Discussion Guide

Managing the emotional impact of von Willebrand disease (VWD)

Bleeding caused by VWD can affect you emotionally as well as physically, but everyone's experience is unique.[1] To be sure you are getting the most effective care for your situation, talk with your healthcare provider about your experience and your feelings.

Because medical appointments are brief, it is good to be prepared. This discussion guide is designed to help. It starts with some questions that help you rate your experience with VWD; you will want to answer these before your medical appointment. We also suggest some questions you may want to ask your healthcare provider, and provide space for you to add your own questions and to write down your healthcare provider's answers so you can refer to them later.

Your experience with VWD

Before talking to your healthcare provider, consider the frequency of your bleeding and the impact it has on your daily life.

In the past six months:

- **How many bleeding episodes have you experienced?**
  ◯ 0-5 ◯ 6-10 ◯ 11-20 ◯ 20+
- **How many days of work/school have you missed due to bleeding?**
  ◯ 0-3 ◯ 4-7 ◯ 8-11 ◯ 12+
- **How many events have you skipped due to bleeding?**
  ◯ 0-3 ◯ 4-7 ◯ 8-11 ◯ 12+
- **How many events have you chosen to skip due to fear of bleeding?**
  ◯ 0-3 ◯ 4-7 ◯ 8-11 ◯ 12+

Questions & Notes

Your feelings about VWD

VWD can impact every aspect of your life. Before talking to your healthcare provider, take a few minutes to pause and reflect on how often you have these feelings in relation to VWD:

	Never	Rarely	Sometimes	Often	Daily
• **I feel limited in the ability to lead the life I want to lead.**	○	○	○	○	○
• **I am challenged by my disease at work/home/school.**	○	○	○	○	○
• **I feel anxious about bleeding in public.**	○	○	○	○	○
• **I feel depressed due to my VWD.**	○	○	○	○	○
• **I feel in control of my bleeding.**	○	○	○	○	○
• **I have difficulty explaining my disease to others (family, friends, colleagues).**	○	○	○	○	○
• **I feel supported by my family.**	○	○	○	○	○
• **I wonder if I would benefit from additional support.**	○	○	○	○	○

Questions & Notes

Living with VWD

It is just as important to address the emotional impact of VWD as it is the physical impact.[1] Be prepared by talking to your healthcare provider:

- **Bleeding is impacting my life. How can I get help?**
- **What do I need to know in order to be prepared to live as positively as possible?**
- **My bleeding feels severe, even though I'm not categorized as "severe." Why is this? How can I get help?**
- **My job requires:**
  Should I ask for special accommodations? What kind?
- **What is important to consider in my home, work, and/or school environments?**
- **How can I safely stay physically active?**
- **What should I discuss with my partner about VWD?**
- **Could VWD impact my reproductive health?**
- **Are there any concerns if I were about to start a family?**
- **I would like to travel. How can I do this safely and confidently?**

Questions & Notes

Reference:
1. 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.

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