Sickle cell disease and thalassaemia screening: your baby carries a gene for sickle cell

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word ‘we’ refers to the NHS service that provides screening.

This guidance is for parents of babies found to carry the sickle cell gene following their newborn blood spot screening test.

Your baby had a blood test (also 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 your baby does not have sickle cell disease.

However, the results show your baby carries one gene for sickle cell and one gene for usual haemoglobin. This is written as Hb AS.

This is common. Every year in England, about 90,000 babies are born with a gene for sickle cell or another unusual haemoglobin. About 5% of the world’s population (1 in 20 people) carry such a gene.

This information explains what being a carrier of a sickle cell gene means for your baby, you and your wider family.

Carriers of unusual haemoglobin genes

Babies inherit characteristics from their parents’ genes. For example, genes control the colour of their skin, hair and eyes.

For each characteristic, your baby gets one gene from their biological mother and one from their biological father. Genes also control the type of haemoglobin they inherit. Haemoglobin is the substance in the blood that carries oxygen around the body.

There are many different types of haemoglobin, including sickle cell (or haemoglobin S). Your baby is a carrier because they inherited one gene that makes usual haemoglobin from one parent and one sickle cell gene from the other parent.

Your baby will never develop sickle cell disease because they inherited one usual gene. But they will always be a carrier.

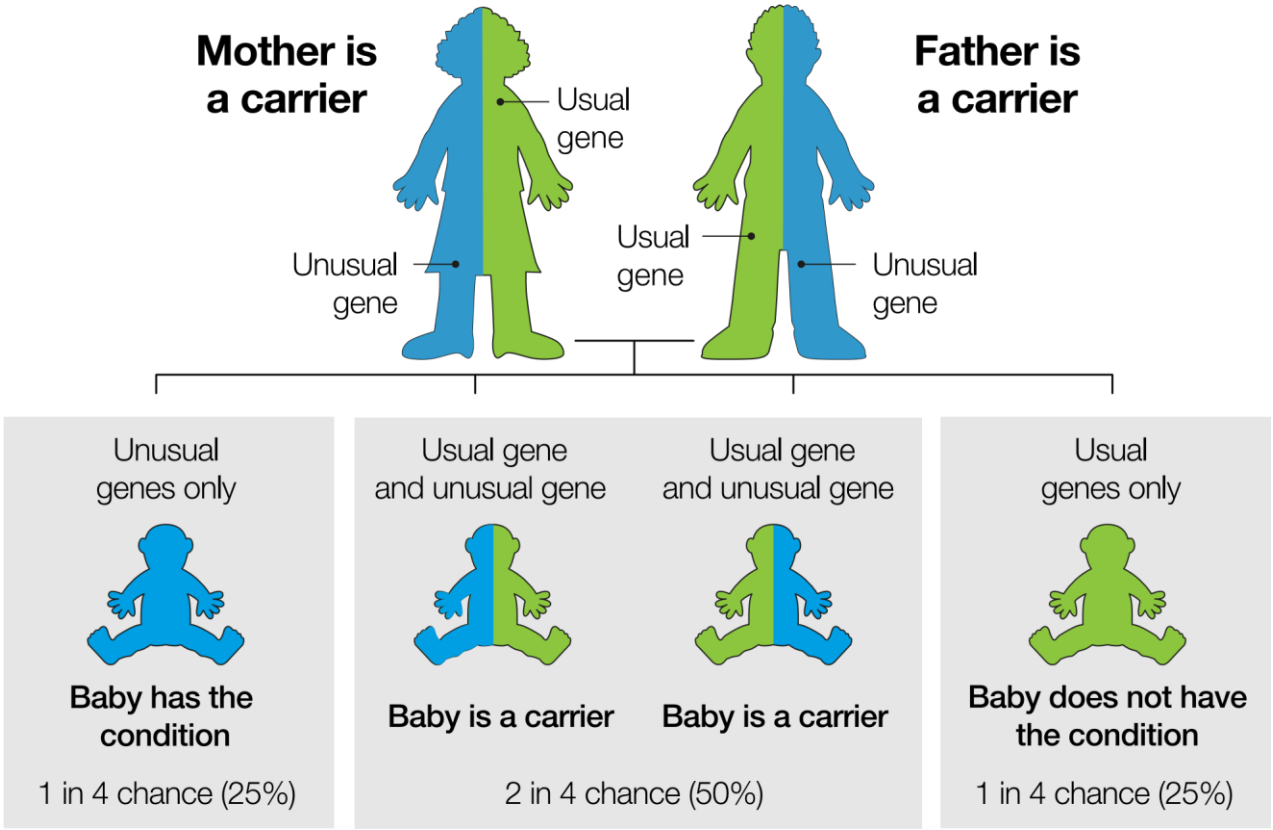
What this means for your child

Having a family

It's important 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 those risks.

When your child grows up, they can ask any future partner to have a test to see if they are also a carrier of an unusual haemoglobin gene. There is NHS counselling to explain the risks and choices involved.

If someone who is a carrier has a baby with another carrier, there is a 1 in 4 (25%) chance their child will inherit sickle cell disease (see diagram below).



The chances shown in the diagram above are the same in every pregnancy for this couple.

Their baby could inherit 2 genes that make unusual haemoglobin. If this happens their baby will have a haemoglobin disorder. There is a 1 in 4 (25%) chance of this happening.

Their baby could inherit one gene that makes usual haemoglobin and one gene that makes unusual haemoglobin. If this happens, they will be a carrier. There is a 2 in 4 (50%) chance of this happening.

Their baby could inherit 2 usual genes. If this happens, the baby will be unaffected. There is a 1 in 4 (25%) chance of this happening.

Protection against malaria

Being a carrier of the sickle cell gene gives children some protection against malaria, but only during the first couple of years of their life.

It is important 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.

Rare health issues for sickle cell carriers

In very rare situations, someone who is a carrier of the sickle cell gene can have health problems, for example during a general anaesthetic if they do not get enough oxygen.

You should make sure healthcare professionals know your child is a sickle cell carrier.

Sickle cell carriers should also take extra care in situations where there might be a lack of oxygen, such as deep-sea diving and mountain climbing. It is also very important they drink plenty of fluids during vigorous exercise.

Apart from these very rare situations, sickle cell carriers can live normally.

Future pregnancies and your wider family

Your baby inherited an unusual gene from either you or your partner. This means that you, your baby’s father, or both of you are also carriers.

We recommend both you and your partner get a test to find out who is a carrier, unless you already know from tests done in pregnancy.

This is particularly important if you are thinking of having another baby. If both of you are carriers, then your next baby could have a haemoglobin disorder.

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 a support organisation.

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

Haemoglobin disorders

People have a haemoglobin disorder if they inherit an unusual haemoglobin gene from both their parents.

The heel prick test picks up other unusual haemoglobin genes – HbC, HbD, HbO and HbE – which cause a sickle cell disorder if combined with the sickle cell gene HbS. Some of these combinations cause very few problems and some are more serious. The most serious is sickle cell disease, which is written HbSS.

People with sickle cell disease need treatment and support for life.

More information

More information and support is available from:

- the NHS.UK website at www.nhs.uk/sct
- Sickle Cell Society at www.sicklecellsociety.org E info@sicklecellsociety.org or tel 0208 9617795.
- UK Thalassaemia Society at ukts.org E info@ukts.org or tel 0208 882 0011.

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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