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

Introduction

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

Key messages

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

- Carrying alpha thalassaemia is a **common** finding and 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.
- If your family origins are from the UK or f Ireland, and there is no family history of sickle cell or thalassaemia, you and your baby will have a lower chance of an inherited haemoglobin disorder and no further action will be needed during your pregnancy.
- **However, if:** you ,the biological father of the baby, anyone in your family, or anyone in the biological father of the baby`s family ,no matter how many generations back, came from anywhere in the world apart from the UK, or Ireland; or
- you or the biological father of the baby does not know your family history for example you or the biological father of the baby were adopted; or
- there is a history of thalassaemia in your family or that of the biological father of the baby;
- we recommend the biological father of the **baby is tested** (see page 3 for more information).

What your blood test has shown

Your test result is written as: **possible alpha thalassaemia carrier.**

Your recent blood test has shown:

- your red blood cells are smaller than expected.

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 an alpha thalassaemia carrier.

What is alpha thalassaemia?

Alpha thalassaemia is one of many possible variations in your blood, called haemoglobin gene variants that can be passed on from parent to child. Most people inherit two alpha globin genes from their mother and two alpha globin genes from their biological father.

Your genes also control the type of haemoglobin you inherit.

An alpha thalassaemia carrier has changes in one or more of these genes.

Alpha thalassaemia of different types occurs in all ethnic groups. The rates vary across the world, with some populations having higher rates of alpha thalassaemia than others.

What you need to know if you are an alpha thalassaemia carrier

We are unsure if you are a carrier of alpha thalassaemia. For instance, if you were already taking iron when you were tested, the ferritin test would not show low iron and your red blood cells may simply be recovering from iron deficiency.

We have written the following information **as if you are an alpha thalassaemia carrier**.

- Being an alpha thalassaemia carrier should not cause you any health problems.
- Alpha 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 alpha thalassaemia as it can be misdiagnosed as iron

deficiency. If they already know that you might carry alpha 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 have iron deficiency.
- 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 an alpha thalassaemia carrier that your children could be affected by a serious haemoglobin disorder if their biological father is also an alpha thalassaemia carrier or a carrier of other haemoglobin variants.

In pregnancy, for most women who may be an alpha thalassaemia carrier it is very unlikely that they will have a child with a serious haemoglobin disorder.

Further action is only necessary if your family origins or those of the biological father of the baby are from anywhere in the world apart from the UK or Ireland , you or the biological father of the baby do not know your family origins, or you or the biological father of the baby has a family history of thalassaemia.

What to do next if your test report recommends 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 an alpha thalassaemia carrier or a carrier of any unusual haemoglobin variant.

If the biological father of your baby is not an alpha thalassaemia carrier and 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, should not be affected by alpha thalassaemia or any other haemoglobin disorder. In this case, no further action will be needed.

If the biological father of your baby is an alpha 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 both mother and 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 alpha thalassaemia carriers, and if the type of alpha thalassaemia means your pregnancy is at high risk of alpha thalassaemia major, you will be invited to discuss this with a specialist midwife as early as possible in your pregnancy.

The midwife may then refer you to either a genetic counsellor or another health professional with specialist knowledge who will be able to tell you how this may affect your unborn baby.

Some alpha thalassaemia disorders are much more severe than others, and the genetic counsellor or health professional will discuss this with you.

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 the baby will be affected by a serious haemoglobin disorder. You will only be offered this if the exact gene change has been identified in both parents.

The specialist midwife or genetic counsellor will discuss the diagnostic test with you.

- 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 the 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
Phone: 0208 882 0011
Email: office@ukts.org
Website: www.ukts.org

This leaflet is based on information developed by the NHS Screening Programmes within Public Health England

Version 2
April 2020

Crystal Mark 21773
Clarity approved by Plain English Campaign