

# **Coronavirus information sheet for children and families with red cell disorders under the care of Birmingham Children's Hospital**

**March 2020**

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

**All children** - Reports from other countries (Italy, China) suggests that children have a milder form of the disease than adults, although we do not understand why this is the case.

**Children with Thalassaemia** - The Italian experience in Milan and Turin is that there has been limited impact in patients with thalassaemia

**Children with Sickle cell disease** - Information from the UK cases so far is showing:

1. The most common symptoms of the infection are fever and chest pain
2. In most cases so far the infection has been mild
3. Not every fever/cough is due to coronavirus
  - a. Acute chest syndrome in sickle cell disease can present with fever/cough
  - b. Sepsis can present as fever/unwell

## **How can I avoid getting infected?**

- Social distancing should be practiced for all patients and families
- Some patients need to be in strict isolation for 12 weeks. This is called 'shielding'.
- The 'shielded' person is able to go outside into a garden provided it is a private space
- The NHS and Haemoglobinopathy Centres have recommended additional isolation protection ('shielding') for certain groups:
  - o SICKLE CELL DISEASE. All patients with sickle cell disease (e.g HbSS, HbS Bthal, HbSC and so on). It does not apply to patients with sickle cell trait (sickle cell carriers)
  - o THALASSAEMIA. Patients with thalassaemia who are at particularly high risk due to iron overload (T2\* <15 ms, previous or current impaired LV function or other cardiac complication related to thalassaemia, severe iron overload LIC >15 mg/g DW or ferritin >3000 mg/L) or those with a splenectomy in combination with another risk factor for complications e.g. diabetes

- DIAMOND-BLACKFAN ANAEMIA. Patients with Diamond Blackfan anaemia who are on steroids as per NHP guidance, with an associated immunodeficiency (or due to age have not yet been assessed), have adrenal insufficiency on steroid replacement, have iron overload as per thalassemia criteria above or have had a BMT within 6 months or are still using immunosuppressive drugs. The best way to prevent serious illness is to keep from getting infected in the first place. One of the terms you may have heard is “social distancing”

#### **FURTHER INFORMATION ON SHIELDING IN THE LINK BELOW**

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

### **What should I do if I am unwell?**

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

**In sickle cell disease the common symptoms are chest pain, cough, fever**

#### **Fever/New dry cough**

- You should call 111 for advice. You must also inform them of your diagnosis
- **Also contact your hospital team to let them know**
- **Remember that not all fevers will be due to coronavirus**
- **If you have any concerns contact your local haematology team**

#### **Sickle Pain**

- Treat pain as usual
- Contact your hospital team if this is not settling with your normal painkillers
- **It is advised to stop ibuprofen if you develop fever/cough/chest pain and medicate with paracetamol or alternative painkillers.**

#### **Medical emergency**

- Dial 999. Always tell the team about your blood disorder.

## **What about my regular visits ?**

- We may delay non-essential or routine investigations.
- Transcranial Doppler scans
  - These scans may be delayed in some stable patients. You will be notified
  - We are prioritising patients needing their first TCD, patients with previous conditional TCDs, younger patients (under the age of 10)
- Blood tests
  - For the time being essential blood tests (hydroxycarbamide/transfusion testing) are still being carried out in BCH
- Outpatient clinic visits
  - Visits to the hospital are being minimised. We will need to make changes to your child's out-patient appointments including the use of telephone consultations

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

- Hydroxycarbamide
  - Continue this medicine as it will reduce the chance of an admission for a pain crisis
  - The dose will not be increased at the current time
  - The time between blood tests can safely be extended to 12 weeks
- Stocks of medication
  - Make sure you have enough stock of medication at home like painkillers, penicillin and paracetamol
- Painkillers
  - Ibuprofen. Safe to continue. Stop only if you have a fever/cough
  - Paracetamol. If you are unable to get hold of paracetamol locally, your GP or local hospital should be able to provide a 2 week supply. Please let them know in advance and they can organise a prescription
- Iron chelation medication
  - You should continue all normal medication

- If a fever develops, all chelation agents should be stopped and restarted once you are better
- Blood transfusions
  - We will continue giving transfusion regularly to those who are on regular blood programmes. There is a lot of work going on at NHS Blood and Transplant to secure the blood supply
- Transplants
  - All non-urgent bone marrow transplants have been put on hold

## **How can I access additional support ?**

Information for businesses

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

Register as a 'shielding' patient to access additional support below

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

Get an isolation note if you have symptoms of coronavirus and you have called 111

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

Information about universal credit

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

Support for your mental well-being

<https://www.gov.uk/government/publications/covid-19-guidance-for-the-public-on-mental-health-and-wellbeing>

Charities for support - please contact. They may be able to help for many reasons including for parents that have jobs where they are unable to observe social distancing

Sickle cell society (SCS)

<https://www.sicklecellsociety.org>

UK Thalassaemia society (UKTS)

<https://ukts.org>

Diamond Blackfan anemia society (DBA UK)

<http://diamondblackfan.org.uk>