The Motor Neurone Disease Association Response to The Department of Health Regional Review of Neurology Services Final Report

July 2025

Name: The Motor Neurone Disease Association

Organisation Type: Charity

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1.0 Introduction

Motor Neurone Disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to move, talk and eventually breathe. There are currently approximately 120 people living with MND in Northern Ireland. This figure is, unfortunately, expected to rise to approximately 200 within the next decade. A person's lifetime risk of developing MND is around 1 in 300. Across the UK. MND kills a third of people within a year and more than half within two years of diagnosis. In Northern Ireland this figure is higher and the time frame shorter due to the delay in diagnosis of MND. There i8s no such thing as a "typical MND patient" – it affects people from all backgrounds. There is no cure for MND.

The MND Association is the only national charity in England, Wales, and Northern Ireland focused on MND care, research, and campaigning. A separate organisation covers Scotland (www.mndscotland.org.uk). The MND Association funds 22 specialist MND care centres and networks in partnership with NHS Trusts across England, Wales, and Northern Ireland. In 2024, we issued 73,477 pieces of care information to people with, or affected by, MND. The MND Association funds and promotes research that leads to new understanding and treatments, bringing us closer to a cure for MND. The value of our whole research grant portfolio by the end of 2024 was £16.4 million which encompassed 89 research grants. The MND Association provides support grants to help people with MND and their carers manage the disease. These grants help by, for example, paying for home adaptations to allow continued home living. We also distribute Emergency Support Grants to help those living with MND struggling with additional costs as a result of their condition.

People with MND typically find their care needs are complex and can change rapidly. This combination of complexity and rapid progression poses a major challenge to health and social care services. Many services and professionals are involved in caring for someone with MND. These include: health professionals in both specialist centres and the local NHS, social workers, therapists, hospices, equipment services, housing services, and the benefits system. This complex web of support is essential to enable people with MND to live their lives as fully as possible and die with dignity. It is therefore vital that these services are well co-ordinated, and that commissioners and processionals always consider and plan for the care needs of people with MND. The NICE guideline on MND published in 2016 provides guidance for this. With this in mind, we welcome this Regional Review of Neurology Services in Northern Ireland, and wish to highlight some issues where people with MND could be better served by the Department of Health in Northern Ireland. These are ambitious plans but necessary to move neurology services in Northern Ireland forward, particularly with regard to MND. We are however concerned about funding, resources, time and commitment to ensure the landscape is changed for the better for people living with MND in Northern Ireland.

2.0 Key Actions

The MND Association endorses the response from the Northern Ireland Neurological Charities Alliance Working Group and calls on The Department of Health to make eradicating the postcode lottery for people living with MND an urgent and key priority in the final Review of Neurology Services in Northern Ireland, and ensuring equal provision of treatment and care is provided equally across all the Health and Social Care Trusts in Northern Ireland.

The Review of Neurology Services in Northern Ireland should include details on:

- How this Review, and any subsequent implementation, will be financed in the current climate with cuts, both actual and in real terms, across all NI Executive departments. The Department of Health has said that there will be investment into this Review, but that it is aligned to a 10-15 year implementation period with approximately £65.4 million in the first 5 years. This is very welcome, but unfortunately, at present, the Department of Health is unable to confirm the first year's funding due to budgetary pressures.
- Outline the time and resources it will take to promote, train and recruit the vast amount of new neurological posts (from consultants to Allied Health Professionals) that will be required to ensure the needs of people living with MND are met There is a significant gap in the requirements of people living with MND in Northern Ireland and the provision of services afforded to them. There is therefore an urgent need for a much greater workforce capacity. This will inevitably take a considerable period of time. This Review should therefore highlight how the Department of Health will promote neurology and attract trainees into that discipline, and, particularly, how and what encouragement will be given to said trainees to specialise in MND. There are currently 10 trainees due to complete their training in 2028. This Review should identify what incentives will be offered to these trainees to stay in

neurology in Northern Ireland. Many trained specialists (and people in general) are leaving Northern Ireland for better pay and opportunities in the Republic of Ireland, other parts of the UK, or beyond
- The Review should make an urgent priority, the establishment of Multi Disciplinary Teams and local neurology delivery teams in each Health and Social Care Trust in Northern Ireland, Each Health and Social Care Trust in Northern Ireland should work collaboratively between the regional centre and each of the Health and Social Care Trusts.
- The Review should identify, create, develop and resource an optimal care pathway specifically for MND in Northern Ireland.
- The Review should ensure that advice and guidance is given through Primary Care.
- The Department of Health should improve awareness and education in neurology for non neurological hospital specialists. We recognise and welcome Project Echo which was established for neurology, but are disappointed that, as yet, no clinical lead has the capacity at present to drive it.
- The Review should identify how the Department of Health will improve appointment times and the whole referral process, Unfortunately there currently is a lack of co-ordination and delayed communication from private neurologists into the MND service. At present a patient may have to wait for many months before any referral comes to the MND care co-ordination team. This Review should therefore outline how are those patients to be identified and supported in the interim period.
- The Review should identify how it will be delivered in a timely and dynamic manner and isn’t going to suffer from the administrative and Executive paralysis that has afflicted other proposed reforms.
- The Review identifies that patients in the Western and Southern Health and Social Care Trusts are not using the in-patient beds at the Royal Victoria Hospital in Belfast. The Department of Health should therefore ensure the creation of in-patient beds closer to home, including using hospices where appropriate.

