

# The provision of care for people living with motor neurone disease (MND) in Northern Ireland



**A report by the Motor Neurone Disease Association**

January 2023

---

## Contents

<b>1. Executive summary</b>	<b>3</b>
<b>2. About motor neurone disease</b>	<b>6</b>
<b>3. MND in Northern Ireland</b>	<b>7</b>
3.1 <i>Figures and prevalence</i>	7
3.2 <i>Delivery of care and services</i>	7
3.3 <i>Regional disparities in care provision</i>	10
3.4 <i>Funding</i>	11
<b>4. Policy context</b>	<b>11</b>
4.1 <i>Overview of delivery of health services in NI</i>	11
4.2 <i>Health transformation</i>	12
4.3 <i>Health and Social Care Trust - Strategic Plans</i>	13
4.4 <i>NICE guideline on MND: assessment and management</i>	14
4.5 <i>Regional Review of Neurology Services</i>	15
4.6 <i>Adult Social Care Review</i>	16
4.7 <i>Rare Diseases</i>	17
<b>5. The Patient Perspective</b>	<b>18</b>
5.1 <i>Case studies</i>	18
<b>6. Key Challenges</b>	<b>19</b>
6.1 <i>Lack of care pathway</i>	19
6.2 <i>Workforce</i>	20
6.3 <i>Housing</i>	21
<b>7. Network model of care: The South Wales Framework</b>	<b>22</b>
<b>8. Recommendations</b>	<b>25</b>

---

# 1. Executive summary

## Overview

Around 140 people in Northern Ireland are living with motor neurone disease (MND) (Craig, 2019), with between 30 and 40 new cases diagnosed each year. While the condition is rare, as an incurable disease, it is devastating for those affected by it, and the majority of those diagnosed with MND will die within two years.

As a key partner in the delivery of support to people living with MND and their families, the Motor Neurone Disease (MND) Association understands the challenges from people living with MND as well as from a service delivery perspective. We also recognise the opportunity to improve both of these aspects to ensure that people living with MND are afforded the best quality of life and dignity possible.

This report makes three key recommendations that are based on the expertise and experience of the MND Association, and include the voices of people living with MND.

The recommendations are directed at the Northern Ireland Executive, specifically the Department of Health and Department for Communities, working in partnership with the Health and Social Care Trusts and delivery partners.

## Who we are

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

In Northern Ireland, the MND Association has a committed branch with 18 active volunteers and four employees, all dedicated to improving the lives of people affected by MND.

The staff team and the [Northern Ireland Branch](#) of the MND Association aims to provide the best possible support to local people with MND, their families and carers, including:

- The provision of trained Association visitor (AV) volunteers to support people living with MND, their families and carers, to ensure they receive the best possible care.
- The organisation of informal support meetings for people with MND and carers.
- The provision of advice and signposting to other services and provision of specialist equipment and access to small grants.

- The provision of materials and advice on how to fundraise or opportunities to volunteer for the Association.
- The delivery of educational and learning opportunities for health care professionals.

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.

## What we are calling for

While the number of people impacted by MND is low, the potential to make a difference to their lives, and those of their families, is huge. The recommendations outlined below will enable people to live dignified lives through a whole system approach that puts them at its centre.

These recommendations chime with the ambition agreed by all political parties in Northern Ireland of the need for reform to the health and social care system, and given the small scale of the population that they would support, we believe they are realistic and achievable.

We are calling on the Northern Ireland Executive, Department of Health and Department for Communities, supported by the Assembly, to deliver the following recommendations:

### 1. The development of a Northern Ireland MND Regional Care Network

The MND Association is calling for a care network to be established in Northern Ireland, similar to the South Wales Framework, to improve care standards for patients living with MND and to ensure the care they receive is in line with the NICE guideline on MND for best practice.

A MND Care Network would ensure:

- That a care pathway is developed that is co-designed around the needs of the individual;
- People gain access to a timely diagnosis;
- Once diagnosed, people are able to access better co-ordinated care;
- Improved access to specialist care under the Multi-Disciplinary Team (MDT) approach, including access to respiratory services and psychological services (with a particular emphasis on community services).

---

## **2. Support for unpaid family carers of people with MND**

- Reviewing the current Carers Strategy 1 with a view to updating or 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 Carer's Assessment which allows for support packages, including access to respite and short breaks;
- Recognise and invest in third sector organisations who provide key support services to carers.

## **3. Improved access to housing adaptation**

- Ensuring that the Northern Ireland Housing Executive puts in place a transparent, fast track process for adaptations needed for people with MND.
- Monitoring and reporting, with the development of appropriate outcome measures, on good practice aligning to timely installation of adaptations.
- Removing financial assessments for Disabled Facilities Grants under £5,000 for people with MND.

---

## 2. About motor neurone disease

Motor neurone disease (MND) is a fatal, rapidly progressing disease of the brain and central nervous system. It attacks the nerves that control movement - motor neurones - which means that muscles no longer work. There is no cure for MND.

While symptoms vary, over the course of their illness most people with MND will become unable to walk, to use their hands, to swallow, and ultimately to breathe. They will find that their speech is affected, and many will lose the ability to speak entirely. Some people with MND may also experience changes to their thinking and behaviour, with a proportion experiencing a rare form of dementia.

Once diagnosed with MND, a third of people die within one year and more than half of people die within two years. Typically, this is as a result of respiratory failure. A much smaller proportion of people have a slower progressing version of MND and can survive for longer, but this is unlikely to exceed 10 years.

### Key Figures:

- Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.
- Around 35% of people with MND experience mild cognitive change, which can include changes in thinking and behaviour.
- A further 15% of people with MND show signs of frontotemporal dementia which results in more pronounced behavioural change.

A person's lifetime risk of developing MND is around one in 300. MND can affect any adult but is more common in older people, with approximately two thirds of people being between the ages of 55 and 75 at the time of diagnosis. Therefore, an ageing population will see an increase in the prevalence of MND as people live longer lives.

