

MND
GUARANTEE

MND Guarantee: **General Election Quick Start** **Guide**

Spring/Summer 2024

mnda
motor neurone disease
association

Find out more on how to raise awareness of MND among politicians and ask General Election candidates to sign the MND Guarantee



mndassociation.org/mndguarantee



campaigns@mndassociation.org

Welcome

This guide will take you through initial actions you can take to support the MND Guarantee campaign - our campaign for the 2024 general election – and help you plan your next moves.

We're here to support you. If you have any questions, please get in touch with us at campaigns@mndassociation.org or 020 3875 8910.

About the campaign

We are asking candidates for the General Election to sign the MND Guarantee, to champion the needs of people living with and affected by MND in the next Parliament.

Discover more, including our priorities for the next government at www.mndassociation.org/mndguarantee

Write to your local candidates in the 2024 general election

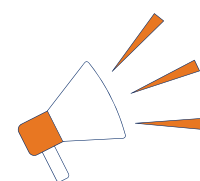
Please follow the instructions on the MND Guarantee webpage to e-mail your General Election candidates, adapting [the template message](#) as needed. You can ask us for help finding your candidates if you need it.

Please contact candidates from all the main parties – we must remain impartial.

Top Tip

Remember to tailor your approach based on what you know about your local candidates. For example:

- Do you have an existing link to a local candidate?
- Does a candidate have a known personal connection to MND?
- Do they have a link with the local branch or group?
- Do they have an interest in health and care issues?



Get others involved

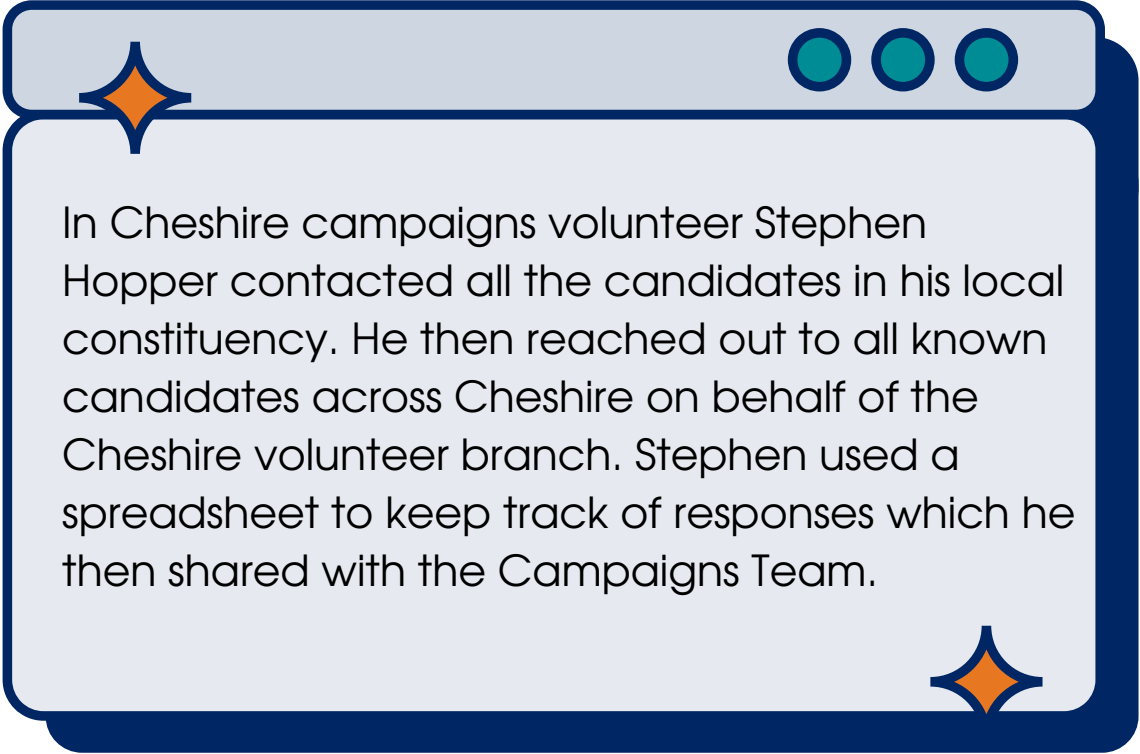
Now magnify that impact by sharing the [MND Guarantee webpage](#) and action with other local volunteers. You could do this by posting in local group forums, asking to speak about it at a branch/group meeting or including an article in your local newsletter.

This is an effective way of ensuring all candidates in your local branch/group area are contacted about the MND Guarantee. And an easy win!

Other ways to help

Covering other constituencies

Once you've contacted your own candidates you could do the same in other local parliamentary constituencies on behalf of your volunteer branch or group. Many of you will be part of your branch or group already so getting permission to do this should be straightforward.



