This chapter provides answers to these questions:

- How may parents react when they learn their son has hemophilia?
- What can be done to provide well baby care for a child with hemophilia?
- What can parents expect as a child becomes a toddler and grows into a preschool age child?
- What can parents expect as a child becomes old enough for school and new activities?
- What issues are typical for an adolescent child with hemophilia and his parents?

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Introduction

Placing hemophilia in perspective is a challenging task. Not only do parents need to concern themselves with their child’s ability to accept and successfully live with hemophilia, but they must also consider hemophilia in parenting and family life. There are a variety of emotional and social issues unique to children with hemophilia. As a result, the family of a child with hemophilia has experiences unlike other families.

Children with hemophilia do not all have the same physical and emotional experiences. Their families have different experiences, too. You, as parents, should therefore always feel free to discuss your concerns with your hemophilia treatment centre (HTC) medical team. In addition, there are many other resources available to support parents, to share with your son and with family members, friends, teachers and others important in your son’s life.

Through newsletters, books, web sites, hemophilia organizations and other families in your HTC, you will soon discover you are not alone. Ask your Nurse Coordinator if there is a buddy system in place at your clinic or contact the Canadian Hemophilia Society (CHS) to be put in touch with a family in your area. Nowadays, the Internet permits people to keep in touch despite barriers of geography. Local chapters of the CHS offer a wide range of family programs and activities for all age groups.

Some of the photos in this chapter come from Paul Wilton’s family album. We would like to thank him for allowing us to use his photos to help illustrate “Growing with Hemophilia”
The information presented here is not exhaustive—it is an overview of the more common experiences of children and their families from infancy to adolescence. This chapter’s message is that parents’ ability to deal positively with hemophilia will help their child do the same.

How may parents react when they learn their son has hemophilia?

The birth of a baby is usually a time of joy and celebration. However, the diagnosis of a chronic illness, whether at birth or during the child’s early years, can be devastating. It is not uncommon for parents to feel overwhelmed, shocked, frightened, angry or even resentful.

Dealing with your child’s hemophilia is difficult and has an emotional impact on you, your child, your partner and the family. Dealing with your child’s hemophilia in a healthy and positive way helps ensure that the good times outweigh the hard times.

How and when you tell other people about your child’s hemophilia is your decision. However, your son will often be with other people including family, friends, teachers, care providers and neighbours. Sharing information with them is very helpful. Giving other people reliable information about hemophilia is the best way to prevent misunderstanding and anxiety about your son’s care.

These are important points to keep in mind.

- Hemophilia is not the result of something a parent did wrong. It is nobody’s fault.
- It is normal to occasionally have negative feelings about your child’s hemophilia.
- Your child will not experience every type of bleed you hear about.

“Looking back, I can see we went through a grieving process. We were in shock. We were absolutely terrified and we could only feel the fear of what it would be like for our son and for us.”
Here are some things you can do to ensure your child experiences a happy and nurturing infancy.

- Learn as much as you can about hemophilia so you will be better able to handle it.
- Enjoy your child. Do not let hemophilia define him.
- Try not to be overprotective. Like other children, your son needs to explore his world.
- Turn to the people at your hemophilia treatment centre for help, guidance and support.
- Join a support group to meet other families dealing with hemophilia. A sibling support group may even be available.
- Don’t be afraid to speak to a health care professional about the added stresses in your life and how they are affecting you and your loved ones.
- Be proactive. Go to your child’s teachers and day care providers, and talk to them about the challenges before they come to you with problems.
- Be willing to explain hemophilia. It is a rare disease. Most people know very little about it.
- Work on having a positive attitude. This will help you, your son and all the other people in your son’s life.

“We watched educational videos and read all the material we were given. We consumed every available web site on hemophilia and slowly started to feel empowered through what we learned. We started talking to other parents on line and eventually met other parents and their kids. That was the best thing we did. The families with older children reassured us that we would cope too and put hemophilia into perspective in our lives.”
What can be done to provide well baby care for a child with hemophilia?

Well baby care for a child with hemophilia is almost the same as for a child without hemophilia. Some aspects, however, need special mention. The purpose of this section is to help you take good care of your child.

We hope this information will reassure you that with today’s medical care, your child can live a full, healthy and productive life. Your job is to help him do this.

For standard baby care, many pediatricians recommend *Your Baby and Child – The Essential Guide for Every Parent*. The book is written by Penelope Leach and published by Penguin Books. Its ISBN number is 014026325X and it can be ordered through the Internet.

