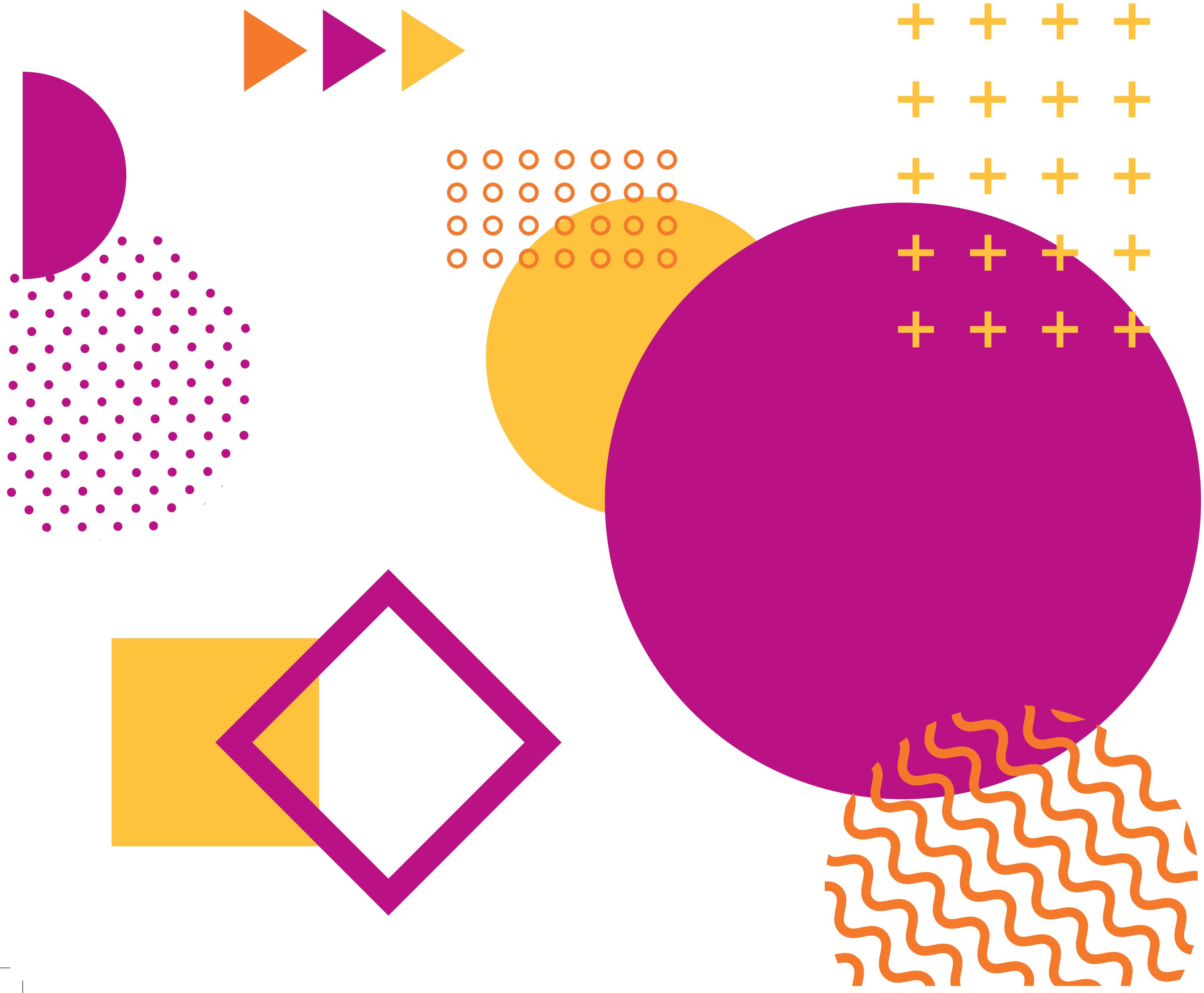
mnda
motor neurone disease
association
cymdeithas
clefyd motor niwron

MND 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. 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.

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 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. We focus on improving access to care, research, and campaigning for people living with and affected by MND.

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.

Universal health and care provision across Wales

Multi-disciplinary care and support in the community is crucial to timely and equitable access to support with a rapidly progressing disease like MND. Decades of investment by Local Health Boards (LHBs) and the MND Association have improved care in Wales, with expert MND care coordinators now working across health and social care services in all parts of Wales to support people living with and effected by MND.

