

The Sickle Cell Disease and Thalassaemia Service

Information for adults and children

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Introduction: What is a haemoglobinopathy?

A haemoglobinopathy is a disorder of the haemoglobin within red blood cells. Haemoglobin gives red blood cells their colour and is the part of the red blood cells responsible for carrying oxygen around the body.

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

Around 80 children and 148 adults are registered at the Leicester Royal Infirmary with a haemoglobinopathy disorder. Most of the children and adults we see have sickle cell disease or thalassaemia major, although a small number of these patients have less common haemoglobinopathies.

Please keep this leaflet safe so that you can refer to it in the future.

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

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

The Haemoglobinopathies Service

The service provides:

- Information, advice, support and care for people living with sickle cell disease, thalassaemia and related conditions.
- Partner testing for antenatal women who are carriers for unusual haemoglobin. We offer haemoglobinopathy counselling to couples found to be 'at risk' of having a child with a major haemoglobin disorder as part of the antenatal screening programme.
- Neonatal haemoglobinopathy counselling to parents of babies identified as carriers through the new-born screening programme.
- Counselling to all carriers of abnormal haemoglobin who have been referred to us, or who refer themselves.
- 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 lead their own care
- Information for families and individuals to ensure they can achieve the optimum health in order to prevent complications and reduce hospital admissions.
- Health care plans for children and young adults in nursery, school or further education diagnosed with health needs that may affect their wellbeing.
- Information about further regular treatment regimes.
- Signposting to organisations regarding benefits and housing advice.
- Community events in collaboration with voluntary agencies to raise awareness of haemoglobin disorders.
- Training sessions for various agencies, health professionals, families and establishments to inform and educate about caring for people with haemoglobinopathies.

We collect data locally and nationally to help us with service improvement.

Haemoglobinopathies Outpatient Clinics

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

We will give you regular follow-up appointments; how often these depend on your individual case.

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.

Blood samples may be taken at the appointment: the child /young person will be offered local anaesthetic cream/spray.

For a child's appointment: 0116 258 6041

Haemoglobinopathies Outpatient Clinics (continued)

The **adult clinic** is held on Thursday afternoons in the Haematology Outpatient Department on Level 0 (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.

Blood samples may be taken at the appointment.

We have a psychology service specifically for patients with sickle cell disease and thalassaemia. The psychologists are present most weeks at clinic.

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

The Transition Clinic is for young people aged 13 to 18. The aim of the clinic is to help them to understand their condition so that they can become responsible for their own health and specific needs and to prepare them to move to adult care.

We begin this process during the clinics in the Children's Outpatient Department on Thursdays. There will be a consultant from the Adult Team at some of the appointments: they will lead the consultations and give you the opportunity to ask questions. As you get closer to 18 years of age, you will meet other members of the Adult Team and be shown around the adult department. We will also 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
- a children's clinical nurse specialist
- an adult's clinical nurse specialist
- a support officer
- a data manager

This service coordinates care, support patients and families and ward staff across Leicestershire, Northamptonshire and Rutland.

The nurses can be contacted via mobile phone or direct line during office hours.

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

For children:

If you or your child are unwell and you need non-urgent advice please call the nurses' office:

Telephone: 0116 258 6081 (office hours, Monday to Friday)

If your child is unwell with temperature of 37.8°C or above on two occasions or if they have a painful crisis that you are unable to manage at home, contact Ward 27 (Leicester Royal Infirmary) with your child's details:

Telephone: 0116 258 5959 . Describe the problem to the staff and they will advise you what to do.

If you or your child need to stay in hospital, you will probably be looked after on ward 27 which is the children's haematology/oncology ward. Sometimes you may be looked after on one of the general paediatric wards but your specialist doctor will still be in charge of your care.

If your child is very unwell dial **999** for an ambulance to take you to the nearest emergency department.

For adults:

If you have a painful episode or sickle cell crisis, you should take your prescribed painkillers, increase the amount of fluid you are drinking and keep warm. If the pain continues, you should ring:

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

Telephone number: **0808 178 2212**

If the nurse or doctor feels you need to be seen, you may be asked to attend:

Osborne Assessment Unit (OAU) (level 1, Osborne Building)

Monday to Friday from 8.30 am to 6pm

Saturday from 8.30am to 4.30pm

OAU is a short-stay unit; if you need to stay in hospital, you will probably be moved to one of the wards in the Osborne Building (39, 40 or 41).

If you are in severe pain and 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 accommodate 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.

Ward 27 (Day Care) is open Monday to Friday from 8.30am to 6pm.

Adults:

You will come to Osborne Day Ward on Level 2 of the Osborne Building at the Leicester Royal Infirmary if you need a blood transfusion.

National Haemoglobinopathy Register (NHR)

The National Haemoglobinopathy Registry (NHR) is a confidential database of patients with red cell disorders including sickle cell disease and thalassaemia living in the UK. The aim of the registry is to improve care and services for people with red cell disorders. Information obtained from the NHR helps to secure funds to develop improvements in treatment and patient care in your treatment centre. The information is also essential for healthcare planning, identifying patient numbers and research into improved treatment.

The storage of your medical information in this database is not optional as its primary use is to support your medical care. The NHR plays a key role in delivering care for inherited anaemias across the country. You can discuss this further with your clinical team.

Useful contacts

Ward 27 Day Care (Children), Leicester Royal Infirmary

Telephone: 0116 258 7801

Ward 27 (Children) Leicester Royal Infirmary

Telephone : 0116 258 5959

Children's Clinical Nurse Specialist

Telephone: 07958 010060 / 0116 258 6081

Osborne Assessment Unit (Adult)

Telephone: 0116 258 6681

Osborne Day Ward (Adult)

Telephone: 0116 258 5263 / 0116 258 5261

Haematology Helpline (Adult)

Telephone: 0808 178 2212

Clinical Nurse Specialist (Adult)

Telephone: 07950 891490 / 0116 258 6081

Sickle Cell & Thalassaemia Nurse Specialist Office Telephone: 0116 258 6081

Clinic Co-ordinators (For appointments) Telephone: 0116 258 6041(Children)

Telephone: 0116 258 6027 (Adults)

UHL Medicines Information

(Monday to Friday 8.30 am to 5.30 pm)

Telephone : 0116 258 6491

Phlebotomy room (for 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

Useful contacts (continued)

Sickle Cell Society

54 Station Road
London NW10 4UA

Telephone: 020 8961 7795

Email: info@sicklecellsociety.org

Website: www.sicklecellsociety.org

UK Thalassaemia Society

19 The Broadway
Southgate Circus
London N14 6PH

Telephone: 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.

Telephone: 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

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



Leicester's Hospitals is a research active trust so you may find research is happening on your ward or in your clinic.

To find out more about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit www.leicestersresearch.nhs.uk/patient-and-public-involvement