

Sickle cell and thalassaemia

Overview

The sickle cell and thalassaemia service cares for people with haemoglobin disorders. We run one of the largest services in the UK to diagnose and treat haemoglobin conditions (haemoglobinopathies).

Sickle cell disease and thalassaemia are inherited and affect the red blood cells.

Our service is run with:

- the South Thames Sickle Cell & Thalassaemia Network (SELSEHCC)
- King's College Hospital

We work with the:

- children's sickle cell and thalassaemia service
- children's sickle cell disease and thalassaemia community service

We care for people from Lambeth and Southwark, and also see people from elsewhere for many of our specialist services.

We run special clinics for people with complications due to sickle cell disease and thalassaemia. Doctors from other specialties work together with our haematologists.

Health information

Read our information about:

- simple blood transfusion
- exchange blood transfusion
- priapism in sickle cell disease
- sickle cell disease and dental care for children
- sickle cell disease and pregnancy
- sickle cell disease and stroke

The NHS website has information about sickle cell disease and thalassaemia

Sickle Cell Society is a UK charity for people with sickle cell disease.

The Sickle Cell Society Podcast features real experiences, healthcare professionals and topics such as work, life, priapisms, crisis and relationships.

South Thames Sickle Cell & Thalassaemia Network offers support and resources for people with sickle cell and thalassaemia.

UK Thalassaemia Society (UKTS) is the main UK charity for people with thalassaemia.

National Haemoglobinopathy Register is a database of people with red cell disorders.

Wards

Our haematology wards are:

- Blundell ward
- Hedley Atkins unit
- Olive ward
- Samaritan ward

Our consultants

Rachel Kesse-Adu

Kate Gardner

Dale Seviar

Anietie Ekong

Heather Rawle

Research and clinical trials

Research is vital to improving the care that you receive when you're unwell. You can help improve healthcare by taking part in research studies at our Trust. During your appointment, ask your healthcare professional about research. They'll be happy to tell you about research studies you could be eligible to join.

You can also email gstt.haematologyresearch@nhs.net for more information.

Appointments

How to get an appointment

Most people come to our service from the children's sickle cell and thalassaemia service.

We also accept referrals from:

- GPs
- other hospitals

If a diagnosis was found through prenatal screening, the genetic counselling team in the community will tell us your results. We'll make an appointment for you in the sickle obstetric clinic.

If a diagnosis was found by a blood test at one of our hospitals or community sites, you'll be referred internally.

Changing or cancelling your appointment

Phone: 020 7188 2724

If we do not answer the phone, please leave a message.

Outside of working hours, please call the main hospital switchboard on 020 7188 7188. Tell the switchboard operator you're a sickle cell patient and you cannot make your appointment. Please also tell them when your appointment is. We'll call you to make a new appointment.

You can also email your consultant's secretary or the clinical nurse specialists at gstt.sickleancnsteam@nhs.net.

Please tell us as soon as possible if you're unable to come to your appointment as we can offer it to someone else.

We have a high number of people who do not come to their appointment. This number is much higher compared to other departments. This may impact the services and resources we provide in the future and lead to you missing the treatment you need.

Before your appointment

Please try to be on time for your appointment.

Please bring:

- ✓ a list of medicines you're taking
- ✓ a list of any vaccinations you've had since your last appointment

During your appointment

Most appointments are face-to-face, especially your yearly annual review appointments. If you do not attend, we may try to call you.

At your appointment you usually see a haematology consultant or a specialist registrar in haematology.

The doctor will try to see you within 30 minutes of your arriving at the clinic, but this is not always possible.

You may also see:

- advanced nurse practitioners or clinical nurse specialists
- psychologists
- a research nurse who will tell you about the research studies we're running
- community sickle cell nurses
- a phlebotomist who will take your blood sample
- a clinic nurse who will check your blood pressure, oxygen levels, pulse and test your urine sample

We run a nurse-led hydroxycarbamide clinic and you'll come every 6 weeks to 3 months. This will be a telephone appointment.

You may also need to come for blood tests. This will be in the hospital, or at one of our clinics in the community.

It is important to come to your appointments even if you're feeling well.

After your appointment

You can make your next appointment with the receptionist.

If you need any tests or investigations before your next appointment can be booked, we'll contact you.

You will receive a text message to your mobile phone about a week before your next appointment. Please give us your mobile phone number if you would like to receive text message reminders.

You will receive a copy of the letter we send to your GP after your appointment. Please tell the receptionist if you do not want to receive this.

On the MyChart app you can see your:

- appointments
- clinic letters
- blood test results

Please ask a member of staff if you would like to sign up to MyChart.

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

Clinics

Sickle cell and thalassaemia clinic

Location: Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Phone: 020 7188 2758

We answer the phone Monday to Friday, 9am to 5pm.

Frequency: Tuesday afternoon and Friday morning

This clinic is for people with non-malignant haemoglobinopathies conditions.

This clinic is led by:

- consultants
- doctors
- advanced nurse practitioners

Hydroxycarbamide clinic

Your appointment will be by telephone.

Frequency: you'll have an appointment every 6 weeks to 3 months

This is a nurse-led clinic.

Renal clinic

Location: Haematology 2, 4th floor, Southwark Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Phone

Haematology office: 020 7188 2724, option 2

Tabard Annexe reception: 020 7188 7188, extension 59579

Frequency: once a month on a Monday

This clinic is for people with problems with their kidneys.

