



Being a Carrier

I'm a carrier of haemophilia

If your father has haemophilia, you definitely carry the affected gene. We know this because of how the genetics work.

If one of your brothers has it, or maybe a cousin or uncle on your mother's side of the family, there's a chance you could be a carrier. Basically if your mother is a carrier, you have a 50:50 chance of being one too.

Haemophilia stays the same in families - if your dad has severe haemophilia, for example, you carry the gene for severe haemophilia.

For other bleeding disorders, we aren't as sure about how they get passed on. Von Willebrand's is usually dominant, meaning that if you have the gene you have VWD and aren't a carrier as such, although you can pass it on.

What is a gene? Genes are the information in your cells that determine things about you, like the colour of your eyes or hair.

What does it mean?

Being a carrier of haemophilia means that if you want to have your own baby in future, if you have a boy they have a 50:50 chance of having haemophilia. If you have a girl she has a 50:50 chance of being a carrier too.

About a third of haemophilia carriers have some symptoms themselves, and can even sometimes be described as having 'mild haemophilia'.

How can I deal with this?

Knowing that bleeding disorders can be passed on in families is maybe one of the most difficult things to deal with. Your parents might feel sad or guilty about passing it on to you, even though it wasn't anyone's fault. They might find it really hard to talk about to you and might avoid answering all your questions. Some people think they're protecting you by not talking about it.

Anything you feel about this is totally normal: sad, angry, frustrated, confused, or worried. We know the genetic side of it looks really complicated and is hard to understand. As a girl, being told you carry a serious condition can be really devastating and you have every right to be upset about it.

I feel left out!

Lots of girls who have brothers with haemophilia will not be carriers (50:50, remember?). People might think you'd be happy with this, but it's common to also feel guilty or left-out in your family.

This goes equally for boys who didn't get the haemophilia gene - it's hard for everyone in the family.

'I'm so worried about the future...will being a carrier of haemophilia mean I can't have babies?'

Here are some tips for dealing with your feelings around being a carrier, or not being a carrier.

- **Admit how you feel.** Bottling it up will only make the feelings much worse. If your parents don't want to talk about it, you could talk to your brother or sister, your aunt, your mates, or maybe a teacher at school. At the haemophilia centre they will also understand what you're going through, and there will be someone there who will be happy to listen to you.
- **Get the knowledge.** Knowledge is power! Knowing the facts about bleeding disorders will help you make your own choices and decisions. This website is a start and will link you to other sources of information.
- **To tell or not to tell:** Nobody will know unless you choose to tell them, but you might want to get it out in the open to help you see it's nothing to be ashamed of. Haemophilia is just one of lots of different genetic disorders.

The future

When do I get tested? Girls get tested at all different ages. It should happen when you and family feel you are ready for it. You have to be able to show that you fully understand the implications of genetic tests in order to give your own consent for testing. This is not something your parents can do for you.

You may have already had your Factor VIII (8) or Factor IX (9) tested when you were much younger. This is not genetic testing. Only about a third of carriers have a lower level of clotting factor in their blood so a normal level does not mean you are not a carrier – this can only be confirmed by genetic tests

Will I be able to have children? Lots of women who are carriers choose to have children, even if they have haemophilia. Equally some women do not want any children, or choose to explore all the options available to them, like knowing before the birth if the baby is affected.

What can be done? There are new techniques coming along all the time to help families, like pre-implantation diagnosis or gene therapy. When the time comes for you to think about having a baby, it's likely there will be lots of support and choices available for you to make your decisions.