

Haematology Red Cell Services



Information for patients

Welcome to the Haematology Red Cell Services at King's College Hospital. We are a leading specialist centre for haemoglobin disorders (sickle cell disorder, thalassaemia and rare anaemias) and part of the Southeast London and Southeast Haemoglobinopathy Coordinating Centre (SELSE HCC). We aim to offer an outstanding personalised service to all our patients.

This information leaflet outlines the services we provide and how you access them. If you have any other questions or concerns, please do not hesitate to speak to the team caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

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1. Red Cell Clinic and joint specialist clinics

Red Cell Clinic

The Red Cell Clinics (for sickle cell disorder and thalassaemia) are held in Haematology Outpatients, Suite 7, First Floor, Golden Jubilee Wing on:

- Tuesday from 1.30pm to 4pm
- Thursday from 9am to midday
- Thursday from 1.30pm to 5pm
- Friday from 2pm to 4.30pm

Clinics are the main place to discuss and review your red cell-related health concerns.

All patients will be offered regular follow-up appointments, which may take place every 3 months, 6 months, or once a year, depending on your individual needs. One of your appointments will be your annual review.

Your annual review appointment lasts around 30 minutes. During this time, we will carry out a full review of your health and discuss if any further tests or specialist referrals are needed.

There are also clinical nurse specialist-led telephone clinics on Wednesday mornings to monitor patients taking the medicine hydroxycarbamide.

The Red Cell Clinics are led by consultant haematologists and supported by a multidisciplinary team, including clinical nurse specialists (CNSs), an advanced clinical practitioner (ACP), a clinical research fellow, and a specialist registrar training in red cell disorders. A specialist psychologist attends selected clinics, and a



welfare officer may also be available on some occasions. A research nurse is present for patients participating in clinical trials.

Red Cell Clinics are by appointment only. You will receive an electronic appointment letter with details of your appointment, as well as a reminder text message. If you have opted out of electronic communications, you will receive a hard copy (paper version) of your appointment details by post.

Joint specialist clinics

Our joint specialist clinics are separate from the regular outpatient clinics and focus on a specialist problem, for example, hip (orthopaedic), lungs (respiratory), heart (cardiac), kidneys (renal), liver, brain (neurology), pregnancy (obstetrics) or pain.

The clinics are run by two consultants, one from the Red Cell Team and one from the specialist area. These clinics are always face-to-face. We also have a joint specialist clinic for adolescents preparing to transition to the adult service.

Specialist clinics are held every 1 to 3 months. Your consultant will refer you to a joint specialist clinic if needed and you will receive appointment notifications in the usual way. You will be notified of the location of your clinic in your specialist clinic appointment letter.

What we ask from you

Appointments last approximately 30 minutes. To make the most of this time and so we can deliver care as smoothly as possible, we ask that you:

- arrive in time for your appointment
- come prepared with any questions or concerns you would like to discuss
- make sure you are warm and well hydrated

- notify the team at least 48 hours in advance if you need to cancel or change your appointment, so we can allocate the slot to another patient

If you have a face-to-face appointment, please arrive 15 minutes before your scheduled time to allow the healthcare assistant to take your observations if needed.

If you have a telephone appointment, please have your phone near you and in an area with good reception. We aim to call you at your appointed time, but this can be earlier or later depending on how busy it is. Please note that our call may show as 'private' or 'number unknown' on your telephone display.

Arriving late may affect your appointment and cause delays for other patients. Please be considerate of others.

Frequently asked questions:

- **How do I change or cancel my appointment?**

Call 020 3299 5554 to change or cancel your appointment. You can also cancel your appointment via the MyChart app.

- **Can I come early?**

No. The Red Cell Clinic does not work on a first come, first served basis. If you come early, you are likely to have to wait until your appointment time.

- **What if I am late?**

Coming late is disruptive and has a knock-on effect on other patients. Priority will be given to those who have arrived at their scheduled time. You might be asked to wait or come back later. If you are more than 1 hour late without prior notification, we may cancel your appointment and reschedule for another day.



- **Can I drop in during clinic afternoons if I feel unwell or if I need help?**

Don't come to clinic without an appointment as you will not be seen. If you are unwell, please attend the Emergency Department (A&E) for review.

If you do not need urgent medical care but would like to have an earlier appointment, please contact the Outpatient Admin Team on 020 3299 5554.

- **Can I ask for a specific doctor?**

The Sickle Cell and Thalassaemia Clinic is run by a team of consultants, senior doctors (such as registrars and clinical fellows), and advanced clinical practitioners. Although your appointment may be booked under a consultant's name, you may be seen by another member of the team.

If you would like to speak to a particular doctor or nurse, please let the clinic receptionist know when you arrive. We will do our best to accommodate your request, but this may not always be possible.

- **Do I need to have a blood test before my appointment?**

Not everyone needs a blood test before every appointment. If your doctor or CNS has asked you to have a blood test before clinic, please attend the Phlebotomy Department at least 1.5 hours before your appointment, or in the days before. Otherwise, please attend your appointment first and your doctor will request a blood test after clinic if necessary.



2. Haematology Day Unit

The Haematology Day Unit, also referred to as the Supportive Therapy Unit, is on the ground floor of the Cheyne Wing. The unit provides treatment for haematology patients, including:

- blood transfusion
- venesection (phlebotomy) - a procedure where blood is drawn out from the vein for treatment of a variety of blood disorders
- medical treatment for sickle cell disorder requiring a drip
- treatment of uncomplicated vaso-occlusive pain ('sickle cell crisis')

Opening times

The Haematology Day Unit is open for treatment 7 days a week by appointment only. From Monday to Friday (excluding bank holidays), the Day Unit also offers a walk-in service for sickle cell patients who have become acutely unwell with vaso-occlusive sickle cell pain ('crisis').

Walk-in service:

- Monday to Friday only, excluding bank holidays. Patients wishing to attend for treatment of pain relief need to check in between 9am and 4pm.
- We have a limited number of chairs for treatment of pain and if the Unit is full, you will be redirected to the Emergency Department (A&E). We recommend that you contact the CNS team if you are planning to attend the Day Unit after 11am to ensure that there is space. Please call 020 3299 3200.
- Please note that these numbers are available during normal working hours (9am to 5pm). They are not manned after hours, or on weekends or bank holidays.



Frequently asked questions:

- **Can I have my blood sample taken on the same day that I have my transfusion?**

In exceptional circumstances we can take your blood sample on the same day as your transfusion. Otherwise, blood tests should be done 2 days before your scheduled transfusion day to allow us to crossmatch effectively.

- **Can I see my doctor while having my treatment?**

There is a resident doctor in the Haematology Day Unit if you are unwell, but this is for emergencies only. You will need to book a clinic appointment for specialist consultation.

The Haematology Day Unit is a treatment unit only. The nursing staff may ask your doctor to come to the unit for an urgent review or a treatment-related question, but not for a full consultation.

Consent

We must by law obtain your written consent to any operation and some other procedures beforehand. Staff will explain the risks, benefits and alternatives before they ask you to sign the consent form. If you are unsure about any aspect of the procedure or treatment proposed, please do not hesitate to speak with a senior member of staff again.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.



3. Apheresis Suite

The Apheresis Suite is located on Matthew Whiting Ward on the first floor of the Cheyne Wing. It provides automated red blood cell exchange transfusion, stem cell collection and plasma exchange procedures.

Treatment is by appointment only. Patients receiving regular red cell exchange blood transfusions will receive their next appointment directly from the Apheresis Team. If you are on a regular red cell exchange programme and need to change your appointment, please call 020 3299 2051 or 020 3299 0558.

Please attend your blood transfusion appointments on time and do not cancel with less than 24 hours' notice.

Also, please notify the Apheresis Unit if you will be late so that we can see if there is still a slot for the same day. We run a very tight schedule, and one chair is used several times per day.

If you arrive more than 1 hour late without prior notice, there may no longer be a place for that day and we will have to cancel and reschedule you.

4. Blood tests and other investigations

Blood tests

Your team will ask you to have a blood test before or after an appointment. Blood tests are taken at the Phlebotomy Department on the ground floor of the Golden Jubilee Wing.



Opening hours: Monday to Friday, 7.30am to 5.45pm, excluding bank holidays. It is strongly recommended to book a time slot in advance. Patients with a reserved time slot have priority over walk-in patients. During busy times, walk-in patients may not be seen.

