

Understanding the experiences of unpaid carers of people living with MND



"I never saw it as a responsibility, I only ever saw it as just being with him out of love and joy, and I would always tell him that. I didn't see myself as a carer, it's just easier to use that word sometimes with other people to make sense of what I was doing."

Former carer of someone with MND

Executive Summary
November 2022

Introduction

Too often the needs of carers are ignored and neglected. Following the COVID-19 pandemic and the current cost-of-living crisis, additional strains have been placed upon unpaid carers, negatively impacting their health and wellbeing.

The MND Association has set out to further its commitment to supporting unpaid carers of those living with MND, making sure that their issues are recognised and addressed by those in power. This report aims to understand and evidence carers needs and experiences to inform responses to ongoing policy issues relating to unpaid carers.

218 unpaid carers aged over 18 completed our survey, with an additional 26 carers participating in a digital focus group, and 3 carers having one-to-one interviews. The survey responses from 184 carers who are currently providing care for individuals living with MND were used in this project.

The report shows that the current care provision offered by UK Governments is inadequate in supporting the needs of those caring for people living with MND, which contributes to the ongoing struggles carers face carrying out their caring role and managing their health and wellbeing.

Mental and Physical Exhaustion

Many individuals experienced physical and mental exhaustion as a result of their caring role, with 66% of carers who responded to the survey stating that they had not had enough breaks to protect their health and wellbeing.

Often local respite care services do not equip care staff with the resources and experience required to support those with complex care needs, and this lack of skilled staff removes the option of respite for some carers and further contributes to feelings of isolation and loneliness.

Additionally, the pandemic placed additional stress onto carers, increasing the need for respite at a time where access to respite was extremely difficult.

Many carers who also have parental responsibilities emphasised the difficulties they have finding the time to care for their children as well. The dual responsibility of providing care and support to a person with MND and meeting the needs of their children, adds additional pressure and stress onto carers, further heightening the mental and physical exhaustion that they endure.

Carers' Experiences of Care and Support

Lack of access to coordinated care and support heavily impacts on the experiences of care and support that carers receive.

From our survey, over half of respondents provide over 75 hours of care per week, but many feel like they have been ignored or unsupported by social care and statutory services.

If support has been provided, carers can often feel excluded from discussions about the care and support that is needed, thus negatively impacting the experiences of care and support that carers receive.

The effect of the COVID-19 pandemic worsened this, with delays to diagnosis, worries over risk of infection, and withdrawal of support services having affected the wellbeing of 53% of respondents.

Carer's Assessments

Carers are legally entitled to a Carer's Assessment to evaluate their support needs in their caring role.

However, our report found that only 25% of carers for people living with MND had either received an assessment or are in the process of having one completed. But 40% were still unaware of their right to an assessment.

Many of those who received an assessment felt that no practical support was offered, or support was not timely enough.

This was felt particularly strongly by those who have to balance caring responsibilities with work, looking after children, and other domestic duties, with 17% highlighting that their caring role prevented them from working altogether.

Financial Impact of Caring

The lack of financial support for unpaid carers contributes challenges they face.

Nearly 50% of those who answered our survey felt that caring caused them financial difficulty, with many stating that this impacts on their wellbeing, relationships, and their ability to care.

Previous research has shown that living with MND has a significant impact on household finances, due to the costs associated with managing the condition as it progresses. These include the cost of care and support, equipment and home adaptations, and enhanced travel and energy costs, as well as the impact of having to give up work.

Key Recommendations:

- Ringfenced funding to help reform and rebuild social care and health services.
- The Government to bring forward its promised workforce plans to address workforce shortages.
- Implement a Recovery and Respite Plan to address issues exacerbated by the COVID-19 pandemic.
- A full review of carers assessments, with a particular focus on improving awareness, availability, and access.
- Increased employment support by the Government and employers for working carers.
- The Government to review the financial support available to carers.

Where can I find out more?

- **Go to our Support MND Carers campaign webpage at www.mndassociation.org/SupportMNDCarers.**
- **You can read the report in full, and access the wide range of campaign resources.**
- **Finally, if you are living with MND or know someone with MND who needs support, please contact MND Connect on **0808 802 6262** or email us at mndconnect@mndassociation.org**