

**Through the roof:**  
**The experience of households affected  
by MND during the cost of living crisis**



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## About MND and the MND Association

Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work.

There is no cure for MND. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop frontotemporal dementia.

There are up to 5,000 people living with MND in the UK at any one time. It can affect adults of any age. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with 90 volunteer-led branches and groups, and 13,000 volunteers. The MND Association's vision is of a world free from MND. Until that time, we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and die with dignity.

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## Executive summary

This report describes the catastrophic costs and challenges faced by people affected by MND during the cost of living crisis. Survey data produced by the MND Association shows that people living with MND have been disproportionately affected by the crisis. In many cases, this forces people to make difficult, and sometimes impossible, choices between essential living expenses and their own health and wellbeing.

Some people are spending £10,000 a year on electricity costs alone for using and maintaining personal powered equipment. This equipment enables people to remain safe, independent and, in some cases, alive, meaning not only are these costs catastrophic but they are also inescapable. As the case study for the report states, "I'm having to absorb all the costs of the disease. I'm running a small hospital from home and I'm paying so dearly for it... When given such a devastating terminal diagnosis all you really want to do is focus on your loved one - make them feel as safe, support, and loved as possible. You don't want to be worrying about paying bills and funding."

Almost three-quarters (72%) of survey respondents reported their household used personal powered equipment. Yet alarmingly, we found that 28% of respondents limited their use of these pieces of equipment in the previous 12 months in response to rising energy costs. The impact has been immeasurable, but people cannot afford to gamble on their health. As one respondent stated:

“

The electric company are not helping us, and I am past caring if I run up a debt.

”

There are also difficult choices managing a reduced income – commonly experienced by people affected by MND – which the crisis has only made significantly more challenging. These difficult choices frequently result in feelings of worry, anxiety, and despair. Almost nine in ten (87%) of survey respondents are worried about being able to pay for living essentials over the next 12 months.

Accompanying these feelings, however, are reactions of frustration and disappointment in a social security system that does not appear to work as it should – to adequately support people facing financial hardship through no fault of their own. This leaves people with nowhere to turn. As one respondent stated:

“

Trying to access a benefit system, it's just so complicated. You feel you want to give up.

”

Although direct Government intervention during the crisis has been welcome, it has also been limited. A total of £1,850 in direct financial support has been made available for disabled people and those on low incomes during 2022, 2023 and 2024. This covers only 13% of the average yearly cost of living with and managing MND, estimated at £14,500. This inadequacy is markedly more when normal essential costs are considered, such as food, energy and rent.

By July 2023, the MND Association's cost of living webpage had received 1,617 views, with an additional 93,862 unique views on our benefits webpage. Between January and June 2023, we financially supported 784 families affected by MND through our Cost of Living Support Fund – a one-off payment towards household bills and food shopping up to £350 – totalling £273,100. Across the sector, many charities like MND Association have stepped up to provide direct and vital support to their communities because of the crisis. Yet the voluntary sector alone cannot provide a long-term solution.

Unless urgent and significant Government investment is forthcoming, people with MND and their families will continue to experience the disproportionate impact of this crisis for years to come. The recommendations set out in this briefing provide a range of measures Government can easily implement to address the immediate financial plight of people affected by MND as a result of the cost-of-living crisis. However, the current crisis has laid bare the underlying financial impact of living with MND, much of which existed well before the crisis had even occurred. It is vital Government look to review the adequacy of broader financial support available to people with a disability and their families, ensuring it is fit for purpose, so people can live well with the conditions they have.

## RECOMMENDATIONS

The UK Government should:

1. Implement an Energy Social Tariff that would provide a discount on energy bills for households affected by MND. Government should ensure all households affected by MND are eligible, and that the discount is below the market rate and applied directly to the unit cost of energy.
2. Review the level of Carer's Allowance to ensure that it better reflects the value provided by unpaid carers. Its strict eligibility requirements should also be addressed such as removing the earning threshold, reducing the minimum time-spent-caring condition, and removing limited eligibility rules if a person is cared for by more than one person and for carers over State Pension age.
3. Address the inequality of entitlement between Personal Independence Payments and Attendance Allowance, ensuring that older disabled people are not discriminated against in their level of disability entitlement.
4. Review the adequacy of benefit entitlements available to disabled people to ensure that those who leave the workforce indefinitely because of their condition do not face significant financial hardship.
5. Implement an Essentials Guarantee that would set a minimum standard allowance of Universal Credit to ensure lower income families can continue to afford basic essentials.
6. Extend the Disability Cost of Living Payment into 2024 and bring it in line with the level of the Cost of Living Payment.

