



**Stage 1:**

## **The Newborn Years (0–12 Months)**



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As the parent of a newborn with hemophilia, you may be experiencing a mix of emotions. It may be a shock to hear this diagnosis. This section provides suggestions for ways to safely manage your child's bleeding disorder and precautions you should take during his first year of life. It is important to build a relationship with your child's pediatrician, hematologist and specialty pharmacy in order to develop a care plan that is best for your child.

One of the earliest discussions you'll need to have with your child's pediatrician and hematologist is around the risks and benefits of circumcision. Some babies may have no problem with the procedure, while others may have prolonged bleeding, with some even requiring stitches to help slow the bleeding. In families with no history of hemophilia, the heel stick for infant metabolic screening or bleeding from a circumcision is often the first sign a baby may have hemophilia.

Over the first 12 months of life, your most common challenge with bleeds is likely to be bruises. These are discolorations of the skin due to small blood vessels being broken under the skin surface. Many children with hemophilia develop bruises from normal handling. As they are lifted or carried, children can develop bruises under their arms or on their buttocks. Hugging can cause a circle of bruising around the chest or body. Bath time can cause some bruises when holding children securely in the tub. When using a high chair or walker, bruises can develop on their sides, feet, under their arms and on their chest. Bruises will fade over several weeks' time.

You can use bath time or diaper changes to monitor bruises. If you notice a bruise getting larger over a few hours, you should contact your hematologist. They may want to see your child to evaluate the situation. Some children may need to have ice applied to the bruised area, and others may require a factor infusion. Your hematologist can advise you on the best treatment for your child.

At approximately 6 months or older, your child will become more mobile as a normal part of development. He will be able to roll over, sit up by himself and begin crawling and exploring the world. You may consider using knee and elbow pads to help prevent some bleeds as your child begins to crawl. He will also be pulling himself up and then falling down. This repeated activity may cause bruising on his buttocks and scrotum. Putting an extra diaper on can help prevent some this bruising.

A bigger concern for parents is when he hits his head or neck during a fall. Your child can hit his head as he falls on the floor, because his neck muscles are not yet strong enough to hold his head up to protect it from the fall. Never second-guess a head bump. For a child with hemophilia, any trauma to the head should be considered an emergency as it could have severe damaging effects. Your child should be evaluated as quickly as possible. Bleeding can occur inside the brain without any signs and symptoms initially, while some may experience any variety of the following symptoms: bruising, bump, headache, sleepiness, neck ache, nausea, vomiting, sensitivity to light or loss of consciousness. Always report any head injury to your hematologist immediately to discuss what to do when your child has bumped his head. Always report any head injury to your hematologist or pediatrician as well.

At approximately 9 months or older, children will begin to pull up and learn to walk, creating pressure on joints. It is important to remember that you may not see blood in all bleeding episodes. Sometimes the bleed can be in a joint or muscle. As blood fills the space around the joint, pressure will build up, pain will occur, and the joint will become stiff or swollen and feel warm to the touch. This type of bleed requires factor infusions to prevent joint damage from occurring. When a child bleeds repeatedly into the same joint, it is considered a target joint. Individuals with target joints tend to have more orthopedic problems as they age. Your hematologist will help you understand how to evaluate your child's bleeding and the best treatment option.

## Developmental guide<sup>9</sup>

During the first year of life, your child will make enormous developmental gains. On average, a baby will nearly triple his birth weight and grow 10 inches; however, each child will develop at his own pace. The following guidelines show some general development stages your child should experience.

By **3 months**, your child should be able to:

- Raise head and chest
- Grasp and shake toys
- Smile
- Communicate more
- Imitate movements and expressions
- Recognize familiar objects and people

By **4–7 months**, your child should be able to:

- Roll both ways
- Sit without support of hands
- Transfer objects from hand-to-hand
- Respond to expression of emotion
- Find partially hidden objects
- Explore with hands and mouth

By **8–12 months**, your child should be able to:

- Get to sitting position without help
- Assume hands-and-knees position
- Cry when parent leaves
- Eat with fingers
- Begin to use objects correctly
- Prefer certain toys and people





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

Children with bleeding disorders can 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, how to deal with it and how to 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." The young infant cannot yet verbally express what he is feeling. This can make it difficult to determine if and where your infant has pain.

