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26th March 2020

Dear Patient

**Advice for patients with red cell disorders (Sickle Cell Disease and Thalassaemia) attending
Guy's and St Thomas' NHS Trust regarding COVID-19**

As you are probably aware there is a new illness called **COVID-19**. This is caused by a virus called coronavirus and it can affect your lungs and airways. As this is so new, the advice about what to do is changing very rapidly. Please look at the [NHS website](#) for the latest information.

We have tried to summarise some relevant information for patients with sickle cell disease (SCD) and thalassaemia attending our clinics, but please be aware that this may become out of date rapidly as the situation changes. We will post updates on the [hospital website](#) so please look at this for latest news.

The latest government guidance strongly advises people with serious underlying health conditions to rigorously follow **shielding** measures and this includes all people with sickle cell disease and some with thalassaemia. Shielding involves staying at home at all times and avoiding any face to face contact for at least 12 weeks, greatly reducing possible exposure to the virus. Full details of the advice can be found [here](#).

Patients are being asked to register if they fall into the above group in order to get support of essential supplies such as food. To register [click here](#).

There is additional advice on the sickle cell society and UK Thalassaemia Society websites:

Sickle Cell Society: <https://www.sicklecellsociety.org/coronavirus-and-scd/>

UK Thalassaemia Society: <https://ukts.org/heads-up/coronavirus-information/>

General advice

What You Can Do to Protect Yourself

Please follow the advice on the [NHS website](#) about frequent hand washing and avoiding people with respiratory symptoms.

As stated above, if you have been identified as someone with a serious underlying health condition, please observe the advice around *shielding*.

What We Are Doing to Protect You

In order to protect you and reduce trips to hospital, we are reducing face to face outpatient clinics (see frequently asked questions). You will be contacted by telephone instead of being asked to attend hospital for your routine clinic appointment. We are currently setting up alternative ways of having blood tests taken and methods of delivering essential medications. If you have not heard from us and have a planned outpatient appointment, please contact us for advice before you travel. Routine monitoring investigations (e.g. ophthalmology, echocardiography, X-rays) are likely to be postponed at the moment. Any emergency investigations will continue as necessary.

Please do not attend the outpatient clinic or the day unit if you have a temperature, cough, shortness of breath or other respiratory symptoms.

Please see our **common questions** below for further information.

Contacting us

Main hospital switchboard: **0207 188 7188**.

Sickle Clinical Nurse Specialists: **07548 152 680** (Mon to Fri 9am – 5pm)

Please text or Whatsapp or leave a voice message.

If you do not get an answer immediately please don't be alarmed, the nursing team may be dealing with an emergency and will get back to you as soon as possible. Please leave your name and phone number so they can return your call.

Out of hours: please leave a message and they will return the call during the next working day.

Alternatively email queries to SickleANPCNSTeam@gstt.nhs.uk and they will aim to answer during the next working day (Mon to Fri 9am – 5pm).

Haematology Day Unit: **0207 188 2743** or ext **51851** via switchboard

Anne Oddotte (Prof Howard/Dr Kesse-Adu/Dr Gardner PA): **0207 188 2741**

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Haematology Health Psychology Service: HPS@gstt.nhs.uk (This will be checked Mon to Fri 9am – 5pm). Please use this email address if you would like to talk to a psychologist about how you are feeling. For medical concerns, please contact the other numbers.

Please be aware that we will do our very best to continue routine care and to return your phone calls in a timely fashion, but it is likely that we will be working with increased inpatient numbers and reduced staff numbers. If you do not get a reply, please do call again.

We wish you all the very best in these challenging times.

The Sickle Team

Common Questions

Am I at increased risk of catching Covid-19?

No, your risk of catching Covid-19 is the same as everyone else in the population.

Will I get a more severe version because of my underlying health condition?

Looking at what is happening in other countries it doesn't currently look as if there is a risk of a more severe version of Covid-19. However the worry with sickle cell disease is that if Covid-19 infections gives you pneumonia (lung infection) and you have lower levels of oxygen in your blood, this could trigger a chest crisis requiring hospital admission and exchange blood transfusion.

Should I stop my hydroxycarbamide (hydroxyurea)?

Please continue taking hydroxycarbamide as prescribed as it should be helping to keep you well and out of hospital. It does not increase the risk of infection. We will be in touch about continuing blood test monitoring and prescriptions.

Should I continue my regular blood transfusions?

We are aiming to continue regular transfusion therapy as this therapy is keeping you well and reducing sickle complications. One of the sickle team will try to review you when you attend the day unit. *If you are unwell when your transfusion is due* please call the day unit on **0207 188 2743** or ext. **51851** via switchboard to discuss the best option for you.

What should I do to protect myself from catching Covid-19?

The latest government guidance strongly advises people with serious underlying health conditions to rigorously follow shielding measures for 12 weeks.

The measures are:

1. Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
2. Do not leave your house.
3. Do not attend any gatherings. This includes gatherings of friends and families in private spaces, for example, family homes, weddings and religious services.
4. Do not go out for shopping, leisure or travel and, when arranging food or medication deliveries, these should be left at the door to minimise contact.
5. Keep in touch using remote technology such as phone, internet, and social media.
6. Do use telephone or online services to contact your GP or other essential services.