The information that follows is provided only as guidelines. Your child’s doctor may have some different recommendations. You may wish to discuss the advice in this section with him/her and with the medical director or Nurse Coordinator at your son’s HTC.

**Bringing Your Baby Home**

Having a new baby at home is a major adjustment for any parent. You have to make an added adjustment because of his hemophilia, but do not forget that you and your baby have normal needs that have to be met. The first year is filled with trial and error and much learning as your infant develops emotionally, socially and physically.

Learning how to ice bruises or swelling is important. Talk to your physiotherapist about ice packs. *(For more information on icing, see*
Chapter 5, Management of Bleeds. Keep in mind babies do not like ice, as it is cold and uncomfortable for them. A handy baby-friendly alternative is a bag of frozen peas. The bag can be easily molded around the swelling. It isn’t as cold and is reusable.

Learning about hemophilia is important for both you and your child. Always talk to your family doctor or a member of you HTC when you are uncertain what to do. Call even just to make sure you are doing the right thing. The HTC staff can give you medical information and much needed support.

It is helpful to keep a bag packed and ready to go. This saves time when your baby needs to go to the doctor’s office or to the hospital for treatment or medical attention. Keep a change of clothes, diapers, a special toy and a snack in the bag to help you pass the time. Waiting will undoubtedly become something you learn to cope with. It can be very frustrating at times. However, keep in mind you are being supported by one of the best hemophilia care systems in the world.

The Emergency Room

Emergency room (ER) visits will be easier for you and your child if you provide medical staff with precise information. In a busy ER it can be very difficult to communicate with staff. Here are some tips.

- Give the ER staff key information. They will learn that you are an informed parent and that you have a treatment routine. For example, you know best whether the child sits up or lies down for an infusion and which vein is the easiest to access.

- Bring your treatment diary with you to share with staff at the hospital.

- Find ways to help the staff at the hospital achieve your treatment goals on behalf of your child. Persist! You are the advocate for your child.
Many HTCs issue wallet size treatment information cards that can be carried by parents of young children. Show this card to the medical staff in the ER.

Along the way, you will meet great people who truly want to help you and your child. Care is a team approach and today’s care for children with hemophilia is outstanding. Highly trained medical personnel, the availability of comprehensive care in most provinces and today’s high-quality factor concentrates mean that children with hemophilia are being well provided for in Canada. Still, no matter how hard you try to prevent your child from injuries, they will occur and you need the help and support of your medical team.

**Examining Your Baby for Bleeds**

Bath time is an excellent opportunity to examine your baby.

- Compare one arm to the other—one leg to the other. Are both arms moving and bending equally well? Are both legs and feet moving and bending in the same way?
- Check for any bruises on his body.

Safety is foremost for all babies when they are being bathed. Some families put a piece of thin sponge rubber on the bottom of the tub. It prevents slipping and is softer for the baby to sit on. Just this simple step may prevent accidental injury for your baby.

“The week I went back to work after a maternity leave, I noticed 2 bruises. I dropped into the clinic for my first time on a work day, with pictures of these yellow bruises. My nurse welcomed me and made me feel very good for coming by. She reassured me that the bruises were very normal for a child with hemophilia.”
Padding and Helmets

From as early as 4 months of age, your child may begin to rock from side to side, roll over and start creeping, crawling, and pulling himself up against furniture. From as early as 7 or 8 months, he may begin standing and taking that first step. During these stages you should consider the use of knee and elbow pads to prevent bruising. It is a good idea to discuss padding with your family doctor or a member of your HTC team.

Some families buy baby-sized elbow and knee pads for their children. They choose to sew extra padding into clothing. Other families choose to do neither. As your child grows you can observe your child’s activity level, the amount of bruising he has and the amount of treatment he needs. With this information in mind, you can discuss padding with your family doctor or a member of your HTC team, and make the right decision for your child.

Not all families choose to put helmets on their child with hemophilia. A common concern parents have is “making him look different”. However, a helmet can provide valuable padding and protection for your child as he explores his environment and develops physically. It may help you allow him to play naturally. Some families choose to make their homes safer by padding fireplaces and sharp or protruding corners. They use helmets to better protect the child outside of the home.

Many HTCs recommend the use of helmets for children up to the age of 2. Helmets are always recommended for children riding bikes, rollerblading, skating, sailing and doing other activities in which there is a risk of a blow to the head. Talk to a member of your care team about where to buy a child’s helmet. Very good ones are available.

“My son screams every time we put the helmet on him. I just don’t understand how families got their children to wear them all the time.”

