allow parametric statistical tests the data would suggest that those with spinal onset are more likely to be diagnosed earlier than those with bulbar onset with 37% of people diagnosed within 6 months of first visiting their GP and 53% within 12 months compared to 14% and 42% respectively of those with bulbar onset or a combination. These findings mirror those of Mitchell et al (2010), although they do not break down their data by diagnostic category.

Pathways to Diagnosis

Below we present three typical pathways to diagnosis, mapping out the key moments as identified by the research participants. We have selected three typical stories, one with spinal onset, one with bulbar onset and one with a combination.

 The first was described by Susan, a woman with spinal onset MND, with the help of her husband Graham. The couple are in their late 50s and live near a major Hospital with an MND clinic.

Table 3: Susan's pathway to diagnosis

Date	Symptom/Action
November 2008	Numb floppy hands, but only when cold. GP said due to poor circulation. Told to wear gloves.
Spring/summer 2009	Started dropping things Went swimming late summer and could not move the water. The GP became 'alarmed'
9th September 2009	GP sent to major hospital with MND clinic Susan suspecting MND or 'something with the brain'
27th October 2009	EMG test results. Susan insisted that the Consultant give her a diagnosis. Told she had MND
March 2010	Next appointment with a MND Consultant

Mark and Fiona, a woman with bulbar onset, mapped out their journey to diagnosis. Fiona had written down these events and Mark read from the notes during the interview. Fiona supplemented her list, and Mark's reading of it, with hand written notes. Fiona and Mark were in their 60s and lived around 40 miles from a major hospital with a MND clinic.

Table 4: Fiona's pathway to diagnosis

Date	Symptom/Action
January 2008	Biting mouth at night causing ulcers – contacted Dentist. They suggested it could be spicy food or pregnancy. Not reassured by this, Fiona asked to be referred to a specialist.
March 2008	Specialist's biopsy came back clear. Met the GP because Fiona now had slurred speech but not taken seriously
February 2009	Pursued with GP until met another specialist who was well thought of by both Fiona and Mark but thought the slurred speech and biting caused by ageing and sagging skin. Invited to consider a face lift.

April 2009	Measured for a gum shield
June 2009	Pursued with GP again, referred to a Locum Consultant Neurologist – said he could not see symptoms of MND, but could not rule it out. Sent for an MRI and EMG
July 2009	Saw a speech therapist, Fiona told that her speech would not improve so no point in giving exercises EMG showed no abnormalities, Consultant wanted to wait to see if other symptoms developed before considering a diagnosis
August 18th 2009	Had to pursue the hospital to get another appointment. Diagnosed with MND.

A final map to diagnosis is given in table 4. Gayle's experience is mostly described by her husband Eric; the couple live with their teenage children around 20 miles from two major hospitals with MND clinics. Gayle visited her GP with some bulbar and spinal symptoms.

Table 5: Gayle's pathway to diagnosis

Date	Symptom/Action
March 2008	Numbness noticed in arm. Contact made with GP. GP is sympathetic but does not refer Gayle.
September 2008	Gayle notices slurred speech.
December 2008	Others have noticed her slurred speech so contacts her GP and is referred to a Neurologist.
January 2009	Neurological tests performed at her local Hospital and at a major hospital 20 miles away. Given a diagnosis of Bulbar Palsy but not told what is causing this. Given an EMG and a Lumber Puncture. Frustrated by lack of progress, Gayle and Eric start searching the internet.
May 2009	Diagnosed with MND. Gayle quits her job.

These three brief outlines highlight a number of key issues. First, many participants noticed early symptoms which were fairly minor and were rationalised away. For example people talked about noticing an increased risk of tripping which they put down to clumsiness, or muscle weakness in leg muscles which they ascribed to ageing or to lifestyle changes. Slurred speech was blamed on tiredness and on problems with teeth or on badly fitting dentures; general aches and pains were blamed on ageing and other conditions such as arthritis. This rationalising away of symptoms meant that there was often a significant delay between the onset of symptoms and seeking medical help. Third there is often a significant gap between seeking medical help and the final diagnosis of the condition. It was often hard for the participant to get their condition treated seriously as many of their GPs also rationalised the symptoms away ascribing similar causes to those applied by the participants themselves.

Deciding Something is Wrong

In this opening section we document how the participants first noticed something was wrong and the immediate actions they took. The data are, where appropriate broken down by diagnostic category. For people with spinal onset typical first symptoms included muscle weakness:

> *I noticed that when I got up in the morning my calf muscles were very tight – as if they had kind of shrunk in the night ... That first few steps as I stretched out it was "ooh, ooh...." And then I noticed, as I was going up and down stairs my thigh muscles were just, you know, I just noticed it as I was coming up I thought "oof I'm no'..." But having said that I had retired from work of course so I wasn't as active as I was every day so I just assumed... "C'mon How old are you?" "You're sixty whatever? You're muscles obviously are not going to be what they were ... You're not out and about so you're not doing as much..." So, everything had a logical explanation.*
> *Marie, spinal onset symptoms*

Fatigue and inability to perform normal tasks was also a first sign:

I first noticed it when I was out playing golf. Eh... I was completely knackered and couldn't wait to get off the course... And after sitting in the club house for a couple of hours ... an hour or so... I went to get up to go to the loo and I completely seized up... it was completely... oh, it was as if... you would have thought that I had been climbing Mount Everest... and then the next time I went out to play golf I was very slightly limping and had no push off of one foot. And that was how it started.
Phillip, spinal onset symptoms

Circulation problems were mentioned by others as the first sign that something was wrong:

... it was cold outside and me and my wife did quite a lot of walking and if it was a cold day and coming back my hands would get numb… and eh.. I didn't think much of it – I thought it was just the cold weather… But one day I come back and I couldn't even get the key in the door to open the door and I had no power to open the door. So, I just jumped in the shower and had a hot shower and problem solved – I thought it was just with being cold and I never thought anything of it.
Mike, spinal onset symptoms

For those with bulbar onset, problems with speech and forming words were often the first symptom noted:

I was working in a [retail] job and I always put the fruit and veg in and in January 2010 I couldn't say, I found it difficult to say "[street name]." That was the first time.
Alison, bulbar onset symptoms

At first these symptoms were easy to ignore or to ascribe to some minor cause for example ill-fitting dentures or other dental problem were often blamed:

Well, first of all I had false teeth
JF: Right.

And my speech started to slur I and kept saying my teeth are too slack and eventually I went to the dentist and told him that my teeth was affecting my speech.

Edith, bulbar onset symptoms

Some of those with bulbar onset thought that they may initially have had a minor stroke and were referred for checks.

People with joint spinal and bulbar onset experienced a mixture of the above. For example Simon told us:

And the first things I noticed was that I had a feeling of 'dead leg' on my left leg when I had been running – as if the circulation had been cut off. Then one day I went on the phone to Amy Rochester and I found that I had a job saying her surname… you know the 'R'.

Simon, spinal and bulbar onset symptoms

Initially the participants ignored these relatively minor symptoms and it was usually only when they became more severe or they started to interfere with their day to day activities or to risk bodily harm, for example tripping and falling heavily that people generally approached their General Practitioner (GP). For example:

[I] found taking notes or typing things up on the computer or whatever – this numbness in my right hand was beginning to cause a problem so I went and saw my GP.

Alex, spinal onset symptoms

And

Sheila had a couple of wee occasion where her left foot had caught on steps going up the way and she'd taken a wee tumble.

Craig, wife Sheila went to GP with spinal and bulbar onset symptoms

For others it was the persistent nature of minor symptoms such as swollen ankles that just would not go away that acted as the trigger for seeking further treatment:

> *So, I left it about a month or something but then I used to think "Oh, I need to get off my, my feet are...." you know how if you have been on your feet all day and they get really, really achy ... that was in the June, and as I say I left it until about July and then at the beginning of August I thought "This is not going away. I'll need to go and see... there's something not right here." So, I went away down to the doctor, ... I told her about the ankles, I told her about the swelling, all this kind of thing. She says "We'll do a couple of blood tests and I'll send you... I'll send you over for an x-ray – it might be arthritis." Marie, spinal onset symptoms*

People also often acted when others, in particular family members, noticed their changes:

> *My two brothers were visiting me and they were in the kitchen of my old house and I was in the living room talking to them and the older brother, he said "Have you heard Alison speak? She's slurring her words." So, I thought then that I had better [see GP]. Alison, bulbar onset symptoms*

For most of our research informants these triggers to visit their GP occurred within 3 months of noticing the initial symptoms although a few took more than 12 months. By the time they made contact with their GP there were usually a number of symptoms to report and a general feeling of ill-health, although participants generally had not considered that any one condition might be the cause.

Convincing Medical Practitioners that Something is Wrong

The first task for our informants on approaching their GP was to try and make the GP take their symptoms seriously. The GPs tended to ascribe the symptoms to a range of minor ailments,

much like the research participants had when they initially noticed the changes. The symptoms were rarely seen as a sign of a serious problem and the GPs looked for a range of other causes, including stress:

> *[The GP said]... "Right, going to press down your thighs and I want you to push back as hard as you can with both legs" and... eh... and he said "Matthew you're as strong as an ox" and...eh...because I was there he said "I think perhaps the two of you need to go home and, sort of, assess perhaps what's going on in your lives that...eh...there's those symptoms happening" and looking back on it I realise he thought there was something psychological going on and you think "oh perhaps we've retired, perhaps you'd just don't know how to handle it" and I thought it didn't seem right but however we accepted it.*
> *Nicola, husband Matthew went to GP with spinal onset symptoms*

GPs were more likely to relate the symptoms to existing conditions such as Type II diabetes, arthritis, damaged knees, dehydration, allergic response and perhaps most commonly, natural ageing. Stroke was also mentioned particularly in response to those with bulbar onset.

This refusal to accept that there was something wrong often caused conflict, for example one participant's GP and local Hospital specialist refused to refer her to a larger Hospital because they were convinced of their diagnosis of trapped nerves. Further, they did not alert her to their decision, leaving her waiting for an appointment that did not come. Having worked as a practice nurse, she was eventually able to argue her point and get re-assessed but only after paying for a private appointment.

Much like the participants, the GPs waited until the symptoms had persisted for a period of time or for the participant to present with other accompanying symptoms before referring them on for further investigation. However in some cases, even multiple symptoms were missed.

And I hadn't seen this GP with the problem, I had seen somebody else who in fact unfortunately had left and he said, he asked me what my symptoms were and I showed him my hand and I told him about my leg and he just said "Just a coincidence..." and I was angry with him.
Patsy, spinal onset symptoms

Many of the participants were frustrated by what they felt was a lack of appropriate response by their GPs and complained about what they felt was 'time wasted' at this stage of the diagnostic procedure. They described how they had to demand that their views were taken seriously

But we had to push and push to get appointments and to get diagnosed because it was just waiting a couple of months and waiting a couple of months and it was too much of a worry, too much of a pressure. So, we just kept phoning up their secretaries and everything. Just push, push, push to get the tests and get the results.
Charlotte, husband Tom went to GP with a combination of bulbar and spinal onset symptoms

Many felt that they were not taken seriously and there was a lack of urgency in the way that their GP responded. This increased the pressure and tension felt by the families:

So, I came off the phone and I thought "My God, if I have to wait another 5/6 months – I don't think I will be able to walk by that time"... My family and my daughter and that – they are cracking up ... So I thought about it and I thought "see to tell you the truth – I don't think that I could wait six months. I'm starting to get a bit panicky now."
Marie, spinal onset symptoms

Once the GP took action and referred the participants on for further investigation the actual diagnostic procedure was also very traumatic and many of the participants felt that it could have been better handled. Even where MND was suspected participants often felt that they were not being seen quickly enough and that they had to fight to get access to the hospital:

"Well, my husband was supposed to be seeing them in three months and this is now six months..." and [the hospital receptionist] said "Well, the next appointment is in a year." And I thought "Well, that's not good enough. He could be dead in a year." So, she phoned me back (this was the Friday)... she phoned me back and she said "I can get you a private appointment with [the consultant] on Monday morning but it will cost you..." (I can't remember how much – stupid money) and I said "Well, that's not good enough. My husband was supposed to have been seen three months ago at that Dr's request. He could be dead in a year and I don't see why we should be in this position..." and she phoned me back... she then said "Well, I'll phone back to the hospital." And she called me back and she said "Right, you can see [the consultant] on Monday and there is no charge."
Kate, husband Phillip went to GP with spinal onset symptoms

Many of those we spoke to felt they were initially kept in the dark about the process and that decisions were made without fully informing about why certain tests were being carried out. For example people were not told why they were being sent for tests such as MRIs, EMGs or lumbar punctures, the latter causing particular issues as it was seen as very invasive and a signifier of something serious and the very fact that it was being carried out raised their concerns. The actual referral to neurology also caused concern and participants spoke of a sense of dread created because it was 'to do with the brain' and therefore '*no very much that anybody can do so ...'* (Marie, spinal onset). The feeling of frustration continued throughout the whole diagnostic procedure right up to the point of diagnosis.

People were however aware of how difficult it was to diagnose MND and that it was essentially a diagnosis of exclusion:

I was sent up to the hospital for a full body scan and a head scan (an MRI scan) and there was no calcification so they ruled out MS. But he was writing about fourteen things down on a list and every test that came back he would score something off until he had MND in the last three.
Rose, spinal onset symptoms

The delay in diagnosis and the time gap between first noticing the symptoms do not have any impact on the prognosis. It does however have a big impact on the wellbeing of those with the condition and their families. Not only did the time lag between the first visit to the GP and the diagnosis put them and their families under considerable stress it also led many to believe that if they had taken action quicker they may have been able to take action and delay onset or ameliorate the severity of the symptoms:

> *I'd asked [the neurological consultant] when he still thought it wasn't MND, "What should I do? Exercise?" He told me that until we had a clear diagnosis that we should just carry on as normal but now I've wasted a year.*
> *Sharon, spinal onset symptoms*

The actual process of getting a diagnosis was, as we have shown, hard for many of the participants. The next section examines the process of receiving the diagnosis.

Shock of diagnosis

Whilst many of those we spoke to expressed confusion about when symptoms started, how they were first noticed, their order or which doctor was seen and when, the point of diagnosis was different. Here participants were able to specify the day of the week, the date and the month accurately. For some the process was handled as well as could be expected:

> *I mean the doctor, I mean he came and he was with his registrar and he took us into a quiet room and eh... I mean, obviously there was no other way of sort of beating about the bush... And he just sort of said "I'm sorry to have to tell you this but you have MND..." but, I mean, I have heard of other people who have had the experience of their doctor saying "Right, you've got Motor Neurone's Disease..." That's it end of story, just get on with it... But, he sat with us for a bit and did say to us that there is support out there for you and that we would be put in touch with a care advisor and that she would*

be in contact with us shortly afterwards... And sure enough, about a week after you got

your diagnosis [the Specialist Care Nurse] was on the phone to us.

Paula, husband Alan went to GP with spinal onset symptoms

For others the process was handled less well. Most of the problems were related to poor communication between health service professionals, where one professional assumed another had already informed the patient. For example one participant described how their GP had been informed about the diagnosis but had failed to get in touch with their patient, leaving it until the next visit to the Consultant:

So, I came home and on the Tuesday I rang my GP and he knew the diagnosis. [The

consultant] was going to ring [GP] and I can guarantee he would know before I had even

got out of the hospital. And I spoke to him three times on the Tuesday and not once did

he say "Come and see me..." or make any reference. And I saw a Consultant on the

Wednesday and on looking back now I realise that he thought somebody else had told me

and I sat down and he looked at me and there was like a silence wasn't there? At first he

just looked at me and he said "This is the most dire diagnosis." And then he said "and

you're to go on anti-depressants".

Patsy, spinal onset symptoms

Similarly, Susan's MND Clinic appointment was with the Registrar and when he failed to disclose a diagnosis, she had to insist on seeing the Consultant who was prepared to diagnose MND. While it can be understood that giving a diagnosis is distressing, the participants were desperate to know. Other problems were related to those who received the diagnosis at a district hospital and had to wait for referral to a centre of excellence:

I would like to stress that we were... He was told at the hospital what he had. We had to

walk out of there and wait... nearly six or eight weeks before we seen [specialist

consultant] or a nurse... and we had to push to get that appointment and that was

horrendous because we only knew what we read. He asked [the local consultant] some

questions and he said "I'm sorry, I'm not the specialist. You will need to ask [specialist consultant]." So, we walked out of there absolutely terrified. We didn't even know if he got out of his bed at night if his legs were going to give way or... If he was going to choke or start choking... or anything – we hadn't a clue.
Charlotte, husband Tom went to GP with spinal onset symptoms

Anticipating bad news did not insulate participants from the shock of a diagnosis of MND.

[Consultant said] "I don't wish to alarm you – but I believe in being upfront..." So, I was saying "What's coming...?" So, he says "There's signs that it might be Motor Neurone..." and that just about finished me...
My heart dropped down here somewhere... I knew what Motor Neurone was... and honestly I was shot to pieces when he mentioned Motor Neurone.
Mike, spinal onset symptoms

Three families received the news the same week as Christmas causing them to 'lose' this family event as they reacted to the trauma of having a diagnosis. Most participants used physical metaphors to express their reaction: '*my heart dropped down there somewhere' (Mike)*; '*it was as if someone had punched me in the gut' (Marie); 'just horrified' (Rose); 'there was nobody there to catch us' (Kate)*. This distress obviously affected health service professionals.

Distress of giving a diagnosis

Participants understood that giving a diagnosis of MND is a very difficult task and were empathetic to the person who had given them their diagnosis. They described the distress experienced by their Consultant or GP as they gave the news:

Jean: ... and then we went to the doctor that afternoon and the GP was just shocked...
Alex: He looked absolutely shattered... em... yes, he said to me that he had never even

contemplated MND…
Alex talking with his wife Jean, spinal onset symptoms

Even once the diagnosis had been confirmed some Consultants backtracked from the original diagnosis as the patients distress became more obvious:

So, it was a morning appointment so by about two o'clock Claire had got herself in a
state worrying about me so she phoned him back… So, she said "I am going to phone
him up and see what he said to you…"
JF: Oh, so she wasn't with you…?
Oh yes she was with me but she wasn't with me in the room when I was being assessed…
She was in the waiting room you see… So, he got quite upset, the [Consultant], to be fair
to him… he said "Tell [Mike] not to worry – it is probably not Motor Neurone… in fact, I
am 90% sure that it is trapped nerves…"
Mike, spinal onset symptoms

Mike waited another 6 months to get a definitive diagnosis of MND.

Bed-side Manner

Most participants were not pleased with the way their diagnosis was delivered. Practitioners were seen as being too abrupt (though interestingly several participants were reassured by having a Consultant with a poor bed-side manner, as if this meant they must be very clever and busy Doctors) and some were insensitive.

Kate: It was quite brutal. It was quite brutal because the two of us were in there not
expecting it and he had Phillip up on the bench and he just did a few wee tests and then
he said "oh, yeah. This is Motor Neurone Disease." And...
Phillip: "And I'm busy just now..."

> *Kate: I started to ask a few questions because... I am like that... I just question, question, question... and he answered I think two questions and then he said "Well, you know, I have got other patients to see..." and I fully understand that and I fully appreciate that but we walked out that door just having been told that Phillip was dying...*
> *Phillip and his wife Kate, spinal onset symptoms*

This is not an isolated experience. Simon and Penelope felt dismissed after their diagnosis.

> *Simon: I had the EMG and that was absolutely clean – it didn't indicate any problem but the guy who gave it to me said "The test is clear but in my opinion you have Motor Neurone Disease and you will...um..." What was the word he...?*
> *Penelope: "Your body will succumb..."*
> *Simon: "You will succumb to the disease within five years..."*
> *JF: oh...*
> *Simon: "...and pick some leaflets on the thing on the way out..."*
> *JF: Oh...!*
> *Penelope: That was a bit shocking...*
> *Simon and his wife Penelope, combination of spinal and bulbar symptoms*

And another couple were not even offered leaflets.

> *He obviously knew that Fiona was an ex-nurse because he had it on record, and he said "how much do you know about MND?"And Fiona said "enough". And he said "well you know that you've got 6 months to 3 years to live then" and I was sat alongside her. And then his next phrase was "by the way, my in-laws live just around the corner from you". ... we were, to say the least, disgusted.*
> *Mark, wife Fiona went to GP with bulbar onset symptoms*

Many were left with a dire yet vague prognosis and a lack of a clear treatment plan. Some were just handed leaflets which for some were *"put up on top of the cupboard after a quick glance*

and didn't look at it, and have not looked at it very often since..." (Eric) whilst for others proved very useful. For others getting any information was problematic. One person was told by their GP not to search on the internet for themselves and that the receptionist would provide background leaflets only to be told by the receptionist that they were unable to print off any information. This left the participant bewildered.

> *I said to [diagnosing consultant] "what happens now?"and he said "what do you mean?" And I said, "well, do I have more tests or do I come back?" He said, "do you want to come back?" and he said I could take the Riluzole, and he said "It can cause liver damage"' ... he was so removed and I really felt as though he might as well have said (and I certainly felt it) "well, you're finished. Off you go ..."*
> *Patsy, spinal onset symptoms*

People whilst recognising that MND was a terminal condition all wanted to do something, to challenge the condition, no matter how futile. They wanted, as one woman put it "to die with MND not from MND", it was advice on how to do this that many felt was poorly handled:

> *[The diagnosing consultant] said I could have physiotherapy and I said "What about massage?" and he said "Well, that's just for your well being." And I said to him "I don't have any well being!" I asked about... I'm not greatly into medication and I tend to be more interested in holistic things. I asked about supplements and vitamins, minerals and he was really quite dismissive and scathing. He said "You get it in your food."*
> *Patsy, spinal onset symptoms*

Our data would suggest that health service professionals, recognizing the very poor prognosis faced by all of these people do not see any options or any hope. The provision of information post-diagnosis forms the basis of the next section in which we explore the role of the MND Specialist Care Nurses.

Conclusions & Recommendations

In order to most clearly represent the 'voices' of the participants, this section has been full of direct quotes. From the interviews we would make eight key recommendations:

1. More effort must be made to reduce diagnosis times I line with the NHS Neurological Clinical Care Standards (2009).
2. There seems to be a trend towards later diagnosis of MND where the person first presents with bulbar symptoms. Further investigation is required to determine if this is a real trend or just an artefact of this research, if a real trend further work could be done to help identify MND earlier in this group.
3. The diagnostic procedure for MND diagnosis is very complicated and drawn out. The centralisation of services has meant that people attend many different clinics (attending multiple GPs visits, clinics, departments, hospitals, seeing several consultants and so on). This increases the potential for communication breakdown, a relatively regular occurrence in our sample. It is recommended that where possible, patients receive test results (whether from GPs or consultants) from a single nominated person.
4. People facing a diagnosis of MND are desperate to know so delays to protect them (from the shock of diagnosis) are not helpful.
5. Notes should be kept with sufficient detail to allow clinicians who have not met a patient before, to know the 'history' of that patient. Participants often expressed anger at having to tell the same story repeatedly.
6. More should be done to prepare people for the tests that they are going to encounter. People should be told what the test is for, what it will feel like and why it is being carried out. There is currently a great deal of confusion in this area.
7. Receiving the diagnosis is always a shock, even where participants were expecting the diagnosis, and so should be delivered with sensitivity giving families the time and space needed to absorb the information.
8. Families diagnosed with MND need a clear treatment plan and an indication of prognosis.

SPECIALIST CARE NURSES

Introduction

This chapter will focus on the role of the Specialist Care Nurses (SCN) in Scotland. There are six nurses employed in Scotland. SCNs work as part of a multi-disciplinary team to provide a 'defined motor neurone disease service' (NHS Neurological Clinical Standards, 2009: 20). The team consists of (as a minimum) a specialist doctor, the SCN, the patient and the carer. The team is likely to extend to include support from physiotherapy, occupational therapy, speech and language therapy, dietetics, pharmacy services and mental health services. Within the team structure SCNs act as a lynch-pin holding the strands of support together and liaising closely with the family to ensure their needs are met.

In Scotland, there are currently three are full-time, two share a full-time post and the sixth SCN works three days a week. MND Scotland fully funds theses posts although their contracts are with the NHS and they are based on NHS premises. Between them the SCNs cover fairly large geographic regions to provide support to families who have MND. Every SCN supports families that live in urban and very rural areas and some support families that live on Scottish islands. The geographical challenges faced by SCNs in being able to fully support families will be discussed in this chapter.

This chapter will begin by exploring how the participants defined the role of the SCN. Particularly valued was their key-working role, their emotional support, their medical expertise and their home visits. While some families received excellent and timely support, others did not feel that they had a trusted or useful relationship with their SCN and the issues that led to this will be discussed.

Data for this chapter was extracted from the transcripts of interviews by initially coding for 'specialist care nurse', 'nurse' and 'MND nurse'. However the participants often did not refer to the SCN by professional title, but by first name so all of the transcripts were mined in detail for

all information that related to the SCN role. In this chapter each SCN is referred to as the SCN so as to protect the identity of which SCN we are talking about. We recognise that this anonymity homogenises each SCN working in Scotland and dehumanises them to an extent. This is regrettable. One SCN in particular was considered invaluable to participants and many of the glowing quotes refer to them.

This chapter will explore the positive and negative impact from the SCNs. It will explore themes such as communication, support for other family members, providing equipment and working with other professionals. The aim of this section is to highlight how the SCNs are useful to families, and what barriers exist that impact on how useful they can be.

Findings

The Role of the Specialist Care Nurse

The roles of the specialist care nurse are many and varied and they include; visits to newly diagnosed patients to offer counselling and support and to assess their needs and liaising with a wide range of health and social care professionals including OTs, nutritionists, physiotherapists, speech and language therapists, palliative care services, social workers and counsellors. They are meant to act both as a key-worker: a coordinator and a link for these services and as an expert source of advice to help support the activities of others. They are also meant to be a resource for information both for the person with MND and their family to be their first point of call for medical advice and to advise on disease progression. Where the NHS's Neurological Clinical Standards (2009: 20) refer to 'specialist motor neurone disease services', they are referring primarily to SCN's as 'the face' of this provision. In addition their experience and expertise allows them to anticipate future care needs and ensure that services are provided in a timely manner. Their successes in achieving these roles were, according to our participants, variable.

