

Talking About Hemophilia at School

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Parents and caregivers are the first adults responsible for their child with hemophilia. As children get older, however, they may attend daycare or school, participate in sports, and have playdates, where they are cared for by others. Families need to make decisions about who should be aware of the hemophilia diagnosis and how much information to disclose.

Making the Decision to Disclose

Telling people about hemophilia is a personal decision. One step in educating others is having a good understanding of the condition yourself. Parents and caregivers may want to take advantage of educational opportunities that are offered from the hemophilia treatment center (HTC), patient advocacy groups, and factor manufacturers. Helping staff learn about hemophilia may lead to an improved experience at school.¹

Tweens and teens living with hemophilia may want to let friends in their class know about their condition. Parents can suggest age-appropriate language kids can use, or even set up a time and place for their child to talk with friends.

Who Does the Talking?

For younger children, parents or caregivers may want to direct the conversation, especially with other adults. As kids get older, they will probably want more say in making decisions about disclosing to friends, people at school, and acquaintances. Parents may want to talk to their kids about the benefits of having close friends know about hemophilia. As kids become tweens, teenagers, and young adults, they could need encouragement to take a larger role in educating others about hemophilia.²

What Others Should Know

Disclosing at school should be important because of the possibility of needing care during the day. Giving teachers, coaches, administrators, and the school social worker and nurse access to information about hemophilia as well as specifics about the current care plan will be helpful.

References: 1. Cassis FR, Buzzi A, Forsyth A, et al. Haemophilia Experiences, Results and Opportunities (HERO) Study: influence of haemophilia on interpersonal relationships as reported by adults with haemophilia and parents of children with haemophilia. *Haemophilia*. 2014;20(4):e287-e295. doi:10.1111/hae.12454 2. Limperg PF, Haverman L, Beijlvelt M, et al. Psychosocial care for children with haemophilia and their parents in the Netherlands. *Haemophilia*. 2017;23(3):362-369. doi:10.1111/hae.13186 3. Cassis FR, Querol F, Forsyth A, Iorio A; HERO International Advisory Board. Psychosocial aspects of haemophilia: a systematic review of methodologies and findings. *Haemophilia*. 2012;18(3):e101-e114. doi:10.1111/j.1365-2516.2011.02683.x 4. Your rights under Section 504 of the Rehabilitation Act. U.S. Department of Health and Human Services. Published June 2000. Updated June 2006. Accessed July 13, 2021. <https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf>

Some families may choose to use this as a teaching moment as well, to discuss the emotional needs of the student while at school and raise awareness about hemophilia among staff.³

There are legal protections in place for children with disabilities who attend school.⁴ Parents can consider putting a 504 plan in place. Personnel at the HTC may be helpful in providing sample 504 wording or suggestions. At least yearly, or more often when needed, parents should meet with school staff to discuss the plan. Some of the specifics can include:

- Accommodations needed (like modifications to physical education classes)
- How to manage an injury or a hemophilia emergency
- Medications or treatments needed during school hours
- Managing schoolwork during medical absences
- Supplies needed at school (either for every day or in the case of an urgent situation)
- Visits to the school nurse

Starting the Conversation

A formalized plan, such as the 504, can provide a framework in talking with school staff. Putting it together helps parents get organized about what their child might need while at school. Meeting with all the stakeholders at school helps in working out the plan and in answering one another's questions. A follow-up meeting is a good option if anyone needs another touchpoint to discuss what is or what isn't working.

For kids, opportunities such as camps or activities designed for children affected by hemophilia provide an excellent opportunity to improve social skills.² Children might also benefit from role-playing scenarios with trusted adults in order to practice telling their friends about hemophilia. Starting small, with the basics of hemophilia, and then offering links to reading material is one way to encourage friends to become more educated.



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