

Special Considerations for Girls

The Onset of Menstruation May Be a Time to Focus on a Hemophilia Care Plan



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Puberty on its own can be a difficult experience, but it can become even more complicated with a hemophilia diagnosis. The start of menstruation is one of the many aspects of a girl's life that may be affected by a bleeding disorder. For girls who are showing symptoms of hemophilia, puberty may be a good time to identify a health care team and develop a care plan.

Identifying a Health Care Team

The lack of knowledge about how hemophilia impacts girls can affect the level of medical care and emotional support received by a girl with this condition.¹ It may be recommended that a girl who is diagnosed with hemophilia wear a medical identifier at all times so that medical personnel are aware of her bleeding disorder in an emergency. It is important for every female with hemophilia to enlist a team that includes a primary care physician, a gynecologist, and a hematologist who can coordinate care and needs.²

Tools that can help girls manage symptoms include³:

- Care plans designed for patients by their team of health care providers to help facilitate care coordination
- Apps that allow patients to track their hemophilia symptoms and care
- Self-monitoring assistance for better symptom accuracy

Heavy Menstrual Bleeding

Periods with heavy blood loss (called *menorrhagia*) can lead to anemia and have a negative effect on quality of life. Girls with bleeding disorders who are experiencing symptoms of menorrhagia should have a discussion with their health care team in order to coordinate management and care.⁴

References: 1. Aldridge S. The carrier barrier: women push for mild hemophilia diagnosis. HemAware.org Web site. www.hemaware.org/story/carrier-barrier. Published July 19, 2012. Accessed February 20, 2019. 2. Canadian Hemophilia Society (CHS). Precautions for pregnant women with a bleeding disorder. Hemophilia.ca Web site. www.hemophilia.ca/en/women/precautions-for-pregnant-women/. Accessed February 20, 2019. 3. Carr S. A new look at patient communications in outcomes-driven healthcare. Pharmaphorum.com Web site. http://pharmaphorum.com/views-and-analysis/a_new_look_at_patient_communications_in_outcomes-driven_healthcare/. Published November 5, 2012. Accessed February 20, 2019. 4. National Hemophilia Foundation (NHF). Effects of puberty on girls with a bleeding disorder. StepsforLiving.Hemophilia.org Web site. <https://stepsforliving.hemophilia.org/next-step/maintaining-a-healthy-body/growing-up-puberty/effects-of-puberty-on-girls-with-a-bleeding-disorder>. Accessed February 20, 2019.

The signs and symptoms of menorrhagia include⁴:

- Having a menstrual period that lasts longer than 7 days
- Needing to change pads or tampons at least every 2 hours
- Passing blood clots larger than a quarter
- Bleeding that affects daily activities

"I am a true testament to the fact that factor replacement therapies can help when it comes to being a woman with hemophilia. Not only do we have to deal with the joint bleeds that men do, but we also have specific issues as women."

- ELIZABETH
Has hemophilia B

Tips for Parents⁴

Parents of a girl with a bleeding disorder can ease their daughter's transition into puberty by preparing her for the experience of having periods and helping her learn how to manage them. It can also be helpful for parents to ensure that a supply of feminine products is available and provide a way for their daughter to carry the products discreetly if needed. Parents can also help by providing honest, accurate information about menstruation and the impact hemophilia may have.

The beginning of menstruation, which can already be a confusing and demanding time in the life of any girl, brings special concerns for those showing symptoms of hemophilia. It's important for girls to talk with health care providers and caregivers about their periods, especially if bleeding becomes heavy.



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