

The Sickle Cell Disease and Thalassaemia Service (adults and children)

Sickle Cell and Thalassaemia Service

Last reviewed: June 2025

Information for patients

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Keep this leaflet safe so you can look at it again later.

What is a haemoglobinopathy?

A haemoglobinopathy is a disorder of the haemoglobin in red blood cells.

Haemoglobin helps to carry oxygen around the body. It also what gives red blood cells their colour.

The most common haemoglobinopathies are **sickle cell disease** and **thalassaemia**. They are passed down from parents (genetically inherited). It affects mostly (but not only) people whose ancestors come from Africa, the Caribbean, the Middle East, the Mediterranean, India, Pakistan, Bangladesh and Asia.

The Haemoglobinopathies Service

The service offers:

- Information, advice, support and care for people living with sickle cell disease, thalassaemia and related conditions.
- Testing for partners of pregnant women who have unusual haemoglobin. We give counselling for couples at risk of having a child with a major haemoglobin disorder.
- Counselling for parents of babies identified as carriers through newborn screening. .
- Counselling for all carriers of abnormal haemoglobin.
- Guidance and support for parents or carers through the process of diagnosis, planning care and liaising with other health professionals.
- Home visits to offer support and encouragement to patients and families to manage their own care.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

- Information to help families and individuals stay healthy and avoid hospital visits.
- Health care plans for children and young adults in nursery, school or further education.
- Information about regular treatment plans.
- Signposting to organisations for benefits and housing advice.
- Community events with voluntary agencies to raise awareness of haemoglobin disorders.
- Training sessions for health professionals, families, and others about caring for people with haemoglobinopathies.
- We collect data locally and nationally to help us with service improvement.

Outpatient clinics

There are 2 separate clinics, 1 for children and 1 for adults. Both clinics are run by a lead doctor for haemoglobinopathies. Sometimes you may be seen by an experienced specialist registrar or clinical nurse specialist.

We will give you regular follow-up appointments. How often you have an appointment is different from person to person.

The children/young person's clinic is held on Thursdays in the Children's Outpatient Department on Level 1 of the Windsor Building at Leicester Royal Infirmary, or in the Children's Development Centre on the ground floor of the Windsor building. We will tell you where to go before your appointment.

We may take blood samples at the appointment. We will offer local anaesthetic cream/spray for the test.

For a child's appointment: 0116 258 6041

The **adult clinic** is held on Thursday afternoons in the Haematology Outpatient Department on ground floor of the Osborne Building at the Leicester Royal Infirmary.

The **annual review clinic** is held on Tuesday afternoons in the Coleman Centre (near the Maternity Department) at Leicester General Hospital.

We may take blood samples at the appointment.

We have a psychology service specifically for patients with sickle cell disease and thalassaemia. The psychologists are there most weeks at yearly review clinic and attend ward round on Thursday.

If you cannot make the clinic appointment for any reason or need to rearrange please call:

For a child's appointment: 0116 258 6041

For an adult's appointment: 0116 258 6027

The Transition Clinic

This is for young people aged 13 to 18 years old. It is to prepare them to move to adult care. The clinic will help you them to understand their condition. This is so that they can become independent with their health and specific needs.

We begin this process in the clinics in the Children's Outpatient Department on Thursdays. As you get closer to 18 years of age, you will have a joint appointment to meet the Adult Team. They will show you around the adult department. They will give you advice and support if you are planning to leave Leicestershire for University or other reasons.

The Haemoglobinopathies Team

The members of the team are:

- Children's and Adults lead consultants
- East Midlands Haemoglobinopathies Lead Nurse
- Sickle cell and thalassaemia screening clinical nurse specialists
- Children's clinical nurse specialists
- Adult's clinical nurse specialist
- Transition Clinical Nurse Specialist
- A support officer
- Support workers
- A data manager
- Administration team

This service works across Leicestershire, Northamptonshire and Rutland. You can contact the nurses through phone or direct line during office hours.

What should I do if I have a sickle cell crisis?

For children:

If your child is very unwell **call 999** for an ambulance to take you to the nearest emergency department. If your child is unwell with temperature of 38.0 C or above on 2 occasions or if they have a painful crisis that you are unable to manage at home, take them to the nearest children's emergency department.

If your child is unwell and you need non-urgent advice please call your haemoglobinopathy nurse: **call 07958010060** (office hours, Monday to Friday)

If you need out of hours medical advice you can call Ward 27 at the Leicester Royal Infirmary with your child's details: **call 07815646984**. Describe the problem to the staff and they will advise you what to do.