Book your blood test online using the Swiftqueue online booking system:

<https://www.swiftqueue.co.uk/synnovis.php>



Please note:

- you do not need a blood form to attend the Phlebotomy Department – requests are made electronically
- if you have been asked to provide a urine sample, ask the phlebotomist to give you a urine sample container and they will also print the sticker to label your sample
- you don't need to fast for your blood tests, unless advised to by your doctor
- we can no longer offer a phlebotomy service during clinic times
- if you have a port or a PICC (peripherally inserted central catheter) line, your CNS will arrange for you to have bloods taken in the Haematology Day Unit, by appointment.

X-rays

X-rays of the chest and of individual bones are performed in the X-ray department on the ground floor of the Golden Jubilee Wing, Monday to Friday, 8am to 7.45pm. Those X-rays are performed on a walk-in basis and the department will not send an appointment letter.

All other investigations are by appointment only.



5. Inpatients

You may need to be admitted to King's College Hospital for a procedure or for urgent treatment.

Admission usually takes place following a review in the Emergency Department (A&E) or in the Haematology Day Unit. Red cell patients are preferentially admitted to one of five haematology wards at King's College Hospital:

Elf and Libra Ward	020 3299 5381
Davidson Ward	020 3299 4336
Derek Mitchell Unit	020 3299 3611
Waddington Ward	020 3299 4551
Matthew Whiting Ward	020 3299 1079

You may be placed on another ward if there are no beds available on the preferred wards, but we will try to relocate you as soon as possible.

What happens during an inpatient stay?

- You will be admitted under the care of a red cell consultant.
- A red cell doctor will review you and confirm your management plan within 24 hours of admission.
- Doctor's ward rounds take place daily in the morning and early afternoon. Report any new symptoms and have any questions ready and do not leave the ward unnecessarily.
- The daily ward round is led by a haematology specialist registrar. This is a senior doctor in training. The registrar is assisted by a resident doctor who may be delegated to perform certain tasks. The advance clinical practitioner (a specialist nurse assessor and prescriber) may join the ward rounds and provide additional support



- On Mondays and Fridays, a red cell consultant will lead the ward round.

As an inpatient, your primary point of contact is your named ward nurse or the ward doctor. They will liaise directly with senior members of staff if needed.

Side rooms are for infection control cases. You may be temporarily admitted into a side room if there is no space in a bay, however, you may be asked to move onto a bed in a bay if the side room is needed for another patient.

Individual wards have their own visiting hours and mealtimes.

All medicine is securely stored on the ward to avoid accidental dosing errors. If you bring any medicine from home, please inform the nursing team.

Often medicine, including pain relief, is prescribed 'PRN' (pro re nata). This means it is only offered when you ask for it. We suggest that you talk to your nurse about how you would like your medicine offered, for example, if they should wake you up if it is due.

Discharge from hospital is a medical decision. Because of the bed pressures in the NHS, we cannot offer a prolonged stay for recuperation. 'Fit for discharge' is an assessment based on factors such as your mobility, independence and need for intravenous medicine.

Your planned discharge date will be discussed with you in advance. We will normally provide you with a limited amount of medicine that you may need 'to take away' (TTA). We aim to offer you a follow-up appointment within 6 weeks following discharge, unless you have a pre-booked appointment within or close to this time.



6. Additional support services

The Red Cell Team offers a holistic service:

- Community Services
- specialist psychology support
- specialist social work
- specialist welfare support
- transition pathway support (for 14 to 24 year olds)
- Patient Support Group

Community Services

The Red Cell Community Team offers support for adults, young people and children with sickle cell disease and thalassaemia and their carers, and families who are residents of Lambeth, Southwark and Lewisham.

Services include:

- preconception, antenatal and newborn genetic counselling and screening programs
- health promotion, training and awareness programs
- assessment and support with social needs, such as housing
- welfare benefits advice and support
- resource and information centre (including leaflets, articles and DVDs)
- GP liaison and support for other community services

People can self-refer to Community Services, or via health care professionals, and national or local screening programmes.

Opening hours: Monday to Friday, 9am to 5pm
(excluding Bank Holidays)

Address: South East London Sickle Cell and Thalassaemia Centre,
Wooden Spoon House, 5 Dugard Way, Renfrew Road,
London SE11 4TH
Telephone: 020 3049 5993



There is also a time limited enhanced community pilot service funded to support patients living within Lambeth, Southwark, Lewisham, Bromley, Bexley, and Greenwich. This team offers additional services such as community physiotherapy, community dietician, community pharmacist. The service is currently funded for a further 18 months at time of this leaflet production. Your Red Cell Team can assist with a referral.

