

Clinical haematology

Haemoglobinopathy services for adults at Hammersmith Hospital

Information for patients, relatives and carers

Introduction

Haemoglobinopathies are a group of blood disorders including sickle cell disease (SCD) and thalassaemia. This leaflet describes the services that are available for adult patients with haemoglobinopathies at Hammersmith Hospital and other helpful information.

The haemoglobinopathy team consists of:

- nurses
- doctors
- healthcare assistants
- student nurses
- administrative team
- clinical nurse specialists (CNS)
- community haemoglobinopathy nurse
- clinical psychologists
- phlebotomists
- social workers
- volunteers
- clinical trials team
- cleaning and catering services staff

Outpatient service

The outpatient department consists of:

- day care unit, which includes an apheresis suite (a specialist service that removes harmful cells from patients' blood)
- day pain service for sickle cell patients
- outpatient clinics
- transfusion service
- phlebotomy (where blood tests are taken).

The haematology outpatient department runs clinics between **09.00 and 17.00, Monday to Friday.**

Day care unit

The day care unit is on the ground floor of the Catherine Lewis building. The apheresis service treats patients with cancer and non-cancer conditions who have planned procedures and treatments such as:

- red cell exchange (RCE)
- therapeutic plasma exchange
- stem cell collections.

The service operates between **08.00 and 20.30, from Monday to Sunday.** It is staffed by nurses and supported by attending specialist registrar and senior house officer.

Apheresis suite

The apheresis suite is on the ground floor of the Garry Weston centre. The apheresis team carry out procedures including red blood cell exchange and therapeutic procedures for SCD patients. Other therapeutic procedures, including stem cell collection for bone marrow transplantation, are also performed in the unit for various haematology conditions.

Phlebotomy service (blood sampling)

The phlebotomy service is on the ground floor of the Garry Weston centre. It runs between **08.30 and 17.00, from Monday to Friday.**

Psychology services

The clinical psychologist is a core member of the haemoglobinopathy team. They can provide support to inpatients and outpatients with red cell disorders. The psychologist can help address:

- any concerns you might have about your treatment
- pain
- depression, stress, or anxiety
- relationships
- communication and more

They will work with you to give you the skills to actively manage your condition.

Patients with haemoglobinopathy disorders can access the clinical health psychologist. For more information, please email: SickleCell.Psychology@Imperial.nhs.uk

Social services

There is a specialist haemoglobinopathies social worker, employed by Imperial College Healthcare NHS Trust. The social worker can provide practical information, advice and support, and advice to patients, relatives and carers about:

- finances
- welfare benefits
- housing
- education and employment
- immigration
- local support and charity services
- local authority social services
- general support

Patients can either be referred by a professional to the specialist social worker or can contact them directly.

Local authority social services

Patients who need extra support and assistance at home can be referred to the adult social services team. Hospital staff will identify if a patient needs additional support. If they do, they will be referred to their local authority adult social care services, who will assess their level of need.

Discharge

A patient might need a package of care at home when they are ready to be discharged from the hospital. Hospital staff may get in touch with (refer to) the adult social services team at the patient's local authority, asking them to organise this. This is coordinated by a social worker who is based at Hammersmith Hospital and covers the London Borough of Hammersmith & Fulham. The social worker forms part of the Adult Discharge Team and works closely with the discharge specialist nurse/coordinator. They help with the discharge planning for elderly and disabled inpatients when they are ready to go back into the community. They also support patients with complex health or social needs. Referrals are made by staff working within the hospital.

Immigration advice

The specialist social worker can provide haemoglobinopathy patients with information and support on immigration. Please inform a member of the haemoglobinopathy team if you require further information on immigration.

Other useful sources of support and advice can come from <http://www.lawcentres.org.uk/other-sources-of-advice>

Benefits advice

Income related benefits

The specialist social worker can provide haemoglobinopathy patients with advice and information about income related benefits they may be able to claim. This will depend on their circumstances. Income related benefits include:

- universal credit
- housing benefit
- council tax support

Patients can receive support and advice about eligibility and how to claim different benefits by being referred to the specialist social worker or contacting them directly.

Disability benefits

Personal Independence Payment (PIP) can be applied for and claimed by adults. If a patient enquires about PIP to the social worker, information about the benefit is provided to patients. Parents who need additional advice or support can contact the specialist social worker.

Patients can ask the social worker for advice or support about applying for PIP

Clinics

The haemoglobinopathy clinic runs at two sites on different days:

- ground floor of the Catherine Lewis Centre at Hammersmith Hospital runs every **Thursday** from **13:30 to 16:30**
- main outpatients at St. Mary's Hospital, every **Friday** from **09:30 to 13:00**

Clinic is only for pre-booked appointments.

You may need a blood test on the day of clinic – we will tell you if you do on the day.

Make sure you check in by 16:30 at Hammersmith Hospital or you may not be seen by the doctor.

The clinical service is supported by research and diagnostic laboratory services that are based in the hospital.

Adolescent clinic (transition clinic) is held in the Paediatrics outpatients department, 6th floor of St Mary's Hospital, on the second Tuesday of the month, from **16:30 to 20:00**.

Joint obstetrics and haematology clinic runs at de Swiet Obstetric Medicine Centre, second floor, Queen Charlotte's & Chelsea Hospital, on alternate Monday mornings. (Queen Charlotte's & Chelsea Hospital, Du Cane Road, London W12 0HS.

