

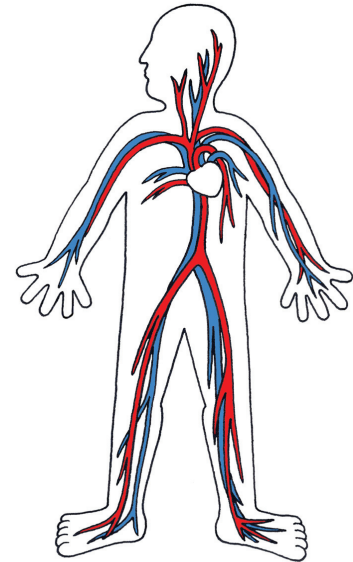
What is beta thalassaemia major?

Beta thalassaemia major, most commonly known as 'thalassaemia major' is a serious blood condition. It runs in families.

Thalassaemia affects the cells that carry oxygen around the body. There are not enough red blood cells to carry the oxygen.

People with thalassaemia major will need extra blood regularly throughout their lives. This is called a blood transfusion. They will also need medicines all their lives to help their bodies to handle iron.

They may get tired more easily and can experience complications with major organs, particularly if they don't take their medicine properly.



People with thalassaemia major may need support from their family, friends and people around them to cope with the illness and the effects that the treatment has on their lives.

Beta thalassaemia major runs in families because it is a 'genetic' condition. People who don't have the condition themselves can have a 'gene' which they can pass to their children. These people are called 'carriers'.



See the factsheet called *How do people get thalassaemia?* for more information about this.

Genes are the code that controls your body. For example, your genes control the colour of your eyes, how tall you are - even if you have a beautiful smile!



You can help to support people with thalassaemia major by:

- Talking openly about the condition and making sure people have the facts
- Offering help and support
- Talking to the person, their partner and their family about the screening blood test. (Please see the factsheet called *Why should I think about being tested?*) If one person in the family has thalassaemia major, others may have it or be carriers. The test will show if there is risk that they could pass the condition to any children they have.
- But remember: people with thalassaemia major are usually well. Don't fuss over them when they want to do things for themselves.



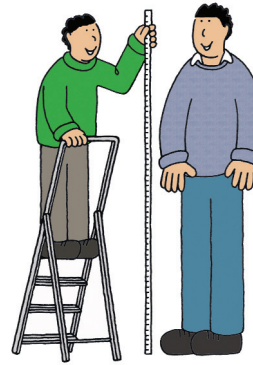
Did you know?

- There are other types of thalassaemia which are not as serious as beta thalassaemia major.
- Being a carrier can help protect against malaria. That's why thalassaemia is more common in areas with malaria such as India, Pakistan, Bangladesh, Cyprus and China. However, carriers should still take the normal medicines to protect against malaria.
- In England about 210,000 people 'carry' the gene for thalassaemia.
- All pregnant women in England are offered testing for thalassaemia.
- You can have the test at any time in your life. It is a good idea to find out about the test before you decide to have a baby.

How do people get beta thalassaemia major?

Thalassaemia is passed from parents to children through genes. Genes are the code that controls your body. For example, your genes control the colour of your eyes, how tall you are - even if you have a beautiful smile!

we can inherit lots of things from our parents...



