

“There is an urgent need to relieve the financial burden of MND...”

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**MND COSTS:  
EXPLORING THE  
FINANCIAL IMPACT  
OF MOTOR NEURONE  
DISEASE**

Simone Vibert

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Simone Vibert

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Any errors and omissions remain my own.

Simone Vibert

May 2017

# Executive summary

This report explores a hidden side of a devastating terminal illness: the financial impact of motor neurone disease (MND).

MND is a fatal neurological condition that attacks nerves in the brain and spinal cord, resulting in weakness and wasting in the muscles. It leads to a loss of mobility in the limbs and difficulties with speech, swallowing and breathing. MND is relatively rare; evidence suggests that up to 5,000 people in the UK are living with it at any one time. However, the exact number affected is unknown as MND is very difficult to diagnose. It is a progressive condition, with symptoms worsening over time. The rate of progression varies, but is frequently very rapid – a third of people die within a year of diagnosis and more than half die within two years. Nevertheless some people with MND live much longer. People living with MND do not know how long they will live for, making it particularly difficult to anticipate future support needs and plan ahead.

In recent years there has been a growing awareness of the financial impact of health conditions. In 2010 Demos published *Counting the Cost*, which drew attention to the conversion disadvantage – the disadvantage faced by disabled people as a result of having to spend more than non-disabled people to achieve the same standard of living.<sup>1</sup> In 2014 Scope found that disabled people spend on average £550 each month in disability-related costs, such as food and drink for special diets, the cost of taxis to get to work or appointments in areas lacking accessible public transport, and increased insurance costs.<sup>2</sup> Similar research by Macmillan has shown that cancer patients spend an average of £570 each month on costs related to their illness.<sup>3</sup>

The purpose of this research was to establish the financial impact of MND on those living with the condition and their families. Before this project there was no research in

the UK that presented a comprehensive picture on this subject, but in this report we demonstrate that the particular nature of MND creates a significant financial burden on those living with the disease and their families:

- The severity of MND leads to a high degree of disablement, leaving a person unable to move, communicate or breathe unaided. As the disease progresses, someone living with MND requires extensive care, support, equipment and adaptations, with large costs attached to many of these.
- The extensive care and support needs generated by MND can place an enormous burden on family members, friends and loved ones providing unpaid care.
- As MND is fatal individuals want to make the most of the time they have left, leading some to make decisions which have challenging financial implications. Sometimes these decisions are made on impulse, in a state of panic, or in haste.
- MND often progresses rapidly, and services can be slow to respond to the individual's needs.
- Because the speed and pattern of the disease's progression is unpredictable, financial planning is challenging. People with MND do not know what they will need to budget for at what point. Some live much longer than they initially expected to on diagnosis.
- As MND is relatively rare, non-specialist services involved in supporting people with MND and their families are frequently unfamiliar with the disease. This can lead to individuals and families being poorly advised or receiving inadequate assistance, with potentially significant consequences for their finances.

## **Methodology**

Research for this project comprised:

- a review of existing research
- a survey of people living with MND, which received 333 responses

- a survey of family members bereaved as a result of MND, which received 441 responses
- one-to-one diary-led interviews with eight people living with MND and two family members of people living with MND
- a policy workshop attended by representatives from the third sector, health and social care sectors and academia.

## Key findings

### *The overall financial impact of MND*

People with MND and their families face a significant financial burden as a result of the disease: 82 per cent of people with MND describe the financial impact of the disease as ‘very negative’ or ‘moderately negative’. Working age people and people with children living at home appear to be particularly vulnerable to negative financial consequences. The financial effect of MND on those living with the condition becomes more difficult to manage as the disease progresses, as a person’s care, support and equipment needs increase.

### *The costs of MND*

People living with MND incur three types of extra costs:

- one-off costs – the biggest are typically housing adaptations, and adapting or buying a vehicle
- regular costs – the biggest are typically care costs, and paying for extra assistance around the home (eg with cleaning, washing, gardening)
- enhanced costs – costs that people with MND would have likely incurred if they did not have MND, but might be greater as a result of having the disease; the biggest are typically energy bills and for travel insurance.

On average, people with MND and their families spend £609 in regular costs and £133 in enhanced costs every four weeks as a direct result of the disease. This is the equivalent of £9,645 every year. On top of that, they must

also manage one-off costs, which typically amount to at least £2,175 over the duration of the disease.

*Lost income from changes to working patterns*

As well as having additional costs, people with MND must also manage the impact of living on a reduced income when they are unable to work. As MND is a progressive, terminal illness, people living with the disease must inevitably leave the workforce at some point. In the vast majority of cases, the benefits received from working age, income replacement benefits (eg Employment and Support Allowance) nowhere near compensate for the loss of a salary.

Some people with MND are pressured into leaving their jobs before they want to, and while they are still able to work. Others are not properly supported to remain in work, despite the Equality Act 2010 requiring employers to make reasonable adjustments for disabled people.

Another significant loss of household income results from family members leaving work in order to provide unpaid care. Four-fifths of people with MND who live at home with care report that their main carer is their partner or spouse, with the majority receiving at least 35 hours of care from that person.

*The adequacy of support*

Many people with MND are not receiving the support they need to meet their needs. Nearly half consider the financial support they have received to be inadequate. Only 1 in 5 consider it to be adequate.

Disabled Living Allowance (DLA) and its replacement, Personal Independence Payment (PIP), go some way to helping people cope with the extra costs of MND. However, in many cases people do not receive these benefits as they do not know about them, or cannot navigate the application and assessment processes. Furthermore, the extra costs benefit designed for those aged 65 or over, Attendance Allowance, is not as generous as PIP and DLA, which is a source of frustration for many older people with MND (who cannot make a new claim for PIP or DLA because of their age).

Crucially, the maximum amounts that can be received annually on these benefits (£7,337.20 for PIP and DLA, and £4,321.20 for Attendance Allowance) do not cover the average extra costs faced by someone with MND.

Carer's Allowance, awarded to people who provide unpaid care to someone for over 35 hours per week and paid at a weekly rate of £62.70, is frequently criticised by people with MND and their families as a 'pittance', failing to recognise the valuable contribution made by unpaid carers.

### *The financial impact of MND after bereavement*

Decisions made during the illness often have a long-term impact on families after bereavement. Only 19 per cent of bereaved family members say that MND had taken no toll on their finances; 6 in 10 said it had taken a toll to a great extent or to some extent.

Over two-thirds of families use their savings to cope with the extra costs of MND during the illness, and sometimes little is left for after bereavement. Furthermore, family members who leave work to provide unpaid care for their loved one frequently face barriers in re-entering work, such as gaps in their CV, their skills not being up to date, or poor physical and mental health. Over three-quarters of people bereaved as a result of the disease said that MND had taken a toll on their physical health to a great or to some extent. For mental health, the figure rises to 84 per cent.

Less than a third of people bereaved by MND consider the support they received after bereavement to be adequate. High quality counselling is very valuable to those who can access it, but many cannot. There is also a lack of awareness around bereavement benefits, and recent changes to these benefits risk reducing the support available to many people bereaved as a result of MND – particularly working age parents.

## Recommendations

On the basis of our research, we make the following seven recommendations to minimise the financial impact of MND on people living with the condition and their families:

- *Recommendation 1:* Health and social care professionals must ensure that people living with MND are signposted to financial advice and support as soon as possible after diagnosis.
- *Recommendation 2:* On learning that an employee has MND, employers should facilitate a planning process in which both parties agree on the steps to be taken at key stages in the disease's progression, enabling the employee to continue in work for as long as they want and feel able to, and to make a smooth transition out of work when necessary.
- *Recommendation 3:* Third sector organisations that provide financial support to people living with MND should review how much funding is used to pay for assistance around the home, and consider redirecting funds to this particular cost.
- *Recommendation 4:* Local authorities and the Northern Ireland Housing Executive should consider topping up disabled facilities grants for people with rapidly progressing conditions, including MND.
- *Recommendation 5:* The Department of Health and relevant health commissioning organisations in each of the devolved nations must act to ensure that people with MND are made aware of NHS Continuing Healthcare in the early stages of the disease.
- *Recommendation 6:* The Department for Work and Pensions (DWP) must reconsider strengthening the assistance available to widowed parents through Bereavement Support Payment.
- *Recommendation 7:* The government should extend funding for 'returnships' to bereaved carers looking to re-enter employment.

# 1 Introduction

Being diagnosed with a progressive, terminal health condition is one of the biggest challenges anyone can face in life. It is difficult to comprehend the mixture of emotions that someone might experience on diagnosis – from shock to anger, sadness to denial. As time goes by and their condition progresses, however long that takes, an individual must cope with the fact that their future plans will be cut short and that their loved ones will be left behind without them. They have to manage the day-to-day impact of their condition on what they can do and how they feel.

Under such difficult circumstances, the last thing anyone wants to do is worry about money. Yet in recent years there has been a growing body of evidence showing that serious health conditions can have significant financial implications for individuals and their families, resulting in added stress and worry at an already challenging time.

This report reveals a hidden side of a devastating terminal illness: the financial impact of MND on those living with the condition and their families.

## **What is MND?<sup>4</sup>**

MND is a fatal neurological disease that attacks cells and nerves in the brain and spinal cord, resulting in weakness and wasting in the muscles. This leads to loss of mobility in the limbs, and difficulties with speech, swallowing and breathing.

MND is a relatively rare disease. Evidence suggests that up to 5,000 people in the UK are living with it at any one time. However, the exact number affected is unknown as MND is very difficult to diagnose, with no specific test available – other possible conditions have to be eliminated, by which time a person's MND might have progressed. Therefore, the number of people living with the disease might be underestimated.

Adults of any age can be affected by MND, but it is less common in people under the age of 40. Onset of the disease usually occurs between the ages of 50 and 70. Most cases are not hereditary, but 5–10 per cent are.

MND is often a rapidly progressing condition, with symptoms worsening over time. The pattern of progression varies from person to person, so individuals cannot know which parts of their body will be affected in which order. Some people living with MND have symptoms that others never experience. For most of them, MND is severely life shortening, although the prognosis is highly variable and difficult to predict. A third of people living with MND die within a year of diagnosis, and more than half die within two years of diagnosis. Nevertheless some people with MND live much longer. People living with MND do not know how long they will live for, making it particularly difficult to anticipate future support and financial needs and plan ahead.

Central government, the NHS, social services and the third sector provide a range of support for people with MND and their families, but the level they are entitled to or can access varies greatly. Good quality care and support for people with MND requires a high degree of collaboration and coordination between professionals working in different sectors and services, so the health and social care needs of many people with MND are managed through a clinic-based, specialist multidisciplinary team.<sup>5</sup> The National Institute for Health and Care Excellence (NICE) recommendations on treatment, care and support for people living MND include one on financial assistance and advice.<sup>6</sup>

Since 1990 the MND Association has developed MND care centres and care networks across England, Wales and Northern Ireland, which facilitate coordinated care, providing a single point of contact for people with MND, access to a multidisciplinary team and strong links with community services.<sup>7</sup>

## Existing evidence of the financial impact of MND

There has been some research into the financial impact of chronic illness on people living with adverse health conditions in general, and those living with certain specific health conditions such as cancer, but very little research into the financial impact of MND on those living with MND and their families.

### Previous work on the financial impact of health conditions

Demos first looked at the financial impact of adverse health conditions in 2010 in *Counting the Cost*. The research drew attention to the ‘conversion disadvantage’ – the disadvantage faced by disabled people as a result of having to spend more than non-disabled people to achieve the same standard of living.<sup>8</sup>

In 2014 Scope published *Priced Out* using data collected by Demos for *Counting the Cost* to estimate the average monthly spend by disabled people on costs directly associated with their condition.<sup>9</sup> The research found that disabled people spent £550 each month on disability-related costs, ranging from food and drink for special diets, the cost of taxis to get to work in areas where there is no accessible public transport, and increased insurance costs. Following publication of *Priced Out*, Scope set up the Extra Costs Commission – a year-long independent inquiry seeking to understand the drivers behind extra costs and to identify ways of reducing them. The Commission has since been highly influential in leading progress on extra costs.<sup>10</sup>

There has also been some work on the financial impact of specific health conditions on patients. In 2013, Macmillan worked with the University of Bristol to estimate the costs of cancer, finding that cancer patients face average additional monthly costs of £570 as a result of their illness.<sup>11</sup> Demos built on this work in *Paying the Price* (2013), which looked further into the drivers behind the costs of cancer and made recommendations to key stakeholder groups aimed at reducing the financial impact of cancer on those with the disease.<sup>12</sup>

### **Previous work on the financial impact of MND**

Research into the financial effects of MND on those living with the condition has been limited. Some international research exists, including a notable economic analysis of MND in Australia by Deloitte Access Economics.<sup>13</sup> However, international research has minimal applicability to the UK as there are variations in the health and social care systems and welfare.

Furthermore, existing research tends to focus on the financial impact of MND to the economy, the state, or health and social care sectors, rather than to the individual with MND and their family. This is the case for the Australian study cited above, and for the MND Association's Year of Care Pathway tool, which lists the care and equipment needs that a person with MND may have over a 12-month period.<sup>14</sup> The latter resource is fit for its intended purpose of helping commissioners to plan and deliver services, but not for calculating the full extent of the financial impact of MND on individual and families.

Where research does focus on the financial impact of MND to individuals, it has concentrated on a single aspect, such as lost income. It has not established a comprehensive view of the total financial impact, taking into account the net effect of MND-specific costs, lost income, welfare benefits and other support, and bereavement.

In short, there is no existing research that:

- is specific to the UK
- considers the financial impact of MND on those with the condition and their family
- presents a comprehensive analysis of the total financial impact of MND on those with the condition and their family.

### **This research**

The purpose of this research is to contribute towards filling the evidence gap presented above – to explore the financial

impact of MND on people living with the condition and their families in the UK.

We aimed to measure the broadest financial impact of MND on those with the condition and their families. First, we did not just consider the impact of MND on individuals living with the disease, but the long-term financial implications for families after bereavement. Second, we wanted to capture indirect as well as direct financial effects. For example, we looked at the health of family carers to explore whether ill health from caring for someone with MND had financial consequences. Third, we considered unmet need – the things that people with MND go without in order to manage their finances. An example of unmet need is when someone goes without heating their home to the temperature they need it to be comfortable, in order to reduce heating costs. Just as high expenditure by a person living with MND is an indicator of a negative financial impact, so is unmet need – although it is more difficult to quantify.

Many of our findings are likely to be relevant to people with not only MND, but also other adverse health conditions or disabilities. However, there are some aspects of the financial impact of MND on those living with the condition which are unique, because of the particular nature of the disease:

- The severity of MND leads to a high degree of disablement, leaving a person unable to move, communicate or breathe unassisted. Someone living with MND requires extensive care, support, equipment and adaptations as the disease progresses, with large costs attached to many of these.
- The extensive care and support needs generated by MND can place an enormous burden on family members, friends and loved ones providing unpaid care.
- As MND is fatal individuals with MND often want to make the most of the time they have left, leading some to make decisions which have challenging financial implications. Sometimes these decisions are made on impulse, in a state of panic, or in haste.
- MND often progresses rapidly, and services can be slow to respond to the individual's needs.

- Because the speed and pattern of the disease's progression is unpredictable, financial planning is challenging. People with MND do not know what they will need to budget for at what point. Some live much longer than they initially expected to on diagnosis.
- As MND is relatively rare, non-specialist services involved in supporting people with MND and their family are frequently unfamiliar with the disease. This can lead to individuals and families being poorly advised or receiving inadequate support, with potentially significant consequences for their finances.

It is particularly important to consider the financial impact of MND on those living with the condition in light of unfolding policy developments. The health and social care systems are in crisis.<sup>15</sup> Real-term budget cuts and increased demand for NHS services can delay diagnosis of MND and result in quicker decline for those living with the condition. The even more extreme funding pressures on social care present a further threat to people with MND, who frequently require support to live safely and comfortably in their own homes.<sup>16</sup> Furthermore, the welfare system continues to undergo rapid change. The implementation of Universal Credit, the recent overhaul of bereavement benefits and plans to review Employment and Support Allowance unveiled in last year's green paper all have implications for people living with MND.<sup>17</sup> Now is the time to reflect on how developments in health, social care and welfare are affecting the lives of people with MND and their families – including their bank balances – and to find solutions to the challenges they face.

## **Methodology**

Research for this project took place between September 2016 and March 2017. It was made up of:

- a review of existing research
- a survey of people living with MND
- a survey of family members bereaved as a result of MND

- one-to-one diary-led interviews
- a policy workshop.

### **Review of existing research**

We reviewed existing research into the financial impact of MND on people in the UK and abroad. We looked for evidence relating to its effect on individuals and families, and how this varies among different groups. As discussed above, there was little existing relevant research.

