



motor neurone disease  
association

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HRH The Princess Royal

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Secretary of State for Health and Social Care  
Department of Health and Social Care  
39 Victoria Street  
London  
SW1H 0EU  
United Kingdom

13<sup>th</sup> April 2022

Dear Secretary of State,

As clinicians who work with patients living with motor neurone disease (MND), we are writing to express our concerns regarding the Government's decision to restrict access to the spring booster vaccine dose.

For both primary vaccine doses and the first booster dose, people judged to be clinically extremely vulnerable were prioritised for access, as were their carers and close household contacts. However, the spring booster will be offered only to people who are either over 75, resident in a care home, or who have compromised immune systems.

The clinically extremely vulnerable group includes people living with MND who have significant respiratory compromise. As MND progresses it impairs the respiratory muscles, restricting the ability to breathe. As respiratory compromise becomes more severe, people living with MND may become unable to breathe unassisted and consequently require either non-invasive ventilation or tracheostomy ventilation. The most common cause of death among people living with MND is respiratory failure.



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People living with respiratory compromise are at significantly higher risk from respiratory infections. Consequently, this group was rightly prioritised in previous vaccine rollouts. The decision to exclude them from the spring booster has come as a shock to many and caused widespread anxiety and concern.

The decision to exclude people affected by respiratory compromise from the spring booster affects not only those individuals themselves, but also their families, loved ones and carers. We know that many families of people living with MND have taken significant steps to minimise the risk of passing on a COVID-19 infection since the outbreak of the pandemic, including by undertaking shielding measures, reducing social contact, and reducing contact with public services including care and support staff. This places a huge burden on families and carers.

The successful rollout of the vaccine programme gave many families the confidence to step back from shielding measures. However, the exclusion of clinically extremely vulnerable people from the spring booster threatens this progress. As infection rates continue to rise, we have heard from worried family members who are once again considering steps to minimise infection risk, including pulling children out of school and restricting contact with vital public services.

The Government states that its decision is justified by the context of the milder Omicron variant and the previous vaccinations provided. However, for people living with severe respiratory compromise, even a “mild” respiratory infection poses a significant risk to life. In addition, it is now well-established that the protection provided by vaccines wanes over time, so that additional booster doses are required to protect the most vulnerable.

We call on the Government to reconsider its decision to restrict access to the spring booster more narrowly than previous doses. People living with MND leading to respiratory compromise deserve the additional protection that the spring booster dose provides, and their families deserve to know that their loved ones are as well-protected as possible from COVID-19.

Yours sincerely,

Dr Aleksandr Radunovic, Co-Director, Barts and London MND Care Centre

Professor Ammar Al-Chalabi, Co-Director, King's MND Care and Research Centre

Professor Chris McDermott, Co-Director, Sheffield MND Care and Research Centre

Professor Martin Turner, Co-Director, Oxford MND Care & Research Centre

Dr Rhys Roberts, Co-Director, Cambridge MND Care Centre