This chapter provides information on how to manage bleeds. It includes the following sections:

- An Introduction to Bleeds
- Bruises
- Mouth Bleeds
- Muscle Bleeds
- Joint bleeds
- Life-threatening bleeds
- Other bleeds
- Guidelines for the Use of Ice

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Management of Bleeds

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AN INTRODUCTION TO BLEEDS

This chapter will describe the common bleeds that can happen in people with hemophilia. It will help you identify the first signs of bleeding so you can quickly get the proper treatment for your child.

This chapter will also describe life-threatening bleeds—bleeds which happen very rarely but which parents need to learn to recognize.

There are also some First Aid tips that you can use along with clotting factor therapy.

How does a bleed happen?

A bleed happens when blood vessels get torn. Blood then leaks out into the surrounding tissues. In a person with normal clotting, the bleeding stops quickly because platelets, tiny cells less than 1/10,000 of a centimetre in diameter, stick to the blood vessel walls. The clotting factors then work to form a substance called fibrin to seal the hole. These three steps are usually sufficient to stop bleeding from minor cuts. It’s only the fourth stage—the formation of fibrin from the chain reaction of clotting proteins like factor VIII and IX—where people with hemophilia run into problems. This coagulation cascade is especially important to stop internal bleeding.

(For more information on blood clotting, see Chapter 1, An Introduction to Hemophilia.)
How are bleeds treated?

The way to stop the bleeding in a person with moderate or severe hemophilia is to infuse clotting factor.

People with mild hemophilia A who have been found to respond well are sometimes treated with desmopressin, also called DDAVP® Injection, Octostim® or Octostim ® Nasal Spray. This is a synthetic hormone, not a blood product. The use of desmopressin will depend on the severity of the bleed. If the bleed is severe or life-threatening, clotting factor concentrates are the treatment of choice. (For more information on desmopressin, see Chapter 4, Clotting Factor Therapy.)

In general, single daily infusions of clotting factor concentrates are given to treat muscle or joint bleeding. Treatment is continued until the muscle or joint has returned to normal. In some cases, especially when treatment is given soon after the bleeding starts, one treatment is enough. In other cases, treatments are given for several days.

More frequent infusions (2 to 3 times each day) are given for more serious bleeding. Infusions may need to be continued for 10 to 14 days after a serious injury.

Many children with hemophilia are treated prophylactically to prevent bleeding from occurring at all.

Bleeding can be slowed by using First Aid. This can be used for minor bleeds in a joint, soft tissue or muscle. The steps of this First Aid to slow bleeding are called RICE. R-I-C-E stands for Rest, Ice, Compression and Elevation. RICE is used not only for hemophilia but also to treat many types of injuries, including those suffered by professional athletes.

Still a Mystery...

The mad monk Rasputin was able to relieve some of the symptoms of hemophilia for the Tsarevich Alexei, heir to the throne of Russia in the early 1900s. It is said he used hypnosis. Did the hypnosis slow or stop the bleeding? Did it relieve the pain? Did it merely calm the boy so that the treatment seemed to help? Or was it a combination of all three? It’s still a mystery.
Rest – While the joint is bleeding, it should be rested. This means that in the case of an elbow bleed, your child should rest his arm, and not use it to lift or carry things. In the event of an ankle or knee bleed, he should be kept off his feet as much as possible and he should not do any physical activities. When your child is about 6 or 7 years old, he will have enough coordination to use crutches. The physiotherapist will teach him how to use them safely. He should keep a set at home to use when a bleed starts.

In hemophilia care, the “R” in RICE can also mean “Replacement of clotting factor”.

Ice – Applying ice to an injured area can help control swelling and reduce pain. You can use crushed ice in a plastic bag or a bag of frozen vegetables, wrapped in a towel. There are many different ways to apply ice, but it is very important not to apply the ice for too long. Ten or fifteen minutes at a time, every 2 hours, is long enough! At the end of this chapter, you will find guidelines for using ice.

