NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.℠

Helping Hand™

Hemophilia A and B
(Factor VIII (8) and Factor IX (9)

Hemophilia (he mo FEE lee ah) is an inherited blood disorder. In hemophilia, a blood clotting factor is missing. In Hemophilia A, Factor VIII (8) is missing. In Hemophilia B, Factor IX (9) is missing. Factor XI (11) deficiency was once known as Hemophilia C.

Without these factors, blood will not clot well. The child may bleed easily or may not stop bleeding once it has started. Hemophilia occurs mainly in males. Females can carry the gene that causes hemophilia but usually do not have bleeding problems. Some children with hemophilia have no family history of the disorder.

Treatment of Hemophilia

The key to treatment is to prevent bleeding. This is not always possible with active children. A child with hemophilia may bleed without any known injury. If your child bleeds, he may be given Factor VIII (8), IX (9), or other replacement factor by IV (into a vein). (Refer to the Helping Hand*, IV Therapy,* HH-II-17.)

Your child may need one or more doses of the clotting factor. Your child will receive the factor in the clinic, the hospital or as part of a home treatment program. Where the treatment is done depends on the extent of the bleeding and its location. For some children the nurse coordinator can arrange a home treatment program.

Ways to Help Prevent Bleeding

Here are some things you can do to help prevent bleeding:

- **Be sure to tell the doctor, dentist or nurse your child has hemophilia.**
- Be sure immunizations are given with a smaller needle. The staff must apply **pressure and ice to the injection site for at least 15 to 20 minutes** after the shot is given. This prevents bleeding
- **Do not let your child get intramuscular (IM) injections** (shots).
- Never let a doctor or dentist do any procedure that involves opening the skin until you have talked with the hematologist (a doctor that treats hemophilia).
- Do not give your child any medicine that contains aspirin. Aspirin and some cold medicines promote bleeding. Read the label or ask your pharmacist if the medicine has aspirin in it.

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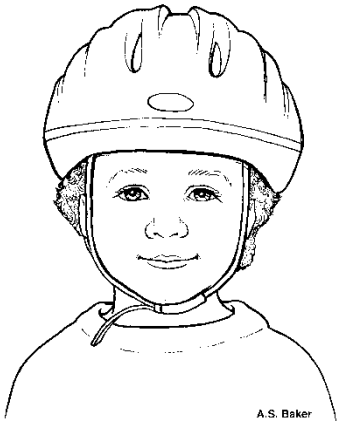
Ways to Help Prevent Bleeding, continued

- A toddler should wear a bicycle helmet when riding a bike (Picture 1).
- Children with hemophilia **must not** play any contact sports such as football, wrestling, boxing or hockey. If you have any questions about sports, be sure to talk with your child's nurse or hematologist.



Picture 1 A toddler should always wear a helmet when riding a bike.

Types of Bleeding and Treatment

Head or Neck Bleeding

If your child is hit hard at his head or neck, call the hematologist at once. He may need to be seen, even if he has no symptoms. Tell the doctor your child has hemophilia. Know whether he has Hemophilia A or Hemophilia B.

If your child has **any** of the following symptoms, he should **see a doctor right away.** These could be signs of bleeding inside the head:

- Headache with vomiting
- Severe headache
- Blurred vision
- Sleeping a lot
- Personality change or child's mood is different
- Seizures

A child who gives himself factor at home should immediately give himself one dose of factor after a head injury. Then he should see the doctor.

Abdominal Bleeding

If your child has any of these symptoms of abdominal bleeding, call the doctor:

- Severe abdominal (stomach) pain with no explained cause
- Severe back pain
- Blood in the urine or stool

Joint Bleeding

If your child has any of these complaints, he may have bleeding into a joint and will need clotting factor. **Call the doctor right away.**

- Tingling or "bubbling" feeling in a joint
- Stiffness and pain in a joint
- Swollen, tender, warm and painful joint
- Limited or painful movement of the joint

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Types of Bleeding and Treatment, continued

Soft Tissue or Muscle Bleeding

If your child has any of these signs of soft tissue or muscle bleeding, call the doctor:

- A raised bump
- Pain, swelling; area is warm to the touch
- Trouble using the injured area

Mouth Bleeding

If your child has bleeding from the lips, gums or tongue, apply pressure and ice packs. If the bleeding does not stop, he will need clotting factor. Call the doctor. Continue to hold ice packs over the cut until your child has been treated or until bleeding has stopped.

Cuts and Scrapes

- Apply pressure over the cut for 5 to 10 minutes.
- If possible, raise the cut part of the body above the heart while applying pressure. For example, if the cut is on the arm, lift the arm up above heart level (Picture 2).

Picture 2 Raise the cut above heart level and apply pressure.

- If the bleeding does not stop in 10 minutes, your child probably needs clotting factor.
- If you think the cut needs stitches, take your child to the doctor.

Remember: Before your child gets stitches, he MUST be treated with clotting factor.

Daily Care

- Your child should wear a medical identification bracelet or necklace. You can get it at your homecare pharmacy or treatment center. It states he has hemophilia. If an emergency occurs, the doctor will know that your child has hemophilia.
- Regular tooth brushing, flossing and dental care are important. When your child goes to the dentist, be sure to tell the dentist your child has hemophilia.
- Call the doctor if your child gets a sore throat. Throat irritation may lead to bleeding and closing of the airway.
- Although your child may not take part in contact sports, he is a normal child in most other ways. Encourage him to join school and social activities.

Giving Clotting Factor at Home

- After your child is 5 or 6 years of age, you can learn how to give clotting factor at home. Talk to the Hemophilia team about this.
- As your child gets older and more mature, he will probably be able to give the factor to himself.

The Comprehensive Hemophilia Center

- When your child is diagnosed with hemophilia, you will meet with the Hemophilia Team (doctor, nurse and social worker) to talk about your child's care.
- Your child will have regular appointments at the Comprehensive Hemophilia Center. This clinic provides specialists in hematology, dentistry, orthopedic surgery, social work, nursing and physical therapy.

Phone Numbers for Emergencies

Contact the Comprehensive Hemophilia Center at (614) 722-3250 Monday through Friday, 8 am to 5 pm.

On weekends and holidays, call the Nationwide Children's Hospital Operator at (614) 722-2000. Ask for the hematologist on call. The doctor will return your call and advise you what to do. If you are unable to reach the hematologist on call, take your child to the closest emergency room right away.

The longer you wait, the more severe the bleeding can become. Delay can increase the amount of damage and the length of treatment.

If you have any questions, be sure to call the Hemophilia Team.