



## Your Questions

### I don't want to take my treatment any more.

If you're on prophylaxis, everyone knows it stops you getting bleeds. But if you've not had a bleed for years, you might be a bit sick of all the injections. Maybe you're thinking of stopping your treatment, because you've not had bleeds in so long.

We have to stress that when people stop their regular treatments it's quite common to have a large and painful bleed, which then makes them start it again very quickly! But we do understand prophylaxis can be frustrating. If you have questions about your treatment, please talk to us or your haemophilia centre first.

### I'm worried that my treatment could make me sick.

Have a look under 'treatments' at our explanation of what happened in the 70s when people caught HIV and hepatitis from their blood products. You may have concerns about the safety of your treatment, especially if you get products made from plasma.

All treatments are now considered very safe. Donors are screened very carefully for the viruses known to be spread by blood including Hepatitis A,B,C and HIV. Their donations are kept aside until the results are known. Each batch of treatment is also tested at different times during its production and before it is released for use. All products which are made from human plasma (from blood donors) have to be treated by at least two methods which are known to kill viruses – usually a heat method and one other.

Your haemophilia centre or our helpline will listen to any worries you have about your treatment.

### Do I need to eat special foods and can I drink alcohol?

Like anyone, keeping fit and eating well will help keep you healthy all over. There is some evidence, still not proven, that certain foods such as oily fish might affect your bleeding. This is because they contain Omega-3, so don't take any supplements without checking with a bleeding disorders specialist.

Smoking and drinking alcohol can irritate and damage the lining of your stomach. With a bleeding disorder this could be serious. Remember that drinking a lot when you are still young can have very dangerous effects on your liver. Some pain killers can also cause problems with your stomach lining. You're also more likely to injure yourself if you've had a lot of alcohol.

### What should I never take?

If you have a bleeding disorder, you should **never** take aspirin or warfarin, and you should only take drugs like ibuprofen (Nurofen) if your haemophilia centre say it is ok. They stop your blood from clotting properly. Some Chinese herbs can also be dangerous if too many are taken. Here are some that are thought to increase bleeding: flaxseed, ginseng, ginkgo biloba, ginger, St John's wort, and green tea. **Always** check with your blood specialist before taking anything like this.

### Are some groups of people more likely to have bleeding disorders?

As most bleeding disorders come from your genes, some particular types can be more common in certain groups of people. People from an Eastern European Jewish background (Ashkenazi) are more likely to have Factor XI deficiency. For haemophilia and von Willebrand's it's about the same. If groups of people tended to marry people who lived close by, or maybe cousins, the rate can be increased as well and with some bleeding disorders when close relatives marry there is an increased risk of their children having a more severe form of the disease.

### I'm sick of not being able to do all the sports I want.

What sports do you do? Most people with bleeding disorders play football, cycle, swim, and even play cricket. Some even go skiing. We can tell you about lots of young people who've travelled the world and had all kinds of adventures.

There are some sports you shouldn't do with a bleeding disorder, especially rugby, boxing, and some martial arts like judo. It's really anything where your head gets hit, as this could cause a bleed. A bleed in your head is really serious.

Does your centre allow you to go skiing? Some doctors say it's OK, some think it's too dangerous because of damage to your legs. Cross-country skiing is usually easier on the joints than downhill.

What about scuba diving? There's no bigger risk of having a bleed underwater, but sometimes you aren't allowed to do it because of the pressure of the water on your eardrums and other parts. As it's not recommended by the British Sub Aqua Group, you might not be insured if you do it.

Remember that **everyone** should wear a helmet for sports like cycling or climbing, not just you. You shouldn't need to wear a helmet for everyday activities.

### I want to get a tattoo or piercing.

Your parents and haemophilia centre probably won't be too keen on this.

Some people have told us that they've had piercings, for example on their ears, with no big problems **BUT** it will really depend on the individual person and their particular levels of clotting factor. Many people have also successfully had tattoos.

Remember if you are under 18 you usually need parental permission for this anyway.

**What piercings bleed the most?** You're most likely to bleed from piercings in your mouth or from dermal punching – really not a good idea!

All piercings take ages to heal properly anyway, and your belly button can take up to a year! It's also very likely to get infected– you might find you need to take

the piercing out in the end because it gets scarred.

People with haemophilia who self-treat sometimes get their piercings done on a treatment day.

**Got von Willebrand's?** If you aren't on prophylaxis this could be more dangerous. Our advice: think about it very, very carefully and tell your haemophilia centre in case they need to arrange for cover.

### **I'm fed up having a bleeding disorder.**

So you take your prophylaxis, and you're allowed to do most things. Maybe you sometimes get joint pains, or nosebleeds. If you're a girl you might get heavy periods when you're a bit older. You cope well with your disorder, but still, you're fed up with it.

Although the treatments are very good these days, and there is a lot of support available, it's totally natural to feel fed up with the injections, or even just being made to feel different. Are you sick of trying to explain it to people? Do you just not want to hear any more about it?

You can talk to us about your feelings, if you're angry or fed up. If you want to talk to someone one-on-one for a bit longer, we could help you arrange this. We also organize trips and holidays so you can forget about it for the day and just have FUN.

### **Help! I've got blood coming out down there!**

It's probably scary if you see blood when you go to the toilet, or even in your semen. This is quite common with haemophilia, and usually harmless, although you should always get it checked in case there is a bigger problem. It could mean you've swallowed blood that's in your mouth, or that you have some bleeding in your stomach. [Here are some good links that explain why you might see blood in some unexpected places. It happens!](#) (The Haemophilia Society is not responsible for external links)

Remember a drop of blood can look like a lot more than it is, especially when mixed with saliva or something else. If you think you might have bleeding in your abdomen, especially if you have blood mixed in with your bowel movements, ask your Centre.

### **'Er, I've got this bruise...'**

For boys, if you've got a bleeding disorder and you have sex for the first time, you might develop a big bruise on your back. This is because of bleeding into your psoas muscle. You should really get this checked out and treat it as you would any other bleed, or it can become serious.

**Will my centre know?** Probably – they've seen it all before. They won't have to tell your parents though, unless they think you're being hurt or abused in some way.

### **Is my bleeding disorder going to put off girls/boys?**

You probably know by now that some people are a bit clueless about any kind of disorder or illness. So a lot of them might not understand that bleeding disorders are manageable conditions. They might be afraid of what will happen – this is because they don't understand. All young people have some kind of hang-up – spots, glasses, braces, too short, too tall – you name it. We know lots of young people with bleeding disorders have had plenty of girlfriends or boyfriends. You can always explain it and make sure your friends all get it and can explain to others. Anyway, do you really want to go out with someone who is so narrow-minded?

**Will you tell anyone what I ask?** Our helpline and emails are confidential. We only have to tell someone if we think you or someone else is in danger of being hurt or abused. If we ask a nurse or doctor more about your question we don't use any names or details.

**My boyfriend and I recently had sex for the first time and there was a lot of bleeding, even with clots. I'm so worried that this will happen again. What can I do? I can't ask my (male) haematology doctor.**

There isn't much research into this, but many women with bleeding disorders have told us they bled a lot after their first time. Everyone is different but it seems to be more common the first time than other times. You might consider getting a referral to a gynaecologist (you can ask to see a woman if you prefer). That was you don't have to tell people at your Centre. A gynaecologist can help discuss different treatment, like the Pill, which can help many women.

Why have a look on [Women Bleed Too](#) or try the forums at <http://groups.msn.com/WomenwhoBleed> ?