



Understanding bleeding disorders

Walgreens
Specialty Pharmacy

Table of contents

What you need to know about bleeding disorders	1
How bleeding disorders affect the body.....	1
Types of bleeding disorders.....	2
Causes	3
Diagnosis	4
Symptoms.....	4
Complications.....	4
Living with bleeding disorders	5
Medications	5
Lifestyle changes	7
Ongoing care	11
References.....	13
Notes.....	14

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What you need to know about bleeding disorders

Learning how to manage a bleeding disorder might feel like a challenge, especially at first. Whether you are living with a bleeding disorder or caring for someone who is, understanding the diagnosis can help you take control of any health concerns. This booklet provides information about bleeding disorders, what to expect after diagnosis and how to manage symptoms to live a full and active life.

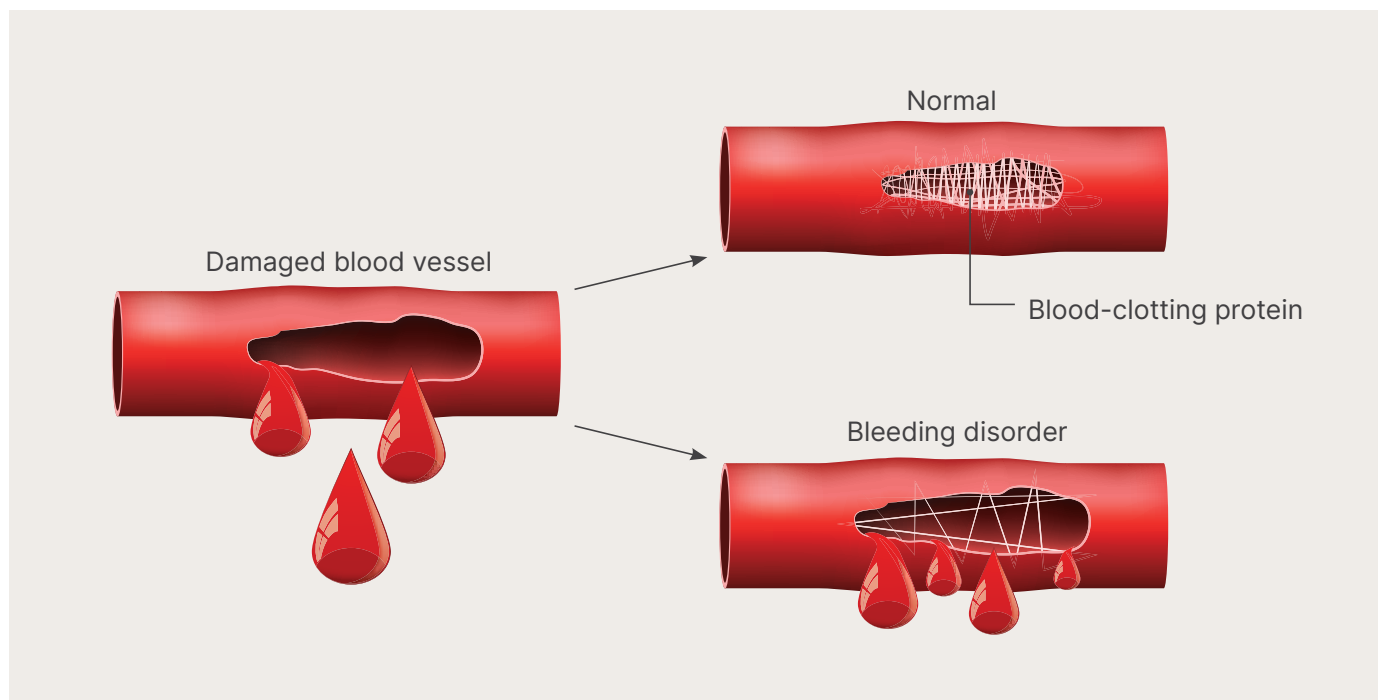
How bleeding disorders affect the body

In response to an injury, the body forms a blood clot to stop any bleeding. (See Figure.) To create blood clots, the body needs cells called platelets and proteins called clotting factors.¹ There are many different types of clotting factors. They help platelets stick together to seal any injuries in blood vessels or the skin.²

In bleeding disorders, the body might not have enough platelets. Or, clotting factors do not work as they should.¹ Because of this, bleeding might last longer than normal.

