



CHAMPION THE CHARTER ON YOUR DOORSTEP

Campaign guide for volunteers

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Thank you for supporting our campaign

This guide explains what the campaign is, why we're running it and what you can do to take part.

We hope this pack provides you with everything you need to get involved. If you have any questions, please don't hesitate to contact us:

Email: campaigns@mndassociation.org

Phone: 020 3875 8910

Post: Campaigns team, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ

Messages to help you talk about the campaign

- People with motor neurone disease (MND) are living with a rapidly progressing disease, which makes timely access to care and support essential. The five-point MND Charter outlines what is needed and serves as a tool to make this happen.
- Councils can have a big say in a lot of services that people with MND and their carers rely on. That's why we are calling on all councils to adopt the MND Charter (England and Wales only).
- By using the Charter to understand the needs of people with MND, councils can help in making sure people with MND in their community receive the right care, in the right place, at the right time.
- The growing number of councils who have adopted the Charter is sending a powerful message to local people with MND and their carers, that they hear their voice and are working hard to ensure they are supported in their community.

About the campaign

The aim of the campaign

The aim is to raise awareness of MND among councillors and ask them to get their council to adopt the Charter.

By councils adopting the Charter, we hope that this will lead to the start of a strong partnership between councils and the Association, where we can work together to improve the lives of people with MND at the local level.

What is a councillor?

Councillors are elected to the local council to represent their community. They are elected by local people 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 (which is always a defined geographical area).

For more information see the Appendix.

Why we're running the campaign

We want to ensure more councillors are aware of MND because they can have a say in the planning of many local services people with MND and their carers rely on, especially in England and Wales. Some of these services include:

- Social care
- Housing and home adaptations
- Carer's assessments and services
- Health care
- Public transport.

So it is important councillors understand the needs of people with MND and their carers.

It is our ambition that the next time a councillor makes a decision, they'll be more likely to think about the impact on people with MND and their carers.

What we're asking you to do

We need you to talk to your councillor about the benefits of them getting their council to adopt the MND Charter.

Time and time again we have seen that politicians are most motivated to act when approached by their constituents. It has helped open doors with key decision makers and politicians both at a national and local level.

This guide will help you get started.

Campaigning together

You may find that there are already like-minded people in your area with the same idea, so it might be a good idea to work on this campaign with a small group. We think that people will find it much easier and more effective if they work with others on encouraging their council to adopt the Charter - it will also help to avoid duplication and make it more fun!

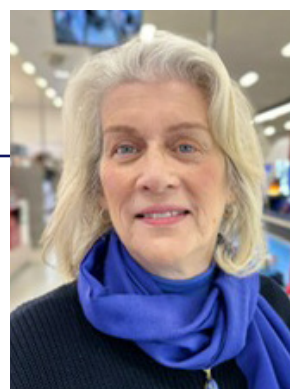
The Association has a number of branches and groups across the country that may be able to help you. If you would like more information about your local branch/ group, go to www.mndassociation.org/getting-support/local-support/branches

Some of these branches/groups will have a dedicated Campaigns Volunteer. Our Campaigns Volunteers may already be leading campaigns on getting councils in their area to adopt the Charter and we would encourage you to get in touch to see how you can help a campaign in your area.

To find out if your local branch/group has a Campaigns Volunteer, and to get in touch with them, please drop the Campaigns Team an email at campaigns@mndassociation.org or phone us on 020 3875 8910.

“Getting the Council to adopt the Charter was for us just the start. It opened the way to working with the council to improve local services for people with MND.”

Debbie Williams, MND Association Wirral group



Background to the MND Charter

The MND Charter was launched in June 2012, and states that:

- 1. People with MND have the right to an early diagnosis and information.**
- 2. People with MND have the right to access quality care and treatments.**
- 3. People with MND have the right to be treated as individuals and with dignity and respect.**
- 4. People with MND have 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.**

You can read the full Charter at www.mndassociation.org/mndcharter

From 2012-2015, we campaigned to gather signatures of support for the MND Charter. Over the three years, the Charter was signed by 33,630 individuals and organisations and we presented it to 10 Downing Street in June 2015.

The Charter lives on as a tool to help raise awareness of the needs of people with MND and through this campaign to get councils to adopt the Charter and bring it to life in practical ways, which will make a difference to people living with MND in your community.

Steps to Charter adoption

How many councils provide services in my area?

