



Taking Care

A Guide to Caring for a Child with **Hemophilia**

- ... for babysitters, teachers, coaches and other caregivers

Connected in Care

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Like any child, children with hemophilia play, learn, and lead full, active lives – with just a little extra care. If you are reading this, a child with hemophilia may have been entrusted into your supervision.

This guide will help answer some of the questions you may have and provide you with information that will make you an important partner in the child's care and support. You will find answers to questions such as:

- **What is hemophilia?**
- **What kinds of activities are safe?**
- **What should I watch for?**
- **What do I do in an emergency?**

Working closely together with the child and his parents, you will be helping to ensure that he has fun and stays safe.



🔥 What is hemophilia?

- Hemophilia is a rare bleeding disorder that a person is born with and usually affects **boys**.
- Hemophilia is not contagious.
- There is no cure, but there is **treatment**.
- In persons with hemophilia, the blood cannot **clot** properly. They do not bleed faster, they bleed longer.
- **Bruises** are common and show bleeding under the skin. Bruises may not always require treatment.
- Bleeding can also happen **deep** inside the body, where you can't see the blood. For example, bleeds can happen in a joint or in the brain.

Factor Replacement Therapy

There are two types of factor replacement therapy – those made from human **plasma**, or those made artificially using DNA (**recombinant**) technology. Both sources provide factor proteins that are nearly identical to the proteins missing in people with hemophilia.

Factor replacement therapy involves injecting clotting factor concentrates, Factor VIII (for hemophilia A) or Factor IX (for hemophilia B), directly into the vein of a person with hemophilia. The clotting factors start to act right away to help form blood clots and stop bleeds.

They are rare, but side effects such as allergic reactions, thrombosis and hemolysis (the breakdown of red blood cells) may occur. There is also a risk of viral transmission. Inhibitors can also develop when a patient is on factor replacement therapy; inhibitors are antibodies that can disrupt the function of a clotting factor.



Make sure you understand the treatment requirements of the child you are caring for.

Other Treatments

When used properly these other treatments can help control a bleeding episode in some patients with hemophilia.

Desmopressin is an injectable, non-blood product that may be used to treat small bleeds in people with mild hemophilia A. It helps by copying the role of the natural hormone that releases Factor VIII and Von Willebrand Factor from the cells lining the blood vessels. (Von Willebrand Factor transports Factor VIII in the bloodstream, to help repair a damaged blood vessel). Desmopressin cannot be used to treat any form of hemophilia B or moderate to severe hemophilia A.

There are some minor side effects with desmopressin, including facial flushing, headache, nausea, abdominal cramps, tachycardia (rapid beating of the heart). More uncommon is hypertension and hypotension. For patients with hypertension their doctor will have to monitor their blood pressure and sodium levels when taking desmopressin.

Tramexamic acid and Aminocaproic Acid help a clot stay once it has formed at the site of a damaged blood vessel. They stop an enzyme called plasmin from breaking down blood clots. Both drugs can be used in hemophilia A and B, but since they do not help clots form, they do not replace Factor VIII or IX concentrates or Desmopressin for treatment.

Topical thrombin and fibrin sealant can be used to control bleeding from a small cut in an accessible area like on a leg or arm, or it can be used after a dental procedure.

What kinds of activities are safe?

Talk with the child's parents about what types of activities he can do. Children with hemophilia should avoid contact sports. Some activities can be made safer with protective equipment such as a helmet, knee and elbow pads.

Category 1:

Most children with hemophilia can safely participate in these sports.

- Swimming
- Bicycling (be sure to wear a helmet)
- Walking

Category 2:

Majority of sports fall into this category, however these sports can sometimes cause a bleed and the suitability must be evaluated for each child.

- Baseball
- Tennis
- Basketball
- Soccer

Category 3:

These are sports to avoid because of the high speed and high contact. They are not recommended for children with hemophilia.

- Football
- Hockey
- Weight lifting (with heavy weights)
- Wrestling

What should I watch for?

Children tend to get different types of injuries at different ages.

In babies, bleeds are usually surface bruises. When babies start learning to walk, they often fall and get bumps and bruises. They can also have mouth bleeds. **After age 2**, bleeding into the joints, soft tissues, and muscles is more common. **Children** can bleed in the mouth, from cuts, biting their tongue, or losing a tooth. Internal bleeds can happen due to rough play, sports, or falls.

