

The Importance of a Care Plan

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Living with hemophilia may leave a young person feeling as though they're different from their friends.¹ The time and effort needed to deal with the everyday management of hemophilia may disrupt school and activities. Even so, it's important to follow the care plan closely in order to prevent complications that could lead to more time away from friends and fun.²

Staying Ahead of Hemophilia

Young people are already coping with many life changes, and hemophilia treatment is another piece to fit into a busy life. Planning ahead to manage hemophilia is important in avoiding complications but it can also be understandably challenging for many reasons. Being proactive might mean thinking about hemophilia several days each week, which some people might find difficult.

In some patients, a hemophilia management plan may include prophylaxis, which means taking steps to prevent a problem before it happens. In hemophilia, this might include treatments to help prevent bleeding episodes.² Thinking ahead does take time, attention, and practice. Reaching out for support can make the process easier and can help with staying on track with treatment goals.

Adhering to Your Care Plan

When patients follow their treatment plan, it is sometimes referred to as adherence. Following your care plan is an important part of avoiding complications. Over time, having bleeding episodes can cause damage to joints.³ Recognizing symptoms and treating them, especially when a bleeding episode first starts, is important.²

When you are feeling well, it may not seem as though being adherent is very important. However, taking care of hemophilia and overall health while young can bring

benefits such as a better quality of life and avoiding complications when you're older.

Being Part of the Team

Learning about hemophilia and asking questions of health care team members, such as doctors and nurses, will help in being prepared and in preventing and treating bleeds. When patients and caregivers create a treatment plan together, it's called shared decision-making. Being an active part of the health care team helps to make sure that the care plan fits into everyday life. The best plan for each person is going to be specific to them and the one that they will follow.

Developing a Comprehensive Plan

Treating hemophilia includes more than just preventing and treating bleeding episodes. Consider other parts of an overall care plan including²:

- Getting regular checkups for overall health
- Learning to recognize a bleed
- Keeping a store of medical supplies on hand
- Knowing how to self-infuse
- Keeping a record of bleeds and treatments
- Getting proper nutrition and regular exercise

Becoming Your Own Best Advocate

Shared decision-making, adherence, and self-care all play a role in living a healthier life with hemophilia. With the help of the health care team and parents or other caregivers, managing hemophilia can become a regular part of a normal day. Learning about hemophilia in order to be more self-reliant is empowering and can lead to a rewarding, healthy life.

References: 1. Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. *Arch Dis Child*. 2004;89(10):938-942. doi:10.1136/adc.2003.045369 2. Srivastava A, Santagostino E, Dougall A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. *Haemophilia*. 2020;26(suppl 6):1-158. doi:10.1111/hae.14046 3. Lindvall K, Colstrup L, Wollter IM, et al. Compliance with treatment and understanding of own disease in patients with severe and moderate haemophilia. *Haemophilia*. 2006;12(1):47-51. doi:10.1111/j.1365-2516.2006.01192.x



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