This chapter provides answers to these questions:

BABY YEARS

- How may parents react when they learn their child has hemophilia?
- Who else needs to know about your child’s hemophilia?
- What is involved in “well baby care” for a child with hemophilia?

TODDLER AND PRE-SCHOOL YEARS

- What can parents expect as their child reaches the toddler and pre-school ages?

SCHOOL-AGE AND PRE-TEEN YEARS

- What can parents expect as a child becomes old enough for school and new activities?

THE TEENAGE YEARS

- What issues are typical for a teenager with hemophilia and his parents?

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NOTES
“Parents’ ability to deal positively with hemophilia will help their child do the same.”

Introduction

It’s hard to step away from hemophilia, and keeping it in perspective can sometimes be a challenging task. Parents need to make sure their child learns to accept and successfully live with hemophilia, adapt to living with hemophilia themselves, and furthermore consider hemophilia in their parenting and family life. There are a variety of unique emotional and social challenges that can arise with hemophilia. Each family must learn how best to cope according to their own unique experiences.

Children with hemophilia do not all have the same physical and emotional experiences. Their families have different experiences, too. As parents, you should 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 child and with family members, friends, teachers and other important people in your child’s life.

The diagnosis of hemophilia will likely cause feelings such as sadness, worry and helplessness. The HTC social worker and psychologist can help guide you and your family through the challenges. Learning to adapt to a chronic illness will involve some highs and lows, achievements and setbacks. Don’t ever hesitate to talk to the members of the hemophilia team if you have a concern or question at any point throughout the years of your child’s growth and development. They are there to teach and support you, guide you through the challenges, and help make sure your child grows up in the best physical and emotional health.

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”.
Through newsletters, books, Web sites, hemophilia organizations and other families in your HTC, you will soon discover you are not alone. Ask the HTC 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 or elsewhere in Canada. Nowadays, the Internet allows people to connect and 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.

The purpose of this chapter is to help you take good care of your child. It gives an overview of the more common experiences of children and their families from infancy to adolescence. 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. It's important to remember that your ability to deal positively with hemophilia will help your child do the same.

www.hemophilia.ca
“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.”

BABY YEARS

How may parents react when they learn their child 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 feel devastating. At first, the world seems turned upside down — the family plans, lifestyle and balance are all thrown into confusion. At first, some parents feel overwhelmed, shocked, frightened, angry or even resentful.

Many parents feel great sadness and sometimes a sense of mourning when they first learn about the chronic illness. All parents hope for and imagine having a perfect little baby. With birth, they discover the reality... and their baby’s uniqueness. The newborn baby already has his own little personality. He is strong in some ways and fragile in others. When parents learn that their child has a lifelong medical condition such as hemophilia, it’s very understandable and very normal for them to mourn for the healthy baby they had hoped to have.

Paul, 24 hours old
Dealing with hemophilia is sometimes difficult. It has emotional impacts on each parent, the child, siblings and other family members. However, with help and support from the HTC team, your family will find the strength and ability to adapt to the reality. Your family will discover your core values in life and a deep loving bond that will guide you through the lifelong journey with hemophilia. And you will come to see the great hope, happiness and opportunities that life holds for your family, just as any other family.

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 such as anger or frustration about your child’s hemophilia.

• Your child will not experience every type of bleed that can occur with hemophilia.

• Everybody has some defective genes. Hemophilia occurs when someone has a defective factor VIII or IX gene that interferes with the clotting process.

• There is excellent medical treatment for hemophilia, and you and your child can look forward to living happy and normal lives.

“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.”
**Who else needs to know about your child’s hemophilia?**

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

Here are some things you can do to ensure your child experiences a happy and nurturing babyhood.

- Learn as much as you can about hemophilia so you will be better able to handle it.
- Enjoy your baby. Do not let hemophilia define him.
- Try not to be overprotective. Like other children, your son needs to explore his world.
- Turn to the team 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 healthcare professional about the added stresses in your life and how they are affecting you and your loved ones.
- Be proactive — take charge of explaining your child’s hemophilia to his caregivers and daycare staff. Spend time with your child’s daycare providers and babysitters explaining his bleeding disorder, what to watch for and what to expect. It is important to establish ongoing, open communication with your child’s caregiver so that you can deal with challenges or problems as soon as they arise.
• Be willing to explain hemophilia. It is a rare disease. Most people know very little about it.

• Work on having a positive attitude despite the challenges and emotional stress of dealing with hemophilia. This will help you, your child, your family, close friends and other people in his life.

