mnda
motor neurone disease
association

SUPPORT
MND CARERS

The MND Carer Triple Burden:

Rising Costs, Falling Earnings and Benefits Shortfalls

Background

Unpaid carers play a vital role in caring for people living with MND. Their contribution enables people with MND to live well for longer and saves health and social care systems substantial costs by addressing needs that would otherwise fall to statutory services. But they cannot do this on their own. Carers need support themselves to continue caring and maintain their health and wellbeing. Carers should never face financial vulnerability as a result of the vital role they perform.

Anecdotally, we know the impact of the cost-of-living crisis has exacerbated the financial difficulties carers face, and we know that benefits available to carers are insufficient. We launched a survey to better understand carers' experiences and insights into the financial issues caused by caring.

The survey reflects the experiences of MND carers in relation to:

Rising costs

The cost of being an MND carer has never been higher. 68% have had to make significant changes to their budget for essential items to cover disability-related expenses. This has caused families to utilise large amounts of savings and even go into debt to cover these expenses.

> "I have lost my salary, home, car, business, job, family, friends, savings and I can no longer see my grandchildren more than once a fortnight or once a month."

Falling earnings

Carers face an impossible choice between work and care. Over one-fifth (21%) of carers have had to reduce their work hours with a further third (36%) leaving full employment altogether. This is having a major impact on household income – 58% of carers said that current carer related benefits do not cover earnings from loss of employment.

> "The financial impact isn't just that of a carer, but you lose two household incomes. Everything has changed."

Benefits shortfalls

The current safety net is insufficient. Almost all (94%) respondents believe the current rate of Carers Allowance (£81.90) is insufficient to meet their needs as carers, with 54% saying they require at least £200 per week. Moreover, many reported being ineligible for support entirely.

> "The whole system is unfit for purpose and an insult to carers. (Our care is) cheap slave labour done out of love and necessity."

Methodology

We held an online survey which ran between May and July 2024 to capture the financial impact of caring for someone with living with MND. This included the increased costs associated with caring, potential impact on of employment due to these responsibilities and the welfare provision available to carers.

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

Theme 1: Rising Costs

The cost of MND has never been higher. Previous MND Association research found 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 significantly more. The recent cost-of-living crisis has exacerbated the financial position further for households affected by MND. In our 2023 survey, we found nine in ten (91%) households were financially worse off than 12 months ago, and half (51%) struggled to afford basic living essentials such as food, home heating and energy.[1]

Due to the nature of MND, people diagnosed with the condition will have to leave the workforce, which places an additional financial burden on their loved ones to support them and their families' livelihoods. In our survey, nearly 70% told us the impact of caring had a severe impact on their personal financial situation.

One respondent told us:

> "The costs just keep escalating, savings just disappear."

These increasing costs are leading to impossible decisions for households. 68% have had to make significant changes to their budget for essential items to cover disability-related expenses. Moreover, 81% have had to use personal savings or retirement funds to cover these with 64% using over £2,000 amount of savings in the past year on these. For many these increased costs have been lifechanging:

> "I have lost my salary, home, car, business, job, family, friends, savings and I can no longer see my grandchildren more than once a fortnight or once a month."

For those without savings the picture only worsens. One-fifth (22%) of respondents reported being in debt or having gone into debt to cover disability-related expenses. Among those in debt, 51% incurred over £2,000 in the past year to cover these expenses. One respondent summed up their precarious situation as:

> "no savings, increasing debts, and then the loss of my partner."

These rising costs can affect all sections of the MND community. It is unfair for older people as they spend their lives working for retirement funds which are then quickly depleted following diagnosis due to the rapidly progressing nature of MND. Younger people and their families, on the other hand, have not often had enough time to build a savings buffer to cover the costs of the condition, and an MND diagnosis can put them back financially across their lifetime.

How much of your savings have been used to cover caregiving-related expenses over the past year (or in a previous year when caring)

Theme 2: Falling Earnings

Alongside rising costs, high care needs associated with MND often means carers spend a significant amount of time caring for their loved ones. Over half (52%) of MND carers report spending over 75 hours a week providing unpaid care to their loved ones, and eight in ten (79%) spend over an average working week (35 hours) providing care.[2]

Also, the complexity of symptoms means MND carers often provide a wide range of care for their loved ones. For instance, 83% and 82% of MND carers reported providing higher level care such as personal care and physical help, respectively, as well as lighter touch care such as giving emotional support (92%), helping with paperwork and financial matters (88%) and keeping their loved ones' company (88%).[3]

These high care needs leave carers with an impossible choice: remain in employment but limit vital time spent with loved ones, or provide needed care but reduce savings and pension earnings for later life. One fifth (21%) of carers have had to at reduce their work hours with 36% leaving full employment altogether. This is having a major impact on household income – 58% of carers said that current carer related benefits do not cover earnings from loss of employment.

