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TDD: 888-220-5446

# Bleeding Disorders



I am 25 years old and love to exercise, eat out, and go dancing. I've always bled heavily during my periods but never talked to a doctor about it. My mother

and sisters also have heavy periods, so I thought it was normal.

A few months ago I realized my period was interfering with my life. Every month I was afraid to go out with my friends when I had my period. I worried I would bleed through my pants. A lot of times I'd miss work and skip the gym because I felt so lousy.

So I decided to speak to my doctor. She ran some blood tests to rule out a bleeding disorder. At first, the test results came out normal. But my doctor repeated them to be sure.

The second time, the tests showed I had a bleeding disorder called von Willebrand disease. My doctor also found I had low levels of iron in my blood, or anemia. Now I take birth control pills to control my periods. Since I started taking the pill I bleed less and have a lot more energy. I'm also less self-conscious when I have my period. So going to work and hanging out with friends is more fun.

**Q: What is a bleeding disorder?**

**A:** A bleeding disorder is a health problem that makes it hard for a person to stop bleeding. Normally when a person is hurt, a clot forms to stop the bleeding quickly. This clotting process, called coagulation (koh-ag-yuh-LAY-shuhn), changes blood from a liquid to a solid state. For blood to clot, your body needs a type of blood cell called platelets. Your body also needs blood proteins called clotting factors.

In people with bleeding disorders, the platelets or clotting factors do not work in the right way or are in short supply. So, these people bleed longer than normal. With treatment people with bleeding disorders can lead full and active lives.

Bleeding disorders tend to run in families. Women normally bleed with menstruation and childbirth, so it may be hard to notice abnormal bleeding. In the United States, 1.5 to 4 million women have a bleeding disorder. And up to 2 million American women have a bleeding disorder and don't know it.

**Q: Are there different types of bleeding disorders?**

**A:** Yes, there are many kinds of bleeding disorders. The two most common are von Willebrand disease (VWD) and hemophilia (hee-muh-FIL-ee-uh).

**Q: What is von Willebrand disease (VWD)?**

**A:** VWD is the most common inherited bleeding disorder. It is caused by deficiencies or defects in a certain substance in the blood that helps clots to form. VWD occurs about as often in men as it does in women.



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Women with VWD may have:

- heavy and long menstrual periods (the most common symptom)
- easy bruising
- bleeding too much or for a long time after surgery or dental work
- bleeding too much after giving birth

### **Q: What is hemophilia?**

**A:** Hemophilia is a well-known but rare bleeding disorder that runs in families. It is caused by an inherited genetic mutation. If men inherit this trait, they don't have enough clotting factors needed to stop bleeding. Women who inherit the trait are carriers of the disease — they do not have hemophilia, but they may pass the trait onto their children. Most women who are hemophilia carriers do not have symptoms. But some have mild bleeding symptoms, such as:

- heavy bleeding during periods
- bleeding too much or for a long time after dental work, surgery, serious injury, or childbirth

### **Q: How would I know if I had a bleeding disorder?**

**A:** Some common symptoms of bleeding disorders include:

- very heavy periods (soaking through a pad or tampon every hour for 2 to 3 hours in a row or blood clots more than 1 inch in diameter)
- heavy bleeding from reproductive disorders that cause bleeding, such as endometriosis (EN-doh-MEE-tree-OH-suhss)

- large bruises from a minor bump or injury
- bleeding too much or for a long time
- nosebleeds that are hard to stop
- anemia

If you have any of these symptoms, talk with your doctor. Keep in mind that symptoms of bleeding disorders in women are often mild.

### **Q: Does heavy bleeding during my period mean I have a bleeding disorder?**

**A:** Not always. Research shows that 5 – 20 percent of women with heavy periods have a bleeding disorder, usually VWD. In other cases, heavy periods may be caused by:

- hormonal changes
- diseases or disorders of the reproductive system
- use of an intrauterine (IN-truh-YOO-tur-in) device (IUD) for birth control
- use of some medicines

Even if heavy periods run in your family, it might still be a sign of a problem. So, if you have heavy menstrual bleeding, ask your doctor about testing for bleeding disorders.

### **Q: How are bleeding disorders diagnosed?**

**A:** Blood tests are used to find out if you have a bleeding disorder and what type you have.

Your doctor will ask about your symptoms and any history of bleeding disorders in your family. Your doctor may perform a physical exam. If you are



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thinking about having surgery to stop heavy periods, you should talk to your doctor about being tested for a bleeding disorder first.