• Invite important people in your child’s life (grandparents and other relatives, babysitters, daycare staff) to attend information sessions at the HTC. The comprehensive care team will help demystify hemophilia. This will also help them understand that as the parent, you are also an expert on your child’s hemophilia and they can have confidence in your knowledge and advice.

■ What is involved in “well baby care” for a child with hemophilia?

The term “well baby care” is used to describe healthcare services for a baby in the first 2 years of life. It involves a series of check-ups with the pediatrician every 2 to 3 months to make sure that the baby is growing and developing as he should. The check-ups are when the baby can get his vaccinations, and parents can get advice about aspects of baby care such as nutrition and safety.

Well baby care for a child with hemophilia is almost the same as for a child without hemophilia. Some aspects, however, need special attention. The following information on caring for a baby with hemophilia are only 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 your child’s HTC physician and nurse coordinator.
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 baby develops emotionally, socially and physically.

Learning about hemophilia is important for both you and your child. It is also important to learn how to treat bruises, injuries and bleeds. See Chapter 4, Management of Bleeds. Always talk to your family doctor or a member of your HTC team if you are not sure what to do. Call 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 in case of a medical emergency. 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 in hospitals 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.
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.

- You may notice bruising on his body. A new bruise first appears as redness of the skin and soon becomes “black and blue.” The bruise then slowly turns greenish yellow. Finally, the skin returns to its normal colour when the bruise completely heals. Although parents can be alarmed by the amount of bruising or unusual location of a bruise, most bruises are generally not too worrisome.

- Watch for swelling without change in skin colour — this could be a sign of a deep tissue or muscle bleed. This type of bleeding is painful and the child will usually avoid using the muscle and move differently. You must consult the HTC team as soon as you notice these symptoms.

Safety is foremost for all babies when they are being bathed. Some parents stick a thin sponge-padded rubber mat on the bottom of the tub. It helps prevent slipping in the tub and is softer for sitting on. Just this simple step can make a big difference.
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 your child likes to sit up or lie down for an infusion and which vein is the easiest to access.

• Bring your treatment diary with you to show the staff at the hospital.

• Find ways to help the staff at the hospital provide the best treatment to your child. Don’t give up! You are the advocate for your child.

• Ask the HTC to provide you with a FactorFirst Card. This wallet-size card will contain your child’s treatment information — show this card to the medical staff in the ER.
Getting support

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 protect your child from injuries, they will occur and you will need the help and support of your medical team.

Routine immunizations (vaccinations)

Vaccines (also called needles, shots, vaccinations and immunizations) are medicines that help protect people from serious infections and diseases. Children with hemophilia should be given the same routine vaccines as all other children. Your child’s pediatrician can give him the immunizations according to the recommended schedule, generally without clotting factor therapy. See Table 1, Recommended Schedule for Routine Immunizations, page 13.

Some vaccines need to be injected into the muscle. If your child is already on a prophylaxis program, the vaccination should ideally be scheduled on an infusion day and given shortly after he infuses clotting factor. 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, a muscle bleed at the site of injection is very uncommon. However, if you notice swelling at the injection site, you should have your baby checked by his HTC team.
Some important points about giving vaccinations to children with hemophilia include...

- **Side effects** – There are also some common side effects after routine immunizations. Your child’s 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.

- **Inhibitors** – Children with hemophilia, particularly those with factor VIII deficiency (hemophilia A), have a risk of developing a reaction against clotting factor. This happens if a child’s immune system interprets clotting factor that has been infused as foreign and harmful. His body then immediately produces antibodies in his bloodstream to fight off the infused factor — this makes the factor not as effective. These antibodies are called inhibitors, and are a serious complication of hemophilia. Inhibitors usually develop early on in treatment (generally within 5 to 50 days of the first treatments).

When a child receives a vaccine, his immune system is stimulated in order to make him develop antibodies against a virus which could make it very sick. However if the vaccine injection causes bleeding that needs treatment with clotting factor, there is a risk that his immune system could also develop inhibitors to the clotting factor. For this reason, some hematologists choose to delay immunizations for children with hemophilia until after they have received their 100th infusion, when the risk is lower. For more information, see Chapter 8, Complications of Hemophilia, Part 1 – Inhibitors.
• **Hepatitis B** – The hepatitis B vaccine is provided free of charge as part of routine childhood immunizations for all children in Canada. It protects against the hepatitis B virus, which causes life-long infection and liver damage. Many HTCs recommend that children with hemophilia be given the hepatitis B vaccination around the age of nine, just as other children.