Specialist psychology support

Experiencing health problems can affect people's lives in many ways. Our Psychology Service can support patients in coping with the multiple challenges of living with sickle cell disease and thalassaemia. Meeting with a psychologist can help by giving you the chance to talk through your health difficulties, the impact they have on your life and mental health and how you can best cope with this.

Your doctor or nurse will offer you the choice of referral to the psychologist. You can also contact the specialist nurses if you would like to be referred.

Specialist social worker

The Red Cell Team has a dedicated red cell social worker who can offer advice and support on a range of problems related to:

- **care support** – arranging extra help at home for you or your family
- **help for children** – for example, advice on Children's Services or young carers, speaking to schools, additional community support for children
- **community access** – support groups or local interest groups available in your community for you and your family
- **immigration** – linking you with local services and helping you access free legal advice, including advice on No Recourse to Public Funds (NRPF)



- **family matters** – if you need help in addressing issues within your family, or you have any worries or concerns
- **housing** – including homelessness, supporting you to discuss your medical needs with housing
- **finances** – including sourcing charity funding, support with paperwork, appealing decisions
- **employment** – supporting you to address your medical needs with your employer, reasonable adjustments, careers support

Please speak to your consultant or CNS to request a referral for social work support. You will then be contacted to discuss your support needs and agree an action plan. You can be seen by yourself, or with family members or friends.

Welfare support officer:

The Red Cell Team can refer you to our welfare support officer if you are a resident of Lambeth, Southwark or Lewisham. The welfare support officer can provide help in the following areas:

- **welfare benefits:**
 - o legacy – Employment and Support Allowance/Housing Benefit/Income Support/Tax Credits system
 - o Universal Credit
 - o Personal Independence Payment/Disability Living Allowance/Attendance Allowance/Carer's Allowance
 - o Council Tax
- **housing issues:**
 - o homelessness
 - o disrepair
 - o adaptations
 - o rent arrears



- **employment and education:**

- o CVs
- o Access to Work
- o reasonable adjustments in the workplace
- o student finance
- o Disability Student Allowance (DSA)
- o Educational Healthcare Plans (EHP)

In all areas, assistance with appeals and tribunal representation can also be provided.

Transition pathway support

The Red Cell Team aims to ensure that children and young people living with sickle cell disease and Thalassaemia are supported throughout their health journey into adult services through a transition process that is individualised and patient-centred.

A dedicated Roald Dahl Transition Clinical Nurse Specialist is available to provide ongoing support to our young people aged 14 to 24 and their caregivers.

You may meet them in one of your paediatric outpatient clinic appointments.

Services include:

- dedicated adolescent outpatient clinic (16 to 18 year olds) – first Monday of the month, 3pm to 6pm
- transition workshop (16 to 19 year olds) – twice a year at start of Easter and Summer school holidays

Patient Support Group

We facilitate a Patient Support Group on the second Thursday of the month. All patients are invited to participate. Information about the



topics for discussion are sent via WhatsApp and email (where known and requested).

The sessions are currently held virtually via Microsoft Teams. We will send out the link before the meeting. Please send a WhatsApp message to 07890 252 387 if you would like to be added to the Support Group Chat.

7. Requests for prescriptions and support letters

Prescriptions:

As per NHS regulations, your regular medicines should be obtained from your GP. Exceptions include hydroxycarbamide, erythropoietin, and iron chelators which need specialist monitoring and are hospital prescribed, and occasionally controlled drugs if your GP is unwilling to prescribe these. Please inform your consultant or CNS if your GP cannot or will not prescribe certain medicines, so that we can liaise with your surgery.

In exceptional situations, the Red Cell Team can provide you with a limited supply of routine medicine as a one off.

The preferred way for requesting prescriptions is by email to: kch-tr.sicklethaladult@nhs.net. Please state name of drug, dose used and number of days needed. Alternatively, you can call the CNSs on 020 3299 3200.

Things to note

- We cannot offer a rapid prescription service. Prescriptions are usually provided by GPs.
- We recommend you sign up to the NHS App for GP prescription requests.