### **Survey of people living with MND**

We created a survey for people living with MND, which we distributed online and as a paper survey, receiving 333 responses. The survey asked respondents to estimate their own and their family's expenditure on 41 different costs related to MND: 9 one-off costs, 18 regular costs and 14 'enhanced' costs (which someone might have incurred anyway without MND, but which can increase or decrease as a result of having the condition). It also asked questions that enabled us to assess the impact of someone having MND on their income: about changes to working patterns, financial support received by the individual and their family, and the overall financial impact of MND on their lives, and its implications. A sufficient sample size was obtained to obtain results at the 95 per cent confidence level. The technical appendix explains our methodology for analysing responses to this survey.

### **Survey of family members bereaved as a result of MND**

We created a second survey for family members bereaved as a result of MND, which we distributed online, receiving 441 responses. The survey asked respondents to estimate the direct costs they faced on bereavement, and about the financial and non-financial support they received to cope with bereavement. There were further questions asking about the effects of MND on respondents' working patterns, and on their long-term financial, physical and emotional health.

### **One-to-one diary-led interviews**

We recruited eight people living with MND and two family members of people living with MND from across England and Wales to keep a diary for four weeks, detailing the costs they incurred during that time, any support they received to cope with the costs, and their reflections on the impact on their lives. A Demos researcher interviewed each diary keeper once they had completed the diary. We carried out eight interviews in person and two using Skype Instant Messenger and Facebook Messenger with participants who could not speak as a result of MND. We took demographic factors into account during recruitment, enabling us to cover a broad range of ages, regions, household incomes, marital statuses and disease progression points.

Please note that we have changed the names of diary keepers quoted directly in this report to protect their anonymity.

### **Policy workshop**

We convened a policy workshop, bringing together professional experts and stakeholders with an interest in our research to inform our conclusions and recommendations.

### **This report**

This report is structured as follows:

- Chapter 2 presents the overall picture of the financial impact of MND on people living with MND and their families, as the disease progresses. It includes an estimate of the annual costs faced by an average person living with MND.
- Chapters 3–5 look more closely at specific sets of costs: one-off costs (chapter 3), regular costs (chapter 4) and enhanced costs (chapter 5). The most significant costs in each group are explored in depth.
- Chapter 6 presents our findings on income lost from unemployment – from both people living with MND who are unable to work, and family members who give up work to provide unpaid care.

- Chapter 7 assesses the financial support available to people living with MND and their families. It focuses on extra costs benefits (including PIP) and Carer's Allowance.
- Chapter 8 presents our findings on the financial impact on families of bereavement caused by the death of someone who had MND. It investigates the long-term consequences of financial decisions made before bereavement, including decisions around use of savings and work patterns. It also looks at the long-term impact of bereavement on mental and physical health, which can have financial implications, and assesses the quality of bereavement support.
- Finally, Chapter 9 presents our conclusion and recommendations, which aim to reduce the costs faced by people living with MND and family members left behind, improve the support available, and ultimately minimise the financial burden of the disease.

## 2 The financial impact of MND on someone living with the condition

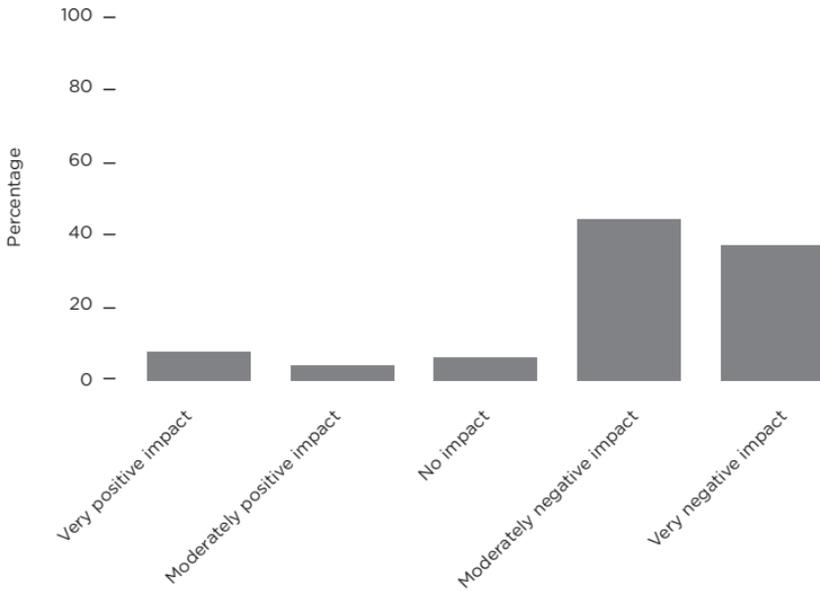
In this chapter we present the overall picture of the financial impact faced by someone living with MND, which primarily results from changes in income (from employment and financial support) and spending on costs resulting from the condition (one-off, regular and enhanced). As the costs of MND are so significant, we present an estimate of them in this chapter before examining them more closely in chapters 3–5. We discuss changes to household income later in the report, in chapters 6 and 7.

Financial impact is not purely a matter of income and expenditure. Financial capability plays a significant role in determining how resilient a household is to changes in its financial circumstances. Families with similar resources and entitlements to support can cope very differently depending on their ability to plan, and the networks they have access to. Throughout this chapter and the rest of the report we consider financial capability in our analysis of who is more resilient to the financial impact of MND on those with the disease, and why.

### **The overall financial impact of living with MND**

Our research showed that individuals living with MND and their families typically face a significant financial burden. In our survey of people living with MND, we asked respondents to describe the financial impact of having MND: 82 per cent reported that the financial impact had been either ‘very negative’ or ‘moderately negative’ (figure 1).

Figure 1 **Survey responses to question asking about the extent of the financial impact on them and their family of having MND**



Certain characteristics appear to make people more vulnerable to a negative financial impact: 92 per cent of survey respondents under the age of 65 reported that they had experienced a very negative or moderately negative financial impact, compared with 72 per cent of people aged 65 or over. People of working age face a number of disadvantages in coping with the financial impact of MND. Perhaps most significantly, younger people tend to be less wealthy – they have lower levels of savings and smaller private pensions to draw on. Working age people who have to leave employment lose their income, while those who remain in work may not be entitled to means-tested support:

*I chose to stay in work (I can't afford to give up work) after my diagnosis, and was not entitled to any financial support from the government or local authorities. People who continue working are penalised.*

Male living with MND, aged 35–44, Northern Ireland

Furthermore, working age people are also more likely to have children living at home (whether dependent or adult), which also appears to increase vulnerability to a negative financial impact. Nearly all (95 per cent) of the respondents to our survey with children living at home reported a very negative or moderately negative impact, compared with 78 per cent of people without children at home. One diary keeper described how she paid for her son to attend a breakfast club at school as it helped him relax, but it was challenging to meet the £10 per week cost of this.

#### **Different experiences of negative financial impact**

Our qualitative work showed that people suffer from different kinds of negative financial impact depending on their circumstances. Younger people and those with children at home were more likely to have difficulty in making ends meet. Day-to-day living expenses present a challenge to this group, and bigger, more significant costs are huge burdens to cope with. Members of this group feel as if they are on a knife edge, worrying about how they will cope when the disease progresses further, or if their circumstances change in any way:

*The thought of all that – the good job going; the money going from the good job – and then the extra income I was able to earn going, then suddenly just going down, and relying on the wife's wages and the state benefit, was very, very stressful. It really was. I was having sleepless nights, worrying about the finances.*

Male living with MND, aged 58, Wales

In contrast, we found a group of more affluent people with MND, typically older and without children at home, who are able to cope financially throughout the duration of the

disease, but who nevertheless report that the disease has an extremely negative financial impact. Members of this group are able to meet their immediate needs by making extensive use of their savings or pensions. Nevertheless, these commitments have a negative financial impact in the long term as they have reduced wealth to pass on to their partner, children or wider family after death. The loss of income from becoming unable to continue to work has a similar effect, requiring individuals to draw on their savings and pensions to meet the costs of living with MND:

*I have been fortunate that I have had some money behind me. I have been able to move from a house to an apartment and to buy a scooter, tri-wheeled walker and odd sided shoes to accommodate my leg brace. I bought my own bespoke leg brace (after trying [the] NHS). I have been able to address issues as they have arisen and am very aware others are not so fortunate.*

Male living with MND, aged 75-84, South West

Some who had worked all their lives felt particularly let down by the system, arguing that they faced an unfair burden:

*If I'd never worked and was on benefits everything would have been funded but we planned for the future and have been penalised and seen our savings eroded!!*

Male living with MND, aged 75-84, South West

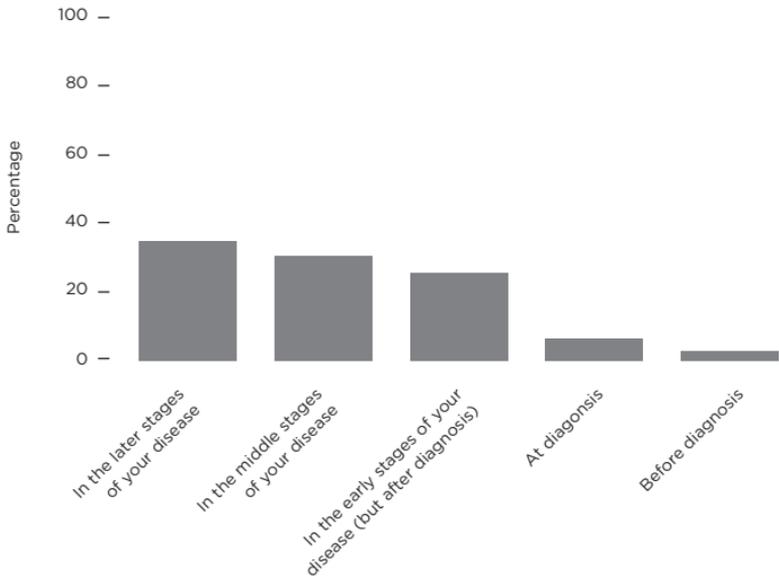
Furthermore, some people who had made extensive use of their savings were worried that their reserves could run out before they died. While MND often progresses very rapidly, it sometimes progresses slowly. Someone living with MND faces the challenge of trying to plan their finances without knowing how long they need to plan for. If someone is forced to use most of their savings early into the disease and then lives for many more years, they could face years of financial struggle, resulting in a very different end of life than might have been envisaged:

*I am worried that when our savings get depleted and I have to apply for help with carers costs, I might have to have less, or poorer, care than I am paying for now.*

Male living with MND, aged 75–84, South West

The possibility of people living with MND depleting their savings is particularly worrying given that the financial impact of living with MND tends to increase over time, as shown in figure 2. As the disease progresses there is greater loss of function, leading to increased costs for care, equipment and more.

Figure 2 **Survey responses to question asking at what point the financial impact of MND was most difficult to manage for the respondent and their family**



### **The unpredictability of MND**

Financial planning for people living with MND and their families is extremely challenging because of the unpredictability of the disease. Although MND often progresses rapidly, it can sometimes progress slowly.

On initial diagnosis people with MND do not know how long they will live for, making it difficult to work out what they can afford and what they are willing to spend on equipment, adaptations, care, leisure and so on.

One of our diary keepers, Gemma, was told on diagnosis that she only had around three months to live, yet when we interviewed her it had been nearly two years since her diagnosis. When she was first diagnosed, Gemma and her partner felt extreme pressure to organise her affairs as quickly as possible, plan for her funeral and write a will at the same time as trying to come to terms with the diagnosis – only to be told at her next appointment that she could live longer than three months. In contrast, some families spend significant amounts on equipment, housing adaptations or a vehicle very shortly before their family member dies. For example, a respondent to our survey of bereaved family members told us that just days before her husband died she had bought a wheelchair-accessible vehicle for nearly £7,000. She sold the car a month later for £4,000.

### **The costs incurred by someone living with MND**

The extra costs associated with MND constitute a significant part of the overall financial impact of living with the disease. In our survey, we asked respondents to estimate their expenditure on 41 cost items separated into three groups:

- one-off costs – including housing adaptations, mobility aids and specialist furniture and clothing
- regular costs – including care costs, further assistance around the home, transport to appointments, and food and drink for special diets
- enhanced costs – costs that respondents might have incurred without MND, but which might be greater as a result of MND, including energy bills, media bills and insurance costs.

Respondents recorded their one-off costs to date, and their regular and enhanced costs over the previous four weeks. Using these responses, we were able to calculate an

approximation of the costs faced by an average person living with MND.

We found that an average person living with MND spends the following on costs directly associated with their condition:

- £7,915 per year in regular costs, or £609 every four weeks
- £1,730 per year in enhanced costs, or £133 every four weeks.

Combining these figures shows that a person with MND typically incurs £9,645 each year in regular and enhanced costs – the equivalent of £742 every four weeks.

Furthermore, on top of regular and enhanced costs people with MND must also pay one-off costs. Respondents to our survey had spent £2,175 to date on one-off costs.

As discussed in the introduction, the progression of MND varies. However, taking a hypothetical case in which someone lives for three years from diagnosis, our figures show that the individual would be likely to incur at least £31,110 in costs – an enormous sum.

### **The three sets of costs**

Our findings show that people living with MND typically spend most on regular costs, although the range in total regular costs is fairly sizeable. Respondents to our survey reported total regular costs ranging from £0 to £3,741 over the previous four weeks.

As we explore in chapter 4, the most significant individual regular cost in our survey was on assistance around the home. This is distinct from care costs, covering assistance with household tasks such as do-it-yourself (DIY) jobs, gardening, painting and decorating. Respondents to our survey had spent on average £216 in the previous four weeks on general assistance around the home (although as discussed in chapter 4, this is likely to be an overestimate). Our qualitative work revealed that this covers a very wide range of different costs incurred by people with MND, including some that might not be anticipated, such as paying extra for hotel rooms with disabled facilities (as they are

typically more expensive than other rooms) and having to take a driving test every six months.

On first glance it might seem that our survey results suggest that people spend the least on one-off costs, but this is not necessarily the case. We asked survey respondents to report the one-off costs they had incurred *to date* – not in the previous four weeks, as regular and enhanced costs were reported. For respondents in the early or middle stages of the disease, it is likely that their expenditure on one-off costs would have increased after the time of the survey. Furthermore, our qualitative evidence suggests that there is a big range in one-off costs, but for methodological reasons outlined in the technical appendix, it is likely that our survey does not capture the largest one-off costs (despite indicating an already significant difference of £7,758 between the highest and lowest total one-off costs experienced). Therefore the one-off costs presented above are conservative estimates of the total one-off costs a person with MND is likely to experience over the entire length of their illness. Nevertheless, it is an important finding that for many people with MND, one-off costs might be a relatively small burden compared with regular costs – particularly as regular costs continue to be incurred throughout the course of the disease.

### **Characteristics of people who typically incur higher costs**

Some groups of people living with MND face significantly higher costs than others, as discussed below.

#### *Households previously on higher incomes before the onset of the disease*

First, households previously on annual incomes of £26,000 or over before the onset of the disease tend to incur significantly greater costs – an average of £1,050 per four weeks in regular and enhanced costs, and £2,730 to date in one-off costs. Households previously on annual incomes below £26,000 incurred average regular and enhanced costs of £630 per four weeks, and average one-off costs of £1,406 to date.

This difference is in some ways unsurprising, as people with MND with higher incomes are entitled to less support

from the state than those with less wealth for key costs such as care and housing adaptations. However, another important reason for this difference is that wealthier people with MND incur costs that less wealthy people with MND do not incur, because the former can afford to spend on them while the latter cannot. A less wealthy person will not experience increased travel insurance costs as a result of MND simply because they cannot afford to travel, and therefore do not need insurance. The fact that people who were previously on relatively low incomes still incur such high costs is worrying.

*People with children living at home (including dependants and adult children)*

There is also a very significant difference between the costs of people with children living at home and people without children at home. Those without children at home faced regular and enhanced costs of £634 per four weeks, and one-off costs of £2,050 to date. This compares with £1,108 in regular and enhanced costs and £2,557 in one-off costs to date for people with children living at home. People with children at home could face a number of extra costs. For example, they may be more inclined to adapt their home rather than move in order to minimise the disruption faced by the children, incurring greater costs in the process. Those with young children may face extra childcare costs or use after-school clubs more frequently.