In all of Northern Ireland, all of Wales and parts of England, a single council delivers all local services. In England, single-council areas are often in cities (e.g. London boroughs) but some rural counties have them too.

Other parts of England have two councils providing services - a county council and a district or borough council. While you'll need to consider local circumstances, **we would usually suggest prioritising county councils** as they have more of a say in designing the services people with MND rely on.

For more information on local councils and what they do, please see the Appendix.

What to do first

Check to see if your council has adopted the Charter.

You can do this easily on our website at www.mndassociation.org/mndcharter

Adopted: If your council has adopted it this is great news! Send your councillors a thank you email and remind them of some of the other actions they can take to support people with MND in your community. You can do this on our website or by using our template letter - see the Appendix. You can also get in touch with us at campaigns@mndassociation.org for more information on how you can help.

Not adopted: Please take the steps to reach the ultimate goal of Charter adoption.

Step 1: Find out who your councillors are and request a meeting

Sitting down with your councillor (or councillors - often you will have more than one representing you) is the best way to communicate why adopting the MND Charter is important to you and local people living with the disease.

An easy way to find out the names of your local councillors and request a meeting is by using our e-action tool via our website www.mndassociation.org/mndcharter

Alternatively, you can use our template letter (see the Appendix). To find out who to send it to, telephone the council and ask them for the contact details.

Councillors don't usually respond to people who aren't their own ward constituents, unless they have broader cabinet responsibilities e.g. they are the Chair of the Health and Wellbeing Board (England only) or are on another committee.

However, if you're writing to *all* councillors on behalf of an Association branch or group, you can say that you support their constituents. This will help the councillors to understand why you are writing to them. To find out who *all* the local councillors are, go to your council's website. Look for a section called 'Council and democracy' or 'Your councillors' - it is usually linked to from the homepage. This can be useful for finding out the structure of your local council - you may have an elected mayor or a cabinet or committee structure. It can also tell you which councillors hold important posts.

And it's also worth finding out from the website which party or parties run the council. Councillors from the ruling party are worth prioritising for approaches and meetings as they will probably have greater influence.

Often councillors hold 'surgeries' which provide an opportunity for any ward resident to go and talk to their councillor face to face.

These take place on a regular basis and details can usually be found on the council's website.

If you're part of an Association branch or group, take a look at your events calendar and see if there is a meeting coming up that your councillors could be invited to. Remember to discuss this with the committee members first.

Note: Most councillors are not paid a salary but an allowance; they work part time in their elected role and often have a paid job as well, so don't be disheartened if they aren't able to set up a meeting immediately.

top tip

We encourage you to complete the action plan in the Appendix - this will help you keep track of all your actions. Once completed, please send a copy to us. The information you provide will be used to write up your campaign success to share on our website and other communication channels.

Tell us if you will be meeting with your councillor

This is so we can:

- Provide you with a key messages briefing. Please allow two weeks for us to compile this.
- Send you materials (electronic or print) to give to your councillor explaining more about the campaign.

Email us at campaigns@mndassociation.org

Step 2: Preparing for the meeting

Now that you have a meeting date with your councillor, you will need to start preparing for it.

Decide who will be going

You may want to invite a few people to join you. A small group who share the same concerns can have more impact. Try to include a person living with MND or someone recently affected by MND.

Decide what you will take

We have a range of campaign materials available from our website that you can take with you to help explain more about the campaign and leave with your councillor.

These include:

- Guide to MND for councillors
- Full MND Charter documents
- Champion the Charter: a guide for councillors

You can order printed copies from us if needed. Just email us: campaigns@mndassociation.org

We will also send you a briefing with key messages.

Step 3: At the meeting

If you've never done it before, the prospect of talking to an elected politician can be a bit daunting. But most of the time, people are surprised by how easy it is!

Here are some talking points to use with your councillor:

- Explain what MND is and the impact it has.
- Give examples of local services that people with MND use and your councillor may have a say in (see the Appendix to help you).
- If you can, give examples of local services that don't work well, or could be improved, and the impact this has. Often it is the speed at which services respond which is the issue for people with MND; for example the time it takes to get a housing adaptation or the knowledge of MND among care agency staff. We may be able to provide some examples in the tailored local briefing.
- Talk about the MND Charter, what it is and why you want the council to adopt it (use the 'Persuading your councillor to champion the Charter' section to help you).
- If you're involved in a branch or group, explain how you support people with MND locally.
- Explain how the council could go about adopting the Charter - see next page.



