



motor neurone disease
association
cymdeithas
clefyd motor niwron



It kills a third of
people within a
year and more
than half within
two years of
diagnosis

Motor neurone disease: a guide for Wales Senedd members (MS)

This short guide is designed to help you better understand motor neurone disease (MND) and how you can support your constituents who are living with this terrible disease.

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.

Over 80% of people with MND will have communication difficulties, for most this means a complete loss of voice.

A person's lifetime risk of developing MND is around 1 in 300.

It affects people from all backgrounds.

It has no cure.

How you can help as an MS



Become an MND champion

You can make sure Health and Social Care systems in Wales work for people with MND, starting by ensuring people with MND have safe and accessible homes.

Please show your support by completing the pledge or add your message at www.mndassociation.org/walesselection to show your support for people living in Wales with MND.

Meet the MND Association in the Senedd

The MND Association is happy to meet with you virtually or in the Senedd, if COVID-19 restrictions allow, to help you understand more about MND, and the specific issues that affect people living with MND in your constituency, region and across Wales.

To meet with the MND Association, contact Sian Guest at sian.guest@mndassociation.org

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.

 www.twitter.com/mndassocWALES

 www.facebook.com/mndcampaigns

Support people with MND

Your constituents may contact you to:

- Ask for your help when they face difficulties accessing local services
- Ask you to support a campaign we're running 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 raise an issue in the Senedd or with relevant Ministers

If you want to meet people with MND in your constituency or region and find out how you can support them, please contact Sian Guest who will put you in touch with your local volunteer-led MND Association branch or group.

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.

We fund a Care Network in South Wales and a Care Centre at the Walton Centre NHS Foundation Trust which provides services for North Wales. We support multi-disciplinary co-ordinated care in Mid Wales.

We employ two Area Support Co-ordinators across Wales who ensure that people affected by MND receive the information and support they need. Our Service Development Manager for Wales works with statutory and other services to drive improvements in care and support. We also have a network of volunteer branches and Association visitors providing information and emotional support.

In 2020, over 57,779 pieces of information were downloaded from our website, while we sent over 23,000 publications to people affected by MND.

We fund and promote research – also in Wales - 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 2020 was £14 million.

In 2020, our support grants to help people with MND in Wales and their carers manage the disease, for example by helping to pay for home adaptations to allow for continued home living, totalled nearly £56,000.

Some 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 safe and accessible homes



We are asking the next Welsh Government to:

- Commit to increased funding for home adaptations over the next five years**
- Require all new housing to be built to an accessible and adaptable standard**

 mndassociation.org/welshselection

#WelshHomesForMND

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.

Those individuals living with MND are becoming trapped in inaccessible homes, sometimes in one room, because they cannot afford or cannot access support for necessary adaptations. Some people have died while waiting for alterations to be made to their homes.

It is therefore vital that applications for home adaptations for people living with MND are fast tracked to ensure that their dignity and independence can be maintained for as long as possible.

Your local MND Association branch or group contact details can be found at www.mndassociation.org/support-and-information/local-support/branches

MND Association

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Front page photograph by RT Adams

Become an MND champion



Please show your support:

**Complete the online pledge at
www.mndassociation.org/waleselection**

OR

Print out the pledge on the last page, adding your details and tweeting a photo of you holding it using the hashtag #welshhomesforMND

OR

Print out the pledge on the last page, adding your details and sending a photo of you holding it to campaigns@mndassociation.org



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Adapt Now Welsh Homes for MND

I pledge to help people with motor neurone disease receive the support they need.

Name:

Constituency/region:

My message (optional):

**Or add your message at
www.mndassociation.org/waleselection**