

Written evidence submitted by MND Association (ASC0031)

MND Association

Consultation Response:

Health and Social Care Committee - Adult Social Care Reform - The Cost of Inaction

About MND and the MND Association

Few conditions are as devastating as motor neurone disease (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 for MND. 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 up to 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 only national organisation supporting people affected by MND in England, Wales and Northern Ireland, 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.

How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

Inaction on adult social care reform imposes significant financial and operational costs on the NHS and local authorities while profoundly affecting patients and the public. NHS Continuing Healthcare (CHC) is a key example of this, particularly for individuals living with progressive conditions such as Motor Neurone Disease (MND). While CHC is designed to provide funding for essential, personalised care packages, barriers to access and inefficiencies in the system highlight the broader failings of an underfunded and inconsistent adult social care sector. These issues lead to higher costs for the public purse, greater strain on carers, and reduced quality of life for patients.

Key Issues in Accessing CHC for People with MND

The challenges in accessing CHC illustrate systemic failures in the social care sector, which have ripple effects across the NHS and local authority services:

- **Inconsistent Assessments:** Regional disparities in how Integrated Care Boards (ICBs) apply the National Framework mean that individuals with MND often face unequal access to care. Assessments are frequently rushed and fail to capture the complexity of progressive conditions, resulting in many being denied crucial support.
- **Remote Assessments:** The use of remote evaluations for CHC assessments limits the ability of assessors to fully understand the patient's needs, particularly for progressive conditions like MND that require holistic observation of symptoms, mobility, and communication challenges.
- **Data and Oversight Gaps:** A lack of robust data collection and oversight prevents equitable access to CHC, allowing disparities to persist and leaving gaps in accountability. This failure directly contributes to an increasing reliance on unpaid carers and personal finances to bridge the shortfall in care.
- **Insufficient Care Packages:** Even when CHC eligibility is granted, care packages are often inadequate, forcing families to cover gaps in support. Delays in receiving therapies, equipment, or home adaptations exacerbate the strain on individuals and carers.
- **One-Person Multi-Disciplinary Teams (MDT):** The use of single professionals to conduct MDT assessments undermines the principles of the CHC National Framework. Without input from multiple disciplines, these assessments fail to provide a comprehensive view of an individual's needs, often leading to inaccurate decisions and inequitable access to care.

Financial Costs to the NHS and Local Authorities

The decline in CHC recipients, from 63,000 in 2015 to 51,548 in 2023, coincides with a rise in CHC expenditure from £4.3 billion to £5.9 billion over the same period. This reflects a system that increasingly restricts eligibility while requiring greater financial outlay to support fewer individuals. These rising costs stem from:

- **Delayed Discharges:** Inadequate social care provision contributes to bed blocking in hospitals, where patients remain inappropriately in acute care due to a lack of domiciliary or residential support. This bottleneck increases pressure on NHS resources and disrupts service delivery for other patients.
- **Emergency Admissions:** Gaps in preventative care result in more frequent emergency interventions, driving up costs for both local authorities and the NHS.
- **Strain on Local Authorities:** Without adequate funding, local authorities struggle to recruit and retain a skilled workforce, further compounding delays in care delivery and increasing the overall financial burden.

Impact on Patients and the Public

For patients, the inadequacies of the CHC system and the broader adult social care sector translate into diminished quality of life. Families of those with MND often face delays in accessing vital support, leading to unmet needs for therapies, specialist equipment, and home adaptations.

Unpaid carers bear the brunt of these systemic failings. Many carers for people with MND dedicate over 100 hours per week to caregiving, with minimal access to respite or support services. This unsustainable pressure leads to physical exhaustion, mental health challenges, and financial hardship for carers, who are left to fill the gaps in a fragmented care system.

Conclusion

Inaction on adult social care reform drives up costs for the NHS and local authorities, while leaving patients and carers to shoulder the financial, emotional, and physical burdens of inadequate support. Reforming CHC and addressing disparities in social care provision could alleviate these pressures, enabling a more equitable and efficient system that benefits patients, carers, and the wider public.

