University College Hospital

Guide to services for people with red cell and iron disorders

North Central London Haemoglobinopathy Network jointly with Whittington Health, Royal Free London and Luton and Dunstable NHS Foundation Trust

Joint Red Cell Unit
If you need a large print, audio or translated copy of the document, please contact us on 020 3447 9638. We will try our best to meet your needs.

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Introduction

Our Joint Red Cell Unit is a leading national unit for investigating and managing transfusion-dependent and transfusion-independent anaemias, and iron disorders. Patients are referred locally, nationally and internationally for tests, treatment and advice about management. The Unit houses the fastest growing Red Cell Apheresis Unit (Auto-Rex) in the country — we perform more apheresis procedures than the rest of the country combined.

Conditions treated

• Haemoglobinopathies including sickle cell and thalassaemia
• Iron disorders including haemochromatosis
• Enzymopathies, for example pyruvate kinase deficiency
• Membrane disorders, for example hereditary spherocytosis
• Secondary polycythaemia
• Non-malignant (non-cancerous) haematology in children younger than 12 years old (excluding bleeding or clotting problems).

Service performance

Across the two sites, we have about 1000 patients with sickle cell disease and thalassaemia under regular follow-up. We also offer an outreach service to Luton and Dunstable University Hospital. Some patients are under shared care with other hospitals.

We are a tertiary referral centre (which means that other hospitals or centres may refer their patients to us) for iron overload disorders, such as genetic haemochromatosis, as well as for other red cell disorders including haemoglobinopathies. The majority of inpatients form the haemoglobinopathy part of the service, while the outpatient and, to a degree, the day care service is more varied.

We also work with the bone marrow transplant team to assess and facilitate stem cell transplants for those with haemoglobin disorders.
Outpatient clinics

Adult Clinics
4th floor, University College Hospital Macmillan Cancer Centre, Huntley Street, London WC1E 6AG
Tuesday mornings 08:30 to 12:00
Wednesday evenings 16:00 to 19:00

Paediatric Clinic
Lower ground floor, Elizabeth Garrett Anderson (EGA) Wing, University College Hospital, 235 Euston Road, London NW1 2BU (access from Grafton Way)
Monday afternoons 14:00 to 17:00

Adolescent Transplant Clinic
3rd floor, University College Hospital Macmillan Cancer Centre, Huntley Street, London WC1E 6AG
Monday afternoons 13:00 to 14:00

Paediatric Transcranial Doppler Clinic
Lower ground floor, Elizabeth Garrett Anderson (EGA) Wing, University College Hospital, 235 Euston Road, London NW1 2BU
Bimonthly Thursday mornings

Clinic appointments can be made or changed by calling the haematology advice line (contact details are on page 19.)

Phlebotomy service
If you need a blood test, there are a number of options available:
• Basement of the Cancer Centre, opening hours 08:30 to 16:45, Monday to Friday. The phlebotomy service at the Cancer Centre can provide you with a print out of your full blood count (FBC) within 10 minutes of having their blood taken. This means that you can have some of your results ready for the doctor in clinic.
• Podium level of the main hospital (Tower building). Please note that the results are not available instantly there.
• Adult Day Care - if you are on regular transfusions or red cell exchanges you may have your blood tests performed in Day Care. You should discuss this with a senior member of the day care team. Occasionally, the ambulatory care team may perform blood tests during the weekend.

• Paediatric ward (T11 south) or paediatric outpatients - this is a nurse-led service and your specialist nurse can schedule an appointment for you.

**Out-of-hours transfusion**

For patients on top-up transfusion programmes, blood can sometimes be administered out of hours if previously arranged.

For patients up to 12 years old — ward T11 south.

For patients aged 13 to 18 — ward T12 south.

For patients aged 18 or over — there is a bed on each of the haematology wards, T16 north and T16 south.

We are exploring the possibility for routine top-up transfusions in the Ambulatory Care Unit during weekends. Out of hours and in case of a clinical need, the apheresis team can perform urgent automated exchange and the medical team provides manual exchange.