*Working age people*

Similarly, people below the age of 65 were more likely to have higher costs than those who were older. Working age people incurred an average of £836 every four weeks in regular and enhanced costs, and £2,308 in one-off costs to date. People aged 65 or over incurred average regular and enhanced costs of £644 every four weeks and £2,025 in one-off costs to date. While working age people may continue in employment in the early stages of the disease and therefore have a greater income than some pensioners, this may reduce their entitlement to certain grants and benefits, forcing them

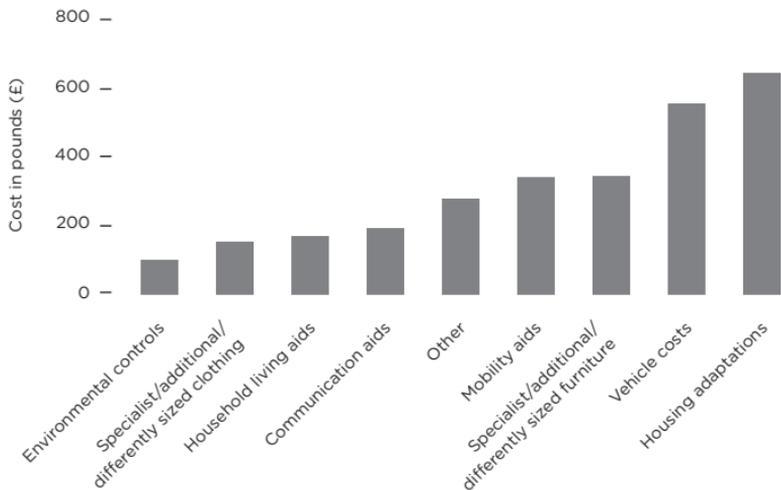
to pay for equipment or adaptations that some pensioners receive financial assistance with.

This chapter has shown that people living with the disease face a considerable financial burden. The burden is partly explained by the fact that they face a range of significantly increased costs associated with adapting to and living with MND. The next three chapters explore in greater depth the kinds of costs people with MND face.

### 3 One-off costs

When thinking about the costs of health conditions, one-off costs might be the first to spring to mind. One-off costs incurred by people with MND range from simple household living aids, to complex and expensive environmental controls and housing adaptations. Our survey showed that people with MND had spent an average of £2,175 on one-off costs to date. However, the difference between the smallest and largest total one-off costs is estimated to be at least £7,758, and our qualitative work confirms that there is an enormous range of expenditure on these costs (figure 3).

Figure 3 **The average amount spent by individual survey respondents and their families on various one-off costs to date**



## **Adapting the home**

Out of all one-off costs, respondents spent most on housing adaptations – an average of £646 to date. While this sum is significant, it is much smaller than the total spent on certain regular and enhanced costs. However, as indicated above, this figure fails to capture the full range of home adaptation costs. Our discussions with diary keepers and comments received to the survey showed that adaptation costs can extend well above the upper limit of £1,001 used in our quantitative analysis, into the tens of thousands of pounds (and in rare cases, hundreds of thousands of pounds). Furthermore, there are indirect costs attached to making adaptations, such as paying to stay away from home while building works are completed. More significantly, adapting a home can reduce its worth, so there can be long-term financial implications too.

Housing adaptations are crucial in enabling people with MND to live as comfortably as possible in their home. As MND progresses, mobility is seriously impaired. This makes getting in and out of the home, getting around the home, and activities such as showering and using the toilet increasingly difficult. Housing adaptations help to overcome these problems. Adaptations range from smaller additions such as installing grab rails or ramps, to complex and expensive changes such as building a wet room, installing a stairlift or through floor lift, or extending the property.

### **Variations in home adaptation costs**

The total cost of making the necessary adaptations varies significantly. Even people whose MND follows a very similar pattern of progression incur very different costs, as the expense of making adaptations depends on more than a person's needs. Certain properties are more costly to adapt than others, for example a large, two storey house would probably require more adaptations than a small, ground floor flat for the entirety of the property to be accessible.

While some may choose to move to a home that is easier to adapt (or one that has already been adapted), this may not be an option for those in privately rented properties or social housing, or those without the funds to afford a move.

Furthermore, some people may be less willing to move than others, such as older people who have lived in their current property for many years, or people with a family who want to try to preserve a sense of normality for their children or stay close to their children's friends or school. Our survey evidence shows that average adaptation costs are 26 per cent higher for people with children at home than for those without.

A second factor that affects total adaptation costs is how the work is scheduled. Some people try to think ahead to what they will require as the disease progresses and do all of the work at once or in the early stages of the disease. One of our diary keepers described how he tried to 'look into the crystal ball' to pre-empt all the adaptations he would need. But as MND is progressive, someone may be able to get by for some time making only minor adaptations, before needing to make bigger adaptations further down the line. As a result, people may be inclined to take an iterative approach to adaptations, adapting as they go along rather than 'future-proofing' the property by adapting it fully early on.

Unfortunately, while an iterative approach may be less expensive in the short term, it is often much more expensive in the long term. For example, someone could spend a significant amount of money making the upstairs of a property fully accessible (eg being able to reach shelves or cupboards), only for the disease to progress, restricting the person to the downstairs of the property. Some people with MND experience a period of denial before they are able to face up to the full realities of their illness, and are therefore more at risk of taking an iterative approach. Furthermore, those with less capital available may be forced to complete the work iteratively.

### **Financial support for home adaptation costs**

As housing adaptation costs are often very high many people living with MND need financial help to pay for them. Of our survey respondents nearly half – 43 per cent – had received financial assistance to adapt their home. Statutory support for adaptations is given in the form of a disabled facilities grant, provided by local authorities and in Northern Ireland by the

Northern Ireland Housing Executive (NIHE). The amount awarded depends on household income and whether the claimant has savings over £6,000. The maximum grant size varies across the UK – £25,000 in Northern Ireland, £30,000 in England and £36,000 in Wales.<sup>18</sup>

In April 2017 the government announced increased funding to be provided to local authorities for disabled facilities grants, which now totals £431million for 2017–18 compared with £394 million in 2016–17.<sup>19</sup>

We found that a major cause of frustration for some people living with MND was that they were not entitled to a disabled facilities grant or were only awarded a small amount, which they needed to top up. This was sometimes a result of having remained in employment:

*There's an income but they're not interested in your outgoings. If you earn a million pounds a month and you're paying £999,000 of that back out they don't care. All they are interested in is what your income is, and he said no straight away.*

Male living with MND, aged 58, South West

Others who had already left the workplace were not entitled to a disabled facilities grant because of their savings. People who are unable to secure a disabled facilities grant, or who need to top up a disabled facilities grant, may be forced to use much of their income and capital in order to cover the cost. Some rely on family – we heard that one diary keeper and his wife spent a staggering £110,000 adapting their home, which they could only afford using money given to them from one of their parents.

In addition to disabled facilities grants, there is financial assistance available from the third sector. The MND Association is able to offer some support for housing adaptations,<sup>20</sup> and other charities and grant foundations provide for people demonstrably in need. However, this funding is limited and may only be available to those in the most extreme financial need. Often applicants have to approach a number of different charities or foundations in order to accumulate the funding they require. This is a slow

and draining process for someone in ill health, whose needs may be becoming more urgent every day:

*I would have carried on applying for grants but it's a nightmare to be honest, and when you're ill the last thing you want to be doing is trying to find money... You have to put the schedule of work, you have to evidence it, you need a professional to back you up with it, a cover note... I'm progressing and all I want is a toilet and my dignity.*

Female living with MND, aged 45, West Midlands

We found that even those in a position potentially to access financial assistance through a disabled facilities grant or the third sector are often so overwhelmed by the complexity of doing so that they choose to fund the adaptations entirely themselves, despite the significant price tag often attached. Some resort to funding adaptations themselves after battling with the system and giving up, or experiencing significant delay. These findings support those of a report from the Local Government Ombudsman highlighting the delays faced by people waiting for disabled facilities grants.<sup>21</sup> Different councils prioritise cases in different ways, which can leave those with needs deemed 'less urgent' languishing at the bottom of the waiting list:<sup>22</sup>

*That was £45,000... I probably could have got some help with the... I don't know. I could have got help with the wet room, but the thing is, until I had the wet room I couldn't wash... I really panicked, I couldn't really face waiting for somebody to help me and arguing about what they did. So I organised it all and paid for it myself.*

Female living with MND, aged 87, South West

*We had to use our limited savings to self-fund an expensive essential urgent bathroom adaptation, as my local authority would not assist at all with costs until I had been paid my final two months' sick pay from my employers. My husband's sudden massive deterioration meant this delay wasn't possible.*

Bereaved spouse or partner, female, aged 45-54, East Midlands

There is an additional question of what happens to people who are not entitled to support, or able to access it quickly enough, but do not have the money to fund the adaptations themselves. Some people living with MND go without adaptations that would significantly improve their quality of life in order to save on the cost, for example they go without a wet room, or turn a living room into a bedroom and no longer have a communal space. Others in rented accommodation may be refused permission to make adaptations that do not fall under the scope of reasonable adjustments:

*If/when adaptations or extensions may be needed I would be hesitant to spend too much knowing that my family will need the money in the future.*

Female living with MND, aged 75–84, East of England

## **Adapting or purchasing a vehicle**

The second highest one-off cost was the cost of adapting or purchasing a vehicle.

For someone living with MND, access to a suitable vehicle can be the difference between living a full and independent life, and being trapped in home or reliant on others to get around. Certain adaptations can be made to enable someone with MND to continue driving for as long as possible, such as replacing a key start system with a push button system. It may be a priority for wheelchair users with limited mobility to purchase a wheelchair-accessible vehicle for their partner, family or carer to drive.

## **Financial support for the costs of adapting or purchasing a vehicle**

Adapting an existing vehicle or purchasing a new one can be expensive. Respondents to our survey had paid an average of £557 on it to date. Some cope with the cost by using a large proportion (if not all) of benefits they receive to cope with the extra living costs of their condition – DLA, PIP or Attendance Allowance, none of which are means tested:

*In terms of disability allowance, it is extraordinarily generous the way DLA works, it is enough to essentially fund a car that is right for me. That is a huge difference. I suppose if we had to pay for these things ourselves we could find a way of doing it, but that is a huge impact that I have a vehicle that I can function.*

Male living with MND, aged 48, South East

However, these benefits are designed to help people cope with *all* the extra costs of their condition, not just their vehicle costs. People on lower incomes are less likely to be able to use the entirety of their DLA, PIP or Attendance Allowance on vehicle costs.

Of our survey respondents, 14 per cent received direct support with vehicle costs, which is primarily available through the Motability Scheme ([www.motability.co.uk/](http://www.motability.co.uk/)). The scheme enables people receiving the higher rate mobility component of DLA, or the enhanced rate mobility component of PIP, to exchange the mobility component of the benefit to lease a new car (or scooter or powered wheelchair). It offers several possible advantages over privately funding a new vehicle. Motability negotiates prices with the leading car manufacturers every three months, so leasing a vehicle through the scheme is often cheaper than leasing one outside it. The cost of the lease includes insurance, breakdown assistance, maintenance and road tax. Finally, each lease lasts for three years, at the end of which the user gets a brand new vehicle.

However, the scheme has disadvantages. For some vehicles, users are required to pay an advance payment – a one-off, non-refundable payment in order to cover some of the cost of the lease. Additional payments may also need to be made in order to have the vehicle adapted. Sometimes people need to pay thousands of pounds on top of the mobility allowance of their DLA or PIP in order to obtain a vehicle through the scheme. Furthermore, the vehicle is leased not owned – so at the end of the three years, the user is required to give it back and be given a new one, even if they are happy with the current vehicle. Apart from the hassle involved, this

is costly, as the user may be required to pay the advance payment and adaptation costs once again.

There are also issues around entitlement to the Motability Scheme. The government is in the process of phasing out DLA and replacing it with PIP. While the two benefits are similar in that they both aim to help working age people to cope with the extra costs of disability, they have different assessment procedures. Someone can be awarded the higher mobility component of DLA if they cannot walk more than 50 metres, whereas for someone to be awarded the enhanced mobility component of PIP this distance is reduced to just 20 metres. As a consequence, some people previously receiving the higher mobility rate on DLA may only be awarded the standard mobility rate when they are transferred to PIP, and therefore lose their Motability vehicle. It has been reported that more than 50,000 people, 45 per cent of claimants, have lost their Motability vehicles since 2013 – with 3,000 rejoining the scheme after the decision to refuse them PIP was overturned on appeal.<sup>23</sup>

A further factor is that older people cannot participate in the scheme. In order to participate in the scheme, a person normally has to be receiving the higher mobility components of DLA or PIP.<sup>24</sup> But people aged 65 or above are not eligible to apply for DLA or PIP. They are eligible for Attendance Allowance instead, but Attendance Allowance has no mobility component:

*I'm only receiving Attendance Allowance for myself and my spouse and nothing else (mainly because we are over 65). [It] has been very annoying and costly. Most notably having to buy a specially adapted vehicle from our own money as we aren't entitled to Motability because of our age.*

Female living with MND, aged 65–74, North West

The discrepancy between DLA and PIP on the one hand and Attendance Allowance on the other can be frustrating given that diagnosing MND often takes a long time. Before a diagnosis is reached, people may be unable to apply for DLA or PIP successfully, and then reach the age of 65 when they are

only eligible for Attendance Allowance. Furthermore, someone receiving PIP before the age of 65 can continue to receive it after they reach 65, putting those who are diagnosed after 65 at an even greater financial disadvantage. A diary keeper who told us that she and her husband had to pay £5,750 for a new car said:

*By the time he was diagnosed, because he was over 65 he wasn't entitled to any DLA or mobilities ... I'd sort of tried to make light of it and said, 'oh you know, at least we'll get a new car', but of course we couldn't get anything like that.*

Wife of male living with MND, aged 66, South West

Some people who are not eligible to participate in the Motability Scheme, or who are put off for the reasons outlined above, may choose not to purchase or adapt a vehicle, which can have a significant impact on their quality of life. But people who can fund a vehicle or adaptations privately can encounter problems too, if they do not give full consideration to the extra costs of financing a vehicle, including maintenance, insurance and road tax. In one sense, purchasing a vehicle privately is not a one-off cost at all once these extra costs are taken into account, and our research showed that some people with MND are misinformed about the costs when purchasing a vehicle:

*In the garage they said that because it is obviously a disabled vehicle, we didn't have to pay road tax... then when I sort of enquired about tax on it, it was £220. Apparently it's only tax-free if you get, I know it's not Attendance Allowance, but it's some benefit.*

Wife of male living with MND, aged 66, South West

In some cases, people make a significant personal investment in a mobility vehicle, only for the individual's condition to deteriorate to the point that the vehicle is no longer usable. Due to the rapidly progressing, unpredictable and terminal nature of MND, individuals may also die before they are able to use a purchased vehicle. Selling an adapted vehicle

## One-off costs

after bereavement can be difficult, leading to an overall loss for the family members left behind:

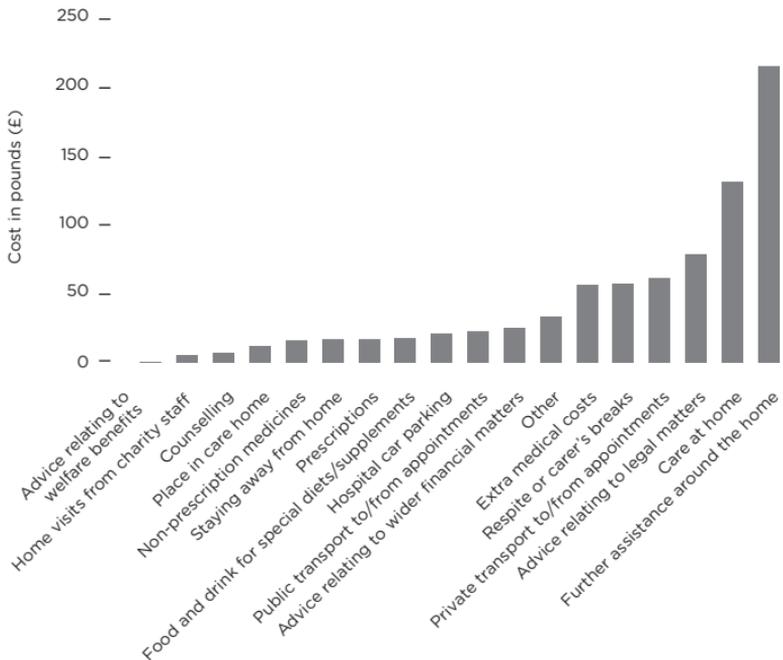
*My husband deteriorated quickly and I was advised to get a wheelchair-accessible car (cost me £6,999 on 4th July, my husband went into the hospice on 8th July and didn't come out). Sold the car a month later for £4,000!!*

Bereaved spouse or partner, female, aged 55-64, South East

## 4 Regular costs

Many people living with MND find that regular costs have the biggest financial impact. The average respondent to our survey spent £609 on regular costs over the previous four weeks – the equivalent of nearly £8,000 per year. Figure 4 summarises the different regular costs we looked at in our survey, and the average amount our respondents spent on them over four weeks.

Figure 4 **The average amount spent by survey respondents and their families on various regular costs over the past four weeks**



Regular costs are difficult to manage. Unlike one-off costs, they continue to be incurred throughout the duration of the disease, quickly racking up. They are challenging to budget for as life expectancy for someone with MND varies significantly. Even more worryingly, regular costs tend to increase over time: nearly two-thirds of respondents to our survey reported that their regular costs had increased as the disease progressed. In other words, as individuals and families deal with the increasing physical and emotional burdens of progressive MND, they have to cope with a mounting financial burden as regular costs increase.

