

Dear

The patient named above currently attends the NHS Highly Specialised Services for Rare Mitochondrial Disorders and has been diagnosed with mitochondrial disease.

Some people with mitochondrial disease have contacted us to ask if they are specifically at risk from COVID-19 and if they should be considered extremely vulnerable? In response to these enquiries we felt it would be helpful to provide some explanation and advice for you and our patient.

Infections in patients with mitochondrial disease can lead to a metabolic crisis. Thus, it is likely that all individuals with mitochondrial disease are at some increased risk of complications from COVID-19, this risk will vary depending on how people are affected by their mitochondrial disease.

**The following conditions in patients with mitochondrial disease make them extremely vulnerable and eligible for government support:**

- Significant myopathy and/or respiratory muscle weakness
- Patients who have metabolic decompensation with infection e.g. Leigh Syndrome
- Cardiomyopathy, arrhythmia or heart transplant
- Chronic kidney or liver disease or organ transplant
- Stroke-like episodes or encephalopathy or epilepsy
- Poorly controlled mitochondrial diabetes
- Swallowing difficulties (dysphagia) where aspiration is a considerable risk
- Severe gastrointestinal dysmotility due to mitochondrial disease
- Severe neuropathy and/or autonomic dysfunction
- Significant cognitive impairment

**We continue to recommend that these patients should be shielding.** Guidance on shielding can be accessed via the Government website link below:

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-person-from-covid-19>

We provide regular patient updates and guidelines on our website: [www.newcastle-mitochondria.com](http://www.newcastle-mitochondria.com)

**We expect that patients will contact you to confirm their extremely vulnerable status.**

Yours sincerely