- The Red Cell Team may in exceptional circumstances provide urgent prescriptions, based on individual assessment by the clinician.
- You may be subject to prescription charges even if King's College Hospital provides you with a prescription (TTA's excluded). If you do not hold an exemption certificate, consider buying an NHS Prescription Prepayment Certificate, which is often cheaper than paying per prescription (<https://www.nhs.uk/using-the-nhs/help-with-health-costs/save-money-with-a-prescription-prepayment-certificate-ppc/>)
- Specialist medicine (hydroxycarbamide and iron chelators) can be collected from a locker system on the ground floor in the Hambleton Wing. Let us know if you want to collect from the prescription locker and we will ask pharmacy to send you the PIN to the locker when your specialist medicine is ready for collection.
- The hospital does not have a medicine delivery service.

Support letters

We are happy to provide letters to support applications for further education, housing, benefits, mobility allowances etc. We can also provide travel letters for air travel and complete in-flight oxygen requests.

Please discuss travel arrangements with us as soon as possible so we can assess your needs and help inform the airline in a timely manner if needed. Also, please think about travel insurance. For travel within the EU, we strongly recommend getting a free Global Health Insurance Card (GHIC): <https://www.nhs.uk/using-the-nhs/healthcare-abroad/apply-for-a-free-uk-global-health-insurance-card-ghic/>

The preferred way for requesting support letters is by email to: kch-tr.sicklethaladult@nhs.net. Alternatively, you can call the CNSs on 020 3299 3200 or speak with the social worker if you have been referred.



Please state clearly what you need the support letter for (for example, Personal Independence Payment (PIP), housing) and highlight any specific problems encountered (for example, specific housing issues or lack of understanding by employer).

We aim to return a support letter within 3 to 4 weeks.

8. Contact details

In an emergency, dial 999 or come straight to the Emergency Department (A&E).

The contact details below are non-emergency and available Monday to Friday, 9am to 5pm, excluding bank holidays.

Outpatient clinic appointments: 020 3299 5554
(for appointment queries)

Haematology Day Unit: 020 3299 2963
(for appointment queries)

Apheresis Suite: 020 3299 2051 or 020 3299 0558
(for apheresis queries)

Clinical nurse specialists:
(for health-related queries)

If you need to contact one of our Clinical Nurse Specialists, please be aware that they may be with another patient and unable to answer your call. If this happens, please leave a clear voicemail with your name, date of birth / hospital number, the best telephone number to contact you on, and, if possible, a brief reason for your call. We aim to return all voicemail messages within 2 working days.



Transition only: **020 3299 4968** or **07890 252 387**
Adults: **020 3299 3200** or **07974 098 640**
Email: kch-tr.sicklethaladult@nhs.net

Haematology secretaries: **020 3299 4152**
(for general enquiries)

Community Services: **020 3049 5993** or
(for general enquiries) gst-tr.referralstosickle@nhs.net

9. Eligibility for free treatment on the NHS

The Red Cell Team can only provide treatment to people who are entitled to receive free NHS healthcare. This is usually because you are ordinarily resident in the UK, or because you meet another exemption under the NHS charging regulations. Being ordinarily resident means that you are living lawfully in the UK on a settled basis as part of the regular pattern of your life for the time being. Please note that having an NHS number, being registered with a GP, or holding a British passport does not automatically mean that you are entitled to free NHS healthcare.

If you are not entitled to free NHS healthcare, you will be charged for NHS treatment. The main exception is that treatment provided in an Emergency Department (A&E) before you are admitted to hospital is free for everyone.

If you are unsure whether you are entitled to free NHS healthcare, or if your circumstances have changed, please contact the Overseas Team at King's College Hospital, who can advise you before treatment is arranged.

Tel: 020 3299 5858. Email: kch-tr.overseasvisitors@nhs.net



10. Further information

The Red Cell Team aims to deliver high-quality, safe and friendly care in accordance with best-practice clinical guidelines. Feedback is incredibly valuable for improvement of the services.

The department routinely circulates questionnaires among service users. The Patient Support Group provides monthly feedback. Please ask your CNS for contact details if you would like to join. We are recruiting more patient representatives to participate in service improvement meetings so do let us know if you are interested.

We appreciate feedback – positive or negative – to the team or services, preferably in writing. When you have a concern or complaint, the sooner you report your concern, the better we can investigate it. If possible, include what you think should have happened or what you think would help improve the services.

How can I raise a concern or give a compliment?

You can approach any team member personally or write or email the department (kch-tr.sicklethaladult@nhs.net).

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. To sign up or for help, call us on **020 3299 4618** or email **kings.mychart@nhs.net**. To find out more visit **www.kch.nhs.uk/mychart**

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: **020 3299 4618**

Email: **kings.pals@nhs.net**

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net



This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

