
When Your Child Has Hemophilia

Hemophilia is an inherited blood disorder. It occurs when your child is missing a protein called a clotting factor in the blood. Clotting factors work with blood cells called platelets to control bleeding. Hemophilia can be serious and may need treatment depending on how severe it is. Your child's healthcare provider can discuss treatment choices with you.

What causes hemophilia?

Typically, hemophilia is inherited, meaning it is passed from parent to child. But rarely it can occur spontaneously with no known family history of the disorder. It is much more common in males than females. This is because the gene involved is linked to gender. Parents and siblings of a child with hemophilia should be tested for the condition. A genetic counselor can answer questions you may have.

What are the types of hemophilia?

There are different types of hemophilia based on the clotting factor involved. The most common types are:

- **Hemophilia A.** This is also called classic hemophilia or factor VIII (8) deficiency. This type occurs when there is too little factor 8.
- **Hemophilia B.** This is also called Christmas disease or factor IX (9) deficiency. This type occurs when there is too little factor 9.

What are the symptoms of hemophilia?

- Excessive bruising or bleeding after an injury or even for no apparent reason
- Bleeding gums
- Nosebleeds that won't stop
- Bleeding from a wound that stops and starts again
- Swollen joints from bleeding into the joints

How is hemophilia diagnosed?

Your child will likely see a pediatric hematologist. This is a healthcare provider who specializes in blood disorders (hematology). The healthcare provider will examine your child and ask about symptoms and health history. They will also want to know if you have a family history of blood disorders or excessive bruising or bleeding. The following tests may also be done:

- Coagulation tests to check the clotting process in your child's blood. These can include the prothrombin (PT) test and the partial thromboplastin time (PTT) test.
- Blood tests to measure the amounts of specific clotting factors in the blood.

Based on the test results, the healthcare provider can tell what type of hemophilia your child has and grade it. Grades are mild, moderate, or severe. The grade is determined by

the amount of factor in the blood.

- **Mild hemophilia.** Child makes more than 5% of the normal amount of factor.
- **Moderate hemophilia.** Child makes 1% to 5% of the normal amount of factor.
- **Severe hemophilia.** Child makes less than 1% of the normal amount of factor.

How is hemophilia treated?

Treatment depends on the type of hemophilia your child has, the grade, and if it causes other health problems. Possible treatments include:

- **Replacement therapy.** With this treatment, the missing amount of factor is replaced in the blood. It may be needed during a bleeding episode. It may also be given on a schedule to help prevent bleeding episodes. This treatment is usually given at home after trained healthcare providers teach you and your child how to give the treatment. It can also be done in a hospital, a hematology center, or a clinic.
- **Medicine called desmopressin (DDAVP).** This may be prescribed for children with mild to moderate forms of hemophilia A. It can help raise the amount of factor 8 in the blood.
- Other medicines to prevent blood clots from breaking down. This helps the blood clots last longer and prevent bleeding.

What are the long-term concerns?

- Hemophilia is a lifelong condition. Regular healthcare provider visits are needed for routine checkups, tests, and vaccines.
- Consider having your child wear an emergency medical bracelet and carry a medical card with information about their condition.
- Work closely with the healthcare provider to learn how to help your child. Follow all directions about how to reduce the risks of bleeding and possible problems. For instance, your child may have to stay away from certain activities. They may also need to take medicines before dental work or certain procedures to help control bleeding.

When to call your child's healthcare provider

Call your child's healthcare provider if any of the following occur:

- Swollen joints
- Nosebleed
- Bleeding gums

Call 911

Call 911 if your child has any of the following:

- Bleeding that won't stop

-
- Signs of bleeding in the brain, including headaches, confusion, vision problems, and weakness
 - Severe pain
 - Serious injury, including head or belly (abdominal) injury

Coping with your child's condition

As much as you can, find support as you care for your child. Counseling can help you and your child cope with worries or concerns. Seek help from family, friends, community, or support groups. And check if your local hospital has a child life program. This helps children cope with illness. A hospital social worker can also answer questions and refer you to other support services. The more you learn about your child's condition, the more in control you may feel.