



**Stage 3:**

## **School-Aged/Pre-Teen (6–11 Years Old)**



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Your child is entering an exciting new stage in life and development. Strollers and potty training are a thing of the past, as are the initial encounters of living with hemophilia. As you move ahead to the beginning school years, it is important to understand the next level of development, milestones and issues related to hemophilia. Staying informed and prepared will help you continue this journey with your child successfully!

### Growing and letting go

We learn about hemophilia through experience. Some parents become expert “bleed identifiers,” while others who have gone to battle with inhibitors (see “Formation of inhibitors” on page 6) can accurately define “Bethesda unit” or “titer.” Then there are parents who live with hemophilia as a daily routine of prophylactic treatment and may have children who do not know how to identify a bleed.

Regardless of your experiences with hemophilia thus far, parents experience similar mixed emotions as they begin to let go. Your child is growing closer to becoming an independent individual. During this period, your child can begin to take on real responsibility for this disorder.

### Bleeds

Bleeds will still continue, and they may occur outside the home environment. With your child in school for a large part of the day, you can no longer monitor every move he makes and must rely on his ability to communicate whether or not he is experiencing a bleed or has been injured. If your child has severe hemophilia, spontaneous bleeds can also pose a big challenge.

Identifying and treating a bleed promptly are essential to maintaining healthy joints and muscles. Now is the time when emphasis must be placed on helping your child understand what a bleed is, how to identify a bleed and the importance of promptly treating a bleed. Emphasize the importance of prompt treatment, and explain the consequences of delayed treatment.

### Involving your child in treatment

Children ages 6 to 11 can understand when and how factor is administered, as well as treatment options. An important step in educating your child about his treatment is to allow him or her to actively participate in his own care by taking on the following responsibilities:

- Taking inventory of medical supplies at home (with supervision)
- Ordering medical supplies and unpacking supplies when they arrive at home
- Scheduling appointments, which enable him or her to establish a relationship with the care team
- Setting up and preparing infusion supplies
- Filling out treatment logs

Treatment logs are important to help keep track of bleeds and to keep notes on infusions. Keeping a log or a journal is not the “coolest” part of learning how to infuse, so added incentives, encouragement and consistency may need to be employed. Remember, learning how to self-infuse is more than a needle stick. It is a process that begins with proper technique and ends in keeping accurate records. Children at this age will be receptive to learning how to keep a log. Instill this in them now before they hit the teen years, when adherence may be challenged.

**Note:** Be sure you don’t make these new responsibilities part of your child’s chores. Managing hemophilia care should be a team effort, reinforced with encouragement and praise.



## General well-being

**Dental care** — By the age of 5 or 6, children generally begin to lose their baby teeth, starting with the incisors. By the age of 10, half of their baby teeth will have fallen out.

Allowing the teeth to fall out naturally and not wiggling them — no matter how tempting — can help to avoid additional bleeding.<sup>7</sup> If bleeding does occur, Amicar (epsilon aminocaproic acid) may be recommended by your hematologist. Amicar can be taken orally or used topically. It neutralizes the enzymes in saliva that often prevent a clot from forming in the mouth. Amicar is available by prescription only; consult with your child's hematologist on dosage. Other helpful suggestions to control oral bleeding include using cold liquids or frozen ice pops.

To prevent tooth decay and gum disease, establish a daily routine of brushing teeth two times per day, eating a balanced diet, and getting regular checkups. Although children at this age are quite capable of brushing their own teeth, supervision and assistance is still recommended to ensure proper dental care.

If your child has a port, your hematologist may recommend a dose of antibiotics prior to dental cleaning or dental procedures to avoid the risk of infection in the bloodstream. If your child is on prophylaxis, schedule dental work on a treatment day when factor levels are highest.

During this stage, some children may require braces on their teeth. The actual process of placing the braces on teeth is not a problem and generally does not cause bleeding. Cuts inside the mouth can occur as a result of wearing braces, but bleeding is usually minimal. Covering the metal brackets with a thin film of wax helps avoid injury.<sup>18</sup> If bleeding does occur, contact your hematologist.

**Immunizations** — Most immunizations are given before entering kindergarten. However, others are typically given during the later grades. Be sure to keep immunization records current. For children with

hemophilia, both hepatitis A and hepatitis B vaccines are recommended. Immunizations should be given subcutaneously whenever possible, with ice applied afterwards.<sup>14</sup> If your child is on prophylaxis, schedule immunizations on a treatment day when factor levels are highest.

**Sports and exercise** — Regular exercise is beneficial for children with hemophilia. Exercise strengthens joints and muscles, which can reduce bleeds. The most common form of exercise for children is sports. Wearing protective gear and infusing factor prior to participation are recommended for certain sports. Stretching is also a good way to avoid injury before participating in an activity or sporting event.<sup>19</sup>

Low-impact sports, such as swimming or golf, are advised for children with hemophilia. Rough contact sports are generally not recommended. As your child becomes interested in a wide variety of sports, it is important to consult your hematologist for advice and treatment options.

