

Bleeding Disorder Patient Goals: Ages 13-15

Teaching your teen to become more independent is important, especially when it comes to taking care of their health. It may be hard for you to think about being less involved, because you fear they won't know how to take care of their bleeding disorder without your help. Remember that teens this age are able to handle more responsibility. They may make mistakes, but they will also learn from them. Help your teen to become more independent by working on the goals below.

Disease basics

Your teen should know:

- The name or names for their bleeding disorder, and they should be able to explain it to others
- That a bleeding disorder is inherited (passed on from parent to child)
- The warning signs of a bleed, and when to call the Hemostasis and Thrombosis Center (HTC)

Communication

Your teen should:

- Know their hematologist's name, HTC team member names, their team members' roles, and how to contact them
- Ask and answer most of the questions during their medical appointments
- Meet alone with the medical team during a part of their appointment
- Fill out medical forms with your help
- Take part in their healthcare decisions
- Have an emergency plan, and wear medical identification at all times

Treatment

Your teen should:

- Know their allergies
- Know the names of their bleeding disorder medications, what they do, what doses they take, and any side effects
- Know their treatment plan, including when and how to take medications without needing much help
- Help keep medication logs and track supplies
- 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

Your teen should:

- Know how to prevent bleeds
- Take part in school 504 plan meetings (if applicable)
- Regularly and safely take part in physical activity
- Make healthy diet choices
- Take care of their teeth by brushing and flossing daily
- Have regular dental check-ups
- Talk with the HTC team when they need help coping with their bleeding disorder

How can I support my child during this time?

- During the teen years, your child will depend on you less. Help them to become their own person.
- Friend groups become more important during their teen years and affect your teen's growth, so allow them to spend time with friends.

- Friendships and love interests also help your teen develop their identity (sense of self) and social skills. These experiences will help them become independent adults.
- Understand that teens may engage in risky behaviors because “everyone else is doing it” and they do not want to be seen as different. Talk with your teen about making good choices and avoiding activities that may cause bleeding.
- Talk with them about how alcohol, drugs and tobacco are bad for their health.
- Talk with them about ways to meet other teens with bleeding disorders, like going to camp or events for people affected by bleeding disorders.
- Be aware that growth spurts (growing a lot in a short amount of time) are common at this age, and they can cause your teen to have less muscle mass around their joints. This change can increase joint bleeding.
- Be aware that “growing pains” are common at this age, and they can be mistaken for joint bleeds. Growing pains usually happen when your child is at rest, and these pains do not affect their movement or activity. Unlike growing pains, joint bleeds cause pain with activity and may limit your child’s range of motion.
- Start talking about future plans for when your teen finishes school.
- Keep a treatment log to track your teen’s important medical information and talk about it with your teen.
- Talk about how you pay for medications and healthcare.
- Give them more responsibility and independence in other parts of their lives.
- Get them more involved in picking food and making meals.
- Teach your teen how to contact the HTC during open hours, or show them how you send a MiChart message to request medication refills, surgery or dental procedures, a school visit, or a travel letter.

- Teach your teen to contact their primary care provider (PCP) for concerns not related to bleeding.
- Learn about the Health Insurance Portability and Accountability Act (HIPAA), and talk with them about how your access to their medical information changes as they get older.

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