



SPEAKING frankly

ABOUT HEMOPHILIA

*Hemophilia and You –
Tough Questions, Honest Answers*

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ALCOHOL, DRUGS AND SUPPLEMENTS

Q: Does drinking alcohol put me at risk?

A: If you have hemophilia, you do need to exercise extra caution when you drink – but not necessarily for the reasons you might expect. While alcohol can affect platelet function and act as a blood thinner, of greater concern are changes it causes in the brain's chemistry that can lead to impaired judgment, loss of coordination, blurred vision and slowed reaction times. These effects can make accidents and injuries more likely, and if you do get into trouble, you may be less able to help yourself afterwards – administering factor or explaining your condition to hospital staff will be considerably more difficult if you've had a lot to drink.

The abuse of alcohol over time can also damage the liver, which may in turn impact the production of clotting factors and platelets, and increase the severity of bleeding.

If you're thinking about drinking, there are a number of things you should consider beforehand. First, drink in moderation – most health organizations recommend that men consume no more than one or two drinks per day at most. This is the key to avoiding alcohol-related problems such as addiction, high blood pressure, liver disease and many other health issues.

Second, you should check with your doctor to ensure that alcohol won't interact in a dangerous way with any medications you're taking. When mixed with alcohol, many over-the-counter and prescription drugs – from cold and allergy medicines to anxiety pills, seizure medications and painkillers – simply do not mix well with alcoholic beverages.

Third, people with certain conditions should stay away from alcohol altogether. If you have hepatitis C, for example, alcohol significantly enhances your risk of developing cirrhosis and cancer of the liver. Again, your doctor can tell you if you should avoid alcohol completely for health reasons.

Finally, if you're going to drink, be responsible and take some common-sense precautions. Before you go out to a bar or party, check that you have your medical alert bracelet with you. It also makes sense to be with someone who knows about your condition – and who knows what to do if you are injured.

Q: What effect will smoking have on me?

A: Smoking is bad for you for numerous reasons, though it doesn't pose a unique threat to people with hemophilia. Smoking can result in a number of different types of cancer, is a significant cause of heart disease, and can also lead to respiratory illnesses such as emphysema.

Q: I'm thinking about smoking marijuana. Is it safe?

A: Marijuana use can significantly impair judgment, cause a loss of coordination and distort perception – all of which make physical injury more likely. In addition, people who smoke marijuana can suffer from some of the same respiratory problems that affect tobacco smokers, including a heightened risk of lung infections.

If you are tempted to experiment with marijuana, be aware of the risks you are taking, and make sure you are with someone who knows what to do if you find yourself in trouble.

Q: Can herbal supplements be dangerous to people with hemophilia?

A: You should always talk to your doctor before you start taking any herbal supplement. There are a number of supplements that can alter the way your liver works and affect the way in which your blood clots.

Your healthcare provider can provide you with a complete list of supplements you should avoid, but some of the more common include foxgloves, echinacea, ginseng, ginkgo biloba, hydroxycut and golden seal. Another concern is that many supplements are not regulated by regulatory agencies such as the Food and Drug Administration (FDA) or the European Medicines Agency (EMA), which makes it difficult to know what they contain.

A number of organizations provide information about alcohol and drug issues, including:

- [insert name and URL for alcohol and drug treatment organization]
- [insert link to relevant online resources offered by national health organization (e.g. NIH, NHS)]
- Always pay attention to local laws governing the consumption of alcohol, marijuana and tobacco.

DEPRESSION, PAIN AND ADDICTION

Q: How do I know if I'm depressed?

A: Depression can affect anyone, whether or not they have hemophilia. Everyone has bad days – times when they struggle to cope with the challenges that life throws at them. When those days turn into weeks or even months, it can be a sign of something more serious.

There is no single set of symptoms that indicate if someone is depressed. There are common signs, however: a decreased desire to be social, feelings of hopelessness, loss of appetite, fatigue, trouble sleeping, irritability, anxiety and risky behavior, to name a few. You might also make less of an effort to look after yourself – taking less pride in your appearance, for example, or not administering your therapy as frequently as prescribed by your doctor.