The systemic nature of the disability resulting from MND means that people living with the condition become dependent on a wide range of health, social, and palliative care services as their condition progresses. Key to providing dignity and comfort to patients is a joined-up approach to care, through a multi-disciplinary team. When this is not in place, patients are at risk of sub-optimum care, poor outcomes, escalation of crisis and traumatic experiences, and premature death. Across the lifespan of the disease, a patient with MND can expect to be referred to approximately 12 or more professionals.

In the experience of the MND Association, most people living with MND want to have their care needs met in their own home for as long as possible. This means that care can also often be a split between community and hospital services. Therefore, it is vital that care is well co-ordinated, preferably by a named individual with specific expertise in MND.

---

## 3. MND in Northern Ireland

### 3.1 Figures and prevalence

Figures and statistics on MND in Northern Ireland are scarce and often difficult to access. However, the most recent Department of Health figures available state that there are 140 people living with MND in Northern Ireland (Craig, 2019) with around 30-40 people diagnosed each year.

In Northern Ireland, the treatment of MND falls under the remit of the Neurology Service within the Department of Health. Recent inquiries and reports have proven the need for significant changes within the Neurology Service at present in Northern Ireland.

For example, the Regional Review of Neurology services interim report published in 2019 stated, 'the service currently falls short in meeting demand, in workforce and in meeting the needs and expectations of people with neurological conditions and their carers' (Craig, 2019).

It is within this framework that this report has been published, acknowledging the need for wider change of neurology services in Northern Ireland and the specific challenges facing patients and families affected by MND.

### 3.2 Delivery of care and services

#### Diagnosis

For most people their first interaction towards a MND diagnosis will be when they present to their GP with symptoms, who will often refer them for further tests.

Currently a patient is diagnosed by the Clinical Director of the Northern Ireland MND Regional Care Network at the Belfast Trust.

Once a patient is diagnosed, they are then referred into the Care Network. The MND Association works closely with the Northern Ireland MND Regional Care Network and other healthcare professionals involved in MND care to ensure patients receive the standard of care they need.

#### Delivery of Services

The NICE (National Institute for Health and Care Excellence) guideline on MND emphasises the importance of co-ordinated multidisciplinary assessment and management of patients with MND (including involvement with social care), which will:

*'Enable all people with MND across the country, whether in hospital, at home, in a care home or hospice, to receive care that is co-ordinated, consistent, comprehensive and responsive to their needs, that will improve their quality of life and go some way to mitigate the effects of this devastating disease' (NICE, 2019).*

Currently clinical care for people with MND is provided by a range of healthcare professionals including:

- Neurologists
- MND Specialist Nurses
- Physiotherapists
- Occupational Therapists
- Dieticians
- Respiratory Physiologists
- Palliative Care Nurses
- Speech and Language Therapists

Community Respiratory Nursing Teams exist across the five Health and Social Care Trusts. They undertake respiratory specialist training and are trained in the provision of oxygen homecare services and non-invasive ventilation (NIV).

Historically, these teams were initially set up and funded to only provide COPD (chronic obstructive pulmonary disease) services in the community. Some MND patients have been fortunate to be included in this area of care provision, however, a fully specialised MND service would be welcomed.

Of 72 people diagnosed between January 2014 and June 2015, 60% were referred to respiratory services including (including NIV) (MND Association, 2016).

For many people with MND, NIV relieves respiratory symptoms, as well as reduces anxiety and fatigue. In some cases, the use of NIV may also prolong life.

Expanding the scope of the respiratory nursing teams within each of the Health and Social Care Trusts to include provision of respiratory care for MND patients would improve access to the vital service of NIV which greatly improves quality of life for those living with MND.

Investment in a well-resourced community respiratory service for people with MND – and potentially other conditions – would also repay itself, preventing unnecessary and expensive admissions to hospital, freeing up staff and beds to deliver other hospital services.

---

In addition, Northern Ireland currently has no specialist neuromuscular physiotherapy service for people with MND. With the creation of this service, people living with MND could access a myriad of benefits including guidance on breathing management and how to conserve energy, access to cough assist devices simulating a natural cough and helping to reduce the risk of recurrent respiratory infections – a serious threat to people with MND.

The unpredictability and typical rapid progression of symptoms can mean that patients with MND are at greater risks of falls and of developing significant respiratory problems and aspiration, which can cause chest infections. Non-elective hospital admissions for people with MND are generally via Accident and Emergency departments as a result of falls, respiratory problems, pneumonia and Urinary Tract Infections (UTIs), which for the most part can be avoided through the provision of effectively managed and co-ordinated community and primary care through MDTs.

Studies have shown (Moore et al., 2019) that lack of provision of care for people with MND costs the NHS far more than would otherwise be the case if adequate care was provided, up to £3,840 per patient and £490 per day due to a lack of a multi-disciplinary approach to MND.

## Care Network and Support

In addition to the above, the MND Association has previously funded a Regional MND Care Network which covers the whole of Northern Ireland in partnership with the Health and Social Care Trusts, with plans to provide additional funding for the Regional MND Care Network in the future. In Northern Ireland, the MND Association has a committed branch with 18 active volunteers and four employees, all dedicated to improving the lives of people affected by MND, now and in the future.

The staff team and the Northern Ireland Branch of the MND Association aims to provide the best possible support to local people with MND, their families and carers, including:

- The provision of trained Association visitor (AV) volunteers to support people living with MND and their families and carers, to ensure they receive the best possible care.
- The organisation of informal support meetings for people with MND and carers.
- The provision of advice and signposting to other services and provision of specialist equipment and access to small grants.
- The provision of materials and advice on how to fundraise or opportunities to volunteer for the Association.

