Your blood test results show you may be a carrier of beta thalassaemia

Introduction

This leaflet is for women who have had a test for sickle cell and thalassaemia in pregnancy and have been told that they may be **a beta thalassaemia carrier** (also known as having a possible beta thalassaemia trait).

Key messages

As we are not sure if you are a beta thalassaemia carrier, we have written this leaflet **as if you are a beta thalassaemia carrier**.

- Being a beta thalassaemia carrier would not normally cause you any health problems.
- It can be passed to your children and this is why it is important to be aware you may be a carrier.
- We recommend the biological father of your baby is tested (see page 4).

What your blood test has shown

Your test result is written as: **possible beta thalassaemia carrier.** The test report will say that further studies are being carried out so that you will get a definite diagnosis and will also recommend that the biological father of your **baby is tested.**

Your recent blood test has shown:

- your red blood cells are smaller than expected; or
- your red blood cells are of the usual size and a further test done at the same time shows you could be a beta thalassaemia carrier but the result is not definite.

Smaller red blood cells are usually caused by a lack of iron in your blood (iron deficiency), which is the most common cause of anaemia. The blood test that is done during your pregnancy checks your ferritin levels and this helps decide if you are iron-deficient. For someone who is healthy and has enough iron, one of the most likely explanations for the blood test result is that the person is a beta thalassaemia carrier.

What is beta thalassaemia?

Beta thalassaemia is one of many possible variations in your blood, called haemoglobin gene variants, that can be passed on from parent to child. For most characteristics that you inherit, you get one gene from your biological mother and one gene from your biological father. For example, your genes control the colour of your skin, hair and eyes. Your genes also control the type of haemoglobin you inherit.

A beta thalassaemia carrier inherits the usual beta globin gene from one parent and an altered beta globin gene, which makes little or no haemoglobin, from the other parent.

Many people carry beta thalassaemia. It is found most commonly among people whose origins are from:

- the Mediterranean (for example Greece, Turkey, Cyprus and Italy);
- the Middle East (for example Iran, Iraq, Saudi Arabia, Oman, Yemen);
- South Central Asia (for example India, Pakistan, Bangladesh);
- South East Asia (for example Burma (also known as Myanmar), Malaysia, Vietnam, Singapore, Thailand, Malaysia, Phillipines, Laos, Cambodia, Indonesia, Vietnam); or
- the Far East (for example China, Korea).

It can also occur in all ethnic groups.

What you need to know if you are a beta thalassaemia carrier

At this stage, we are not sure if you are a beta thalassaemia carrier, but we have written the following information **as if you are a beta thalassaemia carrier**.

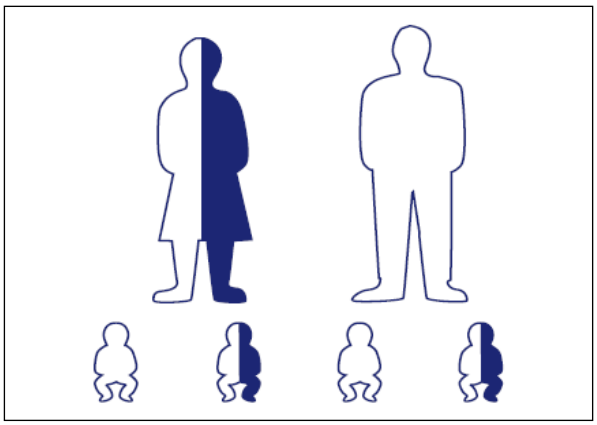
- Being a beta thalassaemia carrier should not cause you any health problems.
- Beta thalassaemia can be passed on to your children and this is why it is important to be aware you may be a carrier.
- If you are having a blood test, tell your doctor that you may be a carrier of beta thalassaemia as it can be misdiagnosed as iron deficiency. If they already know that you might carry beta thalassaemia, they can avoid offering you unnecessary tests and prescribing you iron medicine.
- You should only take iron medication if a blood test shows that you are iron-deficient.

- You are able to donate blood (when not pregnant) as long as you are not anaemic (do not have a lower haemoglobin than usual).
- There is a chance if you are a beta thalassaemia carrier that your children could be affected by a serious haemoglobin disorder if their biological father is also a beta thalassaemia carrier or a carrier of other haemoglobin variants.