Bleeding might also occur inside the body. This might happen in the joints or muscles.³ This can damage organs and tissues. It can also be life-threatening.²

Figure. Clotting process





Types of bleeding disorders

There are different types of bleeding disorders. Some are mild. Others can be more serious.

Von Willebrand disease

The most common bleeding disorder is von Willebrand disease (VWD).⁴ It affects males and females equally. However, women with VWD are more likely to have symptoms. This might include heavy bleeding during menstrual periods, pregnancy and childbirth.⁵

VWD results from problems with a blood protein called von Willebrand factor (VWF).⁴ Problems with VWF affect the blood's ability to clot. There are three types of VWD⁴:

- **Type 1:** The body has lower than normal levels of VWF. This is the most common type.⁶
- **Type 2:** VWF does not work as it should.
- **Type 3:** The body has little or no VWF. This is usually the most severe form.

Another form of VWD is called acquired von Willebrand syndrome.⁶ This develops in adults because of certain medications or medical conditions, such as autoimmune disease, heart disease or some types of cancer.⁷

Most people with VWD don't have serious issues unless they have a severe injury or surgery.⁴ Many people with VWD do not know they have it.³ As many as 9 out of 10 people with VWD have not been diagnosed.⁴

Hemophilia

Hemophilia is less common than VWD. It usually affects males, with rare exceptions.² People with hemophilia do not have enough clotting factor. There are two types of hemophilia⁸:

- **Hemophilia A:** The body does not have enough clotting factor VIII. About 80% of people with hemophilia have type A.²
- **Hemophilia B:** The body does not have enough clotting factor IX.

Both types can be mild, moderate or severe. This depends on how much clotting factor is in the blood⁸:

- Mild: 5% to 40% of normal clotting factor
- Moderate: 1% to 5%
- Severe: Less than 1%

Clotting factor deficiencies and platelet disorders

Sometimes platelets don't work how they should. In rare cases, certain clotting factors are missing or not working as they should. One example of this is factor XIII deficiency.⁹ Like VWD and hemophilia, it can cause prolonged bleeding and spontaneous internal bleeding.⁹

Causes

Bleeding disorders can affect anyone. But most cases are inherited.¹¹ This means they are passed down in a family. Some affected people might have few to no symptoms. They can still pass the condition on to their children.^{2,6}

Sometimes, children are born with bleeding disorders even when there is no family history. This happens because of random changes, or mutations, in the genes that affect blood clotting.²

In some cases, bleeding disorders are acquired. This means they are not present at birth. Instead, they develop during a person's lifetime. These can develop for different reasons, including^{1,11,12}:

- Autoimmune disorders where antibodies attack the body's own clotting factors or platelets
- Certain drugs, including blood thinners
- Kidney or liver disease
- Lack of vitamin K
- Thyroid problems

Bleeding disorders by the numbers

Hemophilia

Affects about **1 in 5,000 males** born each year in the U.S.²

Affects an estimated **30,000 people** in the U.S.¹⁰

VWD

Affects an estimated **1%** of the world⁴

Is the most common type of bleeding disorder in **women**¹¹

Treated in nearly **15,000 people** in the U.S. between 2012 and 2016⁵

Diagnosis

There are several tests to diagnose bleeding disorders. Some can determine their severity.^{2,6} Your healthcare provider likely used many types of information for a diagnosis^{1,2}:

- Blood tests
- Family medical history
- Personal medical history
- Physical exam

Some bleeding disorders are diagnosed in infancy and early childhood.^{2,6,13} Severe types are typically diagnosed in the first year of life. Milder forms might not be diagnosed until adulthood.^{2,6,9}

Symptoms

Symptoms can differ from person to person. Some people have severe symptoms. Others have mild ones.^{2,6}

Some symptoms might include^{2,6,9}:

- Anemia, or low iron levels
- Bleeding in the mouth while teething or losing a tooth
- Blood in urine or stool
- Large bruises and bruising often
- Frequent or unprompted nosebleeds
- Heavy menstrual bleeding
- Recurrent miscarriage
- Stiff, swollen and painful joints
- Problems with wound healing
- Prolonged or heavy bleeding after an injury, surgery or dental work

Complications

If left untreated, bleeding disorders can cause lasting damage. In some cases, they can become life-threatening.^{2,6} It is vital to know the signs of serious complications.

