

# MND Association Manifesto 2024-2025

## About motor neurone disease (MND) and the MND Association

Few conditions are as devastating as MND. It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work.

There is no cure. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop frontotemporal dementia.

There are more than 5,000 people living with MND in the UK at any one time. It can affect adults of any age.

MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

The MND Association is the leading charity in England, Wales and Northern Ireland supporting people affected by MND, with 90 volunteer-led branches and groups, and 13,000 volunteers. The MND Association's vision is of a world free from MND. Until that time, we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and die with dignity.

# Our **5** MND asks of government

**The events of the last few years have placed untold additional pressures on people with MND and their loved ones. In response to this, we have created five key asks of the government to help transform the lives of people with MND:**

## **1: Accessible homes**

We need a major change in the way adaptations are provided in the home for people with MND. Too many are living in unsuitable and unsafe housing. We are asking local authorities to remove the red tape and fast-track assessments for people with MND for these adaptations; as well as for the government to consult on increasing the upper limit of a Disabled Facilities Grant and revising the means test.

## **2: Access to treatments**

This parliament will be a critical period for MND research, with unprecedented levels of research activity to develop new disease-modifying and life-extending drugs for MND. Now is the time for sustained investment and support to bring these drugs to those who need them.

## **3: Improved cost of living support**

People with MND have been hit disproportionately hard by the cost of living crisis, especially regarding energy bills. We are asking for targeted support including a rebate on electricity costs for equipment used in the symptomatic care of MND and a reversal of eligibility changes to the Winter Fuel Payments.

## **4: Sustainable social care**

We need the government to provide a sustainable social care funding settlement with a clear plan to address workforce shortages, to ensure the sector can fully support people with MND.

## **5: Support MND carers**

Unpaid carers are the backbone of support for people with MND. The financial support they receive does not reflect the contribution they make and too many are excluded from support at all. We are calling on the government to review the level and eligibility criteria of Carer's Allowance to ensure it meets the needs of carers.



# Accessible homes

Everyone has the right to live in a safe and suitable home. For people living with MND, this means an accessible home that enables them to maintain their independence, dignity, and quality of life as the disease progresses. Timely home adaptations are vital to ensuring that this is the case. Schemes like the Disabled Facilities Grant (DFG) can provide vital support to people who need to adapt their homes but cannot afford to do so. It is also important that suitable mutual exchanges are available.

## Issue

**Many people with MND are trapped in inaccessible homes because councils are failing to provide sufficient support.** Without appropriate adaptations, people with MND are at higher risk of adverse events such as falls; and negative impacts on physical and mental health resulting from isolation and loneliness, and disengagement from family and community.

Problems in policy and delivery can make schemes such as the DFG difficult to access. People with MND have told us that there is a lack of information on how to access DFGs, and applications can be burdensome and take a long time to complete.

## Recommendations

### National recommendations

UK Government should:

1. Reinstate the previously committed consultation on the Disabled Facilities Grant (DFG). This should cover:
  - a. Proposals to increase the upper limit for a DFG for an individual adaptation, currently set at £30,000 in England, £36,000 in Wales and £35,000 in Northern Ireland.
  - b. Proposals to revise the means test to ensure wider access to DFGs.

- c. How DFG funding is allocated to local authorities to 'help ensure better alignment with local demand so that more adaptations reach those who need them most'.
2. Ensure that all new homes are sufficiently accessible and adaptable by:
  - a. Mandating the M4(2) accessible and adaptable homes standard for all new homes.
  - b. Setting a minimum target of 10% of new homes to be M4(3) wheelchair user homes.
  - c. Ensuring that funding settlements for implementing these standards are equitably distributed across the devolved nations, maintaining parity in the support provided for equivalent housing provisions.

### Local recommendations

Local authorities should:

1. Introduce a fast-track process for people with MND.
2. Remove financial assessments for DFGs for people with rapidly progressing and highly debilitating conditions like MND.
3. Maintain a register of accessible homes for people to move into.