Some participants were very positive about their experiences of the services and support they received from their SCN.

Like, when Alan came out of hospital obviously it had affected his respiratory
again so I had said to [SCN] "I think we might need to be looking at a wheelchair.
To get him out and about. I mean he can walk a few yards which is fine but to go
any further it's a no no." And she said "Just leave it with me..." and she put the
referral into and within the week we had a wheelchair. You can't ask for any more
than that.
Paula, her husband Alan has MND

Here whilst the SCN did not have an immediate solution she assured the family that they would
find one and Paula and Alan appreciated that they could trust her to deliver. They continued to
outline why they found their SCN helpful. For some, the SCN was an extensive and invaluable
resource and one that they could rely on for a variety of tasks.

JF: What is it that she does that you find useful?
Alan: Well, for a start, I had to apply for Disability Living Allowance and when
we got the forms in I thought "What's all this about?" [SCN] says to me "I'll
help you fill it in..." She's helped me get that, she's helped to get the bathroom
adapted... Anything that I need I know that she would do her best to get it...
Paula: What I sort of find really good is that she sort of liaises with all these
other people because I feel that if I had to do all this myself.... You know? Like
contact dieticians, speech and language or whatever, whoever has been involved
in his care... I just feel that I would be banging my head off the wall whereas if I
say to [SCN] .... she said "Leave it with me..." and she contacted them and they
came out and although I sort of deal with them myself now but it was pulling
them all together.
Alan and his wife Paula

They acted as a key-worker and by keeping the needs of those they worked with central in the
decision making process they were, in some instances able to help them overcome the barriers

they faced in planning the management of their care. They were also able to ensure that they were not excluded from the day to day decision making process and in sourcing equipment.

> *We had a wheel chair, we had a bath, we had a couple of bath chairs, and [the SCN] seemed to be brilliant. She decided something was needed, she went and made phone calls and pulled strings and things happened.*
> *Peter, his wife Karen had MND*

The service worked best when it started with the person and when this happened the SCN was able to act in a way that empowered the individual and his or her family. Where it worked it worked well and was an important contributor to the health and wellbeing of those we spoke to.

For others however their experiences of the SCN were less positive. Some were unaware of the support the SCN could offer them or, in other cases felt that their SCN was unable to provide either the desired key-worker role or the sort of support they desired. Some had had not built any relationship with their SCN and only had intermittent or infrequent contact from them. Many families were also really not sure what the remit of the SCN was.

> *I don't really know the function they are serving to be honest with you because I'm quite sure that there's other people that maybe … use them more, and maybe have got more specific needs or requirements or requests but … I certainly look more towards the medical side, the GP, the 'Home Ventilation Team'.*
> *Paul, his wife Rachel has MND*

The role of the SCN was for many unspecified. Their capacity to act as key-worker was not, in some cases widely advertised and there is some evidence to suggest that there was not enough information provided on the role of the SCN. As a result, largely because they were unaware of the sort of services and support their SCN could offer them, people turned to other sources of support. For example, they went to other traditional sources of support such as GPs. While some families actively chose not to use the SCN in a key-working role, it was evident through the

interviews that many were unclear that this service was available to them or of how to use the SCN.

The SCN's role as coordinator was key for many of the families and when we asked people who did not have a good relationship with their SCN what sort of services would help them most they all cited the idea of a key worker who could help coordinate their care:

> *I have had to do it all myself … I have had to ask for physio, I have had to ask for OT …it seems to be that everything that I need I have had to fight for … I have not really had anyone backing me up. In my corner.*
> *Sarah*

This point was echoed by other families:

> *In terms of just, in terms of services and everything falling into place. That did not happen for us and I became … well from the beginning I was like the case manager because there was no-one else to coordinate all this. I'd to fight, and I do mean that, I had to fight, fight, fight for everything.*
> *Nadine, her brother Laurence had MND*

In order for the SCN to adequately support families, they need to build a relationship with them. It is to this, that the next section turns.

Working with the SCN and Building up a Relationship – Someone on our Side

This section will discuss the usefulness of a strong relationship between the SCN and families. Our data would suggest that one of the key factors that helped in cementing the relationship between the person with MND and their family and their SCN was the opportunity to meet soon after diagnosis. The section will then consider the friendship that often emerged from a close working relationship and how families valued the trust that they could place in their SCN.

Those that met with an SCN in their home in the early stage of their condition had a much stronger relationship with their SCN a relationship that strengthened and developed further as their condition progressed. This was particularly important as the disease progressed and their support needs changed it was also very useful when people first received their diagnosis. By contacting the family early on the SCN was able to help at a time when people felt most confused and scared and they were able to offer advice:

> *Sure enough, about a week after you got your diagnosis [SCN] was on the phone to us. So, that … I think that in itself helped because … well I felt … I mean, I don't know obviously how he felt at that particular time but I just felt totally lost … as if to say 'well, what do we do now?' 'what happens now?'*
> *Paula, her husband Alan has MND*

As was discussed in the Diagnosis Chapter, prior to the diagnosis most participants did not have a clear idea of what MND was or what it meant. Their meeting with the Consultant, at the point that the diagnosis was given was for many traumatic and generally not a good time or space to learn about the impact of MND on their lives. They also needed a short period of time post diagnosis to collect their thoughts and to develop questions which might not have been apparent at the time. Not only did an early visit help to establish a relationship it also gave the participants the opportunity to reflect on the implications of their diagnosis. Providing the opportunity for questions and support at this early stage was for many critical.

By visiting the family early post-diagnosis in a safe (non-clinical) environment the SCN was able to lay the foundation blocks for a strong and sustaining relationship that extended into the wider family:

> *As I say [the SCN] has been an absolute… because my sister and my daughter and that… I mean, I think that [SCN] is on first name terms with them all now she has been on the phone to them that often with them. And they were absolutely marvelous in providing*

support for my family and information and everything else. They were absolutely
excellent but I don't know where else we would have went... I really don't know where
else we would have went if they hadn't have been there with the likes of my family. And
then as I say [SCN] came out a few weeks/a couple of weeks after the diagnosis and she
was fabulous.
Marie

. Around one quarter of participants defined their SCN as a friend and as someone they could trust and turn to in times of trouble, demonstrating the strength of the relationship. Many felt that it had had gone beyond the professional and become personal.

In addition to being able to provide emotional support a further key benefit of the SCN was their medical expertise and their knowledge of MND and the surrounding issues:

JF: Had you heard of MND before? Did you recognise what [the Consultant] was
talking   about?
Only, only because of... em... the scientist – the famous...
JF: Stephen Hawking. So, you were aware...?
I knew of it and had absolutely no real notion of what it was...
JF: And did [the Consultant], at that point, take you through what it meant or did he just
sort of give you...?
At that... em... yes, in broad terms but it was really [the SCN] wasn't it...
JF: Right – so the specialist care nurse...?
Was the one who really explained it in much greater detail.
Andrew, his wife Jennifer has MND

The SCN has a unique opportunity to provide more than just emotional support; they also have a clear medical understanding of MND and its potential progression and they were seen as trustworthy and as a source of good and reliable information. Further when meeting with the SCN either for the first time, or in subsequent meeting, they did not need to begin by explaining

their condition as was the case with other professionals. This aspect of their expertise was noted and appreciated by many participants.

> *I met her quite quickly. She came out to my house … and I was still in the emotions … and I remember her coming in to talk to me and it was the first time that I had met her and I started to cry and I got up off my chair to the table and got a tissue and sat back down and she must have been watching me – she went "you're quite good with your physical … you are able to stretch and get up"*
> *Catherine*

Some participants described how the SCN was the first person they spoke to after diagnosis that they did not have to explain what MND was or its consequences. This meant that possibly for the first time post-diagnosis they could talk to somebody and did not have to focus on the progression or deterioration they were facing and could move the focus away from 'what's wrong' to what was going on. The SCN gave them space to cry and to express their emotions.

> *And it's [the SCN's] care and her tactfulness and the way she described what was going to happen. And you knew, but it was done in such a good way, a very professional way. You feel gutted in … you feel shocked and you think "yes, this is going to happen"*
> *Betty, her husband David had MND*

In the focus groups people reflected on the degree to which they relied on their SCN for support and information:

> *I think one of the things this highlights which has become a concerns is, [the SCN]is central to all this. How many other people are there lined up for if [their SCN] retires or moves on to something else. So much of everything came from her, and obviously her very specialist knowledge. Are there other people getting trained up with, who will have that level of knowledge?*
> *Peter, his wife Karen had MND*

Where people had the opportunity to develop an early relationship with the SCN the service worked well however roughly third of the families that we spoke to did not meet or see their SCN in the period immediately following diagnosis:

> *Yes… I'm… We were feeling very… very much as if nothing was happening for some months. We were getting increasingly – I was getting quite agitated…. [wife with MND] was actually getting, naturally, worried… but I was thinking "What the hell is going on?" "What are we going to hear about it?" "Who is this [SCN]?" Eventually [SCN] got in touch with us… So, our first experience was not good.*
> *Andrew, his wife Jennifer has MND*

In these cases a good relationship did not often developed.   An early meeting is recognized as best practice and according to the Neurological Clinical Standards (2009) one should be set up within two days of diagnosis. There were however often good reasons why this did not happen, many of which were beyond the control of the SCN. For example there were occasions where the SCN was on secondment, was absent due to ill-health, worked part-time, the service was too stretched or even the geographical location of the family.

Best Practice Working: Limitations and Barriers

Cases of best practice working existed and some examples have already been given. However, some participants were frustrated with the lack of support obtained from their SCN. This section will explore the limitations and barriers faced by SCNs that prevented them from achieving best practice. Before discussing why people felt unsupported, the section will reflect on the level of frustration felt.

> *[The SCN's] been about as much good as a chocolate teapot and that's the Gods honest truth. We've not had any support or help from MND Scotland. We don't really have much in them at all. We've actually just, not long ago, sent them a letter basically asking*

them to reply to a complaint we've made, and we want nothing more to do with them.
Because we have just not been given... They should be our source of information.
Charlotte, her husband Tom has MND

This was a family with teenage children, facing a fast progressing MND and they had a high level of support needs. In this case, effective support from their SCN was critical. The provision of a service like the SCN is a vital link between a family in crisis and a myriad of professional organizations and personnel. As can be seen in the Social Care Section, many participants were unsure where to ask for help, who to ask for equipment or even where the equipment they had been provided with came from. The SCN can alleviate the stress of navigating the complexities of a system that is often location-specific (in some areas equipment was mostly provided by the District Nurse, in others only by the Occupational Therapists (OT)). When this role was not adequately performed or where mistakes were made, participants became angry or distressed.

Craig: Sometimes the [SCN] will say she will do something and then it doesn't happen
and then you need to try and follow-up and once or twice even that has not …
Sheila: No. It has taken ages to get an appointment with a physiotherapist.
Craig: it has, because we asked about that …
Sheila: And I still haven't seen them …
JF: So that's what, a year that you have been trying?
Sheila: uh-huh
Sheila and her husband Craig

Later the couple discussed the MND fact sheet on physiotherapy and how it cites benefits, including mobility, avoiding stiffness, aiding breathing. The family interpreted this as indicating that they should be accessing physiotherapy and they felt that the waiting time may have been exacerbated by what they perceived to be unresponsiveness on the part of the SCN. This was also highlighted by Charlotte and Tom:

[The SCN's] parting comment to me every time we've seen her was "If I forget to phone you, you phone me..." Excuse me, but you've got our case notes, you know he's one of your patients, that's just... "Text me, or phone me and remind me if I don't get back to you.. If I don't phone you with the blood results, you text me and ask me..." I've got enough... I have totally got so much to do between working, running the house, running Stefan to football training, full-time carer to 1, and no help at all... Doing it all myself, and then she's wanting me to chase up phone calls, and send a text to remind her things and everything she says she'll get you she doesn't do it... She just does not do it... and that's her off on the sick now, she's off on the sick now until next year. So, I know they're stretched, I know they're stretched but at the end of the day that's...
Charlotte, her husband Tom has MND

As discussed in the last section, in many cases the families who were not visited at the outset failed to establish a good working relationship with their SCN and this had long term consequences. It could, for example leave families unsure of who to approach for support as their condition progressed.

The OT came out but she says I need to see the social worker for carers, so I'm always getting shifted round. I never know who to speak to. The [SCNs] are part time so I never get hold of them when I need them. And as I get worse, I have different needs.
Sharon.

It also left them unsure as to how to get in touch with their SCN.

[The SCN] that she would keep in touch and I haven't heard from her since ... I know that they work part-time ... but I don't know the days that they work ...
JF: Right ... so, you don't feel that you can get in touch with her – you have to wait for her to get back to you?
Mm- hmm (nods)
Fred, his wife Lydia has MND

One family, unclear as to how to get in touch with their SCN, called the MND Scotland information line to be put in contact with their SCN. Lorraine wanted advice because Calum, her husband (with MND) had another medical condition that was affecting his ability to use equipment provided (because he had MND):

> *I phoned to see if there was [a SCN] who could come and perhaps advise me on the best way to proceed. "oh, just let us know if it becomes a serious difficulty" ... but you know, the tone was "don't bother us ..."*
> *Lorraine, her husband Calum had MND*

Almost all participants understood the pressures on the SCNs and so did not want to complain, and sometimes during the interviews were protective of the SCN:

> *I mean, [SCN] doesn't come out on a regular basis but that is our choice. She is always there ... well, he always feels that because [SCN] covers such a wide distance and she sees so many people that we only have her come out if she is needed to come out. Any other time we will either speak to her on the phone, or I'll email her.*
> *Paula, her husband Alan has MND*

There were others who felt very much in control of the service offered by the SCN and could call on her when and as they required.   This research does however suggest that there are not enough SCNs in Scotland to fulfil their remit and to provide the support families require.

The geographical distance covered by SCNs was raised by around a quarter of the families as something that acted to limit their access to the service.   Unsurprisingly, those living in rural communities were much more likely to highlight this as a reason that they did not meet regularly with the SCN. Some would have liked to have had more regular contact with their SCN but restricted the amount they called on her because they felt she was too busy or that a visit would place too much strain on her because of the large distances she would have to travel.

We found [SCN] absolutely superb. We can't praise her enough but I did feel as if she was … you know, operating on her own … she was responsible for half of Scotland.
Andrew, his wife Jennifer has MND

SCNs often worked hard to meet the challenges of the large geographical areas that they covered. There were examples of SCNs travelling to the islands and using video conferencing:

We did [video conferencing] twice for apparently [the SCN] couldn't come up because the problem [number of people with MND] was apparently increasing and she didn't have time to come up.
JF: Right, and how was the video conferencing? Did you find that easy to do?
Mmm, yes, well, it was not so bad … it was kind of strange …
Fraser, his wife Joan had MND

While solutions to overcoming the Scottish geography were innovative, they were not as good as a home visit.

Another limitation that forced compromise was the working hours of the SCN. Some families were very mindful that their SCN worked part-time.

The support was always there and again, over the last month or so, [their SCN] was strictly only working part-time but she said that her mobile was on 24 hours a day, 7 days a week … That's all above and beyond the call of duty, I appreciated just having that reassurance that there was somebody there that would understand what was going on.
Peter, his wife had MND

In this example, the SCN was willing to provide ideal support but in doing so was working way beyond their remit, and the level of availability went way beyond their remunerated hours.

Understanding the pressures on SCN to perform their role was enough for some families to avoid contacting them even though they were facing difficulties:

> *[My SCN] was on holiday just when, I sort of needed her and I suppose there was somebody else that would have been in charge ... I think that [my SCN] probably did tell me, probably, and I thought that I didn't want to bother [the other SCN] because she's got double the load or something ...*
> *Bridget, her husband Tim had MND*

Because families were reluctant to call on SCNs, their need for support has sometimes remained hidden.

Having examined the overall role of the SCN from the perspective of those who use the service and the importance of relationships we now move on to look at specific examples of the way the SCN works.

Relationship of SCN with other Family Members

Participants very much valued the role the SCN took with other family members.   This took two key forms. First the SCN was able to provide direct support and advice to other family members about their own health and help them take actions to improve their own wellbeing. This meant that they were better able to provide support and care for the person with MND:.

Many of the people we spoke to appreciated that the SCN was respectful and sensitive as well as being resourceful. People with MND valued this personally, and when sensitivity was extended to their families. The following quote comes from an interview with someone who has MND and discusses the support his wife received.

> *[The SCN] ...who is their outreach person has been absolutely super and kept a good eye on me and introduced me to one or two services that they had. And has been very good*

with my wife who is ... very depressed and has been suffering depression for some
considerable time.
Christopher.

This provision is also outlined in the NHS's Neurological Clinical Standards (2009: 22). The standards specify that a 'needs assessment' should be completed for 'carers' and this did not emerge as a provision actually received by participants.

Second they were able to help the person with MND handle difficult family issues, such as informing children or other relatives about their diagnosis, what it means and about how the condition will progress:

I requested ... so [SCN] came one day and sat them down and we were not present at it
so I don't know how much detail she went into but I think it is pretty much 'this is the
story so you will have to be a bit more responsible in the house and ...' and it went in that
[ear] and came out that one ... but I think that my son was a bit more au fait with the
actual condition I think ....
Paul, his wife Rachel has MND

They were also able to handle potentially emotional issues such as prognosis. Some family members felt that they were unable to discuss prognosis with the person with MND.

One of the difficulties I had was Karen's approach to [having MND]. Right from the very
first day after she was diagnosed, [her approach] was to get on with life and not go over
it or to even talk about it to me. She just simply blanked it out, that was her way of
dealing with it which worked very well for her but it was quite difficult for me because I
wanted to try and find out what was going on, and what was going to happen next but
always having to do that without Karen's knowledge. That's where [the SCN] was
fantastic, she would come and chat to me just to make me aware of what could happen

next, and in most cases the accuracy with which she predicted it was almost spot on.
Peter, his wife Karen had MND

 A few other family members spoke about finding this chance to consider the future with the SCN as useful. With the exception of the focus groups, almost all family members were interviewed with the person with MND present, so may not have felt comfortable raising this issue during the interview. There is some evidence to suggest that families would appreciate time alone with the SCN and this might be added to their workload.

Interactions with other Professionals

Central to the key-working role, and particularly valued by participants, was the SCN's ability to make connections and initiate actions on the participant's behalf.

> *[The SCN] has been an absolute brick. She gets things moving and if she says that she is*
> *going to provide you with something she does, and she is very good at phoning other*
> *people up to get things moving.*
> *Dundee*

The SCN was seen as someone who was particularly effective in intervening with other professionals to either resolve a conflict or to help attain services from a service provider who seemed unresponsive., Marie recounts what was for her a very emotionally upsetting story that happened immediately following what had been a very difficult and protracted period as she sought a diagnosis. Waiting times in excess of 6 months to see an NHS funded consultant had forced her to go privately. Following her diagnosis, Marie made repeated calls and requests to her social work department; calls which had gone unreturned. Her early experiences were defined by distress and poor communication from professionals. Her dependency on care providers had left her unable to find or fund much needed resources for herself. The quote begins by her describing a phone conversation with a social worker who had not answered her calls.

Well, I got a wee bit upset on the phone one day and I said to her and I said "Do you know, [SW]? I am absolutely dependant on you. I am dependant on you and you have let me down. You have let me down and I'm really..." And she said "Well, I'm sorry about that..." and I said "It's all very well saying you are sorry about it but talk is cheap..." and I hate being dependant on people. So, see if somebody says they are going to get you and then don't... I don't want to do it, I do not want to do it. I would rather just say "Well, that's just fine I'll just...." I've went and bought stuff myself rather than having to go through them because... Anyway, that's by the by. So, I did I got a wee bit upset and I raised my voice a bit because I was upset and she said "Oh, [Mrs. Campbell], if you're going to speak like that I won't be able to...." So, I just put the phone down. So, I phoned [SCN] and said "would you do me a favour and would you phone them up? I am upset and she said I was shouting but to tell you the truth I was upset could you phone her and tell her I am sorry." I was a wee bit upset. So, SCN said that she would phone. Marie

The frustration in dealing with unresponsive providers had left Marie anxious and when trying to communicate this, the social worker threatened to end the phone call an action which further exacerbated the situation. By calling on the services of the SCN she was able to resolve the situation. In this example, the SCN's role extended to advocacy.

One particular concern expressed by some of our participants was the potential for SCN to act for an individual or family and to leave them "out of the loop", an action that unintentionally disempowered rather than empowered:

I have seen one of [the SCN]. She came to the house to have a chat. She came when these people from the council were there and she gave her views and they gave their views, etc to see what I was to get... They seemed to be quite amicable about it... amicably agreeable about it all. I was just sitting there and listening. So, I don't know what it was all about really at the time but really I haven't seen any of them since.

JF: Right. So, you weren't really involved in that discussion, even though it was in your house?

Correct. Well, that is the way that I feel. They were talking above my head...

Tony

In this case the SCN was acting on the assumption that having the person with MND present in a meeting was the same as involving them in the decision making process. However, whilst this is a potential drawback in the role of the SCN it was a complaint that was only made by one other family. Most of our evidence would suggest that the SCN worked with, rather than just for, families and included them in deciding how best to meet their needs prior to discussing this with other professionals.

This approach also has the potential drawback of failing to tackle the root of the problem. Our research would suggest that many of the same issues came up across Scotland, in particular issues of cooperation and communication within, between and across different agencies. Rather than resolve the issues centrally the sort of service offered by the SCN merely patches up the problem and there are no central resolutions, structural changes or changes in practice. There appears to be no learning across individual cases with services continuing to offer an inadequate and at times unacceptable level of care and support.

The ambiguity that can surround the role and the specific duties of the SCN can mean that at times nobody is sure who does what and who is responsible for what action or what service and this can leave people feeling unsupported:

My GP I avoid – he can't look me in the eye because he feels uncomfortable and if I suggest something he'll say "See the MND nurse …" I've rung her for advice and she'll say "See your GP" and so it goes. Nobody says "Right, I'm here …"

Patsy

It also means that other health and social care professionals do not have to develop their own skills in this area and they are free to absolve themselves of responsibility in the knowledge, or perhaps hope, that somebody else will pick up the pieces. This hope is, of course, justified where an SCN has built up a good working relationship with the family but where this is absent there is a danger that the already large gaps that exist between the services that individuals and their families can fall between may become even larger. Despite SCNs existing, and providing an excellent and needed service, over one third of our participants felt they had fallen into the gap.

Seeing SCN at Consultations

Many participants saw their SCN at their annual or biannual hospital appointments with a Neurological Consultant. In theory this should work well, ensuring that families have regular face to face contact. In practice, the presence of the SCN was not always as helpful as a home visit:

> *Edith: I've not seen her for a while.*
> *JF: Right.*
> *Edith: She used to come every 4 months.*
> *Richard: Aye but she'd said she's got... she got quite an area to cover apparently.*
> *JF: She has, yeah.*
> *Richard: She said that she would... well she would come… well, when we go to the [Hospital to meet consultant] she appears.*
> *Edith and her husband Richard*

About a quarter of the families felt compromised by seeing the SCN at consultations: they preferred home visits. Further several families reported that the clinics and consultations were difficult to attend because of distance and travelling logistics. As a result they withdrew from seeing the consultant but regretted that this also meant not seeing their SCN.

One family had reported that they had managed to replace meetings with their consultant with regular home visits from the SCN, an arrangement which suited their needs much more:

> *Yes, I think we were kind of left in limbo and then the [the SCN] offered to visit us ... Something happened at home... I think it was...   because at that point we were just going to [the Consultant] in twelve weeks time, so that if she did come and see us and offered to visit us at home rather than us going into the [hospital] it would save us the hassle of the logistics and so on... So, that's what happened... We've never seen the consultant since... Now, it's for the best reasons and I suppose if we really wanted to see the consultant we could say to the [SCN] that we want to see the guy*
> *Craig, his wife Sheila has MND*

In this case the SCN successfully bridged a logistical gap by taking on a role that only could achieve because of their in-depth medical knowledge and their expertise in MND.

The next quote follows a discussion about thinking about getting a PEG tube that the participant resisted because they thought it meant they would not be able to eat normally once it had been inserted. They did not want to ask questions about the PEG at the consultant's clinic because they thought it would be time-wasting given their attitude of not wanting it (because it would stop Julie eating). The participant reflected that it would have been better if she could have sat down with someone, like the SCN, to discuss not just the procedure of getting a PEG but also would it would mean to her lifestyle, without feeling that this had to lead to the actual procedure. She would have raised this has she had a home visit from the SCN and would have learned that she could have the PEG tube and eat 'normally':

> *Julie: Nobody, we don't get anybody … nobody comes in here.*
> *JF: Right, okay. Let's talk about that then, so it should be [SCN]?*
> *Julie: Uh-huh (nods)*
> *JF: But you see her at the [Hospital with Consultant]*

Julie: She's in the room when we are talking to [the Consultant]. And I only get about 5 minutes. ... it would be useful for her to come ... after we had ... the, the visit to [the Consultant]

James: because, it's just for that added support because when you come back home you can discuss it and then there the questions after ...

Julie, and her husband James

Later on in the interview, this family reflected on the support they received and thought that regular visits from the SCN would be very helpful but thought that their rural location prevented this.

.... It's impossible for it to happen but it would be good ... sort of [SCN's] diary has to be, sort of fixed thing ... you're flicking through diaries and "let's make it 3 weeks time on the Friday afternoon, how about 2 o'clock?" and you're like "aye, well fine ... " so that's you know ... and it would be better if it was a ... [the SCN] could phone up and say "I know you are usually at home in the afternoon Julie, I'm down your way and I can just come in, I'll make a cup of coffee and we'll have a chat".

Julie

This 'perfect' model of the SCN dropping in was echoed by four other families. These other families also lived in very rural locations. TAs discussed, although unintentional, the location of SCN's, their work load and part time hours sometimes made families feel that they were a nuisance and an inconvenience to SCNs and put them off requesting home visits.

Sources of Support Allied to the SCN

Within the interviews the welfare officers (WO) and , the counselling service, both funded by MND Scotland, and the information packs were seen as an extension of the services offered by the SCN. Their usefulness will be discussed in this final section of the chapter.

