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.

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.
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

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

We employ 26 Regional Care Development Advisers who are in touch with people living with MND and work 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.

We also have a network of 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
- @mndcampaignsWLS (Wales)
- /mndcampaigns

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.

Dear MND Association helps

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 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.

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

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