

# THRIVE

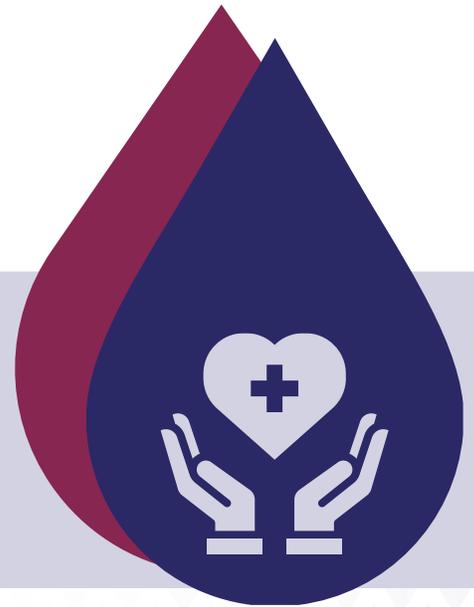


NATIONAL BLEEDING DISORDERS FOUNDATION

## 6 Steps to Living Healthy with a Bleeding Disorder

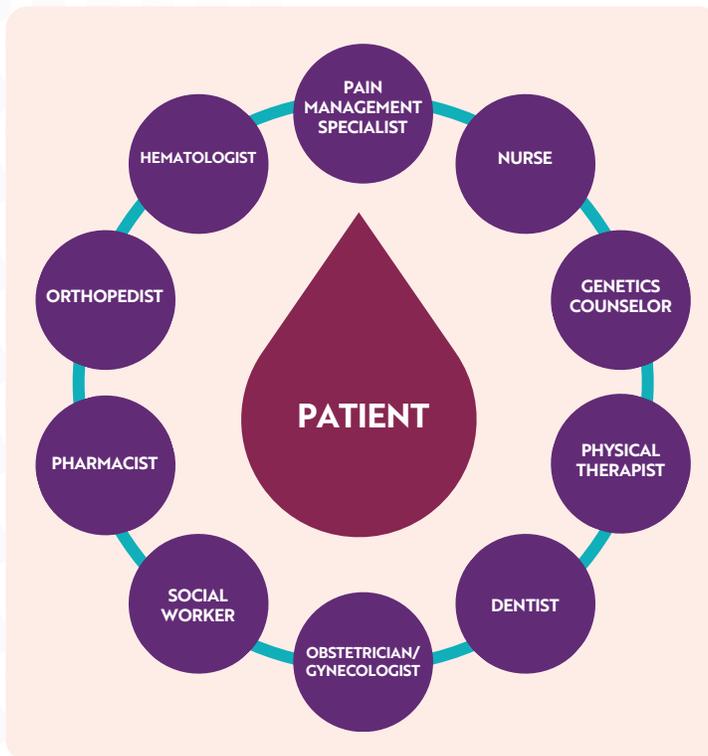
# T

**Take** advantage of regular care from health care providers focusing on bleeding disorders.



Bleeding disorders can be challenging to navigate. Getting good medical care from health care providers who know a lot about bleeding disorders can prevent serious issues. A Hemophilia Treatment Center (HTC) is often the best choice (Soucie, 2000).

HTCs are unique medical centers that have an interdisciplinary team of specialized and experienced health care providers. Despite the name, these centers focus on a variety of bleeding disorders, including von Willebrand disease, platelet dysfunctions, and ultra-rare factor deficiencies. Aside from managing bleeding symptoms, HTCs also focus on preventing and minimizing any complications related to your bleeding disorder. Many people depend on HTCs because the staff understands their unique needs.



While each HTC may have several similar services, not all offer the exact same resources. The HTC team usually includes a hematologist, nurse, social worker, and physical therapist. However, many HTCs also include a variety of other professionals, such as genetic counselors, psychologists, or pain management specialists. They also often have connections to local health care professionals in your community, such as a dentist, who works with people with bleeding disorders.

- Find the closest HTC to you with the [HTC Locator](#).
- Talk to your health care provider to determine how frequent your visit(s) should be.
- To [prepare for your visit please refer to](#) NBDF's Steps for Living

Resource [What to Do Before, During, and After the HTC Visit](#)



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# H

**Have** a conversation with your healthcare provider about yearly **inhibitor testing**.



When people with hemophilia A, hemophilia B, or von Willebrand disease (VWD) use clotting factor replacement products to treat bleeding episodes, their immune system can make inhibitors. Inhibitors are antibodies that can stop or destroy the treatment, causing your medication to no longer work. Inhibitors can happen to anyone, no matter how severe their disease is (mild, moderate, severe) or how old they are (from babies to older adults).

To learn more about inhibitors, please visit [NBDF's Inhibitor Webpage](#)



## Inhibitor Questions and Answers

**Q: I don't have an inhibitor, so does this relate to me?**

**A:** Yes, it's relevant for anyone using factor replacement products to treat bleeding episodes.

**Q: I don't usually treat with factor replacement products; do I still need an annual inhibitor test?**

**A:** If it's been over a year since your last inhibitor test, or if you've never been tested but have used factor replacement products, it's clinically recommended to get an inhibitor test.

**Q: I know my health care provider takes blood at my annual visit to run various tests. Isn't this included?**

**A:** Every Hemophilia Treatment Center (HTC) is different. Have a conversation with your health care provider to determine if inhibitor testing is included in your annual visit tests.

**Q: Isn't this only for younger kids when they first start treatment?**

**A:** No, if you are using factor replacement products, you can develop an inhibitor at any age. It's crucial to talk to your HTC about inhibitor testing.





# R

**Review** the **latest treatment options** for you.



Treatment options for people living with a bleeding disorder have improved a lot in recent years. More treatment options are currently being researched as well. Some bleeding disorders have more treatment options than others, and some are only for people of a certain age or only for specific situations. All these considerations make it important to know about the options available to you.

