

## **Patient Information for COVID-19 and red cell disorders**

We are writing to you regarding COVID-19 and what that may mean for you. Clearly this is an evolving situation and this information may change, so it is important you keep up to date with recommendations at [www.nhs.uk/conditions/coronavirus-covid-19](http://www.nhs.uk/conditions/coronavirus-covid-19) and [www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance](http://www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance)

There will also be information available on the sickle cell society [www.sicklecellsociety.org](http://www.sicklecellsociety.org) and UK Thalassaemia Society [www.ukts.org](http://www.ukts.org) webpages as well as on the British Society for Haematology Website [www.b-s-h.org.uk](http://www.b-s-h.org.uk) where there is a TIF guide too. Please always check you are reading the most recent version of any document. Note there is separate information regarding Diamond Blackfan Anaemia.

This is an unprecedented time for the NHS. Your regular clinical staff are already being deployed to look after sick adults outside of haematology; your consultants are working extremely hard on national panels to ensure the best possible care is offered to our cohort during this period, most teams do not have junior doctors anymore and your teams are already extremely stretched and in some cases unwell themselves. The hope is that we can provide you with as much information as possible so that you are well informed, take the right precautions regarding your own health and understand when and when not to attend hospital areas. Your medical and nursing teams will face intense pressures over this period and it is important that you follow advice, read this carefully and understand they may not be able to respond to anything other than urgent medical queries.

### **Basic information about the virus:**

A novel coronavirus named currently SARS-CoV-2 of a zoonotic origin has emerged and the infection called Coronavirus Diseases 2019 (COVID-19) started spreading worldwide. Incubation period from the time from exposure to symptom development is between 2-14 days. Avoiding exposure by adhering to recommended hygiene procedures, isolation of SARS-CoV-2 infected persons and social distancing are the only prevention strategies. There are no approved treatment options and there is no available vaccine although work is being done on both.

### **How does the virus affect those with sickle cell disease or thalassaemia?**

The knowledge we have about how COVID-19 will affect those living with sickle cell disease and thalassaemia is evolving constantly. In light of this, the risks to our community here in the United Kingdom may change in the upcoming days, weeks and months. Data from China and Italy suggests that children have a milder form of the disease than adults, although we do not understand why this is the case. That does not mean that the young do not get sick, only that the chance is higher the older you get. Only 2 in every 100 diagnosed cases of coronavirus in China have been in children aged <18 years. The Italian experience in Milan and Turin (Prof Nica Capellini and Professor Antonio Piga) is that there has been limited impact in patients with thalassaemia, as a model of a transfusion dependent anaemia in a high-risk area. Similarly, the Monza haematology, oncology and BMT paediatric service (Professor Adrianna Balduzzi) has seen limited impact in children with serious haematological disorders.

In England, the care of patients with haemoglobinopathies is coordinated through Haemoglobinopathy Coordinating Centres and with support from the Clinical Reference Group for Haemoglobinopathies which is part of NHS England. Your team is represented on these groups and as new information is available, we will formulate guidance for our networks. We will be in constant communication with health authorities across the globe as well as within and between our networks.

## What You Need to Know About the Coronavirus (COVID-19)

The pandemic is real.

We are all at risk of getting infected. Individuals with sickle cell disease and people who have had their spleen removed have a weaker immune system than most other people. People with excess iron in their body (iron overload) may not be able to manage infections as well as others. Those with co-existing health problems such as diabetes, heart disease and asthma seem to be worse affected.

### How can I avoid getting infected?

- Shielding

The latest government guidance strongly advises people with serious underlying health conditions to rigorously follow shielding measures. Shielding is a measure to protect people who are clinically extremely vulnerable by minimising all interaction between those who are extremely vulnerable and others. We are strongly advising people with serious underlying health conditions which put them at very high risk of severe illness from coronavirus (COVID-19) to rigorously follow shielding measures in order to keep themselves safe. This guidance includes 'People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID and homozygous sickle cell).