**Proper nutrition**<sup>9,13,14</sup> — Children learn about exercise and proper nutrition in science or health classes at school and are often eager to practice what they have learned when they get home. Involving children in selecting healthy foods and exercising as a family will help reinforce these valuable concepts. Instilling the foundation of proper nutrition and exercise from a young age is priceless!

A report from the Centers for Disease Control and Prevention (CDC) showed that teens with bleeding disorders are almost twice as likely to be overweight as children the same age without a bleeding disorder.<sup>20</sup> Keeping weight in proper ranges is especially important for people with bleeding disorders. Extra weight adds stress on joints (which can increase joint pain and frequency of joint bleeds), makes it harder to find veins for infusion and requires more factor per infusion, since doses are based on weight.

While genetics can be part of the problem, personal choices also affect one's weight. Activity combined with healthy eating can help maintain appropriate weight. Here are some helpful tips to get your family on the path to a healthy lifestyle:

- Eat as a family. Children will follow parents' examples. If children see parents eat properly, chances are they will do the same.
- Don't eat meals or snacks in front of the TV.
- Read the nutritional label. Ingredients are listed in order of proportion. The label also shows calories and serving size.
- Avoid foods that contain high percentages of sugar, fats, sodium and cholesterol.
- Eat from all food groups every day for a well-balanced diet, and eat more vegetables, fruits and lean meats. Limit sweets, pastries and other foods that are high in calories and low in nutrition.
- Avoid fried foods. Instead, bake or grill meats, and steam or grill vegetables.
- Replace vegetable oil with olive oil.
- Don't skip meals; instead, eat smaller meals and healthy snacks.
- Keep nutritious snacks available. Some examples include fresh and dried fruit, vegetables, pretzels, fat-free cookies and sugar-free frozen ice pops.
- Choose healthy beverages. Drink plenty of water, milk or calorie-free beverages instead of soft drinks.



## Physical development

Although the growth pace remains steady, a young child's bones at this stage are growing slowly, but involvement in sports and other physical activities helps your child develop balance and coordination.

Young children may experience "growing pains." The concept of growing pains is half-truth and half-myth. Growing children do have normal pains, particularly in their legs and feet. These pains, however, are caused not by growing but by excessive use of young muscles and joints that are not yet completely developed. Young children are extremely active, and this extra activity places stress on their still-developing muscles and joints.

**Signs and symptoms:** Growing pains generally occur in different parts of the thighs, calves and feet. The pains can be severe enough to awaken a child from sleep. A key symptom of growing pains is that they occur only when the child is at rest, usually at night or during naps. They never occur when the child is active. This fact distinguishes growing pains from pains caused by diseases or injuries, which are typically worse when the child is active. Growing pains do not interfere with or interrupt a child's daily play or routine and are never accompanied by fever or other symptoms of general illness.<sup>21</sup>

To help young children take proper care of their joints and muscles, encourage the following behaviors:

- Exercise and wear protective gear.
- Have the child wear sturdy shoes.
- Keep "in tune" with his body. Look for signs of a bleeding joint, which include limping, favoring a limb or swelling. The extent of swelling can be determined by comparing the extremity in question with the body part measurement on the opposite side using a paper or cloth tape measure.
- Respond to bleeds promptly and accurately with RICE and factor replacement therapy (with proper dosing).

## Cognitive and psychosocial development

Children ages 6 to 11 are becoming more independent by exploring their neighborhood with friends, joining sports teams or clubs and engaging in social media and texting. This group of children is more aware of how peers, teachers and family members perceive hemophilia. The children may be more self-conscious about their hemophilia and not know how to explain it to others. Additionally, they do not want to be perceived as “different.” A child with a port may be hesitant to take off his shirt before going swimming. A child experiencing a bleed may delay his treatment in order to finish a sports event or may just think the bleed will go away on its own.

Emphasize the importance of prompt treatment, and explain the consequences of delayed treatment.

Children at this stage of development have an increased attention span and the ability to reason and process information and may enjoy reading. School-age children are often computer savvy, and many are becoming proficient at using the internet. This combination of skills and access to information is very valuable for a child with hemophilia. When questions about hemophilia arise, parents can teach their children how to search for answers. Be sure to focus on websites from well-respected medical centers and communities, and avoid reading blogs which provide more opinions than facts about hemophilia. It is important to teach children that living with hemophilia means learning for life. Giving them essential educational tools will help pave the way for social and emotional development.

## School issues<sup>22</sup>

As a parent, you have had several years to become accustomed to hemophilia, but, chances are, your child’s school or teachers may never have had a student with hemophilia before. This is an opportunity to be proactive and educate school personnel. Plan a meeting before the school year to give them the information they need. There are resources available for you to share, and your Customer Relations Specialist may be available to assist in scheduling education for school personnel. Visit [www.hemophilia.com](http://www.hemophilia.com) to download a copy of the Coach and Educator’s Guide to Bleeding Disorders.



## Absences

Academic growth, peer relationships and self-esteem begin to come together as a result of positive school experiences. Absence from school can affect academic achievement and impact social relationships. If a child needs to be absent due to a bleed, it is vital he return to school and catch up on any missed school assignments as quickly as possible.