One respondent told us:

> “Your world gets flipped upside down. My wife and I have been lucky in our careers and worked hard to be able to support our family and three daughters. The financial impact isn’t just that of a carer, but you lose two household incomes. Everything has changed.”

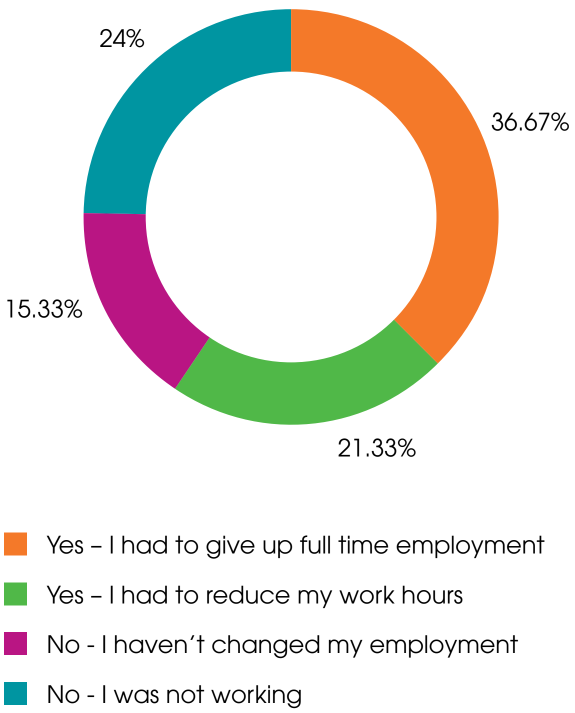
When people are forced to leave work, they are entitled to a range of benefits including Universal Credit. However, only 4%believe that the benefits they do receive adequately cover the loss of earnings from leaving employment. Additionally, loss of employment for carers can lead to a loss of independence. One respondent said:

> “I found having to give up my job very difficult. Caring for someone who is so poorly is all consuming. My work allowed me time away from caring responsibilities and gave me something else in my life.”

For those who do continue to work, the cost of carers in their absence makes working even more difficult. 20% of carers have paid at least £500 per week in homecare whilst working. Some received full or partial support from NHS Continuing Healthcare but some did not and had to pay fully out of pocket. For one respondent:

> “Care cost more than £500 a day, took all our savings and more.”

Have you had to give up any form of employment as a result of caring responsibilities?



Theme 3: Benefits Shortfalls

Where costs are rising and earnings falling, many carers rely on support from the government to look after their loved one. Unfortunately, the system of Carer's Allowance – the rate at which it is paid and who is eligible – is falling short.

Firstly, some carers are not even aware this support exists. Despite the benefit being available to them, 15% of respondents were not aware that they might qualify for Carer's Allowance. Of those aware of Carer's Allowance, 46% did not apply. Often, the process of applying can put unnecessary strain on an already struggling group.

One respondent said:

> "At a time when you are mentally and physically exhausted, any difficulties you encounter feel enormous."

There also exists a strict eligibility criterion which excludes people whose earnings exceed a relatively low income threshold of net £139 per week. This includes many people who are signficantly financially impacted by caring and require support. Of those who didn't qualify, 71% earned over the £139 per week earning threshold and 20% couldn't access the allowance due to being in receipt of State Pension. Moreover, as many as 84% of respondents told us they believed the eligibility criteria is unfair.

One respondent said:

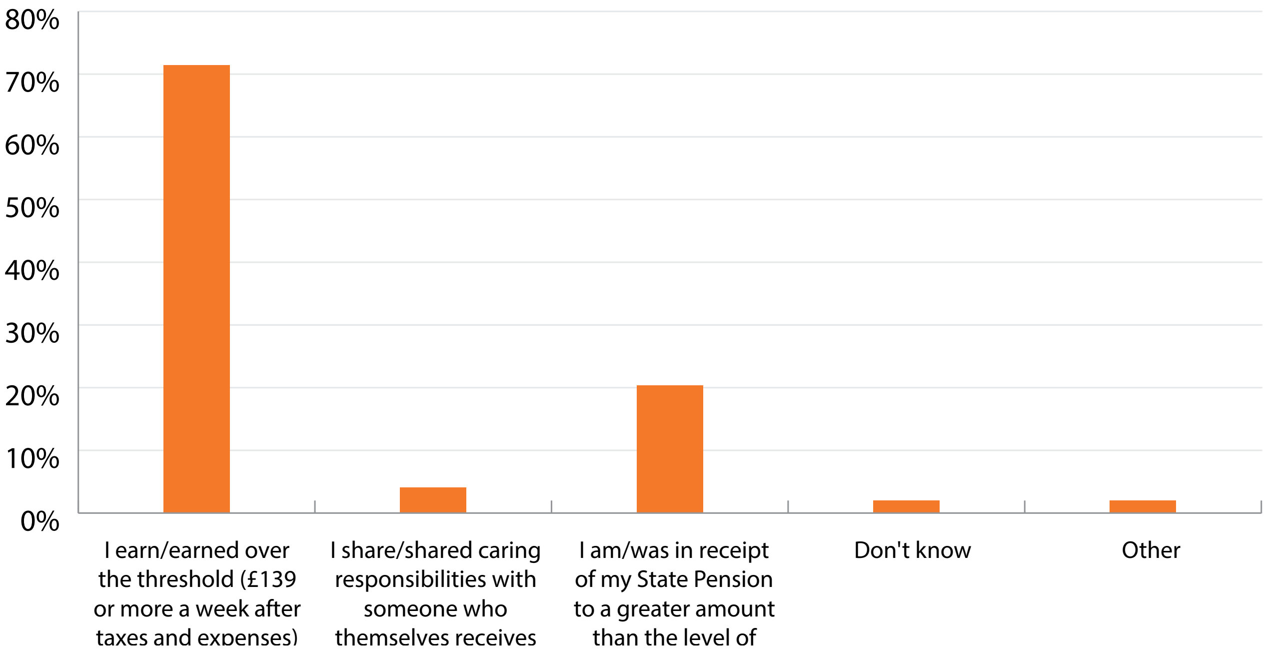
> "I applied for carers allowance but was refused as I worked too many hours, I have since had to cut my hours down as my husband's needs have increased so I will try again to apply for it."

