

Coach and Educator Guide to Bleeding Disorders



This brochure is for people entrusted with the care of a child with hemophilia, von Willebrand disease or other bleeding disorder. You may be an educator, sports coach or activity leader.

Often, finding out you will be caring for a child with a bleeding disorder can cause anxiety, fear and uncertainty.

It is important to remember that every child needs education, social interaction with peers, exercise and healthy outlets for stress.¹

A child with a bleeding disorder is no different.² As a person who educates and/or supervises children, you may have concerns about including a child with a bleeding disorder in physical activities or what your role is in their care.

To be fully prepared, it would be helpful to meet with the parent or guardian (caregiver) of the child with a bleeding disorder prior to the start of the school year or sports season. Use the following items to guide your discussion when meeting with the child's caregiver:²

- Contact information
- How to recognize and report a bleeding episode or injury
- Privacy issues
- Role of school nurse or point person if there is no school nurse
- Storage of factor and supplies at the school
- Absences
- Physical education, sport, and class trips

As an educator or coach, it is important to focus on what the child with a bleeding disorder can do rather than focus on any limitations. Remember, having a bleeding disorder is only one part of this child's life. Children with bleeding disorders are often treated at hemophilia treatment centers and receive medication from a specialty pharmacy. Accredo specialty pharmacy may be able to provide additional educational opportunities from Accredo pharmacists and nurses for you and your staff members.

The following information provides an introduction to hemophilia and von Willebrand disease and includes valuable resources for additional information.



What is hemophilia?

Hemophilia is a hereditary, lifelong blood disorder in which the blood clots more slowly than normal. Normally, when an injury occurs that causes bleeding, our bodies respond by clotting (coagulating) the blood so the bleeding slows down and eventually stops. People with hemophilia have a deficiency of a blood protein called clotting factor, and their blood does not clot fast enough. A deficiency of clotting factor VIII (eight) is called hemophilia A, and a deficiency of clotting factor IX (nine) is called hemophilia B.

The incidence (number of new cases) of hemophilia A is approximately 1 in 5,000 males born in the United States.³ The prevalence (number of existing cases) of hemophilia A is about 4 times as common as hemophilia B with approximately 4,100 cases.⁴ All races and socioeconomic groups are equally affected.

The severity of a child's hemophilia depends on the amount of clotting factor in his blood. This level does not change during his lifetime. It is important to note that many children may know what a bleed feels like inside the body when no visible signs of bleeding are visible.

Classification of severity of factor deficiency⁵

Classification	Factor VIII or factor IX level	What to expect
Normal	50% to 150%	The blood clots normally.
Mild hemophilia	The blood has 6% to 49% of the level of factor needed for normal clotting.	Most individuals with mild hemophilia do quite well and have few, if any, bleeding episodes unless they experience forceful trauma, surgery, injury or dental procedures. They may have frequent nosebleeds and may bruise easily.
Moderate hemophilia	The blood has 1% to 5% of the level of factor needed for normal clotting.	Bleeds can occur with mild to moderate trauma, such as a contact injury, muscle strain, fall or impact in sports. Nosebleeds, bruising and joint bleeds can occur more easily than with mild hemophilia.
Severe hemophilia	The blood has less than 1% of the factor needed for normal clotting.	Bleeding can occur with minimal trauma (bumping into furniture, jumping off steps) or can occur spontaneously, without any evidence of an injury.

Managing hemophilia

There is no cure for hemophilia, but replacement clotting factor can be injected into the body through a vein or central venous access device (also called a port).

A box of clotting factor includes a bottle of freeze-dried factor that resembles white powder and a bottle of sterile water that is needed to mix with the powder. Most clotting factor products need to be refrigerated, but can often be stored at room temperature for limited periods of time. Performing an infusion requires special supplies such as syringes, butterfly needles, tubing, gloves, alcohol wipes, tourniquets, gauze, bandages and a Sharps™ container. Many children learn to do their own infusions, which gives them a greater level of independence and confidence. As a teacher or coach, you would not be expected to perform an infusion unless you had received training and authorized legal approval.

Some patients with mild hemophilia are treated through inhalation of a nasal spray medication. Another medication, aminocaproic acid, is available in liquid or tablet form and is often used to treat mouth or nose bleeds for some children.

