

# The sickle cell outpatient service

## Information for adult patients with sickle cell disease

This information sheet has been given to you to help answer some of the questions you may have about the outpatient service for patients with sickle cell disease at Guy's and St Thomas' Hospital. If you have any questions or concerns, please do not hesitate to speak with the sickle cell doctors, sickle cell nurse practitioners, day unit nurses or psychologists. Their numbers are listed at the end of the leaflet. Please feel free to show this leaflet to other family members or friends.

## What is sickle cell disease?

Sickle cell disease is an inherited disorder which is associated with abnormal haemoglobin. Haemoglobin is the protein in red blood cells which carries oxygen around the body. Patients with sickle cell disease often have anaemia, episodes of intermittent severe pain and chronic complications including kidney problems, eye disease, chronic bone pain, heart and lung problems, leg ulcers, stroke and gall stones.

In the clinic we see patients with different types of sickle cell disease, including HbSS, HbSC and HbS-Bthalassaemia.

We also see patients with other rarer types of sickle cell disease, with thalassaemia and with other types of red blood cell problems, such as hereditary spherocytosis and G6PD deficiency. We do not usually see patients with sickle cell trait in the clinic.

## Why do I need to come to clinic?

Sickle cell disease is very variable and affects different people in different ways. Some people with sickle cell disease have lots of severe pain and are often admitted to hospital. Other people with sickle cell disease experience pain very rarely and may never be admitted to hospital. Even if you have mild sickle cell disease and hardly ever get pain, you can still develop some of the complications of sickle cell disease, including heart and lung problems or kidney problems. We look for early signs of problems with your heart, lung and kidneys when you come to clinic. If we know about these problems early we can offer treatment early and stop you developing serious complications later on. It is therefore important to attend the sickle cell clinic even if you are feeling well and have had no recent painful crises.

Some patients with sickle cell disease are on special treatments like hydroxycarbamide tablets, blood transfusion therapy or are on treatment for the complications of sickle cell disease. These treatments need regular monitoring in clinic.

## What will happen when I come to clinic?

You will book in with the receptionist who will check your details. As we need to take a urine sample every time you come, you will be given a urine pot and will be asked to wait in the waiting area for a blood test.

You will then be called for your blood test by the phlebotomist (the person who takes your blood) and you will be asked to produce your urine sample and take it to the clinic nurse. If you are unable to produce a sample please let the clinic nurse know so that your appointment is not delayed. The clinic nurse will call you and will check your blood pressure, pulse and oxygen levels. These will be written on a piece of paper and given to you to hand over to the doctor or advanced nurse practitioner in the clinic. Once in the clinic, you will be asked about your sickle cell disease symptoms and you may be examined. There will also be the opportunity to ask any questions you may have about your symptoms or about sickle cell disease in general.

When the consultation is finished you will be asked to book another appointment at the reception desk.

The doctor will try to see you within 30 minutes of your arriving at the clinic, but this is not always possible. Sometimes we will have seriously ill patients in clinic whose consultations take a little more time than usual. Sometimes a doctor may even be called away from clinic to deal with a very ill patient on the ward.

The clinic may also run late if patients arrive late for their appointments. Please try and arrive at your appointment time as this will help us to ensure that we are running to time.

When you are waiting to be seen by the doctor, you may be seen by a research nurse who will give you information about the research studies we are running in the department. You may also be seen by a community nurse who can discuss the local community services with you. At some of your appointments, at least once a year, or more often if necessary, you will be reviewed by one of the health psychologists within the sickle cell team. This may happen before or after your appointment with the doctor. You can request to be seen by the psychology team at any time. More information about this service is in the **Health psychology leaflet**.

There is usually a specialist sickle cell nurse in the clinic. They will try to offer a review of your condition at least once a year, or more often if necessary, and may see you before or after the doctor sees you. In some cases you may be seen by the senior nurse in the clinic instead of the doctor.

During your consultation your annual 'Body MOT' may be due which will include a health assessment and a health psychology assessment. These are offered to all patients. If you have regular blood transfusions or are on the red cell exchange programme, additional discussions will take place and specific blood tests and vaccinations will be recommended and your verbal consent obtained.

