



COVID19 information for Parent and patients with Sickle cell disease

What is it and why is it so special?

It is a virus from the same family as some other viruses that cause respiratory infections. What makes this virus so special is that it was first noted in December 2019 in China and is a totally new virus in humans. This means that humans have no natural ability to fight it off and so get infected. Once people are infected then their immune system will try to fight it and in most cases succeed pretty well but in about 20% of people their immune system cannot cope and they can get really ill and unfortunately some people will die.

What else do we know about it?

We know that it can infect anybody so being young is not a protection. We know that it has now been found and is causing trouble in most countries of the world including Africa. At the moment the countries where it is causing most trouble are Italy, Spain, China and Iran but it is about to cause major problems in America, France and UK. But it is really only a matter of time before everywhere will be affected.

The time taken for it to grow and develop seems to be about 14 days and it appears at the moment that people can be infective up to 2 days before they start to feel unwell, we call this being asymptomatic. It is also possible that some people will never become unwell but they can still cause infection in other people.

It appears that the virus can live on surfaces outside the body such as plastic or metal, cardboard and even perhaps hair for a period of hours to days so even touching a surface where the virus is sitting and then touching your nose or mouth might cause you to pick up the infection.

What is being done about it?

Because it is a new virus in humans there is no good treatment available to fight it and there is no vaccine as yet available to stop you getting it, therefore we need to do everything we can to avoid getting it and if we have it or think we have it do everything we can to prevent passing it onto other people. This is why the Government has introduced a series of measures to cut down the possibility of people passing it onto one another. These measures include closing down the schools, bars, restaurants, asking people to stay home, asking people not to pass too close to one another. I have enclosed some posters that the Government and HSE have issued to explain what people can do to prevent spread.

How would I suspect I might have it?

The symptoms are;

Fever (high temperature)

A cough

Shortness of breath

Breathing difficulties

Some people complain of loss of smell or taste but this can be found in other conditions also.

What can I do to help prevent getting infected?

Wash your hands regularly – ordinary soap and water is fine but make sure you wash for 20 seconds

Cover your mouth if coughing or sneezing ideally with a tissue that you should then bin or else into your elbow. Wash your hands after using a tissue

Try to avoid touching your face as much as possible or at least only after washing your hands

Keep surfaces clean

Do not shake hands or hug people

Keep a 2 metre distance from other people

I have enclosed a poster from the HSE to help you remember the things you can do to help.

Are people with sickle cell disease more at risk of getting it?

People with sickle cell disease are not at any greater risk of getting it than anyone else in the community but if people with sickle cell disease do get it they are at greater risk of getting a severe infection because their immune systems are not as able to fight infection as other people. That is why the Government on Friday 27th March asked people over 70 years of age and people classed as “vulnerable” to “cocoon”. **People with sickle cell disease were on the list of “vulnerable” and so you should cocoon as much as possible.** This means not going out at all if possible, although some of you will have to come to clinic or for other treatments. We know that you will be very anxious about doing this but it is important that you continue your treatments in order to prevent getting a sickle crisis. We will make sure that we look after you when you are in hospital. I enclose a poster about cocooning which might be helpful.

What should I do if I have any of the symptoms?

The general advice for people with symptoms is to self-isolate, take some paracetamol and phone your GP.

However as you know people with sickle cell disease can get very sick very quickly. This can be either because the virus is making you sick or because there is another cause for your fever and cough such

as a bacterial infection. Therefore the usual rules still apply; if you are unwell and have a fever and or shortness of breath you should come to hospital to be evaluated and treated.

If you can you should ring ahead and let the Emergency Department know you are coming. Once you arrive you should tell people that you have sickle cell disease and that you are not well. Remember your sickle team are always here for you so if you are unsure feel free to call us. Also remember that the Emergency department is still open for sick people and we really do want to see you if you are unwell.

Should I continue with my Blood transfusion programme?

It is important that you continue your sickle prevention programme, so yes you should. We have organised that the beds are separated by at least 2 metres and we will look after you.

Please contact us before you come for your transfusion if you are unwell with any respiratory symptoms (e.g. cough, chest pain, difficulty breathing or fever) as we will need to make special arrangements for you.

You may have seen that the police are stopping cars to check where people are going so we would suggest you bring a form of identification (e.g. Drivers licence) and your appointment card or letter with you.

Please note that the hospital rules are that only the patient and one guardian/parent are allowed into the hospital. Do not bring other family members such as brothers and sisters.

Can I get COVID19 from blood?

At the moment there is no evidence that COVID19 can be transmitted in blood so we are saying that blood transfusion is safe. This is true even if someone who has donated blood rings up a few days later to say that they have begun to feel unwell although in this case the IBTS would recall any blood from that person that had not be transfused.

Should I continue to take my hydroxyurea?

Yes you should. Hydroxyurea can lower blood counts but those counts tend to be neutrophils that are used to fight bacterial infection. Taking hydroxyurea does not increase your risk of getting viral infections but stopping your hydroxyurea may put you at greater risk of getting a sickle cell crisis and needing to go to hospital.

Please contact us before you come to your clinic appointment if you are unwell with any respiratory symptoms (e.g. cough, chest pain, difficulty breathing or fever) as we will need to make special arrangements for you.

You may have seen that the police are stopping cars to check where people are going so we would suggest you bring a form of identification (e.g. Drivers licence) and your appointment card or letter with you.

Please note that the hospital rules are that only the patient and one guardian/parent are allowed into the hospital. Do not bring other family members such as brothers and sisters.

Should I continue to take my other medications?

Yes you should as these are all there to keep you well

Are there any medications I should avoid?

There is a lot of discussion at the moment as to whether Non-steroidal anti-inflammatory medication (NSAIDs) such as neurofen/ibuprofen can make COVID19 infection worse. The answer is not clear so we suggest that if you have a fever or pain take paracetamol/calpol first but if that does not work after 30-40 minutes you may have to take NSAIDs.

Is there anything else I can do to stay healthy?

Take your medications as prescribed

Stay well hydrated

Make sure to sleep well and get into a good routine – aim for 8 hours sleep per NIGHT!

Get some exercise – even if it following a dance routine on social media or an exercise programme

Relax – if you need some guidance on relaxation feel free to contact us or use some mindfulness tools

Get a thermometer and know how to use it

Useful websites:

www.hse.ie

www.gov.ie/health-covid-19

<https://www.unicef.org/coronavirus/how-talk-your-child-about-coronavirus-covid-19>

<https://young.scot/campaigns/national/coronavirus>

Website for young people- information on COVID-19, simple steps you can take to help prevent catching COVID-19 and spreading to others. Also find out more about what you can do if you are feeling anxious and worried

<https://www.getselfhelp.co.uk>

Handouts and downloads to support and manage emotional distress

<https://www.sheffieldchildrens.nhs.uk/patients-and-parents/coronavirus-resources-for-children-and-families>

Excellent website with resources for parents with social stories for being off from school, how to structure day at home, feelings, self-care etc. Applicable for ASD and Learning disability also.

Headspace App is useful for mindfulness – some parts are free but some do have a charge!

Calm App – is also useful for stress management and relaxation but it does have a charge!

Disclaimer: Every effort has been made to ensure that the information provided is accurate and in accord with standards accepting at the time of printing.