**Adult red cell patients**

**Day Care**

The Haematology Day Care Unit provides the following services for adult (18 years and over) red cell patients:

• Blood tests

• Blood transfusion and venesection

• Red cell exchange transfusion, both manual and automated
• Administration of certain medications - for example pamidronate
• Rapid Access Service for red cell patients with health-related problems
• Advice over the telephone where appropriate
• Management of indwelling lines, for example vortex ports and portacaths.

Haematology Day Care is situated on the 4th floor of the University College Hospital Macmillan Cancer Centre, Huntley Street, London WC1E 6AG. It is open from Monday to Friday, between 08:30 and 19:00. The Rapid Access Service is open from 09:00 to 16:00.

If you are unwell and come to Haematology Day Care, you should be:
• Seen by a doctor
• Offered painkillers and IV fluids as necessary
• Tested for any underlying cause, which may include blood tests, scans and/or X-rays, or referrals to other specialists
• Offered additional medication if required
• Offered a follow-up appointment at an outpatient clinic (book if not already scheduled or bring forward if necessary)
• A return visit to Day Care/GP if needed
• Assessed as to whether you need admission to the ward.

Staffing
• There is a junior doctor on site who can communicate with the red cell team as required.
• There is a day unit manager and two senior nurses as well as staff nurses and other support staff.
• The Apheresis Unit is based in Day Care and the Auto-REX programme is coordinated by Ms Nancy Huntley (adults) and Ms Catherine Mkandawire (children).
Prescriptions
You should request your regular prescriptions from your GP, and not Day Care. Where the medication needs particular monitoring, for example chelation or hydroxyurea, you should receive your prescriptions from clinic. This is because prescribing from Day Care disrupts proper monitoring of your condition and medications. This is particularly important if you are receiving substantial quantities of opiates, where it is safer for one site to issue your prescriptions.

What to do in an emergency
• If you have a non-urgent medical problem or a medical problem unrelated to your red cell/iron condition, such as a rash or a twisted ankle, you should go to your GP or your local Emergency Department (A&E). If necessary, they can always contact us.

• If you have a non-urgent red cell/iron problem, you can ask for your outpatient appointment to be brought forward, or you may be able to have a review in Day Care.

• If you are 18 years old and over, you should call the haematology advice line, or if it is out of hours the adult haematology advice line (contact details are on page 19).

• The haematology advice line is manned by a personal assistant. They can help you with any administrative queries you may have and will inform the CNS if you have any medical concerns. The CNS should ideally call you back within 30 minutes of receiving your message.

• The advice may be to attend the Rapid Access Service in Haematology Day Care, go to your GP or the Emergency Department (A&E), or to bring forward your clinic appointment.

• The nurse may speak to one of the doctors to get further advice.
• The Rapid Access Service is only open for assessments from 09:00 to 16:00, Monday to Friday, after previous discussion with the CNS or medical team. Outside of these times, you will need to go to the Emergency Department (A&E).

• Even if you are going to the Emergency Department, it is always best to call ahead so that we can try to streamline your assessment as much as possible.

Note: If you have an infectious illness, such as cough, cold, diarrhoea, vomiting or chicken pox, do not come to clinic or haematology supportive care unit. You should go to the Emergency Department (A&E) and we will see you there. These seemingly minor illnesses can be very serious for some haematology patients with very poor immune systems, for example those recovering from chemotherapy or stem cell transplants.

Haematology wards
Haematology wards, T16 south, T16 north, T14 south and T13 north, are located in the Tower, University College Hospital, 235 Euston Road, London NW1 2BU. We will do our best to place you directly on the haematology ward at the time of your admission. However, if there are no beds available on either of these wards, you will need to stay on another ward until a bed becomes available. Please be assured that we will make every effort to transfer you to the appropriate ward as soon as possible. To ensure the continuity of care, haematology nurses will look after you on the ward you are on.

• T16 south extension numbers: 71686 and 71602
• T16 south visiting times: open visiting
• T13 north extension numbers: 71387 and 71303
• T13 north visiting times: open visiting
If you develop an infection that carries a high likelihood of transmission to other patients, such as flu, we may move you to either an alternative haematology ward or a specialist isolation ward within the Tower (T8). You may remain on T8 for the rest of your hospital stay, but if the infection resolves we may be able to transfer you back to a haematology ward when a bed becomes available.