## Methodology

We held an online survey which ran between January to March 2023 with the aim to take a snapshot of the impact of the cost of living crisis on people affected by MND. The survey was easy to access and open to individuals or households affected by MND, considering that the wider family may be impacted by an MND diagnosis and the cost of living crisis.

The survey was promoted across our social media channels on Twitter and Facebook, and via our volunteers. It included a broad range of open-ended questions, with space for commentary and individual feedback. It was open to respondents from across the UK.

There were 83 responses in total, although not all answered each question and the survey compiled both quantitative and qualitative data from people's experiences.

A breakdown of the respondents found that:

- 63% were people living with MND, and 37% were people affected by MND – a carer, relative or friend of a person with MND.
- 63% were female, 36% were male and 1% preferred to self-define.
- 86% were from England, 6% from Northern Ireland, 4% from Scotland, 2% from Wales and 2% unknown.

We would like to extend our sincere thanks to all respondents who offered their views and experiences to the survey.

## Introduction

This report illustrates the disproportionate and damaging impacts of the current cost-of-living crisis on households affected by MND. The cost of living crisis refers to the fall in real disposable incomes the UK has experienced since late 2021. The prices of many essential goods and items began increasing faster than household incomes caused, in part, by a significant rise in inflation which, in February 2023, was at its highest level for 30 years.<sup>1</sup>

Government had intended to cut inflation significantly in 2023, with hopes that the rate returns to Bank of England's target of 2% by early 2024. However, at the time of writing, inflation has remained stubbornly high. Even if it does return to the 2% target, this only means that living costs are increasing by less than household incomes. For many households affected by MND, though, they simply do not have the luxury of a sufficient income to cope with burgeoning prices.

This is because people with MND commonly give up work due to the impact of the condition and family members may often reduce or stop work altogether to provide care. This can be devastating, especially given the additional costs of managing MND – an average of around £14,500 a year above and beyond normal living costs – although many spend significantly more. These additional costs may include the cost of care and support, the cost of equipment and housing adaptations to enable people with MND to live safely at home, increased transportation costs due to reduced mobility, and increased energy costs.

The sharp rise in energy costs since 2021 has had a particularly severe and disproportionate effect on people living with MND, who need to use a wide range of powered equipment at home as the disease progresses. These include artificial ventilation systems to communications and mobility equipment, cough assist and saliva suction, adjustable beds and hoists. Many households affected by MND are now struggling to meet the running costs of equipment they rely on daily to maintain life, health and wellbeing.

The reduction in incomes, a stubbornly high inflation rate and the additional costs of the condition means that people affected by MND will continue to experience the damaging effects of the crisis well beyond 2024 and potentially into the next decade.

While everyone in the UK will have experienced the effects of the crisis, people with MND have been disproportionately affected, as this report will show. The crisis has moved beyond 'heat or eat' for people with MND, and they are now forced to take damaging risks with their health. Government intervention is now essential.

## The experience of households affected by MND during the cost of living crisis

### Theme 1: Difficult choices affording basic living essentials

Nine in ten (91%) survey respondents reported that their household is financially worse off than 12 months ago.<sup>2</sup> This is no surprise given the UK inflation rate – as calculated by the Consumer Price Index which measures the percentage change in the price of goods and services consumed by households – rose by 10.4% in the 12 months up to February 2023.<sup>3</sup>

*Of those who reported being financially worse off, almost all (99%) respondents reported their household is paying more for essentials, with a fifth (21%) reporting their mortgage or rent has increased and half (49%) paying more for non-essential items.<sup>4</sup>*



The cost-of-living crisis has impacted us terribly. Not only have the bills gone through the roof but we are being evicted under a no-fault Section 21. The landlord wanted to increase the rent by £350 which is impossible... God knows where we'll end up, but it won't be what we have now. My husband already has quite enough to deal with (as do I) but this is having a massive effect on our mental health, too.