“We used helmets and I never regret it. It makes me feel good to know we tried to do everything we could to prevent head bleeds, which scared us completely.”
**Immunization Schedule**

Even though your child has hemophilia, he should receive routine immunizations according to the recommended schedule.

Immunization ‘needles’ can be given by his regular doctor without clotting factor therapy. Intramuscular vaccines should be given with a small-bore (25-gauge) needle. Firm pressure must be applied to the needle site for 10 minutes after the injection. If this procedure is followed, muscle bleeds at the site of immunizations are very uncommon. However, if you notice swelling at the site of an immunization, you should have your baby checked by his doctor or HTC team.

There are certain common side effects after routine immunizations and your doctor will discuss these with you. Because of your son’s hemophilia, the one extra problem you should check for is excessive swelling of the leg at the needle site. This is an unusual complication but, if it does occur, you should contact your doctor or the medical director or nurse coordinator at your son’s HTC.

“On the first day of school this year, two mothers had younger children in the JK school yard with helmets on, in their strollers. In time I learned one child wore the helmet because she was born with a piece of her brain missing and the second child’s head was not formed symmetrically. It brought back memories.”
### Table 1

#### Recommended Schedule for Routine Immunizations

<table>
<thead>
<tr>
<th>Age</th>
<th>Immunization</th>
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| 2 months       | • Component Pertussis vaccine + Diphtheria + Tetanus combined with inactivate (cPDT Polio) - intramuscular  
|                | • Hemophilus Influenza Type B (HiB) – intramuscular                           |
| 4 months       | • cPDT Polio – intramuscular                                                |
|                | • HiB – intramuscular                                                       |
| 6 months       | • cPDT Polio – intramuscular                                                |
|                | • HiB – intramuscular                                                       |
| After 1st birthday | • Measles, Mumps, Rubella (MMR) – subcutaneous                             |
|                | • Varivax (chicken pox vaccine) – optional                                  |
| 18 months      | • cPDT Polio – intramuscular                                                |
|                | • HiB – intramuscular                                                       |
| 4 to 6 years   | • cPDT Polio – intramuscular*                                               |
|                | • MMR – subcutaneous                                                       |
| 14 years       | • Tetanus, Diphtheria, Polio (TdP)                                          |
| from age 2 months (optional) | • Prevnar, Menjugate – optional immunizations against bacteria that can cause meningitis – Intramuscular |

*Intramuscular cPDT Polio and HiB are given in the same needle.*
In the 1970s and 1980s, factor concentrates often transmitted hepatitis B and C. Today’s concentrates are considered safe. Nevertheless, it is routine for all children with hemophilia to have a blood sample tested for evidence of past or present infection with the hepatitis A, B or C viruses.

Many provinces have introduced hepatitis B vaccine programs for all children. Because this is a wise health precaution, and because children with hemophilia have a greater chance of needing a blood transfusion, it is recommended that they receive hepatitis B vaccine at a young age. This consists of a series of three intramuscular injections given over a period of six months.

Hepatitis A has also been transmitted by plasma-derived factor concentrates on very rare occasions. A vaccine for hepatitis A is available for your child. This vaccine consists of 2 intramuscular injections given 6 months apart.

Talk to your HTC team about these vaccines. (For more information on past transmission of viruses by blood and blood products, see Chapter 8, Complications of Hemophilia.)

**Colic**

We do not know what causes colic (pain in the abdomen) in young babies. This problem can certainly be very trying. Colic generally stops around 3 months of age. During an attack of colic, your baby will be uncomfortable and he may cry for a long period of time. He will often draw his legs up to his abdomen.

There are no sure rules as to how to treat colic, but picking your baby up, walking, talking or giving him a warm bath can often help. Some babies calm down during a car ride. You’ll have to time it so traffic lights don’t stop you; otherwise the attack of colic may start up again!
Sometimes, using gripe water or Ovol drops can help, but if the attacks of colic become unbearable, discuss them with your son’s doctor. He/she may have some helpful suggestions.

A concern of parents of children with hemophilia is how to distinguish between colic and a possible stomach or intestinal bleed. First of all, stomach bleeds are very, very rare in infants.

In addition to having stomach or abdominal pain, a child with a stomach or intestinal bleed has these signs and symptoms.

- He coughs up fresh or old blood (which may be a dark fluid or look like coffee grounds).
- He has bloody, black or tar-like stools.
- He looks weak or pale.

**Teething and Mouth Bleeds**

More problems are probably blamed on teething than on any other condition. Fever, irritability, rash, diarrhea, loss of appetite and poor sleeping patterns are some examples. Teething may cause these symptoms, but you should not assume this. All of these symptoms could be caused by other medical conditions. So if your baby is looking unwell and has these symptoms, your son’s doctor should check him.

