# Key messages

People affected by motor neurone disease (MND) have been disproportionately affected by the cost of living crisis. The need to reduce or give up primary sources of income and spend more to cope with the impacts of the disease has left households particularly vulnerable to the effects of the crisis.

This has resulted in families being unable to afford basic living essentials. In addition, many households affected by MND are facing enormous and inescapable energy costs as a result of their reliance on powered equipment in the home .

Inflation and prices for essential items remain stubbornly high and so the effects of the crisis will be felt for years to come. It is paramount that Government act urgently to increase and extend direct cost of living financial support for disabled people, implement an Essentials Guarantee for lower income families, expand eligibility and delivery of the NHS rebate scheme and introduce an Energy Social Tariff that would provide a discount on energy bills for households affected by MND.

# **Background**

The cost of living crisis refers to the fall in real disposable incomes 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.[[1]](#endnote-2)

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 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.[[2]](#endnote-3)

# The challenge

## Affording basic living essentials

MND Association research during the cost of living crisis found that nine in ten (91%) households affected by MND report being financially worse off than 12 months ago.[[3]](#endnote-4) This is no surprise given the UK inflation rate – as calculated by the Consumer Price Index which measures the percentage change in the price of goods and services consumed by households – rose by 10.4% in the 12 months up to February 2023.[[4]](#endnote-5) Of those who reported being financially worse off, almost all (99%) respondents reported their household is paying more for essentials, with a fifth (21%) reporting their mortgage or rent has increased and half (49%) paying more for non-essential items.[[5]](#endnote-6)

In response to mounting prices, many households have struggled to afford basic living essentials; over half (51%) reported their household experienced difficulties paying for food, home heating and energy over the last 12 months.[[6]](#endnote-7) 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.

Despite Government committing to significantly reduce inflation in 2023, it has remained stubbornly high, meaning the cost of living crisis is not slowing down.[[7]](#endnote-8) Almost nine in ten (87%) households are worried about being able to pay for living essentials over the next 12 months.[[8]](#endnote-9) The Institute for Government predicts that Real Household Disposable Income – a measure for living standards that considers total household earnings after tax and accounts for inflation – will not return to its 2021/22 level until 2027/28.[[9]](#endnote-10)

As a result of worry over finances, in the next 12 months, two-thirds of people affected by MND 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.[[10]](#endnote-11)

In 2022, Government introduced the Disability Cost of Living Payment – a one-off £150 payment for disabled people to cope with the rising costs of the crisis. Similarly, a £650 Cost of Living Payment, was introduced for those on specific means-tested benefits.[[11]](#endnote-12) In 2023, an additional £150 Disability Cost of Living Payment was given to disabled people and a £900 Cost of Living Payment was made available to eligible people through to 2024.

However, it is unclear why the Disability Cost of Living Payment is not being extended until 2024, in line with the Cost of Living Payment. It is also unclear why the Disability Cost of Living Payment is far less of an entitlement to the payment available to low-income households. This has been a missed opportunity to support disabled people, many of whom incur additional costs as a result of their disability, especially for people with MND.

We therefore urge the Government to address this inequality of entitlement by bringing the Disability Cost of Living Payment in line with the level of the Cost of Living Payment and extend support into 2024.

While direct financial support during the cost of living crisis has been welcome, it is currently insufficient for households to rely on ad-hoc support without addressing the underlying causes of many people’s inability to meet the rising cost of essentials, particularly for the most financially vulnerable such as those on means-tested benefits. When people are diagnosed with MND, it is challenging to continue to work, and people will often experience a complete reduction in their income. For many, benefits and entitlements are a vital source of income to help lower-income people and families meet the cost of essential items.

We support The Trussell Trust and Joseph Rowntree Foundation’s ‘Guarantee Our Essentials’ call for the standard allowance of Universal Credit to be set at a rate that protects people from going without essentials. While this rate should be set by an independent and regular process, the campaign suggests it would need to be at least £120 a week for a single adult and £200 for a couple.[[12]](#endnote-13)

## Prioritising health and wellbeing

The nature of MND means that many households affected by MND spend more to manage the symptoms and its impact on daily living. For example, they may spend more on electricity due to their reliance on personal powered equipment. Assistive equipment for MND enables people to remain safe, independent, and well, in and outside their homes. We know that almost three-quarters (72%) of people with MND use personal powered equipment to manage the condition.[[13]](#endnote-14)

Worryingly, MND Association research during the cost of living crisis shows over one-quarter (28%) of people reduced their use of personal powered equipment in the last 12 months in response to rising energy costs.[[14]](#endnote-15) While concerning, it not necessarily surprising given the cost of using these pieces of equipment.