In Cheshire campaigns volunteer Stephen Hopper contacted all the candidates in his local constituency. He then reached out to all known candidates across Cheshire on behalf of the Cheshire volunteer branch. Stephen used a spreadsheet to keep track of responses which he then shared with the Campaigns Team.

Don't forget to reach out to us for help understanding the political landscape and considering which constituencies to prioritise. For example:

- Are there sitting MPs who have an interest in health and social care or research?
- Is there a local campaign issue that can also be highlighted?

We will also be in touch if there are any constituencies in your area on our own priority list to offer additional support.

Offer meetings with your candidates to explain more about MND and encourage them to sign the MND Guarantee

To remain within [impartiality guidelines](#), you must offer invitations to all candidates from major parties in your constituency. They do not have to accept the invitation. A candidate may also offer to meet with you in response to your initial message – either way it is a great opportunity to make local politicians aware of MND and its implications.

If you would like help attempting to organise a meeting with your candidates, please email us on campaigns@mndassociation.org or call 020 3875 8910 and we'd be happy to assist you with this.

A suggested structure and talking points for a meeting is included at the end of this guide. Given enough notice we can also provide information on the local area (e.g. local services, estimated numbers of people with MND) to inform these conversations.

Join the conversation

If you're a campaigns volunteer, please do share what you are doing for the MND Guarantee on the [Campaign Volunteer Facebook group](#) – your fellow campaigners can be a great source of encouragement and support.

If you are not on Facebook, we will help you network with other campaigners in your area.

If you'd like to be part of our campaign volunteer community, helping raise awareness of MND among decision-makers, with access to training and support, please [discover more here](#).

Thank you!

Thank you once again for supporting the MND Guarantee campaign and raising awareness of MND among politicians. Awareness-raising is the foundation of campaigning on the issues – health, social care, research – that all of us are passionate about.

Please do let us know about your activities on the campaign and don't hesitate to get in touch if you have any questions or would like any support.

And when we know for sure when the General Election will take place we will update this guide with more actions you can take.

Candidate meetings – outline approach and suggested talking points

Key aims

- Ensure the candidate understands what MND is
- Ask the candidate to sign the MND Guarantee – to commit to raising awareness of the disease and supporting the MND community in Parliament. Link to pledge here: mndassociation.org/sign
- Ask the candidate to read the manifesto setting out our priorities for the next Government. This can be found here: www.mndassociation.org/mndguarantee
- Provide some information about Association activities – e.g. how does the branch or group support people with MND?

Important to keep in mind:

- Remain impartial - at no time must you or your branch indicate its support for a particular candidate or political party.
- With that in mind it's best to leave any social media to the candidate – you can always like the post afterwards.
- Don't feel you have to know everything – if you don't know an answer take it away and (with our help) reply to them later.
- Additional guidance on how to meet politicians (do's and don'ts) can be found in our '[Meeting your MP' campaigning toolkit sheet](#).
- Bring with you if possible: a print copy of [our manifesto](#) and any relevant information about the local branch or group

Key facts 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 no longer work.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND experience changes to their speech, which may become slurred or quieter. Some people lose their ability to speak entirely.
- Around 50% of people with MND experience some form of cognitive change while living with the disease.
- 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 around 1 in 300.
- There is no cure.

Our priorities for the next Government (from the manifesto) - some key asks

Please don't feel you have to walk candidates through the manifesto word for word – the key thing is to give them a few headlines, starting with the potential good news story of MND research. If you don't know an answer, take it away and (with our help) reply to them later, that's fine.

Access to treatments

The next parliament will be a critical period for MND research, with unprecedented levels of research activity to develop new disease modifying and life-extending drugs for MND. That means we need the next Government to:

- continue to invest sufficiently in MND research to ensure there is a pipeline of effective treatments for the condition.
- ensure that regulation allows for timely and equitable access to new treatments for people living with MND in the UK.

Tofersen and MIROCALS are of course huge issues in this area – however we'd suggest saving mention of these for conversations with sitting MPs who are standing again as they will have probably engaged with us on MND research before. There will be time to fully brief new MPs after the election has finished.

Other key asks in the manifesto for the next Government include:

- Accessible homes: to consult on increasing the upper limit of the Disabled Facilities Grant.
- Energy bills: a sustainable long-term solution such as an energy social tariff.
- Support for MND carers: an increase in Carer's Allowance.
- Social care: a plan for social care which addresses the current crisis in funding and workforce.

If asked about the NHS please say that we support the Neurological Alliance's campaign for a UK-wide Neuro Taskforce to improve services for people affected by neurological conditions such as MND.

Further local briefing information to be provided ahead of meeting – please ask us ahead of time and we can share what we know.