

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

Executive Summary

Introduction

This report shows that people affected by motor neurone disease (MND) have been disproportionately affected by the cost of living crisis. In many cases, this forces people to make difficult, and sometimes impossible, choices between essential living expenses and their own health and wellbeing.

Alarming, we found that people were taking damaging risks with their health by reducing the use of assistive equipment because of burgeoning energy prices. The impact has been immeasurable, but some 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."

People also face 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.

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

Unless urgent and significant Government investment in support 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.

Recommendations

The UK Government should:

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.

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.

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.

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.

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.

Extend the Disability Cost of Living Payment into 2024 and bring it in line with the level of the Cost of Living Payment.

Key findings

Theme 1: Difficult choices affording basic living essentials.

- Nine in ten (91%) households affected MND reported that their household is financially worse off compared to 12 months ago.
- Of those who reported being financially worse off, almost all (99%) respondents reported their household is paying more for essentials, with a fifth (21%) reported their mortgage or rent has increased and half (49%) paying more for non-essential items.
- Over half (51%) reported their household experienced difficulties paying for food, home heating and energy over the last 12 months.
- 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.
- 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.
- 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.

Theme 2: Difficult choices impacting health and wellbeing.

- 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. As a result, a fifth (20%) aim to make home energy efficiency improvements.
- Almost three-quarters (72%) of survey respondents reported their household used personal powered equipment to manage MND.
- 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.
- On average, people living with MND can spend £600 a year on electricity costs for charging and using assistive equipment, on top of other household costs for MND. However, we know some families are spending between £800 and £900 a month on electricity costs for their assistive equipment – equating to an astronomical £10,000 a year.

Key findings

Theme 3: Difficult choices managing a reduced income.

- 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.
- Over half (52%) of people affected by MND are worried about being able to pay their mortgage over the next 12 months.
- In 2022, over half (52%) of unpaid 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.
- Over half (50%) of unpaid carers for people with MND have reported that caring had caused them financial difficulty.
- Just 10% of unpaid carers of people with MND said the welfare benefits they received met their needs as a carer.

Nicola and Mark's story

"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.

Finally, though, 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...

Nicola and Mark's story

... 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."

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.

You can [read the full report on our website here](#).

If you are living with MND or know someone with MND who needs help or support, please contact MND Connect on 0808 802 6262 or email us at mndconnect@mndassociation.org.