### Care costs

One of the highest regular costs incurred by people with MND is the cost of care. As MND progresses, people need increasing levels of help with daily activities – from shopping and laundry in the earlier stages of the disease, through to more intensive help with dressing and washing as the disease progresses. In many cases, people living with MND receive care from family and friends: 81 per cent of respondents to our survey who lived at home and received care reported that their main carer was their partner or spouse, with only 11 per cent reporting the use of agency care or a personal assistant. While unpaid care is often described as ‘free’, it does of course come at a significant cost, as carers often reduce their work or give up work altogether in order to care for their partner or relative, leading to a significant loss in household income (as discussed further in chapter 6).

However, even though an individual’s main carer is normally a family member or friend, unpaid care is often supplemented by some degree of formal care provided by a carer from an agency or personal assistant. Statutory social care is normally provided by local authorities, but is a means-tested service in England and the devolved nations (care at home is free to over 65s in Scotland but means tested for under 65s). Moreover, the eligibility criteria related to a person’s needs have become tighter across the country over the last decade, and fewer people are eligible for financial

assistance. When someone appears to need social care, the adult social services department of the local authority has a legal duty to carry out a care and support assessment. If the person is deemed to have ‘eligible needs’ (which people in the earliest stages of MND do *not* have), then the local authority must draw up a plan explaining how these needs will be met. The local authority staff must also conduct a financial assessment to determine whether the individual will need to contribute towards the cost of the care services they receive. Whether a person must contribute depends on their capital and income, but it is possible for someone to be required to pay for all of their care or none of it.<sup>25</sup>

The cost of formal care can be significant. Respondents to our survey had spent an average of £132 on formal care over the previous four weeks. In keeping with the pattern for total regular costs, expenditure on care tends to increase over time – those who were diagnosed within the previous 12 months had spent just £19 on formal care over the previous four weeks, compared with £173 for those diagnosed more than 12 months ago.

Only around 1 in 5 of respondents had received financial assistance towards the cost of care. Some people may not receive financial assistance because their income and capital are above the threshold set. Some may be in earlier stages of MND and deemed not to have ‘critical’ care needs (a threshold more and more local authorities are now applying). However, some may have been inappropriately assessed – and others may not have been assessed at all. According to the MND Association’s 2016 tracking survey, only 19 per cent of respondents strongly agree that they had received a social care assessment that captured all of their needs.<sup>26</sup> The result is that while some people with MND may have their social care funded, others may not and instead see their savings dwindle over time. The costs can be greater for people living in remote locations, if few local service providers are able to meet their needs. A male living with MND, aged 62, South East told us: ‘We were discussing figures up to £25,000 [in total care costs]’

A person’s formal care costs are likely to be greatest in the very latest stages of the disease, in the weeks or months

before they move to a hospice or hospital. While local authority provision remains the key provider of social care services for people living with MND, those in the later stages of the disease sometimes pursue NHS continuing healthcare (CHC), a package of care arranged and funded by the NHS. Unlike local authority social care provision, it is not means tested but free at the point of access. Only individuals whose primary needs are health related rather than care related are eligible, so only people whose MND has advanced significantly can access CHC.

Accessing CHC can make a huge financial difference to people with MND who would otherwise be required to contribute towards local authority provision. Depending on how long they survive the later stages of the disease, it could save thousands and thousands of pounds – money which can then be used by their bereaved partner or wider family:

*Currently the vast majority of my caring costs are funded via a NHS Continuing Healthcare personal budget scheme. As long as this continues to be funded then things shall remain okay. If this budget was reduced or removed, I don't know how we would cope.*

Male living with MND, aged 45-54, South East

However, not everyone is aware that CHC exists. Before he became aware of CHC, one of our diary keepers said that his biggest financial concern was the cost of the care package he was soon going to need. Later in the diary, the diary keeper describes learning of CHC:

*My wife Harriet had to visit our doctor on Tuesday (6th Dec) on an unrelated condition and the doctor asked after me, so Harriet related the tale of care arrangements. The doctor made a phone call to his home – because his wife is in charge of health commissioning in the area – and she said the costs should be covered by the NHS. The doctor visited, and assessed me in the afternoon and initiated a fast track application for continuing care.*

Male living with MND, aged 62, South East

The fact that people are learning about a care package that can save them such substantial amounts of money through mere luck or chance is worrying. It is particularly concerning that those who may need CHC the most (people above the threshold for free local authority provision, but struggling with their finances as the disease progresses) may be less likely to hear about it than those with greater social capital.

Our findings around the accessibility of CHC corroborate recent research published by the Continuing Healthcare Alliance focusing on CHC in England.<sup>27</sup> In addition to issues around accessibility, the report shows that there are emerging concerns about whether CHC packages are sufficient to meet the needs of people living with MND and other conditions. There is evidence that increasing numbers of clinical commissioning groups in England are capping the cost of CHC packages for people living in their home against 'the equivalent cost of a placement in an establishment' (a care home).<sup>28</sup> These funding limits fall well short of the cost of providing ongoing care in a person's home. Consequently, people living with MND may be forced to move into a care home against their wishes, or to make up the difference in funding themselves, even though there is guidance stating that this is not permitted.<sup>29</sup> A survey by the CHC Alliance found that almost 20 per cent of survey respondents who were awarded CHC said the cost of their care was not met by their NHS funding, resulting in them having to pay top-up fees, even though private top-ups of NHS funded services are explicitly disallowed.

CHC in Wales and Northern Ireland is the responsibility of Welsh health boards and Northern Irish health and social care trusts respectively. Wales updated its CHC Framework in 2014, including by incorporating elements of the English system such as the Decision Support Tool (DST). It is not yet clear what effect this change will have, but in a recent report the CHC Alliance criticised the use of the DST, suggesting that it contributed to problems around eligibility and entitlement to CHC – for example, by leading professionals to measure the absence of care (such as

the presence of serious bed sores) rather than the care needs of a person.<sup>30</sup>

CHC in Northern Ireland is the responsibility of health and social care trusts, which could potentially take a more integrated approach to addressing an individual's health and care needs. However, a study by Age UK Northern Ireland in 2014 found that the number of people claiming CHC in Northern Ireland was low, and assessment for eligibility guidelines were applied inconsistently across trusts.<sup>31</sup>

### **Assistance around the home costs**

Out of all 18 regular costs included in our survey, respondents reported spending most on assistance around the home – paying an average of £216 for this over the previous four weeks.

This figure is surprisingly high. One reason for this may be methodological. In the survey question we make a clear distinction between the cost of 'nursing or personal care at home' and the cost of 'further assistance around the home – eg DIY, gardening, painting and decorating'. However, some people with MND employ personal assistants, who do not provide intensive care, but assist people with tasks such as getting to work. Although we intended respondents to classify support from a personal assistant as 'nursing or personal care at home', it is possible that some instead classified it as 'further assistance around the home'.

However, it is unlikely that the high average assistance costs indicated by our survey are simply a result of respondents mistakenly classifying care costs as assistance costs. Our qualitative research confirmed that many families employ further assistance around the home as a vital means of relieving the pressure on family carers:

*Obviously the worse he got the less he was able to do... It got to the point that I felt completely overwhelmed by the tasks ahead of me, I was doing all the housework, virtually, cutting the grass, doing the back garden, I always do the finances... Yes I have a cleaner, because I was knackered.*

Wife of male living with MND, aged 45-54, North East

Further assistance also helps single people in the earlier stages of the disease, who may not need personal care but can become tired quickly. Our survey suggested that people diagnosed within the previous 12 months spent on average £173 on assistance around the home, compared with £230 for those diagnosed more than 12 months ago. This is a much smaller gap than the amount spent on care by the two groups:

*I've got a cleaning lady who comes to the house and does top to bottom every Tuesday... £32 per week, coming out of my own pocket. If I was well I would, I used to do it myself, but now they're at uni; when they come over I can't get them to do everything... So I've got somebody outside who comes and is trustworthy, and gets on with it.*

Female living with MND, aged 48, London

As with care costs, assistance costs are typically greater for people with children living at home. Respondents with children at home spent on average £302 over the previous four weeks on assistance around the home, compared with £187 for respondents without children at home. This reflects the fact that people living in households with children are less likely to have time for household tasks, gardening or DIY, as they need to spend time on childcare – just as they are less likely to be in a position to provide unpaid care to the person with MND.

There is very little direct support available to help fund assistance around the home. Only 5 per cent of survey respondents had received help with assistance costs. The MND Association is among a number of organisations that provide small grants to help people manage this kind of cost.<sup>32</sup>

As many people must pay for assistance costs out of their own pocket, there is a risk that people on low incomes

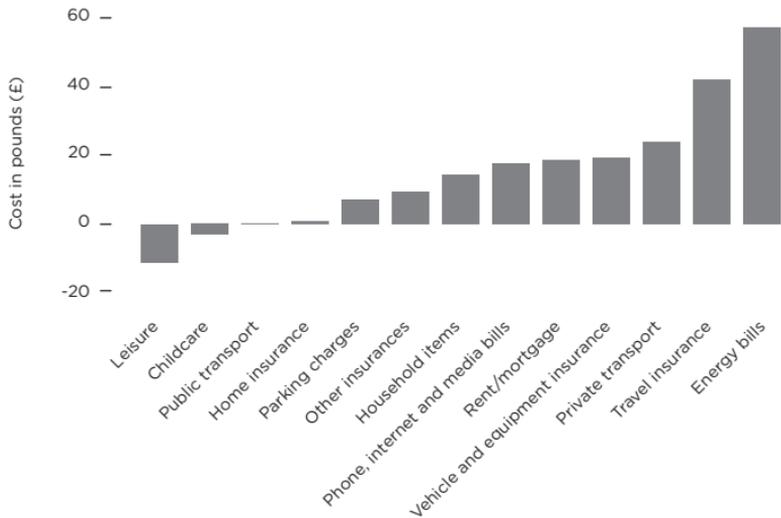
are priced out of accessing it, keeping benefits such as PIP or Carer's Allowance for things they view as more essential or higher priority. This is particularly a risk for people with MND living with a partner – partners may feel pressure to take on all responsibility for household tasks to save money. This may be reinforced by a desire to keep up a sense of normality or 'business as usual' for their loved one.

Worryingly, if family carers take on too many responsibilities they risk jeopardising their own health and wellbeing. Not only is the poor health of carers concerning in itself, but it can have financial implications of its own – as explored later in chapter 8.

## 5 Enhanced costs

When calculating the costs of a disability or health condition, it is easy to overlook the impact of enhanced costs. Enhanced costs are costs that people without MND (or other health conditions) typically incur, but which can be much higher as a result of MND. Our survey found that the spending on enhanced costs of the average person with MND increases by around £133 per four weeks, or over £1,700 per year. As with regular costs, enhanced costs continue as long as someone is living with MND.<sup>33</sup>

Figure 5 **The average amount spent by survey respondents and their families on various enhanced costs over the previous four weeks**



### Energy bills

The biggest enhanced cost identified by our survey was energy – gas, heating and electricity bills (figure 5). The energy bills

of average respondents to our survey nearly doubled, from £78 every four weeks to £135. There are a few possible reasons for this.

First, people living with MND spend increasing amounts of time at home as the disease progresses. In the earlier stages of the disease they may be too tired to leave the house much for leisure and they may begin to work from home. As the disease progresses, they may be unable to leave the house at all. Simply by virtue of being in the home more, energy bills increase – the heating needs to be on for more hours per day, and electrical items are in greater use. This finding is supported by the fact that respondents to our survey who require between 1 and 19 hours of care per week have much smaller enhanced costs than those requiring 70 hours or more – those requiring less care, and likely to be spending less time at home, incur around an extra £26 in enhanced costs over four weeks, compared with £99 for those needing more care.

However, the increase in energy use is more than simply a result of being in the house more. People living with MND may need to heat the home to a higher temperature than in the past in order to be comfortable. Furthermore, they often spend increasing amounts of time using televisions, laptops and other electrical items for leisure, when they might have previously participated in other activities. Our survey showed that internet, phone and media (eg Sky) bills increase by an average of 31 per cent when someone is living with MND.

In some cases, people go without what they really need in order to reduce their energy bills. This can have an extremely damaging effect on the physical health of someone living with a serious condition such as MND. These people do not incur increased energy costs, but their unmet needs are testament to the financial impact of MND:

*Today it's cold, I've got the heating on but I'm warming myself with blankets because I looked at my electric and I've got about £10 left on there. When I'm home at 1.20pm the heating comes on because I'm cold and need the heating on. If my blanket falls down here*

*I can't put it on so I get one of the children to do it for me because I can't do it with my arms.*

Female living with MND, aged 48, London

### **Leisure and entertainment costs**

A unique feature of enhanced costs is that it is possible for them to decrease for people living with MND. Our survey asked respondents to report their expenditure on 14 enhanced costs: 11 of these costs increased as a result of MND, and three decreased – public transport costs, childcare costs and leisure and entertainment costs.

None of these costs fell by an enormous amount when we look at the average for all respondents. The biggest decrease was reported in leisure and entertainment costs, which fell by an average of £11 – from £66 every four weeks to £55.

Some people may not want to participate in many leisure activities when they have MND, or be physically well enough to. However, our evidence suggests that most people with MND do want to participate in leisure, and many are well enough to, but deliberately choose to decrease their expenditure on leisure. It is often seen as an unaffordable luxury at a time when they are feeling the pinch financially:

*You know you can't... even things like going to the pictures, or going for a meal. You have to think twice, and if we do go out it's always Wetherspoons, it's always the cheapest of the cheap.*

Wife of male living with MND, aged 66, South West

An interesting question is whether there are greater unmet leisure needs among specific groups. In our survey, people aged 65 and over reported an average *decrease* of £23 of spending on leisure costs, whereas people under 65 reported an average *increase* of £2 of spending on leisure costs every four weeks. However, a likely explanation of this difference is simply that all older people generally spend less on leisure than younger people. It has been shown that from the age

of 50, an individual's spending on non-essential items tends slowly to decline:<sup>34</sup>

*Because we're old, we don't need or can cope without extras. Got Sky sports package since diagnosed. Use car less, not well enough to walk or go out. Difficult for wife to go out and leave me, her husband, alone. Maybe it's choice.*

Male living with MND, aged 75-84, South West

A more telling difference is between people living with or without a partner. The leisure costs of those living with a partner *increased* by an average of £8, whereas those of people living without a partner *decreased* on average by £14, over four weeks. People with MND who have no partner are often at a disadvantage when paying for leisure activities. They have to pay for two people (themselves and a carer) to participate in an activity, but with a single income. Furthermore, they have to pay for the carer's time, whereas someone with a partner could be accompanied free of charge:

*I used to go to swimming at the health club, but they said if you take a carer, you'll have to pay for her. A spa, which is about three hours, is £15. So I have to pay £15... They're not going to fund it, I have to pay out of my own pocket. But I can't go on my own.*

Female living with MND, aged 48, London

Our research also threw up cases where a person with MND might be willing to spend on leisure activities, including on someone to accompany them or assist them, but cannot afford something else they need in order to participate. For example, someone might need to obtain a powered wheelchair in order to get out of the house. In these circumstances, a person with MND is not only unable to participate in leisure activities but may well have unmet needs in other areas:

*Andrew cannot access the community due to his immobility & lack of a powered wheelchair, which has been promised but has yet to materialise – Sky TV is his only form of recreation.*

Wife of male living with MND, aged 66, South West

This chapter concludes our discussion of the costs of MND on individuals and their families. However, the financial impact of MND on those living with the condition is not a result of increased costs alone – changes to household income also play an important role. The next chapter begins by considering the effect of MND on employment patterns.



## 6 Lost income from changes in working patterns

Household income can change significantly when one member has MND. One reason behind this is the effect of MND on working patterns: working age people with MND inevitably leave work at some point during the course of the disease, and many family members decide to leave employment in order to provide care. Another factor behind changes to household income is the benefits system, which is designed to help compensate for the extra costs and lost income resulting from health conditions. This chapter and the next look at working patterns and the benefits system in turn.

### **Lost income from people with MND being out of work**

As MND is a progressive and terminal condition, there is a point at which people with the condition become unable to work. However, they progress towards that point at highly variable rates, and many wish to continue working while they remain able to. In some cases people wish to remain in work to retain a sense of normality and routine following their diagnosis; others are primarily motivated by the financial effects of potential lost income:

*I was chief examiner and trainer for a professional body. My business accounts indicate I made a profit of £20,000 per year, but I was also doing a PhD (and graduated a month after my*

*diagnosis). I wanted to build a new business on the back of my PhD (teaching creativity in professional bodies).*

Male living with MND, aged 62, South East

Benefits go some way to replacing income, but they nowhere near compensate what medium to high earners could be earning. The extra income from remaining in employment can make a very significant difference to a person's quality of life, and continued employment can provide other benefits to a person's wellbeing such as sense of purpose, a familiar routine, and social contacts and activities:

*Because I'm working, the extra money comes in handy. I'm saving up and hoping that maybe in February I can take my children on holiday. They deserve it. I need to get away for a bit somewhere.*

Female living with MND, aged 48, London

There is evidence that work can have a significant impact on a person's mental health and emotional wellbeing.<sup>35</sup> It is therefore important to consider how far people with MND are supported to work if they would like to.