The “I” in RICE can also mean “Immobilization”. The joint is held still (immobilized) by a half-cast or a splint. This is used if there is a lot of swelling, and if movement is difficult and painful. It is done for short periods only, about 2 or 3 days. If the joint is kept immobilized for longer periods, the joint can become stiff and the muscles can become weak. Then the joint is more likely to be re-injured.

Compression – Pressure on the area that is bleeding can help to ‘pinch off’ the blood vessels and slow down the bleeding. Compression of a joint or muscle bleed is done by using an elastic bandage (tensor). Wrap the injured part in a criss-cross (figure-eight) pattern. Watch carefully for coolness, numbness or a change in colour in fingers or toes. If any of these symptoms occur, remove the bandage and re-wrap it less tightly. An alternative is a Tubigrip® sleeve. Many parents find it easier to
use with young children. If the injury is very sore, your son may find compression increases the pain. If this happens, re-wrap the injury less tightly or remove the bandage altogether.

The physiotherapist at your son’s clinic will help you learn how to apply compression safely.

**Elevation** – Placing the injured limb at a level higher than the heart helps decrease the pressure in the blood vessels and helps to slow the bleeding. Your son can rest his injured arm or leg on pillows.

### Do all bleeds need to be treated with clotting factor?

All bleeding into joints, and significant bleeding into soft tissues, especially muscles, should be treated with clotting factor. A significant soft tissue bleed is one that is large enough to cause pain and limit movement and function in nearby joints. Deep muscle bleeds can cause damage to nerves and blood vessels, and **must** be treated with factor concentrates.

Cuts to the lips or gums may need to be treated with clotting factor. If factor is not given, they can sometimes ooze for several days.

Injuries to the head can be serious and need treatment with clotting factor. Bleeds in the neck, throat or chest can damage the airway and other important organs, and **must** be treated with clotting factor.

Skin bruises often look alarming but may not require treatment with clotting factor.
For children with mild or moderate hemophilia A, treatment with desmopressin may be enough to stop bleeding. ▶️ (See Chapter 7, Mild Hemophilia.)

- **When I learn to do infusions, can I treat all bleeds at home?**

Once you have learned to infuse clotting factor, you will be able to treat most joint and muscle bleeds, as well as mouth and nose bleeds, at home.

For more serious bleeds, such as injuries to the head, neck, chest, or abdomen, you can give clotting factor at home but your child should be seen by a doctor as soon as possible. For these types of bleeds you must contact your HTC or go to the nearest emergency room immediately.

Even when you are on home care, you need to keep in touch with your hemophilia treatment centre.

**BRUISES**

- **Do bruises need to be treated?**

Bleeding into the skin or soft tissues is common in children with hemophilia. These bruises are called *hematoma*.

Although skin bruises can look alarming, they may not require treatment with factor. Ice can be used to decrease the swelling.

Your hemophilia treatment team may suggest treatment with clotting factor if the bruise ...
Management of Bleeds

- is very painful (for example, a buttock bleed)
- seems to be getting larger in size
- limits movement in nearby joints
- is near a critical place (for example, an eye).

As bruises are disappearing, a small bump or “knot” can be felt just under the skin. This is normal and will go away as the hematoma is re-absorbed. It may take several weeks, though.

MOUTH BLEEDS

■ What parts of the mouth bleed?

A child with hemophilia can bleed from the mouth in several ways.

- He can bite his tongue.
- He can bite the gums on the inside of his cheeks.
- He can bleed when baby teeth fall out or after tooth extractions.

■ Do cuts in the mouth bleed a lot?

Yes, they can. Cuts in the mouth may bleed for a long period of time. In some cases bleeding may stop and then restart after a few hours or even days. There are several reasons for this. First, saliva in the mouth may wash away a protective blood clot. Second, movement of the tongue or sharp pieces of food may dislodge the protective blood clot.

