



CHAMPION THE CHARTER ON YOUR DOORSTEP

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Tips for social media

Social media is a quick and easy way of promoting the campaign to a wider audience. Here are some suggestions to help:

- Post on your social media about your participation in the campaign.
- Post a photo of meetings with councillors or a Charter adoption event.
- Mention us (@MNDCampaigns on Twitter or /MNDCampaigns on Facebook so we can share your post.
- Use hashtags #MND and #ChampionTheCharter so your post reaches more people.

You can search for your local councillor or council on social media and tag them in the post, in case they want to share it too.

Starting a Charter campaign: Ideas for branches and groups

MND Association branches and groups are in an excellent position to talk to local councillors about what they do and the issues encountered by local people with MND.

If you are part of a branch or group, your Campaigns Volunteer (if the branch/group has one), secretary or group contact can request some Charter materials in the post or by email, to get you started.

Here are some ideas to help you to get involved in the campaign:

- Make this campaign an item on your next committee meeting agenda. Devise an action plan to ensure as many people as possible hear about it and take action. Consider assigning a small task to each committee member.
- Include an item on the campaign in your newsletter and on your website.
- Consider any upcoming events you're planning and consider inviting councillors to join you. This would be a great engagement opportunity for you and a photo opportunity for them! We can support you with materials and ideas in advance.
- Tell people with MND and carers about the campaign at any upcoming support meetings and social events.
- If you have Association Visitors (AVs), talk to them about any contact they've had with councillors. Councillors have a role in sorting out problems people with MND are experiencing with services, as well as making big decisions about them, so they can be useful people for AVs to know.

Local media resources

Top tips for publicising your campaign activities

Local newspapers

If your council is adopting the Charter, you can approach your local newspaper(s) by using the contact details found in the paper or by searching online.

If you telephone, the reporters will ask you to email them something so please use the template press release below. It sets out exactly what the MND Association is, what MND is and why we are calling on councils to Champion the Charter.

The press release will have much more impact if you can personalise it with some information about why you are involved with our campaign, as an individual or via a branch or group.

Ask your councillor and a local person living with or affected by MND to provide a supportive quote which they would be happy with you using in a press release (see an example in the template below). It's best if they talk about the relevance of the Charter to the local area, for example by naming the council and services that support local people with MND.

Photographs are really important for newspapers but they need the best quality possible. Make sure your phone camera is set to the highest resolution setting.

Email your picture and press release with a clear caption explaining when the picture was taken and who is who.

Local radio

Consider local radio - for example, your local BBC Radio station. There are usually mid-morning, lunchtime and mid-afternoon shows with much more time to hear from real people about their lives, rather than a news, sport and traffic agenda.

Make a note of the presenter, and when you call the station ask to speak to the person who produces the show. Again, they will probably ask you for some information by email, in which case you can email them your press release or other information about why the campaign is important to you.

Template press release

For immediate release: [insert date]

or

Embargoed for: [time/date]

[Council name] hears voice of people with motor neurone disease

[Photo opportunity: details of photo opportunity if applicable]

[Council name] has agreed to adopt the motor neurone disease (MND) Charter in support of local people living with this terminal disease and their carers.

MND is a fatal, rapidly progressing disease that can leave people locked in a failing body, unable to move, talk and eventually breathe. It kills around a third of people within a year of diagnosis, and more than half within two years. There is no cure.

Unfortunately, this condition is still little understood and this contributes to many people with MND not receiving the care and support they need. The MND Charter was launched to change this.

[Councillor quote, amend as necessary]

"I am delighted our council has agreed to adopt the MND Charter. It is vital that more people are aware of the needs of people with MND so those living with this devastating condition can maximise their quality of life and die with dignity."

[Insert quote from local person living with or affected by MND]

Tanya Curry, Chief Executive of the MND Association said: "The importance of the MND Charter is undeniable. We want everyone to be clear that access to the right care, in the right place, at the right time, as set out in our Charter, can transform lives."

