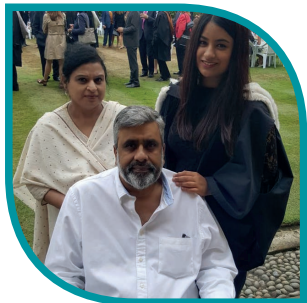


Making sure people with MND have access to the right services



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
Telephone: 020 3875 8910
Email: campaigns@mndassociation.org

www.mndassociation.org

Registered charity no. 294354

4/24

mnda
motor neurone disease
association



A third 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 a third 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

“Once I introduced my councillors to the Charter things moved surprisingly quickly – and all it took was an email and a meeting.”

Christine Crawford,
Flintshire

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.mndassociation.org/mndcharter

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.

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 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](#)

 [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 focuses on MND research, care and campaigning in England, Wales and Northern Ireland. A separate organisation covers Scotland www.mndscotland.org.uk

We fund more than 20 MND care centres and networks in partnership with NHS Trusts across England, Wales and Northern Ireland.

We employ around 30 regional support staff who are in touch with people living with MND and who work with local health and social care service providers. Every year we issue tens of thousands of pieces of care information to people with, or affected by, MND. 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 our whole research grant portfolio on 31 December 2022 was around £20 million.



Every year we support many people living with MND and their families with financial support grants. This includes funding towards home adaptations, specialist equipment and making memories, all of which supports their quality of life. In 2023, for example, we supported over 2,600 people living with MND and their families with over £2.2 million. For the latest figures see the most recent Impact Report on our website.

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.