

Making sure people with MND have access to the right services



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 and local centres, 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 policy-makers and professionals always consider and plan for the care needs of people with MND.



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30%
of people with
MND die within
12 months of
diagnosis

Motor neurone disease: a guide for councillors in Northern Ireland

This short guide is designed to help you understand motor neurone disease (MND) and how you can support your constituents with MND.

About motor neurone disease (MND)



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.

A person's lifetime risk of developing MND is up to one in 300.

It kills around 30% of people within 12 months of diagnosis, more than 50% within two years.

It affects people from all communities.

It has no cure.

How you can help as a councillor



As a councillor you can help improve the quality of life for people with MND in your community, and support them to live as an independent life as possible.

What you can do:

Champion the MND Charter

Help make a difference to people with MND and their carers in your area by encouraging your council to adopt the MND Charter*



Adopting the Charter is a simple way for you and your council to raise awareness of the needs of people with MND and the importance of the right care, in the right place, at the right time.

For more information visit www.mndassociation.org/mndcharter

Support people with MND in your constituency

Your constituents may contact you to:

- Ask you to support the *Champion the Charter* campaign.
- Ask you to help raise awareness and support local people with MND by attending an event or meeting.
- Ask for your help when they face difficulties accessing local services.
- Ask you to support a local campaign to change or improve local services.

If you want to meet people with MND in your area and find out how you can support them, please contact your your local volunteer-led Northern Ireland branch at www.mndani.com.

Keep up to date on social media

Follow our campaigning work on Facebook and Twitter to keep up to date on issues affecting people with MND and their carers.

🐦 @mndcampaigns

🐦 @mndcampaignsNI

📘 /mndcampaigns

*The MND Charter is a statement of respect, care and support that people with MND and their carers deserve and should expect.

How the MND Association helps



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

We fund an MND Care Network covering the whole of Northern Ireland in partnership with Health and Social Care Trusts.

We employ a Regional Care Development Adviser who is in touch with people living with MND and working to influence local health and social care service providers. In 2015, we issued more than 46,000 pieces of care information to people with, or affected by, MND. In Northern Ireland we also have a volunteer-led branch and Association visitors providing information and emotional support.

We fund and promote research that leads to new understanding and treatments, bringing us closer to a cure for MND. The value of our whole research grant portfolio on 1 February 2016 was £13.1 million.



In 2014, our support grants to help people with MND and their carers manage the disease, for example by helping to pay for home adaptations to allow for continued home living, totalled £893,000. We spent £247,000 on lending out specialist equipment to help people with MND carry out day to day tasks and communicate.

Much of the funding provided by the MND Association for care, equipment and other support for people with MND pays for services that could or should be provided by health and social care services in Northern Ireland. We will never walk away from a person with MND, or carer, who is in need, but we do not believe charitable funds should be relied on to cover shortfalls in statutory service provision.