

INHERITED METABOLIC DISEASE AND CORONAVIRUS (COVID-19) **Advice for patients / parents / guardians**

A number of you have been in touch looking for advice relating to the global Coronavirus (also known as COVID-19) outbreak. The information below gives some practical general information and links to useful reliable websites. Some disease examples are given, but these are only a guide – please ask your own metabolic team if you have a query or concern about your specific condition.

The most up-to-date information about the outbreak, including information for returning travellers, can be found on the gov.uk website.

(<https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response>).

The NHS also has up to date advice on what to do if you've recently returned from travel abroad, symptoms to look out for, tips to avoid catching or spreading the disease, and action to take if you become unwell.

(<https://www.nhs.uk/conditions/coronavirus-covid-19/>).

There are specific groups of patients who may be more at risk, because of a second condition or a complication of their inherited metabolic disease. These include:

- those with diabetes
- those with chronic lung or heart disease (this might for example include some patients with a mucopolysaccharidosis, mitochondrial disease or Pompe disease)

In addition, those taking specific immunosuppressant medication eg. following a transplant, may be at extra risk of complications from the virus if they are infected.

Precautions to take for individuals with an 'emergency regimen'

Some people with inherited metabolic disease are at risk of worsening (decompensation) of their metabolic condition if they develop a viral infection. Any patient requiring an emergency regimen, including individuals with urea cycle defects, fatty acid oxidation disorders, maple syrup urine disease, methylmalonic acidemia, glutaric aciduria type 1 or propionic acidemia. These individuals may have specific supplements or medications to keep at home to use in the event of illness and metabolic decompensation.

Practical steps to take:

- Check that any medications or supplements that you keep at home are in date (not expired for use)
- Keep a copy of your written emergency guidelines handy to show to other healthcare professionals if needed
- Keep the contact details of your metabolic team handy eg. on your mobile phone
- If you use an oral emergency regimen (eg. oral glucose polymer) make sure you have enough supply at home to last at least 5 days
- Individuals who are prescribed replacement steroid hormones should follow their 'sick-day rules' if needed

Individuals who are concerned that they may have been exposed to Coronavirus

Please call NHS 111 for advice.

Individuals who may be asked to self-isolate

If you or other members of your immediate household are asked to self-isolate or present for Coronavirus testing, then

- let your metabolic team know (this will help us with planning)
- do not attend any routine outpatient appointments at the hospital but instead contact your metabolic team to discuss if another form of appointment is needed eg. by telephone or video if available.

If you are unwell

If you feel that you are unwell and need to attend hospital for immediate / urgent treatment for your metabolic condition, or are advised to do so by the NHS 111 team, then please do this. Give the contact details of your metabolic team to the hospital staff so that we can be phoned for advice.

Please be reassured that the metabolic services will aim to support all patients through this outbreak and that the metabolic pharmacists have a national network and will be able to quickly transfer specific specialist medications to different parts of the UK as required.

If you have other specific queries or concerns about your condition then please contact your own inherited metabolic disease team to discuss these further.