This chapter provides answers to these questions:

- What is home infusion?
- What are the benefits of home infusion?
- At what age should a child start on a home infusion program?
- Are there any risks to home infusion?
- How can you reduce the risks?
- How will you manage infusions at home?
- What are the family’s responsibilities?

Sara J. Israels, M.D., FRCPC  
*Director, Pediatric Hemophilia Program, Health Sciences Centre, Winnipeg, Manitoba*

Nora Schwetz, RN  
*Nurse Coordinator, Bleeding Disorders Program, Health Sciences Centre, Winnipeg, Manitoba*

Erica Purves, RN, MN, NP (P)  
*Nurse Coordinator, Pediatric Hemophilia Program, BC Children’s Hospital, Vancouver, British Columbia*
Introduction

Until the late 1960s and early 1970s, children with hemophilia received their treatment in hospitals or emergency rooms. However, it soon became very clear to doctors, nurses and people with hemophilia that treating more quickly, at the first sign of bleeding, gave better results.

One way to provide this prompt treatment is with home infusion. Home infusion is the administration of clotting factor concentrates by a parent, or the person with hemophilia, in the home setting. The clotting factor concentrates are injected intravenously (into the veins). For more information on the infusion of factor concentrates, see Chapter 5, Clotting Factor Therapy.

In order to make decisions about whether home infusion is the best option for your child, you may want to know:

- What exactly is home infusion?
- Are there different types?
- What are the benefits for my child and my family?
- What are the family's responsibilities?
- Could there be problems?
- How will we know when we are ready for the responsibility?

The purpose of this chapter is to give you some of the basic information about home infusion, and show you how parents work with members of the comprehensive care team to provide care for the child with hemophilia in the home.

Did you know...

the first Canadian home care program for hemophilia was started in 1969 at the Montreal Children’s Hospital by Dr. Hanna Strawczynski?
Home infusion is the administration, by intravenous injection, of clotting factor concentrates in the home setting, rather than in a hospital or a doctor’s office. The infusion is done by a parent (or other family member) who has been taught, and can show, how to prepare the factor, access the vein and safely infuse the treatment. Prior to beginning home management, this person must demonstrate knowledge of their bleeding disorder including: assessment of bleeds, recognizing serious bleeds, allergic reactions and knowing the correct steps to take for all situations. He/she must also understand the importance of regular communication with the treatment team.

Today, most children with severe hemophilia and some with moderate or mild hemophilia receive home infusion of clotting factor concentrates to treat their hemophilia. These treatments are used to either treat bleeding episodes or to prevent bleeding episodes. The common terms for these two types of treatment are on-demand therapy and prophylaxis.

- **On-demand therapy** – With on-demand therapy, an infusion of clotting factor concentrate is given as soon as the parents become aware of a bleed. The goal is to promptly stop a bleed that has already occurred.

- **Prophylaxis therapy** – With prophylaxis therapy, the child receives regular infusions of clotting factor concentrates, usually 1 to 3 times per week. The purpose of this therapy is to prevent bleeding episodes from occurring due to everyday activities. Many children in Canada, especially young children with severe hemophilia, receive prophylaxis therapy. This is because prophylaxis has been shown to be the best way to prevent joint damage.

For more information on factor treatment to prevent bleeding, see Chapter 6, The Role of Prophylaxis.
Home infusion ...

- makes it possible to give prompt treatment at the first sign of bleeding.
- makes it easier for families to manage prophylaxis therapy.
- helps to avoid frequent visits to the hospital for the child with hemophilia and his family.

What are the benefits of home infusion?

There are many benefits. Home infusion...

- allows the family to treat bleeding at the earliest possible moment. This is the best way to reduce damage to joints and to speed recovery.
- avoids delays in treatment due to travel time to the hospital, and waiting times at the hospital.
- makes it easier for the child to follow a prophylaxis program, designed to prevent joint disease from occurring in children. Most prophylaxis programs require treatment on a regular schedule of 1 to 3 times per week. This can be difficult for the family if they are required to travel to hospital for each infusion.
- reduces the number of in-hospital days and outpatient visits. This means that the child misses less time from school and the parents miss less time from work and family.
• helps the child and family to be more independent.

• reduces disruption to the family’s daily activities.

• helps the family gain more confidence in caring for the child with hemophilia, and a greater feeling of control over their lives. It also allows them to travel.