#### **What helps people with MND to continue working?**

Our qualitative evidence suggests that having a supportive employer makes the biggest difference in enabling people with MND to continue working. There are examples of people with MND who have had their hours reduced while staying on the same salary, been offered extended holiday entitlements, or been allowed to spend a significant amount of time working from home:

*Most companies are 'use it or lose it' when it comes to holiday, but mine came up to me a month or so ago and said I could carry it over, so now I've eight weeks to take next year. Two weeks in January I will use to go away while the bathroom is built. So I'm not being penalised in any way at work at all. If I sit down for an hour or two nobody questions it.*

Male living with MND, aged 58, South West

Access to Work grants can also make a big difference in assisting someone with MND to continue working. These grants are available to people with disabilities or health conditions who incur work-related costs. For example, someone with MND might need to pay for private transport in order to get to work, or for a more ergonomic desk. Access to Work grants can be used to cover these sorts of costs, sometimes with a financial contribution from the employer. In 2015 the government announced extra funding for Access to Work, so that it can support over 60,000 people per year by 2020 – a commitment reaffirmed in last year’s green paper on work, health and disability.<sup>36</sup>

#### **What prevents people with MND from continuing to work?**

Unfortunately, some employers are not as supportive as others. On finding out that an employee is terminally ill, the least sympathetic employers attempt to find ways of dismissing an employee prematurely:

*I got the unions involved because they were really singling me out through the disability, despite the fact I was still able to drive. I'd had a driving assessment, a driving test – all passed. They were sending me for more medicals and they were just being awkward. So anyway, I went on the sick – stayed on the sick for the length of time that I was due, and at the end of it I just retired.*

Male living with MND, aged 58, Wales

The fact that MND becomes progressively worse can make it difficult for well-meaning employers and employees to navigate the employee’s transition out of work. An employer may agree new working conditions or put in place assistance for an employee, only for it to become unfit for purpose as the employee’s condition deteriorates. Without a long-term plan being in place, this iterative, unplanned approach to employment support can lead to frustration on both sides.

Our qualitative evidence shows that employers are more likely to be supportive if they have known a friend or family member with MND or other long-term condition, which suggests that increased awareness and understanding of

MND would help to improve employer practices. The level of support offered also depends on the role of the employee. It is more common to offer flexible working arrangements in some industries than others. For example, service industry employees or teachers cannot work from home as an office worker can. Furthermore, a highly skilled employee may be better supported to continue working than a low skilled worker. There is a risk that lower skilled, lower paid people with MND may be forced out of work sooner than they would like, with implications for their financial health as well as their personal wellbeing.

However, it is not only having a supportive employer that matters. Although Access to Work grants have enabled many people to continue working, the programme has long been criticised for not being widely publicised, leading some people to lose out on support.<sup>37</sup> Furthermore, the way in which the wider welfare system operates may affect someone's ability to work. For example, one of our diary keepers lives in social housing. She is waiting to move to another property more suitable to her requirements, but her need to be within reasonable distance of her workplace is not being considered by the housing department. There is a known shortage of adapted housing in many areas, which increases the pressure on people living with MND to move away from their work. Inability to access mobility support, as discussed in the preceding section, may also restrict people's ability to travel to work and force them to give up employment earlier than they would prefer:

*My priority is my work. I think they're now holding that over me. The housing officer said 'we did offer you this' but it wasn't suitable for me. Why should I go for the sake of it? How am I going to get to work?*

Female living with MND, aged 48, London

### Lost income from family carers not working

Aside from formal care, most people living with MND depend to some extent on unpaid care provided by friends and family. Some rely on it more than others. Our research showed that formal care costs are higher for people with children living at home, and those aged under 65 – one reason behind this is likely to be that these groups are less likely to have a family member with the time to provide unpaid care for them, on top of childcare and/or employment. However, in many families unpaid care plays an important role.

While unpaid care is, by definition, ‘free’, it can still come at a high price, as carers have to reduce or give up work entirely to provide that care. Of the respondents to our survey whose main carer was a partner or spouse, 26 per cent received between 35 and 70 hours of care from that person, and a further 35 per cent received over 70 hours of care from them. For people of working age, this time spent caring is time spent out of employment, so a household previously supported by two wages can become a household with no income from employment:

*I am no longer able to provide for my family and the burden of this falls upon my wife. She would love to be able to give up work and look after me but financially we would not be able to manage and we have a mortgage etc to pay.*

Person with MND, aged 75–84, East of England

*If the wife were to lose her job tomorrow, we'd be really struggling, really struggling.*

Male living with MND, aged 58, Wales

Sometimes a drop in income may make a household eligible for means-tested assistance that they would not otherwise receive – not just for greater local authority support for social care, but also for grants such as disabled facilities grants and benefits such as Carer’s Allowance. But many families find that the extra financial assistance from the state is not enough to compensate for the drop in income from a family member caring rather than working. Those ineligible for such

assistance (perhaps because of the value of their home, or the savings they have) may rapidly spend their assets. Nonetheless, many families find that giving unpaid care is important as a means of spending as much time together as possible:

*It is a question of whether I actually want to go to work every day and leave him, or do I want to spend more time with him, because obviously time is of the essence.*

Wife of male living with MND, aged 45–54, North East

In addition to lost income, there are further financial consequences of unpaid care. Caring can be an extremely physically and mentally demanding activity, which can lead to ill health for the carer and consequently their own health-related costs may increase:

*I had to take on more of the care of my wife than I could really cope with to prevent it becoming a financial burden.*

Bereaved husband, aged 65–74, North West

Help with day-to-day housework, bigger household tasks such as DIY or gardening, and childcare may all need to be paid for as the unpaid carer may not have the time (or be healthy enough) to complete these tasks themselves. Some may need to pay significant sums for respite care, in order to give the family carer an occasional break.

Here is a description of a typical day in the life of a man with MND whose wife has not given up work:

*I'll go through my day with you. We get up at 6 in the morning. She showers me, washes me, because I'm not able to do that myself. Then she does herself. She has to dress me. Then she makes three or four meals for me for the day. Breakfast, lunch and something for the afternoon. She does that every day. Then she goes off to work. She does 8–4.30. Usually gets back here about 5/5.30... Then comes home, and then she's got to make the tea, because I'm unable to use any of the cutlery or cook or anything. So she starts the tea, then has*

*to do all the other things. Cleaning the house, washing. Then we go to bed around 10. Again she has to get me undressed, put the blanket over me because I'm not able to do that.*

Male living with MND, aged 58, Wales



## 7 Welfare benefits

In this chapter we assess the welfare benefits available to people with MND and their families. State-funded benefits provide a vital source of support for many individuals and families affected by MND, and can have a significant influence on a person's ability to cope with the financial consequences of having the condition. Individuals with similar costs and working patterns can cope very differently with the financial impact of having MND, or have very different quality of lives, depending on which benefits they are able to access.

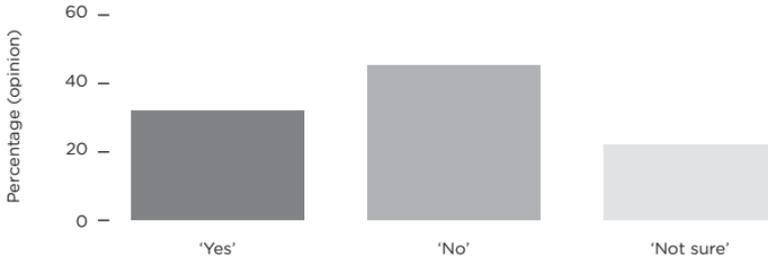
The chapter begins by assessing the adequacy of financial support available to people with MND. It then explores extra costs benefits, including PIP and Carer's Allowance in depth.

### **The overall adequacy of financial support available to people with MND**

People living with MND and their families can access a range of benefits. These include income replacement benefits, such as Employment and Support Allowance (ESA) and Carer's Allowance, and extra costs benefits, such as DLA, PIP and Attendance Allowance. Income replacement benefits are intended to supplement lost income or low income, while extra cost benefits are intended to support people with additional costs incurred as a result of disability or illness.

We asked respondents to our survey whether they considered the financial support they receive (if they receive any) to be adequate for their own and their family's needs. Nearly half (45 per cent) said that the support was not adequate, while a third said it was adequate (figure 6).

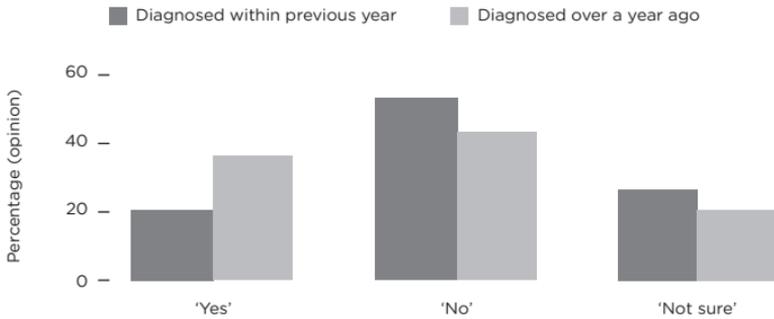
Figure 6 **The extent to which survey respondents consider the financial support they receive is adequate for their and their family's needs**



Working age people were particularly likely to report that the support they received was inadequate, as they were when reporting the overall financial impact and costs of living with MND. Just 25 per cent of working age respondents to our survey said that the support they had received had been adequate, compared with 39 per cent of people aged 65 or over.

Another group vulnerable to lack of support are the newly diagnosed. Just 21 per cent of those diagnosed within the previous year reported that the support they had received had been adequate, compared with 36 per cent of those diagnosed over a year ago (figure 7). This might be surprising given that the costs of living with MND tend to increase over time, potentially creating a growing mismatch between a person's needs and the support they receive.

Figure 7 **The extent to which survey respondents consider the financial support they receive is adequate for their and their family's needs, by recency of diagnosis**



However, our research showed that people can experience significant delays in accessing financial support, often because they lack information about their entitlement to certain benefits or grants. Being diagnosed with MND is a life changing moment, and understandably people with the condition need time to process what is happening to their health before considering the financial implications. During this time, newly diagnosed people may receive little to no support. Many people are not properly directed to where they can obtain financial advice. Our qualitative work revealed multiple cases of people learning about assistance they were entitled to through family, friends and acquaintances, rather than from support services or financial advisers, often many months after diagnosis:

*The ESA bit was the wife. She was doing work for the DWP at the time, and she was, by chance, talking to adults they were placing in work, and one of the colleagues in DWP that she became friends with, they were talking about my condition, and she said: 'he should be able to claim ESA'. We didn't know what ESA was.*

Male living with MND, aged 58, Wales

Furthermore, finding out about the support available is only half of the battle – individuals and families then need to access it. The application process for many forms of financial assistance can be unwieldy, presenting serious barriers to those less informed about the welfare system, which can be extremely slow to process applications and provide the required support:

*I was also in the support group and there was some confusion so I didn't get that, I had to have back pay for the right amount. That was nearly 12 months later.*

Female living with MND, aged 45, West Midlands

It is worth noting that a significant minority (22 per cent) of survey respondents answered 'not sure' when asked whether they had been adequately supported. This demonstrates how complex it can be for someone with MND to assess and manage their finances. Many stated that they could not tell whether the support they had received was adequate because their financial circumstances had changed in so many ways that it was difficult to tell what the overall financial effect had been:

*I am not working any more but I was able to get my occupational pension at age 49 and I get quite a lot of income through benefits. But we had to move to a bungalow and had to use money that my parents left me to build a wet room and an extra bedroom, and we have still got a large mortgage, so it's hard to quantify.*

Female living with MND, aged 55–64, South West

### **Extra costs benefits**

A person's entitlement to benefits depends on a wide range of factors. However, the vast majority of people with MND are entitled to an extra cost benefit – DLA or PIP for people of working age, or Attendance Allowance for people aged 65 or over. DLA is gradually being replaced by PIP for most

claimants, although current DLA claimants born on or before 8 April 1948 will continue to receive DLA.

All of these benefits are designed not to replace income, but to enable people to cope with the extra costs of their health condition. Eligibility does not depend on employment status and is not subject to means testing – it is determined solely by whether the applicant faces difficulties with daily living, such as preparing meals, dressing or making routine decisions. An individual can be awarded a standard rate or higher, enhanced rate of PIP depending on the level of their needs (or a higher, middle or lower rate in the case of DLA).

DLA and PIP recipients may also receive additional support if they have difficulty getting out and moving around. As with the daily living component, the mobility component of these benefits has a standard rate and enhanced rate. Attendance Allowance has no mobility component. Table 1 shows the current weekly rates for DLA, PIP and Attendance Allowance, which have not changed since April 2016.

Table 1 **Weekly rates for DLA, PIP and Attendance Allowance, April 2016**

	DLA	PIP	Attendance Allowance
Daily living – lowest	£22.00	N/A	N/A
Daily living – middle/standard/lower	£55.65	£55.65	£55.65
Daily living – highest/enhanced/higher	£83.10	£83.10	£83.10
Mobility – standard	£22.00	£22.00	N/A
Mobility – enhanced	£58.00	£58.00	N/A
Maximum amount	= £83.10 + £58.00 = £141.10	= £83.10 + £58.00 = £141.10	£83.10
Maximum amount per year	£7,337.20	£7,337.20	£4,321.20

#### **How accessible are extra costs benefits?**

More than half (53 per cent) of respondents to our survey received DLA or PIP, and 34 per cent received Attendance

Allowance. This suggests that the proportion of people receiving extra costs benefits has fallen slightly since spring 2016 – according to the MND Association’s tracking survey, 56 per cent of respondents received DLA or PIP, and 39 per cent received Attendance Allowance in March 2016.<sup>38</sup>

People with MND face a number of barriers to accessing extra costs benefits. Some people find out about them more quickly than others. NICE guidance on MND states that people should be directed to support by a social care professional, but a wide range of care professionals are involved in an individual’s case and it is possible for them to slip through the gaps:

*No one even told me about PIP. I didn’t even have a clue about PIP. It was only on [the] off chance talking to someone, and they mentioned you’d be able to get this Personal Independence Payment. I said, what’s that?*

Male living with MND, aged 58, Wales

People with MND may learn about the benefits they are entitled to from a variety of professionals. This introduces a degree of luck or chance that an individual will be told by the professionals they are in touch with about the benefits they are entitled to. For example, a number of people with MND reported being told about PIP for the first time by hospice staff. Although people with MND and other terminal conditions often access hospices for services other than end of life care at a fairly early stage in their condition, many do not want to contact hospices until they are in a much later stage of the disease. This raises the question of whether people entitled to extra costs benefits could lose out if they are not in touch with a hospice. Given the nature of MND it is essential that people access financial support as early as possible, to help them to cope with what may often be a rapid and severe progression of symptoms.

Another barrier to accessing extra costs benefits is the application process. Our findings show that many people

with MND struggle to fill in the paperwork to the standard required. People who have little previous experience of the welfare system or lack personal connections to assist them are at a particular disadvantage. Although there is a fast track application process for people suffering from a terminal condition, requiring less paperwork and no face-to-face assessment, our research suggests that not everyone is made aware of it:

*Well to do your DLA was 56 pages long and it took me, and I consider myself articulate, five hours to fill that in.*

Male living with MND, aged 48, South East

Furthermore, in order to make a successful fast track application an individual's doctors must expect them to live for no more than six months. This could be the case for anyone with MND as their health can deteriorate very rapidly, though unpredictably. Clinicians with less experience of the disease may be reluctant to support a fast track application for PIP if the applicant appears relatively healthy.

If someone is unfamiliar with what a decision maker is looking for from a claim form or assessment, they are at risk of having their claim denied, forcing them to go through an appeals process. The Second Independent Review of PIP noted the confusion around the types of evidence and information that should be provided to support a benefits application, and calls for better information and communication in this area.<sup>39</sup> If an initial application is unsuccessful, someone unfamiliar with the welfare system can find it very difficult to navigate the appeals process, though some are more successful:

*Well I did get it but it was lower rate, it was madness so I had to appeal. I have a friend who works in welfare rights, and also because the job that I had done I have supported others on appeals, so I knew what the process was.*

Female living with MND, aged 45, West Midlands

Furthermore, such an appeal causes additional delay, during which time a person's condition might have progressed rapidly.

