

# Bleeding Disorder Patient Goals: Ages 19 and Older

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Now that you are an adult, your health needs and concerns are different. Adult healthcare providers are trained to address issues specific to young adults and older adults. When you transfer to adult healthcare, you should be comfortable talking with your healthcare providers about all of the topics below. Talk with the Hemostasis and Thrombosis Center (HTC) team about any topics you do not understand, so you are prepared for a smooth transition to adult care when the time comes.

## **Disease basics**

You should:

- Understand the benefits of HTCs, comprehensive care, and transferring to an adult HTC
- Understand your bleeding disorder and be able to explain it to others
- If you have an inhibitor: explain what an inhibitor is and the treatment
- Explain the genetics of your bleeding disorder (how it can be passed on to any children you may have and how that may affect them)
- Know the warning signs of a bleed and when to call the HTC
- Understand what happens when bleeds are not treated correctly or if you have repeated bleeds in the same location
- Talk about your most common bleeds and target joints (if applicable) with your treatment team

## **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)

## **Treatment**

You should:

- Know your allergies
- Know the names of your bleeding disorder medications, what they do, how much to take (your doses), when to take them, 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 your treatment schedule
- Give your treatments by yourself (without needing 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:

- Know safety measures (like RICE treatment, warming up, needed treatment, etc.) and how to prevent bleeds
- Take part in regular, safe physical activity
- Warm-up before activities, use protective equipment (pads, helmet, shin guards) if possible, and talk with the HTC team to change your activities to make them safer
- Make healthy diet choices and understand how your weight affects your joint health
- Take care of your teeth by brushing and flossing daily
- Have regular dental check-ups
- Understand the risks of getting tattoos and piercings
- Understand the risks of drug and alcohol use
- Understand practices for safe sexual activity
- Understand how bleeding disorders may affect sexual activity and monthly periods (if applicable)

## What are some good tips for support during this time?

- Keep up-to-date treatment logs to track important medical information.
- Review your healthcare coverage with your parents or guardians, employer, or college.
- Find community resources that can help you manage your bleeding disorder.
- When choosing an adult hematologist, think about things like your insurance coverage, services offered by the provider, office location, office hours, and what hospital the office is a part of to help you make your decision.

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