“Tongue bleeds can be very difficult. I didn’t expect the cut to keep reopening.”
The amount of blood lost from cuts in the mouth may be underestimated because a lot of the blood is swallowed. Signs that your son has lost quite a lot of blood are …

- loss of appetite
- vomiting blood
- dark stools.

It is important, therefore, that you have your son checked at the hemophilia treatment centre whenever there is persistent bleeding from his mouth.

**How should a mouth bleed be treated?**

The following treatment plan is recommended for active bleeding in the mouth.

- Infuse clotting factor.
- Use only a soft diet until bleeding stops. Infants should use a cup rather than a bottle, if possible, and avoid using drinking straws.
- Avoid giving your child hot fluids or meals for seven days.

Your doctor may prescribe Amicar® (aminocaproic acid) or Cyklokapron® (tranexamic acid) by mouth. These drugs are antifibrinolytic agents; that is, they stabilize the blood clot and help to prevent it from being broken down by agents that are normally present in our blood. These medications should not be given if your child has hematuria (blood in the urine).

If the bleeding seems to be important, or does not stop after treatment, your child should be seen at the HTC or by your private physician. Persistent mouth bleeding can cause severe anemia. Anemia means that a person has a lower than normal level of red blood cells.
**What can be done to prevent mouth bleeds?**

Some mouth bleeds are caused by sharp corners on foods like potato chips. Others are caused when a child puts sharp objects, such as a pen or pencil, in his mouth. Never let your child run with anything hard in his mouth, and always insist that he sit down to eat. (For more ideas on prevention, see Chapter 10, Staying Healthy.)

**MUSCLE BLEEDS**

**What causes muscles to bleed?**

A bleed in a muscle can occur when it is stretched too far or when there is a direct blow to it. This causes muscle fibres to be torn, and the bleeding begins.

**How will I know if my child has a bleed in a muscle?**

Muscle bleeds can be tricky to detect. The blood can seep between the layers of muscle and not cause swelling right away. Gradually, as the bleeding continues, there will be pain. Movement of the joints near the bleeding muscle will be limited, because the muscle will hurt if it is stretched or used. You will notice that your child holds the arm or leg in an unnatural position, and he will not want to move it. You may feel warmth over the area of the bleed. If the bleed is treated early, you may not notice any swelling or firmness of the muscle.

“One morning I went to pick my son up, from his crib. He was awake and looked OK. As soon as I picked him up, he started to cry as if he had a lot of pain. I pulled off his pajamas and couldn’t see any problem. At the clinic, the nurse showed me how to isolate the area that was bothering him. It was his thigh muscle that was the problem. I couldn’t determine this at first. I learned a lot that day and actually felt more confident.”
What should be done to treat a muscle bleed?

Bleeding into a muscle needs to be treated if there is pain and limited movement. R-R-I-I-C-E is used—rest, replacement therapy, ice, immobilization, compression and elevation.

- Rest the muscle by keeping your child off his feet. Quiet activities like reading books and watching videos will help him rest the injury and allow it to heal.

- Replacement of clotting factor – Follow the instructions of your HTC concerning the dosage. Clotting factor therapy may need to be repeated daily for a few days.

- Ice – Apply ice to the muscle to reduce pain and swelling. See the guidelines for using ice at the end of this chapter.

- Immobilization – Sometimes, if the muscle is very sore, the area may need to be supported in a splint or cast to allow healing. The HTC team will advise you if this is necessary. The splint will need to be changed every few days as the pain decreases. The splint will be adjusted to gently stretch the muscle back to its normal length.

- Compression – Wrapping the area firmly with a tensor bandage, perhaps with foam padding added, or Tubigrip®, can help control the swelling and pain. The physiotherapist at your HTC can teach you to do this.

- Elevation – Keep the arm or leg elevated on pillows to reduce the swelling.
Are muscle bleeds serious?

Yes, they can be.