If I am a carrier, what may this mean for my unborn baby?

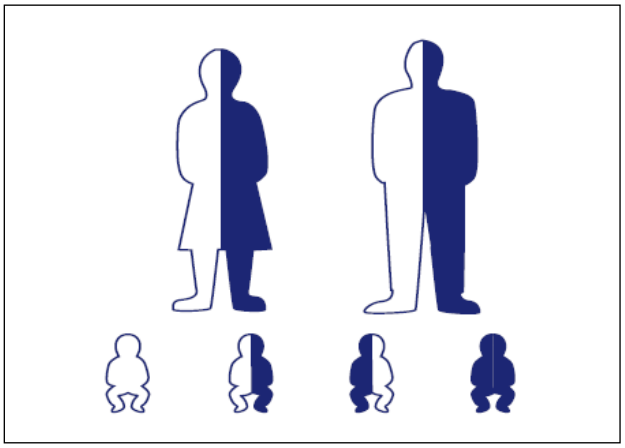
As you may be a beta thalassaemia carrier, there is a chance that you could pass the altered gene on to any children that you have.

If you have a child with a partner who **is not** a beta thalassaemia carrier, your child would be at a low risk of inheriting beta thalassaemia disorder but there would be a 1 in 2 (50%) chance that your child could be a **healthy carrier** like we think you may be. This is shown in the diagram below.



The diagram above shows how this works. One parent is a carrier and one parent is not a carrier. This is drawn in two colours to show that the parent who is a carrier has one usual beta globin gene (white) and one altered beta globin gene (blue).

If you have a child with a partner who **is** a beta thalassaemia carrier, there is a 1 in 4 (25%) chance that your child could inherit beta thalassaemia disorder. This is shown in the diagram below.



The diagram above shows how this works. The parents are both carriers. They are drawn in two colours to show that they have one usual beta globin gene (white) and one altered beta globin gene (blue).
If you have a child with a partner who does not carry beta thalassaemia but carries a gene for any other altered type of haemoglobin, there is a 1 in 4 (25%) chance that your child could inherit another type of haemoglobin disorder. Some of these disorders are mild and some are more serious. Your midwife or genetic counsellor will discuss this with you.

Testing your baby's father

We would like to test the biological father of your baby within **three working days**, or as soon as possible. This is to make clear whether he is a beta thalassaemia carrier, or a carrier of any unusual haemoglobin variant.

If the biological father of your baby is not a beta thalassaemia carrier and he does not carry any other unusual haemoglobin variant, your unborn baby, any other babies that you already have together, and any other babies that you have together in the future, will not be affected by beta thalassaemia disorder or any other serious haemoglobin disorder. In this case, no further action will be needed.

If the father of your baby is a beta thalassaemia carrier or carries any other unusual haemoglobin variant, this could possibly be passed on to the baby from both parents. This may have serious implications for your baby.

If your pregnancy is found to be at high risk of a serious haemoglobin disorder

If you and the biological father of your baby are both beta thalassaemia carriers or carriers of certain other unusual haemoglobin gene variants, you will be invited to discuss this with a specialist midwife or genetic counsellor as early as possible in your pregnancy. They will be able to give you information on how this may affect your unborn baby.

Some parents choose to have a diagnostic test (chorionic villus sampling (CVS) between 11 and 14 weeks of pregnancy, or amniocentesis after 15 weeks of pregnancy) to find out if your baby will be affected by beta thalassaemia major.

- Some parents choose not to have a diagnostic test and continue with a pregnancy that may be affected by a serious haemoglobin disorder.
- Some parents choose the diagnostic test and decide not to continue with the pregnancy if they find out that their pregnancy is affected with a serious haemoglobin disorder
- Some parents choose the diagnostic test and decide to continue with a pregnancy known to be affected by a serious haemoglobin disorder. You will be offered a blood test for your baby soon after it is born so that treatment can be started if necessary. Early diagnosis allows you and the medical team to prepare for the care of your baby.

You can get more information about thalassaemia from the following.

- The hospital midwife who specialises in antenatal screening or the hospital doctor (obstetrician).

- UK Thalassaemia Society
  0208 882 0011
  www.ukts.org

This leaflet has been adapted from NHS Sickle Cell and Thalassaemia Screening Programme (2014) 'You are a beta thalassaemia carrier'

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