Learn about available treatment options for your bleeding disorder and what future therapies might be offered soon.

Discuss any additional concerns or clarifying questions with your health care provider. It's important to understand that each person may react differently to treatment, emphasizing the need to find the right fit for you. Working closely with your health care provider is essential in identifying a treatment that suits your needs,



**Here are some examples of questions you can ask when discussing treatment options with your health care provider:**

- Are there any new treatment options for my bleeding disorder? Are there any coming soon?
- How do those treatments work in the body?
- How are those treatments given?
- What are the benefits and the limitations of this treatment?



**Make sure to review your treatment plan at least once per year with your health care provider.**



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**Identify** treat, and fully heal bleeds.

## IDENTIFY:

Develop the skills to identify when you have a bleed. Talk with your health care provider about what a bleed feels like and what signs and symptoms to look for. Developing these skills will allow you to treat bleeding episodes as soon as they happen and limit further complications.

## TREAT:

Use your bleeding disorder medication promptly and as directed. Many bleeds do not require emergency medical attention, such as a bloody nose, bruises, and mouth bleeds. However, if bleeding doesn't stop or you are concerned, always call your health care provider.

Talk to your health care provider or HTC about providing you with a letter to describe your bleeding disorder and treatment, in case you need it in the future during an emergency. Don't let small problems escalate into major challenges. If something is wrong, address it sooner rather than later. Sometimes major challenges can be avoided if small problems are addressed immediately.

Learn the signs of different types of bleeds and what action you should take. If you experience deep cuts or bleeding on or in your head, eyes, neck, throat or tongue, spine, stomach, kidney, or bladder these require urgent care. If your bleeding is an emergency, first call 911, then contact your bleeding disorder health care provider or HTC, and go to the local emergency room.

## FULLY HEAL:

Ensure you have completely recovered from your bleeding episode before returning to your prior activities. It is easy to rush the recovery process, which may delay healing and can lead to additional complications. Work closely with your health care provider to assess when you are ready.

You can also support your joint health through regular physical activity and safe exercise. Strengthening your muscles and preserving your joint mobility will reduce the risk of injury and bleeding episodes as well as decrease pain. Exercising regularly will also positively impact your emotional and psychological well-being.

To learn more about physical activity and exercise visit NBDFs educational resource [Playing it Safe](#).



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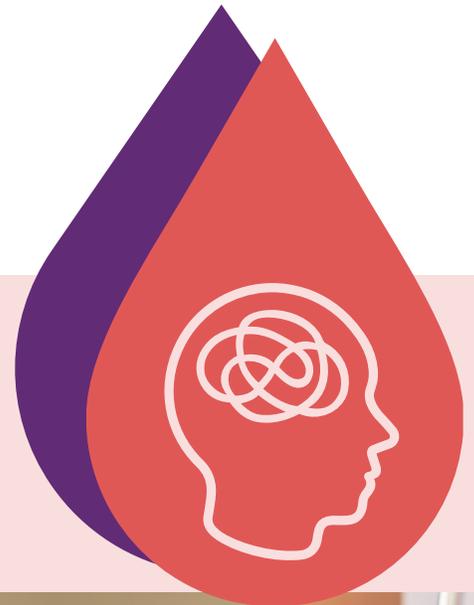


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**Value** and make time for your emotional and mental health.



Mental health is the state of your emotional, psychological, and social well-being. Your mental health affects how you think, feel, and act. It can determine how you handle stress, relate to others, and whether you make healthy choices. Positive well-being, such as having peacefulness and happiness, satisfaction with life, and fulfillment, is important at all stages of life from childhood to adolescence through adulthood.

Having a chronic condition can cause stress and anxiety. Long periods of stress due to a bleeding disorder can result in frustration, anger, and depression. This can occur to the individual with the bleeding disorder and also to their family members.

If you are experiencing poor emotional well-being, psychological well-being, or social well-being due to your bleeding disorder, talk to your primary health care provider or HTC social worker. Or seek support from other mental health professionals if needed.

Additionally, there are many resources available to people with bleeding disorders, including crisis hotlines. These can provide immediate help, especially if you or your loved one is experiencing acute distress of having thoughts of self-harm or harming others.



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# E

**Embrace** your bleeding disorders community and get involved!



There are local non-profit bleeding disorder organizations, for example NBDF Chapters, that offer programs and support for individuals with bleeding disorders all across the country. Each chapter operates uniquely, much like HTC's. These organizations are committed to improving the health and well-being of the bleeding disorders community through education, advocacy, and supporting research to make positive changes in people's lives.

Discover your local chapter organization and get involved in educational events. The National Bleeding Disorder Foundation and local chapter organizations offer diverse educational events, providing individuals affected by bleeding disorders and their support networks with opportunities to learn and connect with others in similar situations. These events feature insights from health care professionals and community members.



**Build lasting bonds and use the provided support from your community.**

Build lasting bonds and use the provided support from your community. Getting connected to other individuals with bleeding disorders can contribute positively to your emotional well-being, so you don't feel alone.

The bleeding disorders community is very unique. Attending events and volunteering your time can be extremely beneficial.

Get your kids involved in bleeding disorders camps. For parents of kids with bleeding disorders, finding enjoyable and safe activities can be a challenge. Specialized summer camps for children and teens with bleeding disorders provide a fantastic opportunity for a memorable summer experience. While each camp is slightly different, they all offer a supportive environment, education, skill development, peer connections, and increased confidence. They allow kids and teens to try new things, make lasting friends, and create special memories. Connect with your local chapter through the Chapter Directory to discover summer camp opportunities for your child.

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