As children with hemophilia get older, and become **teenagers** and then **adults**, they often learn to avoid injuries that will cause bleeds. Bleeds still happen, just less often.



Children with hemophilia do not bleed faster than other children. Their bleeding is just harder to stop once it starts.

Read on to learn the signs of a bleed, and the most serious types of bleeds to watch for.



Bleeds can happen with very minor injuries – a slight bump or twist. Joints bleed easily if they have bled before. When a bleed does happen, you may never know the cause.

Sometimes a bleed is called a hemorrhage (“hem – or – aj”).

What should I watch for? (continued)

Bleeding into a Joint

Left untreated, a joint bleed will last for days. Joints bleed more easily if they have bled before. Repeated joint bleeds can cause lasting damage.

Know the Signs:

- The joint will begin to feel **tight**, and then painful.
- It may feel **puffy** to the touch.
- It may begin to feel **warm** to the touch.

It is important to treat joint bleeds right away to avoid pain and long-term damage.

If left untreated:

- Within hours, the joint becomes **hot** to the touch. The joint is **swollen**, and it is **painful** to bend or straighten it fully or put weight on it.
- Swelling increases and the **joint cannot move**. At this point the joint may be in **extreme pain**.
- The bleeding slows after **several days**, and the blood is then slowly absorbed.

Bleeding in the Brain

Bleeds in the brain can be life-threatening. It is important to notice the signs quickly and get medical help right away.

Know the Signs:

- A headache that won't go away or gets worse
- Throwing up (vomiting)
- Feeling sleepy or acting differently than usual
- An arm or leg that feels weak or clumsy
- A stiff neck, or if it hurts to move the neck
- Seeing double
- Crossed eyes
- Losing balance or coordination
- Convulsions or seizures (fits)

What do I do in an emergency?

1) Comfort the child.

2) Initiate first aid and treat bleeding fast.

Some bleeds need only first aid. More serious bleeds need first aid plus a factor infusion. All bleeds need attention right away to reduce pain and damage.

3) If in doubt, get help. If you think the child has a serious bleed, get medical help even if you are not sure. Call the emergency number provided by the child's parents. Don't wait until the signs become obvious.

For someone not familiar with caring for a child with hemophilia, it may be difficult to know when it is the right time to treat a bleed with an infusion of clotting factor at home. For patients with moderate or severe hemophilia the Canadian Hemophilia Society recommends treating an infusion with clotting factor when:

- There is bleeding into a joint
- There is significant bleeding into soft tissues, such as muscles
- There are cuts to the lips or gums
- The child experiences a hard blow to his head
- There is a bleed to the neck, throat or chest

- There is an injury to the abdomen
- There is a bruise, that is very painful, seems to be getting larger in size, limits movement in nearby joints or is near a critical place, such as the eye
- Bleeding in the urine that is dark red in colour

An infusion with clotting factor is usually not needed for:

- Small bruises
- Nosebleeds that stop after the first or second attempt of sitting upright and pinching the nose
- Bleeding in the urine that is pink in colour (only mild)

First Aid for Minor Bleeds:

Use the **RICE** method to slow bleeding and keep swelling down:

- **Rest** – have the child sit or lie down
- **Ice** – apply ice to the injury
- **Compression** – apply pressure to the injury
- **Elevation** – prop up an injured arm or leg

Also:

- Never give the child ASA (Aspirin®). This can cause more bleeding.
- Carry the child's medical information, including the type of hemophilia they have. For children who require factor therapy at the time of emergency, carry information cards, such as the **Factor First Card**, and/or a **MedicAlert®** bracelet or necklace. Bring these if you go to the hospital.

**Remember, when in doubt,
get help.**

Remember:

- When in doubt, get help.
- Avoid rough activities.
- Watch for signs of a bleed.
- Treat minor bleeds with **RICE (Rest, Ice, Compression, Elevation)**
- Serious bleeds need medical attention.

Where can I find more information?

- Canadian Hemophilia Society:
<http://www.hemophilia.ca>
1-800-668-2686
- World Federation of Hemophilia:
<http://www.wfh.org>
1-514-875-7944