[www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19](http://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19)

The Haemoglobinopathy Coordinating Centre Leads and the Clinical Reference Groups on Haemoglobinopathy have been discussing this, as we think this needs further clarity. Particularly as they told people with sickle cell trait they needed to do this which is not correct. Here is our current advice as of the date of this document as to who this advice is directed at:

- All patients with sickle cell disease (e.g HbSS, HbS Bthal, HbSC and so on). This applies to all patients who are expected to be hyposplenic. It does not apply to patients with sickle cell trait (sickle carriers)
- Patients with thalassaemia who are particularly high risk include those with iron overload (Cardiac T2\* <15ms, previous or current impaired LV function or other cardiac complication related to thalassaemia, severe iron overload LIC >15mg/g/dw or ferritin >3000) and those who have had a splenectomy **and** has additional risk factors such as diabetes or any of the above.
- Patients with Diamond Blackfan anaemia who have an associated immunodeficiency, are on steroids, have adrenal insufficiency and are on steroid replacement, have iron overload or have had a BMT within one year or chronic GVHD.

- **Thalassemia or rare anaemias patients ( eg Pyruvate kinase deficiency, hereditary spherocytosis ) with splenectomy and well chelated and do not have any other significant medical illness ( to name a few such as diabetes, heart disease, asthma , COPD ) do not need shielding. Please adhere to social distancing only.**
- Any of our patients may also have a co-existing condition aside from their red cell disorder that may mean they meet the criteria e.g. diabetes or severe asthma – so please use the link above to check that.

Patients are currently being contacted by letter or text from NHS England or their GPs. The guidance states that if patients think they fall into one of the categories of extremely vulnerable people and have not received a letter by Sunday 29 March 2020 or been contacted by their GP they should discuss their concerns with their GP or hospital clinician.

- Social distancing

This is what everyone else should be doing. The best way to slow the spread of the infection is to not get infected in the first place. One of the terms you may have heard is “social distancing.”

The government has announced Social Distancing measures. Please see this link:

[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](http://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)

- Guidelines for washing and disinfection

[www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance](http://www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance)

- Wash your hands more often than usual, for 20 seconds using soap and hot water, particularly after coughing, sneezing and blowing your nose, or after being in public areas where other people are doing so. Use hand sanitiser if that’s all you have access to.
- To reduce the spread of germs when you cough or sneeze, cover your mouth and nose with a tissue, or your sleeve (not your hands) if you don’t have a tissue, and throw the tissue away immediately. Then wash your hands or use a hand sanitising gel.
- Clean and disinfect regularly touched objects and surfaces using your regular cleaning products to reduce the risk of passing the infection on to other people.

At the current time and based on our understanding of what is known of COVID-19 and other similar respiratory viruses, it is likely that older people and those with chronic medical conditions may be vulnerable to severe disease. As more information emerges, recommendations may change.

### **What should I do if I am unwell? How do I know if I have COVID-19?**

The only way to know for sure that you have coronavirus is to get tested. However, you will only get tested if you meet certain criteria as there is not capacity to test everyone at the moment and we have to save it for people who are sick and in hospital. As the weeks progress, we hope that the capacity to test will increase and we will be able to get a better picture of those who are infected, who are not infected and who have been infected and are now immune.

The most common symptoms of coronavirus (COVID-19) are recent onset of a new continuous cough and/or high temperature.

Patients with a fever of  $>37.8^{\circ}$  C or  $100^{\circ}$  F require a clinical review, either virtually or in person.

You should call **111**, inform them and then urgently contact your clinical team at the same time for review. This is because we want to know what is happening with you, but also you may have a different reason for infection and we don't want that to be missed by those less familiar with your disorder. Always tell the teams about your blood disorder. We will try to treat you in the community where possible but appreciate this may not always be possible. If you have these symptoms, however mild, stay at home and do not leave your house for 7 days from when your symptoms started unless directed otherwise by NHS 111 or your haematologists.

If your symptoms worsen during home isolation or are no better after 7 days, contact NHS 111 online and contact your clinical team. For a medical emergency dial 999. Always tell the teams about your blood disorder.

Management of acute pain: Patients should be encouraged to treat pain as usual but to contact their clinical team if they have a fever or respiratory symptoms.

- What should I do if someone in my household is unwell or I am well but have symptoms?

Please refer to the government "stay at home" guidance:

<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>

If you live alone and you have symptoms of coronavirus illness (COVID-19), however mild, stay at home for 7 days from when your symptoms started. If you live with others and you or one of them have symptoms of coronavirus, then all household members must stay at home and not leave the house for 14 days. The 14-day period starts from the day when the first person in the house became ill.