**Survey respondent**



In response to mounting prices, many households affected by MND had struggled to afford basic living essentials; over half (51%) reported their household experienced difficulties paying for food, home heating and energy over the last 12 months.<sup>5</sup> An impact of this is that many people reduced their spending on these key essentials; a third (35%) of respondents ate or drank less. Similarly, three-quarters (74%) reduced their home heating and two-thirds (68%) reduced their home energy use.



We're just worried about the bills and cutting back everywhere to make ends meet.

Survey respondent



The financial difficulty over the last 12 months has resulted in significant negative outcomes for people affected by MND and their families. Our survey found that almost six in ten (57%) reported that these difficulties have led to a negative impact on their mental health and wellbeing.

***Of those who reported being negatively affected, 86% reported an increase in anxiety, 77% reported affected sleep and almost one-third (30%) have sought support for their mental health, such as through a GP or counsellor.<sup>6</sup>***

Despite Government committing to significantly reduce inflation in 2023, it has remained stubbornly high, meaning the cost of living crisis is not slowing down.<sup>7</sup> Almost nine in ten (87%) of survey respondents are worried about being able to pay for living essentials over the next 12 months.<sup>8</sup> The Institute for Government predicts that Real Household Disposable Income – a measure for living standards that considers total household earnings after tax and accounts for inflation – will not return to its 2021/22 level until 2027/28.<sup>9</sup>

***As a result of worry over finances, in the next 12 months, two-thirds plan to cut down on heating as well as energy use (67% and 68%, respectively), a quarter (27%) plan to cut down on essentials such as food, and 63% plan to use their savings to pay for essentials. Worryingly, 5% plan to borrow money to cope with rising costs and 16% plan to turn charities, such as food banks, for support.<sup>10</sup>***



We are really thinking about every purchase, whether we can buy a supermarket ready meal and a packet of biscuits or have to forego it. We are heating rooms we are in, the parts of the house where my husband is, not the bits I go into like my office, and bedroom. We are thinking about whether we can afford to do anything out of the house.

Survey respondent



The Government has implemented a series of measures to combat the impact of the crisis on those most vulnerable. For example, in 2022, Government introduced the Disability Cost of Living Payment – a one-off £150 payment for disabled people to cope with the rising costs of the crisis. Similarly, a £650 Cost of Living Payment, was introduced for those on specific means-tested benefits.<sup>11</sup> In 2023, an additional £150 Disability Cost of Living Payment was given to disabled people and a £900 Cost of living Payment was made available to eligible people through to 2024.

However, it is unclear why the Disability Cost of Living Payment is not being extended until 2024, in line with the Cost of Living Payment. It is also unclear why the Disability Cost of Living Payment is far less of an entitlement to the payment available to low-income households. This has been a missed opportunity to support disabled people, many of whom incur additional costs as a result of their disability, especially for people with MND. This is particularly the case for younger people with MND and their families, who may not have lifetime savings to manage the financial impact of the disease, as well as contending with additional financial pressures such as raising children and paying mortgages.

## RECOMMENDATION

We therefore urge the Government to address this inequality of entitlement by bringing the Disability Cost of Living Payment in line with the level of the Cost of Living Payment and extend support into 2024.

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Direct financial support was introduced alongside the Energy Price Guarantee – a £2,500 cap on the cost of energy a typical household will pay in a year. While introduced in October 2022, it was only due to run until March 2023 and we were pleased to see Government extend this cap until June 2023 – something which we campaigned for alongside other charities and organisations in the sector.<sup>12</sup>

However, the price cap was frozen at twice the average cost of energy of what it was in 2021. It is also currently insufficient for households to rely on ad-hoc support without addressing the underlying causes of many people’s inability to meet the rising cost of essentials, particularly for the most financially vulnerable such as those on means-tested benefits.