If you or your child needs to stay in hospital, they may be cared for on any of the children's wards. Your haemoglobinopathy nurses will try to review you daily with the pain specialist nurse, if required. Your haematology medical team will be told about your admission.

For adults:

If you have a painful episode or sickle cell crisis, you should take your prescribed painkillers, drink more fluid and keep warm. If the pain continues, you should call:

Haematology Helpline (24 hours a day, 7 days a week)

Phone number: 0808 178 2212

If the nurse or doctor wants you to be seen, they will send you to:

Oncology Haematology Assessment Unit (OHAU) (level 1, Balmoral building)

Monday to Friday from 8.30am to 6pm

Saturday from 8.30am to 4.30pm

OHAU is a short-stay unit. If you need to stay in hospital we will most likely move you to a ward in the Osborne Building (ward 39, 40 or 41).

If you have bad pain, ring the emergency services to come into hospital. Please ask the ambulance crew to ring the Haematology Helpline to see if the Osborne Assessment Unit can take you. If not, you should be taken to A&E.

Blood transfusions

Children: You will come to Ward 27 (Day Care) on Level 4 of the Windsor Building if you need a blood transfusion or red cell exchange. You will need to have a blood test 2 days before any blood transfusion procedure.

Ward 27 day care is open Monday to Friday, 8am to 6pm and Saturday 8am to 4pm.

Adults: You will come to Osborne Treatment Centre on Level 2 of the Osborne Building at the Leicester Royal Infirmary if you need a blood transfusion.

Osborne Treatment Centre is open Monday to Friday, 8.30am to 6pm and Saturday 08.30am to 4pm.

National Haemoglobinopathy Register (NHR)

The National Haemoglobinopathy Registry (NHR) is a private list of patients with red cell disorders like sickle cell disease and thalassaemia living in the UK. The registry helps improve care and service for those living with the condition. Information from the NHR helps get funds to make treatment and care better at your treatment centre. It also helps with healthcare planning, knowing how many patients there are, and researching better treatments.

Your medical information is stored in this database to support your care. The NHR is important for providing care for inherited anaemias across the country. You can talk more about this with your clinical team.

Useful contacts

Ward 27 Day Care (Children), Leicester Royal Infirmary

Phone: 0116 258 7801

Ward 27 (Children) Leicester Royal Infirmary

Phone: 0116 258 5959

Children's Clinical Nurse Specialist

Phone: 07958 010060 / 0116 258 6081

OHAU (Adult)

Phone: 0116 258 6681

Osborne Treatment Centre (Adult)

Phone: 0116 258 5263 / 0116 258 5261

East Midland Planned Care Centre

Phone: 0300 303 1573

Haematology Helpline (Adult)

Phone: 0808 178 2212

Clinical Nurse Specialist (Adult)

Phone: 07950 891490 / 0116 258 6081

Sickle Cell & Thalassaemia Nurse Specialist Office

Phone: 0116 258 6081

Clinic Co-ordinators (For appointments)

Phone: 0116 258 6041(Children)

Phone: 0116 258 6027 (Adults)

UHL Medicines Information

Monday to Friday 8.30 am to 5.30pm
Phone: 0116 258 6491

Phlebotomy room (for adult blood tests)

Ground floor, Osborne Building, Leicester Royal Infirmary

Monday to Thursday 8.30 am to 4.45pm Friday: 8.30am to 12.30pm

East Midlands Sickle Cell and Thalassaemia Network

Website: www.emstn.org

Sickle Cell Society

54 Station Road
London NW10 4UA

Phone: 020 8961 7795

Email: info@sicklecellsociety.org

Website: www.sicklecellsociety.org

UK Thalassaemia Society

19 The Broadway
Southgate Circus
London N14 6PH

Phone: 020 8882 0011
Email: office@ukts.org
Website: www.ukts.org

De Montfort University

Students Disability Advice and Support

Tel: 0116 257 7595 (option 1)

Patient feedback

We are always pleased to hear from you and your carers, about how the service could be improved.

If you feel dissatisfied at any point with the care you have received please speak to a member of the team, so we can help resolve the issue.

Phone: 0116 258 6081 or you can post questions on our website: www.emstn.org on the contact us page.

Questions

If you have any questions write them down and bring them to the hospital to remind you what to ask when you speak to your consultant or nurse specialist.

Patient Information and Liaison Service (PILS)

PILS is a service for patients and relatives. The aim is to provide a confidential listening and support service, and also information about the hospital, services and treatment provided.

If you have any compliments or complaints please contact the PILS service.

Freephone: 0808 178 8337

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk