

Ages 9-12

Guidelines for **Growing:**

An action plan for parents
of children with bleeding disorders



9 through 12 years of age



**Centers for Disease
Control and Prevention**
National Center on
Birth Defects and
Developmental Disabilities



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

9 through 12 years of age

Children with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their health. As a parent of a child with a bleeding disorder, it is important for you to be aware of what you can do to help your child as he or she moves through his or her life stages. This is the third age-specific brochure in the *Guidelines for Growing* series, adapted from the National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council* (MASAC) Transition Guidelines. Each brochure focuses on important milestones of your child's development as they relate to his or her bleeding disorder. This resource is designed to be used along with your hemophilia treatment center (HTC) provider team to guide you as you help your child grow and develop.

1. Social Support and Resources

- ✓ Attend local and national events for people in the bleeding disorders community throughout the year. Attending these events with your child will help you and your child connect with others and get the support you need. Ask your HTC team and local bleeding disorders organization about programs, group sessions, and social activities with other families affected by bleeding disorders. Search for your local HTC on the Centers for Disease Control and Prevention (CDC) Web site (www.cdc.gov/ncbddd/hemophilia/HTC.html).

For a list of local NHF chapters and other bleeding disorders organizations, as well as a list of national events and their locations, visit the NHF Web site: **www.hemophilia.org**.

- ✔ Explore opportunities for socializing within your community. Activities offered by your local recreational center or YMCA, parks department, or various clubs and community centers will give your child the chance to create a network of friends.
- ✔ Various resources are available on NHF's Web site (**www.stepsforliving.hemophilia.org**) or you can contact HANDI, NHF's information resource center (**1-800-42-HANDI** or **handi@hemophilia.org**), to speak to an information specialist about publications and brochures. You also can visit *HemAware*, NHF's bleeding disorders magazine at **www.hemaware.org**. Check with your HTC or local bleeding disorder organization to obtain other resources.



2. Health and Lifestyle

- ✓ Discuss the importance of sports and exercise with members of your child's HTC team. They will be able to help your child choose activities that are safe and beneficial for his or her physical and emotional well-being. Review with your child the NHF brochure "Playing It Safe: Bleeding Disorders, Sports, and Exercise", available through HANDI.
- ✓ Help your child develop his or her own sense of right and wrong. Be positive and focus on increasing good and healthy behaviors when disciplining your child. Discuss positive discipline and stress management with your HTC social worker.
- ✓ Tell your child how important it is that he or she understands his or her bleeding disorder. Explain how your child's bleeding disorder might affect his or her friendships. Meet the families of your child's friends and make sure they understand what to do if your child experiences a bleeding episode during a play date, party or other activity.
- ✓ Have an open discussion with your child about any peer pressure he or she might be feeling, especially as it relates to the use of alcohol, tobacco or drugs, and to sexual conduct. Help your child understand that taking part in high-risk behaviors can increase his or her risk for serious health problems because of his or her bleeding disorder. Role play with your child what to do and say in an uncomfortable situation so your child will know how to handle himself or herself if a situation does occur.

- ✓ Discuss with your child why it is important to wear his or her medical alert identification tags or emblems at all times. HANDI, your HTC team, and local bleeding disorder organizations can provide you with information about these medical alert programs.
- ✓ Be affectionate and honest with all of your children and do things together as a family. Be aware of the range of emotions that your child's siblings who do not have a bleeding disorder might be experiencing, from positive feelings of compassion to more challenging feelings of jealousy and anger. Carve out some special one-on-one time with all of your children.

3. Educational Planning

- ✓ Be involved with your child's school. Go to school events; meet your child's teachers.
- ✓ Develop a 504 plan with your child's school district. Under the Rehabilitation Act of 1973, the 504 plan provides accommodations for students who need them, such as an extra set of books for home use and restricted physical education participation. Visit the Steps for Living Web site (www.stepsforliving.hemophilia.org) for more information or talk with someone in your local bleeding disorder organization or on your HTC team.
- ✓ Continue to educate school administration, classroom teachers, and other staff so they are aware of your child's condition and any recent changes in his or her health care. Contact local bleeding disorder organization or your HTC team if you would like someone to speak with the school personnel. Discuss whom your child should notify of his or her condition and when to do so.