### **What about my regular treatments?**

Hydroxycarbamide: There is no evidence that being on hydroxycarbamide would increase risk of COVID-19 as long as your neutrophils are  $>1$ . Please remain on your usual hydroxycarbamide dosage to maintain good health and avoid hospital admissions. For stable patients we may extend the interval between blood monitoring.

**If you are on hydroxycarbamide and running out of supply, please contact us at least 1 week in advance.**

Blood transfusion: We are planning to continue giving transfusion regularly to those who are on regular programmes. There is a lot of work going on at NHS Blood and Transplant to secure the blood supply as donors will be prevented from donating if there is any chance they can be infected. <https://www.blood.co.uk/news-and-campaigns/news-and-statements/coronavirus-covid-19-updates>

Most units will call you prior to transfusions to check you are still well, if you have symptoms and are well we may defer or test you. If you are unwell they will discuss with the medical staff as to the best course of action. Please do not miss appointments.

Clinic appointments: These should be done virtually (by telephone) or delayed. Routine ophthalmology, audiology, echocardiography imaging for iron overload assessments should not be ordered at present unless absolutely necessary. Any urgent investigations will still be requested as required.

Trans-cranial Doppler (TCD) screening: These may also need to be postponed but we may bring in some patients for these scans, for example: Patients needing their first TCD, patients with previous conditional TCDs, younger patients.

Iron chelation: Routine monitoring for iron overload and for the effects of iron chelation should be continued. For patients on regular transfusions, outpatient review should be coordinated to take place at the same time as transfusion. We will consider if routine MRI monitoring for iron overload can be postponed (e.g. in stable patients, on long term chelation). If a fever develops, all chelation agents should be stopped and you should contact your clinical team.

**If you are on iron chelation and running out of supply, please contact us at least 1 week in advance.**

Ibuprofen: Concerns have been raised about the role of ibuprofen in this condition but there is no scientific evidence to support this concern. If you have a fever and suspected Covid-19 infection other agents e.g. paracetamol should be considered in preference to ibuprofen if possible until further evidence is available.

**What other things can I do to make social distancing more manageable and be prepared?**

- Please check to see if you have sufficient supplies of medication and are not about to run out.

We would discourage you from stockpiling large amounts of painkillers. Even if you cannot get to the hospital there are ways in which your team would be able to get a prescription to you.

- Contact your GP to ask about getting extra medications to have on hand in case we are exploring home delivery of medications that we usually dispense for you.

- Be sure you have over-the-counter medicines (e.g. paracetamol and codeine) and medical supplies (e.g. tissues) to treat fever

- Make sure you have a thermometer to take your temperature.

- Take your prescribed medications unless you have been told otherwise
- Have enough household items and groceries on hand so that you will be prepared to stay at home for a period of time that could be many weeks.
- Stay in touch with others by phone or email. You may need to ask for help from friends, family, neighbours, etc. if you become ill.
- Think ahead about who will watch your children, other loved ones, or pets if you become too sick.
- Make sure your vaccinations are up to date

### **What shall I do as an employer or employee?**

Particularly if you are am being asked to support someone who is vulnerable according to the new shielding guidance.

Please see additional information and refer to the guidance here:

<https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19/covid-19-support-for-businesses>

<https://www.gov.uk/coronavirus-extremely-vulnerable>

<https://111.nhs.uk/isolation-note>

<https://www.understandinguniversalcredit.gov.uk/coronavirus/>

### **What about local arrangements?**

Local arrangements may change. This will depend on the make-up and resources of your local team, the degree to which they are redeployed into acute frontline care. Please contact them in the usual manner, saving clinical questions for the clinical team and administrative questions for the administrative team. Given the pressures on the clinical team, we will be prioritising those with clinical rather than more general queries.

### **What about clinical trials?**

Research is being rapidly refocused on COVID-19. Large numbers of existing clinical trials are being paused until further notice to support this effort and to allow clinically trained researchers and support staff to support front line care. You will be informed separately and individually by your research teams about this.

Adapted from Manchester Foundation Trust, North central London and East Anglia HCC and West London HCC