## Hydroxycarbimide clinic

This clinic is run concurrently with the Tuesday afternoon clinic. Hydroxycarbimide is a capsule taken by mouth and is used in sickle cell patients to reduce the frequency and severity of sickle cell pain/crises and the need for blood transfusions. Regular health reviews & fortnightly blood

tests are initially required. Once the blood measures are stable you'll need to attend the clinic every 8-12 weeks.

## Who will I see when I come to clinic?

We run a multidisciplinary clinic, which means that there are lots of different medical professionals in the clinic. This also means that we can offer you better care. In the clinic you will be seen by several different people, depending on your needs.

- **Doctors**

You will usually be seen by Dr Jo Howard, the lead consultant for the sickle cell service, Dr Rachel Kesse Adu, haematology consultant or by a specialist registrar in haematology.

- **Specialist nurses**

You may be seen by one of the advanced nurse practitioners (Mr Neill Westerdale or Mr Luhanga Musumadi), or the clinical nurse specialist (Mrs Judith St Hilaire).

- **Psychologists**

You may be seen by one of the health psychology team, Dr Nicky Thomas, Dr Heather Rawle, Ms Mina Abedian or Dr Tom Parsloe. You may also be seen by a health psychology trainee working with the health psychology team.

- **Research nurse**

We have a research nurse who may speak to you about the research studies we are running.

- **Community sickle cell nurse**

Ms Emma Gedeon is one of the community nurses in Lambeth, and comes to the clinics on alternate Tuesdays and Fridays.

- **Phlebotomists**

There will be a number of phlebotomists onsite to take your blood sample.

- **Receptionist**

The receptionist will book you into the clinic and make your follow up appointment.

- **Clinic nurse**

A clinic nurse will check your blood pressure, oxygen levels and pulse. The nurse will also test your urine sample.

## What else should I know about clinic?

**Please try to be on time for your appointment.** If you are late for your appointment, the clinic will not run smoothly and you will need to wait longer to see the doctor.

**We can not prescribe your regular medications.** It is hospital policy that your general practitioner (GP) prescribes your regular medications. We do prescribe certain medications such as hydroxycarbamide, etilefrine or desferisirox.

If you have regular top-up transfusions on the red cell exchange transfusion programme we will carry out annual virology and endocrine blood tests.

### Vaccinations

Please see our leaflet **Vaccinations, antibiotics and travel advice: Information for adult patients with sickle cell disease** which gives you full details and recommendations.

### Transport to & from hospital for your clinic appointments

You may be eligible for transport to and from hospital. The Patient Transport Services will assess your eligibility for free transport to & from hospital from your home address. They'll conduct a short telephone interview with you and you'll be informed of the decision right away. The transport leaflets are displayed in the leaflets rack in the clinic area or you may call the transport services office on 0207111 2888.

Under the "Healthcare Travel Costs Scheme" (HTCS) if you're not eligible for free hospital transport you may be able to reclaim your travel expenses. See leaflet HC11 – Help with health costs. [www.nhs.uk/NHSEngland/Healthcosts/pages/Travelcosts.aspx](http://www.nhs.uk/NHSEngland/Healthcosts/pages/Travelcosts.aspx).

### Help with Prescription costs

For more information visit [www.nhsbsa.nhs.uk/1127.aspx](http://www.nhsbsa.nhs.uk/1127.aspx).

### Prescription prepayment certificates (PPCs)

If you need more than 12 prescribed medicines each year, you could save money with a 12-month PPC.

You can also buy a three-month PPC, which will save you money if you need more than three prescribed medicines in three months.

The charge for a single prescribed medicine is £8.20, whereas a three-month PPC will cost you £29.10 and a 12-month PPC £104.00 (prices subject to change). From 1st April 2015 these charges apply, however **please be aware that the charges may change in the future**.

You can ask your pharmacist for more information and an application form or apply on-line.

### We appreciate your feedback

Please let us know if there is something you think we can improve about our clinics. Your comments enable us to improve our service.

### What should I do if I can't come to the clinic?

It is very important that you let us know if you can't come to clinic. If you phone to let us know you can not come to clinic we can book someone else into your appointment time. If you do not attend clinic without letting us know first, this wastes resources and makes the clinic run less efficiently.