What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?

The persistent pressures on adult social care have led to delays and inadequacies in vital service reforms, which have direct and detrimental effects on patients and the public. A key issue is the lack of appropriately skilled staff within the sector to meet the complex needs of people with conditions like Motor Neurone Disease (MND). For example, families frequently report being unable to leave their loved ones in the care of domiciliary care workers who lack training in administering essential interventions, such as non-invasive ventilation. This gap in workforce expertise leaves patients without safe and adequate care at home, forcing them to remain in hospital or move prematurely into nursing care facilities.

The broader implications of these pressures are profound. For the NHS, the inability to discharge patients due to insufficient domiciliary care support contributes to bed shortages and delays in elective surgeries and emergency care. Local authorities, meanwhile, struggle to recruit and retain staff, exacerbating existing capacity issues. While the Government's introduction of the Care Workforce Pathway and the Level 2 Care Certificate is a welcome step, these measures are insufficient to address the scale of the challenge in the short term.

Furthermore, the discontinuation of the Adult Social Care Training and Development Fund, despite the promise of maintaining funding levels for workforce learning and development, raises concerns about the speed and efficacy of workforce improvement initiatives. Without immediate action to implement reforms, patients and their families are denied access to high-quality, timely care, resulting in diminished quality of life and poorer health outcomes.

What is the cost of inaction to individuals, and how might people's lives change with action on adult social care reform?

The cost of inaction is borne most acutely by individuals living with MND, their families, and unpaid carers. Due to the complex nature of MND, social care is a critical lifeline for those affected. However, our 2019 *Improving MND Care Survey*ⁱ revealed that only 26% of people living with MND received social care, despite the significant symptom burden associated with the condition. This stark figure underscores systemic failures in the provision of care, often linked to a lack of skilled providers. Agencies and providers frequently hand back care packages to local authorities, citing an inability to safely deliver care due to insufficient training or resources.

For individuals, these gaps result in delays in accessing essential support, including therapies, specialist equipment, and home adaptations. Families are often left to shoulder the cost and effort of filling these gaps, leading to significant financial strain and emotional stress. In some cases, individuals are forced to rely on informal care or enter institutional settings prematurely, reducing their independence and quality of life.

Action on adult social care reform could transform lives. Implementing robust training programmes, increasing workforce capacity, and ensuring equitable access to care would enable individuals to live with dignity and autonomy. Families would experience reduced financial and emotional burdens, and unpaid carers could access the support and respite they desperately need. Ultimately, addressing these systemic issues would create a more compassionate and effective care system, improving outcomes for all involved.

Where in the system is the cost of inaction on adult social care reform being borne the most?

The burden of inaction is heavily borne by unpaid carers, who provide vital support to individuals with complex conditions like MND. Our research reveals that nearly half (43%) of unpaid carers for people with MND spend over 100 hours per week providing care, yet only 13% receive any form of respite support following a needs assessment. This disparity places an unsustainable strain on carers, who are often left to manage challenging and intensive care responsibilities without adequate resources or training.

The consequences for carers are severe. In addition to the physical demands of caregiving, 64% of carers report feeling physically exhausted, while 66% experience mental exhaustion.ⁱⁱ Many carers reach a point of burnout, which not only jeopardises their own health and wellbeing but also threatens the continuity of care for their loved one. The increasing complexity of care needs in progressive conditions like MND only amplifies these risks, particularly as carers are expected to bridge the gaps left by an overstretched social care system.

Local authorities are also feeling the strain. In 2022/23, 91% of Directors of Adult Social Services reported an increase in carers seeking support with more complex needsⁱⁱⁱ. This trend reflects the broader challenges of an underfunded and understaffed system, where carers are increasingly unable to cope without external assistance. Without urgent reform, the costs of inaction will continue to mount.
