

Red Cell and Haemoglobin Disorders Unit

DEPARTMENT OF HAEMATOLOGY

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Dear Patients,

Information about Covid-19 (the disease caused by coronavirus) for patients with Sickle Cell Disease (SCD) or Thalassaemia

We understand that many of you may be concerned about Covid-19, and the potential impact on you as someone living with a haemoglobinopathy (sickle cell disease or thalassaemia). COVID-19 is a new illness that can affect your lungs and airways. It's caused by a virus called coronavirus. We do not know if you are more at risk of catching it compared to others in the population, but obviously there are some additional factors to bear in mind about how it could potentially affect you. We have prepared this information to give some information and advice at this time.

We don't yet know how sickle cell disease is affected by the virus but we are assuming it could lead to sickle cell complications and/or worsening of crises. We don't know how thalassaemia is affected either but again it is likely to cause more complications.

If you have regular exchanges or blood transfusions, currently there are no problems with blood supply, or any concerns about the virus being transmitted via a blood transfusions – NHS Blood and Transplant are carefully monitoring the world wide situation. We know that patients may be worried about attending hospital at this time. Please be assured that we are reducing the number of people coming to hospital for non urgent appointments to minimise the risk to those coming for treatments like exchanges and transfusions. As you know, the exchanges/transfusions are an important part of your healthcare and it may well be important to prioritise this to keep you well and out of hospital. There may be some patients who are at less risk when missing / delaying exchanges. We are evaluating all of these factors, and these decisions are being made by your clinical team on a daily basis with full care and attention, but do contact us if you have concerns.

It is more important than ever that we do not waste appointments and blood ordered for exchanges and transfusions, **so please let us know if you have any concerns about attending, are self-isolating or have symptoms of the virus as soon as possible.**

If you take hydroxycarbamide –please continue at your regular dose. Taking hydroxycarbamide does not increase your risk of viral infections, but it does keep your sickle cell under control and reduces

your risk of coming into hospital with a sickle cell crisis. You will still need to have blood tests as previously discussed with you to monitor your hydroxycarbamide and we will work with you to ensure you have the right tests done. This may at times be at a different location to where you normally have blood tests.

Please also continue with any other regular medications, like folic acid and anti-biotics, as usual.

If you develop symptoms of the virus, particularly a fever or cough, please follow the most up to date advice, which can be found on the gov.uk website; See <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>. Currently, the recommendation for those with symptoms is to isolate at home. If you are concerned that you are not well enough to be at home, please contact 111 for advice and ensure you mention both sickle cell disease/thalassaemia and COVID-19 symptoms.

If you need urgent medical help, please call 999 and let them know you are experiencing a sickle cell crisis/issues with thalassaemia, and that you have covid-19 symptoms. Do not come to hospital for your regular treatment (e.g. day unit) if you have symptoms of the virus.

Please do let us know if you have symptoms and/or are self-isolating, so we can support you if needed. Please make sure you have enough of your regular medications or someone who can collect these for you.

This is a helpful document about social distancing: <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

Keeping well: The governments are recommending that those with underlying health conditions consider self-isolation/ reducing contact with others, for their own well-being. We have cancelled all face to face outpatient appointments in the Red Cell & Haemoglobin Disorders Unit for this reason, but will offer telephone clinics when appropriate and necessary. Your appointments may also be delayed or postponed as we work with changes in the hospital system.

Employment/working from home: We are happy to let employers know that we consider SCD or thalassaemia to be a high risk group but cannot give direct occupational health advice.

Emotional wellbeing – we recognise that the coming months may be worrying and difficult for many of us. If you are self-isolating but don't have any symptoms consider what you can do to maintain a routine, keep busy and remain healthy (e.g. by keeping hydrated, eating as well as you can, doing some gentle exercise). Please do draw on all your sources of support via telephone, text and social media. Many organisations have developed useful information, for example <https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/#collapse8c54d>

The team will be as available as we can be, within the needs of a busy acute hospital at this time, and you can contact us using the numbers below. If we are unavailable we will try to leave messages on our voicemails to let you know.

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