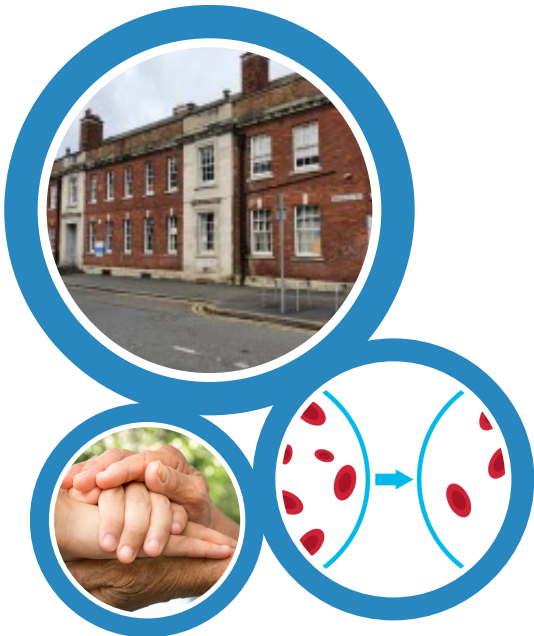


Information about beta thalassaemia trait

Manchester Sickle Cell &
Thalassaemia Centre



Introduction

This leaflet is for people who have just learnt that they, or someone they know, have beta thalassaemia trait.

Many things might be going through your mind. What does it mean? Does it make me different from other people? Is it dangerous?

Do not get worried. Your beta thalassaemia trait does not affect your own health. However, it could affect the health of your children. This is why it is important to know about the trait and what it means.

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.

Anyone can be a carrier of thalassaemia, but it's much more common in people from certain ethnic backgrounds.

Thalassaemia mainly affects people who are from, or who have family members originally from:

- around the Mediterranean, including Italy, Greece and Cyprus
- India, Pakistan and Bangladesh
- the Middle East
- China and southeast Asia.

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

The two types of beta thalassaemia

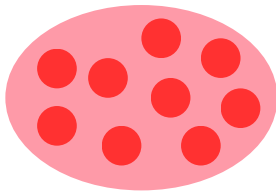
There are two types of beta thalassaemia.

1. Beta thalassaemia trait - also known as beta thalassaemia minor

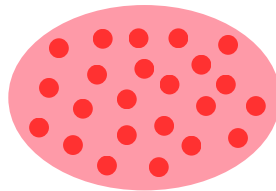
People with beta thalassaemia trait will not ever develop thalassaemia themselves and are healthy. They may sometimes experience mild anaemia. This is because their red blood cells are smaller than usual (see diagram below). This type of anaemia is different from iron deficiency anaemia and does not need any treatment.

Beta thalassaemia trait can only be diagnosed by a special blood test.

Diagram showing the difference between normal blood cells and beta thalassaemia trait red cells



Normal red blood cells



Beta thalassaemia trait red cells

2. Beta thalassaemia major

Children who are born with beta thalassaemia major can not make enough haemoglobin in their blood. Haemoglobin is the red pigment in the blood which carries oxygen around the body.

As a result they become severely anaemic and need regular blood transfusions along with other special treatment.

Can beta thalassaemia trait (minor) develop into beta thalassaemia major?

No. Thalassaemia is an inherited condition handed on from both parents to children. In other words it is a genetic disorder.

If a person is born with the trait it can not develop into thalassaemia major.

However, individuals with the trait will not outgrow the trait. It is something you have for life.

If I have beta thalassaemia trait (minor) how does it affect my children?

The genetic make-up of your child is inherited equally from you and your partner.

If you have the thalassaemia trait, you're at risk of having children with thalassaemia if your partner is also a carrier or has thalassaemia themselves.

If you're planning to have a child and you know you're a carrier, it's a good idea for your partner to be tested as well.

If you and your partner both have the trait for the main type of thalassaemia (beta thalassaemia), there is:

- **a 25% (1 in 4) chance each child you have will not have thalassaemia or carry the thalassaemia trait**
- **a 50% (1 in 2) chance each child you have will be a carrier of thalassaemia, but will not have the condition themselves**
- **a 25% (1 in 4) chance each child you have will be born with thalassaemia.**

That is why it is advisable that both you and your partner are tested and get expert advice.

Testing for the thalassaemia trait

Screening for thalassaemia is offered to all pregnant women in England.

Alternatively, anyone can ask to have a free test to find out if they're a carrier at any point.

The centre can carry out the blood test (see information on the back page for how to contact us) or you can ask your GP.

What should I do if my partner has beta thalassaemia (minor) trait as well?

If both of you are carriers and you're planning to have a baby you can talk to your GP, or our staff at the centre, about getting a referral to a genetic counsellor.

Counselling will provide you with information, options and support.

These include:

- having tests during pregnancy to see if your baby has thalassaemia
- adoption
- trying in vitro fertilisation (IVF) with a donor egg or sperm
- other genetic tests and options.

Useful links and further information

This leaflet just gives an overview of thalassaemia beta trait. Here are some useful links to sources of information on the trait and related topics that you may find useful.

Our own webpage

Find useful contact information for the centre.

www.manchesterlco.org/msctc

NEBATA North of England Bone Marrow & Thalassaemia Association

Providing support for people living with Thalassaemia.

0161 273 7200

UK Thalassaemia Society

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

www.ukts.org

NHS.UK

Accredited information by the official NHS website.

www.nhs.uk/conditions/thalassaemia

How we can help

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. We are part of Manchester Local Care Organisation which is the organisation that provides NHS community services in the city.

We can provide appointments for a blood test, counselling or general advice by contacting us. You can contact us directly.

Contacting the team

Phone



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

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.