

A young boy and girl are lying on a sandy beach, propped up on their elbows. They are both smiling warmly at the camera. The boy is on the left, wearing a white shirt, and the girl is on the right, wearing a white top. The background is a bright, clear sky over the ocean. The overall mood is positive and hopeful.

My brother has
Haemophilia

BAXTER & YOU

Shaping the future of haemophilia together

My brother has Haemophilia

Your brother has haemophilia. You probably have a lot of questions about what this means for him, for you and for the rest of your family. In this booklet we hope you will find the answer to some of those questions.

Then if you want to know more, you can talk to your mum and dad or the nurse who looks after your brother at the hospital. When he is old enough, you can talk to your brother too.

What happens when you cut yourself?

Ouch! You have cut yourself. What do you see? Blood at first, but soon the blood goes dry and crusty – this is called clotting. Clotting forms a scab, which stops your bleeding and covers the cut (like a bandage) while your body repairs itself. When you cut yourself special messengers in your blood – called factors – tell your blood to clot. But for your brother with haemophilia one of the messengers is missing. So there is nothing to tell his blood to clot.

Your brother's blood has a 'factor' missing so it can't clot by itself.

The only way to tell your brother's blood to clot is to give him some of the factor he is missing. Factor is injected into his blood and this tells it to start to clot.





As he grows older,
your brother will learn to
spot when he is bleeding.

Does every injury need an injection?

No. Small cuts and grazes can heal themselves without factor (although deep cuts – the sort that need stitches – can't).

But cuts aren't your brother's main problem. He can also bleed under his skin and in his joints (like his knees or elbows). This sometimes happens if he bumps himself but it can also start for no apparent reason. Injections of factor are needed to stop these bleeds.

Small cuts and grazes can heal themselves.

Are all children with haemophilia treated the same?

If their haemophilia isn't very bad, some children only need injections of factor when they are bleeding. Others have more serious haemophilia and they need injections two or three times every week. This way the factor is already in their blood when they need it, ready to tell it to clot.

Why does it hurt him?

When your brother starts to bleed into one of his joints such as his knee he needs some factor. Otherwise the bleeding won't stop and his joint can become swollen and very sore. It can also feel very warm when you touch it. As he gets older your brother will learn to spot that he is bleeding and have some factor as soon as possible. This will mean that he does not hurt as much or so often.

Where else might he bleed?

Another kind of bleeding you can look out for is bleeding in the mouth. Sometimes your brother might accidentally bite the inside of his mouth, perhaps while he is eating or if he falls over. Your mum might not notice this straight away, so if you spot it, you should tell her.

Will he get better?

Haemophilia is not a germ like a cold or flu. This means no one can catch it but it also means that your brother's haemophilia won't go away. This doesn't mean he will be ill all of the time. In fact most of the time he will be just like anyone else's brother and lots of people won't even know he has haemophilia.

Haemophilia
is not a germ,
so no one
can catch it.

Lots of people won't even know
your brother has haemophilia.

My uncle has haemophilia.
Is my brother's haemophilia the same?

Yes it is the same but there may be some big differences between your brother's haemophilia treatment and how your uncle was treated when he was small.

Nowadays children who have haemophilia can do a lot more. For example, your uncle may not have been allowed to play sport but you will probably find that your brother can join in many sports and games.

Why do Mum and Dad spend so much time with my brother?

Because your brother has haemophilia he needs a bit more of your parent's time; there are injections to be given, hospital check-ups and so on.

But don't think for one minute that this means they care more about your brother than they do about you. It's just that there is simply no way to avoid the extra time that haemophilia takes.

Why has he got haemophilia but I haven't?

Haemophilia generally only affects boys. Have you noticed that some people look like their mum and some don't? One child may have blonde hair like their mum. But their brother may have brown hair just like their dad. Haemophilia is the same; some of the boys in a family may have it and others may not.

In some families there are uncles and grandads with haemophilia but sometimes a baby is born and is the very first person in the family to have it. It seems to come from nowhere.

Perhaps one day you could go to the hospital with your brother to see the treatment he is having? He may enjoy some extra company.

Will my brother go to school?

Yes he will. All children need to learn and your brother is no different. In fact, most children with haemophilia go to the same school as their brothers and sisters.

When I'm grown up will my children have it?

If you are a boy then the answer is no. If you are a girl then you may have children with haemophilia, but not necessarily.

When you go on holiday, your brother can go too.

Can we go on holiday?

If your family is going on holiday then your brother can certainly come too. He will either need to take some factor with him or the local hospital will need to know that he is visiting their area.

Other questions?

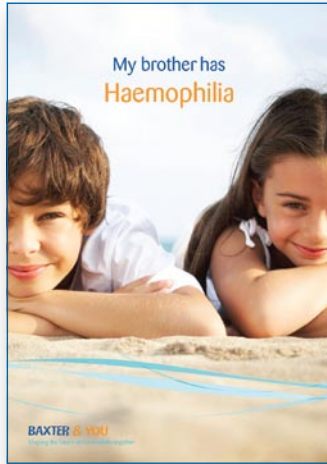
Hopefully this book has answered a lot of the questions you have about your brother's haemophilia. As you can see, although he needs special treatment and a bit of extra care, in very many ways he is just like anyone's brother. But if there is anything else you want to know, just ask at home or at your brother's haemophilia clinic. And when your brother is old enough, you can ask him too.

Can we play games and fight?

Your brother will enjoy playing games with you and there will be no need to leave him out. Exercise is good for him as it will build up his muscles. Strong muscles can help to protect his joints from bleeds. But you may need to be a bit more careful with your brother; try not to be too rough.

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will enjoy playing games
with you.





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Haemophilia Society Helpline – 0800 018 6068

www.haemophiliacare.co.uk

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