Public Health England

NHS

NHS Sickle Cell and Thalassaemia Screening Programme

Your baby carries a gene for sickle cell: information for mums and dads

Your baby had a blood test – called the heel-prick test – about a week after they were born. The test is to check for rare diseases and is offered to all babies.

The test results show that your baby is healthy. There is no need to worry – your child is well.

But the results also show that your baby carries a gene for sickle cell or haemoglobin S. This is sometimes called 'having a sickle cell trait'.

This is very common. In England, at least 240,000 people carry a gene for sickle cell.

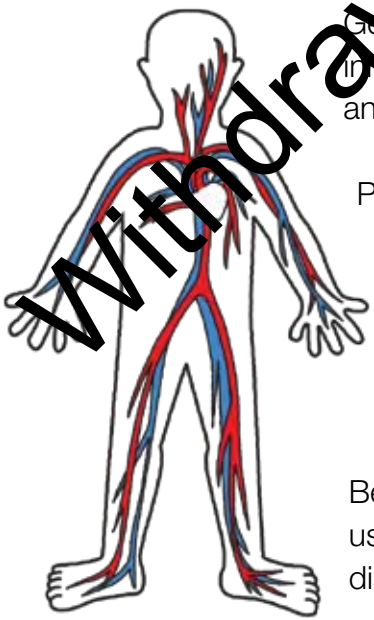
This leaflet gives you information about being a 'carrier' and what this means for your baby and for you and your family.

What is a sickle cell carrier?

To explain this, we must first talk about genes. The genes in your body decide the colour of your eyes, how tall you are – even if you have a beautiful smile!

Your genes also control the type of haemoglobin you have.

Haemoglobin is the substance in your blood which carries oxygen around the body.



Genes work in pairs. For each thing we inherit, we get one gene from our mother and one gene from our father.

People who are sickle cell carriers have inherited one gene that makes usual haemoglobin from one parent. They have also inherited one gene that makes unusual (sickle) haemoglobin from the other parent.

Because your baby has inherited one usual gene, they will never have sickle cell disease.

What does this result mean for my baby?

"Experienced doctors make sure that sickle cell carriers have operations safely like everyone else."

Your child is healthy – there is no need to worry.

However, there are 2 reasons why you and your child need to understand about being a sickle cell carrier. The first is that, in very rare situations, there may be some health issues. The second reason is that your child needs to know the risks of passing on sickle cell disease to their children when they grow up and want to have a family of their own. We explain more about both of these reasons below.

Rare health issues

There are some rare situations where carrying the gene for sickle cell could cause your child problems, for example during a general anaesthetic if they do not get enough oxygen. You should make sure healthcare professionals involved in your child's care know that your child is a sickle cell carrier.

Your child should also take extra care in situations where there might be a lack of oxygen, such as deep-sea diving and mountain climbing. If your child is a professional athlete, it is very important that they drink plenty of fluids during training.

Apart from these very rare situations, your child can live normally.

When your child grows up and wants a family of their own

If your child has a baby with another person who is also a sickle cell carrier, there is a one in four (25%) chance that their child (your grandchild) could inherit sickle cell disease.

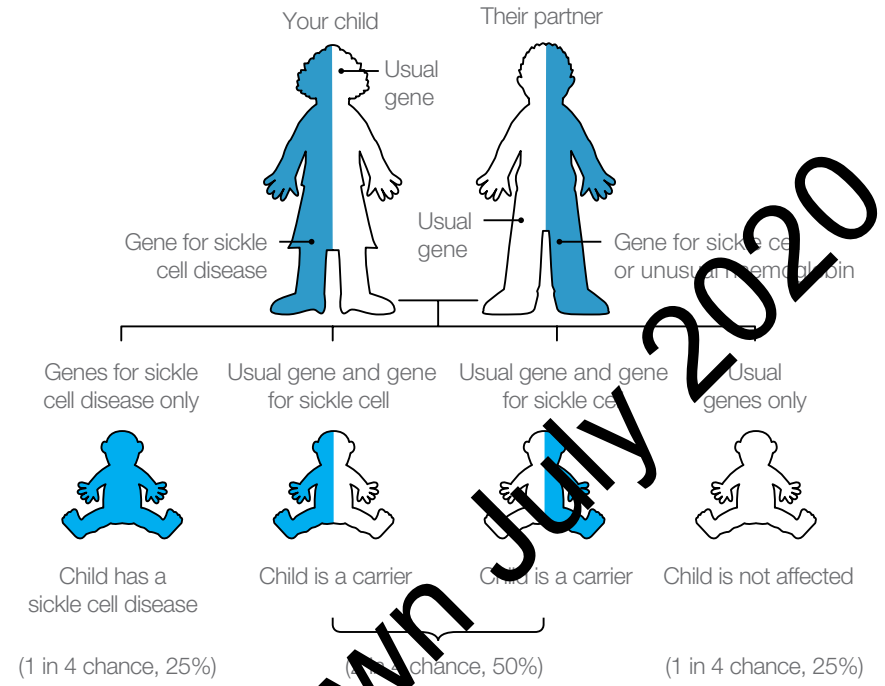
It's important that your child grows up knowing about being a carrier so they can think about the risks involved if they want to have a family, and what they can do to reduce the risks.