What you can expect at your clinic appointment

You will be seen by a haematology doctor when you attend your clinic appointment. Another member of the haemoglobinopathy clinical team may be present during your consultation, and we will inform you of this.

If your first outpatient appointment in the haemoglobinopathy service:

- The doctor will talk with you about your medical history.
- You will be examined. This will include measuring your height and weight, listening to your heart and chest, as well as an abdominal examination.
- You may be asked about any vaccinations you have received and any medication you are currently taking
- Your doctor will talk to you about your diagnosis and any related complications. They will give you advice on how you should take care of yourself at home.

You will also be given written information about:

- sickle cell disease or thalassemia
- support groups
- how you can get further advice

On the day of the appointment, you may need to take a blood test and the doctor will explain what this is for.

A member of the team will inform you about the National Haemoglobinopathy Registry (NHR) and talk to you about consent to sharing some of your clinical information with the NHR.

You will be given:

- a haemoglobinopathy card, and
- a haematology passport

Please keep these safe. These documents are important and contain contact details for emergencies. They also have information on how you can contact the clinical team.

At routine appointments:

- The doctor will ask you how you have been feeling since your last clinic appointment and discuss any concerns you have.
- A repeat blood test and physical examination will usually take place.
- You will normally be sent a record of your consultation shortly after your appointment.

Changing or cancelling your appointment

Check your appointment letter or email for details of how to change or cancel your appointment. If unsure, contact our central booking team on **020 3313 5000** or **email: appointments@imperial.nhs.uk**

When you email, please remember to include your:

- full name
- date of birth
- hospital or NHS number (which can be found on your appointment letter)

Our central booking office is open **08.00 to 20.00, Monday to Friday.**

If your first appointment with us was made through the NHS e-Referral Service (previously known as Choose and Book) call the NHS e-Referral Service appointments line on **034 5608 8888** to reschedule your appointment.

If you **cannot make your appointment** or **want to change your appointment**, please contact us on **020 3313 5000** as soon as possible.

We will do our best to reschedule your appointment as well as offer your existing appointment to another patient. Missed appointments significantly impact on the way we provide our outpatient services, so it is particularly important that you contact us if you are unable to attend.

Inpatient wards

Haemoglobinopathy patients may be admitted to:

Fraser Gamble ward: on the third floor of the Renal Building.

- telephone: 020 3313 4215, 020 3313 4216
- visiting hours: 09.00 to 21.00

Weston ward: on the third floor of the Garry Weston Centre

- telephone: 020 3313 8159, 020 3313 4753
- visiting hours: 09.00 to 22.00

Dacie Ward: on the first floor of the Catherine Lewis Centre

- telephone: 020 3313 3189
- visiting hours: 09.00 to 22.00

Contact the service

If you feel unwell or cannot manage your pain at home, you can call the haematology triage telephone number: **020 3311 7755**.

This line is open **24 hours a day, 7 days a week** for advice.

The triage nurse will assess you over the phone and provide advice and help for how to manage your symptoms.

For out of hours access, you can use the same telephone number, but if you need to be examined or need help with managing your symptoms, we may ask you to come to the Renal and Haematology Triage Unit (RHTU), which is on the ground floor of B Block, Hammersmith Hospital.

Interpretation service

Face-to-face and telephone interpreting services now available

Interpretation services, on call interpreters and translators are now able to take new bookings for face-to-face interpreters. This is in addition to the telephone interpretation service.

To access telephone interpreting, please call **020 3434 3460**, stating the name of our Trust (Imperial College Healthcare NHS Trust) and the language required. You do not need to book in advance for this service and do not require an access code.

Use the same the number if you need face-to-face interpretation services.

Chaplaincy and faith services

We understand that coming to hospital can be a difficult and emotional time for lots of people. If you are facing a time of illness, uncertainty or change you can meet with a member of our friendly chaplaincy team who can provide emotional, pastoral, and spiritual support, as well as a listening ear when you need it most. The team is available from **Monday to Friday, 09.00 to 17.00**. If you would like to speak with a chaplain, please ask a member of staff to contact the team and arrange a time for you.

24/7 emergency chaplaincy service.

The chaplaincy team also provide a 24/7 emergency service for people who are experiencing extreme distress. If you think your need is urgent, please talk to a member of staff and they will contact the on-call chaplain.

Contact details

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| Hammersmith Hospital switchboard | 020 3313 1000 |
| Clinic reception | 020 3313 3297 |
| Day care reception | 020 3313 4594 |
| Apheresis suite | 020 3313 4735 |
| Senior charge nurse (outpatient department) | 020 3313 5099 |
| Dacie ward (including out of hours) | 020 3313 3189 |
| Weston ward (including out of hours) | 020 3313 4753 |
| Fraser Gamble ward (including out of hours) | 020 3313 4215 |
| Lead nurse | 020 3313 5196 |

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| Clinical nurse specialist for haemoglobinopathies/iron chelation | 020 3313 4655 |
| Clinical nurse specialist for haemoglobinopathies (sickle cell thalassaemia etc.) | 020 3313 8553 |
| Clinical psychologist (sickle cell /thalassaemia) | 020 3313 3357 |
| Social worker | 020 3313 7136 |
| Haemoglobinopathies and Haemophilia (Red Cell) Helpline | 020 3311 7755 |
| Outpatient pharmacy – Lloyd's | 020 3313 2360 |
| Main pharmacy | 020 3313 4706 |

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith, and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk