

# How to Get the Most Out of Your Hemophilia Treatment Center Visit

Comprehensive care visits at your hemophilia treatment center (HTC) provide an opportunity to meet with your whole hemophilia health care team in order to address your needs and develop a treatment plan to follow throughout the year. That's why it's important to be prepared for each visit.



Not an actual health care provider.

Not an actual patient.

Part of being prepared is knowing the purpose of your visit. Is this a regularly scheduled follow-up? A lab or test day? A special appointment to review a problem? Keeping this in mind, as well as the following tips, can help ensure that you're set up for a successful appointment.

## Before Your Visit

### Track your health



It's a good idea to keep a health log in between visits to your HTC. Having a detailed record of relevant health information means that your treatment team will be able to provide the most individualized care possible. It can help to keep track of the following:

- **Bleeding episodes**, including:
  - Where on your body the bleed occurred
  - The circumstances of the bleed (be sure to note whether it was related to a certain activity)
  - How many infusions were needed to control the bleed
- **Persistent symptoms**, including:
  - When the symptom started
  - How often it occurs
  - What makes it better and what makes it worse
- **Activity level**, including:
  - Any activities you do on a regular basis
  - The intensity of your activities
  - How you infuse in order to accommodate activities



It's important to speak with your treatment team if you have questions about how to appropriately prepare for physical activity.

### Be prepared



Don't forget to bring your health log to your HTC appointment, as well as any other information that could be helpful to your treatment team, such as:

- **Written questions** with the most important ones listed first
- **Test results**
- A list of **prescription and nonprescription medications** you take, including vitamins or supplements
- **Immunization records for children**
- A list of other **health care providers** you see

Notes:

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## During Your Visit

### Be specific



**Make sure you're prepared to discuss the specifics of your health with your treatment team.**

If it makes you more comfortable, bring along someone you trust to help take notes, ask questions, or provide emotional support. Try to be as detailed as possible, and don't be afraid to speak up if you have any concerns or questions. Consider talking about:

- **Specific goals** for the appointment or for your treatment plan in general
- **Recent lifestyle changes** that may have an impact on your typical activity level
- **Any hospitalizations, surgeries, or emergency room visits** since your last appointment

Notes:

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## After Your Visit

### Follow through



**Remember to review notes, instructions, or other materials from your appointment, and take any necessary next steps as instructed by your treatment team.**

- **Make further medical appointments**, such as with a lab or a specialist, if not done at the HTC
- **Follow up on the results** of any lab tests done previously
- **Make an appointment with your HTC** if you're experiencing complications. Your treatment plan may need to be reevaluated if:
  - You are experiencing more bleeds than expected
  - You are having to infuse more than expected
  - You are having difficulties filling or taking your prescribed treatment



**Contact your HTC or seek emergency medical care in the event of a serious bleeding episode, which may include bleeding in the urinary tract, gastrointestinal tract, eye, or brain.**

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For more than 20 years, we've been standing with the hemophilia community and listening to what its members have to say. We will be standing firm and listening carefully for many years to come.

We're Listening



**Information adapted from:** Preparing for Your Comprehensive Clinic Visit. Hemophilia Federation of America. 2015.  
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