**Are extra costs benefits sufficient for those who receive them?**

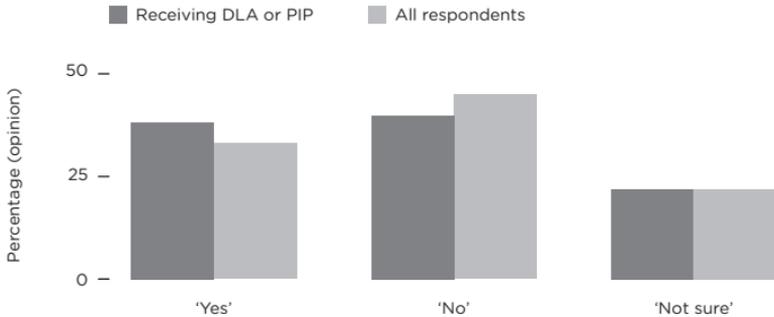
There is an additional question of whether extra costs benefits are sufficient for the needs of people with MND once they receive them.

Our qualitative findings suggest that people receiving DLA or PIP are generally satisfied with the benefit. For some, receiving these benefits is the difference between living comfortably and being unable to afford daily living expenses. One diary keeper told us that she 'didn't know what she would do' without PIP, while a survey respondent said that PIP enabled him to stay on an 'even keel'.

For others, especially people with MND who still have an income from employment, PIP enables them to do things that makes living with MND much more pleasant than it would be otherwise. For example, one diary keeper told us that when he had a hospital appointment away from home, he used his PIP to make it into a long weekend. Another diary keeper told us that it enabled her to enjoy an occasional meal out.

People receiving DLA or PIP were slightly more likely than people not receiving DLA or PIP to report that the overall support they received was adequate for their needs. However, the difference was small – 38 per cent receiving DLA or PIP said that their support was adequate, compared with 33 per cent for all respondents. Furthermore, the majority of people receiving PIP or DLA feel that the overall financial assistance they receive, of which PIP or DLA is one component, is inadequate for their needs (figure 8).

Figure 8 **The extent to which survey respondents consider the financial support they receive is adequate for their and their family's needs, by whether or not they receive DLA or PIP**



This suggests that although PIP can be a vital lifeline for people, and allow them to live a slightly more comfortable life than they would have done otherwise, it cannot compensate for the total financial losses suffered by most people with MND. Indeed, as table 1 shows, the maximum amount that someone can receive in PIP or DLA is around £7,340 per year. Our data suggest that the yearly regular and enhanced costs incurred by someone with MND are around £9,645 per year, leaving a shortfall of approximately £2,305 per year – and this is without taking into account the one-off costs individuals need to budget for.

Speaking about his wife, who had given up work to care for him, one survey respondent wrote:

*I get £300 PIP. It doesn't cover the £900 a month she has lost, so yes, we are financially out of pocket. Others not getting paid must really struggle.*

Male living with MND, aged 55–64, South East

People with MND are generally less satisfied with Attendance Allowance than DLA or PIP. The following comment to our survey was typical:

*We get only Attendance Allowance at the lower rate and this does not cover our extra costs and in the near future will fall far short of covering these costs.*

Male living with MND, aged 65-74, Wales

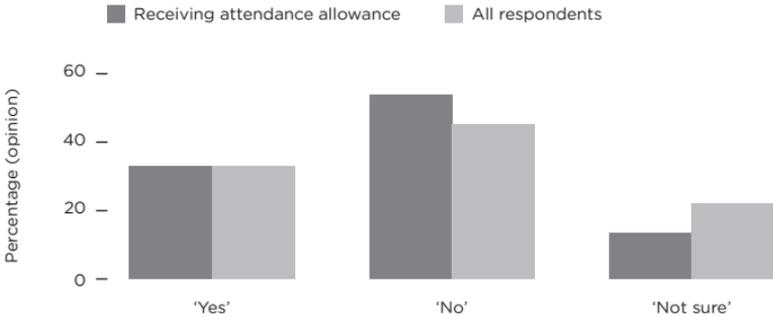
The maximum sum an individual can receive through Attendance Allowance is just over £4,300 per year – a much smaller amount than can be awarded on DLA and PIP as it has no mobility component. This suggests that someone receiving Attendance Allowance could face an annual shortfall of at least £5,324 per year in meeting the costs they face as a result of having MND. Our research found that many who receive Attendance Allowance are frustrated that it is less generous than DLA or PIP – frustration exacerbated by the fact that people receiving PIP before reaching state pension age can stay on the benefit and are not moved on to Attendance Allowance:

*Although I have received great help from the MND Association I'm only receiving Attendance Allowance for myself and my spouse and nothing else (mainly because we are over 65). Has been very annoying and costly. Most notably having to buy a specially adapted vehicle from our own money as we aren't entitled to Motability because of our age.*

Female living with MND, aged 65-74, North West

These criticisms are reflected in respondents' answers to the question asking whether the support they had received was adequate. Attendance Allowance recipients were more likely to report being inadequately supported than others (figure 9).

Figure 9 **The extent to which survey respondents consider the financial support they receive is adequate for their and their family's needs, by whether or not they receive Attendance Allowance**



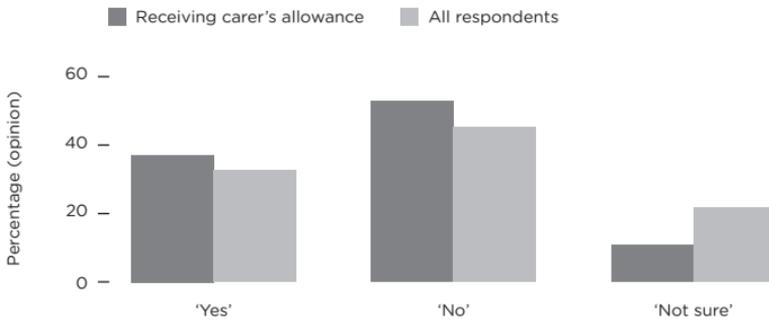
It is worrying that people receiving Attendance Allowance do not feel adequately supported. One reason behind this could be that many pensioners face a smaller overall financial burden than people of working age, as discussed in chapter 2. Receiving Attendance Allowance might make less of a difference to their lives if they are generally managing quite well – in comparison with a working age person who is not coping, who might see PIP as a lifeline. For example a male living with MND, in the age group 65–74, from the South West reported: ‘We are not reliant on the Attendance Allowance as our pensions meet all our needs.’

### Carer's Allowance

Carer's Allowance is an income replacement benefit paid to people caring for someone for more than 35 hours per week. It is not means tested, although only people earning £110 or less after deductions (and of working age) can claim it. Furthermore, only people caring for someone who receives a qualifying disability benefit (such as the extra costs benefits described above) can claim it. There are a number of benefits that overlap with Carer's Allowance, including state pensions, which affect how much of the allowance someone can claim (if any at all).<sup>40</sup>

Just 19 per cent of our survey respondents received Carer's Allowance, and our research revealed a great deal of dissatisfaction with it. Over half of survey respondents receiving Carer's Allowance thought the support they received was inadequate, compared with 45 per cent of all respondents who thought this (figure 10). Although, notably, the proportion of people receiving Carer's Allowance who thought their support was adequate was also greater than the average for all respondents, suggesting that some find the benefit helpful.

Figure 10 **The extent to which survey respondents consider the financial support they receive is adequate for their and their family's needs, by whether or not they receive Carer's Allowance**



The primary difficulties are not around the process of applying for Carer's Allowance, as with DLA and PIP, but around who can apply for it and how much they receive.

Some people reported being ineligible for the allowance because they earned slightly too much or were getting too much from overlapping benefits. For some, the difference was minimal – if they had just a few pence or few pounds less from their existing income they would be entitled to Carer's Allowance. This causes enormous frustration and a perception of unfair treatment.

Even people who received Carer's Allowance in full were frequently dissatisfied. Carers awarded the full allowance

receive £62.70 per week (2017–18 rate), an amount described as an ‘insult’ and a ‘pittance’ by participants in our research. For people who had previously been high earners before giving up work to provide care, the drop in their income is stark:

*I am now eligible for Carer’s Allowance, so £63 a week is it? £62.50 something? What a difference... £150 a day to £62 a week.*

Wife of male living with MND, South East

There is a conflict between how people with MND and their family carers perceive Carer’s Allowance and the rationale behind the benefit. Carer’s Allowance is not intended to match someone’s previous income, but to give them enough of a replacement income to get by. But for people with MND and their families, Carer’s Allowance is taken to be an indicator of how much their caring is worth – understandably so, as it is an income replacement benefit. It is questionable whether the sum of £62.70 per week meets the goal of giving unpaid carers enough to get by, let alone the recognition they deserve for the care they provide. There was a widespread feeling among survey respondents and diary keepers that £62.70 per week does not do justice to the strain that carers put themselves under to look after their loved ones:

*My son (who cares for me) deserves more money for everything he does for me, and as he left his job to look after me. He currently only gets £60 per week, which isn’t enough.*

Male living with MND, aged 75–84, South East

Our evidence suggests that this feeling is perhaps justified given the long-term effects of caring on someone’s life after bereavement – something we discuss in the next chapter.



## 8 The financial impact of MND after bereavement

This chapter presents our findings on the financial impact on partners and families after bereavement.

MND is a terminal condition. For every individual who is diagnosed with MND, there is a family whose members will be left behind at some point – whether after just a few months or years or, in rare cases, longer. Our research has found that as well as being emotionally devastating, bereavement is a time when some people face financial hardship.

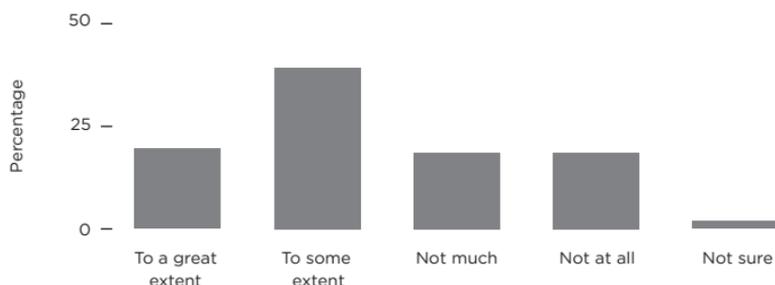
The chapter begins by presenting the overall picture of the financial impact on partners and families after the death of someone with MND. It then discusses the direct costs of bereavement, the lasting consequences of financial decisions made during the course of the disease, and the long-term impact of supporting a family member with MND on the mental and physical health of family members. Finally, the chapter assesses the support available for families coping with bereavement.

### **The overall financial impact after bereavement**

Our research shows that MND has a long-lasting financial impact on many families when one member has MND, which continues after bereavement.

Only 19 per cent of respondents reported that MND had taken no toll on their finances, and 60 per cent reported that it had taken a toll to some or to a great extent (figure 11).

Figure 11 **The extent to which survey respondents believe that their family member's MND has taken a toll on their personal finances**



Some bereaved family members were found to be more vulnerable to the financial impact of MND than others. First, people who had been the spouse or partner of their family member who died reported a greater financial toll than those who had been a parent, sibling, child or non-immediate family member. More than two-thirds (71 per cent) of bereaved spouses or partners said that MND had taken a toll on their finances to some or to a great extent, compared with 45 per cent of people who were not the spouse or partner of the deceased.

There are various reasons why partners might suffer a greater financial impact than other family members of the person with MND in the long term. First, a couple's finances are typically much more closely intertwined than the finances of other family members. Couples tend to pool their budgets, sharing income and expenditure, capital and debt. While the needs of these households drops when someone dies, the partner left behind may retain existing financial commitments – for example, they may have a mortgage that was intended to be paid by two salaries, not one. Furthermore, the couple may have jointly taken on debt, or eaten into joint savings while the person with MND was alive – the effects of which are felt by the partner left behind:

### *Having a mortgage and bills to pay with £90 a week!!*

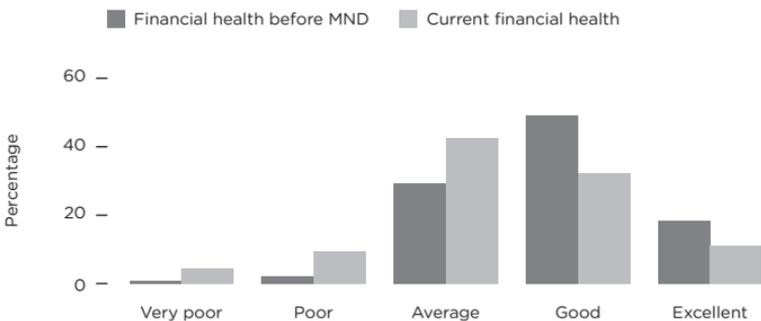
Bereaved spouse or partner, female, aged 35-44, North West

A further group at risk are people who provided extremely high levels of unpaid care to their family member before they died. Nearly three-quarters of people who had provided more than 70 hours of care per week said that MND had taken a toll on their finances to some or a great extent. Just over 4 in 10 of people who had provided less than 35 hours of care per week reported the same. As we explore later in this chapter, caring for someone with MND can make it difficult to re-enter the workforce after bereavement.

#### **The scale of the financial impact on families before MND began and now**

The bereavement survey asked respondents to compare their financial health before their family member was diagnosed with MND with their current situation (figure 12). This enabled us to assess the scale of the financial impact on families of a family member having MND, as outlined above.

Figure 12 **The financial health of survey respondents before MND began and now**



People who describe their financial health as poor or very poor are likely to struggle to afford the basic necessities of life. Just 3 per cent of respondents described their financial health

as poor or very poor prior to their family member being diagnosed with MND. The figure for those reporting the state of their finances as poor or very poor rose to approximately 14 per cent. Although this is only a modest increase in the total number of people struggling to make ends meet, comments to our survey suggest that the impact can be overwhelming:

*We went from two incomes before the illness to one and then I had to manage all bills and buy equipment he needed out of my salary, which meant I had to max out credit cards and get an overdraft. Now I'm struggling to pay bills so have to work extra shifts to be able to eat.*

Bereaved spouse or partner, female, aged 45-54, London

There was a greater change in the number of respondents describing their financial health as good or excellent. Nearly 7 in 10 respondents reported that their financial health had been good or excellent before their family member was diagnosed with MND, compared with less than half in relation to their current financial health. This shows that the financial health of more people went from good or excellent to average than from average to poor or very poor:

*I was out of work for nine years, three caring for my wife, six looking after our daughter and getting back to work. We received money from a life policy but I missed nine years of career progression so I am way behind where I would have been.*

Bereaved spouse or partner, male, aged 45-54, South East

These findings show that just as there are different kinds of financial impact when people are living with MND, so there are different kinds of impact after bereavement. The financial circumstances of some people who were just about managing before MND struck can plummet to the extent that meeting daily expenses is a struggle after bereavement. Others who are more financially secure when the disease began can nevertheless experience a drop in their living standards after bereavement, making do with a much smaller income or much less capital than they expected to have.

### **Short-term bereavement costs**

The immediate costs associated with bereavement are predominantly funeral expenses. Our research found that most people find them manageable. More than one-third (39 per cent) of respondents to our survey said that they or other family or friends had paid for their family member's funeral. A further 4 per cent of people reported paying for it themselves with the help of a funeral payment.<sup>41</sup> The average amount spent on funeral costs by those who contributed to the costs was £3,992. Over half of respondents paid £5,000 or less, and only a small fraction paid more than £7,500 towards funeral costs.

We asked respondents to state how manageable they found the funeral costs. The vast majority of respondents found it either easy to manage the funeral costs, or neither easy nor difficult to manage. Only 18 per cent of respondents found it relatively difficult or very difficult to cope with them.

### **The long-term financial consequences of living with MND**

In previous chapters we showed that living with MND can present significant financial challenges. There is a lack of support, and under such circumstances it can be difficult to make clear-headed financial decisions. This section demonstrates that the financial decisions made by individuals and their families when living with MND do not stop having an effect when a person with MND dies – they continue to have long-lasting, and often serious implications for the financial health of the family, long after bereavement.

#### **The impact on savings and debt**

In order to meet the needs of an individual living with MND, families are often forced to dip into savings. As shown in chapter 2, some of the biggest costs incurred by people with MND are housing adaptations and care – yet the primary financial support available for meeting these costs is means tested, and not available to people with savings above a particular amount. Families often have no choice but to

use their savings for these costs. Our bereavement survey showed that two-thirds of respondents had used savings to cover costs while their family member was alive.

Some people have more savings than others when diagnosed with MND, and some people live for longer than others. Therefore the savings left over at the end of the illness varies. When a family's savings are entirely depleted those left behind after bereavement can be financially vulnerable. The risk of this is even greater when people living with MND dip into their pension pots early:

*My former partner had some savings and took a private pension early in order to help with any costs. However in the long term I will have to move from our family home as I will not be able to afford to live here for very much longer. I had to change my mortgage and I doubt I'll be able to pay it off in full.*

Bereaved spouse or partner, female, aged 55-64, South East

Furthermore, the wider family can face a significant impact too. For example, young people are increasingly reliant on inheritance in order to get their foot on the property ladder.<sup>42</sup> If their parents or grandparents use up all their savings and need to remortgage their home, there may be no inheritance left. Having little to leave behind for future generations is often a source of frustration and sadness for people with MND.