3.0 Next steps and recommendations

We welcome the recommendations in the report that patients must have a designated point of contact as part of an effective care delivery network. The lack of a designated point of contact has been a major issue for many MND patients in Northern Ireland for several years/ To this end, we at the MND Association have made significant recent investment to establish 3 Care Co-ordinator roles working across all of the Health and Social Care Trusts in Northern Ireland. 2 of the Care Co-ordinators we currently fund will lead on the Regional co-ordination and development of the MND service (supporting the awareness-raising, education and development of non-neurology specialists and the wider Health and Social Care workforce on MND, creating Multi Disciplinary Teams etc) whilst the community coordinator will support people living with MND at a local level. This will enhance the support already provided by the Neurologists, the AHPs and the Regional Nursing Team (which includes 2 MND nurses, a pathway co-ordinator and MND navigator).

We are also in the process of establishing a MND Care Network to provide support for people with MND in Northern Ireland, and would welcome the opportunity to work alongside the Department of Health the develop this still further. There currently is no formal MND Care Centre or Network in Northern Ireland, and this review should seek to develop such an initiative. The Belfast Trust previously held such a service but the absence of specialised MND neurologists and only nurse-led clinics has unfortunately caused this service to decline.

We would welcome this Review helping to establish such an MND Care Network. We would envisage a model where such a network would be led by directors and clinical experts. We have 2 or 3 neurologists we'd be keen to include as Co-Directors given the amount of MND patients they see. Dr McCluskey in the Western Trust is one of them. He is keen to introduce MDTs, clear pathways based on NG42 and Optimal Care Pathway, and cementing cross-Trust working. At present, patients can attend clinics in 4 out of 5 HSC Trusts. We believe this Review should support this as part of the review of neurology services in Northern Ireland and would be of great benefit to people living with MND in Northern Ireland. Doing so would help the Department of Health go some way to realising its ambitions for people living with MND in Northern Ireland

4.0 Comments from MND patients and their families in respect of this Review

As part of our outreach to people living with MND in Northern Ireland, we invited comments from them as to their views on the Department of Health's Regional Review of Neurology Services. The below is a selection of some of their responses:

- "An all-island approach would be wise: for example, the north west cancer centre at Altnagelvin hospital treats people from ROI."
- "Equal access to services, drugs and neurologists across the whole of the north."
- "More specialist nursing support. When my wife was ill with MND there was very little specialist support."
- "I would appreciate better links to Belfast and outreach support. I have to travel to Belfast for clinic appointments and it's hard having to do so."
- "I think the late discovery of this awful disease makes things far worse. My brother had to wait so long to get a MND diagnosis that by the time he got it he didn't have time to properly say bye bye to us. It was heartbreaking.

Nothing would have prepared us for his death but it was so sudden, he suffered so much and we felt robbed."

- "Access to research and testing in both the north and the south. We get left behind because we're not in Belfast or the UK or down south. We're forgotten about."
- "I would like the department to end the postcode lottery that exists in Northern Ireland."
- "I think there should be counselling services for families available at hospitals. I try to support my husband but no one supports me."

These comments capture the thoughts and feelings of many of the people with whom we work. The lack of an all island approach, the postcode lottery, the disparity of the provision of care and services across the different Health and Social Care Trusts here, the lack of access to research and genetic testing, delays in diagnosis of MND and the lack of specialist psychological support have been frequently highlighted by our service users as some of the most pressing issues facing them in respect t of their "MND journey". We recognise and welcome that some of these issues have been highlighted in the Review, but we would urge the Department of Health to take urgent steps to address all of these issues facing our service users living with MND as a matter of urgency.

5.0 Conclusion

We thank you for this opportunity to respond to this crucial consultation. If you require any further information, please do not hesitate to contact Patrick Malone, Senior Policy and Public Affairs Advisor (NI) (patrick.malone@mndassociation.org) We reiterate that this submission also supports responses from the Northern Ireland Neurological Charities Alliance and should be recorded accordingly.