Muscle bleeds can heal with scar tissue that is not as flexible as the normal muscle tissue. The muscle may also become weak after a large bleed. **It is very important to make sure that the muscle returns completely back to normal after the bleeding has stopped.** The physiotherapist will help you with exercises to stretch and strengthen the muscle, and will advise you when your child can return to full activity.

Muscle bleeds can also be serious because they can cause damage to important nerves and blood vessels. This happens when there is a **compartment bleed,** a deep bleed inside a closed-in space. A large bleed in these compartments can put pressure on nerves or blood vessels. If this pressure lasts long enough, the damage can be permanent.

Compartment bleeds can occur in ...

- **the forearm.** Bleeding into the deep muscles of the forearm can put pressure on the nerves and blood vessels that go to the hand.
• **the calf muscle.** A bleed into the calf muscle behind and below the knee will cause your child to limp and walk on the toes of that foot.

• **iliopsoas.** *(pronounced ee-lee-o-so-as)* muscle. This is a large muscle in the pelvic region near the hip joint. Bleeding here can damage the large nerve that controls the muscles at the front of the thigh, as well as the major artery at the front of the leg. Bleeding into this muscle is serious; and factor therapy needs to be given immediately to increase the blood factor level to near normal. Children with a bleed in the iliopsoas may need to be admitted to hospital for clotting factor and physiotherapy. This muscle can take a long time to recover.

If your child experiences pain and tingling or a ‘pins and needles’ feeling in his fingers or toes, this may be a sign of nerve or blood vessel compression. Call your hemophilia treatment centre immediately.
How can muscle bleeds be prevented?

Muscles can be protected from injury by using padding for activities that involve rough play. Proper stretches and warm-ups before sports are important as your child gets older. It is also important to make sure that each muscle bleed is completely healed before returning to full activity—muscles are re-injured easily if they have not regained their full strength and flexibility.

JOINT BLEEDS

Why do joints bleed?

A joint is where two bones come together and movement occurs. The bones are held together by a sleeve called a capsule. The capsule is lined with a layer of special cells, called a synovium or synovial membrane. These cells produce small amounts of fluid that make it easier for the bones to move. The synovium also contains a network of small blood vessels that bring food and oxygen to the joint. When there is a tear in the synovium, blood gets out of the blood vessels and begins to fill the joint. In a person with normal clotting, the bleeding stops, and the person does not realize he has had a bleed. In a person with hemophilia, the bleeding takes a long time to stop by itself because a clotting factor is missing or unable to do its job. Bleeding into a joint is called a hemarthrosis.

“...
Why do some joints bleed more than others?

Joints like the hip and the shoulder are formed like a ball and socket. They can move in many directions, and have lots of strong muscles to protect them. While bleeds do happen in these joints, they are not frequent.

Joints like the knee, elbow and ankle can only bend and straighten in two directions, and cannot twist or bend side to side. For this reason, if they are forced to move in the wrong direction, they can be injured and a bleed can start. These joints bleed more often.

In many cases, a child's first joint bleed is into an ankle, when he is just starting to walk. This happens because a toddler often stumbles and can easily twist his ankle as he falls. In other cases, a child's first bleed is into an elbow. This may happen when he puts his hands out to protect himself when he falls, and causes the elbow to bend backwards (hyperextend) slightly.

Bleeds into knee joints are also very common in children with hemophilia, especially as they start to run and play certain sports.

Bleeds into the joints of the hand and wrist can happen, but are less frequent.

How will I know if my child has a joint bleed?

The physiotherapist at your HTC can help you learn how your child's joints move so that you will be able to tell when there is a problem.

In an infant who cannot tell you what is wrong, you have to watch out for telltale signs.
Nicholas: ‘‘You mean—let’s pretend—if a bleed started right now, and I told my mom, and I got my needle right away—you mean, I wouldn’t need a cast?’’

Physiotherapist: ‘‘That’s right. The joint wouldn’t have time to swell and get sore, because the bleeding would stop right away.’’

