

Northern Ireland

Motor Neurone Disease Association

Northern Ireland Assembly Election Manifesto 2022

Who we are and what we do

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

There are between 80 and 100 people living with MND in Northern Ireland at any one time.

Locally, the MND Association has 18 active volunteers and 3 employees, all dedicated to improving the lives of people affected by MND, now and in the future.

Our vision is a world free from motor neurone disease.

About motor neurone disease (MND)

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound, feeling etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.
- It affects people from all communities.
- Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.
- A person's lifetime risk of developing MND is around 1 in 300.

Motor neurone disease has no cure.

Our priorities for the new Northern Ireland Executive and Assembly

1 Development of a Northern Ireland MND Regional Care Network

People living with motor neurone disease in Northern Ireland do not have equitable access to care, support and services. There are 0.8 Specialist MND Neurologists and 1 Specialist MND Nurse. Northern Ireland is the only area of the UK that does not have an MND Care Coordinator.

We ask the next Executive to commit to invest in an MND Regional Care Network to ensure:

- People gain access to a timely diagnosis;
- Once diagnosed, people with MND are able to access specialist multidisciplinary care;
- People with MND in Northern Ireland should be offered equitable access to relevant research studies and therapeutic trials.

2 Deliver safe and accessible homes for people with MND in Northern Ireland

The MND Association published the Act to Adapt² report that indicated that people living with MND in Northern Ireland, England and Wales are becoming trapped in inaccessible homes because they cannot afford or cannot access support for necessary adaptations.

Some people have died while waiting for adaptations to be made to their home, and the pandemic has worsened the situation in many cases.

We ask the next Executive to deliver safe and accessible homes for people with MND by:

- Ensuring that the Northern Ireland Housing Executive put in place a transparent, fast track process for adaptations;
- Monitoring and reporting, with the development of appropriate outcome measures, on good practice aligning to timely installation of adaptations.

3 Support unpaid family carers of people with MND in Northern Ireland

Unpaid family carers provide a significant amount of care and support to their loved ones living with MND. The MND Association is concerned 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, which has been exacerbated by the coronavirus pandemic.

Our Improving MND Care Survey³ in 2019 found:

- 33% of carers spent more than 110 hours per week caring, yet 45% of those 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 next Executive to support unpaid family carers of people with MND by:

- Reviewing the current Carers Strategy ¹ with a view to developing a new Strategy which is co-produced with family carers, is cross-departmental and is fully resourced;
- Monitoring the Health and Social Care Trusts to ensure they are supporting carers rights through the Carers and Direct Payments Act (2002) by offering all carers a Carers Assessment which allows for support packages, including access to respite and short breaks;
- Recognising and investing in third sector organisations who provide key support services to carers.

Contact

For further information contact:

Clare-Anne Magee
Head of Regional Care Partnerships

Mobile: **01604 800624**
Email: **clare-anne.magee@mndassociation.org**

Motor Neurone Disease (MND) Association

Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton
NN3 6BJ

www.mndassociation.org

mnda
motor neurone disease
association

References

- 1 | Caring for Carers: Recognising, Valuing and Supporting the Caring Role (2006) Department of Health
- 2 | www.mndassociation.org/app/uploads/2019/09/Act-to-Adapt-Summary.pdf
- 3 | www.mndassociation.org/improving-mnd-care-survey-2019