



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.

It is now clear that this is a rapidly evolving situation with advice from the government / NHS changing regularly. To avoid confusion and the risk of out of date information on this site, we have now therefore removed any information that is already given nationally and therefore applies to all individuals. We urge you to keep up with current advice on the websites below, or by listening to reliable TV / radio broadcasts.

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/>).

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 academia, glutaric aciduria type 1 or propionic acidemia. These individuals may have specific supplements or medications to keep at home for 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

- Buy a thermometer if you do not already have one at home

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.

Specific higher-risk groups

If you fall into one of the groups below, then you will be considered at higher risk of developing complications from COVID19. Please stay aware of the latest NHS advice for high-risk, more vulnerable patients - <https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>

- a. You are over the age of 70 years
- b. You have documented immunodeficiency or are taking prescribed immunosuppressant drugs (such as after a transplant)
- c. You are prescribed home oxygen therapy
- d. You are using CPAP ventilation or other non-invasive ventilation at home
- e. You have a tracheostomy (an incision in the windpipe made to relieve an obstruction to breathing)
- f. You are known to have obstructive sleep apnoea or upper airway problems
- g. You have moderate to severe asthma
- h. You have severe respiratory or other neuro-muscular weakness (such as Pompe Disease)
- i. You have underlying cardiac problems – such as heart failure, or have an implantable cardiac device/defibrillator
- j. You have significant kidney failure (are on dialysis or awaiting a kidney transplant)
- k. You have had a splenectomy

Please be reassured that the metabolic and lysosomal storage disorder 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.