- The delivery of educational and learning opportunities for health care professionals.
- These services provided are funded by the MND Association and are based solely on local and national fundraising efforts and commitment of volunteers, with no government funding.

## Carers

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 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* survey 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 Carer's Assessment.
- 62% of carers had not had any respite.

In June 2022, in response to the above, we called on the Northern Ireland Executive to commit to supporting unpaid family carers of people with MND by:

- Reviewing the current Carers Strategy 1 with a view to updating/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 Carer's 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.

## 3.3 Regional disparities in care provision

Given the structures of healthcare distribution in Northern Ireland, people living with MND receive different levels of care and support depending on the Health and Social Care Trust area in which they live.

The Regional Neurology Unit is based at Musgrave Park Hospital in the Belfast Health and Social Care Trust and provides assessment, treatment, and review for people with long-term neurological conditions from all over Northern Ireland.

---

The Neurological Care Advice Service is also based in the Belfast Trust at the Royal Victoria Hospital. This service acts as a point of contact for neurological patients, their carers, and relatives.

The Neurosciences Centre is based at the Royal Victoria Hospital in Belfast and provides specialist inpatient care for patients with neurological conditions. This is supported by outpatient clinics across Northern Ireland.

### **What does this mean for patients living with MND?**

Whilst most of the Health Trusts (South Eastern Trust, Southern Trust, and Western Trust) outside of Belfast have resident neurologists, they are also supported by visiting neurologists from the Belfast Trust who provide clinics to patients.

In the case of the Northern Trust, only locum neurologists are available, with consultant neurologists from the Belfast Trust providing clinics in Antrim and Causeway Hospitals and the Braid Valley Care Complex in Ballymena.

There are no dedicated Neurology Units outside of Belfast.

Inpatient care for MND patients is provided by the Regional Neurosciences Unit based at the Royal Victoria Hospital Belfast. Patients coming from any of the other four trusts may therefore have to travel long distances to receive inpatient care and to access some other specialist appointments.

Patients with MND are also often admitted to the other four Health and Social Care Trusts with various physiological conditions associated with their diagnosis of MND.

Patients have told the MND Association that they feel that the standard of care, proximity to care and timeframe of care for patients with MND is better for patients who live closer to the Belfast Trust.

## **3.4 Funding**

Research into the cost of treating someone with MND will vary depending on the severity of a patient's stage of the disease. As reported by the 2019 report *Health Utilities and Costs for Motor Neurone Disease*, the mean 3-month NHS cost of a patient receiving care for MND is £1,889, but this figure can vary greatly depending on the disease severity (Moore et al., 2019).

There is also a significant financial impact on people diagnosed with MND. The extensive care needs for people with MND means someone with the disease requires substantial care, equipment and adaptations, with considerable costs associated. A 2017 report showed that people with MND and their families spend the equivalent of £9,645 on average for every year they have the disease in regular and enhanced costs plus a further £2,175 in one-off costs (Vibert, 2017).

## 4. Policy context

### 4.1 Overview of delivery of health services in NI

Health and Social Care (HSC) is the name given to the publicly funded healthcare system in Northern Ireland. Unlike the NHS in England and Wales, the HSC provide social care as well as healthcare. Whilst health policy is devolved to Northern Ireland, there is a focus on co-ordination with the wider United Kingdom.

The Department of Health, as one of nine departments in the Northern Ireland Executive, sets policy, regulations, and health strategy as well as bearing responsibility for funding.

The Public Health Agency (PHA) collects information, issues advice, and communicates key messages.

The Health and Social Care Trusts manage the day to day running of hospitals, health centres, residential homes and other health and social care facilities (with the Northern Ireland Ambulance Service also counted as a Trust).

Until March 2022, the now dissolved Health and Social Care Board was responsible for commissioning services with these powers now transferred to the Department of Health as the Strategic Planning and Performance Group (SPPG).

### 4.2 Health transformation

In 2016, the *Systems, Not Structures - Changing Health and Social Care* report, commonly referred to as the Bengoa report, was published. Then Minister of Health, Simon Hamilton, had previously appointed Professor Rafael Bengoa as Chair of a panel in 2015 that would produce an extensive report and recommendations for reform of the delivery of health and social care in Northern Ireland.

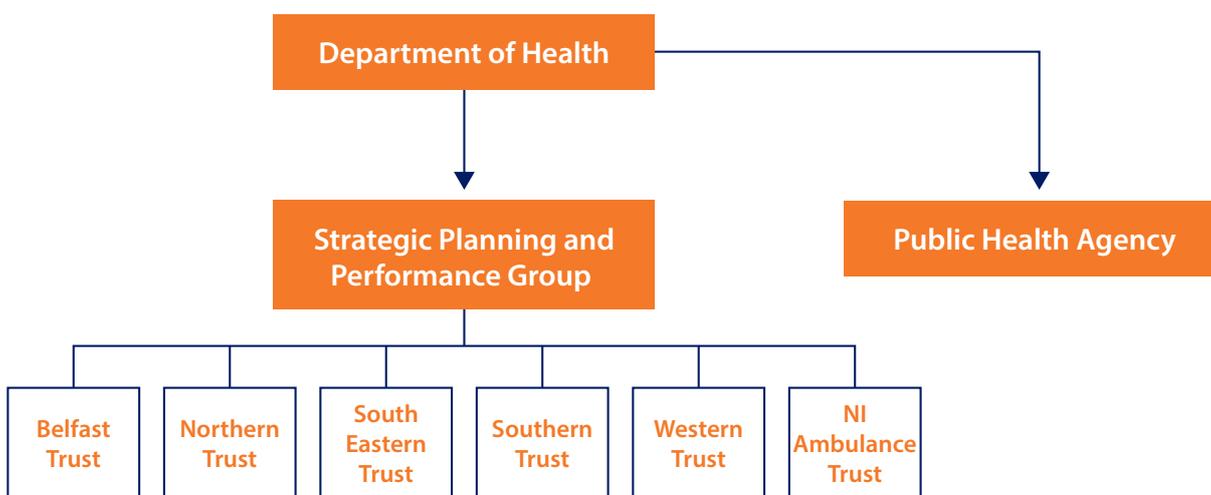
Specifically, the report made 14 recommendations, including a move towards, 'defined population-based planning and service delivery, as well as Regionalised planning for specialist services,' in Recommendation 2 (Bengoa et al, 2016).