• **Hepatitis A** – The hepatitis A vaccine is not among the routine immunizations recommended. However, it is provided free of charge to people who have a higher risk of infection, including people with hemophilia who receive frequent infusions of blood and blood products. It can be given after the age of two.

It is important to remember that each child’s case is different. Decisions to vaccinate a child can be influenced by factors such as whether or not he goes to a daycare. The more contact a child has with other children, the higher his risk of being exposed to viruses and possible infection. The decision to vaccinate your child according to the recommended immunization schedule, or to delay vaccination, should be made following discussion with the pediatrician and HTC team about the specific benefits and risks for your child.
# Table 1

## Recommended schedule for routine immunizations

<table>
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<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    | • Prevnar, Menjugate – optional immunizations against bacteria that can cause meningitis – Intramuscular |

*Intramuscular cPDT Polio and HiB are given in the same needle.*
Colic

The term “colic” is often used when a young baby cries a lot for no apparent reason and for long periods of time, and is difficult to soothe. We do not know what causes colic and medical experts do not all agree on the definition of colic. Some use the “rule of three” — crying for more than 3 hours a day, more than 3 days per week and for at least three weeks straight. During an attack of colic, your baby will be uncomfortable and may draw his arms and legs in towards his belly.

This problem can certainly be very trying but it will eventually stop, generally around 3 months of age. There are no sure rules as to how to treat colic but picking your baby up, walking, talking, singing or giving him a warm bath can often help. Some babies calm down during a car ride.

If you find your child’s colic very difficult to handle, speak to his doctor. He/she may have some helpful suggestions. Sometimes, using Ovol® drops can help relieve symptoms such as gas and bloating but it’s not clear if the gas causes colic or if babies develop gas as a result of swallowing too much air while crying. Be sure to ask your child’s doctor for advice.

A concern of parents of children with hemophilia is how to tell the difference 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.
The doctors’ roles in your child’s care

Your child 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 child needs a doctor to take care of other aspects of his health. This doctor is usually a general practitioner (also called a family doctor) or a pediatrician — a doctor who looks after the routine healthcare of babies and children.

The family doctor or pediatrician has an important role to play in your child's hemophilia care, especially if you live a long distance from the HTC. Remember that few doctors are trained in hemophilia care. You should speak to your child’s doctor and be prepared to provide information about hemophilia.

The majority of HTCs have a 24-hour/7-day-a-week emergency call system. Whenever you take your child to a local hospital for emergency treatment for a bleed, encourage the medical team to contact the HTC. In most cases, it is strongly recommended that you contact the HTC before you head to the clinic with your child for a problem that seems to be due to his hemophilia — the exception is bleeding that could be life-threatening (head, neck, abdomen, groin). Today with digital cameras and the Internet, it is much easier for hospitals to send photographs and even films to the HTC professional who takes the call. This does not altogether replace the hospital medical check-up, but the technologies help the HTC doctor or nurse coordinator to determine the nature of the bleed and recommend a treatment plan to the medical team at your local hospital.

If you live far away from the HTC, it will definitely be very useful to establish contact with the medical staff at your local hospital, to work out an emergency plan in case your child has a serious bleed. This will help prepare them so that they will be ready to give your child the care he needs as soon as possible. The HTC nurse coordinator will be able to support you through this process.
She/he will help communicate the essential information on how to prepare and infuse clotting factor concentrates, and help you develop an action plan for getting treatment at a local hospital.

In order to take an active part in the treatment, your child’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 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, bruises and bleeds need to be treated. This skill comes with time and, until you learn how to recognize and treat different bleeds, the HTC nurse coordinator will be of great help. Do not be embarrassed to visit him/her regularly until you have confidence in your own judgment. For more information on recognizing and treating bleeds, see Chapter 4, Management of Bleeds.

The family doctor or pediatrician has an important role in other aspects of your child’s health and development. Do not forget that hemophilia is only one aspect of his life. Don’t let it take over all other aspects of his childhood and your lives.