A common experience shared in our survey was a reduction in income when leaving the workforce due to MND. Although the risk of developing MND increases with age, younger adults of working age can also develop the disease. When people are diagnosed with MND, it is challenging to continue to work as they lose their functional ability, making the social security system a necessity. In addition, working-age adults diagnosed with MND are likely to have fewer financial assets to fall back on when they are forced to leave the workforce. For many, benefits and entitlements are a vital source of income to help lower-income people and families meet the cost of essential items, with 39% of respondents to our survey saying their household income comes from benefits.<sup>13</sup>

However, the current rate of many means-tested benefits is far too low. The Joseph Rowntree Foundation reports that 90% of low-income households on Universal Credit are currently going without essentials. For a couple aged 25 and over, there is a currently a £66 shortfall between the standard weekly allowance of Universal Credit and the cost of basic essentials.<sup>14</sup>

## RECOMMENDATION

We support The Trussell Trust and Joseph Rowntree Foundation’s ‘Guarantee Our Essentials’ call for the standard allowance of Universal Credit to be set at a rate that protects people from going without essentials. While this rate should be set by an independent and regular process, the campaign suggests it would need to be at least £120 a week for a single adult and £200 for a couple.<sup>15</sup>

## Theme 2: Difficult choices impacting health and wellbeing

The nature of MND means that many households affected by MND spend more to manage the symptoms and its impact on daily living. For example, they may spend more on electricity due to their reliance on personal powered equipment. Assistive equipment for MND enables people to remain safe, independent, and well, in and outside their homes.

*Almost three-quarters (72%) of survey respondents reported their household used personal powered equipment to manage MND.<sup>16</sup>*



I use an increased number of powered items in the home: a powered wheelchair, powered riser recliner, hospital adjustable bed, dynamic powered mattress, technology to assist turning lights on and off. Not to mention future needs which may include powered items to assist with communication and breathing. The cost of running all these powered items concerns me.

Survey respondent



Survey respondents reported significant anxiety around the impact of the cost of living crisis on maintaining these pieces of equipment. For many people, they simply cannot manage without them. We heard several experiences of people staunchly refusing to cut back on their use, given their impact on keeping them safe, independent and, in some instances, alive. Instead, households tried to make savings elsewhere such as reducing their home heating, limiting their food spending, or forgoing leisure activities.



I can't live comfortably without personal powered equipment so that has priority over other expenses.

Survey respondent



*In the previous 12 months, three-quarters (74%) of survey respondents reported reducing their home heating to cope with rising energy costs, and two-thirds (67%) plan to reduce this over the next 12 months.<sup>17</sup> As a result, a fifth (20%) aim to make home energy efficiency improvements.*



(I'm) unable to cut back as the medical equipment keeps me alive.

Survey respondent



*Worryingly, however, over one-quarter (28%) of respondents told us they have reduced their use of personal powered equipment in the last 12 months in response to rising energy costs.<sup>18</sup>*

People with MND are therefore disproportionately vulnerable since they are required to limit support for their health and wellbeing in response to rising costs. While concerning, it not necessarily surprising given the cost of using these pieces of equipment.

*Families managing advanced stages of the condition have told the MND Association that they currently spend between £800 and £900 a month on their household electricity bill, which equates to an astronomical £10,000 a year.*

It is so expensive because these people require a wide range of assistive equipment to keep them alive and independent. These can include: 24/7 ventilation, cough assist and saliva suction, powered wheelchairs, communications equipment, powered adjustable beds and hoists. They may also include adaptations in the home such as through-floor lifts, stairlifts and bath lifts.

People with less advanced MND may use a smaller range of equipment but are still likely to rely on powered home equipment to enable them to live safely at home.

*We estimate that people with MND spend, on average, an additional £600 a year on electricity costs – based on the October 2022 Energy Price Guarantee unit rate – for charging and using assistive equipment, on top of other household costs and other additional costs of MND.<sup>19</sup>*

As well as electricity costs, people with MND may also run up higher bills for other utilities because of their condition. For instance, muscle wastage commonly associated with MND can often result in people feeling pain in colder environments, requiring them to use more home heating. Similarly, people may spend more on their water bill due to cleaning the vast array of assistive equipment for MND or having longer showers as a result of poorer mobility.



Heating is on most of the time as my husband’s muscles become extremely painful if he gets cold.