Most families we spoke to had been visited by one of MND Scotland's WOs. Almost everyone was overwhelmingly positive about the information and assistance that they received.

> *The other thing I found very helpful as well, I had no idea about. I didn't know what they call it … Attendance Allowance? [The WO] from MND Glasgow came over, I said "you can't come all that way!" She chatted to us and I will say she said it may take about 6 weeks for this to come through but it wasn't, it was there within 10 days. I will say [the WO] is absolutely wonderful.*
> *Betty, her husband David had MND*

Many families echoed Betty's points. Further, they all appreciated the efforts made to visit them at home. Without the WO they would have had no idea what they were entitled to or how to apply for it.

> *The MND Scotland sent through their Welfare Officer, she was a lovely girl, and she filled … she asked Susan the questions and she filled in the form on our behalf and applied for DLA [Disability Living Allowance] and she was very good, she was very informative, very supportive and we were awarded DLA I think at the top of the scale.*
> *Graham, his wife Susan has MND*

Some of this 'work' was done by the SCNs too, particularly in terms of encouraging families to apply for benefits:

> *[The SCN] starts off by saying that you should be thinking about getting this allowance, that allowance and Karen was like "there's nothing wrong with me, I'm not disabled, I don't need any kind of allowance".*
> *Peter, his wife Karen had MND*

There are a number of challenges faced by the SCNs and WOs. Families could be resistant to claiming benefits for a number of reasons. First, they did not want to accept they had additional

needs. Second, they did not yet have additional needs and were resisting acknowledging that their symptoms would progress. Third, a cultural resistance to claiming benefits of any kind. In almost all cases, these barriers were sensitively managed by the SCNs and WOs.

> *And [the WO] helped me fill in this form, and she said " Elena, I'm no' asking you to lie but I'm asking you to fill in the form for the worst case scenario", and like three months later it WAS the worst case scenario, I couldn't believe it, do you know what I mean? So, he got the highest rate and that took a lot of pressure off.*
> *Elena, her Dad Patrick had MND*

One family's experience of applying for benefits (a blue badge) without the support of the WO demonstrates how critical their support is:

> *We tried to get the blue badge and MND [Scotland] sent us a form and I started to fill it up and then I realized "oh, wait a minute, I am filling the bit up where the doctor …" so I got on to the [GP] clinic and the clinic said "oh we don't do that now. You go straight down to the one stop shop and they have got a special form …" so I went down and they gave me the forms and I couldn't answer a lot of the questions … I mean, the answers were away in the future… So I went to [Citizen's Advice Bureau] and the girl down there helped us with it, and we sent it in and the next thing I gets a letter in saying that I canny get it … they said that if at a later date [his wife, Lydia] was to deteriorate then fair enough, we could appeal.*
> *Fred, his wife Lydia has MND*

In only one case was a family unhappy with the support that they got from the WO. The following quote is not representative then but it does highlight how critical the role of the WO is and how much people depend on the job being done well, first time.

> *Well, MND Scotland put in a claim for us, their Welfare and benefits Officer put in a claim for us for the higher rate mobility to get the care because he had... the electric*

wheelchair was all getting sorted out and he should have been on it long ago but...
Anyway, the girl came out, filled in all the forms, kept chasing her up, and chasing her up
and heard nothing, heard nothing. And you usually get an answer within eight weeks.
Never returned my calls, never returned my emails, and eventually I phoned the
Department of Works and Pensions in January and she never ever submitted the forms.
So, I had to do it all myself and then I mucked it up and I was distraught by this because
the wheelchair is sitting there, we can't use it.
Charlotte, her husband Tom has MND

Fewer participants discussed counselling services; among those who brought it up it was clear that there were mixed views. Participants did not always feel that the counselling services were forthcoming after the initial point of diagnosis and some participants did not feel that counselling was offered to them at the initial point of diagnosis either.

I thought about the psychological aspect being addressed right from the very
start and something being put in place without you having to ask...if you don't
want it then you could say later on " Well, I don't feel I need that..." but I feel
for everybody that something like that should be put in place along with all the
physical stuff right at the very beginning...Whereas, no, it's not even addressed
until you say I'm struggling with this mentally and they they'll go well, we can
offer you counselling. But I feel that should be in place without you having to
ask.
Marie

Some participants reflected that they found it very difficult to ask for counselling support and they felt that if it was offered to them from the first instance then it might remove their anxiety and sometimes embarrassment around asking. Further, people should be reminded about this service at least annually as their needs change.

When some participants and their families did ask for counselling support, they were at times met with counsellors who were unwilling or seemed disinterested. Craig for example felt that, when he sought counselling over the deterioration of his partner's condition, the MND counsellor was unwilling to make the journey to see him or put him in touch with someone who was willing to see him:

> *I did contact the MND Counsellor which again she had to do to her job and tell me that was available and I had...This was when...I went back to work on a part-time basis and mornings was all it was supposed to be...So, there was a little difficulty in setting up the...because she was based in the west, she said she didn't have anybody in the east so would I mind if we did it by phone? ...So eventually we managed to get together on the phone. It's fair to say that I've always been kind of sceptical about people and counselling and that whole...post traumatic stress...it always seems to be a bit simplistic...The reason that I'm saying that is I don't think I gave the counsellor a fair crack of the whip in as much as...This will sound dreadful...I had this vision in my mind that I was sitting talking to her and she was sitting in her house watching Emmerdale with the subtitles on...*
> Craig – his wife Sheila has MND

Craig was 'sceptical' about counselling and had clearly found it difficult to approach a counsellor in the first place. The actions of the counsellor merely confirmed his scepticism. . Despite agreeing to a phone session Craig would have benefitted from a face to face consultation with a counsellor and this might have made him felt listened to and to built trust. All the phone session did was to increase Craig's anxiety and as a result he contacted his GP. His GP offered him anti-anxiety and anti-depressant medication.

> *So, it was just getting too difficult to manage so the GP had signed me off anyway, but this particular phase where all this anxiety and stress was happening I went to see the GP and he said he felt that I had clinical*

depression which in itself was quite depressing. Because I didn't think that I
had it, I just thought I was a bit anxious...I knew I was anxious and I told him
that I didn't want any medication because, like, during the night when Sheila
wakes up if she needs anything (needs the loo or needs to roll on to one side)
...she can't do it on her own. So I said "I need to be able to respond..."
Craig – his wife Sheila has MND

Craig was stuck between an ineffective counselling service and a GP who was offering an option that would not be suitable for his circumstances. It is possible that his anxiety could have been addressed by a face to face meeting with the counsellor.

As with other services funded by MND Scotland, home visits are essential to providing adequate support. If this is accepted, then more counsellors are needed, and they need to be based in additional locations, not just Glasgow in order to provide optimum support.

The Patient's Information Pack was also mentioned as a valuable resource to help families manage their multiple professional contacts in ways that could help alleviate the pressure on SCNs. Not all participants had a pack, and some received it significantly after they were diagnosed. Whilst most valued the pack many families reflected on rarely opening it, afraid of being overwhelmed by the condition's potential progression, or by seeing a 'worst case scenario'.

You know, she came out with all the big pack. I have never read it by the way, see that
big... I can not... I cannot bring myself to... I said "No, I cannae..." I'll just kind of take
it each wee bit as it comes and deal with it that way
Marie

Owning the Pack encouraged participants to feel connected to the greater resources offered by MND Scotland even if, like Marie, they did not feel able to use the document in the present.

This raises a difficult issue faced by SCNs and other professionals providing information. As discussed a home visit by the SCN just following diagnosis seemed to provide the optimum support. A few strongly resisted this.

> *Monday I had a call from [SCN] but I didn't want to speak to her. Everybody is different and when she rang... I have now met her but when she rang she said about coming to see me and I said "I don't want to see you." And she said "I will send literature." And I said "I don't want anything." I said "I'm not taking it on board". Not meaning that I am ignoring it or it's wrong just that that's how I want to deal with it. "I don't want it to take over." And she said "Well, everybody's like that at first." And I felt pretty upset about that. I wanted to say "I'm not everybody. Neither is anyone else... I don't want to be lumped together... I didn't want to be taken out of life and shoved in the corner with a diagnosis ... I mean don't get me wrong, I respect her and I know she's a lovely person but she seemed to want to get into action what things I might want if I was ill and what things your family will need to know... "And, we don't want you brought in here as an emergency." And I thought "Just a minute, I can't..." It was just too much.*
> *Patsy*

As stated, the shock of diagnosis has a significant impact on participants. In the above example the SCN acted according to the recommendations that this chapter will make. They initiated a visit very soon after the diagnosis. They were sensitive to the barriers raised by the participant and offered to send literature that the participant could consult at their own pace. When a visit did happen, the SCN was inclusive of other family members and wanted to raise issues about the development of symptoms. Still, Patsy resisted meeting with the SCN, felt overwhelmed by any information and was upset by their interactions with the SCN. Clearly then, the SCN have huge difficulty in gauging when to intervene, when to give space and how to handle the extreme emotional reaction. The above quote, demonstrates the necessity of perseverance: the need for the SCN to re-engage with families to see if needs or attitudes have changed. This is very important as the condition progression means that the need for someone able to perform a key-

worker role and provide medical advice, and the participant's own sense of isolation, increases over time. Further views of the Information Pack feature in the Access to Information chapter.

Conclusions & Recommendations

The main conclusion that arose from this section of the research was the need for MND Scotland to thoroughly review the workloads and demands placed on SCNs. It became apparent that there were too few SCN's dealing with a large case load in Scotland. SCNs had to travel long distances to access some participants which was not an efficient use of their time. It is essential because the role of the SCN was so hugely important to participants and their families that they are able to deliver: their presence and efforts were key to the management of MND and therefore a thorough review of the demands placed on them are necessary. Six key recommendations emerged from the data:

1. The role of the SCN needs to be clearly communicated to people with MND and their families. This may need to be re-promoted at regular intervals.
2. The SCN 'hides' gaps in provision particularly where services are suppose to (but fail to) work together. All families needed a key-worker to help them coordinate local services. Not everyone was able to use their SCN in this way.
3. Families in rural areas had less face-to-face time with their SCN and this contributed to their feelings of isolation, this should be addressed.
4. SCNs, WO and the MND Counsellor should be facilitated to home visit participants where possible.
5. Participants valued their SCNs medical knowledge, trustworthiness and sensitivity: they valued their friendship. MND Scotland is essentially providing the correct service, but must ensure that everyone has access to this. Greater investment in the SCN role is required to provide this excellent service across regions and particularly in rural areas.
6. Our data suggest that familial carers would appreciate time with the SCN – that is, not in the presence of the person with MND.

ACCESS TO MEDICAL SERVICES

Introduction

In this chapter we present an overview of how the research participants described their experiences of access to medical services. We explore participants' experiences of going into hospital for medical care, the medical services that they received after diagnosis of MND and the medical processes that participants go through in order to manage MND.

This chapter then, will look at how participants felt about the medical services they received; it will explore the barriers that participants faced and this was particularly evident where participants had to stay in hospital for procedures.

The first section opens with a discussion of how participants accessed medical services and how accessible or inaccessible they found them to be. The data was thematically analysed and coded using a broad code of 'access to medical services'. Throughout the coding process, sub-categories were uncovered and these form the sub-headings within the Findings section. This section will also explore participants' thoughts and feelings about their interactions with their general practitioners (GPs), consultants and nurses. It will explore participants' experiences of hospital visits, PEG feeding and ongoing procedures. What was evident throughout almost every narrative around access to medical services was a feeling, by participants, that they were not properly listened to or given adequate information about health care by medical and health professionals be they GPs, consultants, or district nurses. A lack of control and not being listened to are key themes that run throughout this chapter of the report. Worry, anxiety and a lack of knowledge were considerably prevalent around hospital visits and PEG feeding in particular. However, where participants had good relationships with their GPs or consultants this generally helped relieve anxiety around accessing medical services because trust and good relationships were established. This was often where the time was taken, by medical professionals, to establish rapport with their patients.

Findings

Accessing Medical Services: Barriers and Inaccessibility

This theme documents and describes our participants' experience of physical access to hospitals, primary care and dentistry and the problems they faced. These issues were experienced by a significant number of those we spoke to. People described how their own mobility needs interfered with their ability to use some medical services. For example, Marie talked about negotiating the facilities in the hospital when getting her physiotherapy and felt that the space was not made accessible to her. She described how the consultations themselves only lasted for around twenty minutes or so and getting there in itself was a trek. When she got there she had to walk for long stretches:

> *A lot of effort for me to get, especially at the time when I didn't have this*
> *[walking stick] and I had to walk the length of the blooming corridor...*
> *Marie*

Marie felt that her MND was not considered when she had to access these services; she also felt that access was put in place for people with other conditions that might impact on their energy or mobility. Access continued to be an issue for Marie as her condition progressed:

> *And they're away at the end of the corridor...Double doors? They don't open*
> *themselves by the way! So you're kind of struggling with your balance and*
> *you've got to try and open doors...And I had a wee stick with me this time, so I*
> *had the stick and I'd hold onto the wall as I walked along. And I thought...now*
> *there's people with heart attacks and they come out and all that is put in place*
> *for them, you know?*
> *Marie*

What is clear here is that medical services need to ensure that they support people with MND who are coming to use the services, in this case Marie was attending the appointment alone and had no additional support to help her negotiate the hospital (because her husband could not find a suitable parking space). It undermined her confidence in the services and made her feel like these services were for other people and not for her. She described that the effort was not being put in to support her and this in turn made her reluctant to travel to new appointments:

> *There's no point in putting the effort in [to attending clinics] because we're no' going to get anything out of it at the end of the day...Why would we put all that effort into it?*
> *Marie.*

Our participants also documented that general medical services became inaccessible to them, this became increasingly problematic when trying to negotiate everyday health care and checkups.

> *We changed our doctor about six weeks ago because our doctor is just a waste of time really and I had a smear done...I got one of those letters saying that I hadn't had a smear in so many years and so I phoned them and they can't accommodate me – they haven't got a bed that comes down and they don't have a hoist...and I said "well, how do you suppose we do a smear then...?" So, eventually they sent someone to the house to do it which was great ...she put me at ease, it was dead easy. It was over and done with and then she lost the smear...*
> *Sarah*

While ultimately, in this instance, the problem was solved in terms of having the procedure done at home – there is a wider issue being that participants with MND require increasing medical support as well as the general medical care that is necessary as part of everyday life. It is crucial that medical services be easily accessible to everyone. A lack of access to spaces such as these, render the person feeling unwelcome and isolated. Furthermore, having the procedure done at home increased the risks of the samples taken being misplaced, lost or not delivered properly and there is less risk of this happening in a clinic or surgery. This also meant that the

participant had to have an unpleasant procedure repeated unnecessarily. People with MND, who are coming to terms with loss of mobility, require extra support to access the medical services around them.

Sarah described another event like this whereby she had problems going to the dentist because the dentist proved inaccessible to her.

> *JF: So, what happened at the dentist?*
> *em...I couldn't get my wheelchair through the door and it wasn't wheelchair accessible and they had to give me a dental examination in the hallway with a torch...in front of the waiting room which was right there...and I thought "I am never coming back here"...and I had been going to him for eight years...and then as my disability progressed and I ended up in a wheelchair and everything and I couldn't get into the room... Well, the girls found it highly amusing...not that you knew...but where I was sitting at, the folk thought it was amusing and stuff...and you know everyone is staring at you and it is awful...and you think "If I could just crawl into a hole in the floor..."*
> *Sarah*

In this instance Sarah had to endure the humiliation of having a private dental assessment done in public, and people watching her and finding the situation 'amusing'. There is a clear issue where NHS funded clinics should be accessible. Sarah wasn't trying to access a new service, she had been with the same dentist for over 8 years and yet there was no anticipation of her needs. This experience clearly had a very negative impact on Sarah's sense of wellbeing and confidence which is already strained by the ever changing needs of having MND. Furthermore, in order to maintain a sense of normalcy it is imperative to recognise that while MND may be life limiting persons with condition can still experience dental problems, or general health problems and so everyday health care such as dental care or smear tests are still an important part of everyday life.

A small number of participants talked about the difficulty in getting to hospital, appointments and consultations when they were reliant on ambulance transportation. Some participants found this incredibly unreliable. Angus and Justine, who live in a rural area, found that they consistently had issues with transportation.

> *Several times lately ambulance control let me...ambulance control let you down*
> *for hospital appointments.*
> *JF: So you've got an appointment and you've booked in with the ambulance*
> *and they, sort of, just don't turn up?*
> *Mmm*
> *JF: And do they give you any notice of that?*
> *The day before*
> *Angus*

Getting places, and to the hospital is difficult at the best of times. It also takes a person with limited mobility, mobility aids and equipment more time to prepare for a journey and transportation is more complex in general for someone with MND. In addition to this, dependency on unreliable transportation methods creates significant problems for participants; not least missed hospital appointments that can be difficult to rearrange at short notice (as can appropriate transportation). This is another example where barriers to accessing medical services could be avoided given appropriate timing and communication.

Most participants felt that good access was where medical services were flexible and offered choice about how they were accessed. Craig and Sheila found that when getting to the GP proved too difficult their GP were very flexible in offering a home consultation.

> *We used to see the GP which is just up the road, it's about five minutes walk*
> *but on one occasion we were down for an early morning appointment (ten past*
> *nine or something like that) and we'd said how difficult it had been to get ready*

*and out of the house and up the road for it in time. He said "Oh well, why don't
I come and see you?" So that's what he does now...*
Craig, his wife Sheila has MND

Where participants had experienced flexibility of access and a willingness of medical services to
find solutions to problems, they felt that they were being listened to and that they were welcome
in these kinds of spaces. It meant that they could trust that barriers would be removed when
accessing necessary medical services.

Interactions with General Practitioners

Interacting and meeting with a wide range of doctors and other health service professionals had,
for many, become part of the fabric of everyday life. Participants often had to juggle and
manage meetings and consultations with GPs and consultants, nurses, OTs, physiotherapists,
dieticians and a range of other specialists. Building a good relationship and feeling a sense of
trust within that relationship was crucial to participants' feeling safe and secure in accessing
health care and services. Being able to trust professionals made a considerable difference to their
experience and paramount to building this trust was feeling listened to and supported.

> *We were really spoilt by him...he was a good doctor and he ...he said...his
> words to me were "Between us...between me and you...we will manage with
> it..." I didn't have to take what he said as set in stone and, you know...If I went
> with ideas he would quite readily listen...He was a good doctor and I felt really
> supported...*
> *Sarah*

When, as in this case, doctors or other health service professional took the time to create a sense
of teamwork between them and the person with MND and their family they felt not only
included and consulted in their own health care but also, importantly, in control. They felt that
they were active in making decisions about their own health care. Good rapport was also built

through empathy and understanding and this went a long way to allowing participants to feel as if the professional was interested not just in their wellbeing but also in interacting with them as people.

> *But if I have anything at all I want him for just go down and see him or he'll*
> *come up and see me*
> *JF: So that sounds like his door is open*
> *Yes. He did say "Why should you get such a horrendous disease?"*
> *JF: So there's, kind of, like sympathy there as well?*
> *Yes, oh yes...He's a perfect doctor.*
> *JF: Is he? Good*
> *I mean some doctors are cold... but he is a genuine man*
> *Sean*

'Good' health service professionals were not always determined by their capacity to fix or solve a problem but through their demonstration of understanding. Being listened to by a doctor or other health service professional and feeling like they had a say in their own medical care was, our data would suggest, the single most important factor in building and sustaining trust and was a key marker for a positive experience of their GP or other health service professional.

They were also judged on their willingness to pass on participants to the relevant specialists as Simon stated.

> *Well, that is a good point there – our GP is excellent. They haven't known*
> *anything they could do for me but they have been very supportive...and they*
> *have passed me on to the right specialist very quickly...and I know that if I*
> *have a problem that I would get a good hearing...*
> *Simon*

In terms of GPs it was crucial that the participants felt that where the GP did not know how to provide help or treatment they were willing to act as a support and find ways to get the correct treatment and specialists. GPs were, for many, the first port of call and not only provided the every day, face-to-face and long term medical interventions and but also acted as key gatekeepers to other services. When GPs failed in this role it meant that participants felt isolated and lost and they often had little means of accessing the appropriate medical services. Some further examples of this appear in the Diagnosis chapter.

A small but significant number of participants (around one quarter) found their GPs to be insensitive with some even going so far as describing them of being scared of having to interact with someone with MND. Patsy, for example described her GP as dismissive and unwilling to act on her behalf:

> *My GP I avoid – he can't look me in the eye because he feels uncomfortable*
> *and if I suggest something he'll say "see the MND nurse..." I've rung her for*
> *advice and she'll say "see your GP" and so it goes. Nobody says "right I'm*
> *here..."*
> *Patsy*

Patsy got caught between two professionals, neither of whom was willing to take on the role of advocate or to work with her to resolve problems.

Interactions with Consultants

In many cases it was interactions with consultants that created the most stress and upset among participants. A number of participants found consultants hard to access and felt that they were fairly absent from their care.

> *I've only seen him twice. I've only seen the consultant in a consultation. I have*
> *five appointments there in a year between July last year and July this year. I'm*

> *due to see [SCN] again next week. So, I've had five appointments and I've only*
> *seen the consultant twice. Now, the first time was very early on where basically*
> *he was just confirming the diagnosis...*
> *Marie*

Another family were told that the consultant would not be involved once the diagnosis was established.

> *When we went to see [respiratory consultant] at [the hospital] he said to me that "you have*
> *to realise that [the neurological consultant] has done his job now which is really the*
> *diagnosis and the initial management. It's my speciality ... respiratory care that is going to*
> *take you on ...and really now you want to go down the palliative care route ..."*
> *Maggie, her husband Derek had MND*

Some participants felt that appointments with consultants were not useful to them and that they were a box ticking exercise rather than a forum through which they could ask questions or explore ways of managing their MND.

> *... [the Consultant] says "how are you?" and I say "Fine". "Has there been*
> *any problems?" and I say "Not really..." and he says "OK"...and that's it...*
> *Julie*

Around one third of participants questioned the purpose of the consultations in the first place they were not seen as productive. Marie even went so far as to suggest that the same interaction could happen over the phone rather than having to travel to a hospital.

> *And to tell you the truth I could actually do it on the phone. I could do on the*
> *phone with [SCN] what we actually do in there because I thought when I*
> *started and they said "Oh, you'll come to the [hospital] and you'll get three*
> *monthly check ups and things like that..." I thought I would go in there and see*

the consultant, and they do always take my weight, and they take a blood test
for the tablets to make sure there is no liver damage or things like that, but I
thought what would happen would be that he would examine me and see what I
was doing, what I was capable of and then the next time I went back he would
examine me again and see what the deterioration was. Kind of get a rate of
deterioration and he would be able to determine the rate of deterioration...but
that doesn't happen...
Marie

Participants were looking for more meaningful consultations in hospital and avenues where they would be able to ask for information that was useful to them and they wanted to be actively involved in the process and not passive recipients of services. As with getting the diagnosis, many participants wanted an idea of how the future would pan out; for a prognosis or at least a review of how they were doing compared to the prognosis given at the time of diagnosis (if one was given). Participants felt that the consultation should provide them with opportunities and spaces to discuss the trajectory of their MND or to get an idea of treatment options.

Some felt their consultant to be not only dismissive but also insensitive to their feelings. While they found their consultant helpful and useful in providing them with care and information they felt that he was consistently insensitive or rude and this made them feel vulnerable about being there.

...even [the Consultant] was prone to saying the odd thing...
JF: Insensitive?
Yeah...but he would maybe turn round and say to the MND nurse...he would say
something to her, which would have maybe been better said when we weren't in
the room, you know....You know they've got to do their job and it's quite a
difficult job, and there's obviously a lot of time it will be bad news, but I'm sure
there are ways you can do it without being completely, you know, obnoxious or
abrupt or whatever way you want to describe it.

Paul, his wife Rachel has MND

Our participants described how they were sometimes not treated with respect or sensitivity, were talked about as if they were not in the room and their emotional wellbeing was not taken into consideration. It made them feel 'as *just a diagnosis'* (*Patsy*)

Experiences of Hospital Stays and the Passing on of Information

A number of the participants had experiences of going into hospital for a variety of different reasons; ventilation, procedures to have PEG feeding established and decline in health were the most common reason to be in hospital for participants.

Participants' had mixed feelings about the care they received in hospital. Most participants described how the health professionals they encountered outside of the specialist services rarely had any experience in dealing with a patient with MND. Many had never come across MND before. Further, participants felt that their expertise in MND and how they could be best supported was ignored by non-specialist health care professionals.

The following example from Paul is typical of this kind of experience. The following case recounts their experience of being in hospital, the care they received and the barriers they felt were present during their stay.

> *Yeah we've had a couple instances... em... where, you know, Rachel has*
> *had a fall one time which was quite bad, and we went in... we had to go to*
> *[hospital] and they're not good experiences at all.*
> *Paul – his wife Rachel has MND*

Paul and Rachel that they were not appropriately listened to when they tried to explain what kind of treatment and actions were and were not appropriate.

And regardless of me telling them "Don't do that" or "don't do this..." em...
"no, no we have to do that because..." so we're now told, especially with the
ventilator... em... they'd probably put Rachel on oxygen and that's not
something that she should go on so...
Paul – his wife Rachel has MND

Problems occurred where information regarding the participants' notes were not passed on through the networks of medical professionals. This often made the participants and their families feel insecure and not listened to in a situation where they felt incredibly vulnerable in the first place. Participants and their families were often experts in their own care and they had set up routines of care that they were used to and comfortable with and when this was not acknowledged or listened to by doctors and nurses it resulted in incredibly negative experiences of hospital stays and left participants feeling anxious and vulnerable but more significantly out of control.

Alan and Paula described how during a recent hospital stay they were not listened to and this only added to what became a very frightening and vulnerable time for them. They felt that even when they provided medical staff with the appropriate information about their needs and about MND this was not looked at or acted upon

Alan: But, it even went as far as... [The SCN] gave us a sheet, an A4 sheet that
tells you what is wrong with me and we took it to the hospital - they never even
looked at it...
Paula: It's just like a wee card that says "I have Motor Neuron's Disease."
Some difficulties can arise that can affect their speech, etc. And it just sort of
outlines the difficulties that a person with MND may have. Obviously, if they
maybe need to go under anaesthetic if they have respiratory problems, etc... I
actually cut it down and laminated it all thinking "Keep it by his bedside so that
different nurses/ different shifts are all coming in...." They weren't interested in
it...

