



Stage 2:

## Your Toddler/Preschooler and Hemophilia (1–5 Years Old)



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Welcome to the wonderful world of toddlerhood and preschool, a time of rapid change and transformation. As children grow from 1 to 5 years old, they advance from crawling to playing organized sports. This is the time when the mind is ripe for make-believe, ready to accept adventure at every moment, and the time when a child goes from using single words to using over 1,000 words and speaking in complete sentences. In this section, you will learn more ways to help manage your child's hemophilia and how you can help keep your child safe through the very active toddler and preschool years so you can let your child with hemophilia be just that — a child.

### Homecare

Comprehensive medical care is extremely important for toddlers and preschoolers with hemophilia. The Centers for Disease Control and Prevention (CDC) has issued statements saying the best outcomes for hemophilia come when people with hemophilia receive homecare services.<sup>12</sup>

Your specialty pharmacy provider should be knowledgeable about hemophilia and many times will be able to provide homecare nursing services that are prescribed by your hematologist. Hemophilia homecare professionals should be able to provide services that give you the education you need to help make living with hemophilia easier and assist you in following the treatment plan determined by your child's hematologist. These services may include:

- Home delivery of factor and infusion supplies
- Help monitoring home factor inventory
- Timely billing and collecting
- Help teaching venous access techniques
- Written educational materials
- Nursing services, when needed



## Developmental stages

In addition to your hematologist, it is important to see a board-certified pediatrician and utilize a specialty pharmacy with extensive bleeding disorder experience. A pediatrician must monitor the growth and development of your child and will take care of your toddler's additional health needs. Your pediatrician and hematologist should communicate on an ongoing basis.

Remember, all children are different and will reach these milestones at their own pace. The following chart shows some general development stages your child will experience<sup>9</sup>:

Activity	1 – 2 years	2 – 3 years	3 – 4 years	4 – 5 years
Physical development	<ul style="list-style-type: none"> <li>• Walks and is learning to run and jump</li> <li>• Becomes more independent</li> </ul>	<ul style="list-style-type: none"> <li>• Is eager to explore and dislikes being confined</li> <li>• Copies adult movements</li> <li>• Helps dress and feed self</li> <li>• Enjoys simple art projects</li> </ul>	<ul style="list-style-type: none"> <li>• Has all baby teeth</li> <li>• Is curious about how body works</li> <li>• Has bladder and bowel control</li> <li>• Can ride a tricycle</li> </ul>	<ul style="list-style-type: none"> <li>• Enjoys dancing and singing</li> <li>• Can handle safety scissors or crayons</li> <li>• Is very energetic</li> </ul>
Language development	<ul style="list-style-type: none"> <li>• Says first words</li> <li>• Uses words to express needs</li> <li>• Combines words with action</li> <li>• Understands simple commands</li> </ul>	<ul style="list-style-type: none"> <li>• Asks about names of things</li> <li>• Expresses thoughts and feelings</li> <li>• Adds hundreds of words to vocabulary</li> </ul>	<ul style="list-style-type: none"> <li>• Likes to hear stories over and over</li> <li>• Asks lots of “why” questions</li> <li>• Speaks in sentences of three to five words</li> </ul>	<ul style="list-style-type: none"> <li>• Carries on long conversations, often involving fantasy</li> <li>• Shows sense of humor and enjoys silly stories</li> <li>• Confuses fact with fiction</li> </ul>
Mental development	<ul style="list-style-type: none"> <li>• Thinks aloud</li> <li>• Learns by trial and error</li> <li>• Develops short-term memory</li> <li>• Enjoys role-playing</li> <li>• Doesn't separate fantasy from real life</li> </ul>	<ul style="list-style-type: none"> <li>• Claims things as “mine”</li> <li>• Learns to share</li> <li>• Begins to sort objects by type</li> <li>• Understands time (“in a little while”)</li> </ul>	<ul style="list-style-type: none"> <li>• Can name and sort objects</li> <li>• Understands cause and effect</li> <li>• Shows increased attention span</li> <li>• Makes up stories</li> </ul>	<ul style="list-style-type: none"> <li>• Learns to organize things, such as toys</li> <li>• Is very observant</li> <li>• Loves make-believe play</li> <li>• Grasps the idea of numbers and counting</li> </ul>
Emotional development	<ul style="list-style-type: none"> <li>• Becomes curious and wants attention</li> <li>• Is very self-centered</li> <li>• Begins saying “no”</li> <li>• May react to frustration with temper tantrums</li> </ul>	<ul style="list-style-type: none"> <li>• Wants independence</li> <li>• Imitates other children and adults</li> <li>• Enjoys constant activity (dislikes naps)</li> </ul>	<ul style="list-style-type: none"> <li>• Uses words to express emotion</li> <li>• Likes to make friends</li> <li>• Learns to share, displays fears</li> <li>• Sees him or herself as others do</li> </ul>	<ul style="list-style-type: none"> <li>• Knows difference between right and wrong</li> <li>• Seeks friends' approval</li> <li>• Enjoys being part of a group</li> <li>• May lose control or have mood swings</li> </ul>

## Nutrition<sup>9,13,14</sup>

Children learn about exercise and proper nutrition at daycare and are often eager to practice what they have learned when they get home. Involvement 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!

Keeping weight in proper ranges is especially important for people with bleeding disorders. Extra weight can add stress on joints (which can increase joint pain and frequency of joint bleeds), make it harder to find veins for infusion, and require more factor per infusion since doses are based on weight.

The following are a few tips to practice good nutrition and healthy eating habits:

- 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 containing 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.
- Keep nutritious snacks available. Some examples include fresh and dried fruit, vegetables, pretzels, fat-free cookies and sugar-free frozen ice pops.
- Drink plenty of water. Choose water, milk or calorie-free beverages instead of soft drinks.
- Don't skip meals; instead, eat smaller meals and healthy snacks.



