



30%

of people with
MND die within
12 months of
diagnosis

Motor neurone disease: a guide for councillors

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 may have a say in many of the services people with MND rely on, such as:

- Social care.
- Housing and adaptations.
- Carers assessments and services.
- Health care.
- Public transport.



As a councillor you can:

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.mndcharter.org

Support people with MND in your constituency

Your constituents may contact you to:

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

If you want to meet people with MND in your area and find out how you can support them, please contact your local volunteer-led MND Association branch or group.

Keep up to date

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

 @mndcampaigns

 @mndassocWALES (*Wales*)

 /mndcampaigns

Join the Campaign Network at www.mndassociation.org/campaignnetwork.

*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 22 MND care centres and networks in partnership with NHS Trusts across England, Wales and Northern Ireland.

We employ 36 regional staff who are in touch with people living with MND and work to influence local health and social care service providers. 73,477 pieces of care information were downloaded or sent to people living with MND and their families in 2021. We also have a network of volunteer branches, groups 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 the Association's research portfolio on 31 December 2021 was £15.1 million.

In 2021, 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 £1,158,671.

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 the NHS or local authorities. 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.

**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, commissioners and professionals always consider and plan for the care needs of people with MND.



Your local MND Association branch or group contact details are:

MND Association

Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton NN3 6BJ. UK
Email: campaigns@mndassociation.org

www.mndassociation.org