Nicholas: ‘‘....and I wouldn’t need to come back tomorrow?’’

Physiotherapist: ‘‘That’s right. The sooner you tell someone and get your poke, the easier it is for everybody.’’

Nicholas: ‘‘Wow!’’

• He may become cranky or fussy because of discomfort or pain.
• He may not move his arm or his leg like he usually does.
• He may cry suddenly if you are changing his clothes or picking him up.

You will know that something is wrong, but may not know what it is at first. Check him over carefully; undress him so you can see if there is any bruising. You may be able to feel increased warmth over a joint. He may cry or resist if you try to move that joint for him. These are early signs of a bleed. If the bleed has been present for a while—perhaps it started some time during the night—you may be able to see swelling.

Once your baby starts moving around, you may notice he is not moving the way he normally does.

• He may not crawl smoothly.
• He may walk or run with a limp.
• He may avoid using one arm, or use his left arm when he normally uses his right.

Check him over carefully, and look for warmth and swelling. Assess his joints by comparing the size, shape and movement on both sides of his body. Compare one elbow to the other, or one knee to the other, to see if one is more swollen, or feels warmer or puffier to the touch.

An older child, who has had some experience with joint bleeds, may describe a “funny” or a “tight” feeling in the joint when a bleed first starts. You may not be able to see that anything is wrong, and you may be tempted to “wait and see”. The HTC team uses this motto:

“When in doubt, treat.”
They know that if the bleeding is not stopped, the joint will become warm, then swollen and painful, and movement will become limited. If the bleeding is stopped in the very early stages, it may require only one infusion, and the recovery time is shorter. Delay in giving clotting factor allows more blood to escape into the joint, and means the recovery time is longer. Large or repeated bleeds can lead to more serious joint damage. (For more information on joint damage, see Chapter 8, Complications of Hemophilia.)

Sometimes a child will try to hide the fact that he is having a bleed. He may not want to stop playing or fear missing a special event that he has been looking forward to. He may not like getting his “poke”. Or he might have been injured doing something you had told him not to do! In these cases, you may notice changes in your child’s behaviour or movements. He may avoid walking in your presence so you don’t see his limp. It is up to you to take charge. Take him aside, assess him carefully, and make sure he gets treatment if it is needed. He needs to understand that treatment is not punishment, but a way to get him better and back to his play faster.

How are joint bleeds treated?

Once you have decided that a joint is bleeding, and that treatment is necessary, these steps should be taken as soon as possible:

R-I-C-E – Rest the joint, apply ice, use a tensor bandage and elevate the limb.
Replacement therapy – The most important treatment is immediate infusion with clotting factor. Your HTC will advise you on the amount to infuse. This will depend on …

- the type of hemophilia your child has
- his weight
- the type of bleed.

Certain bleeds require a larger dose than others. For example, a child with factor VIII deficiency having a minor bleed into a joint or muscle needs a dose to bring his factor VIII level to 20 to 30 percent of normal. However, a severe joint bleed or a bleed in the mouth requires a larger dose, one that will bring his factor VIII level to 50 percent of normal. *(For complete information on suggested dosages for different types of bleeds, see Tables 2, 3 and 4 in Chapter 4, Clotting Factor Therapy.)*

For some children with mild or moderate factor VIII deficiency, treatment with desmopressin may be used instead of clotting factor therapy.

If movement is severely limited, the joint may need to be immobilized in a splint or half-cast. Your HTC team will advise you if this is necessary.

After the bleeding has stopped, it is important to regain full motion of the joint. If a joint is rested or immobilized for too long, the muscles around the joint will get weak and will not support the joint. Usually a gradual return to normal activity is all that is needed, but in some cases your physiotherapist may show you some special exercises to help regain movement and strength.
How long will treatment be needed?

If joint bleeding is recognized and treated quickly, a single infusion of clotting factor may be enough. However, if the bleed is severe and/or treated late, a few days of clotting factor therapy may be required.

