

# What Females Need to Know About Bleeding Disorders

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Women of all ages, but particularly teenagers, with bleeding disorders may not be receiving all the information and care they need.<sup>1</sup> Educational materials that were originally made for males may not be as relevant for females, especially around bleeding as it relates to menstruation. For this reason, women and girls, along with close family and caregivers, could find it important to learn how to advocate for themselves in order to get the correct diagnosis and treatment.

## Recognizing Heavy Periods

Between 75% and 80% of adolescent girls who have an inherited bleeding disorder also have heavy or prolonged periods.<sup>2</sup> It's important to know that pain and heavy bleeding around menstruation isn't something that needs to be endured. There are treatments available that can help reduce symptoms and avoid problems like missing school and activities. A trained medical provider can describe all the treatment options and help find the one that will be most helpful.<sup>1</sup>

## Staying Ahead of the Possibilities

Girls and women who are symptomatic carriers or who are living with hemophilia may also experience other complications due to their bleeding disorder. It's important to know about these potential issues in order to watch for them and bring them to the attention of health care providers.

Some of the gynecological health issues girls and women might experience include<sup>3</sup>:

- **Corpus luteum cyst.** A cyst that forms after bleeding during ovulation. These cysts have a risk of causing abdominal pain or of rupturing.
- **Dysmenorrhea.** Moderate to severe pain, which could be associated with heavier blood flow.
- **Menorrhagia.** A menstrual period that includes heavy bleeding or bleeding that goes on for more than 7 days. This could lead to iron deficiency, anemia, and a decreased quality of life.

**References:** 1. Khair K, Holland M, Pollard D. The experience of girls and young women with inherited bleeding disorders. *Haemophilia*. 2013;19(5):e276-281. doi:10.1111/hae.12155 2. Screening and management of bleeding disorders in adolescents with heavy menstrual bleeding: ACOG Committee Opinion, Number 785. *Obstet Gynecol*. 2019;134:e71-e83. doi:10.1097/AOG.0000000000003411 3. Winikoff R, Brownlow M, Stewart P. Symptomatic carriers of hemophilia. All About Hemophilia: A Guide for Families. Canadian Hemophilia Society; 2010:14-1-14-26. <https://www.hemophilia.ca/files/Chapter%2014.pdf>

- **Metrorrhagia.** Abnormal or irregular vaginal bleeding that occurs between periods. Heavy bleeding could lead to bed rest or hospitalization.
- **Mittelschmerz.** Abdominal pain that occurs during ovulation (when an egg is released from an ovary into the fallopian tube), which may be a result of bleeding during ovulation.

## Voicing Your Questions

Talking to doctors about topics that seem personal can be challenging and may seem embarrassing. It's important to know that doctors who work with patients with bleeding disorders are trained in addressing these issues. When something doesn't seem right, being honest and open about symptoms is key to getting treatment and feeling better. It might be helpful to try one or more of these options:

- Speaking to someone you trust about problems or symptoms prior to an appointment
- Bringing a friend or family member to appointments to offer emotional support, to listen, and to ask questions
- Discussing your questions or concerns about conception, child birth, and surgery with your care team
- Using a patient portal to send messages ahead of appointments

## Looking to the Future

Growing up includes a series of changes, and knowing how they may be affected by a bleeding disorder is important. Girls and women who live with bleeding disorders can find that they need to raise their voices and tell their story to get what they need.

Learning how to better express feelings and concerns with family, especially parents, health care providers, and other caregivers will help in getting the right treatment at the right time. Living well with a bleeding disorder may mean owning the journey to advocate for your best quality of life.



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