

Information for adult haemoglobinopathy carriers

You are a **sickle cell carrier**

Your test result shows: haemoglobin S carrier (Hb AS)

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 sickle cell 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 sickle cell 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 that makes unusual haemoglobin (in your case sickle cell) from the other parent. We call this being a sickle cell 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 the gene for sickle cell to your children.

How is my test result written?

The type of haemoglobin you have inherited is written **Hb AS (or sickle cell carrier or haemoglobin S carrier).**

The letters 'Hb' stand for haemoglobin.

The letter 'A' shows your usual type of haemoglobin.

The letter 'S' shows your unusual (sickle cell) type of haemoglobin.

What does this result mean for me?

There are two reasons why you need to understand about being a sickle cell carrier.

The first is you need to know the risks of passing the gene for sickle cell on to your children. We explain this on the following pages.

The second is that, in very rare situations, there are some possible health issues for you.

Rare health issues

Being a sickle cell carrier does not make you ill. In day-to-day life you are just as healthy as anyone else.

The only time there may be health problems is during situations where you might not get enough oxygen. These include the following.

- **During a general anaesthetic.** If you need a general anaesthetic, you should tell medical staff that you are a sickle cell carrier, so they can make sure you always get enough oxygen. **You should check that there is full medical back-up anywhere you have a general anaesthetic (for example, when having dental treatment).**
- **During extreme sports such as deep-sea diving.** If you do sports like these, you should take care that you are never short of oxygen.

- **If you do regular, intensive** athletic activity, you should drink plenty of fluids during training and avoid extreme exhaustion.

Apart from these very rare situations, as a sickle cell carrier you live a completely normal life.

What could my result mean for my children?

As a carrier, there is a chance that you could pass on the gene for sickle cell 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 2 in 4 (50%) chance that your child could be a carrier (like you).

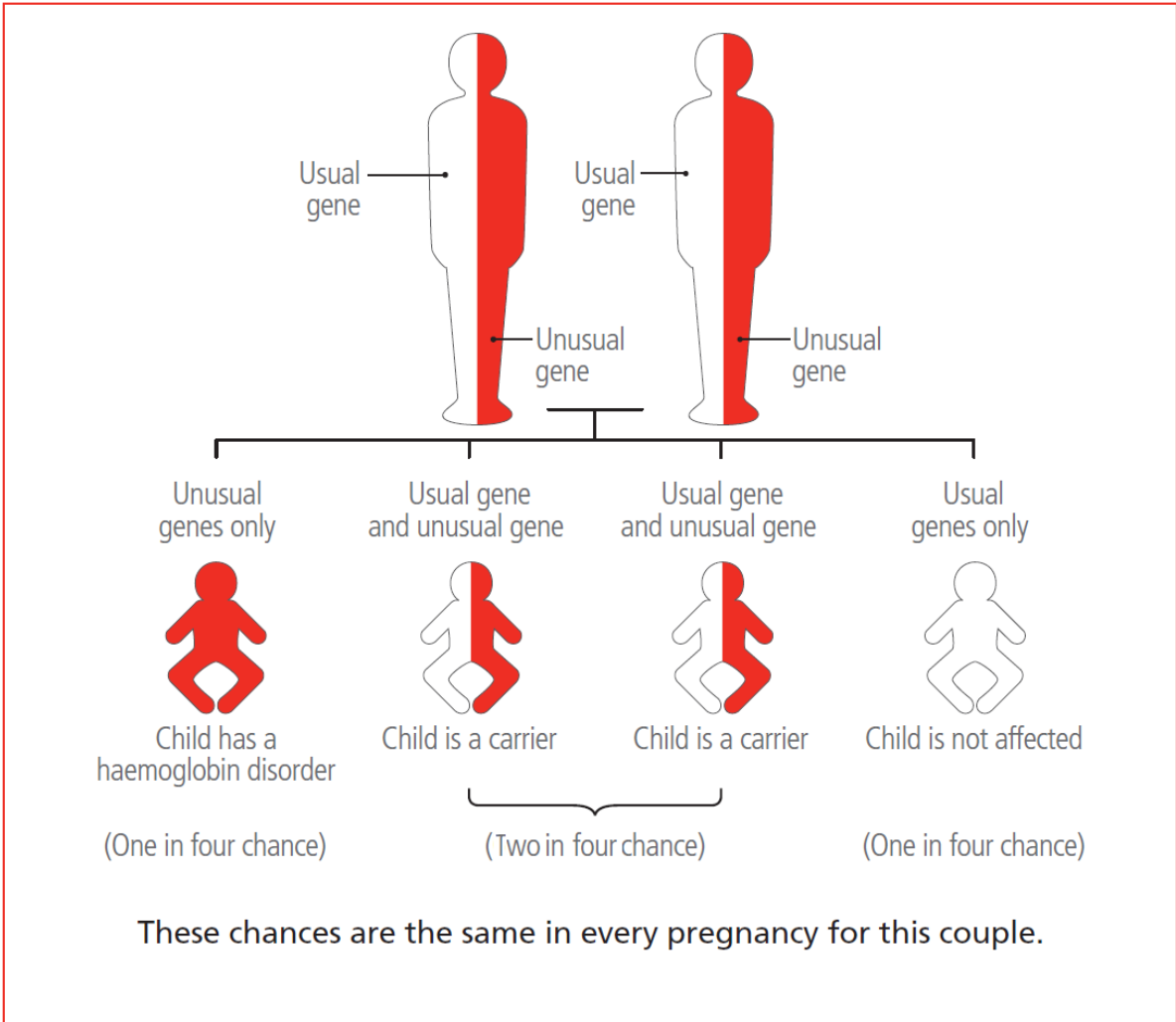
If you have a child with a partner **who is a sickle cell carrier (haemoglobin AS)**, there is a 1 in 4 (25%) chance that your child could inherit sickle cell anaemia (also called sickle cell disease). This is a serious health condition which is explained in the following pages.

