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

Introduction

This information is for you if you are pregnant and have had a blood test which shows you may be a carrier of **beta thalassaemia carrier** (often referred to as 'having a trait'). This leaflet gives you information about being a carrier, and what this means for you and your family.

As your screening test cannot confirm if you are a beta thalassaemia carrier, we have written the information in this leaflet **as if you are a beta thalassaemia carrier** and to help you understand if further action is needed during your pregnancy.

Key points

- Being a **possible carrier** of beta thalassaemia does not mean you are ill or that you will develop an illness. Most carriers are healthy and live normal lives without symptoms.
- Your baby's biological father will be invited for testing.
- Many people carry the beta thalassaemia gene, especially if they are from the Mediterranean, Middle East, South Asia, or South East Asia. It is very common and not unusual.
- More information and support is available. Your midwife will support you through any follow-up testing and help you understand the next steps.
- Be sure to share key information.
  Let your midwife know if your pregnancy involved donor sperm, donor eggs, or surrogacy. This helps them give you the right care.

How your test is written

Your test result is written as: 'Results consistent with possible beta thalassaemia carrier'.

What your blood test result means

Haemoglobin is the substance in red blood cells that carries oxygen around your body**.** Your recent blood test has shown your red blood cells are smaller than usual, or your red blood cells are the usual size and further tests showed you could be a beta thalassaemia carrier.

Knowing that you may be a beta thalassaemia carrier means that you could pass the beta thalassaemia gene onto your baby. If your baby's

biological father is also a carrier, this means together you could have a baby with an inherited haemoglobin condition.

Tell your healthcare professional if you:

- became pregnant following fertility treatment with donor sperm or a donor egg
- have had a bone marrow or stem cell transplant; or
- are pregnant as a surrogate

What is beta thalassaemia?

Haemoglobin conditions are blood disorders inherited from both biological parents. Beta thalassaemia is an inherited condition. There are many haemoglobin conditions. The type of condition your baby could inherit will depend on what type of haemoglobin genes both biological parents have. Carriers usually don't have any problems and don't need treatment. Some conditions are more serious than others. It becomes important if your baby's biological father is also a carrier, because this could increase the chance of your baby inheriting a more serious condition.

Your healthcare professional can discuss this with you, so that you understand what condition your baby could inherit and how this could affect the health of your baby.

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 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, Philippines, 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**.

- 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. During pregnancy you will be tested for iron deficiency.
- You are able to donate blood (when not pregnant) as long as you are not anaemic (do not have a lower level of haemoglobin than usual).
  Giving Blood // Welsh Blood Service (welsh-blood.org.uk)

How would my baby inherit beta thalassaemia?
One biological parent is a carrier and the other biological parent is not
If your baby's biological father has two usual haemoglobin genes (AA), there is a 2 in 4 (50%) chance your baby will be a beta thalassaemia carrier and a 2 in 4 (50%) chance they will have two unusual haemoglobin genes (AA). This is shown in the diagram below.
The chances are the same in every pregnancy for this couple.

What if both biological parents are carriers?
If your baby's biological father is a carrier, there is a 1 in 4 (25%) chance your baby will inherit a haemoglobin condition. The seriousness of the condition will depend on what haemoglobin genes are inherited

There is a 2 in 4 (50%) chance that your baby will be a carrier, and a 1 in 4 (25%) chance your baby will have usual haemoglobin genes (AA). This is shown in the diagram below.

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, for example haemoglobin E, 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.

Should my baby's biological father be offered testing?
If your baby's biological father has an unusual haemoglobin gene it is important to identify the type of gene and the chance of your baby inheriting a haemoglobin condition. For this reason, we will also invite the baby's biological father for screening. He will only know if he carries a gene for unusual haemoglobin if he has a blood test to check his haemoglobin type.

phw.nhs.wales/services-and-teams/screening/antenatal-screening-wales/information-resources/leaflets/sickle-cell-and-thalassaemia/sickle-cell-and-thalassaemia/information-for-fathers-invited-for-a-screening-test-for-sickle-cell-disorder-and-thal/

If the test shows your baby's biological father is a carrier of an unusual haemoglobin gene you will be offered specialist counselling and prenatal diagnosis.

Should I tell my family the result?
Other family members, such as brothers and sisters, aunts, uncles and cousins, may want to consider getting tested as they could be carriers too. Sharing this information with them may be helpful.

Next steps and choices
You can also:

- let your GP or healthcare professional know you are a sickle cell carrier; and
- contact All Wales Medical Genomics Service (AWMGS) where you can get free information and advice to help you understand the implications of being a beta thalassaemia carrier.

More information
You can get more information from the following.

NHS 111 Wales - Health A-Z : Thalassaemia

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