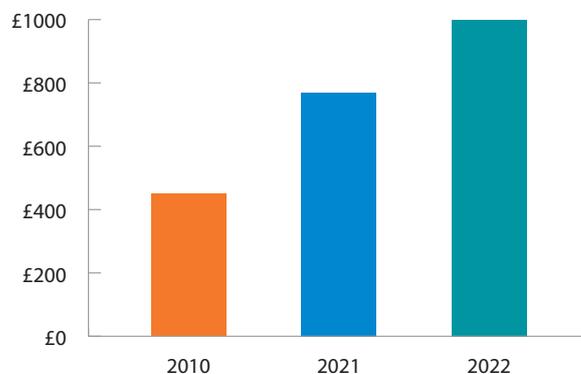
**Survey respondent**



Government support for households during the energy crisis so far has been welcome, but unnecessarily selective. For example, the Warm Homes Discount Scheme – a one-off £150 discount off electricity bills – was only made available to low-income households who have high energy costs.<sup>20</sup> This is unwarranted for those households affected by MND who are excluded from the scheme yet still face catastrophic energy costs.

It is positive the Government’s Energy Price Guarantee was extended until June 2023, capping the unit cost of energy. Following the end of the cap, energy prices have fallen from their peak below the cap level but remain extremely high, especially for heavy energy users such as people living with MND. The average yearly UK household electricity bill in 2010 was £450. However, in 2021 it was £769, a 36% real increase. As of 2022, it was over £1,000.<sup>21</sup> Alarmingly, overall annual energy bills are not expected to return to pre-2021 figures until at least 2030.<sup>22</sup>

### Average yearly UK household electricity bill



Additional and targeted support is therefore required to mitigate the impact of rising energy costs and ensure people can continue to use assistive equipment sufficiently to manage and live with the disease. There are already some schemes in place to financially reimburse – to some extent, at least – disabled people who use assistive equipment. For example, NHS England allows trusts to offer electricity rebates for two types of equipment – oxygen concentrators and dialysis machines.

However, it is unclear why other pieces of electrical equipment are excluded from the rebate. This means that many other disabled people with conditions who rely on assistive equipment are barred from accessing the scheme. Research also suggests that the scheme is not well publicised nor utilised.<sup>23 24</sup> The rebate is also paid for through local NHS budgets which can be unstable and subject to cutbacks.



Mum has been helping me top up the gas meter to keep my husband warm because no amount of extra blankets (will) do it. He needs a baseline warmth in the house.

**Survey respondent**



While the NHS rebate scheme is a positive one, more work needs to be done on eligibility and delivery so more people can benefit from the scheme in the future. However, people with MND cannot wait and currently face catastrophic energy costs. Therefore, there is a need to urgently implement a solution that

helps support a broader number of disabled people who rely on assistive equipment mitigate the impact of rising energy costs.

## RECOMMENDATION

**We urge the Government to immediately introduce an Energy Social Tariff to help support disabled people mitigate catastrophic energy costs. The tariff acts as a discounted energy bill and is targeted towards disabled people who face high energy costs.<sup>46</sup>**

The scheme will be particularly beneficial for people with MND. This is because they currently experience an unfairness in relation to the management of their disease. MND is primarily managed at home, meaning families are forced to cover the high costs of running assistive equipment. Yet if their conditions were managed in hospital, the costs would be covered by the NHS.

Social tariffs already exist across other industries – water and broadband – and there is will from the Office of Gas and Electricity Markets (Ofgem) as well as the energy industry to explore such a scheme, so we know that the tariff is both desired and achievable.<sup>25 26</sup> It is also favoured across patient organisations, 95 of which signed an open letter to Chancellor Jeremy Hunt in January 2023 calling for the introduction of the tariff.<sup>27</sup>

There are various models of an Energy Social Tariff, whether these are discounts applied by a cash payment or a tariff on how much households pay per unit of energy.<sup>28 29</sup> In any consideration of an Energy Social Tariff, Government should ensure that eligibility is extended to all households affected by MND. Passporting only disability welfare claimants to further support risks some households missing out on the benefits of an Energy Social Tariff.<sup>30</sup> For example, some people with MND may not yet be in receipt of benefits, but the often-rapid deterioration of their condition means that they may already be using assistive equipment to manage their condition.