In summary, in your baby’s first two years, your lives will be filled with joy, wonder, many questions, and sometimes anxiety and sadness. This is normal. The bleeds that are most common in the early years and which your baby may experience will be:

- bleeding in the buttock muscles — toddlers have many falls when learning how to walk
- mouth bleeds from a tongue bite, torn frenulum or eruption of a tooth

“*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.*”
Buttock bleeds must be taken seriously. The buttocks (also called the posterior, bum or behind) are made up of a mass of muscles covered by soft fatty tissues. When a buttock injury occurs, a large amount of blood can escape into the buttock tissues before bruising symptoms appear. This can cause a decrease in the child’s red blood cell levels (anemia), which can be treated with iron supplements. Therefore, if your child has a big fall on his bum or bumps it into a sharp corner, you should check him over carefully.

A child who has a serious buttock bleed will often sit or move around differently because normal movements cause pain. The best way to check your child is to lay him down on his belly and check him over for bruises and swelling. Compare the shape of each buttock and check if there is tenderness or pain. Use your fingers to check if the buttocks feel normal — sometimes a hard lump of accumulated blood forms. Be sure to consult the HTC team if these symptoms appear.

Head bleeds, although not common in babies, are definitely serious. If your baby hits his head either from a fall or a collision, he must be seen by your hemophilia doctor or in the ER of your nearest hospital. Contact the HTC as soon as possible so that the hemophilia team can coordinate communication with the ER staff. If the HTC hematologist considers the head injury to be serious, he will advise the ER staff to infuse clotting factor right away. This should be done as soon as possible to stop bleeding into the brain, before doing the medical tests to determine if there is bleeding.

“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.”
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.

“When would our son need treatment? Would we know he needed it? What if we didn't notice something and he bled to death? We didn't have a clue. I want to tell all parents in the same boat to not work yourself into a frenzy over this like we did. Go see the clinic staff when you aren't sure and you will eventually find you have experience.”
**TODDLER AND PRE-SCHOOL YEARS**

- **What can parents expect as their child reaches the toddler and pre-school ages?**

Your child is growing and developing, and so is his world. There are many new experiences during the toddler period (age 1 to 2) and the pre-school years (age 2 to 4). 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 information and support for each other. You are not alone, and it is incredibly uplifting to talk to families with older children. You will see firsthand their success in dealing with the challenges that your family is now undertaking — and they will be more than happy to share their solutions with you.

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 HTC nurse coordinator can put you in touch with an experienced parent who has dealt with challenges like yours.

“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.”
Providing a safe and nurturing environment

This is a naturally curious time for children. Protecting a young child with hemophilia gets harder. Parents often struggle to find a balance between their need to provide a safe environment and their child’s natural need to explore the world around him and beyond his home. During the toddler stage, with increased mobility, he is now developing new skills and interests all the time. It is all too easy to be over-protective at this stage. Any toddler learning to walk will have many bumps and falls before he gets it right. The temptation to constantly watch over a child with hemophilia and try to prevent any falls is an understandable instinct for a parent — but it can unfortunately lead to over-protection.

The development of motor skills is the same for children with hemophilia as for all children. He needs to learn how to walk, run and climb, and do all sorts of other physical activities that probably worry you at some point or another. There will be bumps and falls during this developmental stage but it is important to allow your child to explore and begin developing some independence and social skills, within safe limits.

You may find yourself becoming overprotective at times. Or perhaps the worries and burden of responsibility can seem like too much, and it becomes tempting to pretend that your child doesn’t have hemophilia and to not take the risks and HTC guidelines seriously. These reactions may occur sometimes and are understandable — dealing with hemophilia can be difficult and challenging. However, it is important to be aware of them and manage such feelings and not let them linger and build up over time. Remember that you are not alone — the HTC nurse coordinator can provide support and advice and put you in contact with a psychologist who can help you find ways to cope.

“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.”
Explaining hemophilia to your other children

Sometimes, siblings might feel that their brother gets special treatment because he has hemophilia. They might express sadness, anger, or even jealousy and resentment towards him. It is unavoidable that your child with hemophilia will need more care and attention, or even soothing little treats, because of his bleeding disorder. It is important to reassure your other children that you love them equally and acknowledge their feelings — assure them that you understand how they feel. Remember that your other children are also learning to deal with hemophilia in the family, and could do with a special treat now and then, too. Spending time one-on-one with each child is one way to help all your children understand how important they are to you.

Explain how hemophilia is in the family genes, and how some children get hemophilia by chance but others in the same family don’t. Inviting siblings to support their brother’s needs can also be helpful. (For example, putting them in charge of getting ice or band-aids if their brother has a bleed). 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.
Educating caregivers and daycare staff

As a parent, you will be 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 HTC nurse coordinator if she/he is available to make a presentation, meet or speak by telephone to your child’s caregiver or daycare. Create a positive team approach. You should also discuss your wishes regarding confidentiality about your child’s hemophilia. Keep in mind that educating others is the best defense against misunderstanding and fear.