Of course, there are people living with MND with little or no savings who may be entitled to means-tested support. However, people in this position may experience a shortfall between the assistance they are offered and the cost of the equipment or adaptations they need. Some may want to find the money to purchase equipment and adaptations better suited to their needs than those they are offered. People in this position may find themselves taking on debt: 16 per cent of respondents to our bereavement survey had taken on debt to meet costs associated with their family member's MND. Some 4 in 10 of them had not fully repaid the debt at the time of the survey. Not repaying debt can have a significant effect on all in the family. One bereaved family member told us that her husband had spent his time living with the disease worrying

about the debt he and his family were accruing. Another described having to go bankrupt after bereavement and having her house repossessed. Debt can be a major source of anxiety, instability and insecurity at an enormously difficult time.

### **The impact on employment shortly after bereavement**

As discussed in chapter 7, family members of people living with MND often provide a significant amount of unpaid care. Many – particularly partners and spouses – reduce their working hours or withdraw from employment altogether in order to do so. Sometimes providing unpaid care saves on the costs of formal care in the short term, but unfortunately our research shows that the experience of caring frequently has long-lasting financial implications for family members.

Some family members seek to re-enter the workforce within a relatively short time after bereavement. However, this can be challenging if someone has been out of employment for a long time:

*Because the caring had an impact on my work, I have sometimes felt that it was not only counselling that I needed, but life coaching or careers advice as well.*

Bereaved spouse or partner, female, London

In particular, people in professional jobs may find that their skillsets and training are no longer up to date. They may be required to take a job at a lower salary band than they would have been on previously. Even if they re-enter the workforce at the same salary band, they could have missed out on years of career progression, not to mention pensions contributions. This risk is particularly relevant to those whose family member with MND lived for longer than expected.

### **The long-term impact on employment resulting from ill health**

An even more worrying finding from our research is that some working age family members do not re-enter employment for many months or years after bereavement – if at all – often because of ill health.

Our findings suggest that people bereaved by MND suffer a particularly negative impact on their health, all the more so if they also provided care, because the family of a person with MND often has very little time to adjust to the diagnosis. It may take time before they decide they require support, and then services are frequently slow to respond. In the meantime, carers take on extraordinary levels of responsibility, trying to make their family member's last years, months and weeks as comfortable as possible. This can often result in what has been described as 'carer burnout' – a product of physical and mental ill health.<sup>43</sup>

Over three-quarters of bereaved family members reported that their relatives' MND had taken a toll on their physical health to a great or to some extent. The reported impact on physical health was even greater for those who had spent significant amounts of time caring for their family member before they died. Taking care of someone in the advanced stages of MND is a strenuous activity, as carers must lift and move the person with MND in order for them to wash, dress and perform other essential daily activities. The physical strain is heightened when home adaptations or equipment are delayed, and for women looking after men, given the differences in their body size:

*We were relatively comfortable financially but received no help from statutory services as we were considered not to be able to have financial help towards care costs. This inevitably took its toll on my health. As a carer and I now have back problems.*

Bereaved spouse or partner, female, aged 65-74, North West

The physical problems caused by caring can take months or years to be resolved after bereavement: 76 per cent of respondents to our survey who were bereaved more than a year ago said that their family member's MND was still taking a toll on their physical health to a great or to some extent.

MND has an even greater impact on the mental health of bereaved family members: 84 per cent of respondents to our survey reported that the disease had taken a toll on their mental health to some or to a great extent. As with physical

health, those who spent significant amounts of time caring for their family member before they died were even more likely to report a negative toll on their mental health.

Furthermore, while 9 in 10 people bereaved in the previous 12 months reported that MND had taken a toll on their mental health, this figure only dropped by a small amount, to 82 per cent, for those bereaved more than 12 months ago, suggesting that the impact of the bereavement on the mental health of family members continued for more than a year.

Unsurprisingly, many bereaved family members reported being too mentally or physically unwell to work for a long time after their caring responsibilities have ended, if at all. Those who rely on benefits and other financial assistance rather than a salary live on a much lower income than they would have done had they been able to return to work. In some cases, this jeopardises their overall financial security:

*I have been unable to work to my full capacity and doubt I will ever again. I now suffer physical pain as a direct result of caring for my husband. I have three daughters in full time education. I may lose our house.*

Bereaved spouse or partner, female, aged 55-64, London

*Through my time off work to care for my husband & the significant (& ongoing) impact on my emotional health I lost my job and career. It is appearing unlikely I will be able to return to my lifelong profession (mental health nursing) or any similar work.*

Bereaved spouse or partner, female, aged 45-54, East Midlands

## **Support after bereavement**

Just as support can help people living with MND and their families to cope, so can it help people bereaved by MND. As everyone's experience of MND is different, the support that might benefit any individual varies.

### **The support a person bereaved by someone with MND might need**

Some people may need direct financial assistance in the wake of their family member's death. At the time of our research, the main benefits currently available to support people following bereavement were Bereavement Payment, Bereavement Allowance and Widowed Parent's Allowance.

Bereavement Payment was a tax-free, lump sum of £2,000 paid to an individual under state pension age when their husband, wife or civil partner died.<sup>44</sup> Bereavement Allowance (formerly known as Widow's Pension) was paid to people widowed between the age of 45 and state pension age, for up to 52 weeks from the date of the partner or spouse's death. It was awarded on a sliding scale from £34.11 to £113.70 per week.<sup>45</sup> People bringing up children were entitled to greater support than Bereavement Allowance through Widowed Parent's Allowance. Like Bereavement Allowance, Widowed Parent's Allowance could be paid up to a maximum of £113.70 per week. However, it was not limited to 52 weeks, but continued to be paid until the individual stopped being entitled to Child Benefit or the parent reaches state pension age.<sup>46</sup> Since research for this project took place, these three benefits have been replaced by Bereavement Support Payment (BSP).

A bereaved person might very well need non-financial support. In addition to direct financial assistance, someone bereaved by MND might benefit from companionship and befriending services, specialist health services (including counselling), and help getting back into work and with practical matters (such as sorting out their family member's will). While some of these are not directly aimed at improving a person's finances, many of them would do so indirectly – for example, poor health can prevent someone from re-entering work, as demonstrated in the previous section.

### **The quality of support available to people bereaved by MND**

Our findings show that people who have lost family members to MND are not getting the support they need to cope following bereavement. We asked survey respondents whether

the benefits and other assistance they received following bereavement, if any, was adequate for their needs. Less than a third responded 'yes'. This finding substantiates evidence presented by the MND Association in response to the Department of Health's consultation on a new carers strategy, which found that bereavement support was either not available to all carers bereaved by MND, limited or came at the wrong time.<sup>47</sup>

#### *Features of adequate support*

The minority of respondents to our survey who said that they had been adequately supported mentioned several different kinds of provision. First, there were several mentions of financial assistance. One respondent said that she 'had not expected financial support' but that it had been helpful. Several respondents said they had used their Bereavement Payment or Bereavement Allowance to help cover the costs of their family member's funeral.

The means of support that was most frequently mentioned and praised was counselling. Some people paid privately for counselling, but others were able to secure it through the NHS, charities and hospices. Bereaved family members often found the opportunity to speak confidentially with someone about their experiences as 'invaluable':

*It was good to be able to talk confidentially to someone who was not a friend or family member. It is not easy to tell people to whom you are close your innermost thoughts at such a time.*

Bereaved spouse or partner, female, aged 65-74, Yorkshire and Humberside

Some respondents who said they felt adequately supported explained that they did not think they needed any sort of assistance, because they had private funds and felt that friends and family were enough for them. Some reported that they had been offered support but had turned it down; others had not been offered it. This is worrying because some survey respondents who reported being inadequately supported said they only realised that they needed professional assistance

months or years down the line:

*I did not need financial support. I did not receive any counselling, which in retrospect I very much needed.*

Bereaved daughter, aged 35-44, London

#### *Features of inadequate support*

Several respondents were critical of not having been offered support. Some reported that it was a shock to go from being in contact with so many professionals looking after their family member, to feeling abandoned following bereavement:

*I have received no support, when my wife passed, all contact with the outside world and care agencies ended. I took my daughter to our doctor who referred her for counselling sessions but they were unable to offer support as no appointment would be available for several months.*

Bereaved spouse or partner, male, aged 35-44, West Midlands

Counselling provision is a recurring subject of criticism. Some people never access it as they are put off by the waiting lists being so long, or cannot attend as the only available slots are in office hours when they need to work. Some people wait until they get to the top of the waiting list but then find that it is not useful many months after bereavement. Respondents to our survey also criticised the quality of counselling, saying they did not get enough sessions, or that the staff were poorly trained.

Our survey respondents were often critical of the financial assistance offered. A significant number reported that they were unaware of the existence of bereavement benefits:

*I knew nothing of the possibility of a bereavement grant.*

Bereaved spouse or partner, female, aged 65-74, South West

Some were also unaware that Bereavement Allowance and Widowed Parent's Allowance were classed as taxable income, and therefore made themselves worse off by applying for them:

*[I] was not told/informed it was taxable and had to be repaid in full. If I had been told I would not have claimed it.*

Bereaved spouse or partner, female, aged 65-74, Wales

Recent changes in bereavement payments have benefitted some people bereaved by MND, but disadvantaged many – including some of the most vulnerable. The new BSP, introduced in April 2017, is paid to people widowed under state pension age. Recipients are given a tax-free lump sum – £2,500 for those with no dependent children or £3,500 for those with dependent children. For the next 18 months, those without dependent children receive a monthly tax-free payment of £100, while those with dependent children receive £350.<sup>48</sup> BSP offers some advantages over the old system, which everyone who receives it will benefit from. Unlike Bereavement Allowance and Widowed Parent's Allowance, BSP is:

- tax-free
- fully disregarded in the calculation of income-based benefits
- fully disregarded in the assessment of benefit income that is subject to the household benefit cap
- not withdrawn if the recipient remarries or enters a new civil partnership.

Furthermore, the changes benefit widowed people without dependent children – particularly those under 45 when their spouse or partner died, who were not entitled to Bereavement Allowance under the old system.

However, the new system is less generous than the old system to nearly all working age parents. Under the old system, a working age parent with dependent children would have continued receiving Widowed Parent's Allowance until they stopped receiving Child Benefit. Under the new system, BSP stops after 18 months. Before the introduction of the new system, the Child Bereavement Network estimated that 91 per cent of parents would be supported for a shorter time under BSP.<sup>49</sup> This is worrying as working age people with children experience the worst financial impact of MND (as discussed

in chapter 2), and have to cope with the legacy of this during bereavement – now with less financial support.

The overhaul of bereavement benefits is just one example of how the support system for people with MND and their families is changing. In the next chapter we recommend ways to minimise the financial burden of MND, in light of these developments and our research findings.

## 9 Conclusion and recommendations

The devastation caused by MND cannot be put into words. The disease robs a person of their ability to move, communicate and breathe unaided. It is fatal and often rapidly progressive.

When faced with a terminal illness, the last thing anyone wants to spend their time doing is worrying about the state of their finances. Yet our report has shown that this is the reality for too many people living with MND and their families. The hidden costs associated with the disease can be enormous – and even the smaller ones quickly add up. Working age people with the disease face the additional strain of lost income from employment. The support available, including welfare benefits, is not adequate to cope with the size of the burden. Many people are left struggling to make ends meet daily, some take on debt, while others see their life savings and other assets rapidly shrink.

Furthermore, the financial impact of MND does not end on bereavement, but casts a long shadow on the lives of those left behind. Not only do bereaved family members have to cope with the grief and loss, but they frequently have to manage the consequences of financial decisions made when their loved one was still alive, whether to use a lifetime's worth of savings, to give up work, or to take on debt. For many families, including those suffering from poor mental and physical health as a result of caring for someone with MND, the financial impact of MND does not lessen on bereavement – it grows.

There is an urgent need to relieve the financial burden of MND on those living with the disease and their families. This is no easy task. Financial management is about planning ahead, but planning ahead is complex when someone does not

know how long they have to live, or what their needs will be at different points in the future. People with MND are supported by a vast array of individuals, some with a greater knowledge of the disease than others. Given the pressing health needs of people living with MND, it is all too easy for financial matters to be given less priority than others.

Despite these challenges, our findings have made clear that there are a number of steps that can be taken to minimise the financial impact on people living with MND and their families, from the beginning to the end of a person's journey with the disease. We make the following recommendations.

## Recommendations

**Recommendation 1: Health and social care professionals must ensure that people living with MND are signposted to financial advice and support as soon as possible after diagnosis**

Many of us struggle to manage our finances at the best of times. For someone living with MND, financial decision making is even more complex – there are more costs to manage, the future is uncertain and it is an emotionally turbulent time. Our research suggests that many families do not have this financial support, despite a NICE guideline on MND stating that social care practitioners should direct people with MND to financial support and advice.<sup>50</sup>

It is essential that social care services implement the NICE guideline in full when supporting people living with MND, including informing them of financial advice and support services such as those provided by the MND Association as soon as possible after diagnosis. Individuals newly diagnosed with MND and their families could be given a sense of control if they are helped to consider the possible costs and to plan for them. Our research suggests effective financial advice should be:

- *made available quickly* – as MND can progress rapidly, and people may begin to make financial decisions very quickly after diagnosis

- *ongoing* – as a person’s needs and wishes change, so might their financial requirements; they need continual access to financial advice in order to respond appropriately
- *broad* – as some people are eligible for few means-tested benefits or grants, but still need advice in order to minimise the impact of MND on their finances
- *accessible* – as people with MND are in contact with numerous health and social care professionals, and endless face-to-face appointments can be draining; advice should be available not only in person, but over the phone, or via email, online chat or video chat
- *not overly prescriptive* – as financial advice services must acknowledge that the outlook for someone with MND can change quickly and that individuals need to prepare as best they can for all eventualities (eg quick progression and slow progression).

**Recommendation 2: On learning that an employee has MND, employers should facilitate a planning process in which both parties agree on the steps to be taken at key stages in the disease’s progression, enabling the employee to continue in work for as long as they want and feel able to, and to make a smooth transition out of work when necessary**

Many people with MND want to continue working for some time after diagnosis. Employment can give people with the condition a sense of purpose, structure and normality, as well as a larger income.

Our research shows that some employers are highly supportive of employees who are diagnosed with MND, enabling them to stay in work for as long as possible through reduced hours, working from home options, and so on. Others are less sympathetic, and unable or unwilling to accommodate health deterioration. This may be due to poor understanding of MND as it is a relatively rare condition.

The government should work with employer organisations such as the Confederation of British Industry and Federation of Small Businesses, sector-specific umbrella bodies and unions to provide guidance on ‘health

conversations'. This guidance could equip employers with condition-specific information on diseases such as MND, explaining how it might affect their employee, and the ways in which this could be accommodated in the workplace through flexible working, job carving and other practices, encouraging employers to be understanding and flexible. Employers should be tasked with initiating a health conversation once an employee informs them of a serious health condition, and it should be used to plan the way forward jointly. A health conversation with someone with MND would include deciding at what point in the disease's progression certain changes would be made, such as when the employee would reduce their hours, work from home, and eventually leave work.

Having a plan from the start, even if the unpredictability of MND's progression makes it impossible to complete the plan with timescales, would enable both parties to have a better idea of what to expect from one another, reducing the likelihood of an abrupt end to employment, and helping the family coping with MND to plan their finances.

**Recommendation 3: Third sector organisations that provide financial support to people living with MND should review how much funding is used to pay for assistance around the home, and consider redirecting funds to this particular cost**

Our findings show that people living with MND and their families spend surprisingly high sums on assistance with domestic tasks, such as gardening, housework and laundry – an average of £216 every four weeks. While this might be an overestimate,<sup>51</sup> our survey indicated that these 'assistance costs' are very substantial, even when separated from formal care costs.

And yet there is limited financial support available for assistance costs. Some charities, such as the MND Association, offer financial help for assistance costs, which makes a big difference to the lives of those who receive it – but very many do not. Local authorities consider assistance costs when carrying out carer assessments of unpaid carers, but this is means tested. Those who rely on formal care rather than care from their families are not eligible for any help with assistance

costs, as it does not form part of their assessment. This is particularly problematic for single people with MND, or for those whose partners are too ill to provide informal care – in both scenarios, there may be no one available to carry out domestic tasks, but also no eligibility for covering the costs of buying such support in.

In light of our findings on the amount spent on assistance costs, and the difference that can be made by financing support for these costs, third sector organisations should review the funding they make available for assistance around the home. Existing funding could possibly be used more effectively if redirected towards these costs.

**Recommendation 4: Local authorities and the Northern Ireland Housing Executive should consider topping up disabled facilities grants for people with rapidly progressing conditions, including MND**

A person with MND often needs to make extensive adaptations to their home to continue living there for as long as possible. The cost of this can be enormous – figures in the tens of thousands of pounds are not uncommon.

