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:

1. 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.

2. 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 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 to 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.
Finding breathing space – increasing capacity in respiratory services

With respiratory failure being the most common cause of death in people with MND, respiratory health services play a vital role in care as breathing becomes more difficult. The Belfast Trust and Altnagelvin 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 have the resource or training to provide 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 support, 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 more people with MND than before. Of 72 people diagnosed between January 2014 and June 2015, 56 (77.8 per cent) received NIV. The remaining 16 people 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, see 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 hospital beds to deliver hospital services.

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 rigorously implemented by the Northern Ireland Executive and the Health & Social Care Board.

Improving and joint working between care professionals – with the support of decision makers – can deliver real improvements in the lives of people with MND. NICE argues the involvement of Assembly members as advocates and influences in these processes.

Innovation makes a difference

For example, the Northern Ireland wheelchair service is currently piloting new powered wheelchairs for people with MND. These enable the user to control a vast range of functions with just a few buttons, including sitting position, driving, steering and even the lifting and tilting of the seat to improve posture and comfort.

We offer our support and assistance in developing this care.

Supporting the best approach to care

Although MND can develop in any adult, it is more common in older people. Neurodegenerative disorders like MND are one of the categories of illness that will occur more commonly in the population over.

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.

It is therefore that the 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 also be anticipatory for a rapidly progressive condition such as MND. Prior planning can leave services reacting too late to a crisis which could have been prevented.

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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.

Championing local care – the MND Charter

The MND Association is focused on MND care, research and campaigning.

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 with people with MND and their carers living in the community.

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. Caring 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.

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