Alan: They didn't want to know...

Paula: It was just a case of you are patient number 10 in this bed and this is how we deal with you and it was very, very frustrating for that short period of time that he was in hospital...

Alan has MND and his wife, Paula.

This was not an unusual set of events for participants with MND. For example Sarah recalled:

The biggest thing ... when I was in hospital, when you go in and you kind of get booked in (as it were) and [the nurse] fills out all this paperwork and there is a care plan. And they say "What can you do? What can't you do? What do you need us for? How can we help you?" And nobody else reads it. Ever! It stays in the folder at the bottom of your bed. I mean, it says on there that I need help with eating and I need help with getting dressed ... and every day I got my dinner put down to me and no help. I couldn't even take the lid off the plate.

Sarah

For many the primary barrier experienced in hospitals was not being listened to by medical or health professionals even when they were presented with information relating to the kind of medical care and provision necessary in relation to their MND. It was not unusual for information not to be passed on from one member of staff to another and so there was a lack of continuity of practice. This became increasingly problematic for people with bulbar symptoms where they were less able to vocalise or express their wishes or concern over how they were being treated while in hospital. The removal of control and continuity bred insecurity and fear whilst in hospital. This also meant that participants were reluctant to go into hospital.

I don't want to be back there again – put it that way...

Alan

Similarly Daniel and Doris described their hospital stay where yet again their particular needs were not taken into account and they were not listened to. Doris was also left to operate hospital equipment without training or knowledge because the nurses had not dealt appropriately with the delivery of oxygen.

> *I don't think they understand, like, Motor Neurone Disease, some of the…like*
> *[Daniel's] hands…The other problem we had was that we filled out a menu for*
> *him for his food so that it was soft foods with gravy and everything…they didn't*
> *bring that up – they would bring like, sandwiches and fish and chips and that*
> *which he couldn't eat…*
> *Doris – her husband Daniel has MND*

Despite explicitly explaining the necessity for soft foods Daniel continually received food that he could not eat. His wife had to bring in appropriate food from home in order to feed him through his PEG as he was not getting proper food in hospital.

Again, a lack of information and proper communication had left the participants feeling very anxious and tense about how to deliver medical care in the hospital, this should have been appropriately explained to them or should have been taken on by a medical health professional. Often when our participants challenged the staff they felt that they sometimes:

> *… get a bit shirty….So it's a wee bit like "don't tell me my job" basically….*
> *Paul, his wife Rachel has MND*

Paul and Rachel also experienced problems when medical health professionals changed the routine through which she was PEG fed and that her wishes, and notes, were not consulted or listened to by the nurses (in this particular event).

> *Paul: You know [Rachel] can sleep through the day and be fed through the*
> *day so that's not a problem but you don't feed through the night with the peg,*

> *and... eh... and it was the nurse was... "no I'm going to put her peg on now -*
> *her feed on now" and I says "No you don't...she doesn't get fed through the*
> *night…" and is that not in her notes somewhere?*
> *Paul, his wife Rachel has MND*

Participants and their families became experts in their own care and set up routines of care that they were used to and comfortable with – when this was not acknowledged or listened to by doctors and nurses it resulted in incredibly negative experiences of hospital stays and left participants feeling anxious and vulnerable but more significantly out of control of how to maintain a level of management and control of their MND and procedures such as ventilation and PEG feeding.

Hospital visits and long stays in hospital made participants feel out of control and we had very few examples of where hospital stays had not been traumatic or difficult. In contrast, Paul expressed that on the occasions where they were listened to this helped them to feel reassured and acknowledged as having agency and control over their care.

> *But I did remember one of the accident... one of the doctors, he was a very*
> *young fellow, in A & E did actually pull me aside and said "Well you'll know*
> *more about this than we do…" which I thought was reassuring because before*
> *that they were all just saying '"No".*
> *Paul, his wife Rachel has MND*

Hospitals should be places in which the participants felt comfortable and they should have expected that they would be listened to in the delivery of their care. This is especially important given that medical services and care are a pervasive and core aspect of having MND and many of the participants described occasions where their trust and faith in medical care in hospitals had been undermined and they were left feeling anxious and scared and reluctant to use the services again.

A few participants found NHS services so disempowering that they tried not to use medical services in any way. Patsy for example had actively removed herself from conventional medical services because she felt she was not treated as a person

> *Exactly, exactly... I've had homeopathy, I've had... I haven't gone for*
> *counselling within the NHS – I've gone out with. I have shiatsu and massage*
> *and...Because the people look at... They talk to me as a person not as...*
> *Patsy*

However, most participants had no choice but to use these services, and this for many created anxiety and vulnerability around the prospect of receiving medical care or going into hospital in the future.

PEG Feeding

Percutaneous Endoscopic Gastrostomy (PEG) is commonly used as a means of feeding in people with MND for whom swallowing is too difficult or dangerous. Many of those we spoke to had undergone the procedure to enable PEG feeding either because it was an immediate necessity or, in a small number of cases, pre-emptively to ensure safe feeding when, in the future, swallowing became an issue. Almost all participants were pleased with the results of the PEG feeding once the procedure had been done but some participants found the process of getting it done and the events that took place in hospital during the process very distressing. Some participants did not want the PEG or did not fully understand what getting the PEG might involve and felt that they had not been given adequate information. Julie was resisting the PEG in part because the extent or consequences of the procedure had not been explained to her specifically but had been to her husband and this was realised in the interview itself.

> *Julie: Would I still be able to eat with it?*
> *JF: Yeah you can*

Julie: Oh can you? Oh right I see. I thought once it goes in then that's it? See I
didn't know that. Did you know?
James: Yeah I...yeah, yeah I mean I just...aye, it was just another tool to help
you get nutrients in if you were ever having difficulty swallowing...I didn't
think it was going to stop you from chewing like.
Julie and her husband James

The mixed provision of information was also experienced by Daniel who had a particularly negative experience of the PEG procedure; a result that was not solely due to the discomfort of the procedure itself but rather a lack of information and support from the medical professionals in hospital. Poor communication meant that Daniel and his wife, Doris, were given mixed information which led to the procedure being very traumatic.

And they had said that I could go in with him...and then when we turned up at
the hospital the nurse that came to speak to us says "No, nobody gets to go to
theatre with the patient..." and "no, you can't go down...and undress him...you
will need to come at the visiting times..." and I says " but we pre-arranged
this..." and I explained to her that he couldn't undress himself...So, we went
down to theatre but by this time he was all worked up and his blood pressure
had went up and I got him undressed and then he got a wee bit weepy because I
was saying I had to go away. The nurse that I spoke to previously came in and
said "no no...that's fine you have to stay – I have spoke to the doctor". So they
were ok once we explained to the other nurse but...I mean, he got himself all
worked up.
Doris – her husband Daniel has MND

Removing control and not being listened to increased a sense of vulnerability and unnecessarily raised fear and anxiety. There is a great deal of research that suggests that people with complex needs cope better with a procedure with the support of a partner or family member.

The problems for Daniel did not stop with the procedure and they had significant issues with feeding when they got home. They were told they would receive appropriate training on how to use the PEG feeding system and felt that this did not happen.

> And then we were meant to get home help coming in to clean his PEG and everything…We never got nothing - I had to do it myself.
> JF: Who was supposed to organize that?
> The hospital…we were told that there would be district nurses coming in and the hospital were meant to inform the doctor about the PEG going in and the nurses coming in.
> JF: So they tell the GP and then the GP works it out from his practice and then it is his practice district nurse that comes out? And the communication just collapsed?
> By that time I knew what to do anyway, I'd read up on it and they had shown me once at the hospital and I just done it myself and I have done it myself ever since.
> Doris, her husband Daniel has MND

Whilst Doris had been shown once in hospital how to deal with the PEG tube, they did not receive the additional support they were promised and Doris was left to work out how to use the PEG properly. When practiced and taught properly, the PEG is easily managed but it does require a basic level of medical information and teaching to be given to the appropriate person and in this instance this was not done. Even after reading up on at and after the incredibly basic information given at the hospital Doris was still hesitant as to whether she was cleaning and using the PEG properly *"I didn't know if it was safe to do it or that…"(Doris).*

This was not an isolated experience; Nicola also had poor guidance and information in supporting her husband Matthew who had recently received the PEG.

So I arrived and Matthew was already sitting in the corridor fully dressed in his wheelchair. And I said "well I'll have to see the duty nurse because I need to know what happens with the peg" You know? ... And I had been told that all they need is just flushing, just with a syringe, because he was able to eat so once he's home I'll be able to decide what to do about the formula feeds. So it took a while before we got the duty nurse able to attend to us, so then she...she didn't know Matthew at all.
Nicola, her husband Matthew has MND

Nicola went home and felt ill equipped to be able to handle the PEG feeding for her husband:

...and then it was just a, sort of panic, the situation for me... What happens now, you know? Food? What does he do about that? And because it was a weekend and they...we knew the dieticians, she had said, you know, she was going to be on holiday at the time he was having the operation.
Nicola, her husband Matthew has MND

Nicola's description showed the vulnerable position that the family were left in where trying to operate the PEG system properly without information, support or an avenue to ask questions if necessary. In this instance our participant experienced complications of the PEG and Matthew became increasingly dehydrated leading to a stay in hospital:

Probably because of the just not being hydrated properly, and perhaps, I was partly at fault as well but I don't know because I was only going by the instructions. The feed and then the water bottle, so I didn't give any more than it was saying...Perhaps I should have given more, now I know.
Nicola , her husband Matthew has MND

This example evidences how families, partners, spouses and carers require adequate help and information when negotiating the PEG system for the first time. Managing loved ones' medical

needs is anxiety fuelled and worrying particularly where things are not working as they should. Families should be provided with comprehensive information and support to help them provide a good level of basic medical care and so they feel confident that they are not harming the person with MND. Many family members found 'using the PEG' was difficult for them even with training.

Conclusions & Recommendations

The biggest barrier experienced by participants, in their interactions with any medical or health care professional, was not feeling listened to. It is essential that individuals and their families are treated as collaborative members of a team when their health care is being managed. Best practice was where health care professionals treated the individual and their families as a team member, and offered autonomy and control in decision making-process. Individuals with MND must be recognised, in many cases, as experts in their own conditions and management of those conditions and as such should be appropriately collaborated with in the management of their condition. Three key recommendations emerged from this chapter.

1. Publicly funded (i.e. NHS based) services such as GPs and hospitals should be fully accessible. As this data suggest that this is not the case pressure should be put on NHS boards to review their services.
2. Many participants had negative experiences of hospital stays and this was primarily due to poor communication and a lack of understanding, by staff, what MND is and how the person required support. MND Scotland should, therefore, proactively engage with local neurology units to stress the importance of patient-doctor collaboration.
3. More support is needed by families once a PEG tube is fitted. A very early phone call (even while the person with MND is still in hospital) will help avoid any potential crisis and an early home visit to chat through the feeding procedure would be valued.

ACCESS TO SOCIAL CARE

Introduction

In this chapter we present a broad overview of how the participants described their experiences of social care. We document the different forms of social care and assistance that participants received and how this care supported and hindered participants' lives and the management of MND. Our hope is that we can show what works and what does not and help to provide guidance on the development and delivery of services for people with MND and their families. There are links to earlier chapters, in particular on issues to do with control and autonomy. We seek to explain why so many of the participants were reluctant to use outside agencies in the provision of formal care and support and make recommendations on the changes required so that care is truly facilitating.

Social care is a very broad area and incorporates a diverse range of agencies, and as the data in this chapter shows, pervades almost all aspects of participants' lives. In this chapter, the social care we are referring to comes from a range of different agencies such as social work, occupational therapists, organisations for disabled people, specialist organisations and through benefits providers such as the Department of Work and Pensions. By social care, we are referring to the care and support that was provided to participants in their homes and domiciles; this is inclusive of the adaptations to homes and mobility aids that help with the management of MND. We do not explicitly examine the role of MND Scotland, or of the Specialist Care Nurses (SCN) however, there is some overlap between social care, specialist care and medical care. All of these experiences are presented from the perspective of the participants and their families.

All of the transcripts were thematically analysed using codes such as 'care', 'caring', 'social worker', 'occupational therapist' and so on. What emerged were key themes around being in control and autonomy.

This section opens with an outline and discussion of the kinds of social care that participants received and the intended purpose of this support. While almost all participants received some kinds of social care, there were a limited number of participants who received little to no social care in the form of professional carers; however they still received support in the form of adaptations and mobility aids.

The amount and type of support individuals received from outside agencies varied greatly between different individuals and families. There were, for example, a small but significant number of participants who received little or no social care or support and in these cases all care and support was provided by family or friends. On the other hand there were others who received very comprehensive and full packages of care, some of which were very complex usually involving a range of different types of service providers including occupational therapy (OT) and personal carers.

Whilst in general the amount of care and support people received was dependent on their needs and the extent to which their condition had progressed this was not always the case. Some for example were resisting any form of help, some had not been made aware of the full extent or range of help available whilst others had been unable to access support despite requesting it.

A key focus for families was on confident mobility in and around their homes. It is to this theme, that the chapter now turns.

Findings

Aiding Mobility

Help with housing adaptations and the provision of aids to daily living and mobility aids were the most common forms of support and these were received by all of our participants, however here again levels of services accessed varied greatly. Some of our participants for example had received little more than help with the instillation of a hand rail whilst others had received

financial support for a full range of housing adaptations including funding for adaptations to bathrooms and the instillation of wet rooms, door widening ramps, hoists and powered indoor/outdoor wheelchairs. For example, Marie explained the kinds of mobility aids that supported her mobility in the home and outside:

> *I've got a little motorised wheel chair just for in the house that I use, I've got a wee fold up one that they gave me for just outside. A wee manual one just for pushing... Everything is all put in place. All the physical stuff all put in place.*
> *Marie*

Help and support, where it was accessed, was seen as essential to both the participants' wellbeing and to their independence. Mobility aids such as wheelchairs enabled people to not only move around the house but to also get outside. Participants also spoke of the pathways that enabled them to become more mobile and get outside of the home; often this was provided through the support of a wheelchair or mobility aid and was also facilitated by a personal carer. In Christopher's experience this social care was provided by a combination of care organizations:

> *But because I'm now wheelchair bound, as it were, I don't go out alone in [the car] anymore.*
> *JF: Right.*
> *I get picked up by [outreach care agency]; they take me wherever I want to go. On a Tuesday and Wednesday I go to the [hospice] day centre, on a Thursday I go to the [Local Authority run day centre] and on a Friday I've got a private carer, she comes in the car and takes me out.*
> *Christopher*

Christopher lives in a rural location where public transport was not an option and without the care providers he would have remained isolated at home.

For some, independence meant having access to their own means of transport. Mobility vehicles which were accessed through the mobility component of the Disability Living Allowance supported those participants still able to drive but also were crucial to those participants who needed accessible or wheelchair accessible vehicles:

> *Well that's how we knew about it in the first place but... but yeah the car...? You were fine with the car alright, because it was we got the adaptations for the hand thing - so you kept going with that for quite a while, even after you'd finished work you were still driving the car.*
> *JF: And so did that come through the Disability Living Allowance? The Mobility component to that?*
> *Yes.*
> *Ann, her husband Bob has MND*

To promote independence then, access to routes outside the home is vital whether that be suitable wheelchairs, access to benefits to fund a suitable car or access to services that can help participants get to places that they want to be. It is not clear which professional is responsible for managing this, in the above examples private care agencies, benefits officers, hospices, day centres, OTs and SCNs have all been involved in facilitating mobility. Though unable then to indicate how independence, through mobility, is to be achieved, this report can highlight the critical importance of mobility if well-being is to be optimized. The examples above suggest best practices but many families did not have mobility options. For example, Gayle had the equipment she needed to get around her home, but delays in supplying an external stair lift meant that she had not been outside her home in over 3 months, problems with waiting times will be discussed in more detail later in this chapter.

Future Proofing the Home

As highlighted earlier, not all participants had significant adaptations to their homes. This is not just about accessing the right equipment but about getting timely and informed advice (and

action) from social care professionals. The level of social support and adaption was incredibly variable and diverse. The following quote refers to minor adaptations made to ensure the garden was safe and accessible:

> *JF: And have you had any adaptations done to the house?*
> *Simon: No.*
> *JF: No.*
> *Penelope: only…*
> *Simon: That is the adaptation behind you…*
> *JF: Oh the rail…?*
> *Simon: The hand rail… I had a hand rail put there and a post put there…*
> *Penelope: And a post there because it is very rocky…*
> *Simon and his wife, Penelope*

Hand rails tended to be an early adaptation and best practice examples come from families who met with professionals to discuss what further changes would be needed to ensure their home would stay accessible:

> *Well she put in an extra hand rail … That wooden one inside and a metal one along the wall and in February I'm going to get a wet room, and they're knocking down the door so I can get a wheelchair in…*
> *JF: So they are future proofing the house?*
> *Yes … I was quite unaware what they could do. I didn't even know what a wet room was.*
> *Sean*

Access to appropriate social care was dependent upon being knowledgeable yourself or having key workers/supporters that had the appropriate knowledge. Planning for the future was also important in proving home adaptations that would benefit the person with MND. For many

people they are unable to predict the progression of their condition and so planning for the future and future needs was crucial in providing adequate social support.

Bathroom adaptations were the most common form of housing alteration and were perhaps the most important for those who needed them in terms of their day-to-day lives. It also allowed families to stay in their homes. Generally families relied on professionals, in this case the OT to let them know what was possible. In many cases, major adaptations (such as creating a wet room) were the most difficult area for families to get support and created many problems which often took a long time to resolve:

> *But with [OT], I mean we have spoken about the bathroom last summer [12 months ago]*
> *and we are still no further forward. So we are just sticking with the bathroom and making*
> *it a wet room. We have had two quotes, and they are in but we don't know how long that*
> *we will have to wait.*
> *Patsy*

Understandably a degree of negotiation must happen between families and OTs and local authority budgets and bureaucracy mean that waiting times are inevitable but the consequence of Patsy's experience was that the family put their much loved home on the market as they did not trust local services to complete the 'future proofing' within an acceptable time scale. There is a significant impact on the well-being of Patsy, but also her whole family that could be avoided by proactive professionals.

Grab rails, stair lifts and 'scalamobils' were also used as mechanisms to enable care and mobility in the home. Participants, in most cases, had adapted bathrooms and doorways in order to enable the use of a wheelchair in the home and also to support participants and their families in being able to wash and toilet in accessible and comfortable ways.

Participants described the aids and home adaptations that they received as crucial to their wellbeing. For Catherine, key to her independence was a reclining chair that could help her

move to a standing position; this was provided through her OT. What Catherine's experience highlights is that in some cases the provisions received are not always fault proof and subsequently need to be updated:

> *Well, the chair. She got me the chair for the house and I went through one*
> *chair, two chairs... I am onto my third chair.*
> *JF: Is that a reclining chair?*
> *Because they broke down because the guy came out to fix them and within a*
> *day it was broken again so they had to keep coming and taking them away*
> *and eventually I have got one now that works.*
> *JF: And [the chair is] a life line?*
> *Oh yes.*
> *JF: Because, again, it gives you that independence?*
> *That's correct.*
> *Catherine*

What Catherine's experience of adaptation and equipment shows is that a continued sense of independence both inside of the home and out is fulfilled and maintained by good social care provision. Good social care provision requires social care providers to be vigilant about how equipment is used, what 'needs' remain unmet, and what needs are likely to emerge.

Knowledge of Services Available and of the Needs of Clients

Many of those we spoke told us that they did not know what was available or how to apply for a particular service and that they had to rely on information provided by professionals. There was, many felt, a paucity of good information and people often did not know who to turn to for help. This was made even more difficult as a result of the large numbers of different agencies involved in the delivery of care and support. People had to apply for funding to the Department of Work and Pensions, their local authority or health board or to a third sector organization depending on what particular service it was they were looking for and they had to negotiate their way through

this maze often without support. People described how they lacked the knowledge about which services, benefits and welfare payments they were entitled to and could access and what sort of aids to daily living were available to them. This was true not only for those with MND and their families but we were also told how some of the participants felt that professionals working in the care and support services were also often unaware of all the potential services on offer. It was only by meeting up with other people with MND or similar condition either by chance or at a support group that they became aware of their full entitlement.

There was not just a lack of information there was also a lack of consistency in the information people and many of our informants were told one thing by one person and something different by somebody else:

> *Now the care manager… was saying "We haven't got the money for that so just go and*
> *pay it yourself…" So we did that and then [later another] care manager appeared on*
> *the scene and she said… she phoned me and she said "Why are you paying..?" and I*
> *said "Well, that's what we were told to do…" So she said "I am coming in… " and she*
> *said "From now on I am doing it… and I'll increase your hours…"*
> *Jean, her husband Alex has MND*

This, for many created a feeling of insecurity and people never knew if they were receiving all they were entitled to or even if they would keep the support that they currently received. Consistency was also important in terms of the type of care people received and it is that that we look at next.

Working with Carers

As discussed, equipment is critical in extending mobility for the participants we spoke to. Another solution more suited to some was access to carers. There were varying levels of satisfaction with the services on offer and the quality of care received. Five of our participants

for example reported very high levels of satisfaction with the help and support they received and had few, if any complaints. Christopher for example told us:

The... the services that have come to us from [local authority] – the council ladies who, if
you like, the majority of them have twenty odd years experience in personal care:
absolutely superb.
Christopher

Christopher went on to compare this provision with one delivered through a private care agency (though also funded by the local authority):

[The local authority] – You possibly didn't know this – they franchise it out after six to
eight weeks and we were franchised out to [private care agency] with whom we have got
a reasonable... my wife complains bitterly about them on many occasions. They are
doing their best but I think they are fighting the same sort of battle of staff and costs and
logistics of the rural district. I mean, one of the girls said to me one day that she had
motored more than 360miles because their office is over in [East of the local authority]
and then she had to go there for a meeting and then come back and then do her run
which varies – all around.
Christopher

There was a great deal of variation and for some the provision of care and support was less than ideal. Christopher lived in a rural area and this may have exacerbated the situation but others in similar situations had very good experiences. The following quote refers to outreach nurses:

But they were fantastic, there was never any issues. They knew that they had to get the
drugs by a set time with the patient on a constant drip and without fail, regardless of how
bad the weather was, they appeared. They just parked their car out on the main road and
walking in if that's what they had to do [because of heavy snowfall], Christmas day

included and I can't fault.
Peter, his wife Karen had MND

People expressed dissatisfaction at the care and support they received through statutory organizations:

[The carers who come here are] of a poor quality ... They do as little as possible and all they do is make a mess in your house and then they leave.
Tony

Some families in fact felt that they had to 'police' the carers undermining the service they are supposed to deliver (i.e. giving the families a break):

But carers are difficult. I mean it was fine when I was here but carers for anyone on their own; I mean ... if Thomas needed the toilet ... you know, you can't time it. I felt that I was just so glad that I was here and I really didn't leave ... there was only one person I left him with and she had been a nurse anyway because otherwise ... just to go out and get things ... but otherwise, I wouldn't have left him.
Caroline, her husband Thomas had MND

Or that they were seen as problems rather than clients. The following quote comes from a focus group and begins with Maggie recalling her distress when she asked for emergency cover to help bring her husband Derek home from hospital:

Maggie: I called the GP. It wasn't my own GP but he was very pleasant and he said he would get the [Outreach Nursing Team] in , which is the rapid response tam if someone comes out of hospital and they came and they said, "Well, what you want me to do about it?" And I said, "Well, maybe you can't do anything, but someone must help em I cannot physically move my husband. So, eventually social services provided emergency cover. But that was very traumatic.

Nadine: The language! And it comes across as like they've never been in an environment like this ... and the thing about that is, it's their profession!
Maggie, her husband Derek had MND and Nadine her brother Laurence had MND

and from private sector organizations:

We had a couple of instances with [private agency funded by local authority] and I'd got the lassies off my Dad's rota because I just thought that "you will treat my Dad with respect in this house!". They were kind of talking about him and kind of sighing because they thought that the previous shift had maybe left an incontinence pad or whatever. "You do not speak about this in front of my Dad: you come in and you do the job!"
Elena, her Dad Patrick had MND

It was hard to determine any pattern or single causal factor for the fairly widespread dissatisfaction with social care expressed by our participants. It was felt equally by those just starting out on their journey as well as those who had lived with MND for relatively long period. These stories also were picked up by others at support groups, in online forums and many families were reluctant to get carers involved because they felt they would not get consistency or respect, or it would not suit their routine.

This section aimed to highlight the varying forms of social care that was provided to participants with MND and their families. The level of social care was dependent on the participants' needs and the extent to which their condition had progressed. While all participants discussed their requirement of certain forms of social care, this was not benign. Some participants had extremely positive experiences of social care and some very negative. This was due to a number of factors such as the time it took to provide equipment, adaptation and care but also geographical location and consistency or lack of consistency from those providing social care and support. What also became clear is that the numerous avenues offering and providing support often confused participants as to who to contact and when. People commented on how accessing, or attempting to access care and support and of managing and ensuring the quality of care and support was

often a source of considerable stress, anxiety and frustration. As argued, it is hard to pinpoint exactly why some services worked for some and not for others there are some themes that offer suggestions and it is to an examination of those that this section now turns as we seek to determine what works and what does not.

Providing a Responsive Service

What worked for families, were professionals who came to work in partnership with them. This is not contingent on the type of job the professional does, but in their attitude which may involve working beyond their remit or considering novel solutions to problems.