The report recommended further investigation into the benefits of collaborating across jurisdictions, particularly for patients in experiencing the highest quality services (Bengoa et al., 2016).

Professor Bengoa recommended that specialist care could be delivered in any hospital across Northern Ireland, with all acute hospitals having the potential to be regional centres.

In response to the report, the Department of Health published *Health and Wellbeing 2026 – Delivering Together* which outlines a 10-year approach to transform health and social care in Northern Ireland. This approach included 18 specific actions that would be taken forward over the first 12 months from the reports' publication (Department of Health, 2016).

Figure 1: Health and Social Care structure



---

The most recent Health Minister, Robin Swann, announced that he would consult on plans to reshape hospital care in the Autumn of 2022 (Department of Health, 2022).

However, no consultation was published on these issues and the collapse of the Northern Ireland Executive in October 2022 has prevented progress on this.

In a progress report published by the Department in 2021, they cited progress on the development of multidisciplinary care home support teams; 'Multidisciplinary Care Home Support Teams have been established in each Health and Social Care Trust area with a total of 23 staff including nursing, social work, physiotherapy and dietetic professionals working across five teams' (Department of Health, 2021).

The roll out of this model of Primary Care MDTs is based around GP surgeries. However, this model of working could also be applied to care for patients living with MND, as the NICE guideline on MND recommends as the best standard of care for patients living with MND.

Health Transformation was recommended to take place at speed in the initial Bengoa report and despite welcome achievements including the reform of Adult Social Care and Support since the publication of the Health and Wellbeing 2026 approach, many areas are still lacking (Department of Health, 2021).

The experiences of patients living with MND highlights the need for urgent transformation of our health care service and specific attention to the lack of regional parity of services.

## 4.3 Health and Social Care Trust - Strategic Plans

Strategic and corporate plans for all five Health Trusts place an emphasis on joint partnership working and community collaboration, which is key for the delivery of healthcare services to MND patients.

### South Eastern Health and Social Care Trust

The South Eastern Trust Corporate Plan 2022-23 outlines four key priorities for the Trust. The overarching principle is 'Working in Partnership'. This includes a commitment to work with Trust patients, service users and families to transform services. (South Eastern Health and Social Care Trust, 2022)

### Northern Health and Social Care Trust

Similarly, the Northern Trust Corporate Plan 2021-2022 outlines five key objectives one of which includes improved partnerships

through the 'Northern Area Prototype'. This is a model of care that is focused on a, "joined-up" approach to planning services which involves local communities in the process. This served as the first prototype of the Integrated Care System set to be introduced across the Health and Social Care trusts in Northern Ireland. This system will see a new approach to Planning and Commissioning across the Trusts. (Northern Health and Social Care Trust, 2021)

### Southern Health and Social Care Trust

The most recently available Corporate Plan for 2017/18 – 2020/21 sets out 'Working in Partnership' as one of its strategic priorities, stating the ambition to "embed community development approaches to support local involvement and innovation in the future delivery of services including working with our partners to encourage support for a mixed economy approach to the provision of health and social care across all sectors". (Southern Health Trust, 2017)

### Western Health and Social Care Trust

The Western Health and Social Care Trust have rolled over their Corporate Plan until 2023. This plan notes the Trust's intention to 'work with the wider community and service users to explore and co-produce alternative models of service delivery'. (Western Health and Social Care Trust, 2022)

### Belfast Health and Social Care Trust

The Belfast Trust Corporate Plan features a priority for real-time feedback from patients and from staff. The plan states that the Trust is committed to ensuring that they are making necessary changes and improvements to care delivery. This highlights the importance of stakeholder feedback and input in future health transformation in Northern Ireland. Services must work for those who need them. (Belfast Health and Social Care Trust, 2021)

## 4.4 NICE guideline on MND

The NICE guideline on MND: assessment and management on MND represent the most authoritative and up to date statement of best practice and should be the standard of care implemented by the Department of Health and the Health and Social Care Trusts.

The guideline recommends that a core MDT for MND should consist of the following healthcare professionals:

- Neurologist
- Specialist nurse

- Dietitian
- Physiotherapist
- Occupational Therapist
- Respiratory physiologist or a healthcare professional who can assess respiratory function
- Speech and Language Therapist
- Healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the MDT, or by a specialist palliative care professional)

The NICE Guideline on MND: assessment and management (NG42) also emphasise the importance of a co-ordinated, specialist MND multidisciplinary approach to 'enable all people with MND across the country, whether in hospital, at home, in a care home or hospice, to receive care that is co-ordinated, consistent, comprehensive and responsive to their needs, that will improve their quality of life and go some way to mitigate the effects of this devastating disease' (NICE, 2019).

Currently, Northern Ireland is significantly behind in the implementation of this guideline when compared to Wales and some parts of England. Patients with MND in Northern Ireland do not have access to MDTs consisting of the standards recommended in the NICE guideline including access to each of the healthcare professionals listed above.

The MND Association propose that the Department and Trusts increase provision of regional neuromuscular respiratory services for people with MND, with particular emphasis on community services and the full implementation of the NICE guidelines, in particular relating to access to MDTs.

## 4.5 Regional Review of Neurology Services

The Department requested a 'Regional Review of Neurology Services' under the remit of 'Health and Wellbeing 2026: Delivering Together'. This review of services is 'tasked with identifying an optimal service configuration of neurology services through to 2035' (Craig, 2019). A Neurology Review Team, chaired by Dr John Craig has been undertaking work on this review.

