



Bleeding & Clotting Disorders Institute

Family-oriented care for persons with bleeding, clotting and other blood disorders

Hemophilia is a bleeding disorder that affects a person's clotting process. Individuals with Hemophilia have a lack of or decreased amount of clotting factors VIII (8) or IX (9). There are two main types of Hemophilia:

- Hemophilia A
 - Individual has lack of or decreased amount of clotting factor VIII (8)
- Hemophilia B
 - Individual has lack of or decreased amount of clotting factor IX (9)

There are also different severity levels, ranging from mild to severe. It is important to note that normal levels of factor VIII and IX are between 50%-100%. Levels of severity of Hemophilia are:

- Mild: 6-49%
 - Individual will usually bleed with major trauma, surgery, and tooth extractions
- Moderate: 1-5%
 - Individual will usually bleed with minor trauma, surgery, and tooth extractions
- Severe: <1%
 - Individual may bleed spontaneously into joints and muscles as well as with minor trauma, surgery, and tooth extractions

*Your Hemophilia Treatment Center staff will educate you on your type of Hemophilia at the time of your diagnosis.

- ✓ You have been diagnosed with Hemophilia _____
- ✓ Your primary Provider here is _____

Inheritance of Hemophilia:

- affects approximately 1 in 5,000 live births
- genetic mutation, carried on the X-chromosome
- passed down from parents to children
- may occur in up to 30% of the cases through spontaneous genetic mutation
- Inheritance examples:
 - male with hemophilia (XY) will pass the gene to all of his daughters (XX).
 - female with the gene (XX) has a 50% chance of passing it to her sons (XY) who will then have hemophilia and 50% chance of passing it to their daughter (XX) who will then be carriers

Common symptoms of Hemophilia:

- Bleeding from umbilical cord stump at birth
- Bleeding into joints (hemarthrosis) and soft tissue or muscles
- Prolonged/excessive bleeding after injury or surgery
- Nosebleeds (epistaxis) or gum bleeding (gingival bleeding)
- Heavy menstrual bleeding
- Easy bruising



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- In severe cases (rare): bleeding in stomach, intestines, brain, or spinal cord

If you or a loved one has been diagnosed with Hemophilia, it is important to know when you should contact BCDI.

Please call if the person with Hemophilia has:

- been scheduled for **any** type of dental or surgical procedure
- prolonged (greater than 10 minutes) nose bleeding
- prolonged (greater than 20 minutes) gum or mouth bleeding
- blood in the urine or stool
- excessive or prolonged (more than 7 days) menstrual bleeding
- more frequent bruising or large, painful bruising with knots
- symptoms of a joint or muscle bleed
 - bubbly/tingly feeling, pain, swelling, warmth, redness, decreased range of motion
- suffered an injury to the head, neck, or stomach
 - **If loss of consciousness or significant bleeding – call 911 prior to making other calls.**

When in doubt, we ask that you call our office for recommendations.

- **To reach a nurse, please call (309) 692-5337.**
- **After regular business hours, please call (309) 677-6085 to reach the provider on call.**

*Any of the above situations **may** require a person with Hemophilia to receive treatment. It is important to contact BCDI so that treatment recommendations can be discussed.

Available treatment options for symptoms of Hemophilia:

- **Aminocaproic Acid (Amicar™):**
 - Available in liquid and pill form
 - Used for mouth or nose bleeding
 - Will likely be necessary with dental procedures
- **DDAVP (Stimate™):**
 - Only used for Mild Hemophilia A patients
 - Nasal Spray/IV solution
 - Used for minor bleeding (including minor injuries, nosebleeds, menstrual bleeding, surgical procedures, etc.)
 - If you use Stimate, please ask BCDI for a copy of our “Fluid Restriction Guidelines”
- **Tranexamic Acid (Lysteda™):**
 - Available in pill form
 - Used for heavy menstrual bleeding
- **Factor Replacement Product:**
 - Given as intravenous infusion
 - Indicated with some surgical procedures and with injuries/bleeding episodes
 - Some severe hemophilia patients infuse this prophylactically to prevent bleeding episodes



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There are also certain medications that persons with Hemophilia should avoid due to their ability to cause an increase in bleeding symptoms. Persons with Hemophilia should avoid:

- Aspirin™
- Ibuprofen (Motrin™, Advil™, etc.)
- All other NSAIDS – excluding Celebrex™ and Meloxicam™

Staying active and activities that should be avoided:

- Although you have been diagnosed with Hemophilia, it is still important for you to stay active and participate in the activities that you enjoy. Persons with Hemophilia have few limitations when it comes to sports, but there are some select activities that are too dangerous and should be avoided.
 - **Activities to avoid:**
 - Contact sports
 - Tackle Football
 - Hockey
 - Boxing, or any other contact sports
 - Riding roller coasters
 - **Refer to “Playing it Safe” Manual for more details on activity safety**
 - **Please inform your or your child’s coach of the bleeding disorder diagnosis**
 - **An emergency treatment plan should be in place when playing organized sports**

*If you are interested in a specific activity and are unsure if it is safe, please do not hesitate to contact BCDI for formal recommendations.

How to inform others about your diagnosis:

- BCDI has outreach staff that is available to come to your child’s school, local emergency department, and/or other important areas to do education on Hemophilia. These services are offered by our clinical staff.
- Once diagnosed, a piece of medical alert jewelry should be worn at all times. Your first medic alert tag can be provided by BCDI.
- BCDI can provide you with informational travel letters, wallet cards, and other important documentation that explain your diagnosis and emergency treatment options. These documents should be carried with you or in your vehicle at all times.