WHAT IS HEMOPHILIA?

Hemophilia is a bleeding disorder that develops when blood does not clot properly. This can cause bleeding with no obvious cause or heavy bleeding after surgery or injuries. Proteins in the blood called clotting factors work to form clots and stop bleeding. Someone with hemophilia does not have enough of a clotting factor and therefore has trouble forming clots to control bleeding.

Alden Dunlap, 23, has severe hemophilia. When sharing his personal story he reflected:

> ***"I look at hemophilia and see that it's a part of me. I'm not going to work my way around it. I'm going to work with it. I'm not going to let it define me."***

- Read Alden's story here.

Are there different types of hemophilia?

Yes, there are several different types of hemophilia, which are named based on the clotting factor that is missing. The most common types are hemophilia A and hemophilia B. Hemophilia A is caused by not having enough clotting factor VIII, and hemophilia B is caused by not enough clotting factor IX.

What are the risk factors for hemophilia?

Hemophilia is usually an inherited bleeding disorder, meaning it is passed down from parents and is present at birth. Most people with hemophilia are born with the condition, as it is typically inherited from a parent. However, about one-third of babies diagnosed with hemophilia have no family history of the disorder.

What are the symptoms of hemophilia?

Hemophilia symptoms can range from mild to severe and include:

- Bleeding after having shots
- Excessive bleeding after a trauma or during surgery
- Bleeding into the joints, which can cause pain and swelling (often affecting the knees, elbows, or ankles)
- Excessive bruising or blood pooling under the skin or into the muscle (a hematoma)
- Frequent nosebleeds that are hard to stop
- Blood in the urine or stool
- Bleeding of the mouth and gums

Carrie, her son, and her father all have hemophilia. Her advice to people living with the disorder is:

> ***"Hemophilia is part of your life, it isn't all of your life. This is a component of it. This little thing called hemophilia doesn't get to hold you back."***

- Read Carrie's story here.

How is hemophilia diagnosed?

Since it is usually inherited, people who have hemophilia or have family members with it, should talk to their healthcare provider about having their children tested for hemophilia at birth. In some cases, even if there is no family history of hemophilia, a doctor might check for the condition if a baby is showing signs of it. If a doctor suspects a patient has hemophilia, they will perform blood tests to see if the blood is clotting properly. If it is not, they will run additional tests to find out why. These additional tests help determine which clotting factors might be causing the blood to not clot properly and the type and severity of the hemophilia present.

What is the treatment for hemophilia?

Treatments are similar for hemophilia A and B. Since both are caused by missing clotting factors, treatment involves replacing those clotting factors so that the blood can clot properly. This can be done by injecting clotting factors into the blood, a process called infusing. Patients are able to do this themselves, which allows them to prevent most bleeding issues. People who have either hemophilia A or B may also be able to get gene therapy to replace the defective copies of the genes responsible for making clotting factors. Newer therapies, including the medication emicizumab, which is given as a shot, prevent bleeding by acting like the factor to help the blood clot. Other treatments and specialty care can be given at hemophilia treatment centers (HTC).

How can people with hemophilia manage their condition and live their healthiest life?

If you or someone you love has hemophilia, being proactive about everyday care is critical. Stay educated about the condition and treatment options so you can make the best possible decisions. Find quality medical care. An HTC is often the best choice to support overall health and wellbeing. Community support is also key. A directory of HCTs can be found here. Connect with local groups that can help you meet other families in your area who are also affected. Visit the Blood Health Network page to find organizations that provide information about medical care, educational materials, financial assistance, or community resources.

Make sure your lifestyle supports your efforts to be healthy and lower your risks for complications. To do that:

- Follow a heart-healthy diet.
- Maintain a healthy weight.
- Exercise regularly. Talk to your doctor about reducing your bleeding risk while staying active.
- Manage stress.

Jennifer (now 60) was diagnosed with hemophilia B and von Willebrand disease at age 10. When speaking of the resources that have become available in recent years she said:

> ***"I am overwhelmed by and grateful for the abundance of resources for those living with bleeding disorders. I live in a small community, and online support groups and webinars have been excellent sources of support and education."***
>
> - Read Jennifer's story here.

Learn more about bleeding disorders at nhlbi.nih.gov/health/bleeding-disorders

NIH National Heart, Lung, and Blood Institute
Blood Diseases & Disorders Education Program
NIH Publication No. 25-HL-8232
March 2025