If you have a child with a partner who carries a gene for **any other unusual type of haemoglobin**, there is a 1 in 4 (25%) chance that your child could inherit another type of sickle cell disease. The seriousness of the condition will depend 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) or from their nearest specialist sickle cell and thalassaemia centre.

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 (red).



What kind of disorder could my child inherit?

There are a number of haemoglobin disorders. Some are more serious than others. The most serious disorders are called sickle cell disease. People who have these conditions will need specialist care throughout their lives.

The type of disorder your child could inherit will depend on what types of haemoglobin both biological parents have. The chart on page 6 shows a combination of different carriers and the condition your child could inherit. We have only shown the most common types of carrier in England and the more significant conditions. The most serious conditions are shaded red.

You are a sickle cell (haemoglobin S) carrier.

If your partner is a carrier of haemoglobin S (Hb AS) (sickle cell carrier)	There is a 25% (1 in 4) chance your child could inherit sickle cell anaemia (Hb SS).	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of beta thalassaemia (β thalassaemia carrier)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/beta thalassaemia.	This is a type of sickle cell disease. It can be serious, moderate or mild and needs regular treatment.
If your partner is a carrier of delta beta thalassaemia ($\delta\beta$ thalassaemia carrier)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/delta beta thalassaemia.	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin C (Hb AC)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/C disorder.	This is a type of sickle cell disease. It can be serious or moderate and needs regular treatment.
If your partner is a carrier of haemoglobin D^{Punjab} (Hb AD^{Punjab})	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/D ^{Punjab} disorder.	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin E (Hb AE)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/E.	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin Lepore (Hb A Lepore)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/Lepore disorder.	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin O^{Arab} (Hb AO^{Arab})	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/O ^{Arab} .	This is a type of sickle cell disease. It is usually serious and needs regular treatment.
If your partner is a carrier of HPFH (Hereditary Persistence of Fetal Haemoglobin)	There is a 25% (1 in 4) chance your child could inherit S/HPFH.	This is usually moderate or mild and generally does not need any treatment.

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

The fact that you are a sickle cell 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 sickle cell disease

Please remember that you are a 'carrier' and do not have sickle cell disease. The following is for information only.

The most serious type of **sickle cell disease** is sickle cell anaemia (Hb SS). Other types of sickle cell disease which need treatment are shown in the table on page 6.

People with sickle cell disease:

- can have attacks of very severe pain;
- can get serious, life-threatening infections;
- are usually anaemic (which means that their blood has difficulty carrying oxygen); and
- need medicines and injections when they are children and throughout the rest of their lives to prevent infections.

There are also other, less common haemoglobin disorders. Many of these are not serious.

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 sickle cell disease?

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

As a carrier could I develop sickle cell disease?

No, you cannot develop sickle cell disease 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.

Am I protected from malaria?

No you are not protected from malaria. It is important that you take all the normal precautions if you are travelling to a country where there is a risk of malaria. This includes taking anti-malaria medication.

What should I do now?

- Let your family doctor (GP) know that you are a sickle cell 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 sickle cell 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 have 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.

More Information?

If you have questions about any of the information in this leaflet, please talk to your midwife.

For further information and support contact:

The Sickle Cell Society

Phone: 020 8961 7795

Email: info@sicklecellsociety.org

Website: www.sicklecellsociety.org

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