Inadequate treatment may lead to repeat bleeding into the same joint. For this reason, clotting factor should be used until the joint is completely painless and the range of motion has returned to normal.

How can joint bleeds be prevented?

Many hemophilia treatment centres recommend the use of prophylaxis, that is, regular, scheduled infusions of clotting factor. This means that the child will always have a small amount of clotting factor in his blood in case of injury. (For more information on prophylaxis, see Chapter 6, Home Infusion.)

Proper footwear, knee and elbow pads, and strong muscles can also help to protect the joints from injury. Ankle supports can be worn when playing certain sports. (For more ideas about prevention, see Chapter 10, Staying Healthy.)
LIFE-THREATENING BLEEDS

Bleeding into the head, neck, chest, or abdomen may be life-threatening and requires immediate medical attention. Remember! Bleeding episodes can occur as a result of an injury OR spontaneously (without injury).

HEAD

What should I know about injuries to the head?

All injuries to the head need to be taken seriously because of the risk of bleeding into the brain. The brain is the control centre for all life-sustaining functions. A bleed into the brain is very serious. The next sections describe head injuries and what to do about them, from minor head bumps to serious bleeds in the brain.
How should head bumps be treated?

Minor head bumps can be frustrating because it’s hard to know whether to treat with clotting factor or not. Head bumps are especially common in young children at the toddler stage (ages one to two years) who are just learning to walk and run and who are unsteady on their feet. These children often bump into doors, walls and furniture. Many times the child is not upset by the injury—he doesn’t even cry—and often there is no bruise or cut caused by the bump.

It may not be necessary to treat simple head bumps with clotting factor if the child does not have any of the symptoms listed in the section below. If you are not sure, you should speak to the Nurse Coordinator or medical director of your son’s HTC.

How should minor head injuries be treated?

Minor head injuries are much more common than major head injuries. The child with a minor head injury may have bruising or even a minor cut at the site of the head injury, but does not have any of the signs/symptoms listed below.

A cause of a minor head injury would be a fall from a tricycle, with the child hitting his head on the floor or a piece of furniture.

Children with minor head injuries should receive at least a single infusion of clotting factor, and they should be observed closely for symptoms of a serious head injury.

In general, children with minor head injuries do not need to be admitted to hospital, and special x-ray studies are not necessary.
How can I tell that a head injury is serious? What should I do?

Watch out for:

- headache
- blurred vision
- nausea or vomiting
- mood or personality changes
- drowsiness
- loss of balance or coordination
- weakness or clumsiness
- stiffness of the neck
- loss of consciousness
- seizures.

If any of these symptoms appear, you must seek medical assistance immediately. Serious head injuries are emergencies and require immediate infusion of clotting factor to increase factor levels to 100 percent of normal. If you can, treat your son with factor concentrates before leaving for the hospital. Call ahead to your HTC or the hematology resident on call at your hospital. Inform the staff that you suspect a brain hemorrhage and are en route to hospital. This way, the health care personnel can prepare for your arrival.

Serious head injuries are associated with severe trauma. An example of severe trauma is falling head-first down unpadded steps onto a concrete floor.

Children with hemophilia with serious head injuries need to be admitted to hospital. Special x-ray studies (CT scan or MRI)
of the head should be done to look for bleeding into or around the brain. Your child will need to be watched closely. Clotting factor will continue to be given until the doctors are sure that bleeding into the brain has not occurred, or that the bleeding has stopped completely. If bleeding has occurred, surgery may be necessary to remove the blood clot.

How can head injuries be prevented?

The way to prevent head injuries is to use good common-sense safety precautions. For example, never leave your baby alone on a change table or bed from which he can roll off. Place gates at the top and bottom of all stairs. Some HTCs encourage the use of protective helmets as the toddler learns to walk. When he gets older, insist he wear his bicycle helmet. (For more ideas on how to prevent injuries, see Chapter 10, Staying Healthy.)