• fosters a strong partnership between the family and the comprehensive care team.

• allows the child to participate in normal activities.

• decreases overall health care costs because fewer visits are made to the hospital.

At what age should a child start on a home infusion program?

There is no standard age for starting. The comprehensive care team and the family will make a joint decision about when it is best for the child to begin a home infusion program. Ideally, a home infusion program begins before the child starts school.

Parents are responsible for their child’s home infusion therapy. However, even a very young child can be involved in his own treatment. Small tasks suitable for his age, such as taking the factor concentrate out of the refrigerator, disinfecting the skin with alcohol, and holding still, encourage the child to learn about his care.

The child who has been involved with his treatment at home becomes more responsible as he gets older, which in turn makes the management of hemophilia easier for the family. As the child grows up, he will learn to take on more of the tasks required for his own treatment, encouraging him to eventually become independent.
The following guidelines are used to assess a family’s readiness to begin a home infusion program:

- The family must be committed to starting a home infusion program. Parents have to be prepared to follow the program guidelines such as keeping a diary of infusions and attending assessment clinics.

- Parents must have good communication with the comprehensive care team.

- The child usually needs frequent clotting factor replacement—for example, an average of more than once per month. This could be either on-demand therapy or prophylactic therapy.

- The family must show a solid understanding of hemophilia and be able to assess when a bleed is occurring and how serious it is.

- When managing a bleed at home, parents must have an understanding of when to seek assistance.

- Parents must be able to use clean and safe techniques to prepare clotting factor concentrates.

- Parents must be able to safely infuse the clotting factor concentrates.

- Parents must also be able to recognize the signs of an allergic reaction and what they must do if this occurs.

“Home infusion was our gift to everyone in the family. Good-bye clinic and good-bye emergency room! We gained management of our son’s health and the ability to treat him right away. The clinic is still a central part of his team, we just don’t miss the waiting, the frustration and the constant upheaval in all our lives.”

Comprehensive Care Clinic, Hospital for Sick Children, Toronto
Are there any risks to home infusion?

Several problems may occur when a child is on a home infusion program. The following are some examples:

- Lack of communication with the hemophilia treatment centre – This could result in a bleed being treated incorrectly. Improper treatment includes inadequate treatment of the bleed, or not recognizing the seriousness of an injury, or not identifying the need for additional treatment such as *physiotherapy*. Physiotherapy is treatment that is used to improve the function of a joint or muscle. Improper treatment could result in more serious damage to a joint.

- Poor response to treatment – The child may respond poorly to treatment and the family may be slow to realize this. If a bleed has not shown improvement after two treatments, the family should contact the comprehensive care team.

- Improper storage of clotting factor concentrates – These products should be stored in the refrigerator to prevent the factor concentrate from losing its coagulation activity. Some products, however, can be stored at room temperature for up to 6 months.

- Infection or damage to veins or the venous access device.

- Allergic reactions to the clotting factor concentrate.

- Injury to other family members – This can occur if needles are not disposed of properly. Families should follow the guidelines set out by the comprehensive care team for proper disposal of needles and syringes in an approved “sharps” container.

“I learned to mix my product at camp when I was 7. I started helping mom and dad with the needle after that. I don’t want to try to get it in yet. Maybe when I am 10 or bigger, I will do it myself.”

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How can you reduce the risks?

There are many things that you can do to reduce the potential risks when your child is on a home infusion program. Here are some examples:

- Communicate immediately with the comprehensive care team when …
  - Your child has an injury to a critical part of the body (head, neck, chest, stomach).
  - A bleed has been treated and is not improving.
  - A single joint has more than two bleeds within a short time.
  - You are concerned that your child is having an allergic reaction to the clotting factor concentrate.
  - You are not sure what to do.

- Communicate regularly with the comprehensive care team to discuss any concerns about managing bleeds and home infusion.

- Be well informed. You can do this by frequently reviewing educational material provided by your hemophilia treatment centre.

- Keep accurate home care records of bleeds and infusions as advised by your comprehensive care team.

- Review regularly the home infusion procedures with the comprehensive care team.

- Meet regularly with the comprehensive care team to review your child's treatment plan.

- Set goals for improving your child’s home infusion program.
How will you manage infusions at home?

Parents are often overwhelmed with their child’s diagnosis of hemophilia. They are also deeply concerned about being responsible for home infusion. At first, most parents are anxious and doubt their abilities to perform the tasks required of them.

It is important to remember that learning these skills is a gradual process that occurs in a supportive clinic environment — the comprehensive care team will train and guide you every step of the way. Parents are also encouraged to speak with other families whose children are on a home infusion program. These families have had to deal with many of the same concerns. Despite initial anxieties, parents do develop great expertise and come to see the many benefits of home infusion.

A home infusion program means that parents and children can lessen some of the inconvenience of hemophilia treatment and live more normal lives.

Accessing veins for infusion

Training will be provided at the HTC on venipuncture—how to access a vein with a needle to infuse clotting factor concentrate. The hemophilia nurse coordinator will guide families through all the steps, from applying a tourniquet and sterilizing the surface of the skin, to inserting a butterfly needle for infusion into a vein.

If access to the veins is difficult, as it sometimes is with small children, a central venous access device, for example a port-a-cath, can be surgically implanted under the skin on the chest. Parents are taught how to care for and use this device to infuse the clotting factor concentrate. The use of such a device means that the parent has a designated spot for inserting the needle that is easier than having to find a vein for each treatment. A numbing cream can also be applied over this spot to reduce the feeling of the needle being inserted.

“I was scared when I started treating my son at home. I was surprised I would be allowed to do it. He was 5 and ready to let me try. It was a bit nerve racking at first. In time, I gained confidence and feel good about it now. Even now, after 5 years of treating my son, I miss the vein the odd time. The best thing is that scar tissue has developed around the site we use. He doesn’t feel the needle going in anymore.”
Venous access devices can make it easier for the family to move from the hospital-based treatment to care in the home setting. As the child grows and it becomes easier to insert a needle into the vein, the *port-a-cath* can be removed.

**Keeping a treatment diary**

Hemophilia treatment centres keep records of clotting factor concentrate infusions. When infusions are given at home, families are asked to record details of all home infusions. The diaries keep track of the...

- amount of clotting factor used
- date of treatment
- specific product name and lot number
- reason for infusion and any complications

The treatment diary makes it possible for the comprehensive care team to track the use of the clotting factor concentrates, and to evaluate how effective the home infusion program is. Review of the diary records at the time of clinic visits can identify patterns of bleeding, under- or over-treatment and concerns about specific joints.

All HTCs have paper and electronic home infusion forms. Paper forms are filled in by the patient or parent at the time of each treatment and the records are handed in, mailed or faxed to the HTC on a frequent, regular basis. Electronic forms are filled in on a handheld computer device and records are transmitted using telephone or Internet technology.
Computer technology has made it much easier and quicker for families to keep a home infusion diary and share records with the HTC. Reporting has become more efficient and accurate with the ability to scan information such as product type, name and lot number. In addition, records can be transmitted instantaneously, allowing the care team to review the records sooner and communicate any concerns about response to treatment or patterns of bleeding to the family without delay.

What are the family’s responsibilities?

• When in doubt, treat.

• Maintain frequent communication with the comprehensive care team regarding bleeds and their treatment.

• Seek medical advice for any injury to the head, eye, neck, chest, abdomen and other potentially serious bleeds as soon as they occur.

• Maintain an accurate up-to-date diary of all infusions given, which includes the bleeding sites, the amount of factor infused, and other first aid measures used.

• Use treatments such as rest, ice, compression and elevation of limbs to help reduce the bleeding.

• Know what to do for allergic reactions, and report them promptly.

• Provide a safe environment.

• Teach and encourage your child to be aware of his body so that he can make smart activity choices and can recognize and report bleeds.

“Our kids like using the electronic diaries. It’s easy and they enjoy using the technology.”
• Involve your child in his own health care early on, gradually increasing his role and responsibilities as he gains maturity and more independence.

• Store home infusion supplies (needles and syringes) safely.

• Store clotting factor concentrates in the home setting according to the instructions in the package insert.

• Use clotting factor concentrates, a valuable and very expensive healthcare resource, responsibly.

Home infusion provides many advantages for children who require frequent treatment for bleeding episodes, or are receiving prophylaxis. Your comprehensive care team will help you determine whether a home infusion program is the best choice for your child.

For more information on the prevention and treatment of bleeding episodes, see Chapter 4, Management of Bleeds; Chapter 5, Clotting Factor Therapy; and Chapter 6, The Role of Prophylaxis.