However, inequities in service provision persists, including:

- Neurology shortages. Wales has just 41.1 full time equivalent neurologists for the entire population, with stark regional disparities. Powys has none, and North Wales relies on Liverpool's Walton Centre, who provide satellite clinics across North Wales and assessment and in-patient care into their Centre. Welsh Government released their Quality Statement for Neurological Conditions in 2022, outlining their vision for timely and equitable access to services for people with neurological conditions. However, with such disparate access to neurological services, this is a long way from being achieved.
- Long waits for diagnosis. Related to the above, people living with MND still face long waits for a formal diagnosis partially due to lack of awareness of MND in primary care and partially due to long waits for assessment. Most LHBs were unable to provide us with the average length of time taken to receive a formal diagnosis, while some estimate this takes 4-6 months. People living with MND in Wales, however, have reported much longer waits, with one person telling us *"the diagnosis process went on for three years"*.
- Gaps in psychological support. Receiving an MND diagnosis can create complex emotions for people living with MND and their loved ones. Psychological support such as acceptance and commitment therapy (ACT) can help improve the quality of life and psychological wellbeing of people with incurable conditions like MND. Despite this, only 1 LHB told us they provide psychological support for people living with MND in their area at present, with another 5 starting a 0.6 FTE service from 2025-2028 funded by the MND Association. Psychological support is a key part of the optimal clinical pathway for MND[1] and must be made available to all people living with and affected by MND across Wales.
- Workforce shortages continue to disrupt access to MND support and services in some parts of Wales. One Local Health Board highlighted the issue, stating that "Although the [MND care coordination] service has been running since 2017 there have been significant gaps due to sickness and retirement." Without immediate action to ease the burden on health and social care staff across Wales, such disruptions will persist, putting further pressure on the already overstretched system.
- Uncertainties in funding. A lack of long-term Welsh Government planning leaves Health Boards unable to transition third-sector services such as MND care co-ordination in-house. Information obtained by the MND Association shows that while agreements are in place for some LHBs to fully take over the funding of MND care co-ordination from the MND Association after 2027, we urge Welsh Government to provide all LHBs with ring-fenced funding for these on an ongoing basis to ensure continuity in care and support.
- Ongoing issues with continuing healthcare (CHC). People living with MND in Wales have reported long waits to access to CHC and even when they do receive it, the system is complex to navigate and there are not enough trained carers in their area to provide the care they need. While we welcome the Welsh Government's Workforce Strategy for Health and Social Care[2] and subsequent

delivery plan, recruitment and retention issues persist and must be tackled urgently[3]. People with MND have complex care needs and it is crucial that the social care workforce is sufficiently staffed and trained to manage their care properly.

- Independent User Trusts (IUTs). Though Welsh Government's CHC National Framework[4] allows IUTs, Freedom of Information data obtained by the MND Association found that only one Health Board currently provides them, and only for a single patient. Official guidelines won't arrive until 2025-26, leaving many without much-needed flexibility in care.

Our recommendations:

- 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

> "The diagnosis process probably went on for three years and all that time I was struggling with standing, then going upstairs was a bit more of an effort, I wasn't running upstairs anymore. I was actually using a wheelchair at times before my diagnosis and I had crutches to walk long before my diagnosis."

Person living with MND in Wales

> "To be honest, the best therapy you can have is to be able to talk about MND to somebody who has got that understanding of how you feel and can see how your mind works."

Person living with MND in Wales

> "You go through a lot of trauma caring for a loved one with motor neurone disease… If the (psychological support) service wasn't funded it would be like robbing people of their own healing from looking after someone with motor neurone disease."

MND Carer in Wales

Secure and accessible housing

Everyone has a right to live in a safe and suitable home. The physical changes symptomatic of MND often require adaptations to ensure people living with MND can stay in their homes. This is vital to maintain their independence, dignity, and quality of life as the disease progresses.

Such home adaptations are costly and Disabled Facilities Grants (DFGs) are vital for funding these changes, yet issues in delivery cause long delays or ineligibility for people living with MND.

In 2021, the Welsh Government committed to remove the means-test for small and medium DFGs and fast-tracking adaptations for people living with MND[5]. However, Freedom of Information data obtained by the MND Association[6] shows this is still not the case:

- Four local authorities still means test either all or medium-sized DFGs.
- Another local authority told us that they were "currently considering reintroducing it [means testing] due to the high demand for medium-sized DFGs".
- Only seven local authorities have a fast-track process for housing adaptations for people living with MND.

We believe Welsh Government must mandate all local authorities to comply with their request to remove the means test and implement fast-tracking systems for housing adaptations.

Welsh Government also stated that they would collect data on DFG numbers, completion rates, and waiting times, as well as report on progress annually. While they have made data on DFG numbers and completion rates available[7], data on timeliness has not been published to date. As such, the MND Association obtained this data via Freedom of Information request. Many local authorities were unable to provide us with this data either because they do not record it or because the work is outsourced to Care & Repair Cymru.

From the data we did receive, we found that in 2023-24, the average wait times were:

- Small adaptations: 23 days for assessment, 127 days for installation
- Medium adaptations: 66 days for assessment, 146 days for installation

These all exceed the targets set in the Housing Adaptations Standards of Service[8], which states that small adaptations will usually be installed within 3 weeks (if urgent) or 4 weeks (if non urgent). For medium adaptations, assessment should be within 2 months and the solution installed within 4 months.

Our Recommendations:

- Welsh Government to mandate local authorities to remove the means test and implement fast-track systems for housing adaptations
- 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

> "I've spent about £30,000 on trying to stay in this house. I've just been fortunate that I had that money because I worked hard all my life. That was my rainy day money and I've had to use my pension for bits of it."