The majority of babies with hemophilia cut teeth with very little, if any, bleeding! Occasionally, there may be a problem with a bleed around the gum as the tooth erupts. Contact your nurse coordinator and she will advise you on the best treatment for this.

A note of reassurance — just because your baby has problems with one tooth coming in doesn’t mean he will have problems with all his teeth!
Mouth Bleeds

Mouth bleeds are the most common bleed for infants. Mouth bleeds tend to look more serious than they are, but they should always be examined carefully and followed up by staff at your HTC.

Here are some things you can expect from mouth bleeds of all types.

- A mouth bleed may signal the arrival of a new tooth.
- A blood blister may appear over an emerging tooth in any child.
- Because the mouth is moist and very active, clots can’t form as easily and they are more likely to fall out before the cut is healed.
- A large clot may form in your child’s mouth in the area of the bleed especially during the night. These are called “liver clots”, as they are large, dark red and soft or wobbly. While unpleasant to look at, there is no cause for alarm. Do not dislodge this clot — it will fall off on its own.
- Bleeding due to a torn frenulum (piece of skin attached to the upper lip and gum) requires attention from the HTC team.
- Because the blood is mixed with saliva, it often looks like there is more blood than there really is. This extra blood can stain clothes and crib sheets but is not cause for alarm.
- Swallowed blood can upset your infant’s stomach and cause nausea and vomiting.
- If the bleeding is significant (not just oozing mixed with saliva, but bleeding freely) and lasts longer than 30 minutes, you should consult your child’s doctor or HTC.
- Bleeding due to a cut on the tongue requires attention from a doctor or a member of the HTC team.

“Our family doctor thought the rip in his mouth would heal. We were glad when we went to the clinic the next day and found out that a torn frenulum needed attention. It was our son’s first treatment. We were almost relieved to go through the process.”
(For more information on dental care for a child with hemophilia, see Chapter 10, Staying Healthy.)

Safety

Safety concerns for your child with hemophilia are not that different from safety concerns for any child. All children will incur minor cuts and bruises and bumps to the head.

However, there are a number of safety precautions for different stages of your child’s development. Try to anticipate problems rather than attempting to deal with them after they have occurred. Here are a few suggestions.

• Make sure your son has and always wears a Medic Alert bracelet.
• Consider the use of a helmet and padding in clothes.
• Pad your baby’s crib. Many babies are head bangers.
• Always support your baby’s head and neck. Never shake your baby even if his behaviour frustrates you. Shaking can cause serious injury to any baby.
• Avoid playthings with sharp edges or with small pieces. During the first few years everything goes into your baby’s mouth. Until age 3, small objects remain a hazard. Soft rounded toys are the best choice for you son.
• Once your child is in the toddler phase, protect him from the sharp edges of your furniture by padding them or removing them entirely. Most families remove square or rectangular coffee tables at this stage. You may decide to use a molded safety helmet to protect your child’s head during this stage. Speak to your nurse coordinator about this.
• Strap your infant in his seat or highchair and do not leave him when he is in it.

• Do not use a baby walker or Jolly Jumper. Baby walkers are potentially deadly, and accidents with Jolly Jumpers have occurred. What’s more, they provide no benefit to your child.

• Keep all medicines and cleaning materials in safe places that your child cannot reach.

• Teach your child not to run when he is carrying sharp objects.

• Cover electrical outlets.

• Use child security gates at the top and bottom of stairs.

• Keep knives, scissors and sharp tools out of reach.

• Make sure your child wears a helmet when riding a bike.

• Most of all, use common sense and do not expose your child to unnecessary risks.

**The Doctors’ Roles in Your Child’s Care**

Your son should see two doctors on a regular basis. One of these doctors is the hemophilia specialist at the HTC. He/she is often a hematologist. In addition, your son needs a doctor to take care of other aspects of his health. This doctor is usually a general practitioner (GP) or a pediatrician.

Your son’s GP or pediatrician may have an important role to play even in his hemophilia care, especially if you live a long distance from your HTC. Remember that few doctors are trained in the care of a child with hemophilia. You should speak to your doctor about this.

