

Von Willebrand Disease

A plain-English guide for you and your family

WHAT IS HAPPENING

Normally, when you get a cut or scrape, your blood has tiny cell fragments called platelets that rush to the site and form a plug to stop bleeding. But platelets can't stick to the injured blood vessel wall on their own—they need a helper protein called von Willebrand factor that acts like glue. In von Willebrand disease, your body either doesn't make enough of this glue protein, or the glue doesn't work properly. This means platelets have trouble sticking to the injury site, so bleeding lasts longer than normal. Most people with this condition have mild symptoms like easy bruising, frequent nosebleeds, or heavy periods in women. It's the most common inherited bleeding disorder, affecting about 1 in 100 people.

What you might feel

- Easy bruising
- Frequent nosebleeds lasting more than 10 minutes
- Heavy menstrual bleeding requiring pad or tampon change every 1-2 hours
- Prolonged bleeding after dental extraction or surgery
- Blood in stool or black tarry stools
- Joint swelling and pain
- Excessive bleeding after minor cuts lasting more than 15 minutes
- Bleeding in the mouth or gums with routine tooth brushing

Call the doctor right away if...

- Hemarthrosis (joint bleeding) or deep muscle a pooled collection of blood (hematoma) suggesting severe type 3 VWD with very low factor VIII
- Postpartum bleeding (hemorrhage) requiring transfusion or ICU admission
- Signs of hypovolemic shock (tachycardia, low blood pressure (hypotension), altered mental status) from acute blood loss
- New onset bleeding in older adult suggesting acquired von Willebrand syndrome from lymphoma, myeloproliferative disorder, or aortic narrowing (stenosis)

What the care team will do

- Assess for active bleeding and bleeding risk before any procedures or surgeries
- Monitor menstrual bleeding patterns in female patients and adolescents
- Teach patients to avoid aspirin and NSAIDs like ibuprofen
- Prepare for desmopressin (DDAVP) administration in Type 1 VWD patients before procedures
- Monitor for signs of intracranial bleeding after head trauma
- Coordinate factor replacement therapy (von Willebrand factor concentrates) for severe bleeding or Type 3 disease
- Screen for iron deficiency anemia from chronic blood loss
- Educate patients to wear medical alert identification and inform all healthcare providers of their diagnosis

Medicines you may be given — and why

Desmopressin

Desmopressin is a man-made copy of vasopressin, a hormone that normally controls urine output. When given to people with VWD, it binds to receptors on the cells lining blood vessels. This triggers those cells to squeeze out stored VWF into the bloodstream very quickly. The VWF level can triple or more within 30 minutes.

Von Willebrand factor/factor VIII concentrate (human plasma-derived)

This medicine contains real VWF and factor VIII proteins purified from donated human blood plasma. When infused into a vein, the proteins immediately circulate and fill in what is missing. The VWF molecules stick to platelets and blood vessel walls at injury sites. They also carry and protect factor VIII so it lasts longer in the blood. Both proteins work together to form strong clots.

Tranexamic acid

Tranexamic acid is shaped like the amino acid lysine. The body uses lysine binding sites to break down clots through a process called fibrinolysis. Tranexamic acid occupies those lysine sites on plasminogen (the inactive form of the clot-dissolving enzyme plasmin). This prevents plasminogen from turning into active plasmin. Without plasmin, clots stay intact much longer, especially on mucous membranes in the nose, mouth, and uterus.

Combined oral contraceptive pills (ethinyl estradiol with progestin)

Birth control pills contain two hormones: estrogen and progestin. The estrogen component increases the liver's production of VWF and factor VIII by 20–30 percent over several weeks. The progestin thins the uterine lining so less tissue sheds during periods. Together, they reduce menstrual blood loss by nearly half. The steady hormone levels also prevent ovulation (egg release), eliminating the mid-cycle hormone surge that can worsen bleeding.

Levonorgestrel intrauterine device (IUD)

The levonorgestrel IUD is a small T-shaped device placed in the uterus that slowly releases the progestin hormone levonorgestrel. The progestin acts directly on the uterine lining, keeping it very thin. Thin lining means much less tissue to shed during periods. Most women have very light periods or no periods at all after 6–12 months. Unlike pills, it does not raise VWF levels, but it is highly effective at reducing menstrual blood loss by 90 percent or more.

Recombinant von Willebrand factor (rVWF)

This is VWF protein made in a laboratory using genetically engineered cells, not from human blood. The cells are programmed to produce only VWF with the correct structure. When infused, the recombinant VWF works exactly like natural VWF, binding to platelets and collagen at injury sites. It does not contain factor VIII, so factor VIII must be given separately if needed. Because it is recombinant, it carries no risk of human viruses.

Where this information comes from

- American Society of Hematology (ASH) guidelines on von Willebrand disease diagnosis and management, 2021
- National Heart, Lung, and Blood Institute (NHLBI) evidence-based management of von Willebrand disease, 2020
- National Hemophilia Foundation (NHF) MASAC (Medical and Scientific Advisory Council) recommendations for von Willebrand disease treatment products and protocols, 2022
- American College of Obstetricians and Gynecologists (ACOG) Practice Bulletin on von Willebrand disease in women and adolescents, 2023

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