Person living with MND in Wales

Supporting MND carers

According to 2021 Census data[9] there are around 310,000 unpaid carers in Wales, the largest proportion of whom provide 50 hours or more of care. Among these, 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[10]. As the progression of the disease is rapid, people living with MND and their carers often must leave work suddenly, placing significant emotional and financial strain on the household.

It is vital that MND carers get the support they deserve, but several barriers prevent this:

- Delays to carer's assessments. In a recent report[11], we found that only 25% of MND carers have received a carer's assessment or are in the process of having one. We also found the average wait for a carer's assessment is between 40 and 50 days.
- Inadequacy of Carer's Allowance. At £81.90 per week, Carer's Allowance remains the lowest-paid benefit in the UK. In our recent report[12], 94% MND carers told us that the current rate of Carer's Allowance is insufficient to meet their needs. Further, 46% of MND carers told us that they did not apply even though they were eligible, often because the application process put an additional, unnecessary strain on them.
- Service availability, particularly for things like respite care, is poor especially in rural parts of Wales. In these areas services are few and far between and support groups are limited.
- Lack of awareness of the support available and the complexity of the system is off-putting, particularly for people providing high levels of care in terms of time and the nature of the support required.

We believe that collaboration across Governments and reform within the system are both needed to ensure that MND carers get the support they deserve.

Our Recommendations:

- 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

> "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

> “There were endless needs just to help her get comfortable and to help her escape the emotional and physical demons of MND. She would need hoisting many times during the day and night it should have been a two-person job but I had to learn how to skillfully survive with hoisting her alone.”

MND Carer In Wales

Championing MND research

One of the MND Association’s promises is that we won’t rest until MND is treatable and ultimately curable. There are three areas that are key to making this happen:

Firstly, high-quality, collaborative research is crucial in the quest for a cure. Working with the Welsh Government, we have made great progress over recent years to facilitate ground-breaking MND Research in Wales including MND-SMART[13] and the TONiC study[14].

However, ability to engage in research is still largely dependent on where people with MND live. It is crucial that capacity for research increases so everyone across Wales can take part if desired.

Secondly, it is important that everyone living with MND in Wales can access the treatments they need quickly and effectively. There are several pathways to access medicines in Wales[15] but the availability of these differs across Wales depending on the knowledge of clinicians and operations within the different Local Health Boards.

With several promising new medicines in the pipeline, we need to ensure there is a process by which everyone has the same access to new treatments when they become available, regardless of where in Wales they live.

And finally, as awareness of MND increases, so does the demand for genetic testing. There are several inherited forms of the disease, accounting for approximately 10% of all cases. At present, researchers have identified single gene changes for around 70% of inherited MND. Testing for these allows people living with MND and their families to understand and plan for their future, as well as open up options for accessing emerging treatments and clinical trials.

There is no standardised approach for genetic testing and the process varies from person to person and across regions. Notably, many health boards have no internal capacity for genetic testing for MND and results are sent to laboratories outside Wales for screening. Data obtained by the MND Association found that:

- Several health boards are experiencing waits of up to a year to receive the results from genetic testing
- Fewer than 30 people living with MND in Wales have received genetic testing over the past 5 years
- Fewer than 5 family members of people living with MND have received genetic testing in the past 5 years

Our Recommendations:

- 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

Changing the political landscape in Wales

Without sufficient funding, local authorities and local health boards across Wales will continue to struggle to deliver statutory services, which leaves a patchwork of provision for the people living with and affected by MND across Wales who rely on them.

Many of our asks are limited by the Welsh Government’s funding settlement. Most of the funding for the Welsh Government comes from a block grant from the UK Treasury, the annual change in which is calculated using the Barnett formula, with adjustments made to reflect both need and tax and welfare devolution.

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 on social care and housing[16].

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.

It has previously been suggested in both the House of Commons[17] and the House of Lords[18] that the Barnett formula be replaced by a needs-led formula. Though needs-based uplifts are in place in Wales, these are not sufficient to cover true costs. With comparatively limited ability to generate revenue and restricted borrowing power, we believe the mechanism via which funding is allocated to the Welsh Government must be revisited.

Unlike in Scotland and Northern Ireland, the administration of social security including welfare benefits for people in Wales remains reserved to the UK Government in Westminster. We believe that the devolution of these powers to the Welsh Government has the potential to financially benefit Welsh Government[19] as well as ensure the system is fair and works properly for people living with and affected by MND in Wales. We welcome the Welsh Government's commissioned work to explore this matter, and we urge the Welsh Government under the next Senedd to continue this work.

Our Recommendations:

- 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

> "I don't understand why I wasn't eligible for local authority support for housing adaptations, I've worked hard all my life to have a nice house and the value of that house was taken into account even though we've still got a big mortgage on it and I'm not earning a fortune and my wife doesn't earn that much."

Person living with MND in Wales

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