



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.

As per current NHS 111 guidance, do not go to a GP surgery, pharmacy or hospital if you develop symptoms suggestive of COVID19.

Self-isolate for 7 days from when your symptoms started.

If you are still concerned, seek individual medical advice by contacting NHS 111.

For a medical emergency dial 999.

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 chronic lung or heart disease (this might for example include some patients with a mucopolysaccharidosis, mitochondrial disease or Pompe disease)
- those with diabetes and a underlying metabolic condition
- Those who are taking immunosuppressant medications e.g. following a transplant, may be at a higher 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 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

Stay at home if you have coronavirus symptoms

Stay at home for 7 days if you have either:

- a high temperature – you feel hot to touch on your chest or back
- a new, continuous cough – this means you've started coughing repeatedly

You do not need to contact 111 to tell them you're staying at home.

Testing for coronavirus is not needed if you are staying at home.

Use the NHS 111 online coronavirus service <https://111.nhs.uk/covid-19/> if:

- you feel you cannot cope with your symptoms at home
- your condition gets worse
- your symptoms do not get better after 7 days

Only call 111 if you cannot get help online.

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

Do not go to a GP surgery, pharmacy or hospital if your symptoms are mild and you feel that you can manage at home.

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. If you develop respiratory symptoms (such as dry cough, shortness of breath, increased or change in colour of sputum, or worsening of shortness of breath and/or fever) then **you should self-isolate, and seek medical advice immediately. Ring 999 in a medical emergency.**

- a. You are over the age of 70 years
- b. You have documented immunodeficiency or are taking prescribed immunosuppressant drugs
- 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.