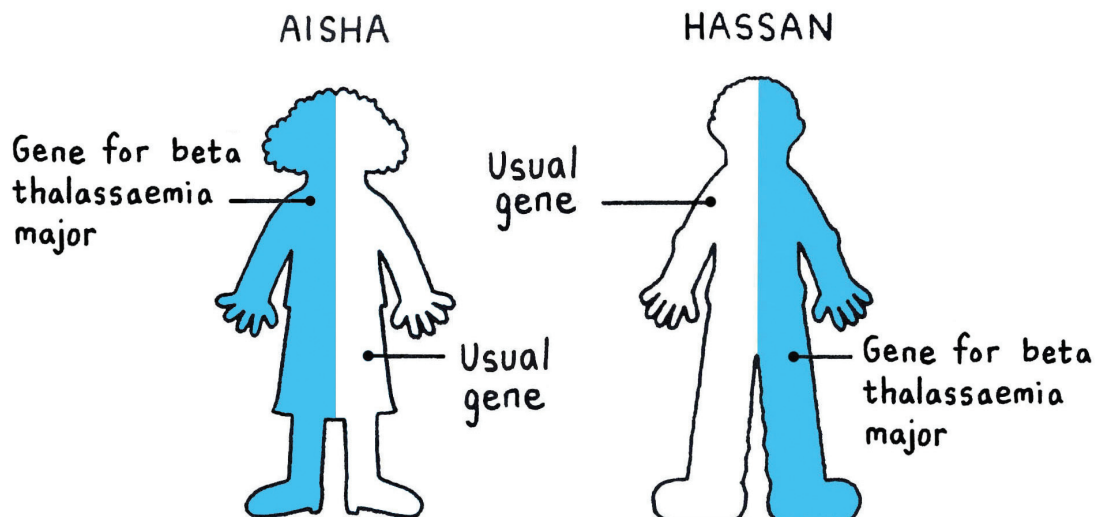
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People can only get beta thalassaemia major if they get two unusual genes - one from their father and one from their mother.

Aisha and Hassan are both healthy - neither of them actually has beta thalassaemia major. But because they both have one unusual gene, baby Imran does have the condition.

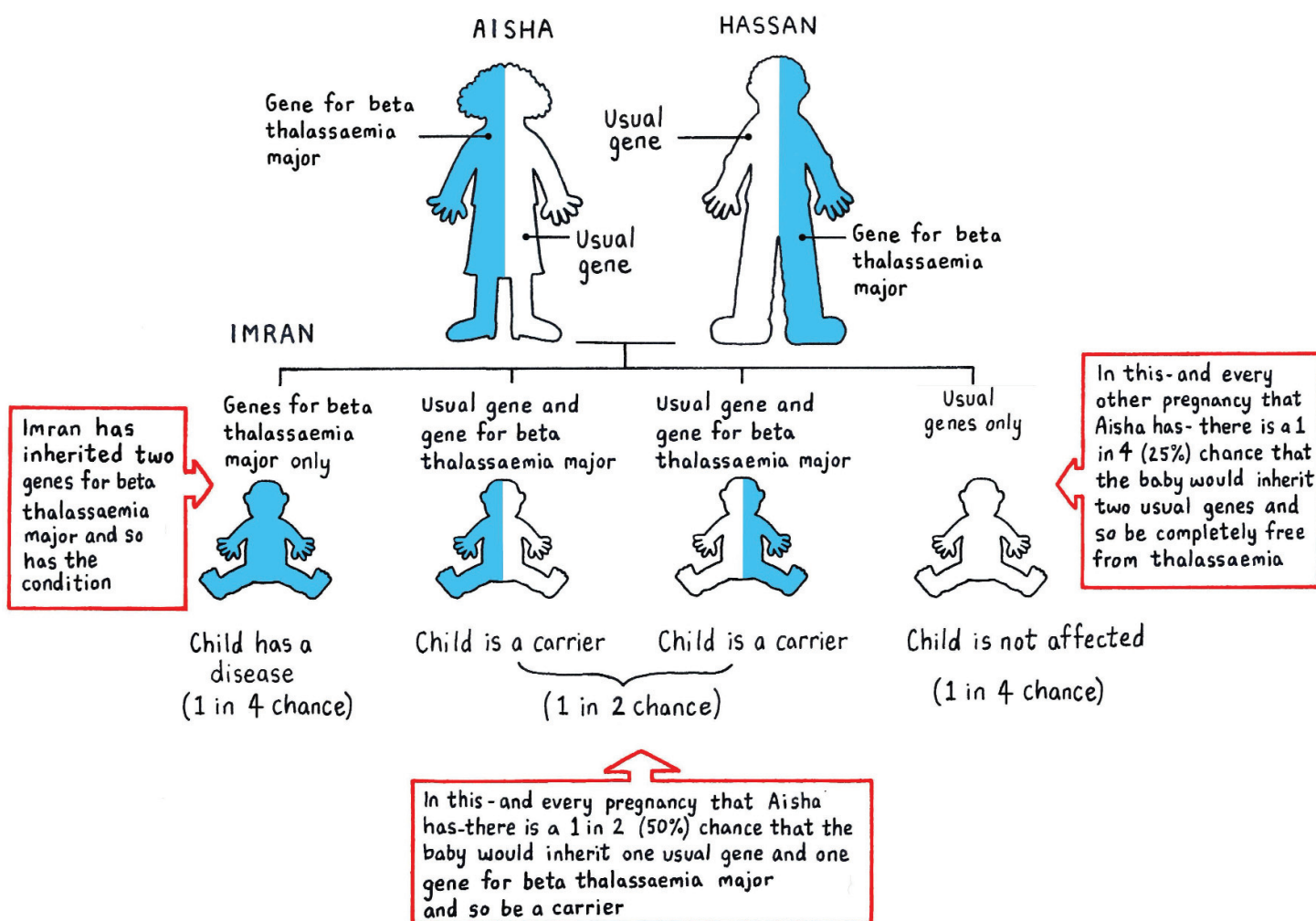
The diagram below shows how Aisha and Hassan each have one gene that makes the usual amount of red blood cells and one 'thalassaemia' gene that makes less red blood cells than usual.



