


Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Improving access to support for unpaid carers](#).

UC20: Ymateb gan: Motor Neurone Disease (MND) Association| Response from: Motor Neurone Disease (MND) Association

Improving access to support for unpaid carers

MND Association Response

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These are the views of:	The MND Association – the leading charity in England, Wales and Northern Ireland focused on funding research, improving access to care and campaigning for people living with or affected by MND.

About MND

Motor Neurone Disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It leaves people locked in a failing body, unable to walk, talk and, eventually, breathe.

Six people are diagnosed with MND every day in the UK, and six people die. The lifetime risk of developing the disease is 1 in 300. MND affects around 5,000 adults in the UK at any one time, around 300 of whom are living in Wales.

MND kills a third of people within a year of diagnosis and more than half within two years. There is no cure.

About the MND Association

The MND Association is the only national charity in England, Wales, and Northern Ireland focused on MND care, research, and campaigning. A separate organisation covers Scotland (www.mndscotland.org.uk).

The MND Association funds 22 specialist MND care centres and networks in partnership with NHS Trusts across England, Wales, and Northern Ireland. In 2024, we issued 73,477 pieces of care information to people living with, or affected by, MND.

The MND Association funds and promotes research that leads to new understanding and treatments, bringing us closer to a cure for MND. The value of our whole research grant portfolio by the end of 2024 was £16.4 million which encompassed 89 research grants.

The MND Association provides support grants to help people with MND and their carers manage the disease. These grants help by, for example, paying for home adaptations to allow continued home living. We also distribute Emergency Support Grants to help those living with MND struggling with additional costs as a result of their condition.

About MND carers

Unpaid carers provide essential support for people living with MND including assistance with personal care, mobility, attending medical appointments, using assistive equipment, providing emotional support, and much more. They help their loved ones maintain a better quality of life while easing the burden on health and social care services. Our research estimates that MND carers in the UK save the health and social care systems £185 million a year, which is equivalent to £37,000 per carer per year¹.

The high care needs associated with MND often means carers spend a significant amount of time providing care and support. In our recent report, we found that over half (52%) of MND carers report spending over 75 hours a week providing unpaid care to their loved ones, with the vast majority (over 80%) spending at least 35 hours per week providing unpaid care².

Many MND carers must balance their caring responsibilities with work, other caring responsibilities such as looking after children, and other domestic duties, which can all take their toll on a carer's quality of life. To do this, MND carers need support themselves to maintain their health and wellbeing. However, MND carers are increasingly facing financial hardship paired with difficulties in accessing the support

¹ [2024 MND Carer Triple Burden full report.pdf](#)

² [Understanding the experiences of unpaid carers of people living with MND](#)

available. Some of these barriers, alongside our suggestions on how to resolve them, will be outlined below.

Carer's Assessments

The Social Services and Well-being (Wales) Act 2014 states that unpaid carers are entitled to a carer's assessment to discuss how caring affects their physical and emotional well-being. These are provided by local authorities in Wales and aim to identify the carer's support needs as well as their willingness and ability to care, and to explore the options available to provide support for the carer.

However, many carers either do not know they are eligible for a carer's assessment or have been unable to receive one. Indeed, recent research from the MND Association shows that only 25% of carers of people living with MND had either received a carer's assessment or were in the process of having one³. Worryingly, 40% of MND carers told us they were not aware of their right to one⁴.

The purpose of a carers assessment is to identify the needs of carers and to provide the appropriate support to ensure they are able to provide that care and be supported in their role. However, alongside difficulties in accessing a carers assessment, MND carers often report a lack of understanding of MND and the full impact of providing care for people living with MND amongst assessors which limits the assessment's ability to understand the full needs of the carer.

MND carers also reported that assessors often miss the greater need of people living with and affected by MND, for example, through offering inappropriate outputs for respite or through offering vouchers for the carer to spend without adequate respite care to enable the carer to use them.

Concerningly, many carers tell us they are not aware that financial support exists which is hampered by lack of access to a carer's assessment. Despite the benefit being available to them, 15% of MND carers we surveyed last year told us they were not aware they might qualify for carers allowance, and of those who were aware, 46% did not apply⁵. Often this is because the process of applying for further support can put additional pressure on an already over-worked group of people. Financial support options, such as carer's allowance, are crucial to allow MND carers to maintain their quality of life (see below) and are often discussed during a carer's assessment.

As such, we believe that action to increase the uptake and awareness of carer's assessment must be an immediate priority of the Welsh Government.

We need:

³ [Understanding the experiences of unpaid carers of people living with MND](#)

⁴ [Understanding the experiences of unpaid carers of people living with MND](#)

⁵ [2024 MND Carer Triple Burden full report.pdf](#)

- Better prioritisation and assessments of all unpaid carers in Wales, ensuring all MND carers are aware of their right to a carers assessment, including the development of a Wales-wide awareness campaign if required
- Better training of assessors on the needs of people living with and affected by MND, including a formal fast-track process for the delivery of carers assessments for those who are caring for people with complex, rapidly progressing conditions such as MND

Respite care

Respite care, or short-term care that helps unpaid carers to take a break, is critical for MND carers to fulfil their caring responsibilities without burning out or experiencing premature physical or mental ill-health.

