**Support MND Carers: frequently asked questions**

Welcome! This is a short guide to our new carers campaign where we try to answer some of the questions you might have about it. If we haven’t answered your question, or you’d like to discuss the campaign some more, please get in touch with us at [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org).

If you are affected by MND and need support with the issues raised by this campaign, please contact MND Connect on 0808 802 6262 or by emailing [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

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

The Support MND Carers campaign is about improving the level of support for unpaid carers of people living with motor neurone disease (MND). Our latest research – as set out in the MND Carers Report - found that MND carers now face many challenges to their physical, mental and financial health.

In the first stage of the campaign, we are focussing on **carer’s assessments.** We are 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.

**Our recommendation:**

* **Government should conduct an urgent review of carer’s assessments, with a particular focus on improving awareness, availability and access.**
* **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.**
* **It is not acceptable that high numbers of carers have not received a carer’s assessment, leaving them without access to vital support.**

1. **What are carer’s assessments?**

Carer’s assessments cover topics such as carers’ mental and physical health, their ability and willingness to care, and their relationships with others. They are the responsibility of local authorities in England, Wales and Scotland, and of Health and Social Care Trusts in Northern Ireland.

The Care Act 2014 in England gives anyone aged 18 years and over - who is looking after another adult who is disabled, ill or elderly - the right to a carer’s assessment. In Northern Ireland, the Carers and Direct Payments Act (Northern Ireland) 2002 gives carers the right to an assessment. In Wales, the right to a carer’s assessment is provided through the Social Services & Well-being (Wales) Act 2014.

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.

Support offered might include help with housework, training to help with caring, breaks from caring or emotional support such as counselling. [More information about carer’s assessments can be found here](https://www.mndassociation.org/support-and-information/for-carers/support-for-carers).

1. **How can I get involved?**

Ask your MP to write to the Secretary of State for Health and Social Care

Use this simple email tool to urge your MP to write to the Government asking them to launch an urgent review into access to, and the adequacy of, carer’s assessments.

It only takes a couple of clicks, [starting here](https://ecampaigns.mndassociation.org/page/117925/action/1?ea.tracking.id=hub).

Meet your MP

Meeting your local MP is a great way to show that this issue is important to you and motivate them to support the campaign.

Follow this link to [read our Action Guide with information about meeting your MP](https://www.mndassociation.org/sites/default/files/2023-05/Support%20MND%20Carers%20Action%20Guide.doc.docx) and the support available from the Campaigning, Policy & Public Affairs Team.

Change your social media headers

Show your support and promote the campaign by changing your social media headers: [Facebook header available here](https://www.mndassociation.org/sites/default/files/2022-12/FB-cover-image-851x315.jpg) and [Twitter header available here](https://www.mndassociation.org/sites/default/files/2022-12/Twitter-header-image-1500x500.jpg).

Other social media action

Keep a look out for updates from the MND Campaigns [Twitter](https://twitter.com/mndcampaigns) and [Facebook](https://www.facebook.com/mndcampaigns) accounts and on the hashtag #supportmndcarers.

It’s particularly helpful if you can share our updates and calls to action around your networks, So, please read, share and retweet!

1. **Where can I read the MND Carer’s Report?**

You can read the [MND Carer’s Report in full here](https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf).

We 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.

The report also contains many other useful findings on the experiences of MND carers which will inform future stages of the campaign. Other recommendations made in the report include:

* Increasing targeted funding for respite and carer’s breaks
* Alleviating pressure on carers with young families through improved access to statutory care services
* Urgently bringing forward the UK Government’s promised workforce plan to address serious shortages in skilled health and care support
* Producing a Respite and Recovery Plan for carers (as proposed by the Carers’ Week Coalition) to address the impact of the COVID-19 pandemic
* Carrying out an urgent review of carers assessments, with a particular focus on improving awareness, availability and access
* Guaranteeing a right to carers leave in the workplace – a minimum of five days as proposed in the Carers’ Leave Bill
* Uplifting the rate of carers allowance by £20 per week and ensure that it continues to rise in line with inflation
* Undertaking a full review of the financial support available to carers in light of the impact of the Covid pandemic and the cost-of-living crisis.

1. **What can I do locally as well?**

**England:** we will also be developing a wider local carer’s campaign later in the year, but if you want to get started now please contact us for more information on [[campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)](mailto:campaigns@mndassociation.org).

One thing you could do now, in addition to reaching out to your MP, is to write to or meet with your local councillors about the [MND Carers Report](https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf), highlighting some of the findings and encouraging them to consider the recommendations locally.

[You can find guidance and some wording to help draft your email here.](https://www.mndassociation.org/sites/default/files/2023-05/Supporter%20lobbying%20for%20local%20council.docx)

**Northern Ireland and Wales:** contact us on [[campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)](mailto:campaigns@mndassociation.org) for more information.

1. **My council has adopted the MND Charter. Doesn’t that mean they should already be helping people with MND?**

The MND Charter is a statement of the respect, care and support that people living with MND and their carers deserve and should expect. Over the last decade around 100 councils have signed the Charter, many with a role in the provision of support for carers.

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.

If your council has adopted the MND Charter then you could use this as a launchpad for conversations about improving access to carer’s assessments, particularly highlighting point 5 of the Charter.

1. **Where can I get support as a carer?**

As the Campaigning, Policy & Public Affairs Team we are unable to give direct support for individual cases and care needs. However, you can contact the

Association’s helpline MND Connect on 0808 802 6262 or by emailing

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

The Association also provides [a support and information webpage](https://www.mndassociation.org/support-and-information/for-carers/support-for-carers) for carers of people living with MND.

In the meantime, we are always on the lookout for people’s experiences to help with our campaigning work. If you wish to share your experiences – good or bad - of caring for somebody living with MND, [please email us](mailto:campaigns@mndassociation.org?subject=I'd%20like%20to%20share%20my%20caring%20experience%20).

1. **What is happening in Wales and Northern Ireland?**

As in England, we are calling on MPs in Northern Ireland and Wales to write to the Department of Health asking them to launch a review into carer’s assessments. So supporters in Wales and Northern Ireland can e-mail or meet their MPs about this. However, the campaign is a little different in these areas too, reflecting the devolution of health and social care.

In Wales, we are also encouraging Welsh MSs to keep pressure on the Welsh Government to publish the findings and recommendations from the planned 18-month review into carer’s assessments. We will work to ensure this review leads to real world change so that carers of people with MND in Wales are properly supported.

Meanwhile in Northern Ireland, we will be looking for opportunities to influence decision-makers in Stormont and raise the needs of MND carers – in coalition with other charities or separately.

1. **Are you collaborating with other charities and organisations?**

Yes. We work with Carers UK and Carers Trust on several issues that also affect carers of people living with MND. We are also members of the Carers Week coalition and the Care and Support Alliance. Working with these groups we will continue to raise other carers issues such as the uprating of Carer’s Allowance.

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

We envisage this to be a long-term campaign for the Association. Our focus on carer’s assessments forms the first phase of this campaign. Tackling wider issues facing those caring for people with MND remains a priority and as the campaign continues we will look to address them.