

SUPER SEVEN



A Discussion Guide
for Parents and Caregivers



A Resource
for Rares



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Super Seven Discussion Guide for Parents & Caregivers

People with bleeding disorders and their family members are the center of the work of the National Hemophilia Foundation. We support research that has a measurable impact on people's lives; deliver education that helps people with bleeding disorders and their family members thrive; and advocate for policies at the state and local level that protects access to healthcare.

The National Hemophilia Foundation (NHF) would like to express its appreciation to Nikole Scappe and Beth Marshall for the content development and the Rare Working Group members for their commitment to those with rare bleeding disorders, insights and review.

Rare Working Group Members:

Barbara Forss
Mohammad Hazama
Carlisa Magee
Jim Munn, MS, BS, BSN, RN-BC
Amy D. Shapiro, MD
Makenzie Sledd, MPT

This publication is supported by a grant from the American Legion Child Welfare Foundation, Inc. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the American Legion Child Welfare Foundation.

American Legion
Child Welfare Foundation



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

This booklet is intended for informational purposes only. It is not intended to be used to make healthcare coverage or treatment determinations. NHF's Medical and Scientific Advisory Council (MASAC) recommends that the product and corresponding treatment regimen used by an individual should remain a decision between patient and physician.

© 2020 National Hemophilia Foundation. Material in this publication may not be reproduced without express permission from the National Hemophilia Foundation.

Foreword

What is a rare bleeding disorder?

Most bleeding disorders are rare and the lived experience of those with rare conditions can have many things in common. However, in an effort to better serve the rarest of the rare, who often get overlooked for resources and information about their bleeding disorder, NHF has created this guide for them. This guide is a companion piece to the book *Super Seven* which is intended to offer insight and education to those with rare bleeding disorders. This companion guide offers follow-up discussion starters. We encourage you to use this with your child to initiate conversations and explore your child's thoughts and feelings about some of the story's themes.

Some rare bleeding disorders such as factor X (10) deficiency or factor XIII (13) deficiency are as rare as 1 in 1 million and 1 in 5 million respectively. Whether your child has a rare factor deficiency such as I (1), II (2), V (5), VII (7), X (10), XI (11), XII (12), XIII (13), or a rare platelet disorder such as Bernard-Soulier syndrome, Glanzmann's thrombasthenia, or platelet storage pool disease, this companion guide is for you! NHF also encourages those with slightly more common bleeding disorders, such as hemophilia or von Willebrand disease, to also enjoy this companion guide and find where there is common ground as a bleeding disorders community.

We hope you find this resource helpful as you navigate your way through living well with a rare bleeding disorder.





Super Seven Discussion Guide for Parents & Caregivers

In the book *Super Seven*, Tanner, a 12-year-old with a rare bleeding disorder, discovers that even though he is sidetracked by an unexpected injury, he is still an important member of his middle-school basketball team. We hope you and your child enjoy reading the story and having conversations about it.

Let's Chat

Super Seven raises many questions around navigating life with a bleeding disorder. Why is it important for kids to be responsible for their own infusion? Why is it important kids understand the responsibility of having a bleeding disorder and why they can and can't do certain activities? As parents or caregivers, what is your role in ensuring kids make smart decisions about their activities?

This guide offers follow-up discussion starters. We encourage you to use them with your child to initiate conversations and explore your child's thoughts and feelings about some of the story's themes, which include taking responsibility, disclosure, and independence. There is no "one-size-fits-all" answer to these questions, however communicating openly about these issues can help you and your children share information and better understand each other's perspectives.

This guide also includes "talk-back" prompts. You can use them to reinforce your child's knowledge of his or her bleeding disorder and some of the common situations that may arise as a result of it. Having children explain in their own words how they would handle a situation is an opportunity for you both to assess if their understanding is complete and for you to provide more instructions or tips, if needed.

Talk Back Prompts





Tips for Discussions (Preparations and During)

These tips can help make your discussions more comfortable:

Feeling confident about the subject matter will make these conversations easier. You can prepare for conversations, especially ones you initiate on specific topics, by:

1. Researching to learn the facts. There is a list of resources at the end of this piece.



2. Speaking privately with your child's healthcare provider to get answers to your questions and advice on how to approach discussing specific topics with your child.

3. Knowing you don't have to be the "expert" to be a support for your child. If you don't know the answer to a question, that is ok and expected! Come up with ways where you can get answers together, by talking to their healthcare provider or researching together.

4. Create a safe space in which your child can ask questions and share their feelings. Listen. Pause and reflect before responding.

5. Listen with compassion. You, your child's caregiver, know how difficult it can be to live with a rare bleeding disorder. Help your child feel they can speak to you honestly about their feelings and their thoughts. Sometimes your child may want you as a sounding board; sometimes they may want your more active help. It can be difficult to know the difference. If you're uncertain, ask. Let them guide you.



6. Help your child voice their questions. If your child is asking rhetorical questions, be accepting. If it feels appropriate, encourage them to explore their thoughts more deeply. If your child is asking non-rhetorical questions, try your best to answer each one. If you don't.

know the answer to a question, suggest finding the answer together. Be mindful that putting it off or deflecting could send a message that the child's question was not okay to ask or is not important enough to talk about.

7. Validate your child's feelings. If your child expresses anger or frustration about the realities of living with a rare bleeding disorder, you should encourage them to talk about these feelings and how to manage them, rather than shame, dismiss or rebuke your child for having the feelings.



8. If your child doesn't respond well to a conversation you're sharing, or seems uncomfortable with it, give them time to process the concept and their feelings. Remind them it's okay if they don't want to talk about it now, but suggest you'll be available when they do. If they don't return to the conversation later, decide if it is one you need to revisit and, if so, find the best time to initiate resuming the conversation.



