**Motor Neurone Disease Association**

**Support MND Carers campaign**

**Template letter for MPs to send to Secretary of State for Health and Social Care**

The [Support MND Carers campaign](https://www.mndassociation.org/get-involved/campaigning/take-action/support-mnd-carers/) 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 implemented.

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

Please write to the Minister of State for Care and Mental Health using the draft wording below to urge them to launch a review into access to and adequacy of carer’s assessments.

---------------------------------------------------------------------------------------------------------------

*Dear Minister,*

*I am writing regarding access to carer’s assessments and implementation of assessment recommendations for unpaid carers of people living with motor neurone disease (MND) and other disabilities in* ***(area)****.*

*MND is a rapidly progressing terminal illness that can affect a person’s ability to walk, talk, eat, drink and breathe. A third of people die within one year of diagnosis and more than half die within two years. As such, people with MND often have complex needs and are reliant on unpaid carers to meet their complex and changing needs as the disease progresses.*

*A report recently published by the Motor Neurone Disease Association 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 one. Carers also felt that assessors displayed a lack of understanding of MND and the full impact of providing care on the carer. The report indicates that around 70% of carers have not had assessment/support plans or re-assessments/reviews of their needs. The report found that of those who did receive a carer’s assessment, 30% reported that they had not received any extra support as a result. You can read the report in full here:* [*Understanding the experiences of unpaid carers of people living with MND.*](https://www.mndassociation.org/get-involved/campaigning/take-action/support-mnd-carers/)

*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. Similar provisions exist in Northern Ireland through the Carers and Direct Payments Act (Northern Ireland) 2002, in Wales through the Social Services & Well-being (Wales) Act 2014, and in Scotland through the Carers (Scotland) Act 2016.*

 *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. The assessment should be an opportunity to discuss how caring affects their mental and physical health, relationships with others, education and work life and opportunity for social interactions and leisure. But MND carers identified frustration with the assessors for not only misunderstanding the complexities of caring for someone with MND, but also for missing the bigger picture of need (through offering inappropriate outputs for respite).*

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

*I back this call and believe a government review is necessary to better understand why unpaid carers are not being assessed and to vastly improve the support offered to people living with MND and other terminal illness in* ***(area)****. I would be grateful if you consider this and look forward to hearing back from you.*

*Yours sincerely,*