**Keeping in contact**

Your family and friends can contact you directly on your bedside telephone. These calls are charged at a premium rate. Please ask your nurse for more information. You can use your mobile phone but we ask all patients and visitors to keep their phones on silent, so that you do not disturb other patients.

Family and friends are welcome to telephone and enquire about your progress but for reasons of confidentiality we will not be able to give out specific patient details over the phone.

Mail is delivered to the wards each weekday. To ensure its correct delivery, your name and the name of the ward must be put on all correspondence. You can place any stamped post you would like to send in the tray at the reception desk.

There are no restrictions on visiting times on the unit. A relative or support person can stay with you in your room, provided that it has been arranged with the nursing staff and that there are facilities available. Children under the age of 16 cannot stay overnight, however they are welcome to visit during the day.

For security, there is an intercom system to gain access to the floors. Visitors will need to press the call button located at the entrance of the ward and wait for the door to be released. They may be asked their name and that of the person they are visiting.
Note: We ask visitors not to come to haematology wards if they have an infectious illness, such as cough, cold, diarrhoea, vomiting or chicken pox. These seemingly minor illnesses can be very serious for some haematology patients with very poor immune systems, for example those recovering from chemotherapy or stem cell transplants.

Ward rounds
Ward rounds are carried out on a daily basis by the junior doctors (Specialist Registrar and Senior House Officer). On Tuesday mornings, when the Red Cell Clinics take place, the Specialist Registrar may not be able to see all patients on the wards and only see those who are unwell. However, the Senior House Officer will review the rest of the patients and report to the Specialist Registrar after the ward round and throughout the day.

The consultant ward rounds take place after the red cell MDT meetings on Tuesday afternoons and Friday mornings. These timings may change depending on the consultants’ other commitments.

Paediatric red cell patients
Paediatric patients (up to 18 years of age) may have their blood test either at the Cancer Centre or podium level of the main hospital (please see page 4 for more details).

For those who are particularly young or who need extra support, blood tests can be taken by the ward or clinic staff — they will discuss this with you in more detail.

There is also a walk-in service in the paediatric outpatient department on Tuesdays and Fridays between 14:00 and 17:00. This is located on the lower ground floor of the Elizabeth Garrett Anderson (EGA) Wing, University College Hospital, 235 Euston Road, London NW1 2BU.
All paediatric patients with significant haematological disorders receive a Patient Passport. This passport alerts the Emergency Department (A&E) staff to request a paediatric team review if they attend the Emergency Department (A&E).

Day Care and inpatient care for children is on ward T11 east located in the Tower, University College Hospital, 235 Euston Road, London NW1 2BU.

There is no Rapid Access facility on wards T11 south or T12 south and patients are seen or treated there by appointment only. If you are 18-19 years old, you can use the Rapid Access facility on Adult Haematology Day Care.

Children admitted to the paediatric ward are under the care of the general paediatric team with support from the red cell team. If you are 18 or older, you will be admitted to an adult ward even if you are still being seen in the Paediatric Outpatient Clinic.

All our school-age children who are on regular transfusion are transfused on the wards during the weekends. Nurses are trained to perform manual red cell exchanges where necessary.

- T12 south extension number: 71201
- T12 south visiting times: unrestricted for parents
- T11 south and east extension numbers: 71100 and 71186
- T11 south and east visiting times: unrestricted for parents

**Ward rounds**

Paediatric ward rounds take place every morning and are attended by the consultant paediatrician and their team. The red cell haematology registrar (the second in command to the red cell consultant) will also review all patients each day and liaise with the paediatric team. The paediatric team will discuss patients’ care with the red cell consultant on a daily basis, and the red cell consultant will visit the children on their ward rounds at least twice a week.
What to do in an emergency
Paediatric patients should attend the Emergency Department (A&E) at UCLH with their Patient Passport. A paediatric specialist will review them and discuss their care and/or treatment options with the haematologist on call.