NECK, THROAT

The tissues in the nose, mouth and throat contain many blood vessels. Injury or infection can result in blood filling these tissues. As these tissues swell with blood, they can press on the airway, making it smaller or closing it completely.

Watch out for:

- pain in the neck or throat
- swelling
- difficulty swallowing
- difficulty breathing.

If any of these symptoms appear, you must seek medical assistance immediately.
CHEST

The lungs, heart and major blood vessels are found in this body cavity. Injury to the chest may cause bleeding. Bleeding in the lung tissues forces blood into the spaces which normally contain air. This makes breathing difficult.

Watch out for:

- pain in the chest
- difficulty breathing.

If any of these symptoms appear, you must seek medical assistance immediately.

ABDOMEN

The stomach, spleen and intestines are just three of the organs found in this cavity. Injury to this area could result in massive bleeding from an organ or major blood vessel. Without treatment, this could be fatal.

Watch out for:

- pain in the abdomen or lower back
- nausea/vomiting.

If any of these symptoms appear, you must seek medical assistance immediately.

“As a toddler, my son fell on a railway tie bordering a sand pit at a park. Later in the day I noticed obvious swelling in the abdomen. An x-ray showed he had torn the lining in his stomach, and a bleed had developed. He has moderate hemophilia. He was kept in the hospital overnight for observation. We were distraught at the time. It wasn’t something we had experienced or heard about.”
OTHER BLEEDS

NOSE BLEEDS

- Are nose bleeds common in children with hemophilia?

Not necessarily. Some children with hemophilia will never have a nose bleed. Others, however, will have them once in a while. In a person with hemophilia, nose bleeds, like other bleeds, take longer to stop.

- How can nose bleeds be stopped?

Nose bleeds may be stopped by sitting upright and firmly pinching the widest part of the nostrils together for 10 to 15 minutes. This applies direct pressure to the septum, the cartilage that divides the left and right nostrils. This is the most common site for bleeding. It may be necessary to repeat the procedure a second time. If after two attempts the bleeding persists, other treatments may be necessary. The nose can be packed, and clotting factor or desmopressin can be given.

Children should be taught to calm down as much as possible in the event of a nose bleed.

Some people find that a cold cloth placed on the back of the neck and on the bridge of the nose is helpful in stopping bleeding.

Antifibrinolytic agents (Amicar® or Cyklokapron®) can be given for 5 to 7 days after the nose bleed to prevent re-bleeding.

“It seems the months of November and December are nose bleed months, even though we have bought a good humidifier.”
Drinking hot liquids and strenuous exercise can cause the nose bleed to restart. Therefore, it is helpful to avoid hot soup or drinks and avoid lifting or straining for 24 hours after a nose bleed.

**When should a doctor be consulted for a nose bleed?**

If the pinching procedure does not stop the bleeding, and severe bleeding continues for more than 20 to 30 minutes, a doctor should be consulted.

**Can anything be done to prevent nose bleeds?**

Yes, there are several easy ways to prevent or reduce the frequency of nose bleeds.

It is important to maintain a certain level of humidity in the house, especially in the child’s bedroom. This is especially important in the winter when heating makes a house much drier. A humidifier is ideal; however, an open bowl of water can also work very well.

Using petroleum jelly (Vaseline) in the nostrils every day can keep the nostrils from drying and cracking.

In some cases, local clotting agents like Thrombin and Fibrin may be needed to prevent bleeding from re-occurring. The personnel at the HTC will be able to help with these treatments.
HEMATURIA

What is hematuria and how is it managed?

Hematuria is blood in the urine. It is caused by bleeding in the kidneys. A child with severe hemophilia will probably have an episode of hematuria at some time during his life. Hematuria generally disappears within a few days and permanent kidney damage does not occur.

If bleeding is mild, the urine is pink in colour and clotting factor therapy is not needed. The only treatment necessary is to make sure that the child drinks a lot and that there is a good output of urine. Since hematuria may be caused by conditions other than hemophilia, it is important to have your son checked by a doctor whenever there is blood in the urine.

