

Helen Whately MP  
Minister of State for Care  
Department of Health and Social Care  
39 Victoria Street  
London  
SW1H 0EU

cc. Julie Morgan MS, Robin Swann MLA

11.06.2020

**Support for unpaid carers of people living with motor neurone disease (MND) during the Covid-19 pandemic**

Dear Minister,

As the CEO of the Motor Neurone Disease (MND) Association, I am writing to you during Carers Week 2020 on behalf of those who are providing unpaid care to their loved ones with MND during this difficult time, many of whom have added their signature and their own experiences to this letter. MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to walk, talk, swallow and eventually breathe. Due to the severely disabling nature of the disease, unpaid carers of people living with MND provide a significant amount of care and support. Our 2019 survey of people living with MND and their carers found that 33% of carers spent more than 100 hours per week caring.

As an Association, we are extremely concerned by the extra pressures being placed on unpaid carers of people living with MND due to the Covid-19 pandemic and the impact this is having on their health, wellbeing and financial resilience. While we acknowledge there is existing guidance for unpaid carers in response to Covid-19, we believe increased support is required, especially as lockdown measures ease in the future.

In our view, unpaid carers of people living with MND are undertaking a vital frontline role to ensure some of the people most vulnerable to the virus remain safe and well looked after. In doing so they are facing increased physical, mental and financial pressures. As lockdown eases for the majority of the population in the future, they will have a key role to play in ensuring those they care for continue to remain safe while wider society slowly begins to enjoy increased freedoms again. On top of already undertaking more caring tasks with little respite or support during this time, carers will be needing to navigate other challenges such as their children returning to school and their own commitments to continue with or



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recommence work, to name but two examples. At the same time they will be experiencing acute loneliness and isolation as the ability to rely on friends, family and support services for help is unavailable.

Given these and many more anticipated challenges, we are seeking a commitment that the impact on carers will be fully accounted for as things change and that extra tailored support will be put in place to meet them.

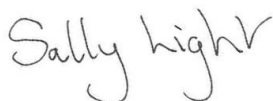
We urge the UK Government, the Welsh Government, and the Northern Ireland Executive to act now to relieve some of the immediate pressures being faced by unpaid carers, including by:

- Ensuring routine testing is introduced for unpaid carers regardless of whether they have symptoms so they know they can continue to provide care safely for their loved ones. This will be increasingly important as lockdown measures ease, children return to school and people are encouraged to return to work where possible.
- Urgently increasing the amount of financial support received through Carers Allowance to help unpaid carers better meet the increased and ongoing financial burden that comes with being a carer. The costs of caring have increased significantly during the pandemic.
- Ensuring access to PPE for unpaid carers to protect themselves and the people they are caring for. This should be prioritised alongside sufficient PPE provision for paid carers coming into the household.
- With lockdown beginning to ease in England and as the situation changes in Wales and Northern Ireland in the future, produce very clear guidance that helps protect carers and those they care for as restrictions begin to be lifted – especially for carers who have to manage work and care or children going back to school. This should include improved access to support provisions that will prevent carers putting themselves and their loved ones at risk, such as access to food and deliveries to avoid needing to go shopping.

We hope the Government agrees that unpaid carers deserve to be properly recognised and supported for their selfless commitment in caring for their loved ones with MND, with the toll of doing so having been significantly increased during this pandemic. Whilst as a nation we have been giving much-deserved attention to the efforts of the health and care workforce, unpaid carers should not be forgotten. They deserve to be invested in just as much as the NHS and Social Care as without their dedication, both systems would suffer directly as a result.

I hope you will respond to this letter at the earliest opportunity.

Yours sincerely,

A handwritten signature in cursive script that reads "Sally Light".

Sally Light – Chief Executive, MND Association

Co-signed by 3,081 individuals affected by MND in England, Wales and Northern Ireland