The Red Cell Unit teams

Medical team
There are three consultants who are responsible for the inpatients:
• Professor John Porter (adult lead)
• Dr Sara Trompeter (paediatric lead)
• Dr Perla Eleftheriou.
They take turns attending the wards, usually on a monthly basis. This means that they take responsibility for what is happening on the wards 24 hours a day in a given month.

There are two other haematology consultants who attend the haematology clinics (adult):
• Dr Davis
• Dr Shah (from the Whittington).

The paediatric patients are cared for jointly between the haematology and paediatric team. There are dedicated specialists who support our patients, including Dr Walker (cardiology), Dr Chatterjee (fertility and bone health), Dr Naik (endocrinology and diabetes), Mr Ralph (andrology) and Prof Butler (paediatric and adolescent growth).
Contact details
There are junior doctors (Specialist Registrar and a Senior House Officer) in both the adult and the paediatric team, and they review each patient on the ward every day. They then report to the consultant after their daily ward round, although it can be sooner if a patient is particularly unwell.

Out of hours, there may be one or two Senior House Officers and Registrars who will care for all the haematology patients. However, the adult haematology Senior House Officer does not usually input much to the paediatric patients.

Nursing team
The nursing staff on our haematology wards are qualified nurses with specialist haematology experience. The nurses on the paediatric wards have specialist paediatric training, with several of them having expertise in the management of red cell patients.

We also have link nurses who are able to perform, and train others to perform, manual red cell exchanges on children.

• Mr Stephen Rowley, Lead Nurse for Haematology
• Mrs Kerry White, Charge Nurse for T13 north
• Mr Jon Derbyshire, Charge Nurse for T16 north
• Ms Dawn Collier and Mrs Marinella Colosio, Supportive Care Sisters
• Ms Nancy Huntley, Auto-REX Coordinator
• Mr Allan Watkins: Charge Nurse for T11 south
• Mr Siyonge Mulope: Charge Nurse for Paediatric Day Care
• Ms Catherine Mkandawire, Paediatric Haemoglobinopathies Clinical Nurse Specialist
Nursing staff can be identified by the uniform they wear:

- Dark red: Divisional Senior Nurse (Matron)
- Navy blue: Charge Nurse/Deputy Sister/Clinical Practice Facilitator, Clinical Nurse Specialists
- Royal blue: Staff Nurses Nurse
- Pale blue: Housekeepers

**Multidisciplinary team**

Other teams involved in the care of patients on the ward may include the pain control team (acute or chronic), the palliative care team, clinical psychologist, pharmacists, specialist nurses, physiotherapists, occupational therapists, dietitians, welfare rights advisor, counsellors, and speech and language therapists. They are all part of the multidisciplinary team caring for you. If you need to be reviewed by other specialist medical teams during your stay or as an outpatient, this will be discussed with you.

The red cell team has a dedicated adult clinical psychologist, Ms Helen de Marco, who can arrange to see you either on a ward or as an outpatient.

The paediatric team also includes play specialists, school teachers and a health visitor.

**Students**

As we are a teaching hospital, student doctors, nurses, physiotherapists, occupational therapists and other healthcare workers may work with your team under their supervision. If you do not want to be seen by students, please tell your team - it will not affect your care in any way.
Complementary therapies
Members of the complementary therapy team regularly visit the wards on weekdays and offer reflexology, reiki, aromatherapy, relaxation and massage. Treatments, which are free of charge, take place either at the bedside or in the treatment room on T13 north.

If you would like to know more about the service and available therapies, please speak to your nursing team.

Infection control
No visitors or members of staff are allowed onto the ward or Day Care if they have viral symptoms, such as cough, cold, flu, mumps, measles or chicken pox. If the patient or any recent visitors develop viral symptoms, they should discuss them with their nurse.

No visitors or members of staff are allowed onto the ward if they have had diarrhoea in the past 48 hours. Some of the haematology patients are at high risk of dangerous complications due to infections, they are difficult to treat and outbreaks have caused units to close in the past.

All visitors should use the hand gel provided when entering and leaving the wards.