Mike and his wife Claire talked about the importance of location and of the 'pot luck' circumstance of receiving the kinds of adaptations that increased independence and that helped with managing MND in the home. Mike felt he had an effective OT that was active in supporting them to get what they required:

> *Mike: [Heather] is the occupational therapist who dealt with us who was very*
> *good all the way through…*
> *Claire: I was going to say that she was the one star…*
> *Mike: She got a lot of equipment of various sorts for us…*
> *Claire: She has been good…*
> *Mike: And she said that even if [local authority] region would have done this*
> *system we wouldn't have got five ceiling tracks – we would have got a maximum*
> *of two whereas we have got five… And also we got a better price she said…*
> *Mike and his wife Claire*

Again, this is an example of positive care and Mike indicated that this particular OT 'was the one star' but this highlights once more the lack of consistency for people in accessing good social care. Finding a useful solution depended on Mike and Claire being able to privately fund the five ceiling hoists. Critically, the OT remained working in partnership, offering their considerable

expertise even though the equipment was not funded by the local authority and this was noted and applauded by Mike and Claire.

Alan and Paula made it clear that what was very helpful for them was to have someone come to their home and explain to them and suggest what might be the most helpful solution. This was seen to be a very important role for OT's because as mentioned before, often people have no idea what is available to them to support their needs. Alan had a very positive experience of getting an accessible bathroom put in his home. Alan was finding it difficult to shower and his wife Paula was finding it difficult in supporting him to bathe properly:

> *We had to apply for a grant, we got the grant – it was obviously the OT at the*
> *Social work that put in a referral in. We got the grant, we got the plumbers, got*
> *the work done and it's been fine ever since. And it's made a heck of a difference I*
> *can assure you. Again, it was the disability OT who put in the referral to the*
> *social work OT (I didn't have to do that). We got all that. We got the level access*
> *shower and it had made a difference.*
> *Alan*

Paula confirmed their positive experiences of social care by saying:

> *I have got no complaints whatsoever about the care and the care team that are*
> *involved. I can't fault them in any way.*
> *Paula, her husband Alan has MND*

Finally, personal choice was important in how people managed their social care. For some participants it was very important to have social workers and OT's being very proactive in contacting them and evaluating their needs regularly while for others successful social care was being able to contact their social workers and OT's as their needs changed or when they required support:

Catherine: She is absolutely brilliant… and she got us everything that we needed like beds… and I go into respite when I need to give Bill a wee break…

JF: So, how does the OT work – does she come and she listens to whatever problem that you have got and then she tries to create a solutions with you or she just, kind of, drops off equipment and you test it…

Bill: No, no… she comes down and we discuss whatever it is that we need and she tells us "Well, I might need to ask my boss if we can get that…" it is the usual – it comes down to money…

JF: No, sure it does but… you feel like you have got…

Bill: But we can't complain because … our OT got us everything that we needed… I mean it is a fancy recliner chair – she got us that… She got us the electric toilet with a washer/dryer thing…

Catherine: And then… Well, what we usually did was… we phone people when we need them like the GP and the REACH team and the… So, they don't come on a regular basis to visit us basically… so, if we had a problem I would phone the OT and she would come down

Catherine and her husband Bill

For Catherine and Bill, their experience of the OT was positive because they felt that they received the necessary equipment and support as required. They also felt that they were listened to and they trusted that their OT was efficient in supporting their needs.

It was very difficult to say that there were a group of participants that had explicitly positive experiences of social care. Even where participants felt that they were receiving good support or that the services 'were doing the best they could' they were in many cases subject to the lack of consistency in care that the majority of participants experienced. This section does hope to highlight what can be achieved through positive and good social care. While negotiating the psycho-emotional impacts of being diagnosed with MND it was critical for participants that their lives and homes remained as stable as possible and one of the key ways that this was achieved was through supportive social care professionals. Good social care, proactive OTs and being

included in the decision making process all increased the wellbeing and independence of the participants with MND, it took additional stresses away from them and their families and was one of the most crucial factors in allowing participants to maintain stability and normalcy in a situation where their conditions were in flux.

It must be noted that the majority of participants felt that they had negative experiences of social care, this was often due to a lack of consistency (both in support that they received, their geographical location, and across the varying care outlets such as OT's, social workers and personal carers).

Trust and Consistency in Care

Accessing the appropriate care and support required was often a source of stress and frustration for participants; this was partly because participants did not always know from which sources to seek care and there was an overall lack of consistency in these care provisions. This was evident in the fact that care was distributed from a multiplicity of avenues, at different times and across different locations. Furthermore, it was often the case that participants felt that if they did not ask they did not get, they rarely felt that they were approached with suggestions of what might support them best. They felt that they had to chase up OTs and social workers in order to secure their needs; along with the emotional, physical and financial management of MND this became an added difficulty to negotiate.

Most participants reported and discussed problems in getting the equipment required to manage MND in the home. Common problems were that participants were unable to get in touch with OT's and when they did they found that they had to chase up the items that they needed. Marie gave a detailed account of how the process of trying to get equipment became very laboured and felt that she had to make constant contact rather than being contacted about what she might need. The next three quotes are from Marie and are included to demonstrate the complexity of her situation and how this led to a lack of trust in her social care providers:

> *Well, I don't know. Maybe it is just my personal experience I don't know but I've had a real problem with OT because first of all [the SCN] had said that she would get in touch with OT and that and they'll get in touch and they'll come up and they'll do an assessment in the home to see what you need... however, that didn't happen.*
> *Marie*

Marie began phoning the OT in order to find out when the 'perching stool' she required would arrive and felt that she could not get in touch with the OT and they rarely returned her calls:

> *Well, they've never ever, never have I phoned and they have phoned back. I can guarantee you that I would need to phone again. So, [the OT] never phoned back of course so the next day, phones again "Oh, she'll be in at lunch time." So I phone back and I phoned back and said "Oh, it's Mrs. Campbell, I was just wondering about the stuff you were going to get and nothing has arrived." "Eh, what was it again?" Well, see when you're feeling.... and you're depending on somebody, dependant on her...*
> *Marie*

For this particular participant it took over a year for her to get the required equipment which was difficult as she felt her needs were changing all the time. She felt dependent on the OT and the lack of proactive action by the OT left her feeling vulnerable and anxious:

> *Any approaches have come from us to them. She has never phoned me and said "How are you now? Will I come up and see if there is any other thing that you are needing?"*
> *JF: So, how long ago was the assessment when she came in here?*
> *Oh, last year.*
> *JF: So, everything [in relation to mobility] has changed since then.*

> *She's never been back. Absolutely.*
>
> *Marie*

Where care and equipment came from often affected on what kind of equipment people received and how long it took to get it. A lack of consistency across geography meant that there is a lack of consistency in the care pathways offered to people with MND.

Catherine was explicitly told that this problem existed and their receipt of the appropriate chair that supported her neck was dependent upon the area in which they lived:

> *Catherine: So, anyway I thought that I needed a chair that reclined so that I can put my head back – like a head rest… and I got this chair eventually and again the seat… When I seen the [SCN] the first time I was showing her my new chair and she said "See if you had stayed in [city she used to live in] – you would never have got that chair…"*
>
> *Bill: The difference in local authorities…*
>
> *Catherine: It was maybe too much… [current city] have really been good… Well, maybe better resources… maybe they have not got as many people that need this…?*
>
> *Catherine and her husband Bill*

In this particular example the participants had received the equipment needed but it highlights the inconsistent nature of how this equipment is rolled out. It establishes a 'pot luck' or 'lottery based' system of care provision that either means participants have to move away from their homes and communities in order to source equipment and care or they have to 'make do' without – either scenario creates an additional stress and burden on participants managing their MND.

For example Sarah had moved from a rural location where her GP had advised her that she may become isolated to a city that had a well-respected neurological unit. However her new GP knew nothing about MND, it took a long time to find accessible housing and build relationships with the OT so in fact staying in their previous address may have improved her well-being.

Consistency and Relationship Building in Personal Care

Personal care and assistance was one of the key areas where participants felt that consistency was crucial. It was often difficult for participants to come to terms with having carers come into their homes; this was particularly hard for participants who had no previous experience of personal carers. Christopher discussed how this was very difficult for his wife and that continuity of carers would better help them keep their home life private and maintain a sense of normalcy:

> *I was originally going to do it privately on the grounds that I felt if a girl was coming or a lady was coming – whatever age group – it would be more consistent. It would be the one person and I wouldn't have to explain where the mop is kept and where the Hoover is and that sort of thing. However, we have done it temporarily for six week – see how it works out, and if we decide that we want to continue it and we can afford it - I may switch to doing it privately and getting somebody in if I can find somebody on a continuity contract... continuity being the key word. We have had 25 different people from [service run by the local authority].*
> *Christopher*

This desire for consistency became a need for some participants because of their specific symptoms:

> *I've gone down the direct payment route so I could have continuity of my carers because I am losing my voice. I need someone that knows me and it was different people every day and this whole direct payment thing has took forever.*
> *Sarah*

Around a quarter of families remarked on the sheer number of different professionals they encountered and how this could be overwhelming.

That was the worst thing being bombarded with all these people doing their own wee bit. You know we had thirteen different people in the house one Friday morning, and I just thought you know ... time is precious and you need to have time together without all these people.

Maggie, her husband Derek had MND

Almost as a paradox to this search for consistent care where a relationship can form between the person with MND and those providing support, one family from a small fairly rural town fought against using a local organization because it heightened the chance that the carer already knew the family. This was exacerbated because the person with MND had previously worked in the local care services.

And we didn't want anybody that knew my Dad, or that my Dad had been out to, or anything like that, to be coming in and caring for him.

Elena, her Dad Patrick had MND

So in rural locations, the need for consistency may run counter to the need for privacy. Elena and her family were able to resolve this because they could afford a private carer and also, as a family were managing to provide a significant amount of care themselves. Unless care providers work in partnership with families, such issues will not emerge and the families will receive inadequate support.

Covering the Cost

This theme has emerged already in this chapter but is worthy of consideration as a distinct concern. In order to optimize choice, many participants had to self-fund their support. Self-funding was not always about choice, some participants found that in order to get the services they needed most or in a relatively quick time that they had to pay them themselves. Mike and Claire initially had a negative experience of getting the hoists required in order to transfer in and

out of the bed. Firstly it was suggested that the couple move their bedroom downstairs so that they had access to the rest of the house,

> So, I says "That's no good…" and then they suggested that I put a bed down here…? I said "And how am I going to get to the bathroom if I am down here…?" I said "I need my Closomat toilet – I can't use a standard toilet… Plus, that[downstairs toilet] bathroom is too small for me – I can't get in there…" "Well, in that case you will have to stay upstairs…" and I said "Well, in that case that is affecting my human rights…" …. "So, you are telling me that I am consigned to the top of this house until I die… Is that what you are telling?"
> Mike

The couple found out about ceiling hoists through personal research and felt that the portable lift that they were advised to use would ruin the aesthetics of their home.

> Claire: It wasn't fit for purpose – the big Oxford hoist…
> Mike: Useless.
> Mike and his wife Claire

Finally they decided to look into buying the ceiling hoists themselves as they were told they could not get them through occupational therapy.

> JF: and so you…? You've had to pay for it yourself…?
> Yeah… that was two and a half thousand quid…
> Mike

This example highlights the way in which each individual person with MND requires different forms of care and equipment. Mike and Claire felt that a 'one size fits all' approach did not work for them which meant they had to fund their adaptations themselves. In fact, as discussed earlier,

their OT was able to negotiate a solution that did work for the family (though it relied on self-funding) but the quotes show how bleak their situation was without this solution to hand.

In the same vein, Rachel and Paul required a stair lift for their home (which is a first floor flat) and found that their local authority, via their OT were unwilling to put one in due to the high cost. The family felt that the stair lift was the safest and most efficient way for the participant to manoeuvre around and have access to their home but also to get outside the home.

> *When [Rachel] was first diagnosed... em... it wasn't good at all. We had a terrible*
> *run in with... we had wanted a stair lift fitted and they wouldn't do it. Despite*
> *being approached by the MSP and everything, they wouldn't do it...eh...*
> *JF: And what reason did they give?*
> *They didn't think basically... and again this 5 year thing came into the equation...*
> *to cut a long story short they basically didn't think they would get their money's*
> *worth out of it.*
> *Paul, his wife Rachel has MND*

Here Paul and Rachel had a unique perspective because they had both worked in fairly senior positions with the social care departments of a local authority. They were clear that they had been turned down for the stair lift, even though they needed it, because the OT had decided that Rachel would not be alive, or living in the family home long enough to be worth the cost. For a few months Paul had to give his wife a 'fireman's lift' to get her in and out their home, until family and friends banded together to fundraise for a stair lift to be installed.

Marie also reported that her OT (on behalf of the local authority) was unwilling to meet the cost of an external stair lift because Marie may not be alive in 5 years time, the participants interpreted this as they were not worth the money. Nadine also recalled struggling to find funding:

> *We had to fight, fight for a wet floor shower room to the extent of "Well, you're not*
> *entitled" Based on what? I had people say to my face about that. I've also had*

people say to my face "Well, he's not got cancer so we've not got all of these things
in place. I actually said to them, "So you're actually grading life limiting illness
now are you?" I said that to them and there was silence.
Nadine, her brother Laurence had MND

Not having the appropriate equipment, as well as footing the cost of the equipment and managing having MND itself only contributed to the stress that participants with MND and their families were already experiencing.

Playing the Waiting Game

One of the other key issues discussed by participants was the length of time it took to get the necessary adaptations and equipment for their homes. As discussed earlier, bathrooms were one of the key adaptations that made a huge difference to people in their homes but this was also one of the adaptations that was most difficult and took the longest to procure. Again, there are examples of this throughout the chapter and in this section we focus more explicitly on the impact of waiting.

Many people had to wait a long time for aids to living. Gayle and Eric had to wait months for a wet room in their home. By the time it was installed, to get safe access to the shower, Gayle needed a chair. The OT ordered this from the same company that supplied the shower but when it arrived (after weeks of waiting) it didn't fit into the shower cubicle and another chair had to be sourced.

Many families resorted to paying for equipment themselves but still relied on care support professionals for other items. For example, because of the length of time it took to get the necessary equipment Sharon ended up paying for the mobility scooter she required herself.

> *I had to buy a scooter myself, it was either that or wait months. And we got*
> *the front and back slabbed at our own expense so I could have clear access*
> *out of the house.*
> *Sharon*

As the scooter is so large, it is kept in the garage, but to access the garage she has to go out the back door and all the way around the house because there is a single step at the front. The family was told they would get ramps to aid access at the front but they were still waiting at the point of interview.

Conclusions & Recommendations.

It is clear that good care makes the process of managing MND easier, the above sections have shown the detrimental effect that a lack of consistency, proactive and supportive OT's and at times inefficiency has on families with MND. There is a lack of knowledge from both the people with MND but also support avenues as to which sources need to be approached in order to receive the necessary support. What is also clear is that different care and equipment providers are not in contact with one another and therefore many families fall between the cracks, do not get processed or wait long periods of time to get the social care that they need. Two key recommendations emerged:

1. What became most apparent, from our interviews, was that social care services were fragmented and so participants were not aware of where these services were coming from, how to contact them appropriately and what were available from these services. Individuals and their families require clear support and information on what is provided by the different services and how to access them.
2. There was a lack of communication between services, some participants were told that they wouldn't be able to acquire a particular piece of equipment and were told by someone else they were. This led to anxiety and confusion. Clarity, communication and consistency are key to providing good social care; it was evident that this was lacking.

FAMILY AND FRIENDS: CARE AND SUPPORT

Introduction

Most of our participants lived in a family unit with at least a husband, wife or partner living at home. Seven participants lived with their partner and children under the age of 18. Seven participants lived alone and had minimal support from family members. This chapter discusses people's views and perspectives on care and support, how this affected their family life and the challenges it placed on their family. We focus in particular on the way having MND affected their ability to socialise and to work. The chapter examines the emotional and physical demands providing informal care placed on both the person with MND and on the care giver. We discuss both how they felt about the care they received, their preferences for the way this care was delivered and their concerns about it.

There was a clear preference for the provision of support and care from family members and this was accompanied by a general suspicion of other care and support providers. Our research participants received support, care and help from a wide variety of different people including the full range of family members. People told us that they received support from their spouses, their partners, their parents, their siblings, their children, their grandchildren, their cousins and their nieces and nephews. Some people also relied on friends and neighbours. The amount of non-familial support they received, the quality of that support and their feelings about who delivered it and how, varied greatly. Informal, familial care givers provided a range of personal and social care including helping with food preparation, shopping, domestic washing and cleaning, moving and handling, bathing, eating and toileting. The role of the familial caregiver, the commitment that was required and the sort of support they provided changed as the condition progressed and the needs of the person increased.

The themes outlined in this chapter emerged from a systematic analysis of all of the transcripts. As with other chapters, 'control' and 'autonomy' emerged strongly, as being important to the people we spoke to. Relative to the other chapters, we were less clear from the outset what we

would find around the topic of families. We initially looked for patterns of support but also a lot of information about psychological well-being surfaced through the interviews.

As symptoms progressed, the family role of the person with MND also changed. The first section explores how their changing roles, responsibilities and duties impacted on their family relationships.

Findings

The Impact of MND: Changing Roles

For many of our research participants a diagnosis of MND was 'life changing', not just because of the progressive nature of the condition or because it is a terminal illness but also because it changed and altered relationships and affected previously held roles and responsibilities. In the quote below Kate succinctly described how the condition affected both her and her husband's lives and their relationship:

> *It's life changing... for both of us. I mean, he is used to working twelve hours a day. I am used to having the house to myself all day every day; albeit I am out at work because I work out there... um, that in itself is life changing because Phillip is like ... So now I have got to cover at home all day. So, that in itself is... I suppose it is like two people who are used to working all day and then are retired and then all of a sudden we are in each other's company all day long. It is an adjustment. I'm not saying that it is a bad experience but it is a definite change, a definite adjustment... I have to now factor in his needs to my day, whereas before I would be out working maybe twelve hours a day and Phillip would shout "Lunch is ready", "Coffee is ready"... at the weekends. Whereas now I have to do everything so it is a big adjustment.*
> *Kate, her husband Phillip has MND*

No matter how hard people tried, the condition affected relationships and people who had previously been independent social actors now had to rely on their partner or other people to get their clothes, to help them get dressed or to get out and about:

> *I had to sell my car and I am not allowed to drive so I am at my husband's beck and call.*
> *Rose*

The loss of independence mattered to the people we spoke to. Their reduced ability to contribute to their families or the running of the home, to the extent that they were used to contributing (pre-symptoms) also mattered and many felt frustrated at not being able to visit the supermarket, cook, make tea and so on.

The progression of MND impacted on some significant family decisions. Several families spoke about making sure absent friends came to visit '*while they had the chance*' (Neil) or made conscious decisions to travel and see the world (Alison). Derek's daughter decided to bring forward her wedding to be sure her Dad could walk her down the aisle:

> *My daughter was due to get married and we asked [the consultant] if we should bring the*
> *wedding forward and were told, "Are you worried about not being able to walk her down*
> *the aisle? You'll be able to but your right arm might be affected". We decided to bring*
> *the wedding forward and it was the best thing we did because if we had waited until when*
> *it would have been, it would have been much more a strain … So he was able just to get*
> *her down the aisle and he was keen to stand through his speech, em, but in the end I*
> *borrowed a bar stool so that he didn't have to stand.*
> *Maggie, her husband Derek had MND*

Older family members, who many of our participants may themselves have expected to provide care and support for as they aged, became in effect their carers. For example some of our participants described how their own parents, who were often very elderly, now took on supporting roles:

Yeah. And my mum… she's great … she is 82 next month but she takes an odd bag of washing away and she'll do the washing and she will come up to me at lunch time… and she will do the wee bit of dishes and make sure that I am alright.
Catherine

These changes in social relationships affected their own perception of their roles within the family and perhaps, for many most importantly their own ability to act as carers for others. For example we were told how people were no longer able to make the family meal, to look after ageing parents, to support children or to care for or look after grandchildren:

Caitlin the oldest one is the only one we've had here staying on her own and I could probably have her still because she is nearly six and so it's easier but I don't see the younger ones.
Patsy

People tried to keep their relationships and their roles as normal as possible, especially those with younger or teenage children. People told us about how despite the many problems they faced they managed to preserve normal, loving relationships and that their life still had quality and they still did things that they valued:

There has still been laughter in our house and I said to Jean one day after I had had one of these bad anxiety attacks "Right, let's keep our feet on the ground and remember there is always laughter in this house…" and yeah, I won't give you examples because you are recording me but… em… we still laugh a lot about stupid things but we have a laugh and that is one of those things that keeps us going…
Alex

Preserving laughter was a key theme that emerged for many, but particularly when talking to families that included teenage children:

I mean, it's been a standing joke the last couple of week – Stefan's been like that "Somebody is coming in to shower my dad? What's he going to wear in the shower?" and I says "What do you mean 'what's he going to wear in the shower?'?" "Well, he can't go in naked if there is two women coming in to shower him..." and I'm like that "oh right..." and then "What happens if they're good looking?" an I says "Well, if they're good looking he will be wearing a wetsuit..." Just trying to make light of it...
Charlotte, her husband Tom has MND

For many of those we spoke to whilst these changes in roles and responsibilities created problems and sometimes conflict or anxiety (as are hinted at in the quotes above and as we discuss further below) these problems were often outweighed by what were described as the significant benefits found in the provision of care and support by a family member. The most important of these were the issues of quality of care and of control. The preservation of the family home as a home rather than as a site of care was also a particular concern for many. Trust was also important and where care was provided by close family members or friends, people with MND felt safe in their hands. They felt they were able to ensure that the provision of care was good and also that it meet their needs:

Like I said before to you, I am getting five star treatment – I wouldn't get that off carers – no way. I mean I am in there over an hour every morning getting sorted... I wouldn't get an hour in the bathroom... No way... that is what I am saying – I am getting good care thanks to my dear wife...
Mike

Providing the level of support required was not without its challenges. Meeting the care needs of those with MND became increasingly difficult as the condition progressed and increased the need for extra support in the future. For many this transition was something that they felt a great deal of concern about:

Kate: I do worry a bit about how I am going to manage in the future because you have said to me in the past that you don't want carers – you only want me looking after you... and I can completely understand that but it puts a huge amount of pressure on me because how am I going to manage with you myself? I have a bad back – I just need to lift a pale of water and I am struggling. So, if I am being completely honest I am really worried about how I am going to manage and I know that there is help there, but it is whether or not he will accept it and we are going to have a problem with that and I think at some point that you are going to have to accept that I am not Super Woman and that I cannot do everything by myself and that we do need outside help and you are the only one that can make that decision.
Phillip: That's right. And I don't have to make it at this moment in time and I would rather not. You were right earlier, I mean, I do have ostrich syndrome... because I would rather not dwell on what is going to happen in the future - going to the toilet, wiping your bum, just things like that. I would rather not think about it.
Phillip and his wife Kate

Several family members had been warned by their SCN to take better care of themselves to ensure that they could maintain the care they provided for the person with MND. Edith had had to have a short (one week) stay in her local hospice after her husband Richard strained his shoulder and was unable to continue lifting and turning.

As we have already stated coupled with a desire to be in charge of who did and did not enter their house people often expressed a wish to preserve their home as a space for the family rather than as a space for caring. This was challenged by 'outside' carers:

You know we had thirteen different people in the house one Friday morning, and I just thought you know … time is precious and you need to have time together without all these people.
Maggie, her husband Derek had MND

Indeed there was for some a reluctance to adopt or to engage with certain aids to daily living, in particular hoists and sometimes hospital beds, for similar reasons. They were felt to be too clinical and too medical and detracted from the domestic environment and served to remind them of their MND:

> *If you are lying in bed and you see a hoist it is just the memorabilia of MND…*
> *Rose*

It was not that people did not want aids and adaptations, it was that they wanted the house '*adapting in a way that makes it feel like home*' (Mike).

Maintaining the family home and relying on support from family or other informal carers was not without its costs and it is to an examination of these that this chapter now turns.

Isolation from Friends and Family

The requirement to provide care and support often meant that social activities were curtailed for the partner as well as for the person with MND. The need for short breaks, where both partners get time away from each other was something that all people talked about. Whilst not all people used or had access to short breaks, for those that did they were seen as being something that was important both for those with MND and for their partners:

> *He goes with his family and... em... I think that it is important for him to go away and to spend quality time with his family, they also go and I think that there is a fair amount of alcohol consumed ...... Also, it lets me have the house to myself which is good for me.*
> *Kate, her husband Phillip has MND*

Opportunities for such short breaks were however few and far between. Some families were able to access such services through a day centre and this allowed weekly breaks however no such services were available for many of those we spoke to.

People's ability to have an active social life was also vary greatly affected and many of those we spoke to lived very isolated lives, often rarely getting out of the house and then only to visit the hospital or hospice. Some people did manage to keep contacts up and where they did these were seen as vital.

> *He's got a couple of good friends that come up every second Wednesday. He has a really good laugh with them, he went to school with them and they reminisce and laugh and laugh and laugh. That's the best company he's got really. They are just pure therapy. They go away and he's like a new man, he really is. They go back to their boyhood days – they act like they're wee boys again and all. And then he's got a really good friend he met up here – Jim, he used to play golf with him. He comes and sees him every single week as well.*
> *Charlotte, her husband Tom has MND*

As the condition progressed people described how even relatively simple mundane activities such as calling round to a friend's house for a coffee became difficult. Some described friendships just slipping away. Access issues as well as symptoms associated with the condition often meant that they had to rely on people coming to them. As the condition progressed toileting in public conveniences or in friend's bathrooms became such an issue that it meant that for many people trips out became impossible. As stated, this had an impact on all the family.

> *Kate: We don't have one – we don't have a social life.*
> *Phillip: [we used to go out] It wasn't every Saturday. It was every other Saturday, kind of thing, but even then in the last month or two it is every three weeks now… It is just… it is difficult…*
> *Kate: when was the last time you took your wife out…?*
> *Phillip: But it is difficult because I have got splints which mean that I can walk a bit further in them than I can without the splints… however, if there is a step, a kerb, stairs*

they are dreadful. Or if there is a sloping bit of ground they are dreadful… or if the
ground is wet it is terrible… So, I really have to…
JF: So, that really limits their use…
Phillip: I've got to ask where am I going…? Can I do that? Is there a step there…?
Everything has got to be planned like a military operation…
Phillip and his wife Kate

Some people did of course manage to continue with trips or with visits but these were rare and where people did go out they tended to visit close family members rather than friends. Any trips out required planning and informal gatherings or spontaneous outings were for many people no longer possible.