Families managing advanced stages of the condition have told the MND Association that they currently spend between £800 and £900 a month on their household electricity bill, which equates to an astronomical £10,000 a year. It is so expensive because these people require a wide range of assistive equipment to keep them alive and independent. These can include: 24/7 ventilation, cough assist and saliva suction, powered wheelchairs, communications equipment, powered adjustable beds and hoists. They may also include adaptations in the home such as through-floor lifts, stairlifts and bath lifts.

People with less advanced MND may use a smaller range of equipment but are still likely to rely on powered home equipment to enable them to live safely at home. We estimate that people with MND spend, on average, an additional £600 a year on electricity costs – based on the October 2022 Energy Price Guarantee unit rate – for charging and using assistive equipment, on top of other household costs and other additional costs of MND.[[15]](#endnote-16)

As well as electricity costs, people with MND may also run up higher bills for other utilities because of their condition. For instance, muscle wastage commonly associated with MND can often result in people feeling pain in colder environments, requiring them to use more home heating. Similarly, people may spend more on their water bill due to cleaning the vast array of assistive equipment for MND or having longer showers as a result of poorer mobility.

Government support for households during the energy crisis so far has been welcome, but unnecessarily selective. For example, the Warm Homes Discount Scheme – a one-off £150 discount off electricity bills – was only made available to low-income households who have high energy costs.[[16]](#endnote-17) This is unwarranted for those households affected by MND who are excluded from the scheme yet still face catastrophic energy costs.

While energy prices have fallen from their peak below the Energy Price Gaurentee cap level, they remain extremely high, especially for heavy energy users such as people living with MND. The average yearly UK household electricity bill in 2010 was £450. However, in 2021 it was £769, a 36% real increase. As of 2022, it was over £1,000.[[17]](#endnote-18) Alarmingly, overall annual energy bills are not expected to return to pre-2021 figures until at least 2030.[[18]](#endnote-19)

Additional and targeted support is therefore required to mitigate the impact of rising energy costs and ensure people can continue to use assistive equipment sufficiently to manage and live with the disease. There is a need to urgently implement a solution that helps support a broader number of disabled people who rely on assistive equipment mitigate the impact of rising energy costs. We urge the Government to immediately introduce an Energy Social Tariff to help support disabled people mitigate catastrophic energy costs. The tariff acts as a discounted energy bill and is targeted towards disabled people who face high energy costs.[[19]](#endnote-20)

The scheme will be particularly beneficial for people with MND. This is because they currently experience an unfairness in relation to the management of their disease. MND is primarily managed at home, meaning families are forced to cover the high costs of running assistive equipment. Yet if their conditions were managed in hospital, the costs would be covered by the NHS.

There are various models of an Energy Social Tariff, whether these are discounts applied by a cash payment or a tariff on how much households pay per unit of energy.[[20]](#endnote-21)[[21]](#endnote-22) In any consideration of an Energy Social Tariff, Government should ensure that eligibility is extended to all households affected by MND. Passporting only disability welfare claimants to further support risks some households missing out on the benefits of an Energy Social Tariff.[[22]](#endnote-23) For example, some people with MND may not yet be in receipt of benefits, but the often-rapid deterioration of their condition means that they may already be using assistive equipment to manage their condition.

The tariff should also ensure that the discount is below the market rate and that it is applied directly to the unit cost of energy, so households pay discounted prices at the point of purchase and not reimbursed at a later date. This would help facilitate access to support that is direct and immediate.

In addition to this, there is also a need to further support people with MND who use assistive equipment. NHS England currently allows trusts to offer electricity rebates for two types of equipment – oxygen concentrators and dialysis machines.

However, it is unclear why other pieces of electrical equipment are excluded from the rebate. This means that many other disabled people with conditions who rely on assistive equipment are barred from accessing the scheme. The rebate is also paid for through local NHS budgets which can be unstable and subject to cutbacks. While the NHS rebate scheme is a positive one, more work needs to be done on eligibility and delivery so more people can benefit from the scheme in the future.

# What changes do we want to see?

**From Government**

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

* Influencing Government through our [Through The Roof](https://www.mndassociation.org/get-involved/campaigning/take-action/through-the-roof) campaign, calling for a consultation on additional targeted energy support for vulnerable households.
* Financially supporting families affected by MND during the cost of living crisis through our Cost of Living Support Fund, a one-off payment of up to £350 to help cover household bills or food shopping costs.
* 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.

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