MND
Association
Cymru

Manifesto for Wales

2026 and beyond

About Motor Neurone Disease

Motor Neurone Disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It kills a third of people within a year of diagnosis, and more than half within two years. There is no cure.

Over 250 people in Wales live with MND and the lifetime chance of developing the disease is 1 in 300. Across the UK, 6 people a day are diagnosed with MND and 6 people die.

The MND Association focuses on improving access to care, research, and campaigning for people living with and affected by MND in England, Wales, and Northern Ireland.

As we approach the 2026 Senedd elections, the MND Association has identified 5 key areas to focus on with the aim of improving the lives of people living with and affected by MND in Wales. We urge all political parties and all candidates to commit to our asks to help us achieve a Wales where MND is treatable and curable, and everyone is able to access the care they need when they need it.

Equitable service provision

Multi-disciplinary care and support in the community is crucial to timely and equitable access to support with a rapidly progressing disease like MND.

Across Wales, people with MND have inequity of access to neurologists, psychologists, and palliative care services, with many having to wait a long time for a diagnosis and travel long distances, often into England, to access the support they need. Having co-ordinated community care with specialist training helps people living with MND with managing their symptoms, improving their quality of life and saving significant costs for other statutory services.

We need:

- Longer-term funding forecasts for local health boards to ensure they commit to transitioning services provided by third-sector organisations in-house
- Targeted investment in neurological services across health and social care that meet the needs of people living with MND
- Increased availability of trained care workers and nursing staff
- Implementation of the Quality Statement for Neurological Conditions and clear targets to measure progress and increase accountability MND.

Accessible housing

For people living with MND, accessible housing is crucial to maintaining their dignity and independence.

It is possible to keep hospital admissions for people with the disease low as long as they can remain safe in their own homes and communities. Home adaptations for complex diseases like MND are costly and the timely delivery of disabled facilities grants (DFGs) is key to ensuring homes are safe and accessible. In 2021, we released our Welsh Homes for MND Report[1]. Welsh Government committed to removing the means test for small and medium-sized DFGs and implementing fast-track programmes for housing adaptations.

Despite this, several local authorities still conduct means testing and many have yet to introduce a fast-tracking process. This needs to change.

We need:

- Welsh Government to mandate local authorities to remove the means test and implement fast-track systems
- Publicly available data on the delivery of DFGs to monitor the implementation of Welsh Government commitments
- The Housing Adaptations Standards of Service to be updated to include guidance on removal of means-testing and inclusion of fast-track process.

- Local authorities to create and maintain accessible housing registers.

Supporting MND carers

MND carers take a huge amount of pressure off the health and social care systems in Wales by addressing needs that would otherwise fall to statutory services.

We estimate that across the UK, MND carers save the NHS £185 million a year, equivalent to £37,000 per carer per year[2].Despite this, the financial support provided to unpaid carers remains the lowest welfare benefit and lengthy waits for carer's assessments limit access to the support that is available.

Almost all MND carers (94%) believe the current rate of carer's allowance is insufficient to meet their needs, and only 25% of MND carers have either received a carer's assessment or are in the process of having one[3].

We need:

- Inter-governmental working to review the level of and reform access to Carer's Allowance
- Targeted funding for unpaid carers in Wales to supplement this, including a long-term guarantee for the carer's support fund
- Monitor local authorities to ensure they are supporting carer's rights by offering all carers a carer's assessment which allows for support packages including respite
- An awareness raising campaign to increase uptake of carer's assessments.

Championing MND research

High-quality, collaborative research is key to finding a cure for MND.

However, not everyone living with MND in Wales is able to access a clinical trial due to varying levels of resource and knowledge across local health boards. Such issues are also creating barriers to accessing new treatments and genetic testing for people with familial types of MND. Investment in this area is key to early detection and prevention prior to symptom onset.

We need:

- Ring-fenced, sustainable funding for MND research
- Dedicated resource for genetic testing for MND within Wales
- Campaigns to educate healthcare professionals on MND awareness and treatment pathways in Wales.

The wider political landscape

Many of our asks are limited by the Welsh Government's funding settlement.

As pressure on statutory services continues to increase, the lack of resource within local authorities and local health boards across Wales cannot be addressed without Welsh Government having sufficient funds to do so. The Welsh Local Government Association (WLGA) has warned that despite the recent uplift in the local government settlement, significant budget pressures remain due to the increase in demand on services, particularly in social care and housing[4]. This leaves a discrepancy in terms of access to support and services both within Wales and across the border, leading to long waits for support, disjointed packages of care, and serious concerns regarding data gathering and access for people living with MND across Wales.

We need:

— A joined-up approach to MND service provision across Wales, with equity across all local authorities and local health boards

— A reconsideration of the funding settlement for Wales, with a move to a needs-led model

— Exploration of the devolution of welfare benefits.

> **"When you're a carer it's almost like you have MND, not in the physical sense, more in the emotional sense. And you just feel so out of control, helpless — the intensity of it was just incredible."**
>
> MND Carer in Wales

References

1. https://www.mndassociation.org/sites/default/files/2022-12/Welsh-Homes-for-MND-Report-ENGLISH.pdf
2. https://www.mndassociation.org/sites/default/files/2024-10/2024%20MND%20Carer%20Triple%20Burden%20full%20report.pdf
3. https://www.mndassociation.org/sites/default/files/2023-11/State%20of%20Carers%E2%80%99%20Assessments%20report%202023.pdf
4. https://research.senedd.wales/research-articles/draft-budget-2025-26-five-things-we-ve-learnt-from-scrutiny/

Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Tel: 01604 611860
Email: campaigns@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

MND Association Cymru

Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.