Discussion of suitable respite care usually happens during a carers assessment so, as outlined above, we believe that it is crucial to tackle the low awareness and uptake of carers assessments among MND carers as an immediate priority to ensure people know what support there are entitled to and how to access it.

However, even in situations where unpaid carers have received a needs assessment and respite care needs have been identified, it is often not accessible to MND carers for several reasons:

- 1) Lack of respite provision more generally. There is large regional variation in the availability of respite services both across the UK and particularly in Wales. In many areas, respite care is provided for by local hospices, which are already stretched far beyond capacity, with many areas of Wales having no in-house hospice provision at all. Indeed, our research shows that nearly half (43%) of unpaid carers of people with MND spend over 100 hours providing care, yet only 13% receive any form of respite support following a needs assessment⁶. In particular, MND carers report a lack of suitable care provision, short-break providers, and replacement care provision.

We welcome Welsh Government's funding of the Short Breaks Scheme, which supports innovative and individualised approaches to breaks from caring in addition to the existing duties on local authorities. However, we are concerned that the funding for this is short-term, currently funded on an annual basis⁷. Long-term funding for these life-changing schemes is crucial to ensure wide-reaching, resilient, and equitable respite provision across Wales.

⁶ committees.parliament.uk/writtenevidence/132364/pdf/

⁷ [Written Statement: Continuation of funding for the Short Breaks Scheme and Carers Support Fund for 2025/26 \(28 January 2025\) | GOV.WALES](#)

- 2) Where there is respite provision, a lack of skilled workforce to care for people living with a disease as complex as MND. MND carers often tell us that in cases where a respite service was available, it did not provide access to care staff with the skills and experience required to support the complex care needs associated with living with MND. For example, the skills required to make use of equipment such as assisted ventilation or suction machines for saliva control require increased staffing ratios as well as care staff who are specifically trained in the use of such equipment.

The lack of access to skilled care workers who can provide the level of care required for people living with MND takes away the option of respite care from some carers who subsequently feel unable to leave the person they care for due to safety concerns. We often hear from MND carers who feel they have to train staff themselves to ensure they can provide the level of care needed.

This lack of sufficient respite care has a significant impact on unpaid carers' health and wellbeing. In a recent survey, 75% of MND carers told us they feel stressed as a result of their caring, with impacts being felt both mentally (66% of respondents) and physically (64% of respondents).

Due to the complexity of a rapidly progressing neurological disease like MND, unpaid carers often have to do extremely physical tasks like washing and lifting their loved ones, which in a paid caring environment would require a minimum of two trained staff per person living with MND, but unpaid MND carers often must do this physical work themselves.

This has a huge effect on people caring for their loved ones, and it is important that they get adequate support and time off to preserve their health and prevent any premature physical or mental illness.

We need:

- Improved access to respite carer across Wales, including long-term funding for the Short Breaks Scheme
- Increased availability of trained care workers and nursing staff, with work aligned to the Workforce Strategy for Health and Social Care⁸

Financial support

Although beyond the scope of this inquiry, it is important to bear in mind that adequate financial support is critical for unpaid carers' health and wellbeing, as well as to enable them to sustain a life beyond caring.

⁸ [A healthier Wales](#)

Previous research from the MND Association estimated that people living with MND and their families spend, on average, £14,500 per year on managing the costs associated with living with the condition⁹. This includes increased energy costs due to high reliance on powered equipment, costs associated with unfunded care needs, and out-of-pocket costs for equipment and adaptations not otherwise provided by statutory services. We know the impact of the cost-of-living crisis continues to exacerbate the financial difficulties faced by unpaid carers and the benefits available to carers remain insufficient.

Our recent research shows that 68% of MND carers have had to make significant changes to their budget for essential items to cover disability-related expenses, and over one fifth (22%) reported going into debt to cover disability-related expenses¹⁰. This increase in cost is coupled with reduced ability to generate income via employment. Due to the rapidly progressing nature of the disease, our research suggests that over one fifth of MND carers have had to reduce their work hours, with 36% reporting having to leave full-time employment altogether to fulfil their caring responsibilities¹¹.

Such financial strain places undue mental strain on MND carers over and above their already significant caring responsibilities. It's vital that unpaid carers get the support they need, but the current level of financial support for carers is insufficient. At £83.30 per week, 94% of MND carers told us the current rate of carers allowance is insufficient to meet their needs, with 54% saying they require at least £200 per week

Many unpaid carers are expected to fund respite care themselves, so we believe it is important to consider lack of financial support as a barrier to accessing wider support such as respite care.

Conclusion

MND carers provide essential support that underpins both the wellbeing of people living with MND and the sustainability of health and social care services.

However, evidence collected from MND carers over the past few years demonstrates clear gaps in awareness, accessibility, and inadequacy of existing support for carers in Wales.

Improving uptake of carer's assessments, ensuring appropriate and skilled respite provision, and addressing the inadequacy of financial support must be considered immediate priorities by the Welsh Government to improve support for unpaid carers.

⁹ [Through the roof report_0.pdf](#)

¹⁰ [2024 MND Carer Triple Burden full report.pdf](#)

¹¹ [2024 MND Carer Triple Burden full report.pdf](#)

Without targeted action in these areas, the health and wellbeing of MND carers and their ability to continue their vital caring responsibilities will remain at risk.