We know that stopping these activities will be difficult. Try to identify ways of adapting activities so that you can do them remotely from home i.e. connecting with friends and family on the phone. Remember, you must not participate in alternative activities if they involve any contact with other people.

Please look at this advice in full. <https://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>.

As usual, we advise you do everything you can to stay well and out of hospital. This includes taking your regular medications (especially the penicillin prophylaxis), keeping warm and well hydrated.

If you are asked to attend the hospital, the Trust is constantly updating their practises to make sure we are meeting national hygiene standards to continue to protect all patients.

In general, wash your hands for a minimum of 20 seconds and stay away from people with symptoms.

How do I get essential supplies such as food if I am unable to leave my house?

Patients are being asked to register if they fall into the above group in order to get support of essential supplies such as food. To register go to <https://www.gov.uk/coronavirus-extremely-vulnerable>

What do I do if I think I have Covid-19?

Current advice from the NHS website (13th March 20) is:

- 1. Stay at home if you have corona virus symptoms (high temperature or new continuous cough).*
- 2. Do not go to a GP surgery, pharmacy or hospital.*
- 3. Use the NHS 111 online coronavirus service if you cannot cope with your symptoms at home, if your condition gets worse or if your symptoms do not get better after 7 days.*

In addition for patients with SCD/Thalassaemia we advise:

1. If you have a worsening cough, difficulty in breathing or a fever >37.8°C you should contact the health services (NHS 111). Say that you are concerned about coronavirus but also that you have sickle cell disease.

2. If you become acutely unwell with fever, respiratory symptoms or chest pain attend A+E/call an ambulance as you would do usually, but let them know you have a fever or a cough and that you have sickle cell disease.
3. During working hours (Mon to Fri 9am – 5pm) call or Whatsapp/text the Sickle Clinical Nurse Specialists: **07548152680**. They will return the call as soon as possible.
4. Please do not come to the day unit at Guy's Hospital if you have a fever or cough, please go to A+E at St Thomas', but let the sickle team know.

Should I come for my planned outpatient appointment?

We are stopping almost all face to face outpatient clinics. We are trying our best to contact patients to let them know if their appointment will be rescheduled. If you are unsure, please contact us to check before you travel.

Transport to the hospital

When attending the hospital for an appointment it is essential you try to avoid public transport. If you are able to travel in a car, please keep the number of people to a minimum and keep your distance as much as you are able.

Hospital transport

If you are unable to make your own safe travel arrangements, people who have been identified as high-risk by the Government and are required to 'shield' can also use hospital transport to attend appointments. Please contact the hospital transport service and say you are required to shield and request a single occupancy taxi. To minimise the risk of infection, please do not bring relatives or friends to the hospital with you as they will be likely to be refused entry.

What do I do if I have severe pain crisis?

If you are experiencing severe sickle cell pain (crisis) with no fever or cough we may ask you to attend the day unit at Guy's for assessment. Please do let us know if you are unwell at home or if you are admitted to hospital elsewhere. You may be asked to attend A&E after you have spoken with one of the specialist nurses.

How do I look after my emotional well-being during this stressful time?

Feeling concerned or overwhelmed by the news of coronavirus is understandable, whether you are thinking about your own health and the possible impact, or for someone close to you. If you are feeling this way, remind yourself that it is normal to experience these emotions and that there are practical things you can do to cope:

- **TRUST:** You know your sickle cell well, use all your usual techniques and strategies to stay well.
- **ACKNOWLEDGE:** notice and acknowledge the uncertainty, thoughts and worry as they come to mind.
- **PAUSE & PULL BACK:** Rather than respond to these try to pause and breathe. Remember: this may be the worry talking, thoughts are not statements or facts. These thoughts and feelings will pass.
- **INFORM:** Limit excessive exposure to the news/social media, if getting information, use up-to-date and reliable sources, eg. NHS website.
- **CONNECT:** Talk to someone about how you're feeling. Reach out for support from others by phone, text or video.
- **CALM:** Stick to your normal routine within your home as much as you are able to. Add in things that help you feel calm, e.g. breathing, calming music/sounds/tv. You can relaxation and meditation exercises free online i.e. <https://www.calm.com/blog/take-a-deep-breath>.
- **STAY PRESENT:** Explore the present moment, because in this moment, all is well. Notice your breathing. Notice the ground beneath you. Look around and notice what you see, what you hear, what you can touch, what you can smell. Then shift your focus of attention to something else - on what you need to do, on what you were doing before you noticed the worry, or do something else - mindfully with your full attention.
- **LET YOUR VALUES GUIDE YOU:** Think of what your values are, what is important to you and how you can take action to live along those values at this difficult time. You may identify that showing care to others is important for you and you may choose to call friends and family. You may identify that you value looking after your health and chose to take action by cooking a healthy meal or dedicate time for self-care.
- **TAKE THINGS DAY BY DAY:** You might feel overwhelmed with the thought of staying indoors for a number of weeks. You may not know how you will cope or fill your time in different ways from how you normally do. Focus on each day as it comes. What could you do *today*? What do you need most *today*? Do you need to relax? Have fun? Feel a sense of achievement?