

Bleeding Disorder Patient Goals: Ages 16-18

The thought of handling your bleeding disorder by yourself may be scary. It may seem easier to let your parents continue to take care of things for you, but it is important for you to step up and take charge of your health. During this time, your family will still be there to help you when you need. Taking on more responsibility for your bleeding disorder now and learning the topics below will help prepare you to transition to adult healthcare.

Disease basics

You should:

- Understand your bleeding disorder and be able to explain it to others
- Understand the genetics of your bleeding disorder (how it can be passed on to any children you may have)
- Know the warning signs of a bleed, and when to call the Hemostasis and Thrombosis Center (HTC)
- Understand what happens if bleeds are not treated correctly, or if you have repeated bleeds in the same location
- Take part in decisions about your health

Communication

You should:

- Contact the HTC if you have an injury or bleed to talk about treatment with medication or physical therapy
- Contact the HTC during regular business hours (Monday through Friday between 8:00 AM - 5:00 PM) or send a MiChart message to request

medication refills, surgery or dental procedures, a school visit, or a travel letter.

- Know the number to contact the on-call hematologist for emergencies between 5:00 PM and 8:00 PM on weekdays, weekends, or holidays
 - Contact your primary care provider for concerns not related to bleeding
 - Know your hematologist's name, HTC team member names and roles, and contact numbers
 - Call to make your own appointments
 - Prepare questions for your healthcare appointment
 - Meet alone with medical providers during appointments and provide a detailed medical history
 - Complete all medical forms by yourself
 - Understand medical information privacy rules (like HIPAA) and the purpose of "Authorization for Release of Information" forms
 - Bring your insurance card to your appointment
 - Order your supplies and medication refills by yourself
 - Track and submit your medication logs to ATHN Robust Health
 - Know your emergency plan and wear your medical identification at all times
 - Understand disclosure practices (when and who to tell information about your bleeding disorder)
- Contact the Office of Accessibility before starting college (if applicable)

Treatment

You should:

- Know your allergies
- Know the names of your bleeding disorder medications, what they do, how much to take (your doses), and any side effects
- Understand how the severity or type of bleeding disorder affects bleeding risk and treatment timing

- Know your treatment plan and be responsible for remembering the day and time of your treatments
- Be able to do your treatments without much help
- Know how to read medication labels (for both prescription and over-the-counter medications)
- Know what medications and supplements can cause more bleeding
- Understand and use the RICE treatment (Rest, Ice, Compression, Elevation) for injuries
- Understand how physical therapy can help after a bleed

Healthy living

You should:

- Participate in school 504 plan meetings and college visits (if applicable)
- Participate in school, church, or community group activities
- Understand safety measures to prevent bleeds
- Take part in regular, safe physical activity
- Warm-up before exercising, use protective equipment (pads, helmet, shin guards) if possible, and talk with the HTC team about changing activities to make them safer
- Make healthy diet choices and understand how your weight affects joint bleeding
- Take care of your teeth by brushing and flossing daily
- Have regular dental checkups
- Understand the risks of getting tattoos and piercings
- Understand the risks of using drugs and alcohol
- Understand the risks of sexual activity

What are some good tips for support during this time?

- Talk with your family, friends, and school counselors about plans for when you finish school. Talk about how your bleeding disorder may

affect you when going to college, getting technical or vocational training, or getting a full-time job.

- Keep a treatment log to track important medical information and check that you're completing it correctly.
- Talk to your parents or guardians about your healthcare coverage. Ask questions about if you have a co-pay for appointments and how long will you be covered.
- Take on more responsibility in all areas of your life (school, chores, job, volunteering, etc.).
- Talk with the HTC team about community resources and participating in support programs.
- Be more involved in choosing and preparing healthy foods.
- Start thinking about where you can get care for your bleeding disorder when you transition to adult healthcare.

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Adapted with permission from Akron Children's Hospital Hemostasis and Thrombosis Center
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