The tariff should also ensure that the discount is below the market rate and that it is applied directly to the unit cost of energy, so households pay discounted prices at the point of purchase and not reimbursed at a later date. This would help facilitate access to support that is direct and immediate.



The rocketing energy cost means we don't have the heating on as much as my husband needs to keep comfortable.

**Survey respondent**



## Nicola and Mark – case study

“My husband, Mark, was diagnosed with MND in June 2019, but he was displaying symptoms months before his diagnosis.

The diagnosis itself was shocking – the consultant told us Mark had MND when we were in a hospital corridor, and we weren’t even offered an opportunity to ask questions about the disease. It really set the tone to how we were going to experience life with the condition, and it’s been a battle ever since to get Mark the care he needs. It is a devastating diagnosis – there’s no hope, no real treatments available. And we were told to just go home.

By the time the Covid-19 lockdown happened nine months later, Mark was struggling to walk, and I was fighting with the council to get the right equipment and adaptations in the house. I did this so he could still remain independent in our home. But I had to do it all on my own. There was no help.

Due to Mark’s condition, he now requires 24-hour care and we’re supported by a team of 13 nurses and carers. This all comes with extra household costs. You’re washing out syringes all day, you need to prevent infection and that requires such a high level of cleaning and therefore water usage. You need to keep the heating on for the carers. These are the costs of MND people don’t really think about.

We’re also using so much more electricity because Mark requires so many pieces of assistive equipment to keep him alive and independent – two hoists, wheelchair, ventilators, back-up ventilators, humidifier, the list goes on. They all run on electricity, and they all cost money to run. If Mark was in hospital, this would all be paid for but I’m having to absorb all the costs of the disease. I’m running a small hospital from home and I’m paying so dearly for it.

Just my monthly electricity bill was £800. How is this affordable? I’m doing my absolute best by Mark, but it’s unsustainable.

The things politicians have to do on a daily basis, I wouldn’t want to be one for all the tea in China. But what they have done is completely disproportionate for disabled people. Everyone is going through the cost of living crisis, but a £150 Disability Cost of Living Payment doesn’t even touch the sides.

I’m working full-time because the costs of the condition means I can’t afford not to work. If I don’t work, then I can’t pay our mortgage. Our bills are through the roof but I’m battling to keep that roof over our heads. I’ve fought tooth and nail for Mark to get the care he needs and I’m paying through the nose for the privilege. When given such a devastating terminal diagnosis all you really want to do is focus on your loved one – make them feel as safe, supported, and loved as possible. You don’t want to be worrying about paying bills and funding. The Government have it in their power to make this life changing situation more bearable.”



I refuse to do less in this department (reducing use of personal powered equipment). The electric company are not helping us, and I am past caring if I run up a debt.

**Survey respondent**



### Theme 3: Difficult choices managing a decreased income

Many people's experiences pertained to what is often called a 'disability tax' – by nature of having a disability, people spend more compared to those without one. For instance, households who cannot drive or have access to a suitable car rely on taxis to get to healthcare appointments, as public transport may be insufficient for their mobility needs.

*It is estimated that households affected by MND spend an average of £14,500 a year on the direct costs of living with and managing the condition, with many households spending much more.<sup>31</sup>*

MND is a progressive and incurable condition, so once people with MND leave the workforce they will never return, resulting in a permanent loss of income. In 2017, 82% of people with MND reported experiencing a negative financial impact following diagnosis.<sup>32</sup> In the context of the crisis, people with MND are disproportionately vulnerable – the cost of living has substantially increased but their financial earning power has also reduced because of their condition.

Many carers may also have to leave the workforce or significantly reduce their hours to continue in their caring role.

*In 2022, over half (52%) of carers for people with MND reported spending over 75 hours a week caring, and 79% providing over 35 hours of care – a normal working week.<sup>33</sup>*

It is therefore no surprise that half (50%) of carers for people with MND have reported that caring had caused them financial difficulty.<sup>34</sup>

Just 6% of our cost-of-living survey respondents said their household income was derived from two income streams from employment or business, with a quarter (28%) reporting income was derived from one income stream.<sup>35</sup> This suggests that many families are managing the impact of an MND diagnosis in a precarious financial position during the cost of living crisis.



