

Bleeding Disorder Patient Goals: Ages 11-12

Your pre-teen child is changing in many ways. As your child grows, they become less dependent on others. Give your child more responsibility as you increase their freedom. Your child should have an active role in taking charge of their bleeding disorder, and by age 11 or 12, they should be able to meet the goals listed below.

Disease basics

Your child should know:

- The name or names for their bleeding disorder
- 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)
- What the HTC is, why they go there, who the different HTC team members are, and what they do

Communication

Your child should:

- Know the name of the HTC and how to contact us
- Ask and answer some questions during healthcare appointments
- Take part in their healthcare decisions
- Know who to ask for help (besides their parents) in an emergency
- Wear medical identification at all times
- Know when and who to tell about their bleeding disorder

Treatment

Your child should:

- Know their allergies
- Know the names of their bleeding disorder medications
- Start learning to take bleeding disorder medications by themselves
- Help update 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

Healthy living

Your child 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 social worker when they need help coping with their bleeding disorder

How can I support my child during this time?

- Watch for bullying. Children with health issues are at higher risk for being bullied.
- Keep a treatment log to track your child's important health information.
- Give them more responsibility and freedom in other areas of their lives, like letting them choose their clothing, food, music, etc.
- Encourage them to take part in camps and programs.
- Get them more involved in picking healthy foods and making meals.

- Talk about how alcohol, drugs, and tobacco can cause harm to their health.
- Your child may notice that they may not be able to do the same activities as their siblings. Talk with them about how all kids are different.
- 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.
- Talk about puberty and let your child know the changes they are having are normal.
- Talk with them about how you 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 them why you contact their primary care provider (instead of HTC) for concerns not related to bleeding.

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