Classification of von Willebrand disease⁶

Classification	VWD or factor level	What to expect
Type 1	<ul style="list-style-type: none"> • Most common • Reduced levels of von Willebrand factor 	Bleeding symptoms are usually mild.
Type 2	<ul style="list-style-type: none"> • Caused by defective von Willebrand factor 	Usually experiences mild to moderate symptoms.
Type 3	<ul style="list-style-type: none"> • Very rare • Absence or very low levels of von Willebrand factor and factor VIII 	Can experience deep and extensive tissue bleeding similar to hemophilia. Precautions similar to those outlined in the hemophilia recommendations should be taken.

What is von Willebrand?

Von Willebrand (pronounced von WILL-uh-bran) disease is an inherited bleeding disorder characterized by bleeding from mucous membranes (mouth, nose, throat, gastrointestinal tract) and skin surfaces that affects males and females equally. It is the most common inherited bleeding disorder, and approximately 1 to 3% of the population is affected. The most common symptoms of von Willebrand disease are excessive bruising, nosebleeds, heavy menstrual cycles (lasting more than seven days) and excessive bleeding following extraction of teeth or tonsils.

Von Willebrand disease (vWD) is caused by a defect or deficiency of a blood clotting protein called von Willebrand factor. This glue-like protein helps platelets in the blood stick together to form a platelet plug over the site of an injury. Since people with vWD do not form a complete platelet plug, bleeding will continue for a longer period of time.

Managing von Willebrand disease

The management of von Willebrand disease is similar to hemophilia, except different types of medications are used to manage bleeds.

Treatments include:

- Aminocaproic acid: This medication is available in tablet and liquid forms. It is used to treat mouth or nosebleeds or heavy menstrual bleeding.
- Desmopressin: This medication is available as a concentrated nasal spray or in an injectable form for intravenous (in the vein) administration.
- Clotting factor concentrates: The products used for vWD contain von Willebrand factor and may contain factor VIII as well. These concentrates must be given intravenously.

Bleeding disorder questions and answers

We realize you may have many questions about children with bleeding disorders.

Remember that the child and his or her family have become familiar with the bleeding disorder, bleeding patterns and treatment. **If the child tells you he or she has a bleed, believe it.**

For your benefit, we have included answers to the most frequently asked questions.

Q: What is a bleed?

A: An episode of prolonged bleeding is called a “bleed.” People with a bleeding disorder bleed at the same rate as everyone else when injured, but they will bleed longer. There are many myths about hemophilia and bleeding. To clarify, children with bleeding disorders:

- Do not bleed to death from cuts or scratches.
- Rarely experience external bleeding (and only after trauma).
- Typically bleed into joints and muscles, and these bleeds are not life-threatening.⁷

Often bleeding episodes occur in the joints (knees, ankles, elbows) and muscles. In these instances, it is important to realize there will be no visible blood. Some bleeds occur for no reason and are called “spontaneous” bleeds. Other bleeds can be associated with injury or trauma.

Q: How can I tell if this child is having a bleed?

A: The symptoms of bleeding in either a muscle or joint include pain, heat, swelling, limited range of motion and the inability to use the affected limb. It is important that an action plan is initiated if the child exhibits the following: limping, stiffness in a joint, swelling, protecting or not using a limb or heat in a joint.

Be advised that the child may not want to tell you that he or she is having a bleed for several reasons: does not want to appear different from classmates, does not want to leave the group or activity or does not want to acknowledge having a bleeding disorder.

Rest, Ice, Compression, Elevation (RICE) to Treat Injuries

When a joint or muscle injury occurs, whether in professional athletes or in children at play, RICE is recommended.⁵ If a child is injured while in your care, then the child should:

R = REST:

Stop the activity, receive clotting factor or medication and protect the body part. To rest the injured area, the child may need to use a sling, splint, crutches or a wheelchair for several days to several weeks after the injury.

I = ICE:

Ice or cold packs are useful in slowing the bleeding, reducing inflammation and reducing pain. Heat should not be applied to an area that is bleeding, hot or swollen.

C = COMPRESSION:

Compression with soft elastic supports helps reduce swelling and pain.

E = ELEVATION:

Elevation above the heart reduces swelling.



