

**The Sickle Cell and Thalassaemia Service
For Adults and Young People**
Information sheet

Introduction

The catchment area of University Hospital Lewisham has a population of great ethnic diversity and there is a high prevalence of Sickle Cell Disease. They are looked after by the Haemoglobinopathy department at the hospital. The Department also cares for people with Thalassaemia major.

The children's Sickle Cell and Thalassaemia service is expanding rapidly and children transfer to the adult services when they are sixteen. This means that patient numbers are increasing steadily in the adult service, both as a result of the transfer process and because of population migration.

Emergency admissions

Emergency admissions are usually via the Acute Medical team, who will work with the Haematology team to look after the patients. The Haematology team will take over the care of some of the patients the day after admission, particularly those whose condition is not responding so well to treatment. The Clinical Nurse Specialist is a key member of the Haematology team.

A doctor from the Haematology team will see all admitted patients the following day at the latest, or urgently the same day depending on your condition.

Please make sure that your admitting team tell the Haematology team that you are in hospital, even if you are doing well!

Patients with Sickle Cell Disease or Thalassaemia who require an emergency admission are usually admitted to Chestnut ward first of all (ext: 8815), and then transferred to Laurel ward if they will be staying longer (ext: 3777/8755). Sometimes, you may be admitted to another ward. Visiting times are 3-8pm.

The Clinical Nurse Specialist monitors both ward and A&E attendance of the Sickle Cell patients and plans any necessary care. They work with the Haematology team and the Community Haemoglobinopathy team, so you may hear from us if you have recently come to A&E.

Clinics

There is a weekly Sickle Cell Disease and Thalassaemia clinic on most Wednesday afternoons in Suite 4 from 2 – 5.30pm. This is a follow-up clinic where hospital staff and the Community Haemoglobinopathy team meet with you. You will discuss your long term care and any medical problems will be addressed.

Hydroxycarbamide, transfusion therapy and treatments for iron overload are monitored in this clinic and other routine care is also given, including Annual Review.

The Transition Clinic is designed for young people reaching the age of 16 who are ready to move to the adult services. This also takes place on a Wednesday afternoon in Suite 4 from 2 – 5.30pm once every three months. Clinical staff from both adult and children's teams meet the patients and their families.

Other new patients are seen in Suite 8 for their first visit, in a general New Patient clinic where patients with other conditions are also seen. You will be transferred to the Sickle Cell Disease and Thalassaemia Clinic for your next appointment.

It is likely that you will have been given a form to have a blood sample taken before your clinic appointment. This takes place in Suite 1, which is open 8am to 4.30pm Monday to Friday.

Patients who need blood transfusions, including routine exchange transfusion, receive their treatment in Suite 8, which is open 9.30am to 5pm Monday to Friday. Suite 8 contact numbers are extension 8601 (Reception) or extension 8521 (Nurses Station).

Contact Details

If you need to change your appointment, please telephone between 9am – 5pm, Monday to Friday.

Haematology Secretaries on 020 3192 6199, or

Clinical Nurse Specialist on 020 8333 3000 ext 8662

You may need to leave a message, and someone will get back to you as soon as possible the same day.

If you need help or advice within working hours, please telephone the Clinical Specialist Nurse on 020 8333 3000 ext. 8662.

If you wish to contact the Community Clinical Nurse Specialist . Please telephone 020 3049 6184 and ask for Ms Emma Gedeon.

If you are feeling unwell, particularly out of hours, please come to the A&E Department or telephone 020 8333 3000 and ask to speak to the Haematology

Specialist Registrar for advice. They can be contacted at any time and have access to a Consultant Haematologist.

Staff

- Three Consultant Haematologists who provide expert care and advice. They are Dr Yeghen (your consultant), Dr Mir and Dr Thanigaikumar.
Telephone: 020 3192 6199
- Dr Sleight, Consultant Paediatrician, who is involved in the Transition Clinic only
- The Clinical Specialist Nurse, Mrs Marian Bonsu, on extension 8662/bleep 7021.. Ms Comfort Lafa covers some of duties in her absence, and can be found on the same extension.
- The Community Clinical Nurse Specialist, Ms Emma Gedeon on 020 3049 6184/ or 07919575720.

If you have any concerns

Please discuss the problem with a doctor or nurse from the Sickle Cell and Thalassaemia team in the first instance.

Alternatively, you can contact the Patients and Public Liaison service (PALS) on 020 8333 3355.

If you wish to get involved in improving the service, please talk to your consultant or Specialist Nurse with your suggestions, and make sure you complete your yearly patient satisfaction survey.

Useful websites

Sickle Cell Society UK - www.sicklecellsociety.org

South Thames Sickle Cell and Thalassaemia Network - <http://www.stsn.co.uk/>

BBC-Health sickle cell anaemia-www.bbc.co.uk/health/physical-health/conditions/sicklecell1.shtml

Patient UK -

Sickle cell disease & sickle cell anaemia (Resources) www.patient.co.uk/health/sickle-cell-disease

Thalassaemia - www.patient.co.uk/health/thalassaemia

NHS Choices – www.nhs.net/conditions/sickle-cell-anaemia/

NHS sickle cell & Thalassaemia screening programme-<http://sct.screening.nhs.uk>

Sickle Cell Thalassaemia Patient's Network- www.sctpn.net

Living with Sickle Cell Disease

Three peoples' stories. Type in 'genetic conditions', then select 'sickle cell' www.tellingstories.nhs.uk/

UK Thalassaemia society - www.ukts.org

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If you would like this information in another language or format including Braille, large print, audio tape or computer disc contact PALS on 020 8333 3355 or e-mail pals.lewisham@nhs.net

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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