In order to take an active part in the treatment, your son’s doctor must be able to recognize which bleeds need factor replacement and how much factor should be given. He/she must also have the expertise to give the factor intravenously. At times, such infusions can be a difficult experience for the child, parent and

“Our family doctor wouldn’t call our comprehensive care clinic to discuss our son’s health. He was very hesitant to treat our son more than once for any reason. We eventually found a more progressive doctor who worked with the clinic staff as a team member. It was very difficult to leave a doctor we both liked, but we needed a different approach. In fact we should have done it sooner.”
doctor. Many HTCs do outreach. Their outreach services include training other medical personnel in hemophilia care.

It is important for parents to learn which bumps or bruises need to be treated. This skill comes with time and, until you learn how to make this decision, your son’s doctor will be of great help. Do not be embarrassed to visit him/her regularly until you have confidence in your own judgement. (For more information on recognizing and treating bleeds, see Chapter 5, Management of Bleeds.)

You need your son's GP or pediatrician for other aspects of your child’s health and development. Do not forget that hemophilia is only one part of his life. Do not make it the all-important one, to the exclusion of everything else.

In summary, in your son’s first year, your lives will be filled with joy, wonder, many questions and some anxiety. This is normal. The bleeds that will be most common and which your baby son may experience will be:

- small soft tissue bleeds (bruises)
- mouth bleeds from tongue bites, torn frenulum or eruption of a tooth.

Head bleeds, although uncommon in babies, are definitely serious. If your baby suffers an injury to his head, either from a fall or a knock to the head, he must be seen by your hemophilia doctor or in the ER of your nearest hospital. Any change in your baby's normal day-to-day routine or personality should be checked. Watch for these signs of a possible head bleed.

- You baby won’t feed as he usually does.
- He is hard to wake up or appears very sleepy.
- He is more irritable than normal.
- He vomits for no apparent reason.
What can parents expect as a child becomes a toddler and grows into a preschool age child?

Your child is growing and developing, and so is his world. He may be placed in the care of a babysitter, or attend a nursery school or daycare for the first time. He may be invited to a birthday party or to a friend’s house to play. Your child needs to experience these new environments just like any child. As a parent you need to be sure your child is in a safe place where his medical needs are clearly understood. The parent’s role as educator becomes very important as your child grows.

Within the community of families living and dealing with hemophilia, there is a tradition of sharing of information and support for each other. You are not alone, and it is incredibly uplifting to talk to families with older children. You see first hand their success in dealing with the challenges you are undertaking.

Speak to your nurse coordinator to get in touch with other families or call the Canadian Hemophilia Society. Most clinics operate a “buddy system”. Your Nurse Coordinator can put you in touch with an experienced parent who has dealt with challenges like yours.

This is a naturally curious time for children. Protecting the child with hemophilia gets harder. Parents struggle with their need to provide him with a safe environment and his natural need to explore the world beyond his home. With increased mobility, he is now developing new skills and interests. During the toddler stage, it is all too easy to be over-protective of your son. Learning to walk will lead to frequent bumps and falls. The temptation to watch over him and try to prevent any falls can unfortunately lead to over-protection.

“Meeting another Dad provided me with hope that I would bond with my son and replace my dreams of hockey arenas with other things. I played a lot of hockey and assumed I would share this experience with my son some day. It was hard for me to let go of that.”
Growing with Hemophilia

Siblings may see their brother as being treated differently. Feelings of resentment and jealousy are not uncommon in siblings, particularly because your son needs extra attention for medical reasons. Spending time one-on-one with all children in your family is one way to help siblings understand their importance to you. Explaining hemophilia and inviting siblings to support their brother’s needs can also be helpful. Siblings deal better with hemophilia if they understand what happens when their brother goes to the hospital and what back-up plans have been made to support their own needs and activities.

This may be the first time you, as a parent, are taking on the role of educator to ensure your child is in a safe environment with people who understand hemophilia and who know what to do in the case of a bleed or emergency. Here are some pointers to consider when you are in this position.

- Ask your nurse coordinator if she/he is available to make a presentation, to attend a meeting or speak to your intended care provider(s) or teachers on the telephone. Create a positive team approach. You should also discuss your wishes regarding confidentiality about your son and hemophilia. Keep in mind that educating others is the best defense against misunderstandings and fear.

- Review with your nurse coordinator what educational materials are available to provide to your care providers.

- Check with the Canadian Hemophilia Society or your local chapter to see what educational materials they have.

- Ensure your care provider(s) are familiar with the signs of a bleed, how to provide immediate first aid and how to get in touch with you or your designated back-up person. Remember! The more they know about hemophilia and your son, the more confident they will be as care providers.
• Make sure care providers can reach you. Some families find cell phones a convenient way to communicate with schools and the HTC about their child.