## How can you tell your infant is in pain?

Your infant may:

- Be irritable or less playful
- Not eat as well as normal
- Bite or squeeze his lips tightly
- Cry with a harsh, high pitch
- Not move out of one position very often, or move around a lot trying to find a comfortable spot
- Frown or squeeze his eyes tightly shut
- Not be comforted by you
- Pull his knees to his chest
- Pull the body part that is hurting away from your touch
- Shudder
- Sleep more or less than usual
- Rub or touch the part of his body that hurts
- Whimper or groan quietly



## What to do

- Call your pediatrician and/or hematologist and explain why you think your baby is in pain.
- If medication is ordered, give it exactly as prescribed, and watch your baby 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 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 baby's skin. Don't leave the cool pack on for more than 20 minutes at a 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.
- Rock and cuddle your infant.
- Play music or sing.
- When a bleeding episode is evident, have factor infused promptly — within three hours of the injury or onset of the bleed. Follow the instructions of your pediatrician or hematologist.
- Plan ahead. Discuss medication options with your child's pediatrician or hematologist, and have those medications available in your home to administer when your child is in pain. **Be sure to avoid aspirin, aspirin-containing products, and nonsteroidal anti-inflammatory drugs (NSAID) like ibuprofen.** Discuss any over-the-counter product with your hematologist or pharmacist prior to giving them to your child.
- 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!

## How to avoid pain

- Prevent pain by avoiding injuries. Use protective padding when appropriate or as advised by your pediatrician or hematologist. Keep your baby safe from falls and injuries.
- Avoid pain associated with the infusion process by using a topical anesthetic cream before needle sticks, if approved by your hematologist.
- Discuss treatment options with your pediatrician or hematologist and consider infusions at the first sign of a bleed to minimize the long-term damage that bleeding episodes can cause, 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>



## Child safety<sup>9</sup>

Keeping your child safe is a big concern for parents. One of the best ways to inspect your home is to get down on the floor and examine your home from your child's viewpoint. Childproofing can eliminate dangers your child could encounter in your home and car.

### To prevent falls

- Never leave your baby alone on a changing table, bed or chair.
- Use safety gates if you have stairs in your home.
- Avoid using walkers.
- Use the harness when your child sits in a high chair, stroller or shopping cart.

### To prevent burns

- Test bath water before placing your child in the tub.
- Do not smoke, handle hot foods or liquids or cook when holding a baby.
- Place screens around fireplaces and heaters.

### To prevent choking

- Inspect toys for any small or broken pieces.
- Remove any drawstrings or ties from clothing.
- Avoid foods children younger than four are most likely to choke on: hot dogs, raw carrots, grapes or raisins, popcorn, nuts and hard candies.
- Don't allow toddlers or young children to wander around the house or play while snacking.

## Around the house

- Clean floors so they are free of small objects.
- Cover unused electrical outlets.
- Install safety latches on cabinets containing hazardous materials.
- Make sure appliance cords or drapery/blind cords are out of reach.
- Take a course in infant cardiopulmonary resuscitation (CPR). CPR is a combination of rescue breathing (mouth-to-mouth resuscitation) and chest compressions. Many organizations, such as the American Red Cross, offer classes.
- Have an emergency plan in place. Post the numbers of the poison control center, police and fire departments, ambulance service and your child's hematologist by your telephone.
- Have a stocked first aid kit.

A baby's first year of life is an amazing time. It will seem as if your baby makes a new discovery every day. As parents or caregivers, you will also be making new discoveries and learning about hemophilia. As your child grows, find additional information available in this guide.