Bleeding in and around the joints is common. This can happen without any cause.^{2,9} At first, it might only make joints feel stiff. Over time, this can damage the joints and cause pain. It can make it hard or impossible to move affected joints.² It can also cause other health problems, like arthritis.⁹

Signs of joint bleeding might include¹⁴:

- Crying or irritability in small children
- Discomfort or pain
- Loss of motion
- Stiffness
- Swelling
- Tingling in the joint
- Warmth
- Young children favoring a limb or refusing to walk

In some serious cases, bleeding can occur in the brain. This might happen after a minor bump on the head or a more serious injury.² In some cases, it happens for no apparent reason.⁹

Signs of bleeding in the brain might include²:

- Clumsiness with arms or legs
- Double vision
- Repeated vomiting
- Severe headaches, neck pain or stiffness
- Seizures or convulsions
- Sleepiness or behavior changes
- Sudden weakness
- Trouble walking

Ask your healthcare provider about how to spot early signs of serious complications. Discuss what to do and when to seek immediate medical help.



Living with bleeding disorders

There is no cure for bleeding disorders. But there are ways to manage symptoms and prevent damage to the body. Medication therapy and lifestyle changes can help.

The goals of treatment include^{2,6}:

- Increasing or replacing clotting factors
- Preventing joint damage and other serious health problems
- Stopping the breakdown of clots

Medications

Along with lifestyle changes, certain medication can help treat bleeding disorders. Treatment depends on the cause.¹ The best approach can differ for each person.

There are a few types of treatments available.^{2,6,15-16} See Table 1. Some treatments are used regularly.^{2,12} Others are used only after an injury or episode of bleeding. This is called demand therapy.² Still others are taken just before surgery, medical procedures or activities with a risk of injury.²

Not all treatments work for everyone. Some might work at first but stop working as time goes on.¹⁷

Some people develop antibodies that attack the clotting factor being used for treatment.² These antibodies are called inhibitors. They prevent treatment from working.^{2,18}

If this happens, a healthcare provider might prescribe larger doses of clotting factor or clotting factor from different sources.^{2,18} Those with inhibitors might also need to use special blood products called bypassing agents. These bypass the factors blocked by the inhibitors, allowing the body to form clots during a bleeding episode.¹⁸



Your healthcare provider will build a plan that is right for you. It is important to follow treatment exactly as prescribed. This means using the right doses at the right times. It also means not stopping treatment without talking to your healthcare provider first.

Staying on track with treatment is vital for controlling a bleeding disorder and preventing serious health problems. If treatment starts to feel too hard, ask your healthcare provider or pharmacist for help. You can always work with your healthcare provider to adjust treatment as needed.

Table 1. Bleeding disorder treatments

Treatment	Action
Antifibrinolytic medication ^{2,6,16}	<ul style="list-style-type: none">• Stops blood clots from breaking down• Controls heavy menstrual bleeding
Corticosteroid medication ²	Reduces pain and swelling in affected joints
Cryoprecipitate ¹⁵	Increases or replaces factor VIII
Desmopressin ¹⁵⁻¹⁶	Stimulates release of factor VIII and von Willebrand factor
Factor concentrate ¹⁵⁻¹⁶	Replaces clotting factors that are low or missing
Fresh frozen plasma ¹⁵	Increases or replaces factors VIII and IX
Fibrin glue	Covers a wound to directly stop bleeding
Hormone treatment ¹⁶	<ul style="list-style-type: none">• Increases VWF and factor VIII• Controls heavy menstrual bleeding
Iron supplement ¹¹	Increases red blood cells and raises iron levels
Non-factor replacement ²⁶	Helps to restore the function of factor VIII
Pain medicine ²	Reduces pain and swelling in affected joints



Lifestyle changes

Along with medication, certain lifestyle changes can improve overall health. Eating well, staying active, getting enough rest and managing emotional health can help.

