

# Manchester Sickle Cell & Thalassaemia Centre

Information for patients and carers on our service and team



# Introducing our service

**We are the community sickle cell and thalassaemia team for Manchester. We are based at the Sickle Cell and Thalassaemia Centre on Oxford Road. We also provide services out in the community.**

Our team is made up of experienced, qualified nurses, midwives and other expert staff. Our staff have undergone specialist training to specialise in sickle cell and thalassaemia disorders.

## What we do

We help anyone with sickle cell or thalassaemia. We provide screening and counselling during pregnancy and then care through birth, into childhood and as adults.

Our service is free and confidential. We aim to provide the very best information to support informed choice. Interpreters are provided as required.

Our services are run from the centre but we also provide home visits and other services in the community.

We are a non-emergency service but will refer emergency cases to the acute (hospital) team. We work closely with the hospital team to coordinate our patients' care.

## Who provides this service?

This service is provided by Manchester Local Care Organisation (MLCO) who are the team who provide NHS community services in Manchester. You can find out more about MLCO at [www.manchesterlco.org](http://www.manchesterlco.org)

# What is Sickle Cell Disease?

**Sickle cell disease is the name for a group of inherited health conditions that affect the red blood cells. The most serious type is called sickle cell anaemia.**

Sickle cell disease is particularly common in people with an African or Caribbean family background.

People with sickle cell disease produce unusually shaped red blood cells that can cause problems because they do not live as long as healthy blood cells and can block blood vessels.

Sickle cell disease is a serious and lifelong health condition, although treatment can help manage many of the symptoms.

## Symptoms of sickle cell disease

People born with sickle cell disease tend to have problems from early childhood, although some children have few symptoms and lead normal lives most of the time.

### **The main symptoms of sickle cell disease are:**

- painful episodes called sickle cell crises, which can be very severe and last for days or weeks
- an increased risk of serious infections
- anaemia (where red blood cells cannot carry enough oxygen around the body), which can cause tiredness and shortness of breath.

*[Information from nhs.uk - 2024]*

# What is Thalassaemia?

**Thalassaemia is the name for a group of inherited conditions that affect a substance in the blood called haemoglobin.**

People with thalassaemia produce either no or too little haemoglobin, which is used by red blood cells to carry oxygen around the body.

It mainly affects people of Mediterranean, south Asian, southeast Asian and Middle Eastern origin.

There are different types of thalassaemia, which can be divided into alpha and beta thalassaemias. Beta thalassaemia major is the most severe type.

## Symptoms of thalassaemia include

Most people born with thalassaemia experience health problems from a few months after birth. The main health conditions associated with thalassaemia are:

- anaemia – severe tiredness, weakness, shortness of breath, irregular heartbeats (palpitations) and pale skin caused by the lack of haemoglobin
- too much iron in the body – this is caused by the regular blood transfusions used to treat anaemia and can cause problems with the heart, liver and hormone levels.

With regular treatment and observations these conditions can be managed.

*[Information from nhs.uk - 2024]*

# The services we provide

We are here to support people with sickle cell and thalassaemia. We develop **care plans** to help patients manage their condition. We work to involve our patients in developing their own personalised plan so they can best support themselves to manage their condition.

## Other key services we provide include:

- **Genetic counselling** - for couples at risk of having a child with a haemoglobinopathy disorder such as Sickle Cell or Thalassaemia. That includes advice on blood testing services when planning a family
- **General support, counselling and education** - for those affected by these conditions including children, as well as their families and carers
- **Education/ training** - for health care professionals and other agencies such as schools, so they are aware of sickle cell and thalassaemia
- **Supporting letters and information** - for employers, schools and colleges on reasonable adjustments that we feel would be beneficial for individuals. We can also provide these for patients wishing to apply for things such as benefits.

We work closely with Hospitals, other community services, primary care (GPs), local authorities (councils) and voluntary sectors, as well as other local and national specialist services.

# Our team

Our friendly team of expert staff have specialist training and experience in sickle cell and thalassaemia.

Our team include:

- **Service Manager**
- **Specialist Midwives**
- **Specialist Nurse Counsellors for Adults**
- **Specialist Nurse Counsellors for Paediatrics**
- **Paediatric Homecare Practitioners**
- **Senior Administrator**
- **Antenatal and Newborn Failsafe Officer.**

Each member of the team plays a key role in helping us provide the service that our patients need.

We can make referrals to adult and paediatric haemoglobinopathy, social workers & clinical psychologists on request

## How can you refer to our service?

You can be referred to us in several ways including by:

- Health care professional referral (a GP, nurse or hospital doctor)
- Self-referral by contacting us directly
- Family/carer referral.

Please call us by using the number on the back of this booklet. We can talk to you and tell you about our services.

# Useful links and information

We work closely with a wide range of organisations to give our patients the support they need. Here are some useful links that you may find useful.

## **Our own webpage**

Find useful contact information for the centre.

[www.manchesterlco.org/msctc](http://www.manchesterlco.org/msctc)

## **Sickle Cell Care Manchester**

Local charity and support group offering advice, advocacy, support and other useful information.

[www.sicklecellcaremanchester.co.uk](http://www.sicklecellcaremanchester.co.uk)

## **CAHN - Caribbean & African Health Network**

Play a role in working to prevent health inequalities in the city as part of the Manchester community.

[www.cahn.org.uk](http://www.cahn.org.uk)

## **NEBATA North of England Bone Marrow & Thalassaemia Association**

Providing support for people living with Thalassaemia.

**0161 273 7200**

## **Sickle Cell Society**

Supports and represents people affected by sickle cell disorder to improve their overall quality of life.

[www.sicklecellsociety.org](http://www.sicklecellsociety.org)

## **UK Thalassaemia Society**

Provide support to people with thalassaemia with a wide range of information and advice.

[www.ukts.org](http://www.ukts.org)

## **NHS.UK**

Accredited information by the official NHS website.

[www.nhs.uk/conditions/sickle-cell-disease](http://www.nhs.uk/conditions/sickle-cell-disease)

[www.nhs.uk/conditions/thalassaemia](http://www.nhs.uk/conditions/thalassaemia)

# Contacting the team

## Address



**352 Oxford Road**  
Manchester M13 9NL  
(Entrance in on Denmark Road)



We are just opposite the main central Manchester hospital site on Oxford Road.

## Phone



**0161 529 6605 (Mon to Fri, 9am to 5pm)**

Alternatively, if you need advice and we are not available, you can call the Haematology nurses (based at the central hospitals) on:

- Adult Haematology - 07971 037 242 or 0161 701 4574
- Paediatric (Children's) Haematology - 0161 701 8444.

In an emergency please call NHS 111 or 999.

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## Compliments, feedback and concerns

If you have any suggestions, comments or concerns about the services you receive please contact the service manager. If you want independent advice, the Patient Advice and Liaison Service (PALS) team are here to help to liaise with the relevant staff to sort out any problems quickly.

- Email: **pals@mft.nhs.uk**
- Telephone: **0161 276 8686**