**If you are unable to make your appointment please call 020 7188 2724. You can leave a message on this number if no-one answers.**

Outside of working hours please call the main hospital switchboard on 020 7188 7188. Tell the switchboard operator that you are a sickle cell patient and that you cannot make your appointment. You should also tell them when your appointment is. One of our administrative staff will call you to make a new appointment.

The sickle cell clinic has a high rate of patients who do not attend clinic. One in four sickle cell patients failed to keep their appointments last year as compared to around one in 20 patients with other blood problems. The impact of this level of non attendance could be that services and resources in the future could be reduced for sickle cell patients and you could also miss out on vital care and treatment.

## **What should I do if I need an urgent appointment?**

If you would like to be seen earlier than planned please call to rearrange your appointment. We can usually see you within a week. **The clinic appointment phone number is 020 7188 2724.**

If you are acutely unwell with severe pain, chest pain, or other symptoms and need urgent medical attention attend the A&E department at St Thomas' Hospital.

We also run a day service for acute pain at Guy's Hospital. This is suitable for patients with uncomplicated painful episodes. It is open Monday to Friday from 9.00am -4.00pm and you must phone the sickle cell nurses before you attend. Please see the **Sickle cell day unit** leaflet for more information.

If you are not sure if you should come to clinic, attend the day unit or go to A+E, you can call one of the sickle cell nurses to discuss the best option for you.

Mr Neil Westerdale Tel 020 7188 7188 ask for bleep 1843

Mob 07770683947

Mr Luhanga Musumadi Tel 020 7188 7188 ask for bleep 2256

Mob 07770678851

Mrs Judith St Hilaire Tel 020 7188 7188 ask for bleep 2868 Mob 07920711266

They are available Monday-Friday, 9.00am-5.00pm.

## **Do I need to bring anything with me?**

Please bring a list of your medications, especially if they have changed since your last appointment. You should also bring a list of any vaccinations you have received since your last appointment.

## **What happens after the clinic?**

You will be given a sheet of paper by the doctor who sees you, which says when your next appointment should be booked. You should take this to the receptionist to book your next clinic

appointment. Please tell the receptionist if you would prefer a Tuesday afternoon or Friday morning clinic and any time preferences you have.

You will be given a letter to confirm your appointment. You will also receive a reminder letter and text message to your mobile phone about a week before your next appointment. Please provide us with your mobile phone number if you would like to receive text message reminders.

You will receive a copy of the letter that is sent to your GP about a week after your appointment. Please let the receptionist know if you do not want to receive this.

We may need to organise other tests, such as X-rays, echocardiographs or scans. The doctor at the clinic will explain this to you fully and the appointments will be sent to you separately.

## How often will I need to come to clinic?

The majority of patients will be seen at the clinic twice a year. Some patients with mild sickle cell disease will be seen only once a year.

Some patients, who have complications of sickle cell disease or who are on special medications such as hydroxycarbamide will be seen by the clinic every two months. You can discuss how often you need to be seen with the sickle cell team.

## Specialist clinics

The sickle cell team also run special clinics for patients with complications due to sickle cell disease. On these occasions, we invite doctors from other specialties to come to the sickle cell clinic to work alongside Dr Howard. You will usually be referred to one of these clinics by the sickle cell team. You may even be referred by the sickle cell team in another hospital.

- **Renal clinic**

This is a clinic for patients with problems with their kidneys. It is attended by Dr Howard and Dr Cormac Breen, consultant nephrologist, and takes place on a Thursday morning once a month.

- **Orthopaedic clinic**

This is a clinic for patients with bone problems due to sickle cell disease including avascular necrosis and osteomyelitis. It is attended by Dr Howard and Mr Marcus Banks, consultant orthopaedic surgeon, and takes place on a Thursday morning once a month.

- **Neurology clinic**

This is a clinic for patients with neurological problems due to sickle cell disease, most commonly strokes or headaches. It is attended by Dr Howard, Dr Paul Holmes, consultant neurologist, and Dr Rawle. It takes place on a Wednesday morning every other month.

- **Obstetric clinic**

This is a monthly antenatal clinic for pregnant women with sickle cell disease. This takes place on Thursday mornings in the antenatal clinic at St Thomas' Hospital. It is run by Mr Eugene Oteng-Ntim, consultant obstetrician and Dr Susan Robinson, consultant haematologist. Neill Westerdale, advanced nurse practitioner also attends this clinic.