Eating well

There is no specific diet for bleeding disorders. A healthful, balanced diet can support overall well-being. This includes¹⁹:

- Carbohydrates, including whole grains, fruits and vegetables
- Fats
- Proteins, such as fish, poultry, nuts, seeds and beans
- Water
- Vitamins and minerals

A healthful diet is key to reaching and keeping a healthy weight. This can help keep extra stress off joints that might already be weakened by bleeding.¹⁹ Or it might increase muscle mass that allows for more physical activity.¹⁹

Some people might need extra nutrients to repair damaged tissue or recover from surgery. Others need nutritional support for related conditions like HIV or liver disease. In these cases, a healthcare provider or dietitian might also recommend certain supplements.¹⁹

Each person has different dietary needs. This can change over time. Work with your healthcare provider or a dietitian to find the best approach.

Staying active

Staying active is vital for overall health, too. It can provide a number of benefits, including^{2,19}:

- Better sleep
- Healthy weight
- Flexible muscles
- Reduced stress and anxiety
- Strong bones and joints

Regular exercise might prevent joint disease associated with bleeding disorders.¹⁹ It might also help lower the frequency and severity of bleeding in those with hemophilia.²⁰ It is important to stay active — with some limits and precautions.²

Staying safe

Living with a bleeding disorder means taking certain safety measures. Some precautions might include^{2,6}:

- Asking your healthcare provider and pharmacist which medications are safe
- Having an injury plan and preparing any needed treatments
- Padding hard edges and corners on furniture around young children
- Sharing an injury plan with medical staff and caregivers at school, day care, work or the gym
- Shaving with electric razors instead of blades

- Staying up to date with vaccines, especially hepatitis A and B
- Telling dentists, healthcare providers and pharmacists about any treatments
- Using protective equipment, like kneepads or elbow pads, when appropriate
- Wearing a medical identification bracelet or necklace
- Wearing safety helmets and safety belts

Ask your healthcare provider what else you should consider. Together, you can create a plan to prevent illness and injury. This can also help ensure prompt treatment if it's needed.

For example, contact sports like football, hockey or wrestling might not be safe choices. But golfing, swimming or walking might be more suitable.² And some people take clotting factors before any physical activity to prevent bleeding in case of injury.²

Talk to your healthcare provider about the right type and amount of exercise. You can ask for a referral to a physical therapist who can help you build an exercise plan.² With the right plan, it's possible to stay active while staying safe.

Getting enough rest

Along with eating well and staying active, getting enough rest is crucial to overall health. Sleep can bring several benefits, including²¹:

- Better mood
- Improved mental focus
- Increased energy
- More growth hormone to boost muscle mass and repair cells and tissues
- Stronger immune system

The right amount of sleep varies from person to person. It also differs by age. See Table 2.²² Sleep needs might also differ for those living with chronic conditions, such as bleeding disorders. Ask your healthcare provider how much sleep is best.

A bleeding disorder can be tiring. Symptoms like anemia can bring fatigue.¹¹ Unfortunately, painful bleeding or aching joints might make it hard to sleep well.²³

Work with your healthcare provider to treat pain that affects sleep. Lack of sleep can make pain feel worse.²³ This creates a never-ending cycle that affects physical and mental well-being.²³

If needed, your healthcare provider might prescribe certain medication to better manage pain or promote sleep.²³ Tell your healthcare provider about sleep problems. It's vital to find ways to rest and recharge.

Emotional health

Some days, life with a bleeding disorder can be tough. Managing safety precautions might get stressful. Dealing with pain or navigating new treatments can feel overwhelming. It might be hard to connect with others.

Table 2. Recommended amounts of sleep by age

Age	Hours of sleep
Newborn (0–3 months)	14–17
Infant (4–11 months)	12–15
Toddler (1–2 years)	11–14
Preschooler (3–5 years)	10–13
School-age child (6–13 years)	9–11
Teen (14–17 years)	8–10
Young adult (18–25) or adult (26–64 years)	7–9
Older adult (65+ years)	7–8



You might feel frustrated or anxious. This is normal.¹⁹ It's good to be aware of these feelings. You can find healthy ways to cope.

