

Key messages

The MND Association's [*Through the Roof*](#) report shows that people affected by motor neurone disease are facing unprecedented financial pressures. Our research found that 91% of households are financially worse off than the year before, with over half struggling to afford essentials such as food and heating, and nearly three-quarters have cut back on heating despite health risks. More than a quarter have reduced their use of essential powered equipment because of unaffordable energy costs.

This mirrors national evidence from the Joseph Rowntree Foundation's 2025 Cost of Living Tracker, which found that 7.1 million low-income households are still unable to afford essentials, with little improvement since 2022.¹

The cost of living crisis disproportionately affects families with children and households including a person with a disability. Roughly 4.4 million households are behind on critical bills, averaging £1,380 in arrears.²

These findings show that the bottom income groups have experienced no meaningful reduction in hardship, underscoring an urgent need for bold policy action to embed economic security and ensure Universal Credit meets essential living costs.

Background

The cost of living crisis refers to the fall in real disposable incomes that 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.³ Although headline inflation has fallen since its 2022–2023 peak, the prices of essentials remain stubbornly high, and households with the lowest incomes continue to face severe financial insecurity.

Despite a modest inflation-related increase of 1.7% in April 2025, benefits have not kept pace with rises in the costs of housing, food, and energy. As of May 2025, the Joseph Rowntree Foundation (HRF) estimates that 7.1 million low-income households still go without essential items, a figure unchanged since late 2022. Crucially, disabled people and families with children remain among the most affected.⁴

People affected by MND are particularly vulnerable to the effects of the impacts of the ongoing crisis. The progressive and life limiting nature of the condition often forces individuals and their carers to reduce or completely cease paid employment. At the same time, they face sharply rising costs associated with managing symptoms and maintaining safety and comfort. These include:

- Paying for personal care, specialist equipment, and home modifications;
- Increased transport needs resulting from reduced mobility;

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- Significantly higher energy consumption due to dependence on assistive and life-sustaining electrical equipment.

This can be devastating, especially given the additional costs associated with managing MND. Households affected by MND spend 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.⁵ With UK energy prices still more than double what they were in 2010, and unlikely to revert to pre-crisis levels before 2030, this financial pressure is expected to remain intense.

While inflation has eased from its 2022–23 peak of over 10% to around 3–4% in 2025, bringing some relief for some households through lower mortgage pressures, this shift offers little comfort to those affected by MND.⁶ Many in this group still face severe financial hardship, and current support measures remain inadequate to prevent deepening poverty and worsening health outcomes among people with disabilities.

The challenge

Affording basic living essentials

People affected by MND are among those most vulnerable to the ongoing cost of living crisis. The progressive and terminal nature of the condition often forces individuals and carers to reduce or stop work, leading to an immediate loss of income when essential expenses are high. These include costs related to personal care, mobility, and basic household needs. Research conducted by the MND Association in 2023 found that 91% of households affected by MND reported being financially worse off than the previous year. Over half found it difficult to afford essentials such as food and energy. Nearly three-quarters had reduced their heating use, and two-thirds cut back on energy consumption, despite the risks to their health and safety.

Recent national data indicate that these financial pressures continue to be persistent. According to the UK Government's 2024 report on the impact of the rising cost of living on disabled people, disabled households are more likely than others to fall behind on bills, reduce their use of heating and food, and report high levels of stress associated with financial insecurity. Scope's 2024 Disability Price Tag report estimates that disabled people face an average of £975 in extra monthly costs, even after accounting for disability benefits.

Despite some government support through one-off payments, these have not addressed the underlying and long-term income shortfalls faced by many disabled households. Families affected by MND will continue to encounter complex and unsustainable choices, with many planning to rely on savings, borrow money, or seek charitable support in the year ahead.

The scale and persistence of hardship make it clear that short-term measures are insufficient. We support calls for an Essentials Guarantee, which would ensure that the standard allowance of Universal Credit is set at a level that prevents people from going without the basics.

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Prioritising health and wellbeing

As their disease progresses, people living with MND need to use a range of powered equipment in the home to live safely and independently with their condition. This includes medical devices such as ventilators and saliva suction machines, mobility aids such as powered wheelchairs, adapted furniture such as riser-recliner chairs and adjustable beds, and a range of communication aids. These are not luxuries or conveniences, but essential tools for maintaining health, managing symptoms and supporting dignity and quality of life.

However, energy costs associated with this equipment can be exceptionally high. Families managing advanced stages of MND have reported spending £800 a month on electricity alone. Those in earlier stages may face lower, but still significant, additional costs from using assistive devices, increased heating needs, and water use for washing and equipment cleaning.

MND Association research in 2023 found that more than a quarter of people had reduced their use of powered equipment due to unaffordable energy bills. This creates unacceptable risks for health and wellbeing. Yet many affected households are excluded from targeted support schemes such as the Warm Home Discount, which narrowly defines eligibility.

The current NHS electricity rebate scheme applies only to a limited range of equipment, such as dialysis machines and oxygen concentrators. It does not cover the essential devices used by people with MND, despite comparable energy usage. This leaves families to absorb the full cost of managing a health condition that would be subsidised if care were provided in a hospital setting.

With energy bills still significantly above pre-crisis levels and expected to remain high for years, there is a clear need for structural support. We are calling for the introduction of an Energy Social Tariff, designed to reduce the cost of energy for high-need households and applied directly to unit rates. We also urge expansion of the NHS rebate scheme to include assistive equipment essential to conditions like MND.

Without urgent action, people with MND will continue to face a dangerous and unjust burden simply for managing their condition at home.

What changes do we want to see?

From Government

- 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.
- 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

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MND are eligible, and that the discount is below the market rate and applied directly to the unit cost of energy.

- Extend eligibility and increase access to the NHS electricity rebate scheme.

What MND Association is doing

- Financially supporting families affected by MND during the cost of living crisis through our [Cost of Living Support Fund](#), which can offer a one-off payment of up to £500 to help cover living expenses such as household bills or food shopping costs.
- Providing information and support on all aspects of motor neurone disease, including information about financial support, through our [MND Connect](#) helpline
- Influencing national policy through consultations, campaigns and meetings, either directly or through coalitions, on the experience of households affected by MND during the cost of living crisis.
- Lobbying MPs and other parliamentary stakeholders and groups ensuring that the experience of families affected by MND during the cost of living crisis remains high on government agendas.

References

¹ Joseph Rowntree Foundation (2025). A year of labour but no progress. Available: <https://www.jrf.org.uk/cost-of-living/jrfs-cost-of-living-tracker-summer-2025>

² Ibid.

³ BBC News. (2023). Inflation hits new 30-year high in February. Available: <https://www.bbc.co.uk/news/business-60833361>

⁴ The Guardian (2025). UK inflation rise makes it clear: the cost of living crisis has not gone away . Available: <https://www.theguardian.com/business/2025/jul/16/uk-inflation-rise-cost-of-living-crisis-interest-rates>

⁵ Demos (2017). MND Costs: Exploring The Financial Impact Of Motor Neurone Disease. Available: <https://www.mndassociation.org/sites/default/files/2022-12/Financial%20impacts%20full%20report%20pdf.pdf>

⁶ Office for National Statistics (2025). Consumer price inflation, UK: June 2025. Available: https://www.ons.gov.uk/economy/inflationandpriceindices/bulletins/consumerpriceinflation/june2025?utm_source=chatgpt.com