

Discussion Guide

Talking with your healthcare provider about your recent von Willebrand diagnosis

Von Willebrand disease (VWD) is a bleeding disorder that can lead to different types of bleeds in patients.¹ If you are recently diagnosed, you may have many questions for your healthcare provider. VWD is a diverse, complex disease and everyone's experience with it is unique.² You should talk with your healthcare provider about your experience, as well as your overall health, your lifestyle, and your treatment options.

Because medical appointments are brief, it is good to be prepared. This discussion guide is designed to help. We have provided ideas for information you may want to have handy and some questions you may want to ask, 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.

- **What types of bleeding do you have?**
- **How frequently do you experience bleeding?**
- **Have you ever been treated for anemia (low blood iron)?**
Yes No
- **Has anyone in your family been diagnosed with a bleeding disorder?**
Yes No
- **Have you ever had a bleeding problem after surgery?**
Yes No
- **What other medical conditions do you have?**
- **What medications are you currently taking?**
- **How does bleeding impact your life? (list ways)**

Questions & Notes

Understanding VWD

The best starting point in caring for your health is to understand your disease and its related complications so you can effectively advocate for yourself. Ask your healthcare provider:

- **Is VWD a common bleeding disorder?**
- **Are my children or other close relatives at increased risk for VWD?**
What should I tell them?
- **Should I be concerned about anemia (low blood iron)?**
- **What other complications/bleeding should I watch for?**
- **How will my VWD change as I age? Will it impact other age-related health issues?**
- **Should I be concerned about joint pain?**
- **My bleeding feels severe, even though I'm not categorized as "severe." Why is this? How can I get help?**
- **Do I need to take any special steps or precautions regarding my other medical conditions? (if applicable)**
- **What do I need to know in preparation for a procedure or surgery?**
- **How can I safely stay physically active?**

Questions & Notes

Treating VWD

Appropriate treatment can reduce the symptoms of VWD and may help you avoid complications.³ Ask your healthcare provider:

- **What are my treatment options? Please explain the risks and benefits of each.**

- **How can I most effectively coordinate care between my primary care physician and my hematologist/hemophilia treatment center?**

- **How can I best advocate for myself if I have to go the emergency room?**

- **How can I best prepare for emergencies?**

- **What information should I carry with me at all times?**

References:

1. Mayo Clinic. Diseases and conditions: von Willebrand disease. <http://www.mayoclinic.org/diseases-conditions/von-willebrand-disease/basics/symptoms/con-20030195>. Accessed May 2, 2016.
2. Haemophilia Foundation Australia. A guide for people living with von Willebrand disorder. <https://www.haemophilia.org.au/documents/item/1301>. Accessed May 2, 2016.
3. National Hemophilia Foundation, Steps for Living. 10 things every adult should know. <https://stepsforliving.hemophilia.org/step-out/10-things-every-adult-should-know>. Accessed May 2, 2016.

Questions & Notes

