

Birth-4

Guidelines for **Growing:**

An action plan for parents
of children with bleeding disorders



Birth through 4 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

Birth through 4 years of age

Young children with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their bleeding disorders. 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 transitions through his or her life stages. This is the first 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 in conjunction 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 within the bleeding disorders community throughout the year. Attending these events with your child will help you connect with others and get the support you need. Ask your HTC team or local bleeding disorders organization about programs, group sessions, and social activities with other parents of children with bleeding disorders. For a list of NHF chapters and other local bleeding disorders organizations, as well as a list of national events and their locations, visit the NHF Web site at www.hemophilia.org.
- ✓ Request resources from your HTC team or NHF chapter. Visit NHF's Steps for Living

Web site at www.stepsforliving.hemophilia.org or contact HANDI, NHF's information resource center (1.800.42.HANDI/1.800.424.2634) to speak to an information specialist about publications and brochures. Also visit www.hemaware.org to find NHF's bleeding disorders magazine available online.

- ✓ Search for your local HTC on the Centers for Disease Control and Prevention (CDC) Web site (www.cdc.gov/ncbddd/hemophilia/HTC.html). Search for your local NHF chapter on the NHF Web site (www.hemophilia.org).

2. Health and Lifestyle

- ✓ Implement safety measures in your home and vehicle(s). Ask members of your HTC team or local bleeding disorders organization about child-proofing your home, proper car seat use, emergency preparedness checklists and other safety measures.
- ✓ Discuss the use of safety gear (padded helmets and knee and elbow pads) with your HTC team. Buy or borrow the recommended items.



- ✓ Discuss infant and toddler oral health with your HTC team. Ask for a list of dentists familiar with treating people with bleeding disorders.
- ✓ Be positive. Stress your child's abilities, not disabilities, both with your child and with others with whom your child will interact.
- ✓ Protect your child with medical alert identification tags or emblems. That way, your child's bleeding disorder and emergency contact information can be identified in the event that the child is not able to speak for himself or herself, or is not old enough to explain. Your HTC team, NHF chapter members and HANDI can provide you with information about these programs.

3. Educational Planning

- ✓ Explore available day care, child care and preschool options in your community. Interview providers carefully using "The Child With A Bleeding Disorder: Guidelines For Finding Childcare", an NHF brochure available from your HTC, NHF chapter or HANDI.

4. Self-Advocacy and Self-Esteem

Express Medical and Physical Needs

- ✓ Explain the need for clotting factor infusions positively to your child and others. Avoid making your child feel that clotting factor infusions are a punishment for his or her behavior.
- ✓ Teach your child to recognize and report pain or symptoms of a bleed as soon as possible.

- ✓ Ask your HTC, NHF chapter or HANDI for age-appropriate books and other materials for your child about living with a bleeding disorder.

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 your local NHF chapter and HANDI to request educational materials on health coverage.
- ✓ Learn about patient rights and responsibilities. Ask for the NHF 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). Consider keeping your own set of your child's medical records with clinic summaries and laboratory and imaging reports.

5. Independent Health Care Behaviors

Participate in Treatments and Decision Making

- ✓ Discuss signs and symptoms of bleeding with your HTC team. Learn to assess your child for bleeding problems and determine what treatment or medical attention is required.
- ✓ Learn about treatment products so that you can make informed decisions together with your HTC team.

- ✓ Begin to learn the steps of treating bleeds (i.e., mixing factor).
- ✓ Learn about options for administering factor into a vein. Discuss these with your HTC team.
- ✓ Speak with your HTC team about treatment options, such as on-demand therapy (treating with clotting factor at the time of a bleeding episode), prophylaxis (regularly scheduled clotting factor treatment), and activity-related prophylaxis (treating before an activity to prevent bleeding). Become an informed consumer.
- ✓ Discuss with your HTC team the universal precautions recommended for all people handling clotting factor infusion equipment. Gloves should be worn by people who prepare or infuse 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 in a location inaccessible to young children.

Keep Records and Communicate With Health Care Providers

- ✓ 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 that your child and other family members know where to find it.
- ✓ Obtain and maintain copies of letters from your HTC specifying your child's diagnosis and treatment protocol.

- ✓ Always call your HTC before you head to an emergency room so they can notify the medical personnel of your arrival. Do not be intimidated by emergency room personnel. Insist that they contact your HTC if you question their treatment plan.
- ✓ Learn about options, either electronic or paper, for keeping your child's treatment log.
- ✓ Be sure to call your HTC if you have any questions, especially during the first few years. Write down any questions so that you can ask your HTC team during your child's next visit.

Begin Planning for Your Child's Active Life

- ✓ Learn about expected developmental stages for infants and toddlers. Plan ahead for safety and other adaptations or protective steps that might be necessary for your child. These can help prevent falls and bumps when your child is learning to walk and becoming more active.
- ✓ Begin to plan for your child's active life. Become familiar with NHF's "Playing it Safe" booklet. Consider swim lessons and other "parent and me" opportunities.

Understand the Genetics of Your Child's Bleeding Disorder

- ✓ Learn about the genetics of your child's bleeding disorder by talking with a genetic counselor or other HTC team staff. Evaluate whether other family members could benefit from being tested to determine if they are carriers or could be affected by a bleeding disorder.

If you have signs or symptoms of a bleeding disorder, consider getting checked by an adult hematologist. Ask 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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