Directions and travel
By bus
Tottenham Court Road  Bus No: 10, 73, 24, 29, 134
Gower Street  Bus No: 10, 24, 29, 73, 134
Euston Road  Bus No: 18, 27, 30, 88

By tube
Warren Street for Northern and Victoria lines
Euston Square for Circle, Hammersmith & City, and Metropolitan lines
Euston and Kings Cross stations are also a walking distance from the hospital.
There is no car park at the hospital and UCLH is located within the congestion charge zone. There is metered street parking nearby (both inside and outside of the congestion charge zone) that is free on Sundays and on Mondays to Fridays between 18:30 and 08:30. To find out if you qualify for help with hospital travel costs and reclaiming the congestion charge if this applies, please ask your nurse for our leaflets.

Valuables

We advise patients not to bring in large amounts of money or valuables but if this is unavoidable, we encourage relatives to take those items home. If you would like to keep any audio devices, phones or laptops in your room, please take responsibility for keeping them safe and ask your nurse to lock your room if you are leaving it for any period of time. Unfortunately, theft does occur and has been reported when patients have been using the ensuite bathrooms.

There is a cashpoint near pharmacy on the ground floor of the Tower and there are cashpoints near the hospital (one outside Sainsbury’s, and one outside Tesco, both on Tottenham Court Road).

Interpreting/link worker services

Our interpreting services are designed to support health professionals in providing high quality professional service to those whose first language is not English. This improves access to health services for users who have language needs.

Our telephone interpreting system ensures that over 170 languages and dialects are readily available 24 hours per day, 365 days per year, to any member of staff who may require this service. An interpreter is available within a minute of stating your details to the 24-hour call centre staff.
We recognise that there are occasions when telephone interpreting may not be suitable. We have therefore made arrangements for those who require face to face interpreters, British Sign Language (BSL) interpreters or DeafBlind Communicators. Visit the Language Line Services website at www.languageline.co.uk or call Client Services on 0800 169 2879 for more information.

Benefits advice

Please contact the Macmillan Support and Information Service at the UCH Macmillan Cancer Centre on 020 3447 8663 for further information, or ask one of the ward staff.

Your comments matter

Your comments are important to us as they allow us to continually improve our service.

You may choose to give us your feedback in person — if so, please speak to one of our nursing or medical leads.

If you prefer to put something in writing, you can use one of our ‘comment slips’ available in all clinical areas, or you can write to one of the lead members of staff at the address provided on page 19:

- For Day Care: Ms Helen Keane
- For nursing issues on the adult wards: Mr Steven Rowley
- For nursing issues on the paediatric wards: Mr Allan Watkins
- For medical matters: Professor Porter, Dr Trompeter or Dr Eleftheriou.
You can also contact the **Patient Advice and Liaison Service (PALS)** with your comments:

Address: University College Hospital  
Ground Floor Podium  
235 Euston Road  
London NW1 2BU

Telephone: 020 3447 3002  
Email: PALS@uclh.nhs.uk

**Where can I get more information?**

**The Sickle Cell Society**
Tel: 020 8861 7795  
Website: www.sicklecellsociety.org

**NHS Sickle Cell and Thalassaemia Screening Programme**
Website: www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

**The UK Thalassaemia Society**
Tel: 020 8882 0011  
Fax: 020 8882 8618  
Email: office@ukts.org  
Website: www.ukts.org

UCL Hospitals cannot accept responsibility for information provided by external organisations.
Contact details

Haematology advice line (office hours, adults and children):
020 3447 7359

Adult haematology advice line (out of hours):
07852 220 900

Paediatric helpline (out of hours):
• nurse in charge 07961 081 645
• ward T11 south 020 3456 7890 ext. 71103 or 71143

Apheresis:
020 3447 1803

Address: The Joint Red Cell Unit
Department of Haematology
3rd Fl West, 250 Euston Rd
London NW1 2PG

Website: www.uclh.nhs.uk/JRCU

Haematology consultants:
Professor John Porter
Dr Sara Trompeter
Dr Perla Eleftheriou
Dr Bernard Davis
Dr Farrukh Shah

Specialist nurses:
Bernadette Hylton (adults)
Nancy Huntley (apheresis)
Catherine Mkandawire (children)