• Provide the contact numbers for your HTC team members for the times you cannot be reached. Whether you travel in your job or forget to charge your cell phone, it is important to establish clear lines of communication for care providers and teachers, should your child require medical attention.

• Be sure you discuss what activities need to be monitored closely and which ones your child is restricted from. Consider whether you should provide safety equipment such as a helmet or padding.

• If you are concerned about how a situation was handled, use the opportunity to review steps taken and what action would have yielded a better outcome for your child. Relationships with care providers and nursery schools will require fine-tuning along the way.

• Provide teachers and care providers with positive feedback to emphasize what they have done well. This will help reinforce the kinds of care that guarantee your child’s safety.

For your toddler the world is an exciting place to be. Much needs to be explored. Balance isn’t totally developed and many falls onto backsides occur. This is the stage when soft tissue bleeds happen. These injuries are to arms and legs, and the body in general. Signs of these bleeds are...

• pain
• swelling
• heat or redness at the site of the bleed
• a reluctance on the part of the child to use the limb.

“Having our nurse at the school gave me credibility as a parent. Our nurse said our son should have gym class, yet the teacher had suggested he sit this class out. Meeting the nurse gave him a chance to alleviate his concerns in a professional format.”

“I always carry my cell phone. It enables me to go to work each day, knowing I am available to deal with anything that may happen. I do not want anyone else making decisions for my son.”
Buttock bleeds are common in this age group as toddlers fall back onto hard objects on the floor. A buttock bleed can be very painful for the child, preventing him from sitting comfortably or walking well.

Mouth bleeds are frequent as everything goes in the mouth and sharp objects can cut the mucosal lining or frenulum. Toddlers are prone to biting their tongues with their sharp baby teeth.

It is at this age that your child may experience his first joint bleed. Joint bleeds can occur as a result of injury or spontaneously (without injury). A toddler with a joint bleed may...

- limp or refuse to walk at all if the bleed is in the ankle or knee
- use his left hand if he is right-handed, and *vice-versa*
- reach for an object with his good arm even though the object is closer to the arm with the bleed.

Head trauma at this stage can be the result of a fall. Head trauma can result in serious bleeds into the brain, so it is strongly recommended that these bleeds be assessed promptly. Do not hesitate to call your doctor or HTC team if you are worried about a head bleed in your toddler. *(For more information on recognizing serious head bleeds, see Chapter 5, Management of Bleeds.)*

Many toddlers in Canada are on prophylaxis. They receive regular infusions of factor concentrates to prevent bleeds. This regular treatment reduces the number of early joint bleeds and soft tissue bleeds—even with your toddler’s busy lifestyle. Many children have no serious bleeds at all. However, this does not mean you no longer have to keep a sharp lookout for signs of bleeding. Talk to your hemophilia team if you have questions about prophylaxis. *(For more information on prophylaxis, see Chapter 6, Home Infusion.)*
What can parents expect as a child becomes old enough for school and new activities?

At School

When your son first starts going to school, it is very important to continue to encourage him to live as normal a life as possible. He, like other children, should be expected to perform at school according to his abilities. Normal relationships with other children are important. Physical exercise is essential. You will need to accept the bumps and bruises that occur in the school setting.

During these years a child learns a great deal about himself. The way he sees hemophilia affects his self-image and self-esteem. As parents you can encourage him to develop a positive, accepting attitude towards...

- his treatment for hemophilia
- the occasional use of crutches at school to rest a joint
- the open sharing of information with his friends about hemophilia
- the days off school that are bound to happen.

Despite your efforts to have your son accept his hemophilia, he will sometimes challenge restrictions, resent limitations and even try to hide the fact he is having a bleed. Be patient. Acceptance is a gradual process.
Many parents find their child accepts his treatment regimes and limitations over time as he starts to understand hemophilia and learns what to expect. Some families encourage their child to maintain his own treatment diary. Some children, with family and medical support, learn to self infuse. (See Chapter 6, Home Infusion.)

Creating open communication between your child and his caregivers at school is vital. In addition to the pointers outlined in the previous section — especially regarding educating people about your son’s hemophilia — consider the following:

- Make sure your child tells his teacher(s) or a member of the school support staff when he is experiencing discomfort, which may indicate a bleed in progress.

- All school staff members should know of your son’s hemophilia and understand what first steps need to be taken to care for him.

- Contact numbers for you and your HTC team and/or local doctor should be posted at the school. School secretaries are great resources in the school environment.
• Schools have first aid procedures for all children. Most likely they also have first aid and emergency response procedures for several other children with special health concerns. Make sure you know what these procedures are and that you have given the school all the required information.

