

Coping With Hemophilia as a Family: Suggestions for Managing the Family Dynamic



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Hemophilia Affects the Whole Family

Despite improvements in the medical management of bleeding disorders, raising a child living with hemophilia still affects the lives of everyone in the family. It's important to address the needs of caregivers and family members as well as acknowledge how a diagnosis of hemophilia alters family dynamics.¹

Hemophilia is a complex disorder that requires treatment for a lifetime. If hemophilia is new to the family, feelings of uncertainty about coping with day-to-day management can occur. In particular, infusing factor may initially be upsetting to the child and stressful for the caregiver who is experiencing challenges with the process.¹

“One thing we learned was that growing up is a learning process for all children, whether they have hemophilia or not.”

— Jill L.

Mother of 2 sons with hemophilia B

Discipline and Limits

It's important for parents and other caregivers to support one another in the daily care of the child, including talking about emotions and overcoming hemophilia-related challenges together.² Some of these challenges can include providing discipline and setting limits. Parents and caregivers are often advised to address these issues in the same way they would for children who are not diagnosed with a bleeding disorder.

Some suggestions from the National Hemophilia Foundation that may help in caring for a child with hemophilia include³:

- Praise your child when he or she reports a bleed to a caregiver
- Reinforce that having a bleeding disorder that requires treatment is not a punishment
- Openly discuss the potential effects of behavior and activities
- Never punish your child for having a bleed

One major concern that parents or caregivers may face is knowing when a child is having a bleed. In some cases, bleeds can be tricky to identify, as a child may exhibit one or more of the following signs or symptoms of a muscle bleed⁴:

- Holding a part of the body in an awkward position or reluctance to use that part of the body
- Complaining of pain or a tingling sensation in the injured area
- The injured area feels warm, swollen, and/or firm to the touch

It's important to recognize that caring for a child with hemophilia may create changes to which the family must become accustomed. Lifestyle modifications are a part of living with hemophilia, and sometimes these changes extend to the entire family. However, these adjustments represent opportunities for positive change through learning and self-awareness.⁵

References: 1. Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia*. 2007;13(5):570-579. 2. Wiedebusch S, Pollmann H, Siegmund B, Muthny FA. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia*. 2008;14(5):1014-1022. 3. National Hemophilia Foundation. Steps for Living website. Discipline. www.stepsforliving.hemophilia.org/first-step/family-life/discipline. Accessed July 12, 2019. 4. Rivard G-E, Blanchette V, Hilliard P, Mulder K, Zourikian N. Management of bleeds. In: *All About Hemophilia: A Guide for Families*. Montréal, Québec: Canadian Hemophilia Society; 2010: 4-1-4-32. 5. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007.



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