



Treating Your Child's Hemophilia

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Understanding Hemophilia



If your child is diagnosed with hemophilia (heem-o-FILL-ee-ah) A or B, their blood doesn't clot properly. They have either low levels of clotting factor VIII (8) or clotting factor IX (9). Clotting factors are proteins needed to form clots and help stop bleeding. Hemophilia can lead to bleeding following injuries or surgery. Bleeding may also occur without an obvious cause. How severe a person's hemophilia is depends on the amount of clotting factor in their blood.¹

Talk with your child's doctor about receiving treatment at a **hemophilia treatment center (HTC)**. The experts at these centers develop comprehensive care plans for patients and families. They also offer a wide range of services and support.²



How Hemophilia Is Treated



Each person responds to treatment differently. Work closely with your child's doctor or HTC to find a treatment that works best for your child. Your input is important.^{2,3}

Factor Replacement Therapy

Factor replacement therapy is the main treatment for hemophilia. It involves replacing the clotting factor that's missing or low by infusing clotting factor concentrates into a vein in the arm or hand, or through a port in the chest.^{3,4}

There are two types of factor replacement products, standard half-life and extended half-life. Half-life refers to how long the factor is effective in the body, which can vary from person to person.³

Standard half-life. This therapy has a half-life of about 8 to 12 hours for factor VIII and 18 to 40 hours for factor IX.⁵

Extended half-life. This therapy has a half-life that's longer than standard therapy – about 1.5 times longer for factor VIII and up to 5 times longer for factor XI.⁵

When is Factor Replacement needed?

Factor replacement therapy is recommended to stop a bleeding event or to prevent bleeding from occurring. Treatment with factor replacement therapy on a regular basis is called prophylaxis. This type of treatment is most often used for patients with severe hemophilia.^{3,6}

Home Therapy^{4,7}

As your child grows, you may want to learn how to give the clotting factor at home (home therapy). Home therapy allows you to treat bleeds quicker, resulting in less serious bleeding and fewer side effects. Home therapy can be especially helpful for patients who have severe hemophilia and bleed often. If you have questions or need help deciding if home therapy is a good option, talk to your doctor or HTC. If you decide to try home therapy, your HTC team will teach you everything you need to know to safely follow your child's treatment plan.

What are Inhibitors?⁸

Inhibitors are a serious complication of a bleeding disorder. Inhibitors keep factor replacement therapy from working, making it harder to stop bleeding. If your child develops an inhibitor, they will need special treatment until their body stops making them. It's best to seek care for inhibitors at an HTC as treatment can be a challenge and requires medical experts. It's important that people with hemophilia be tested for inhibitors at least once a year.

Non-factor Replacement Therapies



There are newer treatments that help prevent bleeds or help the blood clot better without using clotting factor. These are called non-factor replacement therapies.³

- **Monoclonal antibodies** prevent or reduce how often a person bleeds by mimicking the way factor VIII (8) works to help form a clot. It's given by an injection under the skin.^{3,6}
- **Desmopressin** is similar to a hormone that occurs naturally in the body. It works by releasing factor that's stored in body tissues to help stop bleeding. It's used for people with mild hemophilia. It's also given by injection.^{3,4}



Gene Therapy



Gene therapies help treat genetic diseases or disorders by giving the affected person working copies of the mutated gene. This aims to address the genetic cause of the disease or disorder. Gene therapy for hemophilia A and B are different types of gene therapies. Work with your child's health care team to find out if gene therapy is right for your child.³

Ongoing Care



Staying healthy and active is important for all children. This can be a challenge for a child with hemophilia. These are key actions for any parent of a child with hemophilia:⁹

- Ensure your child gets an annual checkup at an HTC
- Get your child vaccinated against Hepatitis A and B
- Treat your child's bleeds early and adequately (within 1 hour)
- Help your child exercise and maintain a healthy weight to help protect their joints
- Ensure your child is regularly tested for bloodborne infections

Be Prepared for Bleeds



- Keep your child's doctor and HTC phone numbers with you at all times¹⁰
- Teach your child to identify and report signs of bleeding, and be sure they know who to ask for help¹⁰

Know when to call the doctor or 9-1-1!

Certain types of bleeds are life-threatening and require immediate attention. If your child shows signs bleeding in the head, spine, eyes, neck or throat, abdomen, kidneys, or bladder get help right away.^{11,12}



Children need age-appropriate protection from things that may cause an injury or bleeding



Here are some ways to help keep your child safe:^{10,12}

- Childproof your home to prevent bumps and falls
- Use safety belts and straps in high-chairs, car seats, and strollers
- Have your child wear safety gear, such as knee pads, elbow pads, and helmets, during playtime activities
- Have your child wear a medical identifier, such as a necklace or bracelet

As your child grows, help them become independent and able to care for themselves



Here are some things you can do:^{7,13}

- Find small ways to involve your child in their care when they're young so they learn the basics early
- Attend educational events together with your child. These are often made available through your HTC or local bleeding disorders chapter
- Consider sending your child to a hemophilia camp
- Have age-appropriate talks with your child about their hemophilia and treatment plan
- Include your child in age-appropriate talks with their medical team
- As your child enters the pre-teen and teen years, gradually help them learn the steps needed to fully manage their care and treatment
- Encourage your child to speak with the medical team, ask questions, and voice concerns they may have
- Over time, help them learn how to self-infuse and keep a log of their medication



Get more information and support at stepsforliving.hemophilia.org

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