For further information please visit www.mndassociation.org/mndcharter

-ENDS-

NOTES TO EDITOR

About the MND Association

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

We are a membership organisation and have more than 11,000 people helping to strengthen our voice. Champion the Charter on your doorstep is a MND Association initiative. For more information see www.mndassociation.org

What the MND Association does

We improve care and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

About motor neurone disease

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

It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound, feeling etc.

It can leave people locked in a failing body, unable to move, talk and eventually breathe. It affects people from all communities.

Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.

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

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

Six people per day are diagnosed with MND in the UK.

It affects up to 5,000 adults in the UK at any one time.

It kills six people per day in the UK, which is just under 2,200 per year.

It has no cure.

The role of councillors

Who are councillors?

Councillors are elected by local people to represent them in a defined geographical area (called a ward, division or electoral area) for a fixed term of four years.

They are responsible for making decisions about, and monitoring, services provided by the council, on behalf of the local community.

Councillors are democratically accountable to residents of their ward, division or electoral area.

There are over 21,000 councillors in England, Wales and Northern Ireland.

Why are councillors important to target?

Councillors are important because they are elected to represent people with MND and their families, and particularly in England and Wales, have a say in many of the local services people with the disease rely on.

Services councillors have a say in

Service	How this affects people with MND and their carers
Adult social care	<p>Social care includes:</p> <ul style="list-style-type: none">• paid care workers who come into the home to wash and dress the person with MND, or to help them continue to take part in leisure or social activities,• the provision of some equipment - such as hoists - to help around the home,• care homes where people with MND might move into if life at home becomes too difficult,• help with information and advice on accessing the right services. <p>In England and Wales, social care is means tested. This means that not all people with MND will be eligible for 'free' social care provided by the council; it depends on their income. However, everyone should receive an assessment of their social care needs by the council.</p> <p>If you live in an area in England where there is a district council and a county council, then it is the county council that is responsible for decisions about social care.</p>

Service	How this affects people with MND and their carers
Housing adaptations	<p>Adaptations to the home (private, rented or council) are often needed when the disease has progressed to the extent that it makes moving around the house and completing normal daily tasks difficult or impossible.</p> <p>Adaptations might include:</p> <ul style="list-style-type: none"> • fitting accessible ramps and widening doors to allow for wheelchair access throughout the house, • installation of a stairlift or through-floor lift to allow the person with MND to access the upstairs areas of their home for as long as possible, • the conversion of a bathroom to a wet room area. <p>In England and Wales, adaptations can be fully or partially funded by a local council through a Disabled Facilities Grant (DFG). This is paid for and administered by councils, and is means-tested based on national criteria. If a person with MND qualifies for a DFG then a council-employed occupational therapist will make an assessment of what adaptations are required. In many areas, problems arise with DFGs when the assessment and/or adaptations take too long to complete.</p>
Social housing	<p>People with MND who live in social housing may rely on the council to help them make adaptations to their flat or house, or re-house them in an accessible property as the disease progresses (see above).</p>
Housing benefits including Discretionary Housing Payments, local welfare payments and Council Tax reductions	<p>People living with MND who are in receipt of housing benefit can face difficulties paying their rent on top of other expenses.</p> <p>In England and Wales, local councils have a limited pot of money to provide short-term assistance in those cases in the form of Discretionary Housing Payments. These payments are short term. Each council determines who should be given a payment, and how much it should be.</p> <p>People with MND who are on low income or claiming benefits may also qualify for their local council's Council Tax Reduction scheme. This is means tested based on personal circumstances, income and savings. Eligible people can receive up to a 100% reduction in their council tax.</p>
Carers' assessments and services	<p>Caring for someone with a rapidly progressing terminal illness can be a stressful and exhausting role.</p> <p>Carers of people with MND have the right to receive a carer's assessment from the council. This gives the carer a chance to discuss their needs with social services. In many cases, this assessment does not happen (usually because it is not offered or a carer doesn't see themselves as such).</p> <p>Based on the assessment, the council can provide a range of services that will benefit both the carer and the person living with MND. These might range from respite care, to allow the carer a short period to recharge, to simpler things such as help with household tasks, provision of a computer or assistance with transport costs. The provision of carers' services varies significantly.</p>