You may need to see a hematologist (hee-muh-TOL-uh-jist) for blood tests. A hematologist is a doctor who specializes in blood disorders.

**Q: Are routine tests for bleeding disorders always accurate?**

**A:** No, they are not. Screening tests may come out normal even when a woman has a bleeding disorder. Varied blood tests need to be done and some may need to be repeated for a correct diagnosis. This is because many things can affect test results, such as:

- hormonal changes during the menstrual cycle
- use of pain killers like aspirin
- use of birth control pills or other hormone therapies
- pregnancy, childbirth, or breastfeeding
- blood type
- intense exercise
- stress

Research shows that diagnosing bleeding disorders, especially VWD, in women is hard. One study found that women had symptoms for an average of 16 years before being diagnosed.

**Q: How are bleeding disorders treated?**

**A:** Although bleeding disorders cannot be cured, medicine can control the symptoms. Treatment for bleeding disorders varies. Most women with VWD don't

need to take medicine. People with mild bleeding problems may only need treatment before or after surgery and dental work or after an injury. More severe symptoms can be controlled with daily medicines.

Treatments for bleeding disorders include:

- **Birth control pills.** They increase the amount of clotting factors in the blood and can control heavy periods in women with some bleeding disorders.
- **Desmopressin acetate (dess-moh-PRESS-uhn A-suh-tayt) (DDAVP).** DDAVP is a hormone that makes the body release stored clotting factors into the blood. It can be given as a shot or nasal spray. DDAVP can prevent heavy periods and nosebleeds. It is also used before surgery or to stop serious bleeding.
- **Antifibrinolytic (an-teye-FEYE-bruhn-uhl-IHT-ihk) drugs.** These medicines are used to stop blood clots from breaking down. They can be used before dental work, to stop nosebleeds, and to control heavy periods.
- **Clotting factor concentrates.** These medicines contain the blood proteins or clotting factors that are missing from a person's blood. Clotting factor concentrates are injected into a vein. Adding these proteins to the blood prevents or controls bleeding. Different clotting factors are used to treat different kinds of bleeding disorders. Clotting factor concentrates are used when other treatments do not work, for surgery, or for serious injury.



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A hematologist can help you find the best treatment options. With treatment and regular visits to the doctor, women with bleeding disorders can lead full and active lives.

**Q: Why is it important to find out if I have a bleeding disorder?**

**A:** Finding out that you have a bleeding disorder and getting treatment can really improve your life. Untreated bleeding disorders often cause very heavy periods. This can cause you to miss work and skip social activities. It can also have a negative effect on your overall quality of life.

If you have an untreated bleeding disorder, you may lose a lot of blood during menstruation or after minor injuries. This can lead to anemia (uh-NEE-mee-

uh), or too few healthy red blood cells in the blood. Anemia can cause fatigue, dizziness, and shortness of breath.

Untreated bleeding disorders can also cause dangerous bleeding after:

- childbirth
- miscarriage
- abortion
- dental work
- minor surgery
- injury

All of these problems can be prevented or controlled with medicine. If you have symptoms of a bleeding disorder, talk to your doctor. If you know you have a bleeding disorder, be sure to tell your doctor, nurse, midwife, and dentist. ■



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### *For more information*

For more information on bleeding disorders, call [womenshealth.gov](http://womenshealth.gov) at 1-800-994-9662 or contact the following organizations:

**Division of Blood Disorders, Centers for Disease Control and Prevention**

Phone number: 800-232-4636 (CDC-INFO)

Web address: [http://www.cdc.gov/ncbddd/hbd/about\\_hbd.htm](http://www.cdc.gov/ncbddd/hbd/about_hbd.htm)

**National Heart, Lung, and Blood Institute Information Center, National Institutes of Health (NIH)**

Phone number: 301-592-8573

Web address: <http://www.nhlbi.nih.gov>

**World Federation of Hemophilia**

Phone number: 514-875-7944

Web address: <http://www.wfh.org>

**National Hemophilia Foundation**

Phone number: 800-424-2634

Web address: <http://www.hemophilia.org>

**American Society of Hematology**

Phone number: 202-776-0544

Web address: <http://www.hematology.org>

**Hemophilia Federation of America**

Phone number: 800-230-9797

Web address: <http://www.hemophiliafed.org/site.php>

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