By school age, some children with a bleeding disorder are aware of the early indicators of a bleed. The child may say he or she feels a tingling or bubbling sensation in the affected area.⁵

Q: What should I do if this child has a bleed at school?

A: Minor external cuts or scrapes generally respond to basic first aid. Some injuries, though, need immediate medical attention. These include:

- A blow to the head, abdomen, eye, throat or neck.
- A broken bone.
- A deep cut that will not stop bleeding with direct pressure.

In these instances, you should contact the child's caregiver immediately for instructions.⁸ Some more common bleeds may include mouth bleeds and nosebleeds. Mouth bleeds (during tooth loss) are messy because blood mixed with saliva makes the bleeding look worse than it actually is.

Usually these bleeds are minor as long as the area under the tongue is not cut, swollen or bruised. Cuts on the lips, gums, tongue or inside the cheek or lips require factor treatment. Nosebleeds are usually not serious. Tilt the child's head forward to avoid swallowing blood and apply firm pinching pressure to the bridge of the nose for at least 20 minutes. Call the caregiver for instructions if the bleeding continues.⁸

For best results, it is important to treat a bleed as soon as possible after it occurs. Some children have been trained to self-infuse clotting factor and can infuse at school if factor and supplies are available. It is also possible for a caregiver to come to school to infuse the child, allowing him to return to class. Sometimes the use of RICE (Rest, Ice, Compression and Elevation) is helpful to avoid lasting complications related to a bleed, but RICE should not be used in place of factor replacement.

Q: Does this child need special accommodations?

A: Hemophilia is one of the conditions covered by Section 504 of the Rehabilitation Act of 1973. Under 504 modification plans, children with chronic diseases and disabling conditions are entitled to appropriate modifications to their educational program to accommodate their special needs.

For example, some children with a bleeding disorder may need to use crutches, wheelchairs or slings while they recover from a bleed. The child may need help getting to and from class. A vast majority of children with bleeding disorders do not suffer from any developmental disabilities as a result of their condition.² These children do not need to be placed in special education classes.

Q: Can I tell the other children that this child has a bleeding disorder?

A: Discuss this issue with the child's caregiver as well as with the child. Some families feel this draws too much attention to the disorder, while others prefer to have the issue addressed openly. It is imperative to respect the child's privacy and not to single them out regarding any diagnosis or any special accommodation they may need.³

Q: Will this child be able to participate in field trips?

A: Yes. Having a bleeding disorder should not keep a child from participating in field trips. A travel bag of necessary medical items should accompany the child. Consider allowing the child's caregiver to act as a chaperone on trips away from school.

Q: Will a child with a bleeding disorder have many absences?

A: Due to the unpredictability of bleeding episodes and their recovery period, the child may experience frequent or extended absences from the classroom or team. The child may require an extra set of textbooks at home. Educators, coaches and caregivers should have a communication system in place so the student can keep up with his or her work.



Q: Can a child with a bleeding disorder participate in physical education?²

A: An area of concern for educators is how, and if, a child with a bleeding disorder can participate in physical activities. One way to ensure increased opportunities for these children is to give caregivers unit plans, lesson plans and a schedule of events. Caregivers may be able to infuse clotting factor on those days when more stressful physical activity is planned. This will allow the child to participate with a reduced risk of bleeding complications. If the planned activity is such that a child with a bleeding disorder cannot participate fully, then the activity or the child's role may be modified. The PE teacher's most important challenge is eliminating the element of contact while maintaining the pleasure and benefits of exercise. It is better to favor activities that all children can enjoy rather than activities some children must avoid. During times of rigorous activity, a child may feel a part of the group if they are encouraged to participate as an assistant gym teacher or an assistant coach.

Before determining whether and how to restrict physical activity, the severity of the individual's bleeding disorder must be identified. The child's age, factor level, maturity, history of injury and previous complications make up general guidelines for determining appropriate types of sports. The most important consideration in decisions about activity is the child's individual condition. Even a recommended sport like swimming should be contraindicated if, for instance, the child has shoulder problems.

Discussions with the caregivers, hemophilia treatment center staff members and the child will help a teacher or coach make the right activity choices. For persons with bleeding disorders, the National Hemophilia Foundation has divided sports and activities into five categories based on risk. (See chart on the following page).

