

Sickle Cell and Thalassaemia Service

Children's Community Nursing Service



Introduction

A service for everybody with Sickle Cell or Thalassaemia, their family, carers, partners and friends. This includes those with Sickle Cell trait or Thalassaemia trait.

What is Sickle Cell?

Sickle Cell Anaemia is an inherited blood disorder. Haemoglobin (Hb) is found in red blood cells and carries oxygen from the lungs to all parts of the body.

It is haemoglobin that gives blood its red colour. A red blood cell is normally round, flexible and 'doughnut'-shaped:

Under certain conditions, such as dehydration or infection, some normal red cells can change shape, becoming more like a farmer's sickle:

These 'sickled' red cells do not flow as easily and can get trapped in small blood vessels. This can cause great pain in the affected area, such as an arm, leg or hip. We call this 'crisis'.

Sickle cell disorders are mainly found in people whose families come from Africa, the West Indies, the Eastern Mediterranean, Middle East and Asia.

What is Thalassaemia?

Thalassaemia is also an inherited disorder of the haemoglobin. Thalassaemia patients fail to make haemoglobin properly, resulting in severe anaemia. People with Thalassaemia need monthly blood transfusions for life. It mainly affects people of Mediterranean, Asian or African origin.

What is a carrier?

A carrier is a healthy person who carries an unusual haemoglobin (sometimes called a 'trait') such as Sickle Cell or Thalassaemia. They will have inherited this from one of their parents. They often do not know that they are carriers.

It is not an illness, is not infectious and these people will not go on to develop the illness. However, if both parents are carriers of an unusual haemoglobin, there is a one in four (25%) chance of their child having Sickle Cell or Thalassaemia. One in 1000 of the caucasian population carry Sickle Cell or Thalassaemia

How do I know if I am a carrier? If you, your parents or grandparents are from the 'at risk' group, it is important that you are tested. You can have the test at any age, but it is particularly important :

- before any surgery
- before starting a family
- before dental surgery.

You can see your GP for a blood test for you and your partner, or the local Nurse Specialist for Haemoglobinopathies can find out your haemoglobin (Hb) type.

Contact details for the local Nurse Specialist for Haemoglobinopathies are on the back of this leaflet.

What are the specialist services available?

We can help you to get:

- Specialist information and advice about Sickle Cell and Thalassaemia conditions.
- Pre-natal, ante-natal and neo-natal screening.
- Counselling and support services for those affected by Sickle Cell and Thalassaemia.
- Home visits to assess and address individual needs.
- Health information to help to maintain the best state of health and reduce hospital admission.
- Links between hospital, community services and home.

We can also help you to access other services such as:

- GPs
- District Nurses
- Practice Nurses
- School Nurses
- Health Visitors
- Social Services
- Physiotherapy
- Local Treatment Centres
- Counselling Service
- Voluntary Service
- Dietitian
- Hospital Services
- Psychology Services

For further information about this service contact:

Community Nurse Specialist for Haemoglobinopathies
The Poynt
2-4 Poynters Road
Luton, LU4 0LA

Tel: 0333 405 0079

If you require this information in a different format such as in large print or on audio tape, or in a different language please contact the service on the details above.

If you have any compliments about this service or suggestions for improvements, contact our Patient Advice and Liaison Service on 0300 131 1000 (charges may apply depending on your network) or email: ccs-tr.pals@nhs.net.

For free, confidential health advice and information 24 hours a day, 365 days a year please contact NHS 111.