

**Media release**

March 2023

**MP joins local campaigners calling on Government to launch an urgent review into carer’s assessments**

Campaigners in **[WHERE]** are calling onSecretary of State for Health and Social Care, Steve Barclay to launch an urgent review into access to, and the adequacy of, carer’s assessments.

This comes after research from the Motor Neurone Disease (MND) Association found MND carers are being left physically and mentally exhausted, unable to access breaks and impacted financially. Many are also juggling caring with work and additional parental responsibilities.

Members of the **[LOCAL BRANCH/GROUP NAME]** of the MND Association had written to **[LOCAL MP]** urging them to raise this issue with the Department of Health and Social Care (DHSC) as a matter of urgency.

**[LOCAL MP]** has backed this campaign and committed to writing to the Health Secretary.

**[ADD ADDITIONAL INFORMATION ABOUT MPs INVOLVEMENT OR A QUOTE]**

MND is a fatal, rapidly progressing disease which affects the nerves in the brain and spinal cord that tell muscles what to do.

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.

MND carers also felt unable to leave their loved one with MND for prolonged periods of time, if at all, due to the lack of access to proficient care staff trained to deal with complex care needs associated with MND. For example, people making use of equipment such as assisted ventilation or suction machines for saliva control require care staff who are trained in the use of such equipment.

**[A LITTLE BIT HERE ABOUT YOUR CIRCUMSTANCES AND WHY YOU CAMPAIGN FOR THE ASSOCIATION]**

**[SPOKESPERSON NAME]** said: “We’re extremely worried that carers of people living with MND are not being properly supported. People with MND deserve great care while living with this devastating disease but that can’t be happen when their carer is physically and mentally exhausted. Carer’s assessments help to identify the needs of carers so that they can be offered the appropriate services and assistance to feel supported.

But research shows only 1 in 4 carers of people with MND have either received a carer’s assessment or were in the process of having one. This needs to change and that starts with a government review.”

To get involved in the campaign Support MND Carers please visit www.mndassociation.org/supportmndcarers

**ENDS**

**For more information:** Please email **[YOUR EMAIL ADDRESS]** or call **[YOUR NAME]** on **[YOUR NUMBER]**

**About the MND Association:**

Please note that style wise motor neurone disease is lower case and then abbreviated to MND. The Motor Neurone Disease Association can be shortened to the MND Association, or the Association but never the MNDA.

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 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):**

* 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.
* Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.
* It affects people from all communities.
* Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.
* 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.
* 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, this is just under 2,200 per year.
* It has no cure.