

Update on motor neurone disease and the COVID-19 clinically extremely vulnerable register

June 2020

The request to consider whether individuals with motor neurone disease should be included in the clinically extremely vulnerable group (and therefore advised to shield) has been reviewed by senior clinicians. The following explains the current rationale and position.

There are several conditions which we understand, on current evidence, may place somebody at a high risk of severe illness from COVID-19 which can be found [here](#). This list of conditions includes motor neurone disease and government advice to this group is that they follow strict social distancing and hygiene measures.

A smaller group of conditions have similarly been identified by senior clinicians as placing people at greatest risk from COVID-19 (Clinically Extremely Vulnerable). People with these conditions are being advised to follow shielding advice. The list was developed by the Chief Medical Officer for England in close consultation with the Chief Medical Officers of the Devolved Administrations and senior clinicians in NHS England, NHS Digital and Public Health England. Inclusion of indications in the shielding criteria was based on understanding of the risk of the disease at that point in time. As a precautionary measure, however, on 23rd April 2020 Northern Ireland's Chief Medical Officer announced that all patients with motor neurone disease should also be considered to be clinically extremely vulnerable. This applies to Northern Ireland only.

As we learn more about the disease and the risk factors involved, the Government expects to steadily make risk-assessment more nuanced, giving confidence to some previously advised to shield that they may be able to take more risk; and identifying those who may wish to be more cautious ([Our Plan to Rebuild](#)). Following [shielding advice](#) can be challenging, and it is important to recognise both potential physical and mental health risks of such interventions. In light of this, only conditions for which there is a clinical indication for blanket inclusion have been included in this list. GPs and secondary care clinicians have been asked to review caseloads to identify any additional patients, not identified centrally, whose individual circumstances and disease severity put them at increased risk. GPs and hospital specialists have been provided with guidance to support these decisions. Anyone who is concerned should contact their GP or specialist to discuss further.

Senior clinicians were provided with specialist evidence that although a majority of motor neurone disease patients have respiratory or bulbar compromise, a proportion do not. Those at the more advanced end of the spectrum (any patient on home ventilation or with significant respiratory compromise) should already be included on the list of Clinically Extremely Vulnerable patients by their specialist due to home ventilation or severe respiratory conditions being a specific inclusion criterion for shielding advice.

In light of the above, the senior clinicians have carefully reviewed this request and evidence and have concluded that patients with motor neurone disease should continue to be recommended by GPs/Specialists for shielding on a case by case basis, to reflect the varying degrees of progression of motor neurone disease. This excludes Northern Ireland, where all patients with motor neurone disease are recommended for shielding in line with the Chief Medical Officer's decision.

If appropriate, instructions on how to add patients to the Shielded Patient List are available on [NHS Digital's website](#), and the latest version of the patient letter has been sent to all GP practices and hospital trusts. In summary, for GPs, to add someone to the list, you should code the patient's record with the 'High risk category for developing complication from coronavirus disease' flag and send them the patient letter. For hospital clinicians, details of everyone who you identify and write to should be submitted through an allocated user of the Strategic Data Collection Service (SDCS) within your trust. These users are the same people who submit the daily SITREP report. If you are unclear who they are within your Trust, please contact emergency.collections@nhs.net who will advise.