An interim report was published in 2019 which revealed that there is a current shortage of neurologists in Northern Ireland. The report also recommended a number of changes to neurology services including the following (Craig, 2019):

- Person-centred with involvement from patients, clinicians, AHPs (Allied Health Professionals), nursing and other stakeholders;

- Safe and effective;
- Comprehensive provision across primary, secondary and community settings;
- Available on an equitable basis;
- Designed to develop MDT working;
- Evidence-based and benchmarked against best practice and NICE guidance;
- Appropriately resourced.

The interim report also calls for the development of multi-disciplinary teams working within neurology services across the Health and Social Care Trusts.

The final publication of the *Regional Review of Neurology Services* report was originally expected in 2020, with the interim report published in 2019 committing to publication in March 2020. However, in a recent [Written Assembly Question](#), the Minister of Health stated that progress on the established workstreams had been slower than anticipated due to clinical capacity issues (Northern Ireland Assembly, 2022).

The Department has now agreed to a date of March 2023 for the final publication of both the report, and an implementation and investment plan. Given the fact that the review is to make recommendations from now until 2035, it is essential that the new timeline is honoured so that effective changes to be made can be made with sufficient time and guidance.

## 4.6 Adult Social Care Review

Another element of health transformation to come from the 'Bengoa' report and subsequent *Health and Wellbeing 2026 – Delivering Together* report was the reform of Adult Social Care.

In 2016 an expert advisory panel was established on Adult Care and Support. The panel published 16 proposals for reform of the Adult Care and Support system in the *Power to People* report in December 2017 (Kelly and Kennedy, 2017).

The Department of Health subsequently took forward these proposals in the shape of six strategic priorities which were consulted on between January and July 2022.

The MND Association responded to the Department's proposals, indicating support for the legislative proposals outlined in the consultation to provide a more cohesive basis for adult social care provision. However, we were also clear that any new service eligibility criteria for service users and family carers should not restrict access to social care for these groups, including people living with MND.

The MND Association supports the proposal to align adult social care commissioning with the new Integrated Care System

model. This would allow for closer integration across health and social care services in Northern Ireland. Such close integration and link-up would benefit people living with MND, as many require a range of complex interventions across both health and social care settings.

In terms of Adult Social Care, the MND Association would ask for wider choice and control in the social care system for those needing care and their carers. MND is a progressive and severely disabling condition and the resulting care needs are often complex and require more specialist support. The MND Association often find this limits availability and choice of appropriate care provision for people living with MND, which impacts on the individual and their family carers.

## 4.7 Rare Diseases

The Rare Disease Partnership states that a disease is categorised as rare when it affects less than 1 in every 2,000 people. (Rare Disease Partnership, 2022)

With around 140 people living with the condition at one time in Northern Ireland, MND meets the definition of a rare disease. As with other rare diseases, MND is often difficult to diagnose, with some patients experiencing symptoms for many months before a final MND diagnosis. (Tucker and Chhetri, 2017)

The MND Association is a member of the Northern Ireland Rare Disease Partnership. The Partnership aims to, 'catalyse transformational change by working with and for people affected by a rare disease, their dependents, carers, and those treating them'. (Rare Disease Partnership, 2022)

The partnership focuses on the following core areas:

**Figure 2: Northern Ireland Rare Disease Partnership priorities**



Better awareness of MND as a condition, as well as stronger levels of advocacy and innovation can vastly improve the quality of care and approach to treatment of MND in Northern Ireland. Just because the condition is rare does not mean that it should be given any less attention or focus within the Health and Social Care system.

The MND Association is particularly advocating for more awareness of the condition amongst primary care health professionals.

---

## 5. The Patient Perspective

### 5.1 Case Studies

For the purposes of this report, representatives of the MND Association spoke to two people who have been diagnosed with MND. These conversations took place in December 2022, with participants remaining anonymous.

#### Case Study A

Person A is a 60-year-old man living with MND. He was diagnosed in May 2021 after experiencing weakness down the left-hand side of his body. Person A went to his local GP in the Northern Trust and was sent for scans which showed nothing of concern. After a few months, Person A's local GP revisited the case and referred him to a Neurologist in the Royal Victoria Hospital in Belfast. Person A received a Nerve Conduction Study which confirmed a diagnosis of MND. He did not know much about MND apart from high-profile names of individuals who had the disease and said that his 'world fell apart' when he heard there was no cure.

After his initial diagnosis, Person A was referred to the lead Neurologist in Belfast in a timely manner. He felt reassured that there were lots of people waiting to help with his MND care after this appointment. However, he felt this proved not to be the case. Person A said that he has not had continuous access to an MND nurse and that appointments with his neurologist do not happen every three months as they should. In the words of Person A, the 'calvary of folk promised' did not arrive and he feels as if he and his family are now on this journey alone.

Person A said that there have been some very dark days where he has wanted to talk to somebody outside of his family and no one has been there. He said that he understood that the health service in Northern Ireland is under pressure but said that 'there's nobody under more pressure than me and my family, because I'm dying. And my family knows that.'

Person A said he is frustrated that grants for people living with MND are means tested in Northern Ireland. Because he is in receipt of a pension, he is unable to fully access grants to make necessary changes to his home. Person A questioned why the grants process is different in Northern Ireland to the rest of the UK. He also expressed frustration at the lack of research available in Northern Ireland compared to the Republic of Ireland. Person A said: "I want research here, and grants available to all in Northern Ireland, whether you have worked or not."

He added that the small number of people who have MND at any one time in Northern Ireland may be why there is so little known about it. He expressed a desire to see a better standard of care and awareness for patients living with MND in Northern

Ireland and questioned the current standard of care saying: "Why does it have to be like that? Why do MND patients have to feel alone?"

