

Hemophilia in the High School Years

Becoming independent is a beneficial skill

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Being a teen can feel like waiting for adulthood and the next chapter in life, but it's a good time to learn about hemophilia, your body, and your mind. Living with hemophilia adds another task to these years, because understanding how to care for yourself is a major part of growing older. Other teens are also learning to care for their bodies, but life with hemophilia also means learning how to empower themselves to become proactive in their hemophilia care management.¹

Connected, But Self-Reliant

Your care team and your parents or caregivers will continue to help you manage your condition, but as a teen, now is a great time to begin to take control of your health. Step by step, you can learn how to manage each aspect of caring for yourself, along with your hemophilia. This can include²:

- Learning to self-infuse
- Knowing when a bleed is starting
- Understanding how to live a healthy lifestyle with hemophilia
- Living with a chronic condition
- Communicating with your health care team about treatment goals

The process of shared decision-making in treatment plans does mean that patients need to take part of the responsibility for their own care. However, being prepared for appointments and clearly discussing the impact of all the available treatment choices could lead to better experiences and outcomes.

Owning Your Truth

Hemophilia may make it seem more difficult to fit in with other teens. Telling your teachers, friends, and classmates about hemophilia is entirely up to you. In some cases, it may make sense to confide in other people, both for support and in case you need care urgently. Connecting with those your age who live with hemophilia or other chronic conditions can also be really helpful. Patient advocacy

organizations, camps for people with hemophilia, and online support groups are all good ways to meet other teens.³

Remixing Your World

Finding your own interests and passions is an important part of life. Learning new skills and developing hobbies are other ways to meet people and have fun. Whatever your interests are, you can find a club, group, or class to help you explore it. Sampling different activities also helps you learn what you might want to do for a career. If something turns out not to be appealing, or doesn't fit into your life with hemophilia, you can always try something else. Exploring as many new experiences as possible is part of being young and learning about yourself.

Working the Plan

Another aspect to discovering new interests is in planning for the future. There are scholarships available to people who live with hemophilia and who want to pursue college or trade school. Being involved in extracurricular activities, such as sports, community groups, and patient advocacy, may be helpful in finding and applying for scholarships. Preparing for these opportunities, while learning about your own interests through developing skills and hobbies, will be an important, yet fun, part of the teen years. Some sources for scholarships include:

- Pfizer Hemophilia Scholarship Program:
Soozie Courter Scholarship
www.hemophiliavillage.com/scholarship-program

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- Hemophilia Federation of America:
www.hemophiliafed.org/scholarships/
- The Coalition for Hemophilia B:
www.hemob.org/scholarships
- National Hemophilia Foundation:
www.hemophilia.org/community-resources/financial-assistance/scholarships

References: 1. Kyngas H. Patient education: perspective of adolescents with a chronic disease. *J Clin Nurs*. 2003;12(5):744–751. doi:10.1046/j.1365-2702.2003.00788.x
2. Garcia-Dasi M, Torres-Ortuno A, Cid-Sabatel R, Barbero J. Practical aspects of psychological support to the patient with haemophilia from diagnosis in infancy through childhood and adolescence. *Haemophilia*. 2016;22(5):e349–e358. doi:10.1111/hae.13018
3. 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



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