When setting limits on physical activity, teachers and coaches should respect the input of the child with a bleeding disorder; however, he/she must not allow this diagnosis to become an excuse for not participating. It is important to keep children with bleeding disorders involved — not set them apart from classmates with differential treatment.

National Hemophilia Foundation risk categories for sports and activities⁹

For persons with bleeding disorders, the National Hemophilia Foundation has divided sports and activities into five categories based on risk.

Aerobics	2	Frisbee	1	Rowing/crew	2
Archery	1	Frisbee golf	1.5	Rugby	3
Aquatics	1	Frisbee (ultimate)	2	Running and jogging	2
Baseball	2.5	Golf	1	Scooter (motorized)	3
Basketball	2.5	Gymnastics	2.5	Scooter (non-motorized)	2.5
Bicycling	1.5	Hiking	1	Scuba diving	2.5
BMX racing	3	Hockey (field, ice, street)	3	Skateboarding	2.5
Bowling	2	Horseback riding	2.5	Skiing	
Boxing	3	Ice skating	2.5	Cross country	2
Canoeing	2.5	Inline skating	2.5	Downhill	2.5
Cardiovascular training equipment		Jet skiing	2.5	Telemark	2.5
Elliptical machine	1	Jumping rope	2	Snorkeling	1
Rowing machine	1.5	Kayaking	2.5	Snowboarding	2.5
Ski machine	1.5	Lacrosse	3	Snowmobiling	3
Stationary bike	1	Martial arts		Soccer	2.5
Stepper	2	Karate	2.5	Softball	2.5
Treadmill	1.5	Kung Fu	2.5	Surfing	2.5
Cheerleading	2.5	Tae Kwon Do	2.5	Swimming	1
Circuit training	1.5	Tai Chi	1	T-ball	2
Dance	2	Motorcycling/motocross racing	3	Tennis	2
Diving (competitive)	3	Mountain biking	2.5	Track and Field	2.5
Diving (recreational)	2	Pilates	1.5	Trampoline	3
Exercise classes		Power lifting	3	Volleyball	2.5
Body sculpting	1.5	Racquetball	2.5	Walking	1
Cardio kick boxing	2	River rafting	2.5	Water skiing	2.5
Physioball	1.5	Rock climbing		Weight lifting	
Spinning	1.5	(indoor/challenge course)	2	Resistance training	1.5
Fishing	1	Rock climbing (natural setting)	3	Power lifting	3
Football	3	Rodeo	3	Wrestling	3
		Roller skating	2	Yoga	2

1 = Safe 1.5 = Safe to moderate risk 2 = Moderate risk 2.5 = Moderate to dangerous risk 3 = Dangerous/not recommended

Guidelines for recognizing and responding to bleeding incidents¹⁰

Incident	Causes	How to recognize	Suggested course of action
Nosebleed	<ul style="list-style-type: none"> • Dry air • Picking at the nose • Blowing the nose too forcefully • Bump to the nose 	<ul style="list-style-type: none"> • Blood drips from nostrils. • Blood drips down the back of the throat, often causing nausea 	<ul style="list-style-type: none"> • Have child sit up and lean forward • Pinch soft spot on nostrils for 10–15 minutes • Instruct child to spit out blood • Consult medical care if bleeding lasts more than 30 minutes
Small cuts, scrapes and bruises	Any childhood activity	<ul style="list-style-type: none"> • Blood oozes from injured area • Bruising and discoloration may appear on the skin surface 	<ul style="list-style-type: none"> • Apply pressure to bleeding area • Clean and apply dressings to the wound
Heavy menses	Girls with bleeding disorders frequently have heavy, uncomfortable or prolonged periods. Her doctor will direct treatment that may involve hormonal therapy, desmopressin replacement, epsilon aminocaproic acid or clotting factor replacement.	<p>Strenuous activity may be difficult.</p> <p>Girls may:</p> <ul style="list-style-type: none"> • Become anemic • Feel tired, faint or lethargic 	<ul style="list-style-type: none"> • Discuss these problems with the child and family • Make adjustments in the amount and vigor of activity





