Introduction to beta thalassaemia

Information and advice for patients, carriers and relatives

Sickle Cell & 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 our 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 thalassemia 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

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or when they have operations. People with BTI will need regular haemoglobin checks. If regular blood transfusions. in Some cases, transfusions may be needed at certain times such as if they:

- Are unwell
- Have infections during pregnancy
- Have surgery

People with BTI will need regular haemoglobin checks. To help the body manage iron levels appropriately, you may require regular blood transfusions which we will monitor for you

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

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be associated with thalassaemia, you should ask either of your GPs to refer you both to a specialist in haemoglobin disorders for advice.

Contact details

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

Sickle Cell & Thalassaemia Centre
Sandwell & West Birmingham Hospitals
City Hospital
Dudley Road
Birmingham
B18 7QH

Tel: 0121 507 6040

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

For further information

Birmingham Sickle Cell & Thalassaemia Service
Soho Health Centre
247-251 Soho Road Handsworth
Birmingham B20 9RY
0121 545 1655
bchc.sicklecellresults@nhs.net

The UK Thalassaemia Society
19 The Broadway
Southgate Circus
London, N14 6PH
Tel: 0208 882 0011
www.ukts.org

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

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For more information about our hospitals and services please see our websites *www.swbh.nhs.uk* and *www.swbhengage.com*, follow us on Twitter *@SWBHnhs* and like us on Facebook *www.facebook.com/SWBHnhs*.

Sources used for the information in this leaflet

- I Okpala and AD Stephens, Oxford: Blackwell, 'Practical Management of Haemoglobinopathies – The genetics and multiple phenotypes of beta thalassaemia', 2004.
- Brent Sickle Cell & Thalassaemia Centre, 'Interpreting common haemoglobinopathy test results – a guide for primary health care professionals,' 2010.

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5495 or email: **swb-tr.swbh-gm-patient-information@nhs.net**

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