- **Urology clinic**

This clinic is for male patients who have priapism due to sickle cell disease. The clinic takes place on the 3<sup>rd</sup> Thursday of alternate months and is run by Dr Majed Shabir consultant urologist and Dr Kesse Adu.

- **Pulmonary hypertension clinic**

This clinic is held at King's College Hospital and is for patients with pulmonary hypertension. The clinic takes place on a once per quarter basis and is run by Dr Moji Awogbade, sickle consultant at Kings College, Dr Gerry Coghlan, pulmonary hypertension specialist and Dr Kesse Adu.

- **Chronic pain clinic**

This clinic is for patients who have chronic pain. It is jointly run by Dr Irene Carey, consultant in managing chronic pain and Dr Kesse Adu. It runs once a month on a Friday morning.

- **Respiratory clinic**

This clinic is held at St Thomas' Hospital and is for patients with chest and breathing problems. It takes place on the first Thursday of alternate months, it is run by Dr Patrick Murphy, consultant chest physician and Dr R Kesse-Adu.

- **Outreach clinic**

We have outreach clinics in Brighton and Southampton for patients who reside in Brighton/Southampton and the surrounding areas. The clinics are run by the local haematology doctors but are attended by a team from Guy's (Dr Howard, Dr Rawle and Neill Westerdale).

## **Community Information**

The South East London Sickle Cell and Thalassaemia Centre is based in Wooden Spoon House  
Mary Sheridan Centre  
5 Dugard Way  
London  
SE11 4TH  
Tel No 020 3049 5993

## **Community Sickle Cell Nurse**

Ms Emma Gedeon is one of the community nurses in Lambeth and is based at The South East London Sickle Cell and Thalassaemia Centre. She can be contacted on 020 3049 5993.

## Welfare Support Advisor

Daniel Nyakutsey is our Welfare Advisor and is based at The South East London Sickle Cell and Thalassaemia Centre. To make an appointment to see him please call 0203 049 6088 or 0203 049 5993.

## Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.



## Contact us

If you have any questions or concerns about the sickle cell outpatient service, the sickle cell clinics are on:

Tuesday afternoon (2.00 – 4.30pm). Once a month the clinic time is extended to 5.00pm

Friday morning (9.00am - 12.00pm)

Both clinics are held at Guy's Hospital, Southwark Wing, Fourth Floor, Haematology 2

Please do not hesitate to call us on **020 7188 54492** (main clinic) with any questions you may have. If your query is more specific, please use the following list of useful contacts:

Haematology clinic (to arrange or cancel appointments)

t: 020 7188 2743/2724

Consultant haematologist

t: 020 7188 2741 for Dr. Jo Howard's and Dr Kesse Adu's secretary Ms Anne Oddette

Specialist registrar in haematology

t: 0207 188 7188 Bleep: 0248

Senior house officer (SHO)

t: 0207 1887188 Bleep: 2283

Advanced nurse practitioner (Mr Neil Westerdale)

t: 020 7188 2710 Bleep: 1843 Mob: 07770683947

Advanced nurse practitioner for adolescents (Mr Luhanga Musumadi)

t: 020 7188 82710 Bleep: 2256 Mob: 07770678851

Clinical nurse specialist (Mrs Judith St Hilaire)

t: 020 7188 82710 Bleep: 2868 Mob: 07920711266

Psychologists

t: 020 7188 2725 Dr Nicky Thomas, consultant health psychologist

t: 020 7188 2718 Dr Heather Rawle, clinical health psychologist

t: 020 7188 2718 Mina Abedian, health psychologist

Haematology Day Unit

t: 020 7188 2745 / 2727

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

### **Pharmacy Medicines Helpline**

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

### **Patient Advice and Liaison Service (PALS)**

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

**t:** 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

### **Language Support Services**

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

**t:** 020 7188 8815 **fax:** 020 7188 5953

### **NHS 111**

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

### **NHS Choices**

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

### **Become a member of your local hospitals, and help shape our future**

Membership is free and it is completely up to you how much you get involved. To become a member of our Foundation Trust, you need to be 18 years of age or over, live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster or have been a patient at either hospital in the last five years.

To join, please call 0848 143 4017, email [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk) or visit [www.guysandstthomas.nhs.uk](http://www.guysandstthomas.nhs.uk)

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