We call Aisha and Hassan 'carriers'. People who are carriers are well in themselves. But they can pass on the unusual gene to their children. Each time Aisha and Hassan have a baby, there is a 1 in 4 (25%) chance that their baby will inherit beta thalassaemia major.

This chance is the same each time Aisha and Hassan have a baby. Their next child could have beta thalassaemia major like Imran **or** be a carrier **or** be completely free from thalassaemia. The same chances are there each time Aisha is pregnant.

The picture below shows how they passed on the condition to Imran



REMEMBER

You can't catch thalassaemia major like you catch a cold. You can only inherit it from your parents.





Why should I think about being tested for beta thalassaemia major?



The test for thalassaemia is to find out if you are a 'carrier' - if you carry one unusual gene. (Some people call this having a 'trait').

If you are a carrier, there is a chance you could pass on the unusual gene when you have a baby. Because carriers are generally healthy, you will not know if you are a carrier unless you have the test.

It is a simple blood test taking just a few minutes.

If the test shows you are a carrier, it is important that the baby's other parent has a test to see if he or she is also a carrier. Babies can only inherit the conditions if **both** parents are carriers.

When both parents are carriers, there is a 1 in 4 (25%) chance that the baby will inherit the condition.

REMEMBER

You can get tested to see if you carry the thalassaemia gene at any time in your life

How do I get tested?

Ideally you and your partner should ask for a test before you plan to have a child. You can ask your family doctor (GP) or your local thalassaemia centre.

If you are pregnant, you will automatically be offered a test as part of your pregnancy care. It is best to have the test as early as you can - before 10 weeks.

What might testing mean for my family?

If you are a carrier, other people in your family may be carriers too.

You can help your family by explaining about testing. This is especially important if any of them are pregnant or planning to have a baby.

Sometimes finding out about being a carrier can be difficult. Some people can feel ashamed or worried about how a partner might feel. That's why it's important to know the facts and stop people passing on ideas that are wrong.



Here are some wrong ideas which you can correct:



MYTH: You can catch thalassaemia

FACT: You only get thalassaemia by inheriting it from your parents

MYTH: Testing is for women

FACT: It is just as important for men to be tested

MYTH: People with thalassaemia major will die young

FACT: Treatments are improving quickly - people can live a long life if they receive the right treatment

MYTH: Thalassaemia is an ethnic minority issue

FACT: It can occur in any population

MYTH: I'm well so I can't be a carrier

FACT: Carriers are well so you can't tell unless you have a blood test