Patient information

Information for Adults Who are Beta Thalassaemia Carrier / Trait

Haematology Liverpool

What is my test result?

The substance in your blood that carries oxygen around your body is called haemoglobin. You had a blood test recently to check your haemoglobin type.

The test result shows that **you are healthy** – there is no need to worry about being unwell. But the result shows that you are a beta thalassaemia carrier (some people call it 'having a trait'). This leaflet gives you information about being a carrier, and what this means for you and your family.

What is a beta thalassaemia carrier?

For everything 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. The usual type is called 'A'.

You have inherited the usual haemoglobin A from one of your parents, and a gene to make little or no haemoglobin A from the other parent. We call this being a beta thalassaemia carrier.

Because you have inherited usual haemoglobin A from one parent, you are healthy. You will never develop a haemoglobin disorder. But there is a chance that you could pass on beta thalassaemia to your children.

How is my test result written?

The haemoglobin gene you have inherited is written β thalassaemia carrier (or beta thalassaemia carrier). The Greek letter "β" means beta.

What does this result mean for me?

Being a beta thalassaemia carrier will not generally cause you any health problems.

The reason why you need to understand about being a beta thalassaemia carrier is because you could pass the gene to your children. We explain this below.

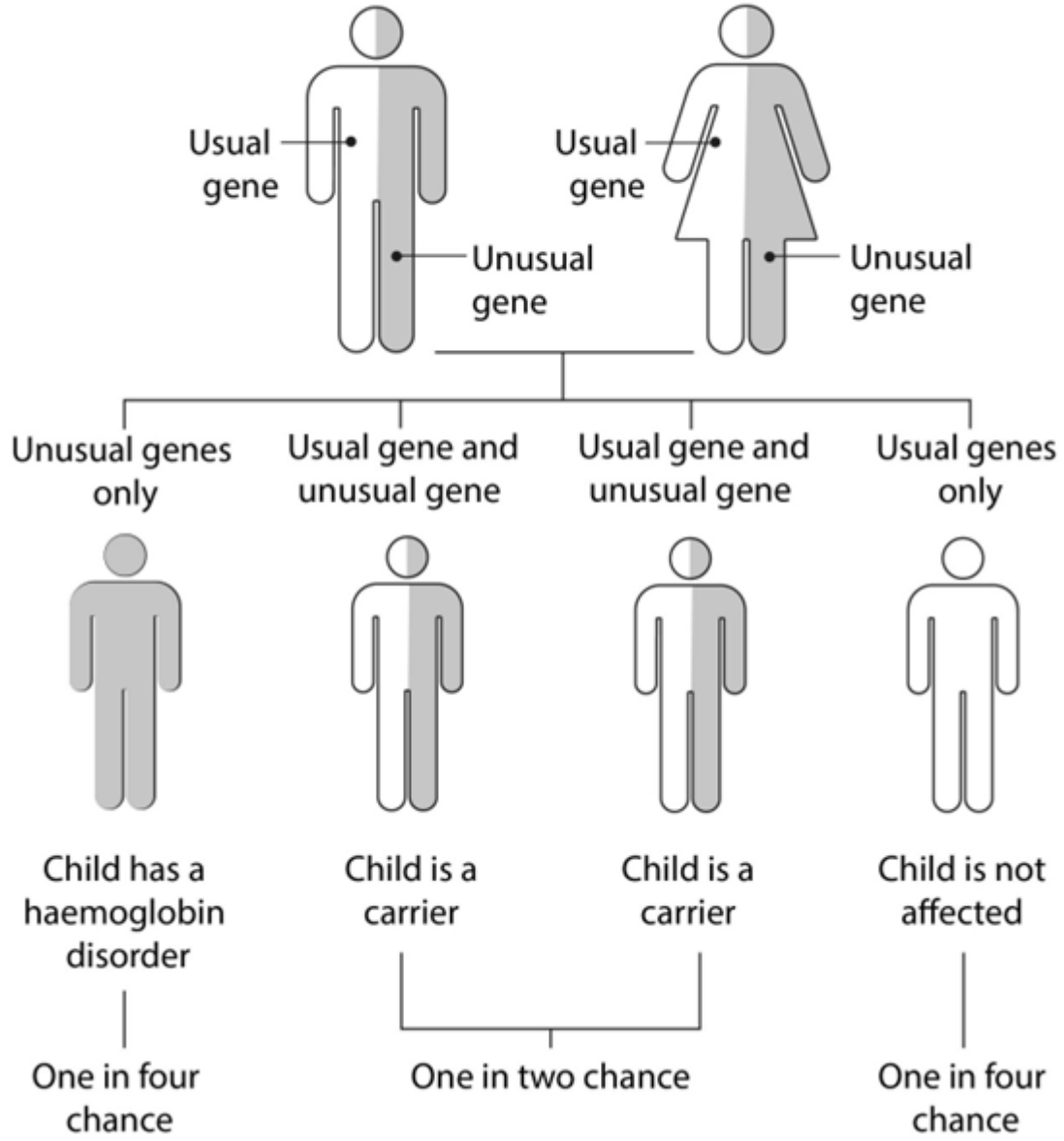
What could my result mean for my children?

