**Support MND Carers:**

**Supporter Action Guide**

We want government to improve the level of support for unpaid carers of people living with motor neurone disease (MND).

Our latest research found that unpaid carers of people living with MND now face many challenges to their physical, mental and financial health. It is no exaggeration to talk of a *crisis in caring*.

It is not acceptable that high numbers of MND carers have not received a carer’s assessment – to which they are legally entitled - leaving them without access to vital support.

Our *Support MND Carers* campaign is calling on the Government to launch a review into why carers aren’t being assessed.

We’re talking to MPs in Westminster, but they also need to hear it from you – the people they are elected to serve in their constituencies.

They need to know it’s important to you. They need to hear from people living with MND and their carers about the support they need.

*Are you in?*

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1. **What is the research?**

[](https://www.mndassociation.org/app/uploads/2022/11/Carers-Report-External-version.pdf)

[Click here to see the full report](https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf)

Unpaid carers of people living with motor neurone disease (MND) face many challenges. Our latest research report *Understanding the experiences of unpaid carers of people living with MND* summarises them as:

* Physical and mental exhaustion
* An inability to access breaks
* Caring in addition to parental responsibilities
* Difficulties coordinating care and support
* The impact of Covid-19 on care and support
* Juggling work and caring
* The financial impact of caring

While the report makes a number of recommendations to address these issues, for now we are focussing on **carer’s assessments**.

Carer’s assessments help to identify the needs of carers so that they can be offered the appropriate services and assistance to feel supported within their role. Carers are entitled to have an assessment – *it is a legal right*.

Support offered might include help with housework, training to help with caring, breaks from caring or emotional support such as counselling.

**However, our research has found:**

* Only 25% of carers of people with MND had either received a carer’s assessment or were in the process of having one
* 40% were unaware of their right to a carer’s assessment
* Carers felt that assessors lacked understanding of MND and the full impact of providing care on the carer
* 70% of carers have not had assessment/support plans or re-assessments/reviews of their needs
* Of those who did receive a carer’s assessment, 30% reported that they had not received any extra support as a result

**Our recommendation:**

Government should conduct an urgent review of carer’s assessments, with a particular focus on improving access to, and the adequacy of, assessments.

[An Executive Summary of the research report can also be found here.](https://www.mndassociation.org/sites/default/files/2023-05/MND%20Carers%20Executive%20Summary..pdf)

1. **What is the Support MND Carers campaign?**

This is where the new [Support MND Carers campaign](https://www.mndassociation.org/get-involved/campaigning/take-action/support-mnd-carers/) comes in. We are working to increase the level of support for unpaid carers of people living with MND, based on the findings of our report.

Over the last few years, we’ve been campaigning as part of the Care and Support Alliance and collaborating with other charities. But we are now stepping up our activity, reflecting on the fact that MND is a complex disease with unique caring challenges.

The *Support MND Carers* campaign is calling on the Government to launch a review into why carers aren’t being assessed and why, when they are assessed, recommendations from the assessment are not being carried out.

The review should work with local authorities to identify and address the barriers that continue to prevent a high proportion of carers from accessing the support they need and to which they are entitled.

The campaign was launched in Westminster at the All-Party Parliamentary Group on MND meeting at the end of November (29 November). They heard first-hand from MND carers who through their own experiences illustrated the realities of life as a carer and highlighted why more support is needed.

All MPs will now have received a copy of the report.

**With your help, we can now begin asking as many MPs as possible to write to the Secretary of State for Health & Social Care Steve Barclay highlighting the findings in our report and urging them to consider launching a review into carers assessments.**

1. **Why meet with an MP?**

* You elect your local constituency MP which means they are accountable to you
* Meeting with your MP is a great way to show them why a particular issue is important to you and your community
* You can talk to them about the Support MND Carers campaign, to make an ask or to explain why the campaign is important to you
* Meeting your MP might also be the start of building a relationship with them
* Because they may hold an important position in their party or in Government, which can make them very helpful for the Association’s work

1. **How do I organise a meeting with my MP?**

You can find out who your local MP is here: [Find your MP - MPs and Lords - UK Parliament](https://members.parliament.uk/FindYourMP).

On this website you should be able to find the constituency office phone number and an email address for your MP. Most MPs also have a local website where you can find this information.

**Top tip:** when contacting your MP always include your postcode in the correspondence so your MP knows that you’re a constituent.

We’ve included a template e-mail/letter in section 9 of this guide; you may also be able to adapt our e-action text to request a meeting. We’d suggest sending in the initial request in writing but then following up with a phone call to the MP’s office so that it’s on their radar.

Think if you’d like to team up with other local volunteers in your branch or group to meet your MP. That can make it less daunting, and also allows you to divide up roles in the meeting such as speaking, covering different topics, note-taking etc. Remember: at least one of you needs to be a constituent!

