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Information for people who carry Alpha Thalassaemia

Information and advice for patients

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.

What is thalassaemia?

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

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

What does it mean to carry alpha thalassaemia?

Carrying alpha thalassaemia does not cause any illness. Most people who carry alpha thalassaemia do not know that they have it. They only discover it when they have a special blood test. However, if your partner also carries alpha thalassaemia, there is a chance that this will affect your children. There are two types of alpha thalassaemia:

- Alpha plus thalassemia which has no serious effects.
- Alpha zero thalassaemia which may have more serious complications.

Alpha Plus Thalassemia

Alpha plus thalassemia can come in two forms, you may be a carrier of the gene (where you have no symptoms) or you may have the genetic condition. If you have alpha plus thalassemia, you may find that you have some form of anaemia, which can be treated. Despite this, it has been found that both carriers and sufferers of alpha plus thalassemia live normal lives.

Who is likely to carry the alpha plus thalassaemia gene?

If you or either of your parents, grand¬parents, or even if any of your ances¬tors originally come from any of the countries that are listed below, there is a chance that you may carry the alpha plus thalassaemia gene:

- Africa (this includes African Caribbean's, unless they have some Chinese ancestry)
- South Asia (In¬dia, Pakistan, Bangladesh)

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About 1 in 3 people originating from Africa or the Indian subcontinent carry alpha plus thalassaemia. It is normal for people whose ancestors come from these areas to carry mild alpha thalassaemia, so you should not worry about it.

What does it mean to be a carrier of alpha plus thalassemia?

Carrying the gene for alpha plus thalassaemia does not cause any illness, however it may have an effect on your children's lives. If both parents are carriers for the alpha plus thalassaemia gene, your child may be normal (this is where your child does not have the gene) or a carrier of the gene or may have a form of anaemia.

If you are a carrier of the gene and your partner is not, your child will either be normal or a carrier of the gene.

How is knowing that I am a carrier of the alpha plus thalassaemia gene useful to me?

It is useful for you to know that you have alpha plus thalassaemia because when you have a blood test as doctors may think you carry a more serious form of thalassaemia; this could worry you unnecessarily.

Your alpha thalassaemia may also be mistaken for iron deficiency. In this case, iron deficiency can be diagnosed only by measuring your serum iron (ferritin) level, which is done by a blood test.

Alpha Zero Thalassaemia

Alpha zero thalassemia can have different effects depending on what genes you have inherited. You may be a carrier of the gene (where you have no symptoms) or you may have anaemia (which can be treated) or, in some rare cases, it can lead to the birth of a stillborn baby.

Who is likely to carry the alpha zero thalassaemia gene?

If you or either of your parents, grand¬parents, or even if any of your ances¬tors originally come from any of the countries that are listed below, there is a chance that you may carry the alpha zero thalassaemia gene:

- South East Asia (particularly Thailand, Vietnam, Cambodia, the Philippines)
- China (this includes people of Chinese origin from Hong Kong, Singapore, Malaysia, Indonesia)
- The Mediterranean area (including Cyprus, Greece, Turkey, Southern Italy)

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- The Middle East
- Northern Europe

What are the effects of alpha zero thalassaemia?

Carrying the gene for alpha zero thalassaemia does not cause any illness. Depending on whether or not your partner has alpha thalassaemia and what type it is, this may have an effect on your children's lives:

- If your partner is not a carrier of the alpha zero thalassaemia, your children may be normal (this is where the alpha zero thalassaemia gene is not passed on).
- If both parents carry alpha zero thalassaemia genes or if your partner is a carrier for alpha plus thalassaemia, your children could be normal or could have anaemia or could become carriers for alpha thalassaemia. In some rare cases, not survive for very long after birth (this is due to a condition called Hb Barts hydrops). The chance of each depends on you and your partner's genes. If your unborn baby has been tested for thalassaemia and it is likely that he or she will have Hb Barts hydrops, you will be given further advice on what you can do.

Is there anything else I should do now?

As alpha 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 your partner is unsure of whether he or she has alpha 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.

If you are not sure what type of alpha thalassaemia you carry and you need to find out, go and see your GP and take this information with you. Your GP can arrange further information and tests for you when necessary, through your local consultant haematologist, or a specialist centre.

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Contact details

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

Sickle Cell & Thalassaemia Centre
Sandwell & West Birmingham NHS Trust
City Hospital
Dudley Road
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Opening hours
Monday, 9am – 4pm
Tuesday, 9am – 6pm
Wednesday, Thursday and Friday, 9am – 5pm
Saturday blood transfusion service only

For further information

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Nineveh House,
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Handsworth,
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B21 0SY
Tel: 0121 466 3667
bchc.sicklecellresults@nhs.net

The UK Thalassaemia Society
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Southgate Circus
London, N14 6PH
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For more information about our hospitals and services please see our website *www.swbh.nhs.uk*, follow us on Twitter *@SWBHnhs* and like us on Facebook *www.facebook.com/SWBHnhs*.

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Sources used for the information in this leaflet:

- Okpala, I. (Ed.). (2004). *Practical management of haemoglobinopathies*. Oxford,, UK: Blackwell.
- United Kingdom Thalassaemia Society (UKTS), (2016). Standards for the clinical care of children and adults with Thalassaemia in the UK. 3rd Edition. Available at: *https://ukts.org/wp-content/uploads/2019/12/Standards-2016final.pdf* (Accessed: 14 August 2020).

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