

10 Things Every Adult With a Bleeding Disorder Should Know

- 1** A bleeding disorder can cause a myriad of emotions throughout the various stages of life. You may have to adjust your aspirations about lifestyle and employment. It's natural to have strong feelings about the impact your bleeding disorder has on you and your loved ones as you age. Take time to ask for help as you work through these feelings.
- 2** Staying active, making healthy choices, and getting regular medical screenings to detect illness at an earlier, potentially more treatable stage are all measures to help you live a long, happy, and productive life.
- 3** Regardless of your particular type of bleeding disorder and its treatment, adhering to the management plan is a big part of success. If you don't stick to the plan, you run the risk of complications. For example, in the case of hemophilia, you may develop permanent joint damage from bleeds into your joints; in the case of von Willebrand disease, you may develop anemia from heavy menstrual bleeding.
- 4** Many of the health concerns you may face as you get older are similar to those that people without bleeding disorders must address. However, you need to be aware that your bleeding disorder may impact those health concerns in ways that may be different from people without a bleeding disorder. Work with your primary care provider (PCP) and hemophilia treatment center (HTC) team to help keep on top of these health concerns and to understand how your bleeding disorder may influence their development or treatment.
- 5** Healthy sexual relationships are an important part of life. To maintain this aspect of your life, it's important to focus on your overall health. Your bleeding disorder need not prevent you from preserving your sexual health as you age. Speak with your health care professional on how to best manage concerns related to your bleeding disorder, such as heavy periods or HIV.
- 6** Physical limitations may occur as a part of aging or as a result of complications from a bleeding disorder. As you get older, you may lose mobility and dexterity. Be prepared for such limitations by planning early to adjust your living environment.
- 7** Regardless of where you are in your working life, your career should ideally be satisfying, allowing you to feel you're making a meaningful contribution in your chosen profession. It is also important to work in a profession that supports your health and your health care rights as an individual with a bleeding disorder.
- 8** People with bleeding disorders are living longer. It's important to have a primary care provider separate from your hematologist who will coordinate care of your health conditions related to or apart from your bleeding disorder and refer you to any necessary specialized health care providers.
- 9** Caring for your financial well being may be as important as caring for your health. Building savings, making smart decisions about investments and spending, and protecting yourself against financial catastrophes are essential for everyone. This is especially true for individuals with bleeding disorders, because health care costs can be a huge financial strain.
- 10** Considering where and how you'd like to live when you get older may seem a long way off, but planning can never start too early. Doing some preparation now can reduce stress on you and on your family later, increase satisfaction with your choices for living arrangements, relieve some worries about your health care, and help maximize your overall quality of life.