Along with healthful eating, regular exercise and enough rest, certain things might help improve mood¹⁹:

- Creating a support system of family and friends
- Identifying sources of stress and avoiding them when possible
- Sharing feelings with people you trust
- Using humor or creativity to cope

Some days might feel sad or overwhelming. This is normal, too. But it's important to know the symptoms of depression and when to get help. Symptoms of depression can include²⁴:

- Aches and pains that don't go away with treatment
- Being tired or lacking energy
- Eating too much or too little
- Feeling hopeless or negative
- Feeling restless or irritable
- Feeling sad, empty or anxious most of the time
- Feeling worthless, helpless or guilty
- Having a hard time concentrating or making decisions
- Losing interest or pleasure in things you used to enjoy
- Sleeping too much or too little
- Thinking about death or suicide

Children and teens might also express depression in other ways, including²⁵:

- Boredom or low energy
- Difficulty with relationships
- Extreme sensitivity to rejection or failure
- Increased anger or hostility
- Low self-esteem
- Poor performance or attendance at school
- Social isolation
- Talk of running away from home

If either you or your child has thoughts of suicide, call 911 or your local emergency services number. You can also call a healthcare provider, mental health professional, crisis center or hotline for help.

Talk with your healthcare provider about depression. Your healthcare provider might suggest counseling, antidepressant medication or a combination of both. You might also consider joining a support group or online community where you can talk to others like you.

Pregnancy and breastfeeding

Pregnancy can pose certain risks for women with bleeding disorders.¹¹ Some might be at higher risk for miscarriage.¹² Others might see levels of certain clotting factors rise during pregnancy.⁶ But, they might also have bleeding problems during and after delivery.^{6,11}



Talk to your healthcare provider if you are trying to get pregnant, are currently pregnant or are planning to breastfeed.⁶ You can discuss several concerns, including^{6,11}:

- Assessing the risk of passing down a bleeding disorder
- Determining the safety of prescribed treatments when trying to conceive, during pregnancy and when breastfeeding
- Finding an obstetrician and medical center specializing in high-risk pregnancies
- Managing both bleeding disorder treatment and prenatal care
- Planning for labor and delivery
- Preparing for testing or treatment of an affected child¹⁵

Certain precautions can support a successful pregnancy.⁶ Talk to your healthcare providers about what to expect. Together you can build a plan to help manage your bleeding disorder while preparing for a baby.



Ongoing care

Work with your healthcare provider to keep track of your symptoms. You can discuss how well your treatment and lifestyle changes are working. Your healthcare provider can also adjust treatment as needed. Each visit can help you stay on track with treatment and avoid serious health issues.

We provide this information because the more you know about bleeding disorders, the better you'll be able to manage them.

Additionally, the Walgreens Specialty360 Therapy Team is here to support you with **dependable, personalized service** to help manage your medication side effects and stay on track with your prescribed therapy.

We look forward to being a member of your healthcare team and helping you get the best results from your treatment.



References

1. Bleeding disorders. MedlinePlus Web site. <https://medlineplus.gov/bleedingdisorders.html>. Updated December 2, 2021. Accessed March 1, 2022.
2. Hemophilia. National Heart, Lung, and Blood Institute Web site. <https://www.nhlbi.nih.gov/health-topics/hemophilia>. Updated September 11, 2019. Accessed March 1, 2022.
3. What are bleeding disorders? World Federation of Hemophilia Web site. https://elearning.wfh.org/elearning-centres/inherited-bleeding-disorders/#bleeding_disorders. Updated May 2012. Accessed March 1, 2022.
4. What is von Willebrand disease? World Federation of Hemophilia Web site. <https://www1.wfh.org/publication/files/pdf-1330.pdf>. Updated June 2018. Accessed April 19, 2024.
5. Von Willebrand disease data and statistics. Centers for Disease Control and Prevention Web site. <https://www.cdc.gov/von-willebrand/data/index.html>. Updated October 26, 2020. Accessed June 13, 2024.
6. The facts on von Willebrand disease fact sheet. National Heart, Lung, and Blood Institute Web site. <https://www.nhlbi.nih.gov/resources/facts-von-willebrand-disease-fact-sheet>. Updated September 11, 2019. Accessed April 19, 2024.
7. Von Willebrand disease. National Hemophilia Foundation Web site. <https://www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders/Von-Willebrand-Disease>. Accessed March 1, 2022.
8. What is hemophilia? World Federation of Hemophilia Web site. <https://elearning.wfh.org/elearning-centres/hemophilia/>. Updated May 2012. Accessed April 19, 2024.
9. Factor XIII deficiency. U.S. National Library of Medicine Genetics Home Reference Web site. <https://ghr.nlm.nih.gov/condition/factor-xiii-deficiency#>. Updated August 2020. Accessed March 1, 2022.