- ✔ Talk with your child about his or her favorite subjects in school, plans for high school, and ideas for careers. Help your child set goals. Encourage him or her to think about skills and abilities he or she would like to have and about how to develop them. Encourage your child to visit a school guidance counselor.

4. Self-Advocacy and Self-Esteem

Encourage Your Child To Express Medical and Physical Needs

- ✔ Your child should be able to tell when he or she has a bleed, and report pain or symptoms as soon as possible. Openly discuss signs, symptoms and treatments to help him or her gain a better understanding of his or her bleeding disorder.
- ✔ Encourage your child to treat bleeds right away by having factor readily available, such as storing factor in a refrigerator at school. Discuss with your child any awkward treatment-related situations that might arise at school or during other activities (such as when participating in sports) and how to handle them.
- ✔ Understand the importance of your child speaking for himself or herself when he or she meets with his or her medical providers. Encourage him or her to keep a journal of questions or issues to discuss with his or her health care team.

- ✓ Talk with members of your HTC team and local bleeding disorder organization about the benefits of your child attending camp for children with a bleeding disorder. Visit www.hemaware.org for more information and articles about camp.

Understand Rights and Responsibilities for Your Child's Health Care

- ✓ Learn what insurance options are available for your family. Some states have insurance programs for eligible children with chronic medical needs. If you already have health insurance, make sure you understand what services and treatments are covered and whether there are limits on coverage. Contact HANDI or your local bleeding disorder organization to request educational materials on health coverage.
- ✓ Learn about patient rights and responsibilities. Ask for NHF's patient bill of rights, available through HANDI.



- ✓ Learn about confidentiality laws related to health care, such as the Health Insurance Portability and Accountability Act (HIPAA). Research HIPAA information on the U.S. Department of Health and Human Services Web site (www.hhs.gov). Keep your own set of medical records with clinic summaries, and laboratory and imaging reports.

5. Sexual Health

- ✓ Talk with a member of your HTC team about how puberty will affect your child and your child's bleeding disorder. If you need help talking about sexual health with your child, discuss your options with a member of your HTC team.

6. Independent Health Care Behaviors

- ✓ Ensure that your child knows the signs and symptoms of a bleed. Make certain that he or she knows who to call in the event of a bleed and has the contact information readily available.
- ✓ Keep a list of important telephone numbers for emergencies. Include contact information for your pediatrician, HTC, factor provider, home health nurse and local emergency room. Make sure it is in a place that is easy to access and your child and other family members know where to find it.