When your child grows up, they can talk to their partner about being a carrier and ask their partner to have a test to see if they are also a sickle cell carrier. There is free counselling to explain the risks and choices involved.

In the section below, we explain how carriers can pass on sickle cell disease to their children.

> "I'm glad that we know – it means she'll be able to plan her family. One of my cousins had a child born with sickle cell disease, and they had no idea they were carriers. That was much, much more difficult.

How can a carrier pass on sickle cell disease to their child?



The chart shows that when 2 people who are both carriers have a baby together, there is a 1 in 4 (25%) chance that their baby may inherit sickle cell disease.

The chances will be the same in every pregnancy with this partner.

In the diagram above, the parents are both carriers. They are drawn in 2 colours to show the 2 genes for haemoglobin that they could pass on to their children. Your child is the figure on the left – shaded white to show their usual gene for haemoglobin and blue to show their gene for sickle haemoglobin. The figure on the right is their partner – also shaded blue and white to show they are a carrier.

Every time your child has a baby with a partner who is also a carrier, there are 3 possible outcomes – see below.

1. The baby could inherit 2 genes that make unusual haemoglobin. If this happens, they will have sickle cell disease. There is a 1 in 4 (25%) chance of this happening, and it is shown in the diagram as the baby shaded completely blue.

2. The baby could inherit one gene that makes usual haemoglobin and one gene that makes unusual haemoglobin. If this happens, they will be a carrier like your child. There is a 2 in 4 (50%) chance of this happening and it is shown in the diagram as the 2 babies shaded blue and white.

3. The baby could inherit 2 usual genes. If this happens, they will be completely unaffected – they will not have the disease and will not be a carrier. There is a 1 in 4 (25%) chance of this happening and it is shown in the diagram as the baby shaded white.

What does this mean for my family?

Your baby inherited their gene for sickle cell from either you or your partner. This means that one of you (or maybe both of you) is also a healthy carrier.

1. We recommend that both you and your partner find out if you are carriers. This is particularly important if you are thinking of having another baby. If both of you are carriers, there is a chance that you could pass on sickle cell disease to your next baby.

2. It may also be a good idea to talk to other members of your family (such as your brothers and sisters, aunts, uncles and cousins) and encourage them to get a test before they start a family, in case they are carriers too. Showing them this leaflet may help.

3. The test is a simple blood test and takes just a few minutes. To arrange the test, you can ask your GP, visit your local sickle cell centre or contact one of the support organisations listed at the back of this leaflet.

> “Sickle cell can pass from one generation to the next. The test result shows this baby is a carrier.

What should I do now?

1. Make sure you write your baby's sickle cell carrier result in their health record (red book), and make sure your child's GP also puts this on their records.
2. As your child grows up, talk to them about being a carrier. It is important that they understand what this means when they come to plan a family of their own.

Information about sickle cell disease

Your child is a carrier, and does not have sickle cell disease. This information will help you understand a little more about the disease.

The most serious form of sickle cell disease is called sickle cell anaemia and happens when a person inherits two genes for sickle haemoglobin. Other unusual genes for haemoglobin are haemoglobin C and beta thalassaemia and can combine with a gene for sickle haemoglobin to produce sickle cell disease. There are also many other related conditions which are less serious.

People with sickle cell disease will need medical treatment and care throughout their lives.

Common questions

Can my baby develop sickle cell disease?

No. Your baby will never get sickle cell disease. But, they will always be a carrier.

Is being a carrier infectious?

No – you cannot catch sickle cell. You can only be a carrier if you inherit the gene from one of your parents.

Why should I tell my child about being a carrier?

There could be some health problems in rare situations where your child does not get enough oxygen (for example, after having an anaesthetic or when doing extreme sports). See page 4.

Also, your child needs to understand about the risks of passing sickle cell disease to their own children and the choices they can make. See page 6.

How many people do haemoglobin disorders such as sickle cell disease affect?

Haemoglobin disorders are some of the most common inherited conditions in the world. Around 5% of the world's population carry a gene for an unusual haemoglobin.

I've heard that people who are carriers are protected from malaria. Is that true?

Being a carrier does give children some protection against malaria, but only during the first couple of years of their life. Because of this advantage, sickle cell disease is more common among people who come from (or whose ancestors came from) places which have malaria. This includes Africa, Asia and parts of Southern Europe.

It is important that your child takes all the normal precautions if they are travelling to a country where there is a risk of malaria. This includes taking anti-malaria medication.

Would you like more information?

If you have questions about any of the information in this leaflet, please talk to your health visitor, GP or local sickle cell centre, which is based at:

Find out how Public Health England and the NHS use and protect your screening information at www.gov.uk/phe/screening-data

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