



Public Health
England

NHS

Screening for sickle cell disease and thalassaemia

An **easy guide** to screening tests when you are pregnant



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Your choice



This booklet has information about a test you can have.

The test can find out if the baby may have sickle cell disease or thalassaemia. These are serious conditions.

The test can find problems with your baby before it is born. The test may not find every problem.

If we find a problem early we can give you information or tell you about treatment for you or the baby.



You can choose if you want to have the test.

The test can show if you or the baby might need extra care.

The test can help you make choices about your care when you are pregnant.



If you are worried, you can talk to your midwife or doctor.

If you say no to the test then your baby can have a test for sickle cell disease when he or she is born.



About this test



We only show the results of the test to health staff who need to see them.



It is important to tell your midwife or health visitor if you have sickle cell disease or thalassaemia.

It is also important to tell your midwife or health visitor if the baby's father has one of the conditions.



This test takes a small drop of your blood to find out if you may give your baby sickle cell disease or thalassaemia.

All women are offered screening for thalassaemia.

Some women are offered screening for sickle cell disease.



You can have the blood test at any time but it is best to have the blood test before you are 10 weeks pregnant.



You may be asked questions about which country you and the baby's father come from.

This is to help health staff know if you need a test and to do the test properly.



Sickle cell disease and thalassaemia



Sickle cell disease and thalassaemia are serious blood conditions.

You get them from your parents. You have them for life.

Sickle cell disease is sometimes called SCD.



Sickle cell disease can cause anaemia. Anaemia means you have problems carrying oxygen in your blood. This makes you pale, very tired and weak.

Sickle cell disease can give you very bad pain and very serious illnesses.

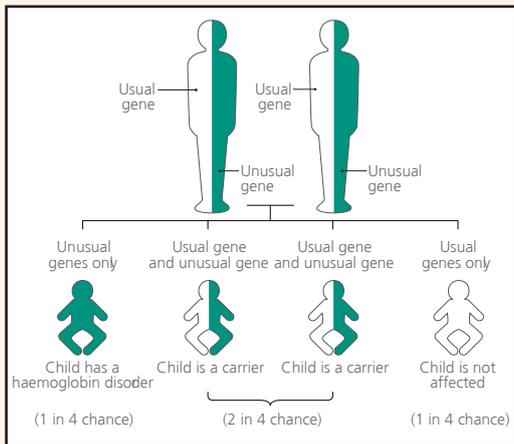
A baby with sickle cell disease can have medicines after they are born. Medicines will help them to be healthy.



Thalassaemia gives you very serious anaemia.

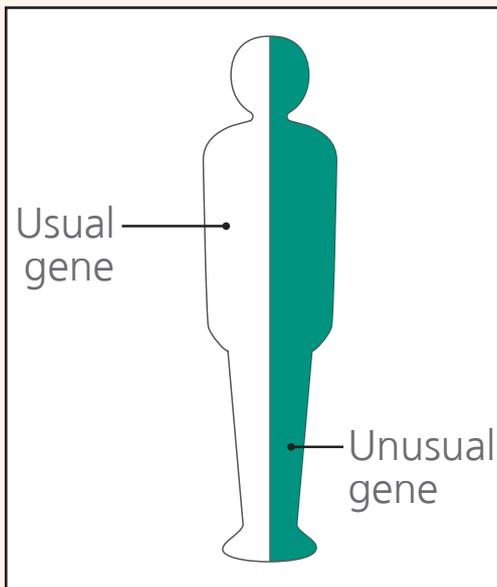
If you have thalassaemia you need blood transfusions every 4 to 6 weeks and you need medicine for life.

A blood transfusion is when blood is taken from a healthy person and put into an ill person.



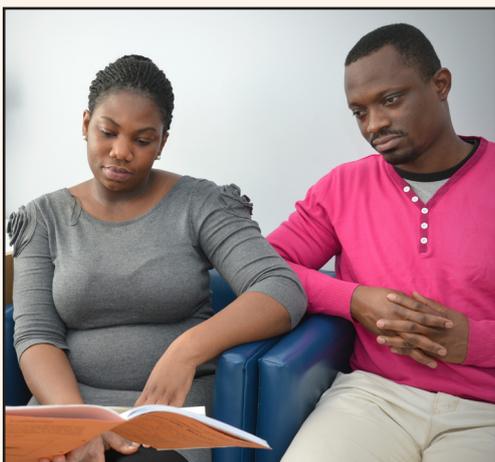
Sickle cell disease and thalassaemia are passed on through **genes**.

Genes are like a code for your body.



People who have just one unusual gene are known as **carriers**.

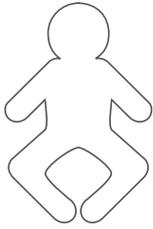
Carriers are healthy and do not have the blood condition.



If the baby's mother is a carrier and the baby's father is a carrier then the baby could be born with the condition.

If you and the baby's father are both carriers then the baby has:

Usual genes only



Child is not affected

(1 in 4 chance)

- 1 out of 4 chances of not having sickle cell disease or thalassaemia

Unusual genes only



Child has a haemoglobin disorder

(1 in 4 chance)

- 1 out of 4 chances of having sickle cell disease or thalassaemia

Usual gene and unusual gene Usual gene and unusual gene



Child is a carrier



Child is a carrier

(2 in 4 chance)

- 2 out of 4 chances of also being a carrier – this means they may then pass the gene on to their children when they are an adult



Anyone may have this gene. But it is more common for people whose family comes from:

- Africa
- the Caribbean
- the Mediterranean
- India
- Pakistan
- south and south east Asia
- the Middle East



Test results



You will usually get the results at your next appointment.

If the test shows you are a carrier for sickle cell disease or thalassaemia then we will contact you.

The person who does your test will tell you about this.



If you are a carrier and have one of the unusual genes, it is really important for the baby's father to get tested too.

If the baby's father also has one of the unusual genes, you will be offered another test. This is called a diagnostic test.



The diagnostic test has a very small chance of making you miscarry.

If you miscarry then the baby does not live.

You can say no to this test.



There are 2 types of diagnostic test.

If you are between 11 and 14 weeks pregnant you can have a chorionic villus sampling test.

This is sometimes called a CVS test.



This means that a very thin needle is put into your tummy.

This takes away a tiny bit of the placenta. The placenta links you to the baby.

We can test this for sickle cell disease or thalassaemia.



If you are 15 weeks or more pregnant you can have an amniocentesis.



If you have an amniocentesis a very thin needle is put into your tummy.

This takes a tiny bit of fluid from around the baby.

We can test this for sickle cell disease or thalassaemia.

Only a small number of babies have one of these syndromes.



This second test may show if your baby has sickle cell disease or thalassaemia.

If your baby has sickle cell disease or thalassaemia you will be given information about the condition to help you decide what to do.



Some babies have the condition worse than others. The test cannot tell you how serious the condition will be.



Some women who are told that their baby has sickle cell disease or thalassaemia decide to carry on with the pregnancy.

Some women who are told that their baby has sickle cell disease or thalassaemia decide they do not want to carry on with the pregnancy. They have an abortion. This means the baby does not live.



If your baby has sickle cell disease or thalassaemia you will be given support to decide whether or not to have an abortion.

This is your decision.



It is important to tell your midwife or health visitor if you move home.

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Public Health England leads the NHS Screening Programmes