10. Fast facts about bleeding disorders. National Hemophilia Foundation Web site. <https://www.hemophilia.org/About-Us/Fast-Facts>. Accessed March 1, 2022.
11. Bleeding disorders. Office on Women's Health Web site. <https://www.womenshealth.gov/a-z-topics/bleeding-disorders>. Updated December 27, 2018. Accessed March 1, 2022.
12. Factor XIII deficiency. National Organization for Rare Disorders Web site. <https://rarediseases.org/rare-diseases/factor-xiii-deficiency/>. Updated 2016. Accessed March 1, 2022.
13. Hemophilia data and statistics. Centers for Disease Control and Prevention Web site. <https://www.cdc.gov/hemophilia/data-research/index.html>. Updated September 14, 2020. Accessed June 13, 2024.
14. Joint damage. Hemophilia Federation of America Web site. https://www.hemophiliafed.org/disease_type/joint-damage/. Accessed April 19, 2024.
15. Hemophilia treatment. World Federation of Hemophilia Web site. <https://elearning.wfh.org/elearning-centres/hemophilia/>. Updated March 2016. Accessed April 19, 2024.
16. Treatment of VWD. World Federation of Hemophilia Web site. <https://elearning.wfh.org/elearning-centres/von-willebrand-disease/>. Updated May 2012. Accessed April 19, 2024.
17. Inhibitors. Hemophilia Federation of America Web site. <https://elearning.wfh.org/elearning-centres/inhibitors/>. Accessed April 19, 2024.
18. Inhibitors. Centers for Disease Control and Prevention Web site. <https://www.cdc.gov/hemophilia/testing/testing-for-inhibitors-and-hemophilia.html>. Updated July 17, 2020. Accessed June 13, 2024.
19. Riske B. Wellness in persons with bleeding disorders. National Hemophilia Foundation Web site. <https://www.hemophilia.org/sites/default/files/document/files/nurses-guide-chapter-17-wellness-in-persons-with-bleeding-disorders.pdf>. Published 2012. Accessed March 1, 2022.
20. Tiktinsky R, Falk B, Heim M, Martinovitz U. The effect of resistance training on the frequency of bleeding in haemophilia patients: a pilot study. *Haemophilia*. 2002;8(1):22-27. Cited by: National Hemophilia Foundation. Playing it safe: bleeding disorders, sports and exercise. National Hemophilia Foundation Web site. <https://www.hemophilia.org/educational-programs/education/online-education/playing-it-safe>. Published 2017. Accessed March 1, 2022.
21. Your guide to healthy sleep. National Heart, Lung, and Blood Institute Web site. https://www.nhlbi.nih.gov/files/docs/public/sleep/healthy_sleep.pdf. Revised September 2011. Accessed April 19, 2024.
22. How much sleep do we really need? National Sleep Foundation Web site. <https://sleepfoundation.org/how-sleep-works/how-much-sleep-do-we-really-need>. Accessed March 1, 2022.
23. Aldridge S. Sleep tight: getting a good night's rest. HemAware Web site. <https://hemaware.org/sleep-tight-0>. Published September 1, 2014. Accessed March 1, 2022.
24. Depression: signs and symptoms. National Institute of Mental Health Web site. https://www.nimh.nih.gov/health/topics/depression/index.shtml#part_145397. Revised February 2018. Accessed March 1, 2022.
25. Depression in children and teens. American Academy of Child and Adolescent Psychiatry Web site. https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/The-Depressed-Child-004.aspx. Updated October 2018. Accessed March 1, 2022.
26. Non-factor replacement therapy. World Federation of Hemophilia Web Site. <https://elearning.wfh.org/elearning-centres/non-factor-replacement-therapy/>. Updated August 2020. Accessed April 19, 2024.



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