As I was diagnosed 12 months ago and was forced to give up work, I have lost my income. My wife is self-employed but is working far less in order to support me.

Survey respondent



This is exemplified by the fact that while just 14% of respondents said their household experienced difficulties paying for their mortgage or rent in the previous 12 months, over half (52%) are worried about being able to pay it over the next 12 months at the time of the survey.<sup>36 37</sup> Current efforts by the Bank of England to curb inflation has resulted in increased interest rates. This has had a significant impact on households affected by MND and their ability to pay their mortgage. It also affects renting households as buy-to-let landlords pass on increased mortgage costs to renters.

People affected by MND are not only experiencing an increase in mortgage repayments but face additional challenges during the mortgage crisis, particularly as many require specially adapted housing. Adaptations such as wet rooms, ramps and hoists are expensive to install and not all properties are suitable for reclined wheelchair users. People with MND cannot therefore move houses easily to alleviate their mortgage situation, as they face having to pay for adaptations again. They are also limited in their flexibility to choose a property before getting the adaptations, as not all properties are suitable.



We do not qualify for a disabled facilities grant therefore our savings are being spent... I have increased care needs which have doubled the cost of my care... I'm over the threshold for assistance from social services and I'm therefore having to spend my savings, but I need the extension for my care.

Survey respondent



The impact of MND on household employment and income means people must rely on the social security system to support them during financial hardship. However, in 2017, of those that received financial support, almost half (45%) of people affected by MND said it was not adequate enough to meet their or their family's needs.<sup>38</sup> The impact of the recent rising costs due to the crisis only increases the need for an improved social security system.



I have not been able to work since June 2022. I'm personally so much worse off. My partner's income has gone up, but our household income has gone down and our costs have hugely increased.

**Survey respondent**



It is important to recognise that full income replacement cannot be achieved from savings, pensions, or benefits. At the very least, support following a loss of income as a result of a disability should protect families from further financial hardship. This is particularly the case for younger people with MND and their families, where they may not be able to rely on lifetime savings or are coping with additional financial pressures such as raising children or mortgage payments.



(I'm) struggling. Never claimed a benefit in my life. Don't know where to turn. Had no income since last November (and I'm) really struggling with normal household bills.

**Survey respondent**



People living with MND may be entitled to a range of benefits because of their condition, depending on their financial circumstances and occupation. Personal Independence Payment (PIP) and Attendance Allowance are common disability-related benefits for people with MND. Carers of people with MND may be entitled to Carer's Allowance, a benefit for

people who provide care for someone with a disability for at least 35 hours a week, though eligibility is limited by restrictive criteria.<sup>39</sup>



After being a self-employed plumber for 40 years... (I) never claimed a benefit in my working life. I need help from the government. But there are so many hoops to jump through. I just find it exhausting and frustrating.

**Survey respondent**



While it is positive that the Government committed to raise the rate of welfare benefits in line with inflation in late 2022, including PIP, Attendance Allowance and Carer's Allowance, more needs to be done to review the adequacy of these benefits. For example, carers may have to leave the workforce or significantly reduce their hours reducing their household's overall income – 17% of unpaid carers of people with MND report being out of work because of their caring responsibilities.<sup>40</sup>

While Carer's Allowance can provide a vital lifeline for carers, the adequacy of the entitlement does not reflect the sheer value they offer, by providing care that would have otherwise been met by formal, paid-for social care. The value of unpaid care in the UK is estimated at £162bn a year, equivalent to a second NHS in England and Wales which, in 2020/21, received an estimated £164bn in funding.<sup>41</sup>

Despite needing to provide at least 35 hours – a normal working week – of care to be eligible for Carer's Allowance, the benefit is set at a lower financial rate than other work replacement benefits. Almost half (46%) of UK adults did not agree that Carer's Allowance is a fair level of support for an unpaid carer providing care for a minimum of 35 hours a week.<sup>42</sup> It is therefore no surprise that, in 2022, 44% of unpaid carers said that the benefit is not enough to meet their needs as a carer. For unpaid carers of people with MND, just 10% said they agreed the welfare benefits they received met their needs as a carer.<sup>43</sup>