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

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

- Make sure your child’s caregivers and daycare staff 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 or emergency contact person. Remember! The more they know about hemophilia and your child, the more confident they will be as care providers.

- Make sure babysitters, caregivers and daycare staff 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. It is important to establish clear lines of communication for caregivers and daycare staff (and later on, teachers), in case your child ever needs emergency medical attention.

“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.”
• Make sure that your child wears the protective gear recommended by the HTC team for particular activities, such as a helmet or padding.

• If you are concerned about how a situation was handled, use the opportunity to review the 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 babysitters, caregivers and day care staff with positive feedback and 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 (bruises) happen. Bruises can occur on the 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
Common bleeds for toddlers and pre-schoolers

Simplify these instructions as much as possible for your child’s babysitters, caregivers, daycare staff and teachers — tell them to contact you as soon as your child expresses any signs of discomfort or pain.

• **Buttock bleed** – This type of bleed is common in toddlers because they often fall back on their behinds and onto hard surfaces and objects on the floor. A buttock bleed causes bruising and can be very painful, preventing him from sitting comfortably or walking well.

• **Mouth bleed** – This happens often in the early years, when everything goes in the mouth. Sharp objects can cause a cut to the gums, inside cheeks or frenulum. Toddlers are also prone to accidentally biting their tongues with their sharp baby teeth.

• **Joint bleed** – As a toddler, your child may experience his first joint bleed. Bleeding into a joint can occur as a result of injury when a lot of stress is put on the joint or the bones are forced to twist or turn beyond the normal range. 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 injury** – 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 4, Management of Bleeds**.

**Prophylaxis: regular clotting factor therapy to prevent 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. However, it is still very important for you to follow the HTC guidelines and keep a sharp lookout for signs of bleeding.

Many parents and children can be tempted by denial — to go about their lives as though the child does not have hemophilia, ignoring the possible risks that can occur if care guidelines are not followed. In the absence of frequent bleeding episodes, it’s easy to want to give in to pressure and pleas from your child in order to ease his sadness and frustration because he feels different. That’s why it is important to teach your child from the start that he will sometimes need to make choices to do things differently but can nevertheless be happy.

Talk to your hemophilia team if you have questions about prophylaxis. For more information on prophylaxis, see **Chapter 6, The Role of Prophylaxis, and Chapter 7, Home Infusion**.

“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.”
SCHOOL-AGE AND PRE-TEEN YEARS

What can parents expect as a child becomes old enough for school and new activities?

At school

When your child 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 the school-age years (ages 5 to 8) and pre-teen years (ages 9 to 12), 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 help your child accept his hemophilia, he will sometimes challenge restrictions, resent limitations and even try to hide the fact he is having a bleed. At times, it will be difficult for you to cope with his sadness and anger and you yourself may feel grief. It is important to talk about these feelings together and acknowledge them, and then explain that there is no choice other than following the HTC guidelines. 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 children to maintain their own treatment diaries. Some children, with family and medical support, learn to self-infuse. In fact, many children learn accurate diary keeping and self-infusion before they reach the teenage years. See Chapter 7, 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 child’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 be a sign of a bleed in progress.

• All school staff members should know about your child’s hemophilia and understand the first steps they need to take to care for him.

• Contact numbers for you, your HTC team and/or family 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 MedicAlert® bracelet or necklace.
• Take the time to meet with your child’s teacher and establish a good relationship. Explain to the teacher that your child may miss school from time to time. Discuss how you will pick up his homework and help him keep up with his lessons. Most parents find this is a positive step. It is really up to you. By communicating openly with his teacher(s), you are showing your child how to do this for himself. You are also letting him 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.

Your child will learn by experience if an activity causes bleeds and may decide on his own not to continue doing the activity, to prevent re-injury. However, it’s also possible that he will only understand that an activity is harmful to his physical health after several bleeds, risking irreversible damage. Therefore, you still have to watch for symptoms of a bleed and follow the guidelines from the HTC team.

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 good 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 take some extra precautions, but he does not have to miss out on all of the activities other children are doing. The process of acceptance can be very difficult, and it won’t happen overnight.

With more physical 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.

The school years are a most challenging time 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.