Barriers to Familial Care

As stated, many preferred to be supported by their family, in their homes for as long as possible. Within the context of this theme, three key arguments emerged around control, dignity and (economic) cost. Support from family optimised the person with MND's control and optimised their (perceived) dignity. Best practice models will be discussed as well as barriers encountered by families. This first section highlights some key barriers including economic considerations which prevented some family members being able to take on as much of a caring role as they would have liked.

Caring for somebody with MND had an economic cost. The care and support that people's family provided often meant that not only did those people with MND have to give up work but also often their partners. Whilst many of our participants had already stopped work by the time they developed MND for others the onset of MND occurred prior to their retirement. At first people tried working part time, flexibly or from home but despite most reporting that their employers had been very considerate people fairly quickly realised that they could not manage both:

JF: And you stopped work 2 years ago, was that you naturally retiring? Or did you finish earlier?

No I finished... em... I stopped... Rachel had... they were actually very good with me because Rachel had fell pretty unwell and I came home, and literally one of these ones where I got a phone call and came home. And then I spoke to them and they said "well you can take sometime off", and which I did, and that stretched to the 6 months and they were good enough, they actually paid me for the 6 months without me having to flannel, you know, that I was depressed or anything like that... nothing like that, they actually just put me down as caring for a sick relative. And I asked them if there was anything happening and they offered me a package, so that was that.

Paul, his wife Rachel has MND

People eventually had to give up work and dedicate themselves entirely to the care of their partner. This not only affected their immediate income it also had knock on effects in terms of their pension, effects that would continue far into the future.

Work also often meant that many of our participants' children, whilst they might be willing and in many cases very keen to help, were often unable to. They could not for example regularly accompany their parents on hospital visits or be in the house when therapists or other professionals visited to discuss issues around care, aids or adaptations:

The trouble is that they've got to get time off work……..You can't just keep on getting time off work now, these days.

Edith

The adult children of those with MND often took on key supportive roles, as did in one case a grandchild. For many of those we spoke to these roles were very readily accepted and their children or other family members or their friends and neighbours were very willing to take on the associated tasks. Many of their children were also willing to change their own lives and adapt to the needs of their parents, changes that were often not wished or desired by those with MND:

[My sons] will be here if we need them. There is no doubt about that and my daughter also. I mean she has even said... She's works away but her company is re-organising "Which means, mum, if you need me back home, I should be able to get transferred." That is the last thing that I would want. The last thing that I would want is for any of my family to come back here once they have got out of here.
Kate, her husband Phillip has MND

Patsy's daughter had offered to take a career break but was resisting this too.

It is very daunting. I don't want the attention and the pressure ...
Patsy

Parents did not want to feel a burden to their children or to stop them doing the things they wanted to do. They did not want to feel that they were holding them back or denying them opportunities. People for example voiced concern about their children not taking opportunities for advancement in work because they felt that they could not leave the area or taking a less well paid job to be near the family home.

A small number of participants and their partners explicitly rejected the role of care and were wary of providing too much support or assistance because of the demands that it would place on them

My wee wife, who is not my legal carer and has stuck out not to be because she just could not cope with it - either physically or mentally. If I do fall it is a problem to get me up because I am big and heavy. I am not overweight but I am heavy. I mean you wouldn't like to try and do it – it would be a real hassle.
Christopher

Not only were these demands physical, we were told how some of the family members were unable to accept some of the intimate roles that providing care produced:

> *And there was one instance where I had said to my son that if I were to go out would you be comfortable taking your dad to the toilet and he kind of hummed and hawed and I don't think he wanted to come out right and say No but I felt as though I had to take the pressure of him by saying "Look, I'm not putting you under any pressure. I would rather that you were honest with me. If you don't feel comfortable doing it just say..." and he went "Well, no I wouldn't really be..." And I don't think it is a case of he didn't want to, I think it was just because it was his dad and...he said "Mum, I don't want it to be coming across as if I don't want to do it and I'm selfish and..." and I says "No, you're no' comfortable with it and that is fine..."*
> *Paula, her husband Alan has MND*

For some there was a distinction between general caring (like taking more responsibility with the house or driving the person to appointments) and dealing with medical issues. Following having her PEG tube inserted, Patsy found her husband resisted any associated caring role:

> *On Sunday, when he came, I said "do you want to see [the PEG]?" And he said I'd rather not ..." and then I asked "how do you feel?" And he looked panic stricken and he said "I would rather not look." Which is honest .. and people are squeamish .. I think he sees it as overwhelming.*
> *Patsy*

Providing care and support caused anxiety and concern for a number of reasons other than those associated with a change in roles, chief of these were participants' concerns about their ability to provide good, adequate and safe care and support. Comments such as 'it's me hurting her that worries me' or 'it's him not lifting me properly' were very common.

Control in Care

If support was provided by family and friends they were in control and they had some say in how the care they required was managed and delivered. This allowed them to maintain their own routines. They were also able to decide who could and who could not enter their home and were able to maintain consistency:

> *I would rather do it myself… than having a different person constantly coming in… I think that is one of the things… you wouldn't like a different person every day…*
> *Doris, her husband Daniel has MND*

This latter issue was another key concern and one of the main reasons people felt uncomfortable with services and care provided through outside agencies. In many cases it left family members resisting care to promote the person with MND's sense of control, but at a cost to themselves:

> *A lot of people … neighbors would offer to come and sit with him and let you get out because you needed a break but I knew that he didn't really want that. You know?*
> *Bridget, her husband Tim had MND*

Similarly Sarah rejected help from her friend because she felt it would impact negatively on her 'marital home':

> *She wanted to drop everything, her whole family, and come and live with me and take care of me and do everything. I am just "No thank you … no. I love you for who you are, not who you want to be." I don't want her here 24/7 taking care of me. That's not her role in my life … and how can you say that to someone without really hurting their feelings?... I love her dearly, like a sister … but she needs to understand when to back off …*
> *Sarah*

Managing care, particularly where it came from outside the primary family unit, was stressful and required negotiation and patience.

For those who used carers provided by the local authority or outside agency there was often some confusion about what their actual role was and what sort of care or support they could provide. In particular people were unsure of the extent of the carer's roles and their ability to carry out activities beyond those directly associated with personal care. People were unsure about the sort of work they could do in the home and did not know if, for example they were able to carry out activities such as general cleaning or cooking, especially where this might be for other family members.

Dignity in Care

There was a feeling amongst the participants that if they were placed in a position where they had to rely on support from an external agency they would not be able to control the level of care they received or, perhaps most importantly, who gave that care and this would impact directly on their dignity:

> *He has got very little dignity left and I just feel that when it comes to his personal care that I would rather do it. If the worst came to the worst one of our sons would do it. They might not be comfortable with it but rather than a stranger coming in. That's my own personal feeling on it but if things became too much and I couldn't cope then I would consider it but at this particular stage – No, I just feel that he's got little enough dignity left and whatever wee bit of dignity left I'm looking to keep.*
> *Paula, her husband Alan has MND*

Because of the increased demands some people had been forced to use outside carers to provide intimate care and this sometimes caused feelings of guilt.

Oh, you feel guilty because I know he wants me to do it... Doesn't want anybody else doing it...
Charlotte, her husband Tom has MND

Providing care and support placed increasing demands on the families and brought about major changes in roles and in relationships. Perhaps the most significant of these was the effect that care had on people's abilities to maintain a sense of privacy.   Whilst many were happy to receive help with washing or bathing from their partner there were other intimate tasks that people found difficult. Helping and providing care meant that people often had to perform even the most intimate bodily functions in front of their partners:

My husband – I have never did the toilet in front of my husband.
Edith

People told us how they now had to accept that, where necessary their friends and neighbours would help them go to the toilet. This change was, for some, very difficult to come to terms with.

Physical and Psychological Stress of Caring

As is evident from the quotes already used, caring placed pressure on families. Caring affected both people's physical and mental health. People complained of bad backs and shoulders and about the actual physical demands that providing care placed on them. Many of the carers we spoke to had a variety of other conditions including multiple sclerosis and muscular skeletal injuries, some of which were pre-existing and some of which had been caused by or exacerbated by the caring demands placed on them. This meant that people were now no longer able to meet the physical demands associated with caring and lift their partners as they may have done in the past. As Paul succinctly put it:

Whereas it used to be a fireman's lift and run with you but I can't do that anymore..."
Paul, his wife Rachel has MND

Many families talked about the physical pressures of being a carer. This emerged more strongly as a theme in the focus groups probably because they had the freedom to talk without the risk of hurting the feelings of the person they supported. Family members were generally determined to provide as much support as they possibly could for the person with MND but in committing to this, they put their bodies under significant stress:

> *You find it quite exhausting to be on your feet almost ... was nearly 20 ... 18 hours per day. Never sitting down. I remember one day that I never got any food and at about 5 o'clock I said "Tim, I'm afraid I'm going to have to go and eat something." I was beginning to feel faint and do you know I couldn't think of anything to eat so I opened a tin of beans and I think he called me three times when I was trying to eat my beans on toast and I never finished it. It was constantly like that.*
> *Bridget, her husband Tim had MND*

Most participants felt that either their own or their partner's moving and handling skills were not sufficient either and there was little evidence that they had received any help or support in this matter:

> *He knows nothing about lifting, handling, transferring... Nothing, so they give you the chair and then you get on with it...... So, if nobody ever said "Well, now that you're doing this we better say to your husband. This is how you can lift people..." "Do it this way/ Do it that way" There's been absolutely nothing about lifting, handling, transferring, toileting.*
> *Marie*

Nobody talked about having received training in moving and handling. As a result participants expressed concern that their support needs would increasingly place their partners at risk of

physically harming themselves because they did not know how to lift properly or they were simply too old to perform the task. For example we were told

> *I am always scared that my husband hurts himself trying to lift me up.*
> *Rose*

This lack of training and preparedness for care extended beyond moving and handling and some described how they had worries about their partner's ability to help when they choked or other similar medical event:

> *That could be a cause for concern. I mean like choking, breath, catching your breath... things like that which he knows absolutely nothing about and gets a bit worried... because sometimes if I start to cough, I start to choke and then I start gagging... You know the "retching sound..." and it goes on and on and he doesn't know what to do...*
> *JF: And he doesn't know what to do?*
> *The tears are running down my face, and I'm going "I'll be alright..." and I can see he is starting to panic then... Nothing has been discussed any of that side of... So, maybe that is another area that MND could... training for carers? Handling and lifting? Transferring? If this happens do... Just to give him... So, that if something is going on maybe he won't panic so much?*
> *Marie*

This argument was echoed by Alistair who felt out of his depth in providing care to his wife Lucy:

> *Now it's a lot to ask people who are not medically minded to have to proceed with procedures like [using the PEG tube] and also to clear the throat because on occasions I've seen us up all night.*
> *Alistair, his wife Lucy had MND*

Again, Lorraine talked about the anxiety she felt in performing some care duties:

> *I do remember thinking "oh goodness! Will I be able to manage [the PEG tube]?" I was*
> *frightened that I would cause more harm and choke him because I have no experience of*
> *it.*
> *Lorraine, her husband Calum had MND*

Mental wellbeing and anxiety was a major theme throughout all the interviews, both for the person with MND and also for their partner. For some the levels of anxiety became so great that it not only affected their physical ability to help but also own their mental health:

> *I went to see the GP and he said he felt that I had clinical depression, which in itself was*
> *quite depressing. Because I didn't think that I had it, I just thought that I was a bit*
> *anxious... I knew I was anxious you know and I told him that I didn't want any*
> *medication because, like, during the night when Sheila wakes up if she needs anything*
> *(needs the loo or needs to roll on one side) whatever... she can't do it on her own so I*
> *said "I need to be able to respond..." and he said "Well, that shouldn't discount*
> *medication..." and he wanted to prescribe a tranquilizer... So, that's me, I'm on drugs as*
> *well now...*
> *Craig, his wife Sheila has MND*

In this case Craig felt that the stress and anxiety he was experiencing owed as much to other ongoing problems in particular managing housing adaptations and trying to continue with work as it did to providing care for his partner.

Providing care and support also sometimes led to conflict and disagreement and although some of our informants were reluctant to criticise their partner or to openly voice concerns about the demands the provision of care was placing on them, tensions were often hinted at and care and its delivery was often at the root of these conflicts. Charlotte was frustrated that they had not been told about technology that would enable Tom to control his local environment:

Environmental Services are coming out... a week on Monday and they are putting a button on his chair and he'll be able to turn the television on and off... if you get it done properly you can get everything done: the curtains closed on a button. It's amazing... Because he has not had the use of his limbs for ages and you're in the kitchen and he shouts "Turn the telly up." And they wee things start to niggle on you and then you start narking at each other and all that could've been in place...
Charlotte, her husband Tom has MND

Tension in the home was exacerbated by mundane aspects of caring that in many cases could have been easily avoided if aids to daily living had been supplied early. In an early interview Patsy said:

And I find that difficult the fact that... and I know that you get ratty with me when I suggest you should do it so I can't help. I do shut up and don't say it but then every now and then again I say it.
Patsy

In a later interview Patsy felt that her family were under significant pressure. While Patsy understood why her husband had been reluctant to learn about the PEG tube and how to use it, her daughters were upset at what they perceived to be a lack of care:

I have an issue with my daughters at the moment .. they are getting angry at him and I am having to keep the peace ... they feel that he is not pulling his weight ... I think he just shuts down emotionally. When I am feeling OK I can stand back and see the process with him but when I am feeling down I can't ... it is a hard one ...
Patsy

MND can place an enormous pressure on marriages. Sarah and Alexander have been married for under 5 years and have fought hard to keep in a double bed (the OT has tried to move Sarah into

a single hospital bed to help the carers). Sarah spoke about how sometimes she feels her relationship is no longer a romantic one:

> *I think I am just grieving for my relationship. Every time I spoke [to the SCN] about my husband … because I was worried about him and I would cry … and when I cry I can't talk because of my voice …"*
> *Sarah*

Sarah was one of the few who talked so openly about the impact of MND on her close relationships and so it's difficult to say if her experience is representative. Our data does suggest that coping with progressing symptoms places stress on people, and on relationships.

Conclusions & Recommendations

The data presented in this chapter have shown how MND can affect family relationships and how it can impact on people's lives, on their roles, their independence and on their social life. It affects people's dignity, their mental and emotional wellbeing and their physical health. These changes occur both for those with MND and their partner and the wider family. Whilst clearly some of the demands placed on families are the result of living with MND and are hard to either ameliorate or mitigate against others are more social in origin and can, with better planning be resolved. Much of the stress that is placed on the family is the result of not trusting the care provided by outside agencies. This means that people often take on the majority of the care themselves and are reluctant to use outside support. Access to good, trusted and safe care support would help many people, and again here control is central. People want support but they want it provided in a way that allows them to continue with their own family life and to stay in control of their home. If people had access to good support some of the stresses of dealing with MND could be alleviated. Our data would suggest that for this to happen people would need access to a small number of outside carers that they could build up a good relationship with and that could work not just with the person with MND but with the whole family. Such an approach would optimise the family's sense of control and the person with MND's dignity. This best practice

model did not exist in reality for any of our participants and so families had to take on a large share of the care and support work. Two key recommendations emerged from this section:

1. Better training and help in the delivery of care and access to information on both what services are available and what tasks those services can perform would help. People need advice on tasks such as manual handling and how to deal with people who are choking. There needs to be some recognition that some of the roles that families may be expected to take on are sometime not readily accepted. In particular roles that people might feel are more medical.
2. Families are under enormous pressure and very few were accessing counselling or psychological support and perhaps this is another area that MND Scotland could look at further developing.

ACCESS TO INFORMATION

Introduction

This chapter focuses on how and where participants accessed information about MND, and social and health care services. Many of the quotes in this chapter have been used elsewhere to reflect specifically on how supportive different professionals have been. Here the quotes will be used to consider what information people with MND have, what kinds of information participants want but are not getting hold of, and the consequence of delays in getting good information.

The chapter will begin by considering what information people knew about MND at the point of diagnosis to give an idea of how little they know. The chapter also explores how participants used the internet, particularly MND Scotland's website and other sources of information allied to MND Scotland, such as the SCN and support groups. A section on professionals generally as sources of information follows and finally this chapter considers how families cope with limited information, and also reflects on the expertise, often untapped, that families have and the information they can provide to professionals, many of whom may only have a limited understanding of MND.

Findings

Knowledge about MND

The diagnosis chapter covered in some detail the shock of getting a diagnosis of MND and the ensuing call for information about what having the condition means, and how it will progress. Around two thirds of participants did not know someone personally who had had MND but many were aware of public figures with MND. These often helped to communicate to families what MND is:

Sheila: I knew of David Niven and that was fine but then …

Craig: And then the doctor mentioned Stephen Hawking.

Sheila: And that was really depressing.

Craig: that was like a blow to the … you see, it's terrible to say, it's not a prejudice. It's a reaction when you see this guy sitting in a wheelchair with his head supported with a frame and it's "Oh God! No!"

Sheila, and her husband Craig

Many of the families we talked to mentioned famous people who had been diagnosed with MND and this was reinforced by the consultant at the time of diagnosis as an efficient way of sharing an understanding of what MND is. By constructing an image of MND based on figures like Stephen Hawking, participants formed an idea of what the trajectory of their MND might be for them and what living with MND might be like. Whilst this may at first sight appear to be a useful way of explaining the condition for many it established a stark and very depressing first impression of MND. This was not challenged or clarified by consultants. This strategy works in the sense that the participants could quickly get an idea of the severity of the condition but it does present a risk that the person could fixate on the end of life.

Where people already knew somebody with MND or had some prior knowledge much the same picture emerged and people initially became very fixated on the terminal nature of the condition:

JF: When you got the diagnosis … had you heard of it before?

Richard: Yes. We had known somebody who died of it actually.

JF: So you knew when they saw what it was, you had an idea?

Edith: I thought I was going to die … we came out of the hospital and went in the car and we both cried … and I said "I am going to die …" but that was probably 5 years ago now.

Edith and her husband Richard.

The emphasis for many people appears to be the worst case scenario and people focus on the end of life and on the very substantial impairment that can occur with MND. Our data would suggest that little was done at the time of getting the diagnosis to either counter this or to help families assimilate this news meaningfully into their lives. For example, providing information that allowed participants to reflect on whether, or for how long they should continue working, or how the prognosis could impact on travel would have deflected focus from end of life. If families are provided with meaningful information on how to continue their lives within the limitations or constraints of MND there is the possibility that this tendency could be countered. Here the emphasis could be on optimising opportunities to work, or optimising opportunities to retire, and allowing space to consider the next steps for the family, for example, they may need advice about benefits. The focus should not be on dying with MND, but on living with MND. None of the families we spoke to felt supported in renegotiating their perspective from an emphasis on dying to living.

There is a danger here that if families are not given 'useful' information at the point of diagnosis, they will seek it elsewhere. After being told the following by their Consultant:

> *[the consultant] said, "it is a disease that nobody can give you an accurate prognosis*
> *because there are so many different ways that it affects [you]*
> *Doris, her husband Daniel has MND*

Doris and Daniel borrowed books from the library, as Doris remarked, '*that answers a lot of questions'*. The book referred to gave a very medical overview of MND and further reinforced the 'tragedy' related to MND. Similar tendencies were reported by those who used the internet, as we discuss in the next section.

Using the Internet

The internet was, for many of those we spoke to, one of their primary sources of information. The internet should be a valuable source of information about MND, about the equipment and

other aids to daily living that are available and about support services and benefit entitlement. It has the advantage of allowing people to access information at their own pace. It is, however, uncontrolled and people were often made aware of the future consequences of having MND in harsh and uncompromising detail. Many of our participants described how they had been advised not to look at the internet.

> Rose: We went onto the internet which you shouldn't do … and my daughters … they immediately went on and looked [MND] up.
> Robert: Well one of them was a nurse; she wouldn't have had to do that
> Rose: No, she didn't really have to look it up. She knew the nuts and bolts of it … but the other one was just horrified.
> Rose and her husband Robert

Information available on the internet is easily accessible and despite warnings many families were tempted into researching for themselves. The websites they accessed tended to focus on clinical and medical issues and on the definitions of MND. This again serves to reinforce the negative aspects of life with MND and fails to engage positively with MND.

It was precisely because of this that some informants such as Patsy purposefully avoided the internet so that they did not get trapped into focusing on symptoms and disease progression which could impact negatively on their well-being:

> I think [the internet] can affect the way you look at things and sometimes if I am down I can say "what is the point?" As I'm sure lots of people do, but I try hard to stay out of that place.
> Patsy

Around half of the families we spoke to had used MND Scotland's website as a source of information and the Fact Sheets that could be downloaded were generally considered useful. Not everyone had access to these though because they did not have access to a computer, or to a

printer, and this was a particular source of frustration. Accessing the website through publicly available computers, such as in libraries, was also for many not possible because of access issues. Sharon for example described how she generally felt isolated and uninformed. Some people had forgotten about the fact sheets, even though they may have been told about them at an earlier stage and alerting everyone to their existence would be useful. As noted in earlier chapters, participants may need reminding about the availability of fact sheets as well as other information sources as their condition progresses. This is particularly important as access to the fact sheets could change.

> *When you read the website it said that you could download the information fact sheet which while I was at work I was doing at work and then I contacted the MND [Scotland] just a couple of weeks ago to ask for another couple of fact sheets which I hadn't managed to download [because no longer working] but I wanted to look at and I mentioned the information pack and the girl said "did you not get one?" and I said, "well, no." And it wasn't a big deal but it was if you like, another aspect or feature that had been neglected or not followed through.*
> *Craig, his wife Sheila has MND*

The fact sheets and MND Scotland's information pack are for many a key link to the organisation. Together they help to build up and then maintain a strong bond between those with MND and the organisation. In this case receiving the information pack earlier, (rather than 6 months post-diagnosis) would have helped build this family's relationship with MND Scotland. There is a case to be made for early access to this book, as the family above wanted. Continuous easy access to the fact sheets can help families feel supported. Craig and his wife Sheila were also cautious about using the fact sheets. For example, the fact sheet on physiotherapy was encouraging and the couple sought this service but it was fully 12 months before they got their first appointment with a physiotherapist, which may have significantly impacted on how useful the service was.

MND Scotland's fact sheet was correct, the problem is that whilst the fact sheets present a best practice model this often does not reflect the availability of services. Perhaps MND Scotland could consider the production of a further leaflet full of advice on how best to access services. Whilst there is some general information on this topic and people are encouraged to use their Specialist Care Nurse if they are having trouble of this sort, it would help participants to not only know about the usefulness of the service, but also advice on how to access it.

Whilst many people were complimentary about the MND Scotland website, there were a few families who felt that it was geared more towards fundraising than providing families with information about MND:

> *We went on the MND website but frankly it seemed to us to be very much a "Let's have a bake to raise money"*
> *Andrew, his wife Jennifer has MND*

A similar point was made in relation to the MND run Support Groups (discussed in the next section of this chapter). Many families were involved in raising funds for MND Scotland and they needed access to this information, but some families (albeit only three of those we spoke to) felt that the website did not meet their needs in terms of information because they were 'put off' by requests for funds or information on fund raising activities.

MND Support Groups

The MND Scotland website was not the only strategy used to help inform families in Scotland with MND. Support groups exist throughout Scotland, though are generally located in larger cities. Four families were recruited to participate in this study through the support groups and generally these families found them useful and continue to attend. In some areas the support groups are run with the support of people who have lost someone with MND. There is a culture of these groups being 'dominated' by past carers and this was a theme that came from a number of participants that they were not always able to meet other people with MND.

Less than one quarter of families had attended a support group though almost all knew of them. Of those that had never attended, around half felt unable to get to their nearest group (many of these people lived over 30 miles away from their closest one) and the other half did not think they would benefit. Sharon went to her local group only to find the venue was inaccessible and that the accessible toilet was up a flight of stairs: this venue is no longer used, but it put Sharon off from attending further groups. Others who had attended had been put off by seeing someone with more progressed MND:

> *I think that's probably what bothers you, you see other people and it doesn't necessarily mean you're going to go down that track … but you automatically feel for the person … especially newly diagnosed people. They see people that are a long way down the track and it's really emotional for them.*
> *Sarah*

It was clear from those that talked about the support groups that they were emotional places. Alison had attended her group regularly and had been upset by people she had made friends with, getting too ill to attend.

The groups were also important sources of information. Julie and James were put off their group because of the extensive buffet lunch provided which Julie could not eat because of the way MND has progressed with her. She felt the emphasis on food was insensitive. However, they had found it a useful source of information:

> *James: Yeah I wouldn't say it was dreadful but I mean they were useful because of the lecturer that was... eh... that was given. But there's nothing worse than going into a room full of people that have...some of which, some of who know each other and others that don't.*
> *JF: So are you going to go back?*
> *Julie: No.*

James: No I wouldn't... I wouldn't knock it for the sake of individuals that are doing it
because it's the right reason and the rest of it... and there will be a purpose to it and folk
will get a benefit to it but...
Julie and her husband James

Alison had enjoyed presentations on research, had made friends with other regular attendees and had been able to request a presentation on benefits. A discussion with someone at a support group had put her off getting a PEG tube fitted:

JF: Have you spoken to anyone about getting a PEG tube fitted?
No. Don't mention that. I will never have it. I will die before I have it …
JF: Really?
Yes. I don't want it. It scares me.
JF: oh, really? The using it, or the getting it put in?
All of it. I know somebody who has had it. And he said it was too soon.
Alison.

Alison participated in four interviews and her attitude against the PEG remained consistent. In her last interview she expanded on the above:

I know a man who goes to the support group meeting. He was talked into it … and he
hated it.
Alison

This can be perceived in two ways, that Alison is placing too much credence in one person's experience of getting the PEG. Or alternatively that Alison is able to challenge the advice given by medical professionals because she has information that she finds more salient and accessible. The informal networks that she built up at the support group gave her control over the decision whether to have a PEG tube, or not.

MND Specialist Care Nurses

The other major source of information that people turned to was the Specialist Care Nurses (SCN). Whilst some of what we discuss here has already been mentioned in that earlier chapter, here there is closer focus on their role in meeting people's information needs and in providing adequate and timely information to participants.