If your child has trouble attending school, he may qualify for a Section 504 plan. As part of the Rehabilitation Act of 1973, school districts are required to reasonably accommodate students whose disability limits one or more major life activities. These include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself and performing manual tasks. You may not think of having hemophilia as a disability, but hemophilia is recognized as one of the qualifying conditions covered by Section 504.

Section 504 plans are created for students who require some accommodations to place them on the same level as other students. For some people with hemophilia, certain activities included in a mainstream physical education class can be too strenuous. Your child may be able to participate in alternative activities or take a different class to meet that educational requirement. This accommodation may be as simple as the teacher knowing your child has hemophilia and being familiar with signs and symptoms of a bleeding episode. Please note that each state or school district will have specific procedures for implementing a Section 504 plan.

## Privacy

Since fitting in is now paramount to your child, he does not want to be perceived as different. For children with hemophilia, disclosure of their medical condition can become a sensitive issue. Some children elect to tell their closer friends but are more discreet with other peers. Of course, a select few don't mind telling everyone about hemophilia.

Although your child may be shy about letting others know he has hemophilia, wearing medical identification jewelry (bracelet or necklace) alerts medical professionals to his condition in case of an emergency. It can save your child's life!

Keep in mind that, although it is important to respect your child's privacy, you will need to reinforce the need for school personnel to be informed of your child's condition.

## Bullying

Bullying is a challenging issue that all children face. Unfortunately, we cannot protect our children from all the browbeaters of the world. Instead, we must educate them on how to handle such situations and, most importantly, to tell an adult if someone hurts him or her.

## Pain and your school-age child<sup>10</sup>

Children with bleeding disorders experience pain as a result of their condition and its treatment. As a parent, you can significantly impact how pain affects your child by understanding what pain is and how to deal with and avoid it.



## What is pain?

Pain is how your child's body reacts to an injury or an illness. It is a sign that something is wrong. Pain can be protective — it's the body's way of saying, "Pay attention to where you hurt."

## How can you tell if your child is in pain?

### He may:

- Tell you
- Decrease his activity level
- Eat less, sleep more
- Limp or not use the injured area
- Protect where it hurts
- Be unable to sleep
- Try to conceal the injury or pain from his family, teacher or nurse

## What to do

- Ask your child directly if he is in pain. Talk over what you have observed and what your child is experiencing.
- Determine if the pain is related to hemophilia.
- Use a scale of 0 to 10 (with 10 being the highest) to have your child point out how much he hurts.
- Encourage your child to express what he is feeling. Ask questions: Where does it hurt? Does the pain move from one area to another? How does the pain feel — sharp, dull, throbbing? Does anything make it feel better?
- Call your pediatrician and/or hematologist, and explain why you think your child is in pain.
- If medication is ordered, give it exactly as prescribed, and watch your child to see how well it works. How long was he comfortable after the medication? Does it make him or her sleepy? How many times did you give him or her the medication? Does his pain seem better or worse?
- Follow up with the hematologist if the pain doesn't go away.
- Apply cool packs to bruises.
- Apply RICE (rest, ice, compression, and elevation) to an injury (see page 13).



- Encourage your child to participate in his pain management. Talk with each other, and make a plan for how to best control the pain.
- Provide positive reinforcement when your child expresses pain promptly and participates in his treatment.
- Play music or sing.
- During the infusion of factor, encourage your child to select a vein, gather supplies and complete his treatment log. Playing a favorite video or music will help him or her relax.
- Be sure to note any pain on the treatment log.

## How to avoid pain

- Prevent pain by avoiding injuries. Use protective devices, such as helmets, knee and elbow pads or shin guards.
- Treat bleeding episodes immediately or at least within 2-3 hours to prevent long-term damage and resulting chronic pain. Follow up with infusions as required or ordered.
- Avoid pain associated with the infusion process by using a topical anesthetic cream before needle sticks, if advised by your hematologist.

Remember, do not give your child any medication containing aspirin or nonsteroidal anti-inflammatory drugs (NSAID), such as ibuprofen, as it can cause bleeding. Be sure to check with your pharmacist and read the ingredients list on any medication to see if aspirin is included. It can also be listed as "acetylsalicylic acid" or "ASA."<sup>11</sup>

## Safety<sup>9</sup>

Parents want to keep their children safe, and children depend on their parents for safety. Safety can be challenging during a time when your child wants to play and explore his world. Many common childhood injuries result from preventable causes:

- **Sports safety:** Wear a helmet and protective pads when bicycling, inline skating or riding a scooter. Use all protective gear suggested for any sport or activity.
- **Auto safety:** Always use seat belts. Children under the age of 12 should avoid riding in the front seat of a car, and children should not be placed in a seat equipped with an airbag.

As a parent, you will be amazed at all the things your child will learn, experience and accomplish during this brief five-year span — from mastering cursive writing and multiplication tables to gaining independence and becoming more involved in his care.

This time provides a chance to bond with your child before heading into adolescence, a stage that has its own milestones and challenges. As your child matures, you will find additional information available in this guide.