#### Case Study B

Person B is a 40-year-old woman who was diagnosed with MND in May 2022 after experiencing eight months of symptoms. She noticed weakness in her hands and limbs which led her to go to her local GP Practice in the Northern Trust. She visited the GP four times before being referred to a neurologist in the Antrim Area Hospital. Before this, Person B was diagnosed by the GP with Carpal Tunnel Syndrome.

Person B waited for three months to receive a Nerve Conduction Study in the Antrim Area Hospital before taking the decision to pay £400 for the test privately. She said that early diagnosis is important for MND, and that GPs and other healthcare professionals should be more aware of MND. After this, she was referred to the Royal Victoria Hospital and was admitted as an inpatient. Person B was in hospital for two and a half weeks receiving tests and scans before being diagnosed with MND. She describes feeling scared and said: "I didn't want to go home, didn't want to be alone. I'd just been hit with this massive diagnosis."

In the first month after her diagnosis, she received no communication from the Northern Trust. She later relocated for family reasons meaning her care was now under the Western Trust, where she has received commendable care from a range of healthcare professionals. She described how she now uses a wheelchair and has had to have a stairlift installed at home.

Person B said that she has also struggled to get Personal Independence Payment (PIP) sign-off from her GP. As previously self-employed, this meant that she was earning no money for four months as she had to stop working due to the impact of her MND. She has lost income, her job, and her business.

Person B said that MND has 'consumed and destroyed my life' describing the diagnosis as a 'grieving process'. She said that there needs to be proper psychological support in place for patients living with MND and for their families. She added that there is no help offered to spouses or children of patients living with MND: "You are stripped of everything that makes you human."

Person B is currently pursuing research trial and treatment opportunities in the Republic of Ireland and asked why everyone on the island of Ireland cannot receive the same standard of care, she called for more trials and treatment to be available in Belfast. She said that in Northern Ireland there is nothing for MND. There is no help. It's a 'terrible, cruel, cruel disease.'

---

## 6. Key Challenges

### 6.1 Lack of care pathway

Currently in Northern Ireland, there is no official care pathway for patients diagnosed with MND. Given the terminal, and often short nature of an MND diagnosis, patients need immediate access to a structured care plan and specialised healthcare professionals to help them manage the wide-ranging impacts that an MND diagnosis can have.

As cited in many of the Health and Social Care Trust's corporate plans, it is vital that patients and carers are included in the development of any such care pathway. Through the development of a dedicated care pathway, it is essential that models of care are patient-focused and meet the needs of each individual.

People living with MND, those affected by the disease, and carers should be included in the process to ensure that the pathway appropriately meets the needs of those affected by MND.

### 6.2 Workforce

#### Shortage of Neurologists

In Northern Ireland there is a significant shortage of neurologists. For example, across Northern Ireland there are 21 Consultant Neurologists with 18 working full time and three working part-time. These neurologists have a wide-ranging remit which extends to stroke and dementia care (Craig, 2019).

In the recent interim review of neurology services, the report stated that there were 'insufficient consultant neurologists to deliver a 24/7 on call rota on any site other than the Royal Victoria Hospital' (Craig, 2019).

It was added that there is 'insufficient capacity to ensure that all patients admitted with a neurological emergency can be provided with advice within 24 hours as advised by the Association of British Neurologists' (Craig, 2019).

The workforce is also stunted in terms of growth due to the lack of training places available for neurology as a specialism. Out of 138 core training places available in Northern Ireland, only two are attached to neurology (Craig, 2019).

Fundamentally, clinicians are under-supported and under-pressure. For example, the Clinical Director for the MND Care Centre in Belfast is the singular lead neurologist for MND. Health and Social Care, patients can only be diagnosed with MND by the lead neurologist and therefore, there is considerable pressure both on this position and for patients in the care and support they can access.

#### MND specialist nurses

This workforce issue also extends to MND specialist nurses. Currently, there are two MND specialist nurse posts in Northern Ireland. This is not enough to support the 140 people in Northern Ireland who are currently living with MND (Craig, 2019). The MND Association have made recent efforts to fund a third MND specialist nurse post.

In total, across the Neurology service in Northern Ireland there are 37 specialist nurse posts (Craig, 2019). This is not adequate to properly support people living with a wide range of specialised neurological conditions, which includes MND.

For example, in cases of sickness and personal leave, MND patients are left with no specialist nurses for support and necessary care advice. This was the case in October 2022, when there was no MND specialist nurse cover due to staff absence/leave, placing clinicians and subsequently the MND Association Northern Ireland Branch under severe pressure to deliver essential support for people living with MND.

### 6.3 Housing

People living with MND also face challenges in relation to housing requirements to fit their changing needs in an acceptable timeframe.

Many people are becoming trapped in inaccessible homes because they cannot afford or cannot access support for necessary adaptations. A recent report by the MND Association, *Act to Adapt* (MND Association, 2019) demonstrates the extent of this issue.

Given the life expectancy of a person diagnosed with MND, timeliness in delivering adaptations is vital but not always achieved, and sadly people have died waiting for adaptations to be made to their home. The pandemic has worsened the situation in many cases.

In Northern Ireland, homeowners and private tenants living with a disability can access the Disabled Facilities Grant from the Northern Ireland Housing Executive. This grant helps to adapt the home of a person living with a disability to make it more suitable to their specific needs. This grant is a vital means of support but is not always easy to access for people living with MND.

The size of the grant depends on the individual's financial circumstances and takes into account income, pension and savings. The amount available is up to £25,000 depending on the work required. In some cases the Housing Executive state

---

that the maximum amount of award may be increased to £50,000. (Housing Executive, n.d.)

Due to the often fast progressing nature of their condition, housing adaptations need to be made as soon as practically possible and therefore, the process of grant application and delivery is often not undertaken at the necessary pace for MND patients.

