



Discussion Guide

Talking with your healthcare provider about joint bleeds and von Willebrand disease (VWD)

Joint bleeds, a type of bleeding that can occur with VWD, can cause pain and affect your quality of life.¹ To better understand VWD and the joint bleeds that are associated with it, you should discuss the causes, symptoms, and treatment options with your healthcare provider.

Because medical appointments are brief, it is good to be prepared. This discussion 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 frequently do you experience joint bleeds?
- Are there specific activities that trigger bleeds?
- How long do your joint bleeds typically last?
- Do your joint bleeds require emergency care?
- How does bleeding impact your life? (list ways)

Questions & Notes

Understanding joint bleeds

Joint bleeds can be a serious complication of VWD.¹ Blood fills the joint cavity, and the pressure can cause considerable pain and swelling.² Ask your healthcare provider:

- **Why does bleeding occur in the joints?**
- **Why are joint bleeds a complication of VWD?**
- **What joints are subject to bleeding?**
- **How can I quickly identify a joint bleed?**
- **What are future complications of joint bleeds?**
- **Does it matter if my bleeding is mild, moderate, or severe?**
- **How can joint bleeds impact daily activities?**

Understanding joint damage

Joint damage in people with VWD is similar to that in people with arthritis.² Ask your healthcare provider:

- **What is meant by joint damage?**

Questions & Notes

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- **How is cartilage affected?**
- **How does joint damage occur?**
- **How common is joint damage in people with joint bleeds caused by VWD?**
- **Which joints are most often damaged by bleeding?**

Managing VWD and joint bleeds

It is very important not to avoid the signs of a joint bleed.² Ask your healthcare provider:

- **Can anything be done to slow joint damage?**
- **What can be done to treat joint bleeds?**
- **What are ways to effectively treat acute or chronic pain due to joint damage?**
- **What are the long-term implications of joint bleeds?**

References:

1. Haemophilia Foundation Australia. A guide for people living with von Willebrand disorder. <https://www.haemophilia.org.au/documents/item/1301>. Accessed May 2, 2016.
2. Hemophilia Federation of America. Joint damage. <http://www.hemophiliafed.org/bleeding-disorders/complications/joint-damage/>. Accessed May 2, 2016.

Questions & Notes