

Life with motor neurone disease (MND) is hard.

As a councillor you can help to make it a bit easier.

You can champion the MND Charter



**CHAMPION
THE CHARTER
ON YOUR
DOORSTEP**

Locked in a failing body. Unable to move, talk and eventually breathe.

This is life with MND.

"I was approached by one of my constituents whose wife had died early after being diagnosed with MND. His personal story and passion to raise awareness inspired me"

Cllr Susan Quinn,
Tameside council

About MND

MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.

It attacks the nerves that control movement so muscles refuse to work.

A third of people with MND die within a year of diagnosis, and more than half within two years.

It kills six people per day in the UK, and affects up to 5,000 adults at any one time.

There is no cure.



How you can help

A vital role

As a councillor you can play a vital role in supporting people living with MND and their carers in your local area.

As well as helping individuals with casework, you can influence the planning of services people with MND rely on, such as:

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

Whatever kind of council you're part of, there will be ways you can support people with MND.

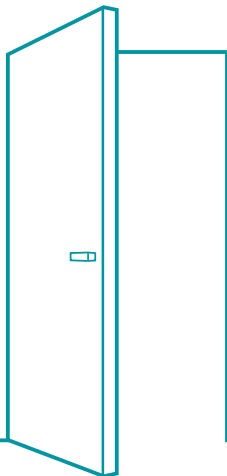
"MND is devastating and can be really isolating, but with the right support, we can enjoy the time we have left" Stephen Rhodes, who is living with MND

Champion the MND Charter

Getting your council to adopt the MND Charter is a powerful way of supporting people with MND in your community.

Like the growing number of councils who have already adopted the Charter, you would be sending a powerful message to local people with MND that you hear their voice, and are working hard to ensure they are valued, respected, and well supported by your council.

Read on to find out how it works.



The MND Charter

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

The five points of the Charter are:

1. **The right to an early diagnosis and information.**
2. **The right to access quality care and treatments.**
3. **The right to be treated as individuals and with dignity and respect.**
4. **The right to maximise their quality of life.**
5. **Carers of people with MND have the right to be valued, respected, listened to and well-supported.**

"I was overwhelmed when I learnt how quickly the disease takes hold of people. As a council we are committed to ensuring people living with MND are afforded the support and help they require"

Cllr Donna Jones, Leader of Portsmouth City Council

While councils aren't responsible for everything outlined in the MND Charter, they are a significant part of the jigsaw. When services such as social care and housing are provided in a timely person-centred way, this has a huge impact on the person with MND and their family.

MND is a devastating, complex disease and particularly difficult to manage. If you can get it right for MND, you can get it right for residents with other neurological conditions and disabilities too.



How it works

Adopting the MND Charter is a straight forward process, and doesn't cost a penny.

Get on board → **Adopt** → **Celebrate**

Get on board

Your journey will usually start with a meeting between you and a local resident who wants to discuss how the council supports people with MND and their carers in your community. If you've approached us about adopting the Charter, a meeting might not be necessary, you might just need some information and support. It's up to you.

Adopt

There's no set process you must follow, but we'd recommend either:

- Proposing a motion to adopt the MND Charter at your next full council meeting, or
- Writing to the leader or elected mayor and asking them to adopt the MND Charter on behalf of the council.

You'll also need to rally the support of your fellow councillors, asking them to vote for the motion or join you in writing to the leader or elected mayor. If there is a vote, we can help

you to present the case, for example by putting you in touch with a local person living with or affected by MND who can explain to your colleagues why this matters.

Celebrate!

You can publicise the Charter adoption with a press release, on your digital platforms, and perhaps by organising a reception. We will provide you with postcards, leaflets and posters to disseminate, as well as advice and support.

Adopting the Charter...

... allows you to:

- help people with MND
- show your support publicly
- know that you're making a real difference.

... means:

- you agree to promote the MND Charter as widely as possible
- you will share the promotional materials – for example with councillors, council staff, and health and social care professionals who deliver services for the council
- you will consider other ways of working together to support people with MND.

Next steps

After you've adopted the Charter

It's up to you how you take the Charter forward to help improve the lives of people living with MND after the adoption. We're here to support you on that journey, and can discuss additional steps we could take together. We'll also celebrate the good work you choose to do.

Adopting the Charter isn't about us accrediting you or giving you a kitemark. We do hope that adopting the MND Charter is the start of a strong partnership between your council and the MND Association.

To find out which councils have already adopted the Charter so far, visit www.mndassociation.org/mndcharter

PO Box 246, Northampton NN1 2PR

Telephone: 020 7250 8447

Email: campaigns@mndassociation.org

www.mndassociation.org/mndcharter

 @mndcampaigns

 @mndcampaignsWLS (Wales)

 /mndcampaigns

Further information

To find everything you need to get started please visit www.mndassociation.org/mndcharter

If you'd like to talk to someone about what adopting the Charter means or how it works, please email campaigns@mndassociation.org or call 020 7250 8447.

Adopting the MND Charter is easy, and could make a big difference to people with MND in your community. We'll help you every step of the way, and won't stop until there's a world free from MND.

Your local MND Association branch or group contact details are: