

6 Home Infusion

This chapter provides answers to these questions:

- What is home infusion?
- What are the different types of prophylaxis?
- 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 at home?
- What are the family's responsibilities?

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Did you know...

the first Canadian home care program for hemophilia was started in 1969 at the Montreal Children's Hospital by Dr. Hanna Strawszynski?

■ 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 administering of clotting factor concentrates by a parent, or the person with hemophilia himself, in the home setting. The clotting factor concentrates are injected *intravenously* (into the veins).  (For more information on the infusion of concentrates, see **Chapter 4, Clotting Factor Therapy**.)

In order to make decisions about your child's care, and whether or not to opt for home infusion, you may want to know:

- What exactly is home infusion?
- Are there different types?
- What are the benefits for my child and my family?
- Could there be problems?
- Will we be able to manage?

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.



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■ What is home infusion?

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 a person with hemophilia who has been taught how to access veins.

Today, most children with severe hemophilia and some with moderate or mild hemophilia receive home infusion to treat their hemophilia. There are two approaches to home infusion.

- **On-demand therapy** – With on-demand therapy, an infusion of clotting factor concentrate is given as soon as the parents are aware of a bleed. The goal is to promptly stop the bleed.
- **Prophylaxis therapy** – With prophylaxis therapy, the child receives regular infusions of clotting factor concentrates, usually 2 or 3 times a week. This is done in order to prevent bleeding episodes from happening. Most children in Canada, especially the younger ones, receive prophylaxis therapy. This is because prophylaxis has been shown to be the best way to prevent joint damage.

Home infusion ...

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



“Never bug the parent who is going to give you the needle.”

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. Parents are taught how to care for and use this device to infuse the factor concentrate. The use of such a device makes giving treatments simpler because parents don't have to find a vein for each infusion. The family can move more easily from the hospital to the home setting.



■ What are the different types of prophylaxis?

There are three types of prophylaxis:

- long-term prophylaxis,
- short-term prophylaxis
- occasional prophylaxis.

Long-term prophylaxis is the most common type of prophylaxis presently used. Infusions of factor concentrates are given 2 or 3 times per week throughout the boy's childhood. The goal of this therapy is to prevent bleeding and avoid joint damage.

Short-term prophylaxis is often used by families to halt the development of “a target joint”. This is a joint that bleeds frequently. For example, a child may have three or more bleeds in the same joint in a short period of time (usually less than six months). In this case, there is a great risk of joint damage if bleeding repeats. Regular infusions can protect the joint from permanent damage. Thus, infusions are given over a period of 3 to 6 months, or until bleeding in the target joint stops happening. These infusions may be given 2 or 3 times a week, depending on the type of hemophilia.

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Children often take part in activities that can cause bleeding. Some of these activities pose little risk of causing a bleed. Others pose a higher risk. An infusion prior to the high-risk activities can be effective in preventing bleeding. This is called **occasional prophylaxis**.

■ 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 the delays in traveling to the hospital, assessing the child there and prescribing treatment.
- makes it easier for the child to follow a prophylactic treatment program, designed to prevent joint disease from occurring in children. Most prophylaxis programs require treatment on a regular schedule of 2 or 3 times per week. This can be hard if the family is 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 of the health care system.
- 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 more easily.



“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

- fosters a strong partnership between the family and the comprehensive care team.
- allows the child to participate in normal activities, including, most sports.
- 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. Both parents and child must be ready. 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 become 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.

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

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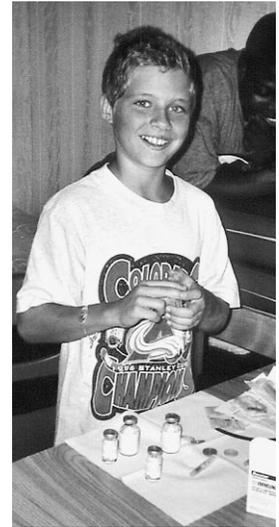
- The family must show a solid understanding of hemophilia and be able to assess when a bleed is occurring and how serious it is.
- When managing a bleed at home, parents must have an understanding of when to seek assistance.
- Ideally, parents must have good communication with the comprehensive care team.
- 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.

■ 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 can lead to a bleed not being treated properly. Improper treatment includes inadequate treatment of the bleed, or not realizing the need for **physiotherapy** quickly enough. Physiotherapy is treatment to improve the function of a joint or muscle.
- 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 potency.
- Infection or damage to veins or the venous access device.
- Injury to other family members – This can occur if needles are not properly disposed of. 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.”



■ How can you reduce the risks?

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

- Communicate immediately with the comprehensive care team when ...
 - the child has an injury to a critical part of the body (head, neck, chest, stomach)
 - a bleed does not respond after two treatments
 - one joint has several bleeds in a short time
 - the child has an allergic reaction to the clotting factor concentrate
 - you are not sure what to do.
- Communicate frequently with the comprehensive care team to discuss general concerns around managing bleeds and home infusion.
- Keep yourselves 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.
- Regularly review the home infusion procedures with the comprehensive care team.
- Sit down regularly with the comprehensive care team to discuss how well the home infusion program is working.
- Set goals for ways you can improve your child's home infusion program.

Test Your Knowledge

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What are the three different types of prophylactic clotting factor therapy?

(For some help in finding the answer, see page 6-3.)

(The correct answer is on page 13-18.)

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■ What are the family's responsibilities?

- When in doubt, treat with clotting factor concentrates.
- Along with clotting factor, use treatments such as rest, ice, compression and elevation of limbs to help reduce the bleeding.
- Maintain frequent communication with the comprehensive care team regarding bleeds and their treatment.
- Seek appropriate advice for head bumps or bangs and other potentially dangerous events 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 and other first aid measures used.
- Know what to do for allergic reactions, and report them promptly.
- Provide a clean and safe environment.
- Educate and encourage your child to be aware of his body so that he can recognize and report bleeds.
- Involve your child in his own health care.
- Store and dispose of home infusion supplies (needles, syringes...) safely.
- Store clotting factor concentrates according to the instructions in the package insert.
- Use clotting factor concentrates, a valuable health care resource, responsibly.



 (For more details on home infusion, see **Chapter 4, Clotting Factor Therapy**, and **Chapter 5, Management of Bleeds**.)

“I was scared when I started treating my son at home. He was 5 and almost ready to let me try. I was surprised I would be allowed to do it. 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.”

■ How will you manage 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.

However, learning these skills is a gradual process that occurs in a supportive clinic environment with the guidance of the comprehensive care team. Parents are also encouraged to speak with other families whose children are on home infusion. These families have had to deal with many of the same concerns. Despite their 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 inconveniences of hemophilia and carry on with activities of daily life.