The MND Association is therefore asking the Department for Communities to deliver safe and accessible homes for people with MND by:

- Ensuring that the Northern Ireland Housing Executive puts in place a transparent, fast track process for adaptations for people with MND.
- Monitoring and reporting, with the development of appropriate outcome measures, on good practice aligning to timely installation of adaptations.
- Removing financial assessments for Disabled Facilities Grants under £5,000 for people with MND.

## 7. Network model of care: The South Wales Framework

An example of a network model which provides co-ordinated and multidisciplinary care is the South Wales Framework. The South Wales Motor Neurone Disease Care and Research Network has improved support services for people living with MND in Wales by co-ordinating care in one care centre.

12 clinics are now in operation across South Wales, compared to one previous centre for the same area. The five-person team as shown in the table below, develop, manage, and work with specialist MND MDT clinics and community services based in each Local Health Board to provide person-centred care for people living with MND and their carers, and families across South Wales.

This Network removes the need for multiple separate appointments and visits to healthcare professionals (Swansea Bay University Health Board, 2022).

The below outlines the costs for a network lead, three care co-ordinators and an administrative assistant for the South Wales area.

**Figure 3: MND Care Network set-up in South Wales, MND Association**

Post	Band	WTE	Yr1	Yr2	Yr3	Yr4
Network Lead	8a	0.85	58,975	58,975	58,975	58,975
SE Care Co-Ordinator	7	0.80	48,017	48,017	48,017	48,017
SW Care Co-Ordinator	7	0.60	35,682	35,682	35,682	35,682
SW Care Co-Ordinator	7	0.60	35,682	35,682	35,682	35,682
SW Administrative Assistant	3	0.27	7,061	7,061	7,061	7,061
Uplift Band 6 to 7 (C&V CC)	6 to 7		6,131	6,131	6,131	6,131
<i>Figures include NI and superannuation costs</i>						
Travel & Other Costs (e.g. groups)			10,000	10,000	10,000	10,000
<b>Total Cost £</b>			<b>201,548</b>	<b>201,548</b>	<b>201,548</b>	<b>201,548</b>

Care co-ordinators facilitate multidisciplinary clinics for MND patients where all necessary professionals can be seen on the same occasion. This enables patients to spend less time in healthcare environments and allows them to focus on enjoying other areas of life.

This framework provides a costed and scaled model that could be applied to the Northern Ireland context and used to develop a similar practice of care for patients in Northern Ireland.

---

Since its implementation the Network has worked to achieve the following NICE recommendations for high quality patient care in MND:

- Reduce health inequality
- Provision of co-ordinated care using a clinic based specialised MND MDT approach
- Support and information for people and their family members and carers at point of diagnosis and throughout the disease trajectory
- Community and clinic-based multi-disciplinary teams across the five Local Health Boards
- Robust protocols and pathways, including the ability to make urgent referrals to appropriate services
- Continued and integrated care of people with MND
- A single point of contact, and information about what to do if there are any concerns between assessments or appointments, during 'out of hours' or in an emergency
- Cognitive assessments
- Managing symptoms
- Equipment and adaptations
- Psychological and social care support
- Interventions such as NIV / gastrostomy
- Communication
- Planning for end-of-life

More broadly, the South Wales MND Care and Research Network has also promoted effective integrated working between sectors including primary and secondary care.

A report by Rare Diseases UK has also found strong evidence that care co-ordinators represent good value for money for service providers. It found that their work can lead to significant cost savings, for example by saving consultants' and GPs' time, helping to prevent unplanned admissions, reducing hospital stays, helping patients receive timely access to specialist services and information, meeting their information needs, and being that single point of contact. (Rare Disease UK, 2013)

This South Wales Network is funded by the MND Association and five Local Health Boards.

As was the case in Wales, prior to the establishment of the care network, healthcare professionals often worked in isolation. However, with a care network, healthcare professionals can work in a co-ordinated team, and support one another in dealing with the complexities of MND. (Swansea Bay University Health Board, 2022)

The MND Association is calling for a similar care network to be established in Northern Ireland to improve care standards for patients living with MND and ensure the care they receive is in line with the NICE guidelines on best practice.

## 8. Recommendations

This report brings together research and evidence from existing policy and practice in Northern Ireland as well as best practice elsewhere, coupled with the perspective of patients and the MND Association to provide recommendations on how care and support for people living with MND in Northern Ireland can be improved.

As a rare disease, and with a scalable template for an approach as demonstrated in South Wales, the MND Association believe that Northern Ireland can also become a leader in treatment

and support for people with the condition, improving quality of life for patients and their families, as well as in support of the direction of travel more broadly within the Department of Health.

The MND Association want to work with the Northern Ireland Executive, Department of Health and Department for Communities to improve the lives of people with MND, and propose the following recommendations to achieve this:

### 1. The development of a Northern Ireland MND Regional Care Network

The MND Association is calling for a care network to be established in Northern Ireland, similar to the South Wales Framework, to improve care standards for patients living with MND and to ensure the care they receive is in line with the NICE guidelines for best practice.

A MND Care Network would ensure:

- That a care pathway is developed that is co-designed around the needs of the individual;
- People gain access to a timely diagnosis;
- Once diagnosed, people are able to access better co-ordinated care;
- Improved access to specialist care under the MDT approach, including access to respiratory services and psychological services (with a particular emphasis on community services).

### 2. Support for unpaid family carers of people with MND

- Reviewing the current Carers Strategy 1 with a view to updating or 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 Carer's Assessment which allows for support packages, including access to respite and short breaks;
- Recognise and invest in third sector organisations who provide key support services to carers.

### 3. Improved access to housing adaptation

- Ensuring that the Northern Ireland Housing Executive put in place a transparent, fast track process for adaptations needed for people with MND.
- Monitoring and reporting, with the development of appropriate outcome measures, on good practice aligning to timely installation of adaptations.
- Removing financial assessments for Disabled Facilities Grants under £5,000 for people with MND.