Incident	Causes	How to recognize	Suggested course of action
Joint bleed	<p>Any activity that causes:</p> <ul style="list-style-type: none"> • Strain • Collision • Twisting • Impact to the joint <p>Example: Sliding into base in baseball</p> <p>Can also occur for no obvious reason (spontaneous bleed)</p>	<p>Joint may appear:</p> <ul style="list-style-type: none"> • Swollen • Red • Warm • Tender <p>Child may:</p> <ul style="list-style-type: none"> • Limp • Not want to use the extremity • Be quiet or cranky • Hold affected area as if it hurts • Report pain in joint 	<ul style="list-style-type: none"> • Stop physical activity • Rest, ice, compress and elevate (RICE) the joint • Contact family • Arrange for treatment as soon as possible (preferably within 3 hours)
Muscle bleed	<p>Any activity that:</p> <ul style="list-style-type: none"> • Stretches a muscle beyond its limit • Causes strain, twisting or impact to the muscle <p>Example: Being kicked by another player in soccer</p> <p>Can also occur for no obvious reason (spontaneous bleed)</p>	<p>Strenuous activity may be difficult.</p> <p>Girls may:</p> <ul style="list-style-type: none"> • Become anemic • Feel tired, faint or lethargic 	<ul style="list-style-type: none"> • Stop physical activity • Rest, ice, compress and elevate (RICE) the muscle • Contact family • Arrange for treatment as soon as possible (preferably within 3 hours)

Incident	Causes	How to recognize	Suggested course of action
Head injury	<ul style="list-style-type: none"> • Bump or blow to the head • Whiplash-type injury <p>Example: Performing a “header” in soccer</p> <p>(Never allow a child with hemophilia to perform headers!)</p>	<ul style="list-style-type: none"> • Blurred vision • Nausea • Sleepiness • Dizziness • Headache • Lethargy • Loss of consciousness <p>These symptoms may appear very gradually if bleeding is occurring inside the skull.</p> <p>If a child receives a blow to the head, notify family immediately.</p>	<p>This is an emergency!</p> <ul style="list-style-type: none"> • Stop the activity • Notify family immediately • Get treatment immediately • Transport the child to an emergency facility that is equipped to treat hemophilia. Have the facility go to HemophiliaEmergencyCare.com for guidelines.
Throat injury	<ul style="list-style-type: none"> • Bump or blow to the throat • Whiplash-type injury <p>Example: Getting hit with an elbow in the throat while rebounding in basketball</p>	<ul style="list-style-type: none"> • Difficulty breathing or swallowing • Hoarseness • Feeling of tightness in the throat <p>These symptoms may appear gradually as the bleeding blocks the airways.</p> <p>If a child receives a blow to the throat, notify family immediately.</p>	<p>This is an emergency!</p> <ul style="list-style-type: none"> • Stop the activity • Notify family immediately • Get treatment immediately • Transport the child to an emergency facility that is equipped to treat hemophilia. Have the facility go to HemophiliaEmergencyCare.com for guidelines.



Incident	Causes	How to recognize	Suggested course of action
Internal organ injury	<ul style="list-style-type: none"> • Blow to the torso of the body <p>Example: Colliding with another player or being tackled</p>	<ul style="list-style-type: none"> • Blood in sputum, urine or feces • Pain in abdomen, chest or back <p>These symptoms may appear gradually.</p> <p>If a child receives a blow to the torso, notify family immediately.</p>	<p>This is an emergency!</p> <ul style="list-style-type: none"> • Stop the activity • Notify family immediately • Get treatment immediately • Transport the child to an emergency facility that is equipped to treat hemophilia. Have the facility go to HemophiliaEmergencyCare.com for guidelines.
Spinal injury	<ul style="list-style-type: none"> • Blow or fall that impacts or twists the spine <p>Example: Falling abruptly or being tackled</p>	<ul style="list-style-type: none"> • Back pain • Change of sensation in arms or legs • Weakness or paralysis in arms or legs <p>These symptoms may appear immediately after the injury or may develop gradually as the bleeding fills the spinal canal.</p> <p>Notify family immediately.</p>	<p>This is an emergency!</p> <ul style="list-style-type: none"> • Stop the activity • Notify family immediately • Get treatment immediately • Transport the child to an emergency facility that is equipped to treat hemophilia. Have the facility go to HemophiliaEmergencyCare.com for guidelines.



