

What is sickle cell disease?

Sickle cell is a serious blood disease. It runs in families.

Sickle cell disease affects the way blood carries oxygen around the body.

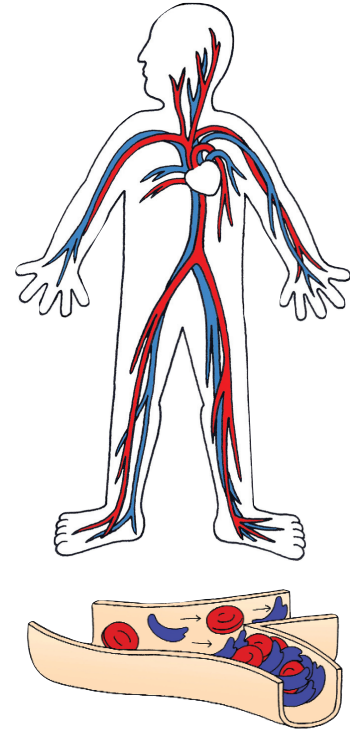
In sickle cell disease, red blood cells can become stiff and get stuck when they try to go through veins. This means that oxygen cannot get around the body.

People with sickle cell disease can have very serious pain. They can also have problems with other parts of their body.

They will need medicines to protect against infection all their lives. Sometimes they will also need medicines to help with pain.

They should have regular check ups with their doctor and make sure they have healthy foods, drink lots of water and are careful taking exercise.

When they are feeling ill or struggling to cope with life, people with sickle cell disease may need support from their family, friends and people around them. Some people may need support for all their lives.



Sickle cell runs in families because it is a 'genetic' disease. People who don't have the disease itself can have a 'gene' which they can pass to their children. These people are called 'carriers' (or sometimes we say they have the 'trait').

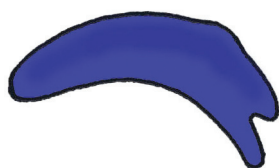
Genes are the code that controls your body. For example, your genes control the colour of your eyes, how tall you are - even if you have a beautiful smile!

You can help to support people with sickle cell disease by:

- Talking openly about the disease and making sure people have the information they need
- 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 sickle cell, others may have it or be carriers. The test will show if there is risk that they could pass sickle cell disease to any children they have.
- But remember: people with sickle cell disease will have times when they are well. Don't fuss over them when they want to do things for themselves.



Did you know?

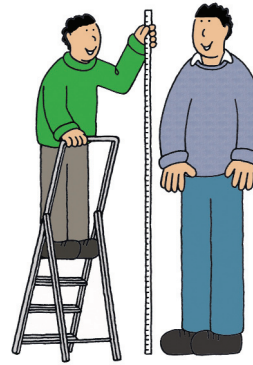


- There is a family of sickle cell diseases. Some are more serious than others. The most serious form is called sickle cell anaemia.
- Sickle cell is one of the most common diseases in the world that is passed through families.
- In England about 240,000 people 'carry' the sickle cell gene.
- Being a carrier can help protect against malaria. That's why sickle cell is more common in areas with malaria such as Africa. However, carriers should still take the normal medicines to protect against malaria.
- All babies and all pregnant women in England are offered testing for sickle cell.
- 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 sickle cell disease?

Sickle cell disease 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...



our height

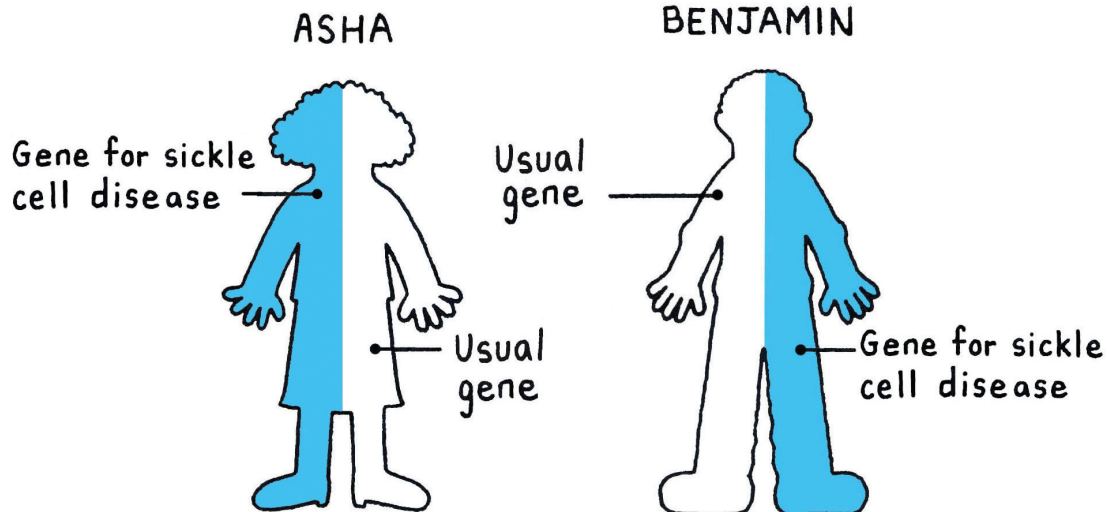
a nice smile



People can only get sickle cell disease if they get **two** unusual genes - one from their father and one from their mother

Asha and Benjamin are both healthy - neither of them actually has sickle cell disease. But because they both have one unusual gene, baby Rose does have the disease.