The SCN was valued for their medical expertise and their medical knowledge in addition to the support they provided as a key-worker. The SCN was also trusted and many families spoke of how they felt that they could be critical of other health care professionals and services and feel that the SCN would always take their side:

> *[The SCN] came in from a different level and I felt at ease with her and comfortable that she listened and she gave back from a practical knowledge base.*
> *Patsy*

They were a valued information source both in terms of their knowledge about the condition but also, in many cases, those with MND and their families felt that the SCN knew them and therefore they did not have to continuously explain their position or their needs and wants. They SCN provided them with information from a position of knowledge both of the condition and also, importantly, in terms of their own social circumstances. They were often more trusted than other professionals.

Information from Other Professionals

The reality of living with MND is that families deal with a number of different professionals and often they require information from them. Many families for example relied on professionals for information about equipment and services. They needed to know not only what was available but what would most suit their particular needs and how it could be adapted to meet their own personal requirements, and relied on service providers to offer this information as early as possible. Information about equipment was an area that many people felt was lacking. The

following quote refers to equipment obtained from the social worker that can manually move a wheelchair up or down stairs.

> *So, all these things of which we had no knowledge or limited knowledge, and very little experience and I think it's fair to say that the policy of the Social Worker is to do everything they can to enable people to remaining living in their own homes. The 'Scalamobil' unfortunately was delivered when the snow started at the beginning of December so we never really got any use of it … There was a reluctance on my part really to … I didn't feel confident going down stairs.*
> *Craig, his wife Sheila has MND*

The family appreciated this approach as it had the potential to enable them to continue to live in their own home. However they had no knowledge of how to best use the equipment provided, information that should have been provided by their social worker. In this case (though this example mirrors reports by two other families) the scalamobil arrived at a time where heavy snow placed an interval between the training (in how to use the equipment) and the actual use, and this interval contributed to Craig feeling unable to use the equipment. If the social worker had been more proactive in their dealing with the family, for example visiting them after it was delivered and checking that it was working as intended then this problem might have been rectified.   The family had no idea whether any other solutions were available so that when the 'scalamobil' failed to work for them, they stopped going outside rather than refer themselves back to the social worker.

Access to information is a two way street. Families needed good information to make informed decisions and professionals needed access to information to ensure the equipment was in fact fit for purpose. Indeed, for many of the families that we spoke to, an informed professional was a 'good' professional.

> *Doris: The doctor [GP] couldn't be nicer.*
> *Daniel: He is brilliant.*

Doris: We have a good doctor.

JF: That is great. And do they know much about MND or are they just, taking it as it comes …?

Doris: I think that he has dealt with somebody that had MND before, our doctor, eh? He seems a bit genned up.

Daniel: Aye, genned up.

Daniel, and his wife Doris.

Not only is having information important, but communicating this well to the families was valued. Best practice examples include professionals working together to inform families.

Certainly the arrangement for the feeding tube, the PEG operation, of all procedures went quite quickly and smoothly. So, and that's down to the MND nurse, the dietician at the [hospital] and the gastro nurse. We had an interview with them so that they could explain what was involved.

Craig, his wife Shelia has MND.

Best practice was not however generally experienced by the families that we spoke to. Many were confused about who to speak to, and did not have strong trusting relationships with professionals:

I'm always getting shifted round. I never know who to speak to. The [SCNs] are part time so I never get hold of them when I need them. And as I get worse, I have different needs.

Sharon

Professionals are a necessary and valued source of information about services, equipment and MND. Professionals were also integral to providing training on how to use the equipment that they provided and in the next section we will review examples of where this was missing.

Professionals Giving Information on How to Provide Care

As the condition progressed, around a third of families found themselves using equipment like the PEG tubes or ventilation systems. All these required training. Five families spoke in some depth about how scared they were to use equipment, equipment that they associated with medical professionals. Their lack of confidence with the PEG tube meant that some people with MND became dehydrated or had significant weight loss because key information on their use had not been passed on from the professionals to the families. The following example comes from Nicola describing how her husband had been sent home just before the weekend following a procedure to insert a PEG tube, but without the correct food.

> *So it was Monday afternoon before eh, [expert from food supplement company] he was able to get the formula feed and everything else ... water bottles ... and he spent an hour with us to understand how this works. We were absolutely exhausted trying to take it all in. So what I remember is the beep, beep, beep of the pump at the end of the cycle ... it was 5 days without the formula feed ... yes, so 5 days without food.*
> *Nicola, her husband Matthew has MND*

This was a distressing episode for Nicola to recall, and she blamed herself for not having the confidence to use the feed and equipment herself. She had understandably felt intimidated by the medical equipment and was scared of causing her husband damage. A similar story was told by Daniel and Doris:

> *And then we were meant to get home help coming in to clean his PEG and everything. We never got nothing. I had to do it myself. We were told that there would be district nurses coming in and the hospital were meant to inform the [GP]. By that time [that a nurse finally came out] I knew what to do anyway... I'd read up on it and they had shown me once at the hospital and I just done it myself and I have done it myself ever since.*
> *Doris, her husband Daniel has MND*

As with Nicola and Matthew, Doris had been given inadequate training to use the PEG. She eventually used a book about MND that gave a vague guide to using a PEG, to replace promised services. The dietician who had visited before the PEG was fitted had told Doris to contact an outreach nursing team two weeks post-procedure to 'turn' the PEG.

> *So I phoned the dietician up a the [outreach] team when it was time, after the fourteen days, to push the PEG in and turn it so that the skin doesn't turn round ... well, I didn't have a clue what I was doing and I thought "is it maybe too soon ...?" I didn't know ... and then I phoned up for someone to come out and show me and our dietician was off, so they had to send out another nurse from [another Hospital] to come and show me what to do ... because I didn't want to do it too soon ...*
> *Doris, her husband Daniel has MND*

In a case such as this, where the dietician knows that in two weeks her services are required; arrangements should have been made for a home visit. This is particularly true if the professional knows that they will be on annual leave, so that another member of the team can step in.

This section will now return to a point made by Craig that professionals may need to use the families to access information about MND.

Information From Families

In order to get the most appropriate services or equipment from professionals, they need to have a clear idea of what MND is and how it impacts on individuals and families. Not all professionals had this (as noted in the Medical and Social Care chapters). In these circumstances, a best practice model might be to work more in partnership with families, but there was evidence from most families that this was not happening:

But I think with the OT .... I don't' think she has the concept of what a Motor Neurone's patient actually goes through ... it's more elderly people [that the OT works with]. And I think that she struggles with that.

JF: So she has never really talked to you about MND or what it means ...

No.

Rose

Here a professional is not delivering the right kinds of support and it is perceived as being unhelpful due to their ignorance about what MND is. There is a need for professionals, who may only see one case of MND in their careers to work closely with families to define the barriers that they face and negotiate the best solution.

Understanding MND is not just about appreciating how symptoms impact on the individual but also understanding progression. Many families felt that they got equipment early enough to use it but there were examples of equipment coming too late.

Drop foot they call it, so there are orthotic aids available to help minimise the effect of that and that was another issue which I think it would be fair to say we were disappointed and irritated by the time involved in this ... getting it provided. I think what happened was because it took so long getting it provided, that the opportunity to wear them had to be pushed into the past.

Graham, his wife Susan has MND

Better knowledge of MND may have meant that the professional would have acted quicker and the equipment may have arrived before it was rendered useless. A lack of awareness meant that some professionals did not have 'future proofing' in mind, and it was often the families that had to think in this way.

> *My* approach *at that stage very much was that we need to plan ahead … tell me what the*
> *next step is going to be and what is going to be the next problem, I need to get the*
> *facilities in place.*
> *Andrew, his wife Jennifer has MND*

Andrew had expected meetings with the neurological consultant to help him prepare for the future:

> *I remember coming away thinking "well, what did we get out of that?"*
> *JF: it wasn't what you needed?*
> *It wasn't what we needed. We needed advice, help … what is next? What is going to*
> *happen?*
> *Andrew, his wife Jennifer has MND*

In this kind of situation, families found it difficult to ask questions, aware that they had limited time, and not sure which question would yield a useful response. Where families felt that they were not getting informed advice or support, they were often forced to find solutions for themselves.

> *But my daughter came up with an idea to get a roll of foam and to just shove it under*
> *your bum so that you can't slide under the sheet – I think that might actually work.*
> *Robert, his wife Rose has MND*

Other families talked about moulding packing material into handles to help them control their knives and forks (because their OT could not source something similar) or using coat hangers to help them do up buttons (rather than have carers come in to help them dress). Therefore the families did not just possess knowledge about MND, or about the barriers that they were facing they also had expertise in how to overcome barriers. This information could usefully be shared with other families, (these solutions could be useful to a whole range of people, not just those with MND). As Sarah reflected:

Somebody somewhere has all the answers Jo, they are not sharing it with anyone else … you go to your doctor and they have never had a patient with MND … the OT might have only ever seen one other person with it. So they, have only got little tiny snippets of knowledge. Somebody somewhere has all the answers … and that database needs to be able to be accessed by everyone.
Sarah

The 'somebody' in Sarah's quotes is in fact all the people with MND and their families. This resource of knowledge and information could be accessed by others if a forum existed on MND Scotland's website.

Families had to become innovative and industrious, especially where necessary equipment had not been provided. On the one hand this innovation shows the willingness to overcome barriers and be active in tackling the limitations of MND; on the other it also represents a failing on the part of professionals.

This is not just about professionals respecting the expertise of their clients. Some families ended up finding solutions for themselves but then they had to fund the solution and not the Health Board or Local Authority:

Craig: I have a niece who is a speech therapist and she had been talking to a friend, a colleague of hers who has had dealings with MND patients where she lives south of the border, and she had said that the iPad has a range of apps which are suitable as communication aids and our daughter-in-law had just an iPhone so she downloaded one of these apps to show its capability. And we went out and we bought the iPad and Sheila downloaded the apps and that has proved a real asset.
Sheila: I use it for communication.

Craig: it has been great from that point of view. Email, Sheila has re-established contact with cousins, former colleagues, and this in turn has led to people coming to visit and it really has been a great tool.
Sheila, and her husband Craig

The iPad was a great solution to Sheila; mainly because she had early access to it and was able to practice using it to aid communication well in advance of 'needing' it. Further it helped her avoid isolation from family and friends. It seems a shame though that they paid for this themselves given the equipment became vital.

There may be an assumption by professionals that they are working with 'lay-people' (which doesn't excuse treating professionals as ignorant) but many of our participants or their families worked in health and social services. Elena was able to get home support for her Dad because she knew what he was entitled to.

I worked in the NHS for a while before I got my current job, and I knew that you could get a podiatrist to come to your home and cut your toe nails: so I got that service for my Dad. I knew that I could get the home dentist out to him, things like that.
Elena, her Dad Patrick had MND

Conclusions & Recommendations

People with MND and their families are sources of useful information and perhaps MND Scotland could create a space for a discussion forum on their websites where people with MND can communicate with one another and share ideas of what works for them or does not or ask advice as to how a particular problem can be resolved. It could also potentially help to tackle some of the isolation by creating an online community and form a space where informal sources of information and experience could be developed. It would allow MND Scotland to acknowledge people with MND as experts in their own conditions/equipment – it could also be a useful tool for health and social care professionals. Six key recommendations emerged:

1. More comprehensive information about what living with MND might be like would help people understand and assimilate their diagnosis. MND Scotland could help people achieve a balance of positively living with MND whilst also appreciating the limitations and consequences of end of life.

2. A thorough review of what people want from the MND Scotland website would be useful.

3. Families require information around living with MND very quickly after diagnosis as this may shift the focus, for them, from dying to living.

4. Using the internet was both a risky activity and a fulfilling one for participants. On the one hand it gave people a sense of control over making sense of MND on the other, they were faced with information that they didn't always understand and that was frightening. Here, it would be useful for MND Scotland to provide people with information on good, informative and meaningful internet resources that will help people further understand what MND is, the impact of diagnosis and what is available to them.

5. Participants felt they would have benefitted from frequent reminders as to the availability of both the MND fact sheets and the information pack. Some participants received these late or not at all and so this is an area where MND Scotland could ensure that participants were always aware of the existence of these materials so as to better support them gaining appropriate information.

6. MND Scotland could consider providing a space on their website (by way of an online forum) that allowed families to communicate with one another, to talk about what works and what doesn't and share useful information and support. This is a useful part of the support groups; however an online community might bolster this.

END OF LIFE

Introduction

This chapter explores the preparations that participants made and their reflections on end of life. This theme was not part of the planned project initiated by MND Scotland and so not all participants were asked about their preparations or thoughts on this matter. We were also sensitive to the potential upset this theme might cause and we waited for participants to raise the topic rather than for us to introduce it, in many interviews, end of life was not raised by the participants at all whilst in others even where it was raised it was sometimes difficult to interrogate sensitively. This chapter is shorter than the others and it features many fewer voices. It is included because of its importance and because of the potential it offers in terms of recommendations. It must be remembered that the ideas presented here are only tentative and need further research.

It deals with a very emotive topic that some may find uncomfortable to consider. During the research a recurring theme from some participants was that information, particularly about how the condition will progress, was resisted. If as a reader, this has been your approach to living with MND then this chapter may not make comfortable reading. However, the recommendations are less emotive and may be of interest, you can find these on pages 178/9 at the end of the chapter.

The chapter begins by discussing how people face the end of life and then moves on to discuss decisions around end of life such as 'do not resuscitate' orders and living wills. The experience of palliative care is also explored in this chapter. During the course of the interviews several participants spoke about 'Dignitas' and how they would like access to such a service and to be in control of when and where end of life occurred. The chapter will end by considering how some participants have rationalized their end of life in ways that have enabled them to focus more on life in the present.

Findings

Facing End of Life

Perhaps not surprisingly, many of the discussions around end of life materialized in the later interviews with participants. Maybe this is because the condition had progressed and people had had time to reflect further on their future or maybe a relationship of trust had been built up with the researcher. There was a great deal of heterogeneity and a complexity of feelings about end of life. Our data suggests three key ways people looked at end of life. There were those who resisted any mention of the concept, there were those who were more accepting that having MND would hasten their end of life and a third group who were more philosophical and sanguine of their mortality. The data suggests, and based in part on being able to return to talk to families, that these views changed over time and they were not fixed. The different ways people approach end of life mean that SCNs and other health and social care workers have to adopt an individual approach to the topic and also to be aware that people with MND may not share the views of their family and that their views may change, as demonstrated by the following quote from Patsy. Here she describes her first contact from her SCN:

> *Monday I had a call from [SCN] but I didn't want to speak to her. Everybody is different and when she rang... I have now met her but when she rang she said about coming to see me and I said "I don't want to see you." And she said "I will send literature." And I said "I don't want anything." I said "I'm not taking it on board". Not meaning that I am ignoring it or it's wrong just that that's how I want to deal with it. "I don't want it to take over." And she said "Well, everybody's like that at first." And I felt pretty upset about that. I wanted to say "I'm not everybody. Neither is anyone else... I don't want to be lumped together... I didn't want to be taken out of life and shoved in the corner with a diagnosis ... I mean don't get me wrong, I respect her and I know she's a lovely person but she seemed to want to get into action what things I might want if I was ill and what things your family will need to know... "And, we don't want you brought in here as an*

emergency." And I thought "Just a minute, I can't..." It was just too much.
Patsy

Patsy's views at the time represent those of the first group, people who were more resistant to the thought of their death. Typically they were more likely to be people who had only recently been diagnosed. Not only were this group more resistant to end of life, they were also more likely to also invest in a discourse of hope. Following his diagnosis where the consultant gave him a prognosis of living for a further 5 months, Sean said:

What a buffoon he was to say I'd be dead in 5 months.
JF: Oh, so it was whole end of life? He said you would be dead in 5 months?
I said to myself "I know I'll be here in 5 months..."
Sean

The focus for these people was on survival and on fighting the condition. They were very resistant to any discussion of death and it was almost as if to acknowledge death would in some way speed up its arrival.

The second group were those who had accepted that they were going to die and were aware that for them MND was the most likely cause of their death. Whilst they were fatalistic in that they knew it was going to happen, death still held a fear. For example the following quote came from an interview with a couple, the husband has MND and his wife said:

MND is similar to being on death row without reprieve or date of execution… yes it is, yes...eh...well, of course, that goes for a lot of...eh...illnesses as well.
JF: Yeah. But that's interesting because you were talking about having really a strong emotional state but you're realistic about where you are as well.
Oh yes.
Nicola, her husband Matthew has MND

End of life for this group is on the horizon but this does not mean that they have stopped living in the present or that they cannot enjoy life. It's difficult to establish because the number of participants that informed this chapter are relatively small, but it seems that participants moved into this second phase once they had got over the 'shock' of diagnosis. Again, it also seems to be the case that it was easier to move into this second phase if progression was slow or if the participant reached a 'symptom plateau'.

The third group we could identify looked on death much more philosophically. They tended in the main to be those who had slower progression and were more able to see the reality of their future without it feeling as distressing as perhaps the other groups:

> *Death doesn't frighten me at all in the least. I really don't. Nobody wants to go –*
> *don't get me wrong, but it doesn't hold any fear for me. This disease frightens the...*
> *rather than the end result. I'd rather the end result came quick.*
> *Marie*

This participant felt that currently she had very good quality of life, and it was not death per se that frightened her but the process of dying. It is MND and the way that it may kill her that she was most scared of. In the interview she was clear that if she could avoid this phase then she would. Being dead is easy; it is the dying that is difficult.

Participants who had survived with MND the longest usually had managed to adapt to their diagnosis. They had made a kind of peace with it.

> *He just said, "You know, I am ready to go. I know that I'm not going to get out of this"*
> *Betty, her husband David had MND*

In a few cases their fear of end of life diminished as they lost others within their family or friendship circles.

The thing is Jo I have never attended so many funerals of folk that were sorry for me and that thought that I had a tough ending... And I keep going to their funerals... and in that way I feel quite at ease – I know that the chances are that if it is not one thing that it is another... and there are guys out there that are very fit and nothing wrong with them - could be dead tomorrow... And that's the way things are.
Simon

So here, end of life is seen more philosophically as something that everyone must face. Having MND may not mean that you will be the next to die. In fact some talked about 'fighting' MND in terms of being able to die of something else:

And God forgive me I used to say to Stephen [husband] "Do you know Stephen it would be better if I had cancer..." and I know I don't mean ... but there is always a certain element of, for people with cancer ... because there is treatments and there is this and there is that. It's everywhere...
Marie

Where people reached this stage of acceptance of death other family members sometimes construed it as giving up. This view can upset other family members and in the case of Marie, her husband Stephen argued that she was giving up hope and that there should always be hope, a point echoed by Bridget:

My husband kept saying that he wanted to die because he knew the outcome which I found very difficult in the middle of the night when he would say this.
Bridget, her husband Tim had MND

Most of these types of quotes came from interviews with people who had survived with MND for some time, at least beyond 2 years and so many of the other families involved in this research may not have had enough time to process their distress at the diagnosis sufficiently to reach a peaceful place. Further, these quotes came from older people (although not old) and were more

likely to have friends and peers (without MND) also reach end of life during the period of their illness. The younger families we spoke to did not talk about end of life in peaceful terms, nor were they able to take any philosophical positives from their situation.

End of Life and the SCN

SCNs and other professionals working with people with MND have to take account of these differences in approaches to end of life and tailor their approach accordingly. For the first group raising the topic of end of life or of asking if the person had any requests such as the use of Do Not Attempt Resuscitate (DNR) notice or other form of forward planning are likely to be met with resistance:

> *Some of the first questions that [the SCN] asked "Do you want to be resuscitated?" and about the peg tube. Now, bearing in mind that she asked me these questions the week after I was diagnosed. Really, it was like putting a nail in a coffin. You were still reeling from the diagnosis and it is like somebody is saying to you "Well, you have got a month to live."*
> *Patsy*

This does not however mean that SCNs should avoid the topic all together. As we discuss in the diagnosis chapter many people felt that a lack of a clear prognosis was something that stayed with them and not knowing how the condition would progress affected their sense of well-being. This can create difficulties and tensions, problems that many were aware of:

> *That must be a terribly difficult part of their job, it's a huge balancing act between not wanting to alarm you unnecessarily but at the same time trying to warn you … Full marks to [SCN], I thought she was realistic and honest.*
> *Peter, his wife Karen had MND*

End of life is something that should be raised as an issue early on in the process. When it is not, for whatever reason this can also create difficulties. For example we were told of occasions where this had happened and then when twelve months post diagnosis an SCN tried to raise the topic of a living will this created panic with people thinking that the SCN had made a judgment on their life expectancy and that their end of life was now imminent.

However as the end of life nears having information about when it may occur can become very important to families. If it is possible to give people a warning sometimes this can be very helpful, allowing families to say goodbye. It is something that families rely on professionals to guide them about but it is we tentatively suggest information that may be sought more by the family members rather than the person with MND.

> *And if only I had been brave enough to say [to the consultant] "well, what are the chances of him being here in a month's time? Or three weeks time?" I just wish I had been braver – I don't think it was up to him to tell me, but I should have asked. And, I just think I should've been a bit more knowledgeable about reading those signs [of end of life]. I had never come across it before.*
> *Betty, her husband David had MND*

Where families lived far apart, some prior warning of imminent end of life allowed them to travel home. It is difficult on the basis of these data to recommend a best practice strategy. We would suggest that mentioning end of life very early on but within a frame of 'we'll talk about this again later, when you're ready' if that is what people want. This strategy allows participants to avoid the issues early on, but may prevent them feeling alarmed when it is raised at a later date. It is clear however that end of life is something that must be discussed if people with MND and their families are going to get control over the process. There are important decisions that have to be made and people need to make these from an informed basis. It is to a discussion of this that this chapter now turns.

Controlling End of Life

There are many strategies to help form a plan for end of life. For example living wills and 'do not resuscitate orders' (DNR) provide a clear mandate for professionals to follow. In this section we look at some of the issues raised and discuss the role of palliative care and its early use and the use of hospices. We then move on to discuss the views of those who talked about taking even more proactive action around end of life and raised the issue of euthanasia and services like Dignitas.

A living will, and as part of this a DNR had the potential to not only help participants plan their future care, it also allowed them to make their wishes clear to other family members. Some appreciated discussing this with their SCN and family very early on in the process:

> *The other thing that [the SCN] helped us with at an early stage and Karen was always keen on this and that was the living will. And this was something that I would recommend to anybody in that sort of situation but right from the outset, Karen was clear about what treatment she wanted, or what, and probably more importantly, treatment she didn't want. And it was a very specific living will for somebody with her ... so , you know if this happens, treat me and if this happens, don't. And things like the ventilation as a 'no no 'kind of thing.*
> *Peter, his wife Karen had MND*

These issues need to be discussed early so that people can thoroughly discuss their wishes and their fears with family and professionals. This can be a different subject to broach:

> *It is difficult for your family ...it is really difficult to talk to your family about [end of life] ... it is easy for me because I am the one that is dying and I have to come to terms with it. I had to. I don't really have a choice. At [the hospice] somebody talks to you about things like resuscitation and whether or not you want ventilation or intervention at the end when things are bad ... How do you want to die..? Where do you want to die...? And it's like*

Great! I can talk to someone about this who is not going to burst out crying.
Sarah

It does perhaps demonstrate how important it is for families to be aware of living wills and DNR orders, how they work, their limitations and who has control over them. For those that lose their ability to speak, it is crucial that such decisions are made early enough but with some plan for renegotiation should the individual's view change. These sort of early discussions are particularly important for people with bulbar-onset symptoms.

Despite the value of a living will, other participants reflected that getting the will written was a '*nightmare*' because it was such an emotional process. Maggie, whose husband Derek had MND, praised their hospice for helping them consider their wishes and working with them to produce the will.

It may not need to be said, but for many participants, facing end of life was distressing. Using hospices was symbolic of end of life for many participants and for this reason, some people avoided using them. People in the main wanted to die at home:

> *He went to the hospice and that was horrendous. He didn't like it. He, he asked, he*
> *begged and cried when he came home that we didn't take him back to the hospice and*
> *that he wanted to die at home.*
> *JF: And you think that's what it was? The fear of not being able to come out or ...?*
> *I think so.*
> *Elena, her Dad Patrick had MND*

Dying at home was expressed by many as an 'ideal'. In the focus groups particularly where we met with people who had lost a family member who had MND, their parent, partner or sibling dying at home was considered an achievement.

> *We were lucky, he died at home in his own bed and that was the way he always wanted to*

go. He always ... to be, no interference and he was determined that he was never going to
hospital again. "I'm not going there. Don't take me to hospital again".
Betty, her husband David had MND

So for many hospices and hospitals are resisted and this means that the participant's experience of using them, even for short stays where everyone anticipates a return home, is couched in negative terms.

Provision of care and support from the palliative service brought positives for some families. Their expertise in end of life was very welcome, in particular they valued their attitude and the way that they spoke to them, for example:

> *I knew I was going to like [consultant in palliative care] the minute that I saw her at the*
> *door. She was straight [with us]. Tim would ask "how long have I got?" and she said*
> *"have you asked this question before?" ... and I said "you asked that 24 hour doctor last*
> *week" and she said "well what did he say?" "well, he said it's normally one to five years*
> *– average is two" and she just looked straight at Tim and she said "you think in months,*
> *not in years". And that was in May [Tim died in July] ... she was wonderful.*
> *Bridget, her husband Tim had MND*

The '24 hour doctor' was only able to give an accepted time frame that can be found in fact sheets and in books. It is generic, and without any expertise or experience of working with people with MND they can give little useful information. This can leave the family knowing no more than before they asked. In contrast the palliative consultant was not only sensitive in the way that she handled the situation but she was able to be specific. She based her prognosis on Tim's circumstances and was able to use her own clinical expertise and this was valued by the family.

There were a good number of participants for whom hospices and the services they offered were seen positively. One way of encouraging the use of hospices was to use them as a day centre.

This worked particularly well where the hospice's facilities offered provision not available in the home. For example, Rose had a bath once a week at her hospice and her hair cut, both of which energized her. The day-use of the hospice also worked very well for Derek:

> *I went with Derek every Tuesday and we spent a day in the hospice and we had a day programme and it was such a positive place, and it was just great and the idea was that if I needed respite, they would get to know Derek in the day service and they would give him a week's respite.*
> *Maggie, her husband Derek had MND*

Unfortunately the good care and support they received as day-guests did not extend to longer visits because of issues around equipment.