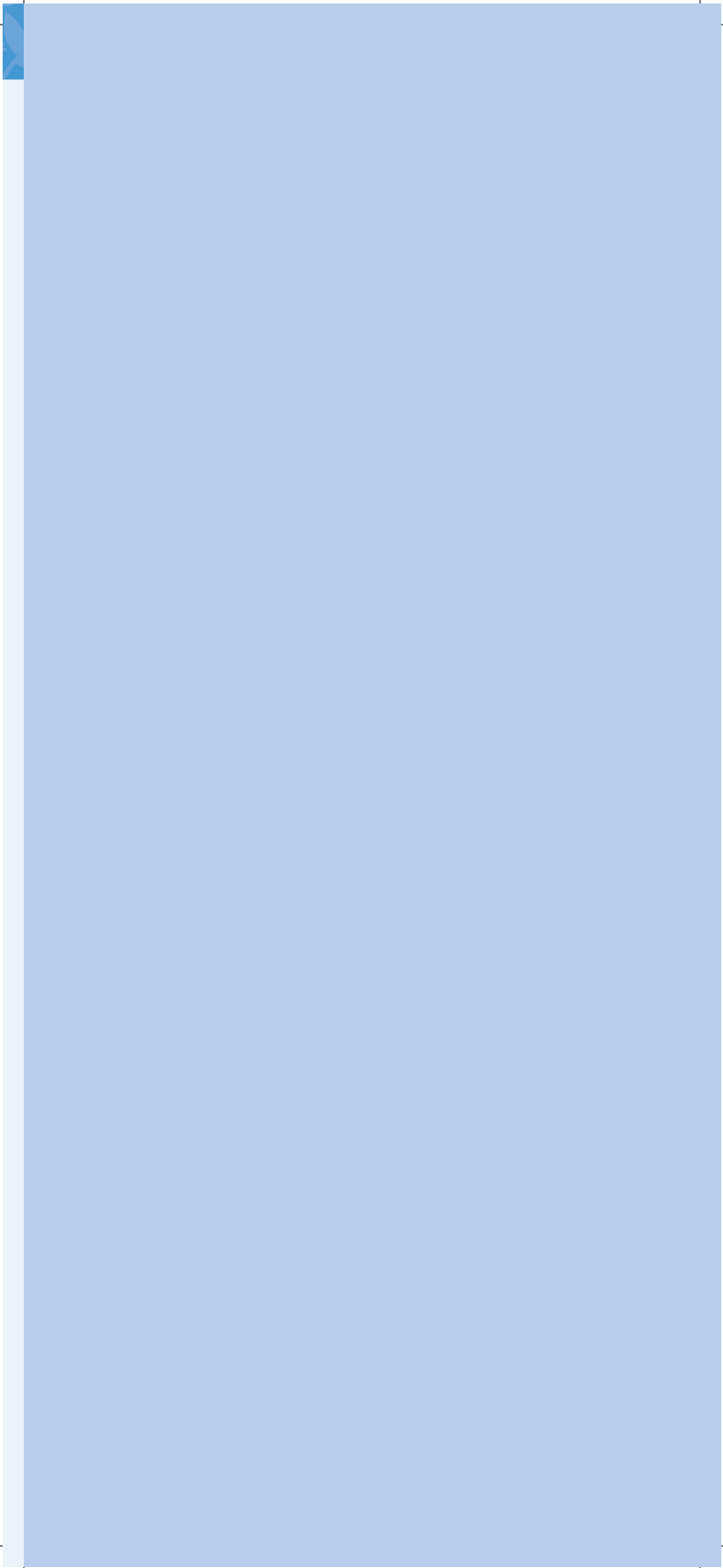
- ✔ Encourage your child to become involved in record keeping, tracking medications and supplies, and communicating with his or her health care providers.
- ✔ Involve your child in discussions with the HTC team about his or her treatment plan. Your child should review with his or her HTC team which therapy is best for him or her at this time, (on-demand therapy, prophylaxis, or activity-related prophylaxis), including switching from a central venous access device (CVAD) to venipuncture (placing the needle in a vein), if applicable.
- ✔ Teach your child about the universal precautions recommended for all people handling clotting factor infusion equipment. Practice good handwashing before and after administering factor. Gloves should be worn when preparing or infusing products, and during disposal of clotting factor infusion equipment and waste. A needle that has broken the skin should not be reused; used needles should never be recapped. Used needles should be placed in a sharps container out of reach of young children.
- ✔ Help your child to understand when he or she needs to go to the emergency room (ER). Remember to always call your HTC before you head to the ER so staff can notify medical personnel there of your arrival. Insist that ER staff contact your HTC if they have questions about your child's treatment plan.

Supporting Your Child's Active Life

- ✓ Urge your child to take part in fitness activities offered through school or community centers. Your HTC physical therapist can recommend safe sports or ways to modify activities so your child can fully participate, as well as any home exercises or physical therapy that might be needed.
- ✓ Help your child to understand that regular exercise can prevent or reduce complications of his or her bleeding disorder. Review with your child the NHF brochure, "Playing It Safe" and discover what activities interest him or her.

Understand the Genetics of Your Child's Bleeding Disorder

- ✓ Speak with your child about why he or she has a bleeding disorder or ask for help from a genetic counselor or other HTC team member. Find out if other family members might benefit from being tested to see if they are carriers or could be affected by a bleeding disorder.
- ✓ If you have signs or symptoms of a bleeding disorder, get checked by an adult hematologist. Ask someone from your HTC team for a referral.



The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy, and research. Its programs and initiatives are made possible through the generosity of individuals, corporations, and foundations, as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

The contents of this brochure are the sole responsibility of the authors and do not necessarily represent the official views of the CDC and other NHF funders.

The information contained in this publication is provided for your general information only. It is not intended as a substitute for visiting with your physician, nurse, or social worker. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

For more information or for help, please contact HANDI, NHF's informational resource center at **800.42.HANDI/800.424.2634** or e-mail **handi@hemophilia.org** or go to: **www.stepsforliving.hemophilia.org**.

Additional parenting resources can be found online: **www.cdc.gov/parents**.

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