Moreover, a couple receiving a higher rate of PIP and Carer's Allowance are eligible to receive £12,974 a year. This leaves more than a 10% shortfall in covering the average direct cost of living with and managing MND – £14,500 a year, although many people spend much more – which lays bare the inadequacy of entitlements for disabled people.<sup>44</sup> The shortfall is considerably

higher when other costs outside the direct costs of having a disability, such as food, energy and rent, are considered. The Department of Work and Pension's White Paper, 'Transforming Support: The Health and Disability White Paper', published in March 2023 and billed as the biggest change to the welfare system in a decade, did nothing to address this inadequacy.



**My mortgage fixed rate is up in August and I'm looking at a £200 rise. I live alone and now reliant on benefits.**

**Survey respondent**



The White Paper focuses strongly on enabling more disabled people to re-enter the workforce. Although we welcome appropriate support for people living with disability to remain in or re-enter work, it is essential that this approach does not lead to inappropriate requirements placed on people with progressive and terminal conditions such as MND. The government's own research found that two-thirds (67%) of people in the Limited Capability for Work and Work Related Activity group on Universal Credit, or who are in the Employment and Support Allowance (ESA) Support Group had ruled out paid work as being a future option for them.<sup>45</sup> Any work-related activity offers for people with severe, progressive conditions such as MND must be voluntary and should have no impact on their entitlement to financial support through the benefits system.

In addition to the adequacy of benefit levels, there is also an issue of eligibility for some entitlements. In particular, there is an inequality of entitlement for people living with MND based on their age. For example, people under 65 are eligible for PIP, which contains a mobility assessment and additional entitlement on top of the standard benefit rate. However, those living with MND over 65 are not entitled to PIP but are entitled to Attendance Allowance, which does not include a mobility element. This not only means older people receive less in total entitlement but are also denied access to welfare schemes that could help support their independence such as the Motability scheme.



**I have had to give up work to care for my husband and now only receive carers allowance.**

**Survey respondent**



Similarly, strict eligibility requirements govern access to Carer's Allowance, meaning many unpaid carers providing direct care to people living with MND do not qualify for the entitlement. For example, only carers who earn less than £139 a week after tax, National Insurance and expenses are eligible, as well as only those who care for more than 35 hours a week. Where a person is cared for by more than one person, only one carer is entitled to Carer's Allowance, which does not reflect the present-day nature of caring amongst different family circumstances. There are also eligibility implications for carers who are in receipt of State Pension.

It is clear that the strict eligibility requirements of some benefits mean many struggling people cannot access financial support. Yet even when they do, it is not even enough to cover the cost of their disability and essential living expenses. This is exacerbated by the fact that many households affected by MND will lose incomes because of their condition.

## **RECOMMENDATION**

**We therefore urge the Government to conduct a review into the provision and adequacy of welfare benefits. This should include addressing the inequality of entitlement between those eligible for PIP and those for Attendance Allowance.**

**It must also do more for carers and ensure that as many carers as possible are eligible for financial support, and that this financial support is sufficient for them to continue in their caring role. This should include reviewing the level of the entitlement to ensure that it reflects the value unpaid carers offer, as well as addressing the strict eligibility requirements for the entitlement.**

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## Conclusion

This report describes the unique experiences of people affected by MND during the cost of living crisis. It details the disproportionate impact they have experienced which has often led to difficult choices being made between their quality of life and their health and wellbeing.

People affected by MND are particularly vulnerable to the effects of cost of living. The nature of the condition means people and their families often must reduce or give up their primary sources of income, while spending more to cope with the impacts of the condition. This leaves many families to rely on a social security system to support them through challenging financial times. Yet this system is not working as it should and is failing people with disabilities.

This report sets out a series of measures – both short and long term – that the Government can easily implement to ensure families affected by MND are protected from the effects of the cost of living crisis. This includes targeted interventions to support those most vulnerable to the crisis as well as addressing some of the barriers that prevent people from accessing social security support.

Inflation and prices for essential items remains stubbornly high and so the effects of the crisis will be felt for years to come. It is paramount that Government act urgently on the recommendations set out in this report.





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