---

## References:

- Belfast Health and Social Care Trust (2021) *Belfast Health and Social Care Trust Corporate Plan 2021 – 23*. Available at: <https://belfasttrust.hscni.net/2021/09/27/belfast-trust-corporate-plan-2021-23/> (Accessed 14 November 2022)
- Bengoa, R., Stout, A., Scott, B., McAlinden, M. and Taylor, A.M. (2016) *Systems, Not Structures – Changing Health and Social Care – Full Report*. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/expert-panel-full-report.pdf> (Accessed 7 November 2022)
- Craig, J. (2019) *Review of Neurology Services – Interim Report*. Available at: <https://www.health-ni.gov.uk/review-neurology-services-interim-report> (Accessed 7 November 2022)
- Department of Health (2016) *Health and Wellbeing 2026 – Delivering Together*. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf> (Accessed 7 November 2022)
- Department of Health (2021) *Health and Wellbeing 2026 Delivering Together – Progress Report – 2021*. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-progress%20-report-full-document.pdf> (Accessed 7 November 2022)
- Department of Health (2022). *Swann announces design plan initiative for reshaping hospital care*. Available at: <https://www.health-ni.gov.uk/news/swann-announces-design-plan-initiative-reshaping-hospital-care> (Accessed 7 November 2022)
- Housing Executive (n.d) *Disabled Facilities Grant*. Available at: <https://www.nihe.gov.uk/housing-help/grants/types-of-grants-available/disabled-facilities-grant> (Accessed 5 January 2023)
- Kelly, D and Kennedy, J (2017) *Power to People*. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-full-report.PDF> (Accessed 6 January 2023)
- MND Association (2019) *Act to Adapt – Access to home adaptations for people with motor neurone disease*. Available at: <https://www.mndassociation.org/app/uploads/2019/09/Act-to-Adapt-Full-report.pdf> (Accessed 7 November 2022)
- Moore, A., Young, C.A. and Hughes, D.A. (2019) *Health Utilities and costs for Motor Neurone Disease*. *Value in Health*, 22(11), pp. 1257–1265. Available at: <https://doi.org/10.1016/j.jval.2019.05.011>. (Accessed 7 December 2022)
- Motor Neurone Disease Association (2016) *Every Breath Counts*. Available at: <https://www.mndassociation.org/app/uploads/2021/06/every-breath-counts-briefing.pdf> (Accessed 6 January 2023)
- Motor Neurone Disease Association (2019) *Improving MND Care survey 2019*. Available at: <https://www.mndassociation.org/improving-mnd-care-survey-2019/> (Accessed 20 December 2022)
- NICE (2019) *Recommendations – Motor neurone disease: assessment and management*. <https://www.nice.org.uk/guidance/ng42/chapter/Recommendations> (Accessed 4 November 2022)
- Northern Health and Social Care Trust (2021) *2021/22 Corporate Plan*. Available at: <https://www.northerntrust.hscni.net/about-the-trust/corporate-information/corporate-reports/> (Accessed 14 November 2022)
- Northern Ireland Assembly (2022) *AQW 4804/22-27*. Available at: <http://aims.niassembly.gov.uk/questions/printquestionssummary.aspx?docid=384414> (Accessed January 6, 2023)
- Rare Disease Partnership (2022) *What is a Rare Disease?* <https://nirdp.org.uk/about/what-is-a-rare-disease/> (Accessed 7 November 2022)
- Rare Disease Partnership (2022) *Our Vision*. Available at: <https://nirdp.org.uk/our-vision/> (Accessed 6 January 2023)
- Rare Disease UK (2013) *Rare Disease Care Coordination: Delivering Value, Improving Services*. Available at <https://www.raredisease.org.uk/media/1639/rduk-care-coordinator-report.pdf> (Accessed 7 December 2022)
- South Eastern Health and Social Care Trust (2022) *Corporate Plan 2022-23*. Available at: <https://setrust-hscni.pagetiger.com/SEHSCT-Corporate-Plan-2022-23/1> (Accessed 11 January 2023)
- Southern Health and Social Care Trust (2017) *Southern Health and Social Care Trust Corporate Plan 2017/18 – 2020/21*. Available at [https://southerntrust.hscni.net/download/89/ppi/3743/corporate\\_plan\\_2017-2021\\_v10\\_may\\_17\\_170517\\_smt.pdf](https://southerntrust.hscni.net/download/89/ppi/3743/corporate_plan_2017-2021_v10_may_17_170517_smt.pdf) (Accessed 7 December 2022)
- Swansea Bay University Health Board (2022) *Network offers better support for people with MND*. <https://sbuhb.nhs.wales/news/swansea-bay-health-news/network-offers-better-support-for-people-with-mnd/> (Accessed 4 November 2022)
- Tucker, H and Chhetri, S (2017) *PO249 Delays in diagnosis of motor neurone disease* *Journal of Neurology, Neurosurgery & Psychiatry* 2017;88:A78.
- Vibert, S (2017) *MND Costs: Exploring the Financial Impact of Motor Neurone Disease*. Available at: <https://www.mndassociation.org/app/uploads/2017/06/DEMOS-FULL-report.pdf> (Accessed 7 December 2022)
- Western Health and Social Care Trust (2022) *Corporate Plan 2022-23 (Addendum to Corporate Plan 2019-21 and Roll Forward Plan 2021/22)*. Available at: <https://westerntrust.hscni.net/about-the-trust/corporate-information/> (Accessed 14 November 2022)



**Motor Neurone Disease Association**

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

Tel: 01604 611860

Email: [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)

[www.mndassociation.org](http://www.mndassociation.org)

 [/mndcampaigns](https://www.facebook.com/mndcampaigns)

 [@mndcampaigns](https://twitter.com/mndcampaigns)

 [mndassoc](https://www.instagram.com/mndassoc)