Incident	Causes	How to recognize	Suggested course of action
Compartment syndrome	<ul style="list-style-type: none"> • Blow, strain or injury to the muscle • Severe bleed into the muscle and soft tissues, especially the forearm or calf • Fibrous “compartment” around the muscle fills with blood and can cut off circulation and damage the nerves to the arm or leg. <p>Example: Being kicked or falling off a bike</p>	<p>The muscle will:</p> <ul style="list-style-type: none"> • Feel very tight • Be painful or discolored • Limit motion of the limb <p>The child may report:</p> <ul style="list-style-type: none"> • Numbness, weakness or change of feeling in the limb <p>This condition can appear gradually as the bleeding fills the compartment.</p> <p>Notify family immediately.</p>	<p>This is an emergency!</p> <ul style="list-style-type: none"> • Stop the activity • Notify family immediately • Get treatment immediately • Transport the child to an emergency facility that is equipped to treat hemophilia. Have the facility go to HemophiliaEmergencyCare.com for guidelines.

*This is a guide only and not an all-inclusive list. Consult with the child’s family for a specific course of action. Please use the Discussion Points for Caregivers and Coach/educator found on page 15.

Sample permission to authorize treatment form

This is a sample form for what the parent/guardian and the school/organization should discuss pertaining to the care of a child with a bleeding disorder. Each school or organization may have their own forms to be completed in addition to this.

In case of emergency, I give _____ permission to authorize
(Coach/Educator)

emergency medical treatment or hospitalization for _____.
(Child's name)

I understand that the above named individual will make a reasonable attempt to contact me in case of an emergency. To facilitate the efforts of the school/organization, I am including the attached contact and medical information.

(Parent/guardian signature)

(Date)

Important information about my child

Child's name	
Date of birth	Social Security number
Address	
City/state/zip	

Important contact information

Mother's name	Father's name
Address	Address
City/state/zip	City/state/zip
Home phone	Home phone
Work phone	Work phone
Cell/pager	Cell/pager
Alternative contact's name	Alternative contact's relationship to the child
Alternative contact's home phone	Alternative contact's cell/pager

Health insurance information

Insurance provider
Group number/name
Subscriber name or ID number
Toll-free phone

Emergency medical information

My child is diagnosed with	<input type="checkbox"/> Hemophilia A: <input type="checkbox"/> Severe <input type="checkbox"/> Moderate <input type="checkbox"/> Mild <input type="checkbox"/> Hemophilia B: <input type="checkbox"/> Severe <input type="checkbox"/> Moderate <input type="checkbox"/> Mild <input type="checkbox"/> Von Willebrand disease: <input type="checkbox"/> Type 1 <input type="checkbox"/> Type 2 <input type="checkbox"/> Type 3 <input type="checkbox"/> Other disorder _____: <input type="checkbox"/> Severe <input type="checkbox"/> Moderate <input type="checkbox"/> Mild
His/her usual dose is	
His/her usual treatment is	To be delivered by: <input type="checkbox"/> IV injection <input type="checkbox"/> Port injection <input type="checkbox"/> Nasal spray
Factor is stored and available at (location)	
Other medication(s) my child takes are	
He/she is allergic to	
Other conditions/disabilities	

Physician information

Hematologist
Name of practice
Phone
Other physician (primary care, pediatrician or internal medicine)
Name of practice
Phone

Discussion points for caregivers and coach/educator

Please contact caregivers or emergency contact if the following occurs: (Caregivers should check any or all that apply to this child.)

- Child experiences a blow to the head, neck, throat, eye or abdomen.
Plan of action: _____
- Child has a deep cut that will not stop bleeding with direct pressure.
Plan of action: _____
- Child suffers a broken bone.
Plan of action: _____
- Child is observed limping, favoring one leg or arm or refusing to use a limb.
Plan of action: _____
- Child says he or she is having a bleeding episode.
Plan of action: _____
- A menstruating teenager has excessive bleeding.
Plan of action: _____
- Rash or irritation is observed around the site of the central venous access device (port).
Plan of action: _____
- Child has a fever.
Plan of action: _____
- Other situations that merit caregiver contact: (please list) _____



This booklet contains general educational material and is not intended to constitute medical advice or the rendering of medical care. Accredo is not licensed to practice medicine. The diagnosis and treatment of bleeding disorders should only be undertaken by, or under the direction of, a qualified physician. The patient's physician should always be consulted with regard to the patient's medical treatment.

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