



Frequently Asked Questions about Bleeding Disorders

What is a bleeding disorder?

A bleeding disorder exists when it is hard for a person to stop bleeding. When a person bleeds, the blood clots, stopping the bleeding. The clotting process, also called *coagulation*, changes blood from a liquid to a solid state. It takes both blood cells (called *platelets*) and proteins (called *clotting factors*) for blood to clot properly. When a person has a bleeding disorder, the blood platelets are not working like they should, or there are not enough platelets or clotting factors in the blood. This causes a person to bleed for longer periods of time than normal. Bleeding disorders tend to run in families and can be hard to detect in women. These disorders can be controlled, so a person can have a healthy and full life.

Are there different types of bleeding disorders?

Yes, there are different types of bleeding disorders a person can have. The two most common types of bleeding disorders are:

- **Hemophilia** - while this well-known disease affects men and women, most people who have hemophilia are men. Even though most people think hemophiliacs bleed to death from cuts, they actually suffer problems with internal bleeding into the joints, muscles, and organs. Treatment involves replacing the missing clotting factor in a person's blood, done through *intravenous (IV) treatment*, where a small tube is inserted into a vein.
- **von Willebrand Disease (VWD)** - a lesser known bleeding disorder that affects both women and men, VWD is the most common bleeding disorder in women. This disease causes bleeding in the intestines, bleeding gums, and very heavy menstrual periods in women. Treatment involves the release of stored clotting factors in the blood, or in severe cases replacing the clotting factor through IV treatment or with a nasal spray. When a person with VWD has a dental procedure or dental surgery, they need to take medication beforehand to reduce bleeding. Over the past 20 years, researchers have made great progress in diagnosing and treating VWD.

Is heavy bleeding during menstruation a bleeding disorder?

Heavy bleeding, or *menorrhagia*, during menstruation is not necessarily caused by a bleeding disorder. But, heavy bleeding can be a symptom of the bleeding disorder von Willebrand Disease (VWD). When a woman has heavy bleeding, it can be hard to find the exact cause of the bleeding. Certain gynecological diseases, using an intrauterine device for birth control, and taking medications can also cause heavy bleeding in women.

What are the symptoms of bleeding disorders? How would I know if I had one of these disorders?

Symptoms of bleeding disorders include:

- Very heavy bleeding with menstrual periods (menorrhagia)
- Unusual bleeding after injury or surgery
- Bleeding from small cuts that starts and stops over several hours
- Frequent or prolonged nosebleeds
- Unusual bleeding from the mouth or gums after a tooth extraction

If you have any of the following symptoms, you should discuss them with your health care provider. Your doctor may order tests to rule out a bleeding disorder, including a test for VWD. Be aware that your test results could be affected by your menstrual cycle. Because of this, tests may need to be done at different points in your menstrual cycle. Also know that just because your mother or your sister may also have had heavy periods, this may not be normal for you. If you are having heavy periods with no known reason, you need to be tested for VWD. Not all health care providers test for VWD when a woman is having heavy bleeding. In December 2001, the American College of Obstetrics and Gynecologists (ACOG) issued a report to health care providers to consider VWD as a possible cause for heavy menstrual bleeding in women. ACOG now recommends testing for VWD when:

- a woman is having heavy menstrual bleeding with no known cause;
- an adolescent is having heavy menstrual bleeding without other cause (testing should be done before starting any hormone therapy like birth control pills);
- hysterectomy for heavy menstrual bleeding is being considered.

Why is it important to know if I have a bleeding disorder?

When a bleeding disorder is not diagnosed and treated, it can cause serious problems, some of which can be life threatening. Women can have severe bleeding during and after childbirth or with a miscarriage. Severe bleeding can also happen during or after dental or other kinds of surgery, and after an injury or accident. A person can suffer internal bleeding, as well as bleeding in the brain. If you know that you have a bleeding disorder, be sure to tell your health care providers, especially before dental procedures, surgery, pregnancy and childbirth.

How are bleeding disorders treated?

The treatment for bleeding disorders varies. Disorders that cause minor bleeding problems may need no treatment. Medications are available to prevent or treat more severe bleeding problems, such as heavy periods or extreme bleeding during dental or surgical procedures. Birth control pills are frequently used to treat heavy bleeding in women with VWD. Nasal sprays, like *desmopressin acetate* (DDAVP), are used for both heavy menstrual bleeding and nosebleeds. A form of DDAVP can also be injected into a person's vein before surgery or if they are having serious bleeding. Medicines to clot the blood, called *clotting agents*, help control bleeding. For women who have extreme menstrual bleeding that does not go away with medication, sometimes surgery is an option. *Endometrial ablation* can be done, which applies heat, laser, or radio waves to the inside of the uterus, or womb, to control bleeding. *Hysterectomy*, or removal of the uterus may also be done to stop bleeding. But, both of these surgeries, for women with bleeding disorders, increase the risk of bleeding from the surgery itself.

There are health care providers, called *hematologists*, who have special training in bleeding disorders that can help you find the best treatment options. For information about hemophilia, VWD and other bleeding disorders, contact HANDI, the National Hemophilia Foundation's information clearinghouse toll free at 800-42-HANDI. Or, log on to their Internet web site, <http://www.hemophilia.org>.

For More Information...

You can find out more about bleeding disorders by contacting the National Women's Health Information Center (800-994-96620) or the following organizations:

Centers for Disease Control and Prevention,
Hematologic Diseases Branch

Internet Address: <http://www.cdc.gov/ncidod/dastlr/Hematology/>

Project Red Flag

Internet Address: <http://www.projectredflag.org/>

World Federation of Hemophilia

Phone Number: (514) 875-7944

Internet Address: <http://www.wfh.org/>

National Hemophilia Foundation

Phone Number: (800) 424-2634

Internet Address: <http://www.hemophilia.org/>

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