## Dental care<sup>15</sup>

A child usually starts teething at approximately 6 months of age. Teething does not usually cause serious bleeding, because it is a slow process. A child should start visiting the dentist at around 1 year of age, and parents should take the responsibility of cleaning their child's gums and teeth until the child can begin to brush on his own. Do not give toddlers a bottle of milk or juice to help put the child to sleep. This can lead to tooth decay.

Allowing the teeth to fall out naturally and not wiggling them — no matter how tempting — can help to avoid additional bleeding.<sup>16</sup> If mouth bleeding does occur, Amicar (epsilon aminocaproic acid), which can be taken orally and used topically, may be recommended by your hematologist. It neutralizes the enzymes in saliva that often prevent a clot from forming in the mouth. Amicar is available by prescription only, and you should consult with your child's hematologist on dosage.

To prevent tooth decay and gum disease, have regular dental checkups, eat a balanced diet and establish a daily routine for brushing teeth (two times per day). Children require adult supervision when brushing teeth.

## Immunizations

Immunizations provide protection against a number of infectious diseases. In addition to the standard immunizations, it is recommended that children with hemophilia be immunized against hepatitis A and hepatitis B. Some childhood immunizations are usually given into the muscle (intramuscular or IM), and some are given under the skin (subcutaneous or Sub-Q). Most immunizations can be given subcutaneously rather than intramuscularly to avoid bleeding.<sup>14</sup> If your child is on prophylaxis, schedule immunizations on a treatment day when factor levels are elevated.

## Pain and your toddler<sup>10</sup>

Children with bleeding disorders can experience pain as a result of their condition and its treatment. As a parent/caregiver, 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 toddler is in pain?

He may:

- Be less active or less playful
- Cry intensely or whine
- Tell you
- Be unable to sleep
- Eat less
- Exhibit physical resistance by pushing your hand away when you try to touch the spot where it hurts
- Protect where it hurts



## What to do

- Ask your toddler directly if he hurts.
- Use a smiley face scale, and have your child point to how much it hurts.



Source: <http://wongbakerfaces.org/>

- Encourage your child to express what he is feeling. Does it hurt to move?
- 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 or swelling. Be careful of tender skin! Put a cloth between the pack and your child's skin. Don't leave the cool pack on for more than 20 minutes at one time. Check the skin frequently to be sure it isn't too cold (evident as white or purplish coloring of the skin). Reapply every two hours.
- Apply RICE (rest, ice, compression, and elevation) to an injury (see page 13).
- Allow for quiet time. Read, play games or watch a movie to allow the injury to heal.
- Listen to your child. Let him or her tell you what feels best. Your child is developing skills to cope with his pain and to demonstrate self-control and the ability to modify his pain.
- During the infusion of factor, play music, sing a song, or blow bubbles as a distraction. A favorite toy, stuffed animal or blanket is a must!
- 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 when appropriate or as advised by your pediatrician or hematologist. Keep your child safe from falls and injuries.
- Avoid pain associated with the infusion process by using a topical anesthetic cream before needle sticks, if advised by your hematologist.
- Discuss treatment options with your pediatrician or hematologist to minimize risks of bleeding episodes while allowing your child to remain active.

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.

- **Falls:** Stairs, windows, and bicycles represent hazards during these years. Place safety gates in front of all stairs. Make sure windows remain closed and locked. Wearing a helmet when bicycling is recommended for all children.
- **Choking:** Cut finger foods into small, bite-size pieces. Keep your child from putting non-food items in his mouth.
- **Burns:** Inspect your home for fire hazards. Don't overload electrical outlets, and cover outlet plugs. Matches and smoking materials should always be disposed of safely. Keep a fire extinguisher and fire alarms on each level of your home. Do not leave your child unsupervised in the kitchen while cooking.
- **Drowning:** Never leave a small child alone in the bathtub or swimming pool. Use safety devices on toilets. Always use life jackets while boating.
- **Poison:** Keep medication, cleaning products, paints, gasoline, pesticides and other chemicals locked in cabinets and stored in original containers. If poison is swallowed or spilled on skin, follow instructions on the container. Keep the poison hotline number (800.222.1222) posted by the phone.
- **Car crashes:** Always use a properly installed child seat, even for short outings. Some states require the use of booster seats. Children under 12 years should avoid riding in the front seat of a car, and young children should not be placed in a seat equipped with an airbag.
- **Trampolines:** The American Academy of Pediatrics cautions against trampoline use for all children due to ongoing and increasing injuries. Children with bleeding disorders are at even greater risk for permanent damage from fractures and neck injuries.<sup>16</sup>

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



## Discipline<sup>17</sup>

The goal of discipline is self-control, and all children need to develop a positive self-image while learning to control their emotions and behaviors. Most experts today agree that physical punishment is the least effective method for accomplishing these ends. In addition, spanking or striking a child with hemophilia could lead to bleeding episodes. When children need help modifying their behavior, experts recommend some basic rules for parents:

- Focus on the child's poor behavior, not on the child.
- Have a plan, and be consistent in your responses.
- Stay calm and in control.
- Allow the child to express his feelings, even those considered negative.
- Be a good role model.
- Try to treat all children in the family equally.
- Realize that change takes time.

Living with your child's hemophilia may be challenging, but it can be managed. Keep its impact to a minimum, and focus on the beautiful child in front of you.

With knowledge and a supportive team on your side, watching your toddler/preschooler play, grow, and explore will provide one of life's greatest rewards. As your child matures, find additional information available in this guide.