Tweet from Councillor Beverley Clack during Charter adoption meeting at Oxford City Council. Campaigner Mark Stone presented at the meeting. Sadly Mark lost his battle with MND in February 2016.

Adopting the Charter

There's no set process a council must follow in order to formally adopt the Charter, but we'd recommend the councillor either:

- **Proposes a motion to adopt the MND Charter at the next full council meeting**

or

- **Writes to the leader or elected mayor (if applicable) asking them to adopt the MND Charter on behalf of the council.**

They will also need to rally the support of their fellow councillors, asking them to vote for the motion or join them in writing to the leader or elected mayor (if your council has one). If there is a vote, the councillor might ask for your help presenting the case for adoption. We've found that having a person living with or affected by MND explain to the councillors why this matters is really effective in convincing councils to adopt the Charter.

Remember

- We can provide a local briefing to support you.
- You don't need to be an expert to talk to politicians about MND.
- You're there to talk about your personal experience of the disease, not to explain the science behind it.
- You will almost certainly know more about it than they will!
- If you can't answer a question say you're sorry you don't know the answer, but can find it out for them (we can help you to find the information if you want). You could then include that information in your follow-up letter after the meeting.

“I took a simple approach by writing to the various council leaders and setting out my personal reasons for seeking adoption of the Charter. This led to the councils taking time to look at the Charter's points, and then formally passing motions in full chambers.

“I was also asked to formally address Rochdale's full council which was quite an experience, but it allowed me to convey my passion and explain MND practically.”

Greg Broadhurst, Manchester and District Branch Campaigns Volunteer, who campaigned to get several councils in the North West to adopt the Charter

Persuading your councillor to champion the Charter

- Explain that getting your council to adopt the Charter is a powerful way of supporting people with MND in your community.
- Tell them that the council will receive a pack of materials to help them promote the Charter. It will include a poster, a template press release and suggested wording for the council's website and social media.
- Explain that the MND Charter is not a legally binding document. They are not obliged to make specific pledges or commitments. Similarly, we're not accrediting or giving councils kitemarks. Instead, we hope that beyond raising awareness, adopting the MND Charter is the start of a strong partnership between the council and the Association.
- Explain that the MND Charter covers all aspects of care and support for people with MND. We are aware that they will not be responsible for all points in the Charter, for example 'the right to an early diagnosis'. But by adopting the Charter they are sending a message that they are supportive of these rights.
- (England and Wales only) It's a tough time financially for councils. They are under great pressure to 'do more with less'. Let them know that:
 - By understanding the needs of people with MND and their carers they are more likely to spend the limited money they have on services that people actually need, rather than are assumed to need.
 - If a council invests in good services in the community, people with MND are less likely to experience a crisis at home and require more costly care.
 - By making use of the assets and services funded and provided by the MND Association locally (for example, branches and groups, Association Visitors and Regional Care staff) they can complement and enhance local statutory services.
- Point to the other councils who have adopted it, especially any that are very close by or neighbouring your council. See www.mndassociation.org/mndcharter
- Tell them that it is a good publicity opportunity for the council. They will be provided with a template press release and sample wording to use on their own website and to send to local media. You could also consider working with the council on a celebration event, and use photos to help generate more publicity. We will also publicise the news nationally on our website.
- Remember that councillors are elected to represent local people, so you're not asking for anything more than for that councillor to represent local people with MND and their carers.

Possible outcomes of your meeting

If your councillor agrees to champion the Charter

Brilliant! You are well on your way to getting your council to adopt the Charter.

If your councillor doesn't agree to champion the Charter

It is possible that despite your efforts your councillor will not agree to support the council adopting. Try not to be disheartened. There will be other ways we can try to hopefully get your councillor to change their mind and ultimately get your council to adopt the Charter.

Please get in touch with the Campaigns Team on campaigns@mndassociation.org or 020 3875 8910.

Step 4: Follow up immediately after your meeting

Call or email to thank your councillor for meeting with you. In your letter, summarise any commitments that were made.

Share any positive outcomes of your meeting. Your news could help inspire someone else to take action. You can do this by:

- Talking about it on social media - see the Appendix for advice and sample wording.
- If you are part of a branch or group, put an article in your next newsletter and on your website, including any photos you have.

Finally, tell us about it. We want to publicise your efforts nationally and show other supporters how it can be done.