Overall, the process has been found to be difficult to navigate. There are major logistical barriers to people accessing the allowance with 35% finding process of applying for Carer's Allowance difficult. Even with successful claims, delays have been common, with 11% only receiving their allowance 3-6 months after applying.

> "It was a very lengthy process in which I did not receive any payment for four months."

> "I missed almost a year of benefits as I wasn't aware that I could claim. It took a long time for it to be sorted."

Why do you or did you not qualify for Carer's Allowance?



Finally, the vast majority (94%) of respondents believe that the current rate of Carer's Allowance (£81.90) is insufficient to meet their needs as carers – over half (50%) said they require at least £200 per week.

One respondent said, "The whole system is unfit for purpose and an insult to carers. [Our care is] cheap slave labour done out of love and necessity."

This is even more important given the value unpaid carers provide and pressure they take off the health and social care system. In 2020, the value of unpaid care was estimated at £530m per day.[4] Unpaid carer labour saves costs from what might have otherwise been met by formal, paid care such as local authority-commissioned homecare. We estimate that carers of people living with MND in the UK save health and social care systems £185m a year, equivalent to £37,000 per carer, per year.

Carer's Allowance overpayments

In the context of the scandal into overpayments of Carer's Allowance, it was important the survey captured the experience of people living with MND in relation to this. Overall, nationally, 30,000 people were told to repay sums relating to Carer's Allowance earnings breaches in 2022-23, with more than 800 repaying sums of between £5,000 and £20,000, and 36 repaying more than £20,000.[5]

This survey found the story of Christopher and his carer. Christopher spent his final seven weeks in hospital. His carer was with him 24 hours a day to care for him and ensure he had his medication on time. Christopher had Bulbar MND so he was unable to talk. The carer had an 'overpayment' after Christopher's death telling them that they had to repay four weeks' worth of Carer's Allowance. This is unacceptable.

Moreover, the survey found a wider issue around people whose earnings were changing throughout periods. One survey participant told us:

> **"I earned £1 too much one week and got my allowance stopped for months. It was so stressful on top of everything else. They have no system for averaging out earnings. It made me consider giving up work all together, but that's the only time I get social interaction."**

Policy Recommendations

Given the rising costs, earning loss and benefit shortfalls faced by MND carers it is essential the welfare system is reformed, namely Carer's Allowance which is not adequately meeting their needs. To address this, the Government should:

- Address strict eligibility requirements for Carer's Allowance such as removing the age threshold, tapering the earnings threshold and the minimum time-spent caring condition, and removing the limited eligibility rules if a person is cared for by more than one person.
- Reform Carer's Allowance by uplifting the rate to a level that reflects the value unpaid carers offer.
- Modernise and digitise the delivery of Carer's Allowance to make it less complicated for claimants and to protect carers from overpayments.

References

1 *MND Association (2022). Through the roof: The experience of households affected by MND during the cost of living crisis*

2 *MND Association. (2022). Understanding the experiences of unpaid carers of people living with MND*

3 *MND Association. (2022). Understanding the experiences of unpaid carers of people living with MND*

4 *Carers UK. (2020). Unseen and Undervalued*

5 *The Guardian (2024). Calls to end 'persecution' of carers over UK benefits rule breaches*

mnda
motor neurone disease
association

Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton
NN3 6BJ

Tel: 01604 611860
Email: campaigns@mndassociation.org
www.mndassociation.org

/mndassociation
@mndassoc
mndassoc

Registered Charity No 294354 © MND Association 2024