

Information about Beta Thalassaemia

Information and advice for patients, carriers and relatives

Sickle cell and Thalassaemia Centre

Many people originating from the Mediterranean area, the Middle East, Africa or Asia carry Thalassaemia. It is common in these regions because it helps to protect carriers against some types of malaria. It is rare in northern Europeans.

What is thalassaemia?

Thalassaemia is a genetic blood disorder caused by the haemoglobin, a substance that carries oxygen around your body, not being made properly. The gene for thalassaemia is passed on from parents to their children through genes, just like eye colour and hair colour are. If both parents are carriers, they are equally likely to pass it on. Moreover, as it is a genetic condition, you can't catch it and carriers will have not become ill as a result of it. There are two forms of thalassaemia:

- Alpha thalassaemia (please see the leaflet on alpha thalassaemia)
- Beta thalassaemia

What does it mean to carry a gene for beta thalassaemia?

Carrying a gene for beta thalassaemia does not cause any symptoms. Many people who carry beta thalassaemia do not know that they have it and may discover it when they have a special blood test. Carrying the gene can result in the carrier passing it onto their children. If the carrier's partner is also a carrier of the gene, this may result in their children having beta thalassaemia. There are two types of Beta thalassaemia:

- Beta thalassaemia major
- Beta thalassaemia intermedia

Beta thalassaemia Major

What is beta thalassaemia major (BTM)?

BTM is a severe form of beta thalassaemia. People with BTM will need blood transfusions to provide them with haemoglobin. They will need these regularly throughout their lives. Without transfusions every few weeks, children diagnosed with thalassaemia major would usually die by age 7 due to the effects of severe anaemia on the body. They will also need medicines for all their lives to help their bodies to control the amount of iron in the blood.

Beta Thalassaemia Intermedia

What is beta thalassaemia intermedia (BTI)?

BTI is a mild form of beta thalassaemia. BTI affects different patients in different ways: for some it only causes mild anaemia whereas others may need regular transfusions or even transfusions at certain times such as if they are unwell or have infections during pregnancy or when they have operations. People with BTI will need regular haemoglobin checks. If regular blood transfusions are required with BTI then monitoring and medications to help the body manage iron is required. Without treatment the iron will build up in the body. Some patients, who do not have blood transfusions, can have excess iron because their body may struggle to process iron in the normal way, there are other treatments you can discuss with your team.

What are the symptoms of beta thalassaemia?

Most of the time there are no symptoms, however over time some patients may experience some of the symptoms below:

- Fatigue or shortness of breath (especially leading up to a transfusion) are very common
- Gallstones are common.
- Mild jaundice or the liver and the spleen may be enlarged in some patients
- Bone abnormalities and bone pain. Patients can experience enlargement of their cheek bones, foreheads, and other bones.
- Poor growth may occur (as a result of low haemoglobin and reduced ability of the blood to carry oxygen to the body).

It is important to remember that carriers will have no symptoms.

Is there anything else I should do now?

If you are a carrier

As beta thalassaemia is inherited and you are aware that you are a carrier, it is important to advise your siblings and other blood relatives to make sure they are tested before they have children. This is more so the case if you have ancestry which reaches into the regions that have been mentioned in this leaflet.

If you are unsure whether you are a carrier

If you have ancestry which reaches into the regions that have been mentioned in this leaflet or if you have a blood relative that has beta thalassaemia or is a carrier of the gene, go and see your GP. Your GP can arrange further information and tests for you when necessary, through your local consultant haematologist, or a specialist centre.

If your partner is unsure of whether he or she is a carrier of beta thalassaemia, you should advise him or her to have a blood test before you have children. If your partner does not have any type of thalassaemia, there is no risk for your children and you have nothing to worry about. But if your partner's blood test result shows any unusual finding which might be associated with thalassaemia, you should ask your GP to refer you to a specialist in haemoglobin disorders for advice.

How to contact the SCAT centre

If you have any questions or concerns, please contact the Sickle Cell and Thalassaemia Centre.

Sickle cell and Thalassaemia Centre

C3, 3rd Floor
Midland Metropolitan University Hospital (MMUH)
Grove Lane
Smethwick
B66 2QT

Telephone: 0121 507 6040

Opening Hours

Monday, 9am – 5pm
Tuesday, 9am – 6pm
Wednesday, 9am – 5pm
Thursday, 9am – 5pm
Friday, 9am – 4pm

Saturday blood transfusion service only

The information in this leaflet is general and is intended to be a guide only. Please discuss the specific details of your treatment with your GP/doctor.

More information

For more information please see our regional website:

www.westmidsstn.nhs.uk

For more information about our hospitals and services

Sandwell and West Birmingham Hospitals NHS Trust; website www.swbh.nhs.uk you can also follow us on X @SWBHnhs and like us on facebook www.facebook.com/SWBHnhs.

OSCAR

Organisation for sickle cell and anaemia research and thalassaemia support (OSCAR)

Birmingham: www.oscarbirmingham.org

Sandwell: www.oscarsandwell.org.uk

UK Thalassaemia Society 19 The Broadway, Southgate Circus, London, N14 6PH. Telephone: 020 8882 0011. office@ukts.org

Thalassaemia International Federation, PO Box 28807, 2083 Acropolis – Strovolos, Nicosia, Cyprus. www.thalassaemia.org.cy

For more information about sickle cell disease and the support available to you, visit the sickle cell society website:

www.sicklecellsociety.org

You can also read more about sickle cell disease on the NHS Choices website: NHS Choices: www.nhs.uk/conditions/sickle-cell-anaemia

Sources used for the information in this leaflet

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United Kingdom Thalassaemia Society (2023). *Standards for the clinical care of children and adults with Thalassaemia in the UK*. (Online). 4th ed. London: UKTS Available at: <https://ukts.org/3d-flip-book/standards-for-the-clinical-care-of-children-and-adults-living-with-thalassaemia-in-the-uk-4th-edition-2023/> [Accessed 29th May 2024].

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