

OVERCOMING CHALLENGES IN HEMOPHILIA CARE

A practical guide for people with hemophilia and their families

You're not alone!

Living with hemophilia can bring worries and even fear about the future. But it's important to remember that, with proper medical care, family support, and community connections, it is possible to have a good quality of life and achieve your dreams. You don't have to face this alone—your care team and patient groups are here to walk with you.

Understanding your condition

Hemophilia can be **mild, moderate, or severe**, depending on the level of clotting factor in your blood. This difference influences how often bleeding occurs and what kind of treatment you need.

Keeping regular appointments is essential, because your needs may change over time. Knowledge is your best ally for living with hemophilia safely.



Questions? Need support?

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

Main challenges and how to overcome them:



Frequent treatment

In some cases, clotting factor must be infused several times per week. This routine may feel tiring and may interfere with school, work, or family life. Still, following treatment correctly is crucial to **prevent bleeds and protect your joints**. Try setting a fixed schedule and ask your care team about long-acting therapies when available.



Inhibitors

Some people develop **inhibitors**, which are antibodies that block the effect of clotting factor. This makes treatment more complicated—but there are solutions. Specific therapies, such as immune tolerance and other alternatives can help. **It's not your fault:** this is a natural response of the body, and your care team can guide you on the best next steps.



Difficult vein access

Finding a vein can be painful and stressful, especially for children. To make this easier, stay well-hydrated, use warm compresses before infusion, and seek help from experienced professionals. In some cases, a port-a-cath may be recommended. There are also newer therapies available in some countries that don't require frequent infusions.



Communication with your care team

Some patients feel unheard or left out of decisions about their care. **Remember: you have the right to be listened to.** Bring your questions to appointments, ask for clear explanations, and, if needed, seek a second opinion. When there is trust and open dialogue, care becomes less of a burden and more effective.



Distance from a treatment centre

Living far from a hemophilia treatment centre can make follow-up and access to medication more difficult. To help, **plan your visits ahead of time**, ask if telehealth is available, and explore shared care with nearby clinics. Always have an **emergency plan** in case of a bleed.



Financial challenges

Hemophilia treatment can be very expensive in some regions. Access may depend on government programs, public health systems, or patient organizations. If your family struggles with this aspect of your care, seek guidance from social services, non-governmental organizations (NGOs), or patient groups. Global advocacy efforts—like those led by the WFH—are working to ensure **fair and equal access to treatment for everyone**.



Acceptance of your condition

Receiving a hemophilia diagnosis can bring feelings of fear, anger, or frustration. Some people may hide their condition or avoid talking about it. Over time, however, acceptance helps you live with more peace and confidence. Joining **support groups**, connecting with other families, or seeking counseling can make a big difference.



Living with hemophilia takes strength, but you don't have to walk this path alone. Every step in treatment is an investment in your future.

Stay connected with your care team, ask questions, and seek support whenever you need it. **You deserve quality care, respect, and a life full of possibilities.**