Financial assistance is available for some through a disabled facilities grant, but the maximum grant value is £25,000–36,000 depending on where in the UK the grant is awarded, and many adaptations cost more than that. Local authorities (and the NIHE in Northern Ireland) have the power to top up disabled facilities grants though a discretionary payment, but research has shown that few local authorities use it.<sup>52</sup> As a result, people with MND and other conditions are forced to apply to charities and grant foundations to try to make up the shortfall if they are unable to fund the shortfall themselves.

Our findings show that applying to third sector organisations for further funding is a long and draining process, especially for people with MND, whose conditions often progress rapidly. They can have to go without what they need to live comfortably as the end of their life approaches and sometimes are moved to a care home against their will. They need to devote significant amounts

of time to application forms and other bureaucratic procedures when they should be making the most of the time they have left.

In March 2017 it was announced that the amount of funding available for disabled facilities grants in England would increase from £394 million in 2016–17 to £431 million in 2017–18 and £468 million in 2018–19.<sup>53</sup> Although we recognise the continued pressure on disabled facilities grant funds, we recommend that local authorities and the NIHE should consider topping up disabled facilities grants where necessary for people with rapidly progressing conditions, so they do not need to look elsewhere to find funding to make up the shortfall. People with rapidly progressing conditions, such as MND, suffer particularly badly from delays in having their homes adapted, yet cannot afford to spend time securing funding from the third sector.

**Recommendation 5: The Department of Health and relevant health commissioning organisations in each of the devolved nations must act to ensure that people with MND are made aware of NHS Continuing Healthcare in the early stages of the disease**

As described in chapter 4, social care costs can be a huge burden for people with MND. Yet as the disease progresses and support needs move from social care to primarily health based services, people with MND become eligible for CHC and costs are covered by the NHS. Awareness of NHS continuing healthcare (CHC) remains very low.

We fully support the findings and recommendations made by the Continuing Healthcare Alliance in their 2016 report concerning how CHC needs to be improved in England, including speeding up the application process, and also raising awareness of the funding stream overall.<sup>54</sup> Given the nature of the disease, it is almost inevitable that people with MND will become eligible for CHC at some point. Therefore people diagnosed with MND ought to be told about CHC by health and social care professionals as a matter of course, and early on in the disease. This includes being told about the fast track option available, as well as

sources of advice to support an application, such as the services provided by Beacon ([www.beaconchc.co.uk](http://www.beaconchc.co.uk)).

**Recommendation 6: The DWP must reconsider strengthening the assistance available to widowed parents through Bereavement Support Payment**

The DWP's stated aim in overhauling the bereavement benefits system earlier this year was to 'shift the focus of bereavement benefits from replacing the deceased spouse or civil partner's earnings to helping with the additional and more immediate costs of bereavement'.<sup>55</sup> Our research shows that for people bereaved by MND, this approach is flawed for two interrelated reasons:

- The short-term, immediate costs of bereavement pale in significance to the long-term costs.
- People bereaved by MND often remain unemployed for a significant period of time following bereavement, and therefore require bereavement benefits not to replace their spouse or partner's income, but their own.

Our research has shown that working age people are particularly vulnerable to the financial impact of MND. Those with dependent children face an even greater impact. The financial consequences of MND do not end on bereavement – parents and children continue to feel the effects, both financial and non-financial, for long after their loved one has died. While many parents are able to return to work shortly after bereavement, and should be supported to do so (see recommendation 7), those who cannot should not be forced to claim Universal Credit in order to secure an income, given its conditionality requirements. Widowed parents need to be available to their children if necessary, and they may need money to meet their child's bereavement-related needs (such as counselling).

Under the previous system, widowed parents received Widowed Parent's Allowance until their youngest child left full time education. In light of our research, we urge the DWP to consider strengthening BSP so bereaved

parents continue to receive support for as long as they receive Child Benefit.

**Recommendation 7: The government should extend funding for ‘returnships’ to bereaved carers looking to re-enter employment**

People bereaved by MND should not be pushed to re-enter the workplace before they are ready, but those who want and are able to should be supported to do so. Not only can work make life more fulfilling after bereavement, but it can also help people to become financially resilient again by increasing their income, repaying debt, and building up their savings once again.

However, returning to work can be challenging. Depending partly on how long they have been out of the workforce, returners may need help in refreshing their skills and boosting their confidence in order to return to a career. Others might need to have their mental or physical health accommodated, if this has suffered as a result of caring and/or bereavement.

Increasing the availability of returnships to bereaved family carers could be part of the solution. A variant of internships, returnships are paid roles designed to enable people who have taken career breaks to re-adjust to the workplace. Returnships offer people mentoring, coaching, training and personal development. Although they are short-term placements, typically lasting up to 12 weeks, some people are offered permanent roles on completion. Those who are not offered permanent work have gained valuable skills and experience, which enables them get a job elsewhere.

Although still a relatively new concept, returnships are receiving growing attention in the UK. In January the All Party Parliamentary Group for Women and Work called on more employers to offer returnships to women seeking to re-enter work after raising a family or caring.<sup>56</sup> Subsequently Theresa May announced £5 million of funding to support returnships.<sup>57</sup> While these returnships are open to men and women, the focus is on helping mothers to return to work. We recommend that the government provides dedicated funding

to returnships for bereaved carers, equipping them with the support they need to make a successful return to work. Thought should be given to how these returnships can be enhanced to meet the specific needs of this group, eg priority access to the employer's counselling provision.



# Technical appendix - quantitative analysis of costs incurred by people living with MND

## **About our survey of people living with MND**

We gathered quantitative evidence on costs through a survey of people living with MND. The survey consisted of 33 open-ended and closed-ended questions. The survey asked about:

- the demographics of the respondent, and condition-specific questions (such as time since diagnosis, amount of care required)
- costs incurred as a result of MND; our analysis of these questions is explained below
- changes in household income and salary as a result of MND
- financial support received, including welfare benefits
- the overall financial impact of MND, including the scale of the impact, how it varied over time, how it affected the lives of the respondent and their family, and the adequacy of the financial support received.

The survey was open from 7 November 2016 to 27 January 2017. Respondents had the option of answering a paper survey or submitting their answers online through SurveyMonkey. Paper copies of the survey were sent to MND care centres and MND Association branches and groups, and included a link to the online survey for those who preferred to submit their answers online. The survey was publicised by Demos and the

MND Association through our networks, social media and flyers.

The survey received a total of 333 responses – 245 online and 88 on paper.

### **The approach taken to quantitative analysis of costs questions**

The survey asked respondents to estimate how much they and their family had spent on 41 different costs related to MND: 9 one-off costs, 18 regular costs and 14 enhanced costs. We also asked respondents to indicate whether an organisation (such as their local authority, the NHS or a charity) paid for an item, or contributed towards the cost. For each set of costs, we asked one question and supplied one table for respondents to fill out. As explained below, we took different approaches to analysing each cost group.

#### **One-off costs**

We asked for estimates of spending on the following one-off costs:

- housing adaptations
- vehicle costs
- mobility aids
- household living aids
- communication aids
- environmental controls
- specialist, additional or differently sized clothing
- specialist, additional or differently sized furniture
- other one-off costs not listed above

Figure 13 shows the question we asked, and the first row of the table that respondents filled out.

Figure 13 The survey question on respondents' one-off costs

We are interested in the costs you pay as a result of having MND, and whether anyone else helps pay for these costs.

One-off costs

20. Which one-off costs have you paid (or your partner/other family member on your behalf) as a result of MND? Fill in all that apply. Please indicate if another organisation has contributed, in whole or in part, in the final column.

One-off cost	Total amount paid by you or your family (£) - tick one	Did another organisation (such as the NHS, a local authority or a charity) cover some/all of the costs or 'top up' your contribution? Tick if so
Housing adaptations / building works - eg stair lift, grab rails, wet room	<input type="checkbox"/> £0 <input type="checkbox"/> £1 - £25 <input type="checkbox"/> £26 - £50 <input type="checkbox"/> £51 - £100 <input type="checkbox"/> £101 - £250 <input type="checkbox"/> £251 - £500 <input type="checkbox"/> £501 - £750 <input type="checkbox"/> £751 - £1,000 <input type="checkbox"/> £1,001 or more	<input type="checkbox"/>

For each one-off cost, we asked respondents to estimate their own and their family's expenditure *over the entire duration of the disease so far*. Respondents ticked one of nine bands, from '£0' to '£1,001 or more' (figure 13).

To calculate the average amount spent on a given one-off cost, we recoded the survey responses, replacing each band with a single midpoint figure for each respondent. For example, '£26-50' was recoded as a response of '£38'. There were two exceptions: '£0' was not recoded, and '£1,001 or more' was recoded as '£1,001'. Using the recoded responses, we calculated the average (mean) amount spent by respondents on the cost.

To estimate the average total amount spent on all one-off costs, we added up the total amount spent on one-off costs for each respondent. We then calculated the mean.

Our approach to calculating one-off costs has two limitations:

- By re-coding '£1,001 or more' responses as '£1,001', we fail to capture high expenditure ranging into the thousands or tens of thousands. For example, someone who spent £20,000 on adapting their home would show up in our results as having spent £1,001 on housing adaptations. The same limitation applies to the way we calculated regular costs and enhanced costs.
- We asked respondents to estimate their one-off costs *to date*. This approach had the advantage of enabling us to capture expenditure on costs that might have otherwise been missed, as a result of falling outside the four-week time frame used for regular and enhanced costs (see below). However, it is likely that the expenditure on one-off costs of respondents in the early or middle stages of the disease would further increase after the time of the survey. As a result, the average amounts spent on individual and total one-off costs presented in this research should be treated as conservative estimates of what a person with MND would likely incur over the duration of the disease.

### **Regular costs**

We asked for estimates of the following regular costs:

- care at home
- a place in a care home
- respite care and carer's breaks
- further assistance around the home
- staying away from home (eg for appointments far from home)
- home visits
- public transport to and from appointments
- private transport to and from appointments
- hospital car parking charges
- prescription medicines
- non-prescription medicines
- extra medical costs

- advice on welfare benefits
- advice on wider financial matters
- advice on legal matters
- counselling
- other regular costs not listed above.

Figure 14 shows the question we asked, and the first row of the table that respondents filled out.

Figure 14 **The survey question on respondents' regular condition-specific costs**

Regular condition-specific costs

The table below has a list of **regular** costs that people with MND (or their families) may have to pay because of the condition.

21. Over the past **FOUR WEEKS**, how much did you (or your partner/other family member on your behalf) spend on each of these items? Fill in all that apply. Please indicate if another organisation has contributed, in whole or in part, in the final column

Item	Total amount paid by you or your family (£) - tick one	Did another organisation (such as the NHS, a local authority or a charity) cover some/all of the costs or 'top up' your contribution? Tick if so
Nursing or personal care at home	<input type="checkbox"/> £0 <input type="checkbox"/> £1 - £25 <input type="checkbox"/> £26 - £50 <input type="checkbox"/> £51 - £100 <input type="checkbox"/> £101 - £250 <input type="checkbox"/> £251 - £500 <input type="checkbox"/> £501 - £750 <input type="checkbox"/> £751 - £1,000 <input type="checkbox"/> £1,001 or more	<input type="checkbox"/>

Our approach to calculating regular costs was very similar to our approach for calculating one-off costs. However, for each regular cost we asked respondents to estimate their own and their family's expenditure *over the previous four weeks* – rather than to date, as with one-off costs.

Respondents ticked one of the same nine bands used for one-off costs. We recoded responses in the same way as with one-off costs – we replaced each response with a midpoint value, with the exception of ‘£0’, which was uncoded, and ‘£1,001 or more’, which was coded as £1,001. Using the recoded responses, we calculated the average (mean) amount spent by respondents on each regular cost. To calculate the average amount spent on all regular costs, we added up the total amount spent on all regular costs by each respondent and then calculated its mean.

A limitation to our evidence on regular costs concerns the cost of assistance around the home. The average amount spent on this cost was higher than expected. While the survey makes a clear distinction between the cost of care and the cost of assistance around the home, it is possible that some respondents classified help from a personal assistant as an assistance cost, when we intended it to be classified as a care cost. Thus the average amount spent on assistance costs is likely to be a slight overestimate.

### **Enhanced costs**

We asked for estimates of the following enhanced costs:

- energy bills
- rent or mortgage
- phone, internet and media bills
- home insurance
- travel insurance
- vehicle and equipment insurance
- other insurance
- public transport costs
- private transport costs
- parking charges
- household items (eg cleaning products)
- leisure and entertainment
- childcare
- other enhanced costs not listed above.

Figure 15 shows the question we asked, and the first row of the table that respondents filled out.

Figure 15 The survey question on respondents' enhanced costs

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Enhanced 'everyday' costs

The table below has a list of costs that you might have already had, but which may have increased as a result of having MND. We are going to ask how much you are currently spending on a range of items, and also how much you think you would be spending if you did not have MND. This will help us understand the 'extra' hidden costs.

1. Over the past FOUR WEEKS, how much did you (or your partner or other family member, on your behalf) spend on each of the items? Approximately how much do you think you would have paid if you did not have MND?

- If a particular cost does not apply to you (or your family), tick '0' in both columns.

Item	Total cost paid by you over the past 4 weeks (£) - tick one option	How much do you think you would have spent on this item over the past 4 weeks if you did not have MND? - tick one option
Energy bills - eg heating	<input type="checkbox"/> £0 <input type="checkbox"/> £1 - £25 <input type="checkbox"/> £26 - £50 <input type="checkbox"/> £51 - £100 <input type="checkbox"/> £101 - £250 <input type="checkbox"/> £251 - £500 <input type="checkbox"/> £501 - £750 <input type="checkbox"/> £751 - £1,000 <input type="checkbox"/> £1,001 or more	<input type="checkbox"/> £0 <input type="checkbox"/> £1 - £25 <input type="checkbox"/> £26 - £50 <input type="checkbox"/> £51 - £100 <input type="checkbox"/> £101 - £250 <input type="checkbox"/> £251 - £500 <input type="checkbox"/> £501 - £750 <input type="checkbox"/> £751 - £1,000 <input type="checkbox"/> £1,001 or more

As with regular costs, we asked respondents to estimate their expenditure on enhanced costs *over the previous four weeks*. Respondents ticked how much they spent on each enhanced cost in one of the nine bands used for one-off costs and regular costs. However, we wanted to calculate the average amount spent on these costs *as a result of MND*. Therefore, in addition to indicating their actual expenditure on each enhanced cost, we asked respondents to estimate how much they would have spent on each enhanced cost over the same period *if they did not have MND* (see figure 15). We recoded all responses using the midpoints of each band, as with one-off and regular costs.

To calculate the average amount spent on a given enhanced cost *as a result of MND*, we first calculated the average actual expenditure on the cost for all respondents. We then deducted the average total amount that respondents estimated they would have spent without MND.

To calculate the average amount spent on all enhanced costs *as a result of MND*, we calculated the total amount actually spent on all enhanced costs over the previous four weeks for each respondent. We then calculated the mean. We then calculated how much each respondent said they would have spent in total on enhanced costs without MND, and calculated the mean. We deducted the estimate of what a respondent would have spent on average if they did not have MND from the average of what that person actually spent as a result of having MND. Finally, we decided not to include the average amount spent on 'other enhanced costs' as a result of MND, as respondents' answers to what they included in this category gave us reason to believe the data was unreliable, as explained below.

There are two limitations to our data on enhanced costs:

- Estimating how much one would spend on a particular cost under very different conditions is difficult. As a result, respondents' estimates of what they would have spent on a particular cost without MND may be inaccurate, and should be treated as indicative.
- Some respondents misinterpreted what was meant by an 'enhanced cost', including one-off costs and regular costs in their calculation of 'other enhanced costs', such as housing adaptations and vehicle costs. As a result we exclude other enhanced costs from our calculation of average total enhanced costs. Our estimate of the average amount spent on all enhanced costs is therefore likely to be a slight underestimate.

# Notes

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Being diagnosed with a progressive, terminal health condition is one of the biggest challenges anyone can face in life. Under such difficult circumstances, the last thing anyone wants to do is worry about money. Yet in recent years there has been a growing body of evidence showing that serious health conditions can have significant financial implications for individuals and their families, resulting in added stress and worry at an already challenging time.

This report reveals a hidden side of a devastating terminal illness: the financial impact of motor neurone disease (MND) on those living with the condition and their families. The research shows that while living with the disease, people with MND incur a number of extra costs related to their condition. Frequently they must also cope with reduced household incomes, resulting from the individual with MND leaving work and, in some cases, their family members leaving work to provide unpaid care. The financial support available is insufficient for the majority of families to meet their needs. Furthermore, the research shows that the financial impact of MND does not end at the point of bereavement, but casts a long shadow on the lives of those left behind, as family members are left with reduced savings and pensions to draw upon and may struggle to re-enter the workforce.

The report concludes with a series of recommendations which aim to minimise the financial impact of MND, from the beginning to the end of a person's journey with the disease as well as after bereavement. Taken together, these measures will help to reduce the financial burden faced by people with MND and their families, allowing them to focus on making the most of the time they have left and overcoming their loss.

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