**Top tip**: get to know your MP. What issues do they cover on their website? On social media? In Parliament? Appealing to their interests might well help you on the day. We will also let you know if we have an existing relationship with them.

If possible, mention any plan you have for promotion up front as this may help to engage the MP in the meeting. To help with this we are providing a photo prop and template press release – see section 7 of this guide for more details.

Once you have arranged a meeting, please let us know on [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org). We will then check in with you to see if you would welcome any further advice or support.

If you live in Northern Ireland or Wales, we will also make sure you have some useful information about what’s going on with the carer’s issue in Stormont or Cardiff.

1. **What is a constituency surgery?**

MPs are most often in the constituency on Fridays and at weekends.

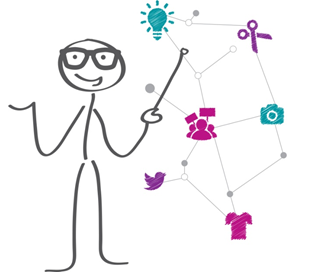
Many MPs hold regular constituency surgeries to give people an opportunity to meet them and discuss matters that are important to them.

You could arrange to meet your MP at one of these surgeries. These are often held on Fridays at their offices or in local venues such as community centres. Check your MP’s website for details - however even if none are listed you can still ask for a meeting.

1. **On the day**

* Print a copy of the [**executive summary of the MND Carers Report**](https://www.mndassociation.org/sites/default/files/2023-05/MND%20Carers%20Executive%20Summary..pdf), the [**template letter for MPs to send to the Health Secretary**](https://www.mndassociation.org/sites/default/files/2023-05/Support-MND-Carers-template-letter-for-MPs.docx), and our [**meeting photo prop**](https://www.mndassociation.org/sites/default/files/2023-05/Photo%20prop%20Support%20MND%20Carers.pdf) to take with you.
* Arrive at the venue in advance, allowing extra time for your travel, or unexpected delays.
* If you are meeting your MP with others, it’s also often helpful to meet shortly beforehand to go over your approach to the meeting.

1. **What happens at the meeting?**



* Introduce yourself to your MP and their staff and why you are involved with the Association.
* Open with sharing a summary of the findings from the **MND Carers Report** and explain some of the key messages.
* Talk to your MP about what life is like being an unpaid carer of somebody with a complex disease like MND.
* MPs want to hear why this is important to you. It always powerful to draw on your own experience or the experience of somebody locally to demonstrate why this is an important issue for the MND community in your constituency.
* People remember stories with concrete details far better than statistics, so have some stories and anecdotes to tell. We want the MP to *remember* the meeting, amongst all the other meetings, cases and issues that they have to deal with
* Ask them to write to the Secretary of State for Health and Social Care, Steve Barclay MP, asking the Government to **launch an urgent review into access to, and the adequacy of, carer’s assessments**.
* Your MP can use this draft wording to write to the Health Secretary: [www.mndassociation.org/sites/default/files/2023-05/Support-MND-Carers-template-letter-for-MPs.docx](http://www.mndassociation.org/sites/default/files/2023-05/Support-MND-Carers-template-letter-for-MPs.docx)
* Take a photo of the meeting, we have a [photo prop on the website](https://www.mndassociation.org/sites/default/files/2023-05/Photo%20prop%20Support%20MND%20Carers.pdf) that you can print and take to the meeting for your MP to hold
* Promote the meeting:
  + Through social media – raise awareness and help to build momentum for the campaign. When tweeting ensure you use the hashtag #SupportMNDCarers and feel free to tag us @MNDCampaigns
  + Edit and share [this press release](https://www.mndassociation.org/sites/default/files/2023-05/Support%20MND%20Carers%20media%20release.docx) with local media like the local newspaper or radio station. Alternatively, you can share the release with your MPs office if they would prefer to put it out themselves.
* MPs will sometimes have questions for you on the campaign or about MND in their constituency. We’ve anticipated some of the questions which are likely to be asked and provided some answers. See Section 10 for more details.

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| **Think about what you want your MP to leave the meeting feeling. For example…**   1. They have a greater understanding of MND, and the impact it has on unpaid carers. Get them thinking “what if it happened to me?” 2. Shocked and moved by the personal accounts they have heard from their constituents 3. Compelled to take action |

1. **After the meeting**

* Send an email to follow up from the meeting thanking your MP for taking the time to attend and discussing Support MND Carers. Remind them of your asks and send a link to the [full MND Carers Report](https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf) for their reference
* Tell us how your meeting went by emailing [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org). We will send you a quick form to complete to make that even easier. Getting feedback helps us to support you, and to coordinate our local and national lobbying of MPs.
* (Optional) Write an article for your branch/group newsletter/Facebook page reporting on the event, using the photo taken of the MP to accompany the piece.