There are also different types of depression. With situational depression, our mind withdraws while we develop the tools we need to cope with a particular problem. You may be feeling isolated because of your hemophilia, but more universal triggers are just as likely – the end of a relationship, for example, or financial problems. Clinical depression, on the other hand, is caused by an imbalance in the brain's chemistry.

Whether depression is situational or clinical, there are always ways to beat it.

Q: What should I do if I'm depressed?

A: Depression is common in young men, so the first thing to realize is that you're not alone. If you think you might be depressed, the best thing you can do is talk to someone you trust. This could be a friend, a relative, a teacher or a counselor – it doesn't matter who you turn to for support, so long as you turn to someone. Hemophilia treatment centers in many countries offer mental health services, but you can also talk to your general practitioner or a psychiatrist. They may encourage you to have counseling and/or prescribe antidepressants.

Q: Should I worry about becoming addicted to pain medications?

A: People with hemophilia are particularly at risk of becoming addicted to pain medication because the pain they are experiencing is real and does need to be managed. Pain medications provide immediate relief, and after a severe injury people may find them necessary in order to carry on with everyday life. Unfortunately, a dependency on pain medication can also lead to reduced prophylaxis – which leads to more severe and frequent bleeds, and the abuse of painkillers can cause significant liver and kidney damage.

In addition, some common over-the-counter painkillers – particularly aspirin, ibuprofen and many anti-inflammatories – can increase the frequency and duration of bleeds because they block the normal function of platelets. Acetaminophen is considered a safe treatment option for people who have hemophilia, though it's important to pay attention to the recommended dosage because it can harm the liver if taken in excess.

If you are constantly seeking stronger painkillers, often find yourself calling for a refill before your prescription expires, or go to different physicians asking for the same medication, you may be at risk of addiction and should talk to a qualified health care professional about the way you are managing your pain.

The most important thing you can do if you are worried about an addiction – whether to painkillers or any other substance – is talk to someone. Family members, treatment center teams and other health care professionals can help you manage your pain and live a long, healthy and addiction-free life.

- Do not take aspirin or ibuprofen.
- Maintain regular contact with your Hemophilia Treatment Center (HTC), which can advise you on how to safely manage your pain.
- Make sure that any health care provider you talk to knows about your hemophilia.
- If you are feeling depressed, the most important thing you can do is talk to someone you trust.





There are a number of online resources that provide an easy-to-understand overview of hemophilia that can help you explain your condition to your partner, including:

- www.LivingWithHemophilia.com
- [The World Federation of Hemophilia at www.wfh.org](http://www.wfh.org)
- [\[Insert country-specific hemophilia organization Web site\]](#)

Q: Does my partner need to know that I have hemophilia?

A: Telling anyone that you have hemophilia can be difficult, and it can be particularly hard to be open about it with a girlfriend or boyfriend. Some people have pre-conceived and uninformed ideas about the condition. It's natural to be scared that your partner might react negatively before you have a chance to explain what it is, and how it affects you.

It is, however, worth remembering that great relationships are based on truth, honesty, and an intimate personal knowledge of each other. You should ask yourself if you would like your partner to tell you about something that was such an important part of their life.

And, of course, your partner has a right to know if you have HIV, hepatitis B or C or other sexually transmitted diseases before the two of you engage in any sexual activity.

Ultimately, only you can decide whether you should tell your partner, but you have everything to gain from being bold and honest about it at the appropriate time in your relationship.

Q: How and what should I tell them?

A: Telling your partner that you have hemophilia isn't easy, and there is no right or wrong way to do it.

You might want to think about giving them some time to get to know you before you tell them, unless of course you have HIV, hepatitis B or C or other sexually transmitted disease. This will allow them to see that you are capable of living as full a life as anyone else, provided you have access to appropriate treatment.

You should also remember that if your partner knows and likes you, they will still know and like you when they find out you have hemophilia – particularly if you take the opportunity to educate them about the condition, and explain to them that having hemophilia simply means you have to take some extra precautions. Have confidence in yourself and you will be surprised how much confidence others have in you.

When you tell your partner that you have hemophilia you have a great opportunity to reassure them. You can explain to them that the condition is not contagious, and that you will live a long and happy life. While they may be scared at first, their greatest concern is likely to be for your well-being.