> *Derek was in a reclining wheelchair when he was showered and when he went to the loo he had to be in this chair and it would go over the toilet but the toilets they had weren't compatible. And I said "you know, you must have cancer patients that are going to need a shower chair like this ..." so, they went out and purchased one, but I had to go through that ... They were very helpful but it sort of fell down because the day that he went in for respite I said "where's the alarm system?" Because Derek had no use of his hands and so they went to get it and it wasn't working and they went and got another one and I said "look, I'll go home and get mine" so I was actually very stressed about putting him in for respite ... so I delayed going on holiday.*
> *Maggie, her husband Derek had MND*

Most hospices seem to have been set up to support cancer patients and it seems to have been a fairly recent trend that hospices have extended their services to other people with life-limiting conditions. The following quote from Patsy describes a hospice-like service located in her local hospital.

> *It is a palliative care unit but [my GP] fought hard to get, I suppose neurological people,*

to be able to use this ... I mean she said to me "I will arrange for you to come here
because it is too stressful on a general ward" .... Apparently she had huge opposition ...
people thought it should just be a cancer ... or a palliative care for cancer patients and
this is where I came when I had the chest infection ... and I was very anxious about
coming but it has a relaxed feel in here. I couldn't believe the feeling of calm – it was
palpable.
Patsy

A few families had used palliative care nurses, notably Macmillan nurses and were overwhelming appreciative of their support. Patsy contrasted her Macmillan nurse with the support she received from her SCN:

I have seen the difference with the Macmillan nurse ... I feel [my SCN] is full of
platitudes. She will say the right, the professional thing ... but really in this situation most
people are in a vulnerable position and you want somebody to talk to ... I want someone
to talk to me from a friendly point of view and not a textbook. Maybe that's unreasonable,
but that is what I want.
JF: and then the Macmillan nurse is better in giving you that?
Yeah.
Patsy

Here again control was critically important to the participants and their families who spoke about end of life. Some participants were keen to talk about Dignitas and the following quotes, all in support of some form of UK based euthanasia represent the views of eight families. No family expressed outright opposition to legalized euthanasia, but as no other families explicitly discussed this we cannot estimate overall how much support/opposition there actually is.

In the following quote, Marie recalls a conversation that she had with her SCN.

Because I said to [the SCN] "Oh [SCN], I'm starting to get a bit panicky" and I keep
thinking see when the things [the body] all start to go and you're feared of getting buried
alive and then.... I've been saying "Take me to Dignitas..." I'm angry that we don't have
that option here. I really am.... He [Stephen, husband] doesn't want it to be an option
but I just.... you know, I think that would be a great option....
Marie

Not only does this show the extent of the bond between Maggie and her SCN, it also shows that what scares some of those with MND the most are the month's immediately preceding end of life. The idea of being 'buried alive' recurred in this phase of the interview and the perceived lack of control of the body was exacerbated by the fear of lack of control they would have in general. In a very rational way, the opportunity to be totally in control of end of life was seen by this participant and some others as a positive. It would allow her to avoid the final and most difficult stages of the condition. It is also important to point out here that in this case, and in many others, the views were very much those of the person with MND. Talk of euthanasia or Dignitas often made family members uncomfortable.

All those who expressed a view on the topic were adamant that a UK based provision for people to control when their life ended was necessary. The following quote comes from a focus group:

Peter: I've now got very, very strong views on whatever you want to call it 'assisted
suicide' or 'Margo MacDonald's ...' you know? And having been through what we've
been through, people should be allowed much more control, themselves of not prolonging
this when that's what they want to do.
Betty: Oh, I agree with you. I agree with you.
Peter, his wife Karen had MND and Betty, her husband David had MND

People with MND did not just want to avoid the physical pain and discomfort associated with dying with MND they also felt that they could lessen the impact that their death could have on the rest of the family:

I don't want to have to put me through it, put him through it.... The grandchildren? I
mean just now it's alright.... You know? Gran's got bad legs? But I keep thinking "I
don't want my kids to see me further down the line...." If I get to that stage I do not want
my grandkids.... because they won't be able to understand Jo... They'll no be able to
understand…
Marie

People had talked this over with family members and some had gone so far as to ask relatives if they would be prepared to accompany them to Dignitas. The fear of prosecution was sufficient to prevent some families from pursuing the use of Dignitas:

At one point my Dad did ask us to take him to Dignitas … He begged me to take him and
I just says to him "We'll get prosecuted!" and he was trying to tell me he had money …
Elena, her Dad Patrick had MND

We are not endorsing the use of euthanasia and neither are we suggesting that a service such as Dignitas should be set up in the UK. Very few participants raised it as an issue or spoke about this. In fact only four people with MND and four people from the focus groups specifically mentioned voluntary euthanasia though all of these were very strongly in favour of it. The families who supported a service like Dignitas based in the UK argued that it would deliver ultimate control over end of life, make it affordable, and could more easily include family members. As discussed at the opening of this chapter, we could not canvass opinion on whether a service like Dignitas was supported, we relied on this issue appearing spontaneously, and so the views expressed in the quotes may not be representative.

Conclusions & Recommendations

Planning for end of life is necessary for families to feel in control. People with MND may need different support than family members. As people will need time and space to discuss their

wishes with family and friends, end of life should be raised fairly soon after diagnosis. Four key recommendations emerged from this section.

1. Continued and regular reminders/offering of counselling support to individuals and their families would help participants.
2. Supporting families in knowing what their options are and collaborating with them in controlling how they want to approach end of life
3. If SCNs have struggled to manage home visits (particularly where people live in rural areas) they could coordinate support with a local hospice or Macmillan nurse to bridge the gap and help avoid families being left with too little information.
4. Providing families, where possible, with illness trajectories so that they are able to make decisions about how to live their lives and when to consider palliative services would also aid decision making.

DISCUSSION AND CONCLUSIONS

The overall aim of this project was to explore the experiences of those who are diagnosed with MND and their families from their own perspective. In the data that we have presented above we have explored how people with MND experience the diagnostic procedure, their feelings about the specialist care nurse (SCN), their perceptions on health and social care, exploring what works and what does not and how MND affects the family. We also examined people's experiences in terms of accessing information and their thoughts on end of life and the role of palliative care. In this section we bring together the key overarching themes that transcend across the various sections we have presented in the findings as we consider the broader context of what it is like to live with MND in Scotland.

The research approach we adopted has enabled a rich, deep and complex data set and pulling together the various themes we have presented has allowed us to provide an accurate, detailed and nuanced picture of what it is like to live with MND. We have been able to not only present a very full range of experiences but have also through the use of longitudinal data been able to contextualise these experiences. By focussing on the views of those with the condition, their family and from bereaved family members we have been able to evaluate and present their own views on the services they receive and the impact MND is having or has had on their lives. Given the size and the breadth of our sample and the strength of the data we have presented and the robustness of the analysis we have a great deal of confidence in our findings and our recommendations.

There are three key points that we wish to make in this section; the first relates to the Clinical Standards for Neurological Health Services, the second to the issue of choice, autonomy and control and the third to the organisation of services.

Following the publication of the Clinical Standards for Neurological Health Services (NHS=QIS 2009) the delivery of care and support has undergone a radical overhaul in recent years in Scotland. There are now key guidelines which should ensure the quality of services to people with MND and that service delivery to people with MND is uniform and not prone to variation by area. Most of our data were collected after the publication of the standards and many of the

recommendations contained in that report should have been implemented. Whilst we cannot be certain that this is the case our findings would suggest that there is still some way to go before these standards achieve their full impact and before their effects can be measured. This is particularly the case for Standard 13, *Ongoing Management of Motor Neurone Disease.*

This Standard sets out the criteria for the provision of health and social care for those living with MND and states that people should be offered the widest range of services at all stages.   It includes the need for regular care needs assessments for both those with MND and their carer/partner, support and assessment for eating, breathing and communication and the naming of an individual with responsibility for overall coordination of care. We found little evidence to suggest that there were regular assessments and there exists a substantial number of people for whom there is no named individual with overall responsibility for care.

Our findings would suggest that if these standards were to be met then many of the concerns raised in the data section on social care and on the family could be alleviated. Currently much of the care and support for people with MND is provided by people's partners or family and it is through their efforts that many of the care needs that are un-assessed and consequently not provided for are met. Whilst many family members are willingly taking on this role it is placing them under a great deal of stress. Better support and better needs assessment of people's requirements for care would greatly help both those with MND and their family.

That this Standard has not received the same level of attention as the other two more medically dominated Standards is perhaps not surprising given the overall emphasis on the importance of medicine traditionally found in the delivery of care to people with MND.   In a recent presentation on the Standards and their implementation Standards 11 and 12 were seen as the most important with Standard 13 described as 'waffle' (Davenport *no date*). The evidence presented here counter this claim. People we spoke to did not ask for better or more hospital based services or more or better access to therapists. Their main concerns revolved around poor provision of social care and social support in terms of both quantity and quality. For the current model of care to work family members must be available and willing and able to provide care at home and for this to continue people must be provided with support.

This moves us on to the second key point we wish to make. Many of the services provided for people with MND operate on paternalistic model of professional decision making and this is particularly the case for hospital based healthcare. Most of the medical services for people with MND are still delivered through a hospital based service and a lack of choice, involvement in decision making and control over such services was a major critique. Whilst this critique was most strongly applied to the medical services it ran over all the themes that we have highlighted in this report. People wanted to be involved in the design and delivery of the services they receive and where this happened people tended to speak much more favourably about that service. The SCN was a case in point and this service was seen by many as offering a person centred service which provided people with the appropriate support services and the necessary information for them to make informed decisions about their health care. Where this service worked the role of the SCN was appreciated and she was seen as somebody who could improve information and coordination between services. People valued the knowledge that help and support was readily available, that they could draw on it as they wished and that it was delivered in a manner of their choosing. On this basis we would argue that not only should more resources be put in place to extend and increase the service offered by SCNs but also that their mode of working be replicated by others involved in the care of people with MND.

The final point we wish to make revolves around access to information. Providing people with good, reliable and accurate information is one way of helping them feel in control of their situation and this relates as much to information about MND as it does to information about care and support. People wanted to know more about self care and self management and how they could take more control in their own health care and people were often left without knowing some of the basic information that they expected to know. For example knowledge about moving and handling, simple emergency medical procedures and advice on how to use various health technologies were often lacking. Providing this sort of information would make people feel much more comfortable. Further while some people reported good examples of care and support overall many people were confused about the different care systems and the different funding streams that were in place and for many there appeared to be a bewildering array of services and people. Ensuring that people were aware of all the services they could access would greatly help here.

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APPENDIX 1: Research Questions

1. Perceptions and meanings
   - How was the diagnosis of MND experienced? What did it mean when they were told they had MND?
   - Where did they get their information on MND from?
   - How are the symptoms of MND experienced by those with the disease and their families?
   - How does having MND change over time?
   - How does having MND impact on their and their families' sense of wellbeing, perceptions and experiences? Does this change over time and if so how?
   - How are the various institutions that work with people with MND perceived ? What are their thoughts on the health and social care services, MND Scotland and other sectors?

2. Participation
   - How has MND impacted on people's ability to participate in society? How has MND impacted on their relationships, friendships and their ability to participate in social events?
   - How involved are people with MND and their families in decisions about their treatment, their future plans and other decisions about their lives?
   - How can participation be improved?

3. Expertise
   - Who do they see as the experts in MND?
   - What are their thoughts on social and health care professionals?
   - How do people with MND and their families feel about the people who make decisions about their lives?
   - How do health and social care professionals feel about their riole as experts?

4. Resources
   - What resources were available to people with MND and their families, and how do they employ them?
   - How have those who work with them approached the design and delivery of services?
   - How is information on resources accessed?

5. Institutional factors
   - How have the various institutions worked together and how are the care pathways for people with MND experienced?
   - How have they experienced the care they have received from the various institutions and how have they negotiated their way through these various institutions? How have the various health boards, local authority services and voluntary sector organisations worked together? How have people with MND experienced the transition between

the sectors?
- What are their thoughts on the role of the voluntary sector and how is the care support received through this sector experienced?
- What has been the nature of their interactions between these institutions and how has that impacted on their experiences?

6. Best Practice
   - What examples of best practice can those with MND and their families identify?
   - What has worked best and why?
   - What services would they like to see improved?
   - What do service providers think works best and why?

APPENDIX 2: Table of Participants

Gender of person with MND	If carer interviewed – nature of relationship	Age range of person with MND	Geographical location	Other people interviewed
Male	Wife	70-80	Rural	
Male	Wife	60-70	Small town	
Female	Husband	60-70	Small town	
Female	Husband	50-60	Rural	
Male	Wife	60-70	Rural	
Male		60-70	Small town	
Female	Husband	60-70	Urban	
Female	Husband	70-80	Small town	
Female		60-70	Small town	
Female	Husband	60-70	Small town	
Female	Husband	70-80	Small town	
Female	Husband	60-70	Small town	
Female	Husband	40-50	Rural	
Male		70-80	Rural	
Male	Wife	60-70	Small town	
Female	Husband	60-70	Rural	
Male		60-70	Urban	
Male	Wife	60-70	Small town	
Male	Wife	40-50	Small town	
Female	Wife	50-60	Small town	

Male	Wife	60-70	Small town	
Female	Husband	60-70	Rural	Daughter
Female	Husband	60-70	Small town	
Male	Wife	40-50	Small town	Uncle
Female	Husband	70-80	Urban	
Male	Wife	30-40	Urban	
Female	Husband	40-50	Small town	
Male	Wife	40-50	Small town	
Female	Husband	50-60	Rural	
Male	Husband	30-40	Rural	
Male	Wife	50-60	Rural	
Male		60-70	Rural	
Male		30-40	Urban	
Female	Husband	30-40	Urban	
Male		70-80	Small town	
Female	Husband	60	Small town	Daughter
Male		60	Small town	
Female	Husband	70-80	Rural	Daughter
Female	Husband	70-80	Small town	
Male	Wife	60-70	Rural	

APPENDIX 3: Interview Schedule for Participants attending focus groups.

These questions are to be used as a guide, not all questions will be relevant and the interviewer is free to explore any issues that emerge from answers given by the participants that relate to health and social care services even if a question does not exist on this schedule.

Interviewer introduces themselves and the study.
Check that the participants have read the plain language statement and understood the need to consent to the research. The consent form itself does not get signed until the end of the interview so that participants are fully aware of what they are consenting to.

1. So thinking about the person with MND that you cared for, could we start by listing the health or social care services that have been accessed over the span of their illness?
    a. Cue health, social, community and MND Scotland funded services if necessary
[take each service noted in turn and proceed until all services are covered]

2. At what stage of the illness was ** service accessed?
3. How did you come to access the service?
    a. Cue referred, self-sought, word of mouth …
4. Did you access this service throughout the illness?
5. Did you have contact with a key person at ** service during this time?
6. Did the service meet your needs?
    a. If so, how did they do this?
    b. If not, what could they have done differently?
7. Did the service ever operate outside its remit by offering you support that it did not traditionally cover?
8. Thinking about when you first accessed this service, would it have been useful to have accessed the service earlier? Or later?
9. Are you still in touch with the service?
    a. If not, would you still find it useful to be?
    b. If so, has this continuity been useful?

[when all services have been exhausted move on to Q.10]
10. Thinking about your experiences caring for someone close with MND. Do you think there needs were totally met by the services available?
11. If you could change something about the services available, what would it be?
    a. Cue timeliness, number of hours offered, continuity of professionals, service continuing beyond the death of the adult with MND, a more accessible venue …
12. And now thinking about your experiences accessing services to support you during the time you cared for someone close to you with MND. Were your needs totally met by the services available?
13. If you could change something about the services available, what would it be?
    a. Cue timeliness, number of hours offered, continuity of professionals, service continuing beyond the death of the adult with MND, a more accessible venue …

14. Are there any services that you did not access (either for yourself or for the person you cared for) that would have been useful?
    a. Why didn't you access this service?
15. Thinking of the services run by MND Scotland, what kind of support did they provide?
16. Did the MND Care Workers ever work outside their remit?
17. The MND Care Workers are funded through MND Scotland, should the service they provide by funded through public money (i.e. through the health board or social services)?
18. Did you ever ask an MND Care Worker to provide a service for you, that you knew you could access elsewhere, just because you had a better relationship with that care worker?
    a. If so, what service was this?

Focus Group ends with a full de-brief. The focus of the research will again be stated. Participants will be reminded of the dissemination plans for the project as stated in the Plain Language Document. Participants will be reminded of their right to withdraw from the study and asked to complete consent forms.

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APPENDIX 4: Plain Language Statements for All Participants.

Information Sheet for Adults with Motor Neurone Disease

An evaluation of care pathways available to adults with, and the families or carers of adults with motor neurone disease (MND).

1. Study title and Researcher Details

This research is being carried out by researchers working in the School of Social and Political Science at the University of Glasgow in collaboration with MND Scotland.

The project is called 'An evaluation of care pathways available to adults with, and the families or carers of adults with motor neurone disease'. It aims to explore what care strategies and services are in place for adults with MND and their families and to find out what those with the condition and their families and relatives think about the services and the way they are delivered. The project will look at social and health care services.

The research study is being carried out by two members of staff. Dr. Joanna Ferrie is working full time on this project and will be conducting all the focus groups. Professor Nick Watson will be doing some analysis and is supervising the project. Any enquiries about the project can be passed to Jo by phone (0141 330 3175) or by email (Jo.Ferrie@glasgow.ac.uk).

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Feel free to discuss it with others if you wish and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

2. What is the purpose of the study?

The study will take place between October 2010 and November 2012. It has two phases. The first phase involves running group interviews with family members or carers who have supported someone with MND. This will help us understand what social and health care services exist, which ones are useful, and in what ways could they be improved. This information will be used by MND Scotland to campaign for changes that will impact positively on those who have MND and their families and carers.

We are asking you to participate in the second phase of research running throughout 2011 and 2012. The second phase will follow twenty families over the period of 12 months. The aim is to explore how access to services change as the condition progresses. A primary focus will be on you as the person who has MND and the health, social care and support services that you use. A secondary focus will be on other family members and the support services that they use. Families will be visited up to three times over the 12 months and interviewed individually. In addition, we will interview key professionals that you nominate (you may choose not to nominate anyone), working in support services that you have accessed and found of benefit. Each interview should last around 1 hour, we are happy to meet for less time if this suits you better. Depending on how many of your family members or close friends choose to participate this may involve spending an afternoon with you.

3. Why have I been approached?

With the help of MND Scotland, we are approaching families affected by MND across Scotland. You have been invited to participate because you have motor neurone disease. Your contact details were accessed through MND Scotland. To protect your identity, these details were not passed on to the research team. Rather this information has been sent to you by MND Scotland. The research team will only know of your identity if you wish to find out more, or agree to participate in the research.

4. Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This means that you are free to withdraw even after you have completed the interviews (if this is the case then all you have said will be erased).

This research will focus entirely on the health and social care services that you have accessed because of MND.

A decision to not participate will not, and can not affect your services in any way. MND Scotland will not notify us of any potential participants. They will get in touch with you directly. MND Scotland will be contacting ALL eligible families in Scotland. You will only be known to us if you ask for more information or agree to participate. If you choose to participate and then change your mind, then you are free to withdraw. We will not inform MND Scotland of who has agreed or who has declined to participate and for this reason your decision will not impact on your relationship with the MND Scotland in any way.

5. What will happen if I take part?

If you agree to participate, we will contact you to arrange a first meeting in your home. If you would prefer to meet outside your home, this can also be arranged. This may be a chance to discuss the project more fully so that you can make an informed choice about whether you wish to participate. You may prefer more time after this to make a decision about whether you want to take part. Alternatively you may feel ready to complete your first interview. It will be useful to speak to those closest to you at this meeting. After each meeting, another meeting will be arranged with your agreement. A total of three meetings will take place with your agreement.

As well as being interviewed, you are welcome to keep a diary. This may record the time and dates of key meetings with health or social care professionals. It may be a more personal story about how you are dealing with the impact of MND. You are not required to keep a diary, but if you do, and if you agree, we

would be keen to take a look at this. We can use the diary, as we would use the interviews, to gain a greater sense of your experience. As with the interviews, if we choose to quote from the diary we will anonymise all information so that no one can identify you. You may wish to keep a diary, not to show us but for you to use, to prompt you about key moments over the past few months. Similarly you may want to take photographs to also help your memory. We will not publish any photograph without your permission.

We hope you will agree to the interview being taped. This will allow us to make sure that we don't misrepresent what you have said. Only the researchers will gain access to this recording, it will be kept in a locked office and will be destroyed 2 years after the research has ended. There will be no label on the recording that would enable someone to identify it as yours.

6. Will my taking part in this study be kept confidential?

All information, which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a pseudonym and any information about you will have your name and address removed so that you cannot be recognised from it. Your interview audio-tape will be kept in a password protected computer, and any transcript of the interview will be kept in a locked filing cabinet.

7. What will happen to the results of the research study?

Once the entire project is complete, we will publish, with MND Scotland, a full project report that will be available online to download. We also plan to present at conferences organised by MND Scotland. You will be notified about the details of this. We also hope to publish in academic journals and present at conferences at the end of the 2-year project. All participants will be anonymised, so if we use your quote, no one will be able to identify you from it.

8. Who is organising and funding the research?

This research is funded and supported by MND Scotland.

9. Who has reviewed the study?

This project has been reviewed by the School of Social and Political Science's Ethics Committee at the University of Glasgow.

10. Contact for Further Information

Any comments, questions or complaints can be forwarded to Professor Nick Watson who is supervising this project at Nick.Watson@glasgow.ac.uk. You can reach Joanna, the main researcher working on this project at 0141 330 3175 or at Jo.Ferrie@glasgow.ac.uk

If you have any concerns regarding the conduct of the research project then you can contact the Research Officer of Sociology Dr. Andy Smith Andrew.Smith.2@glasgow.ac.uk

Thank you for taking the time to read this. Please keep this form safe for future reference. If you decided to participate, then thank you so much for agreeing to this.

Information Sheet for the Families of an Adult with Motor Neurone Disease

An evaluation of care pathways available to adults with, and the families or carers of adults with motor neurone disease (MND).

1. Study title and Researcher Details

This research is being carried out by researchers working in the School of Social and Political Science at the University of Glasgow in collaboration with MND Scotland.

The project is called 'An evaluation of care pathways available to adults with, and the families or carers of adults with motor neurone disease'. It aims to explore what care strategies and services are in place for adults with MND and their families and to find out what those with the condition and their families and relatives think about the services and the way they are delivered. The project will look at social and health care services.

The research study is being carried out by two members of staff. Dr. Joanna Ferrie is working full time on this project and will be conducting all the focus groups. Professor Nick Watson will be doing some analysis and is supervising the project. Any enquiries about the project can be passed to Jo by phone (0141 330 3175) or by email (Jo.Ferrie@glasgow.ac.uk).

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Feel free to discuss it with others if you wish and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

2. What is the purpose of the study?

The study will take place between October 2010 and November 2012. It has two phases. The first phase involves running group interviews with family members or carers who have supported someone with MND. This will help us understand what social and health care services exist, which ones are useful, and in what ways could they be improved. This information will be used by MND Scotland to campaign for changes that will impact positively on those who have MND and their families and carers.

We are asking you to participate in the second phase of research running throughout 2011 and 2012. The second phase will follow twenty families over the period of 12 months. The aim is to explore how access to services change as the condition progresses. A primary focus will be on the person in your family or circle of friends who has MND and the health, social care and support services that they use. A secondary focus will be on friends or family members and the support services that they use. We would like to talk to you about your experience of supporting someone with MND and to gain your thoughts about how well services work. Families will be visited up to three times over the 12 months and interviewed individually. Each interview should last around 1 hour, we are happy to meet for less time if this suits you better.

3. Why have I been approached?

With the help of MND Scotland, we are approaching families affected by MND across Scotland. Someone close to you has been invited to participate because they have motor neurone disease and they have suggested that we also invite you to participate.

4. Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This means that you are free to withdraw even after you have completed the interviews (if this is the case then all you have said will be erased).

This research will focus entirely on the health and social care services that someone close to you has accessed because of MND.

A decision to not participate will not, and can not affect your services, or the services of the person with MND in any way. MND Scotland has contacted ALL eligible families in Scotland. You will only be known to us if you ask for more information or agree to participate. If you choose to participate and then change your mind, then you are free to withdraw. We will not inform MND Scotland of who has agreed or who has declined to participate and for this reason your decision will not impact on your relationship with MND Scotland in any way.

5. What will happen if I take part?

If you agree to participate, we will contact you to arrange a first meeting in your home. If you would prefer to meet outside your home, this can also be arranged. This may be a chance to discuss the project more fully so that you can make an informed choice about whether you wish to participate. You may prefer more time after this to make a decision about whether you want to take part. Alternatively you may feel ready to complete your first interview. After each meeting, another meeting will be arranged with your agreement. A total of three meetings will take place with your agreement.

As well as being interviewed, you are welcome to keep a diary. This may record the time and dates of key meetings with health or social care professionals. It may be a more personal story about how you are dealing with the impact of MND. You are not required to keep a diary, but if you do, and if you agree, we would be keen to take a look at this. We can use the diary, as we would use the interviews, to gain a greater sense of your experience. As with the interviews, if we choose to quote from the diary we will anonymise all information so that no one can identify you. You may wish to keep a diary, not to show us but for you to use, to prompt you about key moments over the past few months. Similarly you may want to take photographs to also help your memory. We will not publish any photograph without your permission.

We hope you will agree to the interview being taped. This will allow us to make sure that we don't misrepresent what you have said. Only the researchers will gain access to this recording, it will be kept in a locked office and will be destroyed 2 years after the research has ended. There will be no label on the recording that would enable someone to identify it as yours.

6. Will my taking part in this study be kept confidential?

All information, which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a pseudonym and any information about you will have your name and address removed so that you cannot be recognised from it. Your interview audio-tape will be kept in a password protected computer, and any transcript of the interview will be kept in a locked filing cabinet.

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