If bleeding is persistent and the urine is dark red in colour, treatment is needed. Your HTC team will advise you what dosage to administer. Factor therapy should be continued daily until bleeding stops.

Make sure that your child drinks a lot of fluid and that the urine output is good.

Note that the antifibrinolytic agents (Amicar® or Cyklokapron®) are NOT to be given when your child has hematuria.
SUMMARY

This chapter has covered outpatient management of common bleeding episodes including bruises, mouth bleeds, joint and muscle bleeds, nose bleeds and bleeding into the urine. It has also shown ways to recognize life-threatening bleeds into the head, neck, chest and abdomen. Quick recognition of these dangers is the key to successful treatment.

If you have any questions concerning management of a bleeding episode in your son, speak to the team members at your son’s hemophilia treatment centre.

Finally, if your child is on a home therapy program and a bleed does not seem to be responding to standard treatment, you must have your child examined by your doctor or the hemophilia comprehensive care team.

GUIDELINES FOR THE USE OF ICE

How does ice help?

Ice ...

- decreases pain
- decreases inflammation
- decreases swelling
- slows down bleeding
- reduces muscle spasms.

Still a Mystery...

Many boys with hemophilia go through periods when they hardly bleed at all. Then, during other periods, they bleed often and for no reason. Is this caused by a small fluctuation in factor levels? Is it the result of another physiological cycle? Or is there a psychological explanation? Some people even say it is caused by the waxing and waning of the moon. It’s still a mystery.
What kinds of ice should I use?

There are many ways to apply ice to an injury. Here are some recommendations:

**Ice Packs**

Use crushed ice (or a bag of frozen peas or corn) wrapped in a damp towel. Wrap the towel and ice firmly around the injured area. (Large ice cubes are not as easy to ‘fit’ around a joint.) Apply the ice for 10 to 15 minutes.

**Cold packs (gel packs, chemical cold packs)**

Wrap the pack in a thin damp towel. Make sure the pack is flexible and is molded to fit the area to be treated. Never put the cold plastic directly on the skin. Leave the cold pack on for 10 to 15 minutes.

**Ice cups/ice massage**

Fill small paper cups or popsicle makers with water and keep them frozen in your freezer until they are needed. Rub the ice directly over the injury, in smooth strokes up and down or in circles. Have an extra towel close by to catch the drips. Massage lightly for 5 to 7 minutes. This way of using ice is VERY cold.

**Ice bath**

Add ice cubes to a bucket of cold water. Put the injured limb in the water for 5 to 15 minutes. This works well for a bleed in the ankle, foot, wrist or hand but it is also VERY cold.

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Test Your Knowledge

Which of the following are signs of a serious head bleed (intracranial bleed)?

- a) headache
- b) blurred vision
- d) a small bruise
- e) nausea or vomiting
- f) a minor cut on the head
- g) mood changes
- h) loss of balance or coordination

(For some help in finding the answers, see page 5-20.)

(The correct answers are on page 13-17.)
Are there any things I should be careful of when using ice?

Yes, there are.

• Do not use ice over open cuts or scrapes.
• Do not use ice if there is poor circulation or poor sensation in the injured area.
• Be sure the person can tolerate the ice. Some small children may think that the ice is more uncomfortable than the bleed!
• Do not leave the ice on longer than the recommended times. Leaving ice on too long (longer than 15 minutes) can cause muscle weakness and may also cause an INCREASE in blood flow.

“Many of the ice pack products are so cold and rigid. We use the blue powder bags in our house. The bags are moldable and not as freezing cold as other products we have used. When our son was small we used Dixie cups that we had filled and frozen. He hated them.”

Test Your Knowledge

What do the letters R-I-C-E stand for with regard to hemophilia care?

(For some help in finding the answers, see page 5-3.)

(The correct answers are on page 13-17.)