You will see a consultant haematologist and a consultant nephrologist.

The sickle cell team will refer you. You may also be referred from another hospital.

Orthopaedic clinic

Location: Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Phone

Haematology office: 020 7188 2724, option 2

Tabard Annexe reception: 020 7188 7188, extension 59579

Frequency: monthly, Friday afternoon

This clinic is for people with bone problems due to sickle cell disease including avascular necrosis and osteomyelitis.

You will see a consultant haematologist and a consultant orthopaedic surgeon.

The sickle cell team will refer you. You may also be referred from another hospital.

Neurology clinic

Location: Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Phone

Haematology office: 020 7188 2724, option 2

Tabard Annexe reception: 020 7188 7188, extension 59579

Frequency: every 3rd Tuesday of the month

This clinic is for people with neurological problems due to sickle cell disease, most commonly strokes or headaches.

You will see a consultant haematologist, consultant neurologist, and consultant clinical health psychologist.

The sickle cell team will refer you. You may also be referred from another hospital.

Obstetric clinic

Location: antenatal clinic, 8th floor, North Wing, St Thomas' Hospital, Westminster Bridge Road, London, SE1 7EH

Phone: 020 7188 2300

Frequency: every 4th Thursday morning of the month

This clinic is for pregnant women with sickle cell disease.

This clinic is run by a consultant obstetrician and a consultant haematologist. A sickle cell specialist nurse or advanced nurse practitioner also attends this clinic.

The sickle cell team will refer you. You may also be referred from another hospital.

Respiratory clinic

Locations

Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Chest clinic, 1st floor, Lambeth Wing, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH

Phone

Haematology office: 020 7188 2724, option 2

Chest clinic: 020 7188 5809

Tabard Annexe reception: 020 7188 7188, extension 59579

Frequency

- Every 1st Wednesday of the month in the chest clinic
- Every 3rd Tuesday afternoon of the month in Tabard Annexe

This clinic is for sickle cell patients who have breathing difficulties, disturbed sleep breathing or other lung problems due to sickle cell disease.

clinics are run by a consultant urologist and a consultant haematologist

The sickle cell team will refer you. You may also be referred from another hospital.

Urology clinic

Location: Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT

Phone

Haematology office: 020 7188 2724, option 2

Tabard Annexe reception: 020 7188 7188, extension 59579

Frequency: the second Wednesday morning of alternate months (January, March, May, July, September and November)

This clinic is for male patients who have priapism or erectile problems due to sickle cell disease.

The clinic is run by a consultant urologist and a consultant haematologist.

The sickle cell team will refer you. You may also be referred from another hospital.

Haematology psychology service

We provide psychological support to people over the age of 16 with sickle cell disorder (SCD) and thalassaemia and their families.

You may experience challenges at different times when living with sickle cell disorder (SCD) or thalassaemia. It may be useful to talk to a psychologist about the difficulties you experience, including:

- understanding and adjusting to your changing health
- managing treatments
- coping with your feelings, such as stress, anxiety, low mood
- adjusting to being in hospital

Seeing a psychologist is a normal part of your care.

We offer:

- one-to-one therapy sessions in person, by phone, or by video
- group support
- inpatient consultation

- support with memory or concentration difficulties
- support in routine clinics for people with SCD and thalassaemia

We also offer cognitive assessments.

Cognitive assessment

Some people with SCD or thalassaemia experience changes and challenges in their cognitive abilities as a result of their health condition.

A cognitive assessment can identify changes in your abilities such as memory, concentration and problem solving. It shows what your strengths and limitations are, so we can work with you to find ways for you to cope. This can help you in your everyday activities, working life or studies.

If you're interested in finding out more, please ask us about this.

We work with other health professionals. We support them in providing psychologically informed medical care.

This service is led by:



Heather Rawle

Consultant clinical and health psychologist

How to get an appointment

You can ask your nurse or doctor in the sickle cell team to refer you. You can also contact us by phone or email.

Changing or cancelling your appointment

Please contact us by phone or email. Please tell us 24 hours before your appointment.

If you miss many appointments, we may discharge you from our service.

During your appointment

Your first appointment will be by phone. It will last 30 minutes.

We will talk to you about your concerns and get to know more about you. This will help us decide if:

- psychology sessions may be helpful for you, or
- another service may be more suitable to meet your needs

After your appointment

After your appointment, we may offer you individual therapy with our team. We will add you to our waiting list. We will contact you to arrange your first therapy appointment as soon as we are able to offer you this.

The waiting time will depend on the demand on our service.

Sharing what we talk about

It may sometimes be useful to share some information with the team caring for you. This is so we can support your physical and mental health as best as possible. We will ask your permission to share this information.

You can always ask us to keep certain things confidential.

If we are ever worried that you or someone that you know is at risk or unsafe then we have a duty to tell other professionals.

Contact us

Secretaries phone: 020 7188 2741

Clinical nurse specialists: 020 7188 7188 extension 52716 or 07548 152680

We answer the phone Monday to Friday, 9am to 5pm.

If we're unable to answer your call, please leave a message or send a message. We aim to get back to you within 1 to 2 working days.

Email: gstt.sickleanpcnsteam@nhs.net

We aim to respond to your email within 1 to 2 working days.

If your condition is urgent and you're unable to contact us, please go to your local emergency department (A&E).

Address: Tabard Annexe, ground floor, Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT