## **Discussion Guide**

## Talking with your healthcare provider about menorrhagia and von Willebrand disease (VWD)

VWD is the most common inherited bleeding disorder among women—yet many women go undiagnosed.<sup>1</sup> Often, their most common symptom is menorrhagia, which is defined as periods that last longer than 7 days, accompanied by bleeding that limits daily activities and/or blood clots larger than a quarter.<sup>1</sup> Many women with menorrhagia find it impacts their quality of life. Since VWD is genetic, women with a history of a bleeding disorder may think their periods are normal because the bleeding is similar to that of other female family members.<sup>1</sup> To help identify menorrhagia, the Centers for Disease Control has created a checklist.<sup>2</sup>

Your healthcare provider can answer many of your questions about VWD and menorrhagia. Because medical appointments are brief, it is good to be prepared. This guide is designed to help. We have provided questions, as well as space for you to add your own questions and to write down your healthcare provider's answers so you can refer to them later.

## **About you**

At the beginning of your appointment, you will want to share some background information with your healthcare provider. These questions can help you get organized before your appointment, so you remember key points to share.

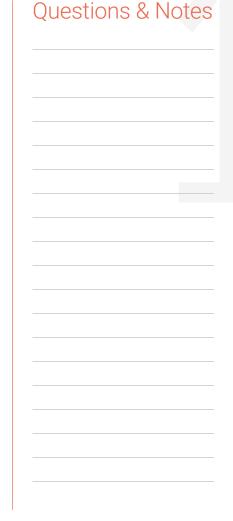
- How many days does your period usually last, from the time bleeding begins until it completely stops?
- How often do you bleed through a pad or tampon in 2 hours or less?
- How often do you experience a sensation of "gushing" during your period?
- Do you experience a period with blood clots the size of a quarter or larger?
   Yes
   No
- Have you ever been treated for anemia (low blood iron)?

) No

Yes

- Have you ever had a bleeding problem after surgery or following childbirth or a miscarriage?
   Yes
   No
   Please explain.

continued...







What other medical conditions do you have?	Questions & Notes
How does bleeding impact your life? (list ways)	
Understanding menorrhagia	
Heavy menstrual bleeding can lead to anemia (low blood iron), which may cause a lack of energy and shortness of breath. <sup>3</sup> Ask your healthcare provider:	
What is menorrhagia?	
What is the length of a normal menstrual period? When is it considered menorrhagia?	
What other gynecological conditions might have symptoms similar to menorrhagia associated with VWD?	
Proactive healthcare	
Hemophilia treatment centers provide a multidisciplinary team of medical professionals—from hematologists to mental health professionals—who specialize in treating people with bleeding disorders. <sup>4</sup> A comprehensive, holistic approach to your healthcare may help improve your quality of life. Ask your healthcare provider:	
Tell me about hemophilia treatment centers	
What are the benefits of specialized gynecological care?	





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Treating menorrhagia	Questions & Notes
Appropriate treatment can reduce the symptoms of menorrhagia. <sup>5</sup> Ask your healthcare provider:	
What treatments are available to help women with VWD who are experiencing heavy bleeding?	
What are the benefits and risks of the various types of treatment options?	
Living with menorrhagia	
As your body matures through puberty and adolescence into adulthood and menopause, you will experience many changes. Ask your healthcare provider:	
How will my menorrhagia change over my lifetime?	
If I want to get pregnant, what risks do I need to consider during and after my pregnancy?	
What do I need to consider if I'm taking these treatments while nursing or pregnant?	
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I'm worried about passing this on to my child. Can you explain the genetics of VWD to me?	Questions & Notes
What do I need to know about VWD and menopause?	
References:  1. National Hemophilia Foundation, Steps for Living. Common bleeding disorders and signs for women. https://stepsforliving.hemophilia.org/basics-of-bleeding-disorders/bleeding-disorders-in-women/common-bleeding-disorders-and-signs-in-women. Accessed May 2,	
<ul> <li>2. Centers for Disease Control and Prevention. Screening tool for identifying women with menorrhagia for testing and evaluation for underlying bleeding disorders. http://www.cdc.gov/ncbddd/blooddisorders/women/documents/menorrhagiafortesting.pdf. Accessed May 2, 2016.</li> </ul>	
<ul> <li>May 2, 2010.</li> <li>Haemophilia Foundation Australia. A guide for people living with von Willebrand disorder. https://www.haemophilia.org.au/documents/item/1301. Accessed May 2, 2016.</li> <li>Hemophilia Federation of America. Hemophilia treatment center. http://www.hemophiliafed.org/?s=hemophilia+treatment+center. Accessed May 2, 2016.</li> <li>National Hemophilia Foundation, Steps for Living. 10 things every adult should know.</li> </ul>	



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https://stepsforliving.hemophilia.org/step-out/10-things-every-adult-should-know.