Step 5: Maintain dialogue with your council

How fast things move with getting your council to adopt the Charter will depend on the actions your councillor agreed to take. There may be a number of steps involved before your council agrees to adopt the Charter.

Things may move slowly for lots of reasons - try to be patient and maintain polite dialogue, gently asking for updates on what has been done, and ask your councillor how they can help move things forward.

If, despite your best efforts, the council will not adopt the Charter, you can discuss other ways they can be supportive. For example, ask if they will disseminate information and resources about MND to councillors and council staff.

Step 6: Put forward your case at a council meeting

If your councillor has proposed a motion to ask the council to adopt the Charter, you should liaise with your councillor about local people with, or affected by, MND attending the meeting where the motion will be discussed.

You can ask your councillor if you can have a spokesperson to put forward the case for adopting the Charter. It can be very powerful to have a person living with, or affected by MND, explain to all councillors why this is important and can help influence their decision to pass the motion.

If your Council has a leader or elected mayor and they have agreed to adopt the Charter on behalf of the council without a motion, you may want to organise a Charter adoption certificate signing event to help celebrate this and maximise publicity.

Step 7: The council agrees to adopt!

Congratulations on your council adopting the Charter!

Now that your council has agreed to adopt the Charter you can present your council with an adoption certificate and materials to help them promote the Charter with colleagues working for, and with, the council.

These materials will include:

- Thank you letter
- Charter adoption certificate
- Full MND Charter
- MND Charter posters
- Template press release
- Sample wording for the council website and social media
- Guide to MND for councillors.

You may also want to consider organising a celebration event. This could be a reception for councillors and local people living with and affected by MND.

We have materials we can send you for Charter adoption events/meetings, including an extra large Charter adoption certificate that your leader of the council or elected mayor or other representative can sign. Email us on campaigns@mndassociation.org to let us know what you'd like.

Signing the adoption certificate or presenting the 'Champion the Charter' materials will make a great photo that could interest your local media when you come to promote your success.

Please let us know as soon as the council agrees to adopt the Charter so we can update our website and inform colleagues and stakeholders.

Step 8: Promote your success locally

You should promote your success by suggesting a photo opportunity with your councillor.

- Don't forget to request some campaign props and materials to use in your photo - email us on campaigns@mndassociation.org
- Use your photo with the template press release and send it to your local press. See the Appendix.
- Ask for a supportive quote from your councillor or another council representative, to include in your communications.
- And finally, don't forget to promote your success on your social media channels and in your branch or group newsletter/website.

“It was amazing when the whole County Council signed the Charter. We felt like we had achieved something huge...

“We have already seen an increase in awareness of MND; there have been more offers of help and signposting to carers support groups and carer’s assessments. It has also opened doors with us working with wider partner organisations such as Healthwatch Kent.”

East Kent Group Campaigns Volunteer Katy Styles, who campaigned to get Kent Council to adopt the Charter

Step 9: After the adoption

It's a good idea to follow up with your council after a few weeks to find out how they are promoting the Charter with colleagues.

The main purpose of the campaign is to raise awareness of MND amongst councillors, as so many know little to nothing about the disease and its impact.

Ideally, we want this increased awareness to lead to tangible change for people living with MND, but it's up to councils to decide how they'd like to take the Charter forward after the adoption. You may want to make some suggestions of small (or big!) changes they could make or actions they could take. This might be ways to improve services for people with MND, fundraising or volunteer initiatives or education/information sessions for local health and social care professionals.

Talk to the Campaigns team if you'd like ideas or advice.

Case study: Bridgend Council adopts the MND Charter

Bridgend County Borough Council adopted our Charter in February 2013. It was featured on their website and they tweeted about it to over 3,500 followers.

Local social care professional Amanda Aldridge said, "The team were really moved by the acknowledgement of the councillors and the Mayor of the importance of integrated working. Their endorsement and support in signing the MND Charter makes us proud of what we are trying to achieve."

Local MP at the time, Huw Irranca-Davies, said, "By endorsing the Motor Neurone Disease Association's Charter Bridgend County Borough Council is building on the successes they have already achieved working with people who suffer from MND. It is a truly horrible disease and good services and information can make a real difference in the standards of living for people with MND.

"In backing the Charter, BCBC is helping to maximise the quality of life for people who must live with motor neurone disease."

This fantastic achievement came about after a Bridgend councillor attended a Charter event at the Welsh Assembly in November 2012, organised by an Association Campaigns Volunteer and the South Wales branches.