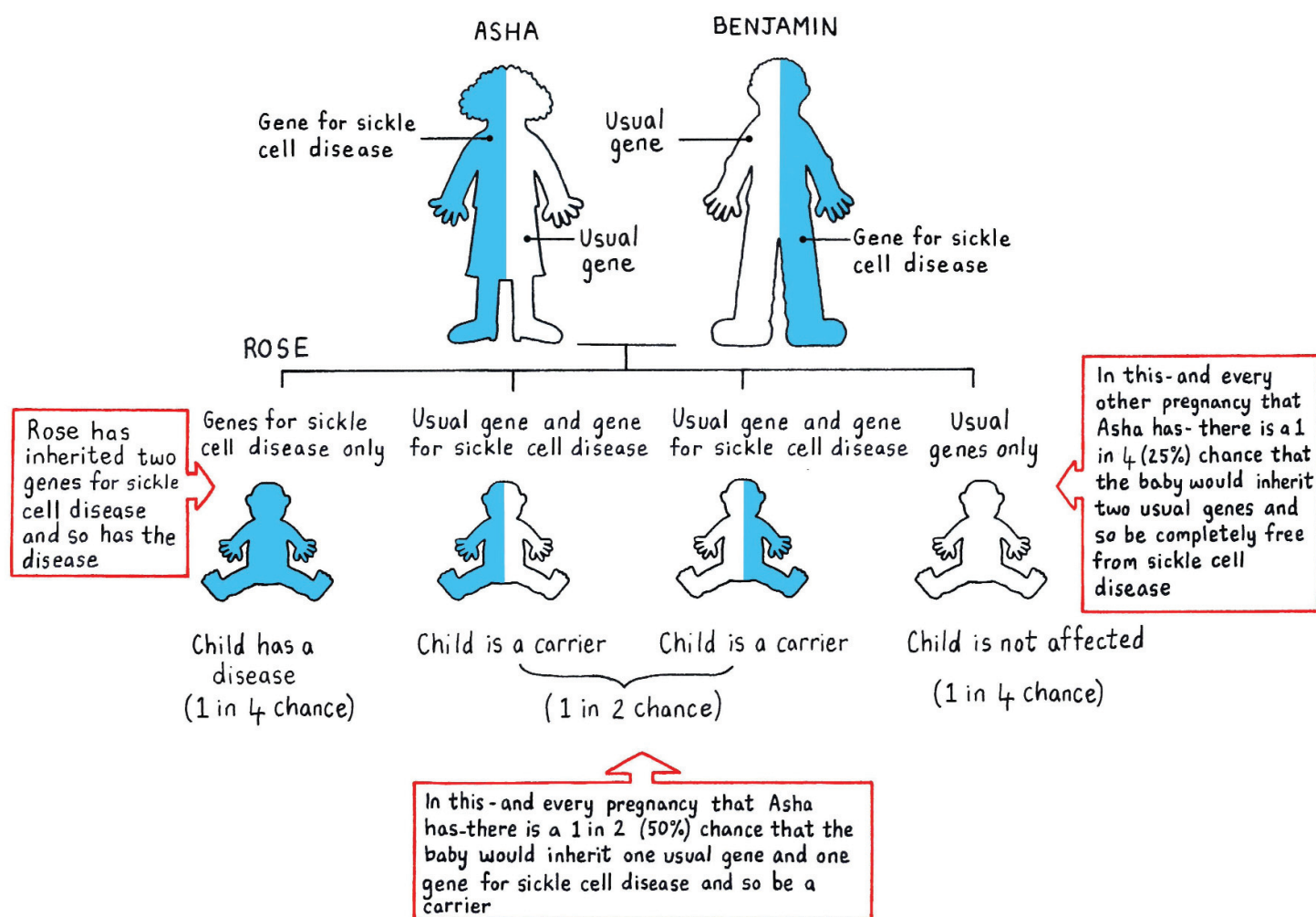
The diagram below shows how Asha and Benjamin each have one gene that makes usual blood and one gene that makes unusual or 'sickle cell' blood.



We call Asha and Benjamin 'carriers'. Sometimes this is also called having sickle cell 'trait'. People who are carriers are well in themselves. But they can pass on the unusual gene to their children. Each time Asha and Benjamin have a baby, there is a 1 in 4 (25%) chance that their baby will inherit sickle cell disease.

This chance is the same each time Asha and Benjamin have a baby. Their next child could have sickle cell disease like Rose or be a carrier or be completely free from sickle cell. The same chances are there each time Asha is pregnant.

The picture below shows how they passed on the disease to Rose.



REMEMBER

You can't catch sickle cell disease like you catch a cold. You can only inherit it from your parents.





Why should I think about being tested?

The test for sickle cell 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 get the disease if **both** parents are carriers.

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



REMEMBER

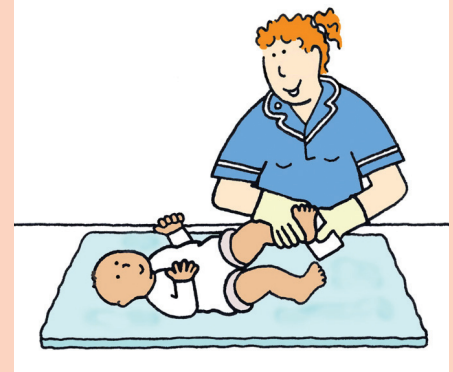
You can get tested to see if you carry the sickle cell gene at any time in your life

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 sickle cell 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.

All newborn babies in England are offered a test for sickle cell. This is because it's important to start treatment straightaway. The test will also show if the baby is a carrier.



The test for babies is a simple prick on the heel to get some blood and is done at the same time as other bloodspot tests.

This factsheet has been published by the NHS Sickle Cell and Thalassaemia Screening Programme. For more information, go to www.sickleandthal.org

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 sickle cell

FACT: You only get sickle cell disease 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 sickle cell disease will die young

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

MYTH: Sickle cell is a 'black issue'

FACT: Sickle cell 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