• Have your child wear a Medic Alert bracelet or necklace.

• Take the time to meet with your child’s teacher and establish a good relationship. Explain to the teacher that your son may miss school from time to time. Discuss how you will pick up homework for your child and help him keep up with his work. Most parents find this is a positive step. It is really up to you. By communicating openly with your child’s teacher(s), you are showing your son how to do this for himself. You are also letting your son know he is expected to manage his classroom responsibilities. This does not mean he won’t need help. As parents, this is already part of your job.

Activities Outside of School

During these years, children are involved in many different activities outside of the home and school environments. Whether your child plays soccer, goes to summer day camp, plays at a friend’s house or is a Boy Scout, it is up to you to use common sense to be sure your child is with people who know about hemophilia. If your child is raised in an open and positive environment, he will learn that hemophilia means he has to consider some extra precautions, but he does not have to miss out on the activities other children are doing. The process of acceptance can be very difficult, and it won’t happen overnight.

With activity comes a greater chance of injury. However, exercise also helps children strengthen muscles and lead healthy lives. Good physical conditioning can help to prevent bleeds. For each child the balance between healthy activity and bleeding is different. The family’s preferred activities, and the child’s interests and accomplishments must be considered.

“My son hated needles. When he was younger, he wouldn’t tell me about his bleeds, because he didn’t want to get a needle.”

“On one of his visits to emergency, after the infusion site had been established, the doctor invited our son to depress the plunger. He instantly agreed; he was absorbed with the self-treatment, and very calm. It was a turning point. I think he felt he could exercise some control in his treatment, and I think he felt more mature and responsible.”
The school age years are the biggest time of challenge for a boy with hemophilia and his parents. This is the age when peer pressure is strong. It is important to be part of a group or team. However, belonging to this group or team may put your son at risk of injury if his activities are not safe ones. Large soft tissue bleeds, muscle bleeds and joint bleeds can be the result. These are the years of chipped teeth and broken bones. Again, prophylactic treatment will go a long way to reducing the impact of hemophilia.

Openness and good communication are essential. Talk to your son. Provide him with alternative activities. You could even join a sport or team and play with him. Be sensitive to his growing development and need to “be one of the gang”. Talk to your HTC team. They are experienced with boys in this age group and can help you and your son navigate some of the obstacles.

What issues are typical for an adolescent child with hemophilia and his parents?

Adolescence is a time of change for all children. There is an increased need for independence, having control and conformity with friends. It is a time when your son can take on new responsibilities, such as monitoring hemophilia for himself and starting to perform his own infusions. In fact, for many children, accurate diary keeping and self-infusion may start at an earlier age. Learning these skills can increase feelings of control, independence and self-esteem. At the same time, the need to conform with the behaviour of other children his age can lead to trying more risky behaviour.

Being accepted by his peers becomes very important. Boys may be very sensitive to their body image and sense of masculinity. Some teenagers experience anger because they feel different and left out. Some reject hemophilia by ignoring standard care.
routines and hiding bleeds and the need for treatment. Teenagers may feel emotional stress. Some teens shy away from close relationships with friends, both male and female, because they are scared to disclose their medical condition. It can be very difficult to convince your son that hemophilia does not rule his life.

On the other hand, for other boys with hemophilia, their acceptance of the disease and the maturity they have developed because of it enable them to reach far beyond their limitations. Their ability to deal with the challenge of hemophilia spills over into other areas. They lead full and active lives.

This can also be a trying time for parents who are watching their children struggle to assert themselves. Parents may feel their children are not making good decisions. Through these maturing years, it is essential for parents to supervise their sons to ensure appropriate decisions are being made related to infusions, infusion techniques and diary keeping. Keep in mind that your hemophilia clinic can play a supportive role, especially in the adolescent years when your advice may be less welcome. There is no magic recipe for success. It is important to know your child and develop together your own way to be sure he is receiving the medical attention he requires, and that he is doing so safely and effectively.

The social worker at your HTC is a good person to turn to. Don’t be afraid to seek his/her help.
This is a time when your child will most likely benefit from talking to other teens and adults with hemophilia. The teen years can be confusing. They are marked by the need to fit in and be accepted. Relating to others with the same problems may prove very beneficial. Your child will see he is not alone and not the only one to have the feelings he has.

The Canadian Hemophilia Society offers family weekends and specific programs for teens. Seek out these opportunities, even if you feel your son is managing his health well. The opportunity to meet with other families and adolescents provides invaluable support. Imagine the impact if your son were able to help another adolescent struggling with something your son understands. These programs are designed to encourage give-and-take amongst kids within the same age group. They are a natural extension for children who have had the opportunity to go to camp over the years.

