

Wales

Motor Neurone Disease Association **Manifesto 2021**

Who we are and what we do

Motor neurone disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It kills a third of people within one year, and more than half within two years of diagnosis.

There is no cure.

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

In Wales, we have over 50 active volunteers and six employees, all dedicated to improving the lives of people affected by MND in Wales, now and in the future.

We, the MND Association have identified four key areas heading towards the 2021 Welsh Senedd Election. We believe that all political parties and candidates should commit to our 'asks' to help improve the lives of all people living with MND, their families and carers in Wales.

1 Implementation of the current Neurological Conditions Delivery Plan for Wales

The delivery plan is a long-term strategic approach to raising standards in treatment, services and support for people with MND in Wales.

The Cross-Party Group on Neurological Conditions conducted an Inquiry Report into the impact of the **Welsh Government's Neurological Delivery Plan** [2].

We ask the Welsh Government to:

- Commit to invest in Neurological Services across Health and Social Care to meet the needs of people living with MND in Wales
- Develop and implement a national system for collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions, to include MND, and the third sector

2 Improvements in NHS Continuing Healthcare (CHC) for people with MND in Wales

We, the MND Association published a report, **No Time to Waste** [1] which examines the experiences of people living with MND in relation to CHC in Wales.

We ask the Welsh Government to:

- Make CHC a Healthier Wales priority area
- Take urgent action to ensure CHC assessment is not a 'harrowing' experience for individuals and families
- Publish the revised National Framework for Implementation of CHC in Wales
- Address the limitations of the Decision Support Tool
- Increase the availability of trained care workers and nursing staff [1]

3 Delivering safe and accessible homes for people with MND in Wales

We, the MND Association published a report **Act to Adapt** [3] indicating that people living with MND in England, Wales and Northern Ireland are becoming trapped in inaccessible homes because they cannot afford or cannot access support for necessary adaptations. Some patients have died while waiting for alterations to be made, and we fear the pandemic has worsened the situation in many cases.

We ask the Welsh Government to:

Funding

- Make a clear commitment to increasing funding for local authorities to provide home adaptations over the next five years
- As a minimum, ensure local authorities put in place a transparent, fast-track, non-means tested process for adaptations under £5,000

Timing

- Implement the Equality and Human Rights Commissions recommendation to require that all new housing to be built to accessible and adaptable standard by default, and a minimum of 10% to Wheelchair Accessible Standard [5]
- Monitor and report, with the development of appropriate outcome measures, on good practice aligning to timely installation of adaptations as set out in the Welsh Government document Housing Adaptations Service Standards [4]

Information and Integration

- Allocate funding to help local partnerships continue to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations, as part of a wider package of support for people living with MND

4 Support unpaid family carers of people with MND in Wales

Unpaid family carers provide a significant amount of care and support to their loved ones living with MND. We, the MND Association have concerns that unpaid carers of people with MND are having to take on too many hours of care a week without sufficient support due to a poorly funded and unsustainable care system, this has been exacerbated as a result of the coronavirus outbreak.

Our **Improving MND Care Survey** [6] in 2019 found:

- **33%** of carers spent more than 110 hours per week caring, yet **45%** of these received no benefits at all
- **76%** of carers had not had a carers assessment
- **62%** of carers had not had any respite

We ask the Welsh Government to:

- Influence the UK Government to ensure a review and increase in the rate of Carers Allowance to a level that truly accounts for the values and contribution that unpaid carers make
- Monitor Local Authorities to ensure they are supporting carers rights through the Social Services and Wellbeing (Wales) Act by offering all carers a Carers Assessment which allows for support packages including respite
- Recognise and invest in third sector organisations providing key support services to carers, particularly at this challenging time

Contact

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References

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