Hungry to do more? Drop us an email and we’ll point you to the latest actions on this campaign and more!

Continue below to see the template e-mail or letter to MP requesting a meeting and key messages/tricky questions.

1. **Template e-mail or letter to MP requesting a meeting**

*Please do feel free to change the wording, for example if you have an existing relationship with your MP which you’d like to reflect in the text.*

*E-mail subject header: Please meet with me to support those caring for people with motor neurone disease*

Dear **[MP name]**

As my MP, I’m asking you to meet with me ***[and other members of my local branch/group]***to find out more about *the difficulties local unpaid carers of people with motor neurone disease face*  and how you can join our call for a national review into carer’s assessments.

As you may know, motor neurone disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. MND leaves people locked in a failing body, unable to move, talk and eventually breathe. Six people a day die from MND in the UK.

Caring for somebody with a complex and progressive disease like MND is an enormous responsibility which impacts carers in multiple ways. It is often family who take on the bulk of caring responsibilities. Research conducted by the MND Association found MND carers are physically and mentally exhausted, unable to access breaks and impacted financially. Many are also juggling caring with work and additional parental responsibilities. You can read the report in full here: <https://www.mndassociation.org/support-mnd-carers/>.

In response, the MND Association are calling for a national review into carers’s assessments. As you may well be aware these are a statutory right and help to identify the needs of carers so that they can be offered the appropriate services and assistance.

However, our research suggests only 25% of carers of people with MND had either received a carer’s assessment or were in the process of having one. Many are simply not aware that they are entitled to one.

I would appreciate it if you could show your support for people living with MND, and especially their carers and families living in our constituency, by meeting me to find out more about their concerns and how you can help.

I look forward to hearing from you in due course.

Best wishes,

**[name]**

**[branch/group – if appropriate]**

1. **Key messages and tricky questions**

What’s the problem?

Carer's assessments are a legal right but research from the MND Association has found too many unpaid carers are not aware of them or have found them to be inadequate.

Our recently published report *Understanding the experiences of unpaid carers of people living with MND* found that:

* Only 25% of carers of people with MND had either received a carer’s assessment or were in the process of having one
* 40% were unaware of their right to a carer’s assessment
* Carers felt that assessors lacked understanding of MND and the full impact of providing care on the carer
* 70% of carers have not had assessment/support plans or re-assessments/reviews of their needs
* Of those who did receive a carer’s assessment, 30% reported that they had not received any extra support as a result.

Unpaid carers from all parts of the UK consistently highlighted failures in access to and the adequacy of carer’s assessments.

It is not acceptable that high numbers of carers have not received a carer’s assessment, leaving them without access to vital support they are entitled to.

What needs to change?

The *Support MND Carers* campaign is calling on the Government to launch a review into why carers aren’t being assessed and why, when they are assessed, recommendations from the assessment are not being carried out.

Carer's assessments are a legal right but research from the MND Association has found too many unpaid carers are not aware of them or have found them to be inadequate.

Join us in calling on central and local government to ensure that every MND carer:

* is aware of their right to an assessment
* gets an assessment if they want one
* receives extra support as a result.

Tricky questions

We will update this section of the guide with new questions – and answers – based on the feedback we hear from you,

**Q: How many people with MND / MND carers there are in the local area?**

Due to the fast progression of MND overall numbers in an area can change very quickly, and not everyone with MND is known to the Association. However, if you let us know when you have a meeting scheduled with your MP, we can provide an estimate based on population. Your answer could also mention:

* A person’s lifetime risk of developing MND is around 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.

Similarly, we cannot give an exact number for the number of MND carers in an area. Each person with MND may have one or more family members and friends involved in providing care and support.

**Tell me about the quality of carer’s assessments in the local area**

If you let us know when you have a meeting scheduled with your MP, we can confirm which council is responsible for carer’s assessments in your area (if you’re not sure) and let you know if we have any anecdotal information to share.

You may be able to find out some information on local assessments from your local branch or group or from your Area Support Coordinator. However, please remember not to share any individual stories without their permission.

**If assessments are carried out by local councils, why a national review?**

Because our research shows that the system is not delivering for people with MND across the entire country. We believe that only a review on a wider scale will bring to light the root causes of the problems and set out solutions.

**How much would this cost?**

We can’t predict the outcomes of the review. But, by reviewing the carers assessment system and making recommendations for change, the Government would be helping councils to improve carers’ wellbeing and support. This in turn, would reduce the likelihood of other perhaps more costly health and social care services being needed either for the carer or the person with MND.

**What other issues do carers of people with MND face?**

Please see the research summary on page 2 of this guide

**What can I do to help local people with MND with local carer’s assessments?**

Please share the report with the cabinet member with responsibility in this area and urge them to review processes locally to make sure unpaid carers of people with MND are made aware of their right to assessments.