

Summary

We are asking Northern Ireland Assembly candidates and the Northern Ireland Executive to ensure people with motor neurone disease (MND) have the support they need to maintain as high a quality of life as possible and to die with dignity.

Our three key requests are:

The increased provision of regional neuromuscular respiratory services for people with MND with particular emphasis on community services.

Treating people with MND for respiratory problems close to home would improve quality of life and reduce costly unplanned hospital admissions.

The implementation in Northern Ireland of best practice in care and support for people with MND – such as the new National Institute for Health and Care Excellence (NICE) guideline.

For Assembly members to champion the needs of people with MND in their constituency, including encouraging local councils to follow the example of Belfast City Council in adopting the MND Charter.

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 so 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 in thinking and behaviour, with a proportion experiencing a rare form of dementia.

MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people have a more slowly progressing version and survive for longer, but more than ten years is highly unusual. Timely and effective respiratory care

is essential in helping people improve their survival and quality of life.

A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people – approximately two thirds of people are diagnosed between the ages of 55 and 75. At any time, around 120 people are living with MND across Northern Ireland. Around 30-40 people in Northern Ireland will be diagnosed each year.

To help coordinate this essential support, the MND Association funds a Care Network covering the whole of Northern Ireland in partnership with the Health and Social Care Trusts.

Why community care for MND matters

The rapidly progressive nature of MND means people need to receive the right care at the right time.

While specialist hospital care is essential, well-coordinated community care is equally important. It enables a timely response to changes in a person's condition, minimising traumatic and costly emergency hospital admissions. And by providing support at home or close-by for people with MND,

community care can also improve quality of life.

Working together with health professionals, we've identified a key area where community care for people with MND should be strengthened: respiratory services.



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Every Breath Counts

Championing care for people with motor neurone disease

Finding breathing space – increasing capacity in respiratory services

With respiratory failure being the most common cause of death in people with MND, respiratory health professionals play a vital role in care as breathing becomes more difficult. The Belfast Trust hospitals and Altnagelvin Hospital are lead centres for neuromuscular respiratory care in Northern Ireland.

At present, however, there is limited capacity to support people with MND in the community. While there are community respiratory nursing teams across the five Health and Social Care Trusts, they do not all have the resource or training to provide a full service for MND including non-invasive ventilation (NIV). This puts additional strain on hospital staff.

Northern Ireland also has no specialist neuromuscular physiotherapy service for people with MND. Such a service could offer benefits including guidance on breathing management and how to conserve energy. It would also provide cough assist devices simulating a natural cough and

helping to reduce the risk of recurrent respiratory infections – a serious threat to people with MND.

Between January 2014 and July 2015, around three quarters of people with MND in the Belfast Trust requiring NIV were admitted as an emergency admission.

There are a number of reasons for this, including access to neurology and respiratory outpatient services and recognition of the onset of respiratory symptoms, but the lack of monitoring in the community is a significant factor.

Supporting NIV in the community

Providing more nursing support for NIV in the community would improve care for people with MND.

Non-invasive ventilation (NIV) machines are portable devices which provide extra air through a mask to help with breathing difficulties. While they require initial training and some ongoing oversight, on a day to day basis they can be used in the home without medical supervision. For many people with MND, NIV relieves respiratory symptoms, as well as reducing anxiety and fatigue. In some cases, it may prolong life.

In Northern Ireland, these benefits mean many more people with MND (and other conditions) are using NIV than before. Of 72 people diagnosed between January 2014 and June 2015, 60% were referred to respiratory services (including NIV).

Providing greater resource and training for NIV in the community would therefore reduce the pressure on hospitals. More importantly, it would also improve

access for people with MND to a service which greatly improves quality of life.

Finally, in economic terms, we believe a well-resourced community respiratory service for people with MND - as well as potentially other conditions – would repay itself in preventing unnecessary and expensive admissions and in freeing up hospitals to deliver hospital services.

We therefore propose that the Executive and Health and Social Care Board consider a business case for increased provision of regional neuromuscular respiratory services for people with MND, with particular emphasis on community services.

We offer our support and assistance in developing this case.

Supporting the best approach to care

Although MND can develop in any adult, it is more common in older people. Neurodegenerative illnesses like MND are one of the categories of illness that will occur more commonly as the population ages. All care systems are having to adjust to these changes, through greater integration and shifting more care to community settings. With its already integrated system, Northern Ireland is well placed to do this.

The disabling effects of MND mean care rapidly becomes complex and requires the involvement of many disciplines. A person with MND can have over a dozen professionals involved in their care at a time.

Generally the best approach is to keep the person as well as possible in their own home, which means care will often be split between a hospital (on an outpatient basis) and community services.

It is therefore vital that care is well coordinated, preferably by a named individual with expertise in MND. This could be a specialist nurse or other therapist, in a hospital clinic or community setting. Care must be planned in collaboration with the person with MND.

Care must also be anticipatory: for a rapidly progressive condition such as MND, poor forward planning can leave care services reacting too late to a crisis that could have been prevented.

Bringing in new best practice

Clear guidance to professionals is therefore essential – while some specialise in MND, many generalists will encounter only a handful of cases in their entire career.

The National Institute for Health and Care Excellence (NICE) guideline on MND represents the most authoritative and up to date statement

of best practice, and should be vigorously implemented by the Northern Ireland Executive and the Health & Social Care Board.

Innovation makes a difference

Innovation and joint working between care professionals - with the support of decision-makers – can deliver real improvements in the lives of people with MND. The Association urges the involvement of Assembly members as advocates and influencers in these processes.

For example, the Northern Ireland wheelchair service is currently piloting new powered wheelchairs for ten people with MND. These chairs enable the user to connect via a Bluetooth-enabled joystick with wi-fi devices such as phones or tablets. This makes it easier for them to operate environmental controls for lights, televisions, radios and other devices.

The chairs will be immediately available on assessment and can be adapted to suit the changing needs of a progressive condition, saving cost and time on reassessment and the reissue of another

chair. With the right support (grants or equipment) to make homes wheelchair accessible from Health and Social Care Trusts and the Housing Executive, they could make a big difference in helping people with MND to live more independently.

To support innovation and the exchange of knowledge, the Northern Ireland Rare Disease Partnership, of which the Association is a member, is also looking to create a virtual centre of excellence for professionals and people. For more information, please see their website at www.nirdp.org.uk.

Championing local care – the MND Charter

We are urging all councils across Northern Ireland to adopt the MND Charter. Assembly members and candidates can support local campaigns to make this a reality. By adopting the Charter, the council can help raise awareness of the disease as well as of people with MND and their carers living in the community.

One night in September 2015, Belfast City Hall was lit up in the colours of the MND Association to dazzling effect. There was more going on inside, where the Lord Mayor of Belfast was welcoming people with MND, their families and carers to a civic reception.

The event marked Belfast City Council's continued support for local people with MND and the work of the Association's Northern Ireland Branch. In December 2014, the City Council had been the first council in Northern Ireland to adopt the MND Charter.



The five points of the MND Charter are:

- 1. People with MND have the right to an early diagnosis and information.**
- 2. People with MND have the right to access quality care and treatments.**
- 3. People with MND have the right to be treated as individuals and with dignity and respect.**
- 4. People with MND have the right to maximise their quality of life.**
- 5. Carers of people with MND have the right to be valued, respected, listened to and well-supported.**

About the MND Association

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. We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.