



# PSYCHOSOCIAL SUPPORT FOR FAMILIES AT THE CHILD'S DIAGNOSIS STAGE

Learning your child has hemophilia or another bleeding disorder (BD) can be overwhelming. Feelings of shock, fear, guilt or uncertainty are natural. Everyone processes it differently, and even parents in the same family may go through different emotional rhythms.



**Tip:** Trust reliable sources. Keep a list of questions for your care team and maintain open communication with healthcare professionals. You are not alone!

## Emotional support matters

Beyond physical care, emotional wellbeing is essential. Seeking support can reduce anxiety and give you strength. Psychosocial professionals, such as psychologists and social workers, play a vital role in helping families navigate challenges and build coping strategies.

Your local hemophilia association can offer you psychological support and opportunities to connect with other families. They often have informational and psychoeducational community spaces, such as workshops, conferences, and chapters. Some establishments even offer summer camps!

## How to talk about it

Children with hemophilia or other BDs learn to accept them naturally as part of their life. When questions arise, respond honestly but simply, only providing as much as they ask—don't overexplain. Let their questions guide you. Your presence, listening and emotional support are what matter most.



**When to seek help:** persistent sadness, anger, withdrawal, or regression in the child—or with one of their parents—may signal a need for professional support.

# Supporting your child with a bleeding disorder:

## Movement, play and growth

Play and movement are vital for development. Overprotection can hinder confidence and learning. Preventive treatment (prophylaxis) enables safe participation in many sports—like swimming, cycling, and tennis. Encourage physical activity to strengthen your child's joints and self-esteem. Participation in team games has physical, psychological, and social benefits.

## Navigating life stages

Each stage brings new challenges:

- **Infancy:** Establish routines and support bonding. Help identify and validate emotions. Help incorporate treatment-related routines as part of your child's daily life. Set healthy boundaries.
- **Adolescence:** Encourage treatment responsibility and social confidence. Adapt healthy boundaries to this life stage.
- **Transition to adulthood:** Plan for independence, their career, including the transition to other healthcare teams.

## School and everyday life

Hemophilia should not prevent normal schooling. Children can attend preschool and mainstream school. Educators should receive clear, calm guidance on the child's condition, and know who to contact in case of an emergency. Integration into peer groups is essential for the learning process and for promoting socialization at this stage. Your national hemophilia association can provide you with school support, including guidance materials and training.



## Helpful resources

Hemoaction playing cards:



The book "The Child with Hemophilia and Their Family: A Different Story" explains hemophilia through play:





## Family balance

A diagnosis impacts the whole family—siblings, grandparents, extended relatives. Everyone adjusts differently. Some may become more involved; others less. Cultural, social, spiritual, and geographic diversity, among other things, influences the acceptance process. The key is to work with the support you have.

If you have other children, make space for each one's unique experience. Siblings may feel left out or anxious—help them express emotions and understand the condition. Involve siblings when appropriate and promote emotional connection.

Help your child build confidence by focusing on what they can do, encouraging autonomy, independence and self-responsibility when they're old enough. Celebrate achievements. Confidence grows through support and responsibility.



## Practical support and resources

Managing hemophilia and other BDs involves logistics—appointments, treatments, and costs. Seek financial guidance, plan transport, and organize routines to reduce stress.



### **Your treatment centre and local association can help.**

We invite you to contact your national member organizations (NMO) or a hemophilia treatment centre (HTC) by consulting our global directory:  
[wfh.org/find-local-support](https://wfh.org/find-local-support)