

# Sickle cell carrier and having a baby



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Sickle cell disorder is a genetic condition. This can make the thought of having a baby more daunting. It may leave you with many questions like 'what will this mean for my child?' or 'what are the options for conceiving as someone with sickle cell trait?'

Some people who do not present with sickle cell disorder themselves, may still be a carrier of the condition. This can also be known as being a carrier of sickle cell trait. Being a carrier can influence whether your child inherits the condition, so it's understandable that people would like to be aware of this before they start trying for a baby.

If the parents know their carrier status before pregnancy, it allows more choice in the options they have to progress in their journey to having children. However, it has been highlighted that when people ask their GPs for sickle cell disorder genetic testing, they are sometimes told that it's not necessary to be tested until they are already pregnant. This presents a clear issue.



It's important that patients are tested to establish if they are a carrier of sickle cell trait BEFORE they begin trying for a baby.

## What does it mean to be a carrier of sickle cell trait?

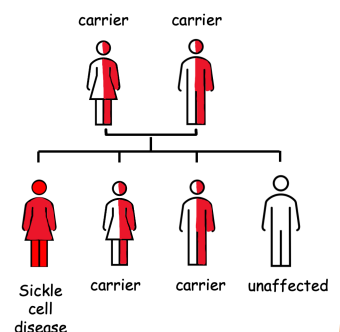
To be a carrier, it means that you have inherited one normal gene and one gene which contains the sickle cell trait. This is relatively common, in the UK roughly 1 in 79 babies born are sickle cell trait carriers. A carrier does not present with sickle cell disorder themselves, but they are able to pass the condition on to future offspring.

## What will this mean for my baby?

Sometimes being a carrier can mean that your child will inherit sickle cell disorder. This is why it's so important for people to be aware of their carrier status before they get pregnant.

If only one of the parents is a carrier and the other parent is unaffected, then the chances that your child will have sickle cell disorder is zero. The chances of the child being a carrier will be 50% and the chances of your child being unaffected is also 50%.

However, if both parents are carriers then there is a 25% (1 in 4) chance that the child will have sickle cell disorder. There is a 50% chance that the child will be a carrier and a 25% chance that the child will be unaffected. This scenario is shown in the diagram on the right.



## What are the options for conceiving as a sickle cell carrier?

Some people choose not to have a child with another carrier. This can be very upsetting. It can be difficult to know how to ask the other person if they are a carrier. This is also sometimes called asking someone for their genotype (this is the name doctors use for the genetic result of whether or not someone is a carrier).



Some people choose to still try for a baby naturally. In this case they can then decide if they would like to undergo prenatal diagnosis. This means that tests can be done during pregnancy, to see whether the baby has sickle cell disorder, is a carrier of sickle cell trait, or neither one. The family are then aware of the status of their baby and they can make an informed decision to continue the pregnancy as normal or think about options like termination, if they wish.

For couples who are both carriers, or one partner is affected with sickle cell disorder and the other is a carrier, pre-implantation genetic diagnosis is an option. This is a method that can be done using IVF, where the embryos are tested for sickle cell disorder or sickle cell trait. Only the ones which are unaffected are used to implant back into the mother. This is a way of selectively knowing that the baby will not have sickle cell disorder.



As you can see, most of these methods do require planning. This is very hard to do if people are not aware if they are a sickle cell trait carrier. Genetic testing before trying for a baby is essential to offer the most options and grant couples the maximum choice about important life decisions, like starting a family. You have the right to ask your GP for you to be tested (find out your genotype). Please take this leaflet to your GP if you are struggling to get a test.



It's important to remember to reach out for help if you need it. You can contact us at [info@togetherwecan.uk](mailto:info@togetherwecan.uk) for support or if you have any questions.



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