Teenagers are very comfortable with Internet technology these days. They can e-mail each other and form friendships all over the country.

Attending workshops can teach them a great deal about coping, give them confidence and knowledge, and provide perspective in a fun environment. Over time your son may choose to become involved as a volunteer in the hemophilia community in Canada or internationally.

**Alcohol and Drug Use**

Abuse of alcohol and drugs represents a threat for all adolescents. It is of extra concern to families raising children who are desperately trying to fit in, or for children dealing with anger and resentment. Drugs and alcohol affect judgment and increase risk-taking. This increases the possibility of serious injury, especially worrisome for parents of a boy with hemophilia.
Discussing these issues at an earlier age will help prepare your son to make good choices. If you have dealt openly with hemophilia issues in a positive environment up to this point, your past experiences will help you deal with drug and alcohol issues as well. Again, seek out the available services and support at your clinic to help you and your son.

**Body Piercing and Tattoos**

Body piercing and tattoos are very popular among young people. Anyone getting either puts himself at risk whether he has hemophilia or not. The risk of blood-borne infections from contaminated needles and body-piercing equipment is never zero. Many tattoo and body-piercing shops do not practice sterile technique. Add to this the risk of bleeding from a tattoo or body piercing and a simple event can become a complicated, unpleasant experience.

If your teen has decided on getting a tattoo or having a part of his body pierced, simply forbidding the procedure may not work. Try to support him with common sense.

- Suggest he wait until he is older. (A reputable shop will not tattoo anyone under 18 without the parents’ written permission.)
- Have him study how HIV, hepatitis B and hepatitis C can be transmitted. The Internet is a good source of such information. Your nurse coordinator can also provide documentation.
- Insist that he look into the tattoo shop’s reputation.
- Insist that he finds out how the tattoo artist makes sure that blood-borne infections are not transmitted.
- Insist that he treat himself with factor concentrate before the procedure. Be alert to any signs of swelling or bleeding in the area and treat again if necessary
- Consult with the HTC team.

“When he started high school, he didn’t want to let the school know, so he wouldn’t feel set apart. You see the problem is that teachers tend to over react and freak out.”

“These years were difficult for both of us. I am a single mom—it is just the 2 of us. My son was trying to be like everybody else and he started to rebel against treatments. He refused to talk about his bleeds and he made some very bad decisions. We got through it, but it was tough.”

All About Hemophilia
A Guide for Families
Sexuality

Talking to your children about relationships at an early age will help all of you prepare for this part of growing up. Open conversations about sexuality and relationships will help your child understand the complexities of relationships, including concepts of respect, alternatives and consequences.

During these years, regardless of your feelings as a parent, your son may become sexually active. Trends in society indicate children are becoming sexually active at younger ages. Sometimes, teenagers with hemophilia are fearful about sex and the chance of a bleed during intercourse. This rarely happens. It is important, however, to educate your child to help him face the challenges of these years as best he can, including helping him decide whether he is ready to have sex. With or without hemophilia, this decision is based on many factors including values, religious beliefs, and psychological readiness. Talk to him about birth control and sexually transmitted diseases (STDs). Talk to your hemophilia doctor, nurse and/or social worker for support. Your son should also feel comfortable talking to these health professionals.

Conclusion

Listen to your son. Let him express his feelings without adding your opinions. Just as he fell and was bumped and bruised as a toddler, he will hit stumbling blocks as a teenager. Let him learn from his mistakes and experiences as he becomes more independent. In this way he will also learn to become responsible for himself. This includes managing his hemophilia.

By the time they have reached adolescence many boys have discovered through trial and error what they can safely do and what will result in a bleed. Many boys who are on prophylaxis on a regular basis will have maintained healthy joints and an active lifestyle.
Some boys elect to treat themselves with factor only when necessary. They will self-infuse at the first sign of a bleed or before they play sports.

Other boys will struggle with the fact they have hemophilia. They are more limited in their activities and lifestyle and, despite good care, have some damage to their joints. Extra care will be needed to avoid further problems in the future.

In all cases, your comprehensive care team is there to help you and your son.

“I first self infused when I was seven. Besides me, my father and nurses were the only ones to have ever given me a needle. A couple of months ago, my girlfriend pictured here gave me a needle. I kept asking her to try and she finally gave in. I was nervous—but I didn’t tell her. It was rough going but we got the vein, which was the ultimate goal. It was a great experience for me and I felt even closer to the girl I love.”