Service	How this affects people with MND and their carers
Blue Badge scheme	<p>The Blue Badge scheme allows people with MND who have reduced mobility to park closer to their destination.</p> <p>In England and Wales, the scheme is now administered by local councils either through assessment based on national criteria, or on receipt of the Personal Independence Payment (PIP) mobility component.</p>
Public health	<p>Local authorities in England are responsible for public health. This includes measures to prevent disease, prolong life and promote good health. For example, helping people to quit smoking and take up a healthier lifestyle. It can also include measures which promote <i>quality</i> of life and wellbeing; for example, initiatives to improve support at the end of life and after bereavement.</p>
Local transport; leisure and recreation facilities; roads and footpaths; parks and public places; local planning	<p>Ensuring full access to these services will be important to people with MND, as they help to achieve the quality of life aspiration in the Charter.</p> <p>Full disabled access to these facilities should be expected.</p>

Other council services may include public health, waste and recycling, regulation of local business, education services, electoral registration, environmental health and libraries.

Who is responsible for these services?

Councillors are the key decision-makers: they set the priorities and local policy for the local area. The decisions they make are then implemented on a day-to-day basis by staff members employed by the council, who are called officers.

Councils retain overall responsibility for ensuring the services organised and delivered by officers meet the needs of local people.

In England, since the Health and Social Care Act 2012, councillors also have a say in some health matters. Since the introduction of the Health and Care Act 2022, upper-tier local authorities are responsible for social care and public health services in their Integrated Care System Area, as well as other vital services that contribute to health and wellbeing such as housing, education, leisure and transport.

How do decisions get made in councils?

Most councils in England and Wales have a leader (or an elected mayor) and a cabinet who make the big decisions. Councillors not in the cabinet are known as backbenchers, and their role is to scrutinise the decisions.

It can be useful to find out what role your local councillors have. Find out by looking on the democracy section on the council's website. You will see a list of councillors and the positions they hold.

Look out for councillors who are members of council committees or boards dealing with health, wellbeing and adult social care (in England and Wales). These have an important role in making decisions about services used by people with MND and their carers.

Different types of local government in England and Wales

In Wales, a single council delivers all local services in each area. In England the structure of local government is more complex, but it is worth taking the time to understand what system your area has.

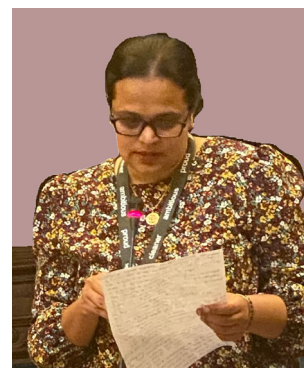
If you live in London or many of the larger cities of England (like Birmingham, Manchester, Leeds or Liverpool), you will have a **London Borough** or **Metropolitan District Council (MDC)**. These councils provide all local services, so their councillors have an important role in issues affecting people with MND.

If you live in a large- to medium-sized town or city like Reading or Nottingham, you'll probably have a **unitary or 'single tier' authority**. These councils also provide all local services. Some counties like Cornwall, Shropshire and Northumberland have also moved to having only one unitary council.

If you live in a rural or semi-rural part of England, your local government might be split between a **county council** and **district or borough council**. County councils cover large areas, like Devon or Kent, and provide about 80% of services for that area. District and borough councils cover smaller areas and provide more locally based services. If you have both in your area, we'd recommend you prioritise the county council, as they have more influence over the services used by people with MND.

As well as local councils, the UK also has around 10,000 **parish, town and community councils**. These form the most local level of local government and are responsible for things like allotments, bus shelters, car parks, public toilets, cemeteries, footpath lighting, litter bins, local halls and community centres, parks and public ponds, public clocks and war memorials. We are not prioritising councillors of these very local councils in this campaign, but there would be no harm in finding out who they are and asking them to adopt the Charter!

I was so pleased to see the motion pass unanimously. It was great too to have Mike Cole, the chair of the MND Association's Nottinghamshire branch, in the chamber to speak about MND and what they do to support local people.



Councillor Dr Nayab Patel, who persuaded Nottingham City Council to adopt the MND Charter in August 2023.

We continue to explore working with councillors, including support for fundraising initiatives.