9. Research to find children's or middle-grade books, nonfiction or fiction, about children living with various kinds of differences, including illnesses and, if possible, bleeding disorders. Share these with your child. Ensure you read the book as well; if possible, read it together. Discuss it together afterwards.



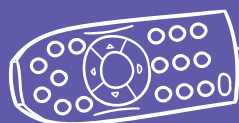


Discussion Starters After Reading Super Seven



1. Tanner has to tell Jax and his parents about his bleeding disorder so they can have a sleepover, but he doesn't tell any of his friends on his team. What do you think about that? Are there some people you don't tell about your bleeding disorder? Why not?

2. Have you even been in a situation where you want to participate in an activity, but your body can't? How does that make you feel?



3. Tanner gets mad at Victoria and blames her when he has a bleed. Have you ever blamed someone for getting a bleed? How did you handle it?



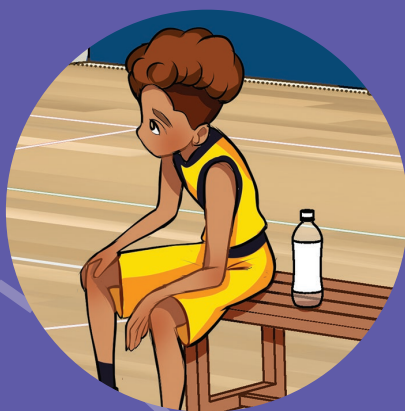
4. In the story Tanner's school nurse asks him about his bleeding disorder and what a bleed feels like. Have you ever explained your bleeding disorder to an adult? To anyone?

5. Talk Back

“Let's say you needed to explain to someone what a bleeding disorder is. How would you explain it?”

6. Tanner feels lonely sometimes because he feels like no one has the bleeding disorder he has. Do you ever feel like that?

7. Did you ever have to sit out of a gym class or a team practice because you had a bleed? How did you talk to your coach or teacher about it?



8. Talk Back



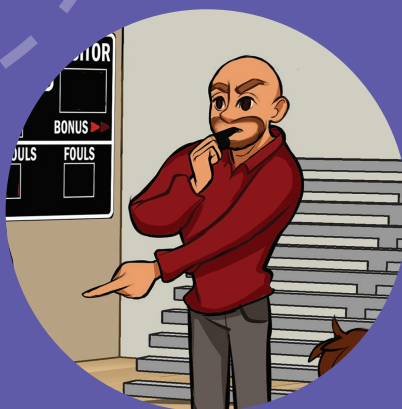
“Let’s say I’m your teacher and you wanted to tell me that you had a bleed yesterday. What’s the first thing you would say?”

9. Tanner is upset he can’t play because of his ankle bleed. Have you ever had to sit out of something you didn’t want to? How did that make you feel?

10. Tanner didn’t play in the championship game but still feels that he helped them win. How did he do this?



11. Describe how Tanner finally made the decision to talk to Coach Velasco about his injury and what happened next. Would you have done the same?



12. Can you talk with me about a time you had to make a difficult decision because of your rare bleeding disorder?

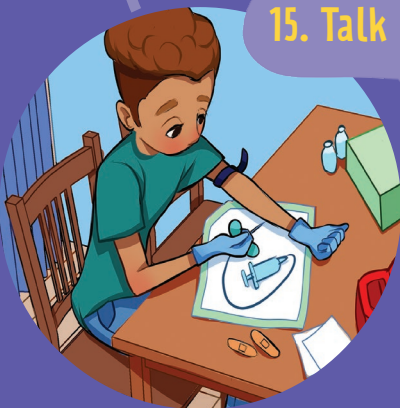
13. How do you think Tanner might feel after spending a week at the bleeding disorders summer camp?

14. Talk Back

“Imagine you were in school and felt like you had a bleed. Tell me all the things you would do when you realized it was happening.”



15. Talk Back



What did you think about the picture of Tanner infusing? Can you tell me the steps we do when you need to infuse?

Additional Resources

Steps for Living

This life stages education resource has age appropriate tips and tools for everyone. Created by healthcare professionals, parents, and patients from the bleeding disorders community, the Steps for Living website provides information and resources to help you and your family adjust to life as your child with a bleeding disorder grows and matures.

- www.stepsforliving.hemophilia.org

Hemophilia.org

NHF's website can provide information, resources, and help you connect with your local hemophilia treatment center (HTC) and chapter.

Rare Educational Programs

NHF offers unique educational programs for individuals and families affected by rare bleeding disorders. To learn more about our upcoming events please visit the link below.

- www.hemophilia.org/educational-programs/education/rare-bleeding-disorders

The Rare Coagulation Disorders Resource Room

This is a resource created for healthcare providers. Individuals and families affected by rare bleeding disorders can utilize this information to help guide discussions regarding shared decision-making with their healthcare providers.

- www.rarecoagulationdisorders.org

Other Organizations with Rare Information

These organizations offer a variety of programming and resources for those affected by rare bleeding disorders along with their support network. For more information about these organizations please visit their pages by using the links below.

- NORD (National Organization for Rare Disorders) - rarediseases.org
- HFA (Hemophilia Federation of America) - hemophiliafed.org
- CHES (Comprehensive Health Education Services) - ches.education



Do you have questions about living with a rare bleeding disorder?
Please contact HANDI, NHF's information resource center:

- Call 1-800-42-HANDI
- Email handi@hemophilia.org
- Submit a request for information form via the "Contact Us" section of the NHF website



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

www.hemophilia.org