# ASK **2** Access to treatments

## Background

There have been no new effective drugs for MND in over 20 years, and current treatments focus primarily on managing the impacts of the condition. However, in recent years, renewed focus on MND research has led to the development of a number of promising emerging treatments, both disease-modifying and those with the potential to slow down the progression of the disease.

As a result of tireless and dedicated campaigning by the United to End MND coalition of patients, charities, and researchers, the Government committed in 2021 to invest £50m into MND research over the next five years to further develop these treatments.

Sustained investment in MND research from the sector has also made these achievements possible. The MND Association is the largest charitable funder of MND with a research portfolio worth £20 million, as of the end of May 2023. Much of this funding focuses on translational research – taking potential medicines from the laboratory to patients. The MND Association also works to further these aims with the UK MND Research Institute (UKMNDRI).

## Issue

**One third of people with MND will die within a year of diagnosis and a half within two years.** This means that people with MND do not have time to wait. It is positive there are now promising treatments in the pipeline, but this has only been possible through sustained investment in MND research as well as the broader life sciences sector. It is essential that requisite funding for MND research is continued to ensure that greater discoveries in the treatment of MND are secured.

However, while we are now seeing more and more promising treatments for MND, regulatory barriers prevent patients accessing them in a timely and equitable way. Due to sizeable capacity issues, licensing and regulatory bodies in UK are often too slow assessing medicines, and their processes are not always uniform resulting in confusion in how best patients can access treatments quickly.

## Recommendations

### National recommendations

UK Government should:

1. Continue to invest sufficiently in MND research to ensure there is a pipeline of effective treatments for the condition.
2. Support and help strengthen the UK's life sciences sector.
3. Ensure that NICE methods, processes and performance fall under the remit of the proposed Regulatory Innovation Office.

# ASK **3** Improved cost of living support

## Background

MND is a complex disease. As it progresses, people with the condition will have to leave the workforce indefinitely, resulting in a permanent loss of income. Carers and family members may also be required to cut down on work or leave work altogether to provide care.

People affected by MND will often have to spend more in order to manage and live with the condition, such as extensive housing adaptations. **Our research finds that, on average, people with MND spend £14,500 a year meeting the full costs of the disease**, with many households spending much more. This leaves households affected by MND particularly vulnerable to cost of living increases.

## Issue

People living with MND use a wide range of energy-intensive electrical equipment at home to help manage their condition as it progresses. These include essential medical devices including ventilators, saliva suction and CoughAssist machines; mobility equipment such as powered wheelchairs; communications devices, environmental controls and home adaptations such as stairlifts, hoists, adjustable beds and through-floor lifts.

In 2023, the MND Association conducted a survey on the experiences of households affected by MND during the cost of living crisis. It looked at the number of people reliant on personal powered pieces of equipment and the impact the crisis has had on their use. It found that:

- 72% of households with MND used personal powered equipment to manage the condition.
- 28% of respondents have reduced their use of personal powered equipment in the last 12 months in response to rising energy costs.

This is no surprise given the cost of running personal powered equipment. We estimate that, on average, people with MND can spend up to £600 a year alone on using and maintaining these pieces of equipment, but some households managing more advanced stages of

the condition report spending an astronomical £10,000 a year on their electricity bill.

This equipment enables people to remain safe, independent and, in some cases, alive, meaning not only are these costs catastrophic but they are also inescapable. This necessitates additional support for households who use energy-intensive equipment to help manage and live with their condition.

## Recommendations

### National recommendations

UK Government should:

1. Ensure that any prospective shift to volumetric standing charges has an exemption for high usage energy users such as people living with MND.
2. Retain the Winter Fuel Payments for people whose conditions mean they have significantly higher energy bills.

### Local recommendations

1. Every NHS Trust, Local Health Board and Health and Social Care Trust in England, Wales and Northern Ireland, respectively, should extend eligibility for the NHS Rebate Scheme to cover equipment used in the symptomatic care of MND.

