

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 South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC). We aim to offer an outstanding personalised service to all our patients.

This information leaflet outlines the service 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 on Thursday from 1.30pm to 4.50pm and Friday from 2pm to 4.30pm, in Haematology Outpatients, Ground Floor, Cheyne Wing. Clinics are the main place to discuss and review your red cell-related health concerns.

Clinical nurse specialist-led telephone clinics are on Tuesday mornings (annual review) and Wednesday mornings (hydroxycarbamide follow-up).

All patients will be offered routine follow-up appointments of either 3 monthly, 6 monthly, or annually, as appropriate. These appointments are scheduled for 15 min.

In addition, all patients can expect one annual review appointment per year. These are scheduled for 30 minutes, during which your doctor or nurse will carry out a holistic review and discuss any further investigations and/or referrals required.

The Red Cell Clinics are run by consultant haematologists, clinical nurse specialists (CNSs), a clinical research fellow, and a specialist registrar on the training rotation for red cell disorders. Our clinical psychologist also attends on selected dates.

Red Cell Clinics are by appointment only. You will receive a letter and a reminder text message with details of your appointment unless the booking was made less than 72 hours before the actual appointment. Appointments can be face-to-face or via the telephone.



Please attend the reception desk after your consultation to book your next appointment if you attend face-to-face.

Preparing for your Red Cell Clinic appointment:

Typically, we have 40 to 50 patients scheduled for each Red Cell Clinic. To reduce the waiting time, we ask you to keep to your appointment time:

- by arriving at least 15 minutes before your scheduled face-to-face appointment to allow the health care assistant to take your observations
- by having your phone near you and in an area with good reception if you have a telephone consultation. We aim to call you at your appointed time, but can be earlier or later depending on how busy it is. Please note that our call usually shows 'private or number unknown' on your telephone display

Please prepare for the consultation by writing down in advance what you would like to discuss and bringing a record of your medications with you.

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 in the Haematology Outpatient Department. Your consultant will refer you to a joint specialist clinic if required and you will receive appointments by letter in the usual way.

Frequently asked questions:

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

Call 020 3299 5554 to change or cancel your appointment.

To cancel or change an appointment in one of the joint specialist clinics, please contact the Clinical Nurse Specialist Team on 020 3299 4968.

- **Can I come early?**

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 on 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 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?**

If you would like to speak to a particular consultant, please notify the clinic receptionist. However, it will not always be possible because we aim to ensure that our patients receive the same standard of care from all our doctors. Please be aware that your clinic booking is always in a consultant's name, but this does not mean that the consultant is the person you will see on the day.

- **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 located in the Haematology Outpatient Department (HOP). 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 (for example, crizanlizumab)
- treatment of uncomplicated vaso-occlusive pain ('sickle cell crisis')

Opening times

Treatment in the Haematology Day Unit is by appointment only. In addition, the Day Unit offers a walk-in service for sickle cell patients



registered to Haematology at King's College Hospital who have become acutely unwell with vaso-occlusive sickle cell pain ('crisis').

- The unit is open Monday to Friday, 8am to 8pm (excluding Bank Holidays). Patients wishing to attend for treatment of pain relief need to check in before 4pm.
- We have a limited number of beds for treatment of pain and if the Unit is full we will have to redirect you to A&E. We recommend that you contact the CNS before you attend the Unit on 020 3299 4968 or 07890 252 387.
- The Day Unit service will gradually be extended to include a similar service on Saturdays and Sundays. Please check with your team before attending until further notice.

Please note that at present, you will not receive an appointment letter or text message reminder for treatment in the Haematology Day Unit.

What we would like to ask from you:

In order to deliver the care as smoothly as possible, we ask that you:

- arrive in time for your appointment, ideally 15 minutes before your scheduled time
- 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

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?**

If you would like to see one of the doctors, you will need to book a clinic appointment or a telephone clinic appointment. 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 the 2nd floor of the Guthrie Wing at King's College Hospital and provides automated red blood cell exchange transfusion, stem cell collection and plasma exchange procedures.

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



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 are 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 the transfusion.

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 on a walk-in basis.

Opening hours: Monday to Friday, 7.30am to 5.45pm, excluding Bank Holidays.

Please note:

- you do not need a blood form to attend the Phlebotomy Department – requests are made electronically
- some people have blood tests for different specialists, please mention that your blood test is for haematology
- if the scientist is unable to find your order, please ask them to call the CNS on 020 3299 4968 for clarification
- if you have been asked to provide a urine sample, make sure you have an appropriate container and ask the phlebotomist to 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 HOP, 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 A&E or in the Supportive Therapy Unit. Red cell patients are preferentially admitted to one of four 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

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 responsibility a red cell consultant.
- A consultant 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 senior house officer. This is a junior doctor, who, based on their experience, may be delegated to perform certain tasks. The advance nurse practitioner (a specialist nurse assessor and prescriber) often joins the ward rounds.
- 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 required.

Individual wards have their own visiting hours and mealtimes etc.

All medication is kept by the nurses to avoid accidental dosing errors. If you bring in any medication from home, please discuss this with your ward nurse.

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



Discharge from hospital is a medical decision. Because of the bed pressures in the NHS, we are not able to offer a prolonged stay for recuperation. 'Fit for discharge' is an assessment based on factors such as your mobility, independence and need for intravenous medication. Your planned discharge date will be discussed with you in advance. We will normally provide you with a limited amount of medication that you may need 'to take away' (TTA). We aim to offer you a follow-up appointment within 6 weeks following discharge.

6. Additional support services

The Red Cell Team offers a holistic service:

- Community Services
- psychology support
- social work
- welfare support
- 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 center (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

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.

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.

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 medications should be obtained from your GP. Exceptions include hydroxycarbamide, erythropoietin, voxelator, crizanlizumab 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 medications, so that we can liaise with your surgery.

In exceptional situations, the Red Cell Team can provide you with a limited supply of routine medication 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 required. Alternatively, you can call the CNSs on 020 3299 4968.

Things to note

- We cannot offer a rapid prescription service. Prescriptions are usually provided by GPs. The Red Cell Team provides this as an extra but does not have adequate resources to guarantee urgent prescriptions.
- 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 exception 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/>)

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.

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 4968 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 personalised support letter within 4 weeks.

A standard letter or statement with general information and your personal details can usually be provided within a week.

8. Contact details

In an emergency, dial 999 or come straight to 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
(for apheresis queries)

Clinical nurse specialists: 020 3299 4968, 07890 252 387 or
(for health related queries) 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. 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 will routinely circulate questionnaires among service users. The Patient Support Group provides feedback on a monthly basis. 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. When 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).



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. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net