**Prevention of bleeds with prophylaxis**

Preventative therapy (prophylaxis) will help prevent the types of bleeding episodes that often occur with severe hemophilia but it is not enough to prevent bleeding from injuries that can happen when participating in a risky sport that involves a lot of body contact. Such injuries can cause serious joint and muscle bleeds with long-term consequences such as permanent joint damage.

At the beginning of each school year, ask your child’s gym teacher for the class’s physical education program and review it with the HTC doctor and physiotherapist. Sports that involve a lot of body contact, speed and unpredictable movements are generally not recommended. Talk to his teacher about alternative arrangements that are possible and will contribute to your child’s sentiment of self-esteem and peer belonging. HTCs frequently recommend cycling, swimming, body-building and cross-country skiing for children with 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.

“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.”
What issues are typical for a teenager with hemophilia and his parents?

Adolescence (ages 13 to 17) is a time of great physical, emotional and social change for all teenagers. There is an increased need for more independence and control over their lives, and to fit in well with their friends. They also take on new responsibilities such as managing their health needs, self-infusions, hemophilia check-ups and school commitments. In fact, for many children, accurate diary keeping and self-infusion may start at an earlier age. Learning these skills can help increase a sense of control, independence and self-esteem. But at the same time, the desire to participate in all the same sports and physical activities as other teenagers presents many challenges and can lead to risky behaviour.

Peer acceptance — fitting in with his friends and classmates — becomes very important. Teenage boys can be very sensitive about their body image and sense of masculinity. Some teenagers experience anger because they feel different and left out. Some reject hemophilia by ignoring standard guidelines and precautions on routine care, and hiding bleeds that need 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.

It is important to teach him that he can take power over his hemophilia and that he cannot ignore it. This must be taught early on, before the teenage years. A child who has been encouraged to talk about his feelings about hemophilia, and taught how to take good care of his body and choose safe activities, will likely be able to deal better with teenage challenges. In fact, there are many teenagers with hemophilia who adapt very
well. Their acceptance of the disorder and the maturity they have gained 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 as their child struggles to assert himself. Parents may feel their child is not making good decisions. Through these maturing years, it is essential for parents to guide and supervise their son to ensure appropriate decisions are being made related to infusions, infusion techniques and diary keeping. This is a critical period when you will be transferring all the knowledge you have learned from the HTC team over the years to your child. Take every opportunity to ask him about how he is managing and review the HTC treatment guidelines with him. Keep in mind that your HTC care team can provide key support, especially during the teenage years when advice from parents may be less welcome. There is no magic recipe for success. It is important to know your child and together develop 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 and psychologist at your HTC are good people to turn to. Don’t be afraid to seek their 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. Connecting with 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 organizes family weekends and specific programs for teens. They are a natural extension for children who have had the opportunity to go to hemophilia summer camp over the years. 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. These programs are designed to encourage give-and-take amongst kids within the same age group. Imagine the impact if your son were able to help another adolescent struggling with something your son understands.

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

Teenagers are very comfortable with Internet technology these days. They can e-mail each other and form friendships all over the country. It is important to be able to tell which Web sites can be trusted to have reliable information. They can also get accurate information about hemophilia and its treatment from the Web sites of the Canadian Hemophilia Society (www.hemophilia.ca) and the World Federation of Hemophilia (www.wfh.org). Working closely with health professionals from HTCs across Canada, the CHS has produced a range of publications specifically for teenagers. When your child reaches the teenage years, encourage him to get informed at his own pace. Every now and then, ask him questions to check what he has learned and retained.

“These years were difficult for both of us. I am a single mom—it is just the two 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.”
Alcohol and drug use

Abuse of alcohol and drugs represents a threat for all teenagers. 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 teenager 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 HTC.

It is very important to regularly make time as a family to discuss all things happening in your child’s life, and not just hemophilia. Having an open mind and ear will be especially important to your relationship and maintaining his trust. This will help reduce your stress and anxiety (somewhat at least), and allow him to be more self-confident and independent.

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 infectious viruses such as HIV, hepatitis B and hepatitis C can be transmitted. The Internet is a good source of such information. Your nurse coordinator can also provide publications and resources.

• Insist that he look into the tattoo shop’s reputation.

• Insist that he find 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.

**Sexuality**

Talking to your child 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 his hemophilia doctor, nurse and/or social worker for support. Your son should also feel comfortable talking to the members of his care team one-on-one.
Conclusion

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.

Finally, listen to your son. Let him express his feelings without adding your opinions. Just as he fell and got bumps and bruises 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.