# ASK

# 4

# Sustainable social care

## Background

Good social care can help people living with MND to prolong independence and maintain wellbeing, dignity, and quality of life as the disease progresses. Adult social care encompasses a wide range of support, including personal and nursing care, help maintaining independence, access to specialist equipment, information and advice, as well as financial support. This includes support for working-age adults as well as older people.

## Issue

**Funding:** Social care is chronically underfunded, and many local authorities struggle to meet the care needs of their populations. The Health Foundation has suggested that an additional £14.4bn a year is required by 2030/31. These gaps in funding, lead inevitably to lack of access. Our 2019 Improving MND Care Survey found that only a quarter (26%) of people living with MND said they received social care in spite of the majority requiring it. This may be driven in part by a lack of appropriate providers and funding to undertake the complex care packages related to MND.

**Workforce:** In 2021/22, there were 165,000 vacant posts which had risen from 110,000 in 2020/21 – or by one half (52%) (Skills for Care 2022). Driving a wedge in the social care workforce gap is the inability of the sector to recruit and retain the number of staff needed to provide care to those who need it. People with MND also often have complex needs, but there is a lack of appropriately skilled care staff within the sector.

**Social care reform:** While we were pleased to see the Government bring forward proposals for funding reform in September 2021, those proposals have not been progressed. The Conservative Government announced £7.5bn of funding for broader social care reform up until the end of the 2024/25 financial year in late 2022, but a portion of the funding was recycled from budgets used to introduced reforms for social care charging, which have now been delayed for two years.

In 2022, the Government announced a tranche of funding to move forward with the proposals set out in

the White Paper, including a £500m investment into the social care workforce. However, in April 2023, the Government had slashed this by a half to just £250m.

## Recommendations

### National recommendations

UK Government should:

1. Commit to an increase in social care funding so it is sufficient and sustainable over the long term to ensure all people can access the support they need.
2. Address the shortfall in current social care spending and put in place a long-term funding commitment to meet current and future demand. Piecemeal pots of funding will not deliver the change, services or stability the sector and care users need.
3. Develop a fully funded social care workforce strategy. This should include sustained workforce planning to give the sector parity of esteem with the NHS and improved pay and conditions for social workers, so that people can access the right care, at the right time.

# ASK

# 5

# Support MND carers

## Background

Carers are entitled to a Carer's Allowance if the person they care for is in receipt of a disability-related benefit such as Personal Independence Payment or Attendance Allowance. As of 2024, the rate amounts to just £81.90 a week.

Those whose earnings exceed £139 a week after tax, National Insurance and expenses do not qualify for the allowance, and if someone shares caring responsibilities with another, then only one person is entitled to Carer's Allowance. This is not suitable for a condition like MND where 24 hour care by more than one carer is often required. In short, many who require the allowance are not entitled to it.

Unpaid carers save health and social care systems substantial costs by providing care that would have otherwise been met by formal care. Assuming there are 5,000 unpaid carers of people with MND, our analysis shows that they save local authorities in the UK £185m year, equivalent to £37,000 per carer per year, or £712 per carer per week. It is necessary and appropriate that carers do not therefore face financial difficulty while, and because of, caring.

## Issue

**Many carers of people with MND face financial hardship because of their caring role; 47% of unpaid carers report worrying about money and almost half (49%) report that caring had caused them financial difficulty (MND Association 2022).**

The recent cost of living crisis has exacerbated financial worries 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 (MND Association 2023).

Carers of people living with MND have also previously reported frustration with the strict eligibility requirements of Carer's Allowance, as well as calling the adequacy of payments into question. It is therefore

no surprise that just one in ten (10%) carers of people living with MND report that the welfare benefits they receive meet their needs as carers (MND Association 2022).

## Recommendations

### National recommendations

UK Government should:

1. 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.
2. Reform Carer's Allowance by uplifting the rate to a level that reflects the value unpaid carers offer.
3. Modernise and digitise the delivery of Carer's Allowance to make it less complicated for claimants and to protect carers from overpayments.