

## Clinical haematology

# Haemoglobinopathy services for adults

## Information for patients, relatives and carers

### Introduction

Haemoglobinopathies are a group of blood disorders including sickle cell disease (SCD) and thalassemia. 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
- community haemoglobinopathy nurse
- clinical psychologists
- phlebotomist
- social worker
- volunteers
- clinical trials team
- cleaning and catering services staff

### Outpatient service

The outpatient department consists of a day care unit which includes an apheresis suite, day pain service for sickle cell patients, outpatient clinics, transfusion service and 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 located on the ground floor of the Catherine Lewis Centre. The service treats patients with cancer and non-cancer conditions who have planned procedures and treatments such as red cell exchange, therapeutic plasma exchange and other procedures such as stem cell collections.

---

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

## Apheresis suite

The apheresis suite is located on the ground floor of the Garry Weston Centre. Procedures undertaken by the apheresis team include 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 runs between **08.30 and 17.00 Monday to Friday**, and is located on the ground floor of the Garry Weston Centre.

## Psychology services

The psychologist is a core member of the haemoglobinopathy team and can provide support to inpatient and outpatients with red cell disorders. The psychologist can help address any concerns you might have about your treatment or about, pain, depression, stress or anxiety, relationships, communication and more, and 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: [imperial.sicklecell.psychology@nhs.net](mailto:imperial.sicklecell.psychology@nhs.net)

## 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 regarding:

- finances
- welfare benefits
- housing
- education/employment
- immigration
- local support/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 additional support and assistance at home can be referred to the adult social services team. If it is identified that a patient is in need of additional support, then hospital staff can make a referral to their local authority adult social care services who will carry out an assessment of their level of need.

## **Discharge**

Hospital staff may make a referral directly to adult social services to provide a package of care upon discharge.

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/co-ordinator. They help with the discharge planning for elderly and disabled inpatients into the community or patients with complex health/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 tell a member of the haemoglobinopathy team if you need further information on immigration.

Other useful sources of support and advice can come from:

[www.lawcentres.org.uk/other-sources-of-advice](http://www.lawcentres.org.uk/other-sources-of-advice)

## **Benefits advice**

### **The income-related benefits**

The specialist social worker can provide haemoglobinopathy patients with advice and information about income-related benefits they may be entitled to, universal credit, housing benefit, council tax support, depending on their circumstances.

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

### **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.

---

## Clinic

The haemoglobinopathy clinic is located on the ground floor of the Catherine Lewis Centre at Hammersmith Hospital and runs every **Thursday from 13.30 to 16.30** and every **Friday 09.30 to 13:00** in St Mary's Hospital's main outpatients. The clinical service is supported by research and diagnostic laboratory services which are based in the hospital. 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.

Patients attending clinic at Hammersmith Hospital should check in by 16.30 or may not be seen by the doctor.

**Adolescent clinic (transition clinic)** is conducted every second Tuesday of the month at St Mary's Hospital, sixth floor, paediatrics outpatients department from **16.30 to 20.00**.

**Joint obstetrics and haematology clinic** runs on Monday mornings (alternate weeks) at De Swiet Obstetric Medicine Centre, second floor, 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 for your clinic appointment. There may be another member of the haemoglobinopathy clinical team that is present during your consultation and we will inform you of this.

If you are attending for your first outpatient appointment in the haemoglobinopathy service, a discussion about your medical history and an examination will take place (such as height, 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; any related complications and give you advice on how you should take care of yourself at home. We will also give you written information on sickle cell disease or thalassemia and provide you with information on support groups and how you can access further advice. On the day of the appointment, you may need to have 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 issued with a haemoglobinopathy card and a haematology passport. Please keep this 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 consultant shortly after your appointment.

---

## Changing or cancelling your appointment

You should 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: [imperial.appointments@nhs.net](mailto:imperial.appointments@nhs.net)**. Please remember to include your hospital or NHS number (which can be found on your appointment letter), your full name and your date of birth in your email. 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 can't make your appointment or want to change it 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 very important that you contact us if you are unable to attend.

## Inpatient wards

Haemoglobinopathy patients may be admitted to:

**Fraser Gamble Ward:** Located on the third floor of the Renal Building.

- Telephone: 020 3313 4215, 020 3313 4216
- Visiting hours: 09.00 to 21.00

**Weston Ward:** Located 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:** Located 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**. The triage nurse will assess you over the telephone and provide advice and help for how to manage your symptoms. We deliver a nurse-led day pain service, from **08.00 to 17.00** to help manage patients experiencing acute pain. This service is located on the ground floor of the Catherine Lewis Centre (near the day unit). For out of hours access, you can still 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) located on the ground floor of the B Block. The telephonic triage line is open **24 hours a day, 7 days a week** for advice.

---

## 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 on call on **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.

If you require face-to-face interpretation services, you should contact the number above.

## 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

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

Clinical nurse specialist for haemoglobinopathies/iron chelation	020 3313 4655
Clinical nurse specialist for haemoglobinopathies (sickle cell thalassaemia etc.)	020 3313 8372
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](mailto: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](mailto: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](mailto:imperial.communications@nhs.net)

## Wi-fi

Wi-fi is available at our Trust. For more information visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)