As a carrier, there is a chance that you could pass on the gene for beta thalassaemia to any children that you have. Only the biological parents can pass this genetic information on to their child.

If you have a child with a partner who has the usual haemoglobin AA, there is a one in two (50%) chance that your child could be a carrier (like you).

Below is a diagram showing an example of how haemoglobin inheritance works.

The parents are both carriers. They are drawn in two colours to show that they have one usual haemoglobin gene (white) and one unusual gene (grey).



These chances are the same in all pregnancies for this couple

If you have a child with a partner who is also a beta thalassaemia carrier, there is a one in four (25%) chance that your child could inherit beta thalassaemia major. This is a serious health condition which we explain in the following pages.

If you have a child with a partner who carries a gene for any other type of unusual haemoglobin, there is a one in four (25%) chance that your child could inherit unusual haemoglobin from both parents. The type of disorder depends on which genes are inherited.

Your partner will only know they are a carrier if they have had a specific blood test to check their status. Fathers-to-be will be offered this test when antenatal screening shows the mother is a carrier. But both men and women can ask for a test at any time from their family doctor (GP).

What does my result mean for other people in my family?

The fact that you are a beta thalassaemia carrier means other members of your family could be carriers too.It is a good idea to talk to your blood relatives (such as your parents, brothers, sisters, uncles, aunts and cousins) and encourage them to get a test before they start a family or have any more children. Showing them this leaflet may help.

Information about the most serious haemoglobin disorders

Please remember that you are a ‘carrier’. You do not have any of the haemoglobin disorders described below. The following is for information only.

The most severe haemoglobin disorders are thalassaemia major and sickle cell disease. People who have these conditions will need specialist care throughout their lives.

People with thalassaemia major:

- are very anaemic (their blood has difficulty carrying oxygen);
- need blood transfusions every three to five weeks; and
- need medicines throughout their lives to stop the iron overload which is a result of the blood transfusions.

Common questions

Why didn’t I know about this? I have had blood tests before.

Routine blood tests do not show if you are a carrier. To find this out you need a special blood test for unusual haemoglobin.

What’s the difference between being a carrier and having thalassaemia?

Carriers are generally well and are only identified with careful testing. People with thalassaemia are often ill and need treatment.

As a carrier could I develop thalassaemia?

No, you cannot develop Thalasaemia because you have one gene which makes the usual haemoglobin, Hb A. But you will always be a carrier.

Is being a carrier infectious?

No, you can only be a carrier if you inherit the gene from one of your biological parents.

Does being a carrier affect my ability to have children?

No, it does not affect your ability to have children.

What should I do now?

- Let your family doctor (GP) know that you are a beta thalassaemia carrier.
- If you are expecting a baby or planning to have a baby, now or in the future, we strongly recommend that your partner gets tested to see if they are a carrier.
- You can get free information and advice to help you understand the implications of being a beta thalassaemia carrier. Ask your doctor or health professional to refer you to your nearest sickle cell and thalassaemia centre.
- If you already have children, you may want to have them tested as well.
- It is a good idea to talk to other members of your family and encourage them to get a test before they start a family or have any more children. It is equally important for men and women to be tested.
- The test for unusual haemoglobin is a simple blood test and takes just a few minutes. People can ask for the test at any time in their life.

Specialist Haemoglobinopathy Team:

Consultant Haematologist

Lead Clinical Nurse Specialist

Two Clinical Nurse Specialists

Haematology Specialist Registrar (Rotational Position)

Clinical Psychologist

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your Outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

NHS Sickle Cell and Thalassaemia Screening Programme Leaflets
www.sct.screening.nhs.uk/eta thal tra

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