The most important way for you to prepare is to anticipate and plan for the moment. Do some background reading so that you're ready to answer any questions your partner might have. Be prepared to show them literature and Web sites that provide hemophilia information and feature stories about people who live with the condition.

SEX & HEMOPHILIA

Q: Does masturbation pose a health risk?

A: Masturbation is often considered a taboo subject, but it's a healthy and natural way of exploring your own body and sexuality. It's also nothing to be ashamed of: it has been estimated that 98 percent of boys have had an orgasm through masturbation by the time they are 18-years-old¹.

Remember that you can get a bleed anywhere that blood flows, including your penis. A penile injury may cause external bleeding, discoloration of urine, swelling or pain. If you have any of these symptoms you should seek professional medical help.

You should also be aware of the potential for experiencing an internal bleed in your psoas muscles. These muscles, which are anchored on either side of your lower spine and extend through your pelvic area to your hip joint, allow you to move your hips freely and help you maintain an upright posture. Psoas bleeds may not be immediately apparent, but if you find that you can't straighten your legs while lying down or get out of bed without using your hands to support yourself, you should go to the emergency room for treatment.

Q: Should I worry about making out?

A: Making out – including kissing and oral sex – can seem like a less risky option than penetrative sex, but you do still need to be responsible and aware of the potential for problems. It pays to remember that anything which involves deliberately drawing blood to the skin's surface – including biting, nibbling or getting a hickie – can cause more of a problem if you have hemophilia than it would for someone without the condition. If someone bites you and breaks the skin, you will bleed for a long time, it will hurt, and you may be at risk of infection.

Q: Is it safe for me to have sex?

A: Yes. Your decision to have sex should be guided by your own beliefs and values, but it can be a natural and important part of a healthy relationship. You do have to be responsible, however. In some ways sex is like any other activity: the more strenuous or adventurous it is, the greater your risk of getting a bleed.

It is also essential that you use a condom whenever you have vaginal, anal or oral sex – not because you have hemophilia, but because condoms can protect you against becoming infected with viruses such as HIV, hepatitis B or C or other sexually transmitted diseases. Of course, condoms can also help prevent unwanted pregnancies if used correctly.

Q: Are some sexual positions better than others?

A: While the type of sexual position you adopt has little to do with an increased risk of bleeds, if you have limited movement in your joints or suffer from joint pain you will find that some positions are easier than others. The key is to know your limitations.

For example, positions that require you to support your weight or that of your partner will be harder to maintain, whereas positions that place less strain on your joints will be more comfortable. If you have restricted movement or pain in your knees, you can lie on your back with your partner above you. This allows them to support their own body weight and provide most of the movement during lovemaking. It may also be easier for you to have intercourse while laying side-by-side.

Watch for signs of a bleed after sexual activity, including:

- Bruising on the surface of the skin
- Prolonged bleeding in the mouth after making out
- Bleeding into muscles like the calf, forearm or hip, which can lead to stiffness, tingling, swelling, pain and restriction of movement
- Bleeding into joints like the knees, elbows and ankles after twisting or putting weight on them, which can be identified by stiffness, pain and restriction of motion



¹Siimes, Martti A, Veikko Aalberg & Pia Petrini. Boys with Hemophilia. Helsinki: Nemo, 2006.

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FURTHER RECOMMENDED READING

Jones, Peter. *Living with Haemophilia (Fifth edition)*. Oxford University Press, 2002.

Siimes, Martti A, Veikko Aalberg & Pia Petrini. *Boys with Hemophilia*. Nemo Publishers, 2006.

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RESOURCES

There are several organizations that provide expert, confidential support and information for people with hemophilia, including:

World Federation of Hemophilia (www.wfh.org)

- To locate hemophilia treatments centers (HTCs) and organizations worldwide, visit www.wfh.org and click on *Treatment Centre Directory (Passport)* under “Resources.”

European Haemophilia Consortium (www.ehc.edu)

National Hemophilia Foundation (www.hemophilia.org)

[Insert local patient advocacy group contact information]

[Insert hemophilia treatment center contact information]

This booklet is part of a global initiative, created by Bayer HealthCare, patients and healthcare professionals, to provide information about real-life issues of concern to teenagers and young adults with hemophilia.