

Ages 16-18

Guidelines for **Growing:**

An action plan for teens
with bleeding disorders



16 through 18 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

16 through 18 years of age

Teenagers with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their bleeding disorders. As a teenager, it is important for you to be aware of the things that will help you begin to live independently. This is the fifth 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 development as it relates to your bleeding disorder. This resource is designed to be used along with help from your hemophilia treatment center (HTC) provider team to guide you as you grow older and become more independent. Below are some suggestions for what you can do to more effectively manage your personal development.

1. Social Support and Resources

- ✓ Attend local and national events for people in the bleeding disorders community throughout the year. Attend youth-specific events to connect with others and get the support you need as your needs change. Ask your HTC team and NHF chapter or local bleeding disorders organization about programs, group sessions, and social activities with other teens with 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 disorder organizations, as well as a list of national events and their locations, visit the NHF Web site at www.hemophilia.org.

- ✓ Explore opportunities for group activities within your community. After school and extracurricular activities offered by your school, local recreational center or YMCA, parks department, or various clubs and community centers will give you the chance to meet new people and make friends.
- ✓ Various resources are available on NHF's Steps for Living Web site (www.stepsforliving.hemophilia.org) or contact HANDI, NHF's information resource center (**1.800.42.HANDI / 1.800.424.2634**) to speak with an information specialist about publications and brochures. Also, visit www.hemaware.org, NHF's bleeding disorders magazine available online. Check with your HTC or local bleeding disorder organization to obtain resources.



2. Health and Lifestyle

- ✓ Discuss the importance of sports and exercise with members of your HTC team. They will be able to help you choose activities that are safe and beneficial for you physically and emotionally. They also can help you adapt activities so you can fully participate. Review the NHF brochure "Playing it Safe: Bleeding Disorders, Sports, and Exercise", available through HANDI.
- ✓ Know how to care for bleeds and the consequences of not caring for bleeds appropriately, such as long-term joint damage.
- ✓ Understand how your bleeding disorder can affect body image. Discuss any concerns you have with a parent, the social worker at your HTC or other trusted adult.
- ✓ Discuss with a trusted adult any peer pressure that you might be feeling, especially as it relates to alcohol, tobacco, or drug use, or sexual conduct. Understand that practicing these high-risk behaviors can increase your risk for serious health problems because of your bleeding disorder. Practice what to do and say in an uncomfortable situation so you will know how to handle yourself if such a situation does occur.
- ✓ Discuss with your HTC staff long-term health plans, including following your treatment plan, having factor on hand at all times, and moving from pediatric care to adult care (for example, how that will change treatment, staff relationships, and confidentiality issues).

3. Educational Planning

- ✓ Think about jobs and careers that might interest you and that are compatible with your condition. Consider how your bleeding disorder could affect your career choice. For example, you might want to consider avoiding work that puts stress on your joints or jobs that place you at higher risk of injury. Speak with a school guidance or career counselor to further explore your interests and choices, and the education that is needed. Begin to pursue those careers. Begin volunteering, summer jobs, and extracurricular courses that further your interests and potential career choices.
- ✓ Explore your post-secondary school choices in relation to how such a choice might affect your health care and insurance.
- ✓ Discuss with a school counselor appropriate course work, vocational training or other opportunities that will assist in career choices.
- ✓ Begin learning about and researching insurance options for your future plans. Find out how your career or job choice could affect your insurance options. Explore the insurance alternatives available in your state or local area.
- ✓ Learn what your rights are with employers regarding work-related adaptations you might be entitled to. Find out what your rights are regarding disclosure, insurance and other issues with different employers.

4. Self-Advocacy and Self-Esteem

Express Medical and Physical Needs

- ✓ You should be able to identify the signs and symptoms of a bleed, report pain and symptoms to your health care provider as soon as possible, and be able to begin treatment of most bleeds on your own. Openly discuss signs, symptoms and treatments with your health care provider to make sure you understand how to manage your bleeding disorder.
- ✓ Make it a habit to treat bleeds promptly by having factor readily available, such as in a refrigerator at school or at friends' houses. Discuss with members of your HTC team and/or your parents, any awkward treatment-related situations that might arise due to and during treatment, especially at school or during other activities (for example, sports) and how you can handle them.
- ✓ Understand why it is important for you to speak for yourself when you meet with your medical providers. Keep a journal of questions or issues to discuss with your health care team to ensure that your needs are being met. Discuss with your health care team what will be expected of you as you mature and how your role and the role of your health care providers will change as you move from pediatric care to adult care.



Understand Rights and Responsibilities for Your Health Care

- ✓ Learn what insurance options are available for you. 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 a local bleeding disorders 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). HIPAA protects your individually identifiable health information and sets national standards for the security of electronically protected health information. Research HIPAA information on the U.S. Department of Health and Human Services Web site (www.hhs.gov). Consider keeping your own set of medical records with clinic summaries and laboratory and imaging reports.

5. Sexual Health

- ✓ Talk with your HTC team about how puberty will affect you and your bleeding disorder. Understand how your bleeding disorder will affect your sexual health (groin bleeds, menstruation, sexually transmitted diseases and joint bleeds). Know about such issues as contraception, pregnancy, sexual identity and your rights as a sexual person. Discuss your concerns about changes that are taking place with you physically and emotionally.
- ✓ Determine your stance on physical intimacy and avoid making decisions under pressure. Understand and practice abstinence or safe sex.
- ✓ Know how and where to access sexual health services if needed, such as how to prevent unwanted pregnancies or how to ensure you are having safe sex.

6. Independent Health Care Behaviors

- ✓ 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 easy to access and your family knows where to find it.

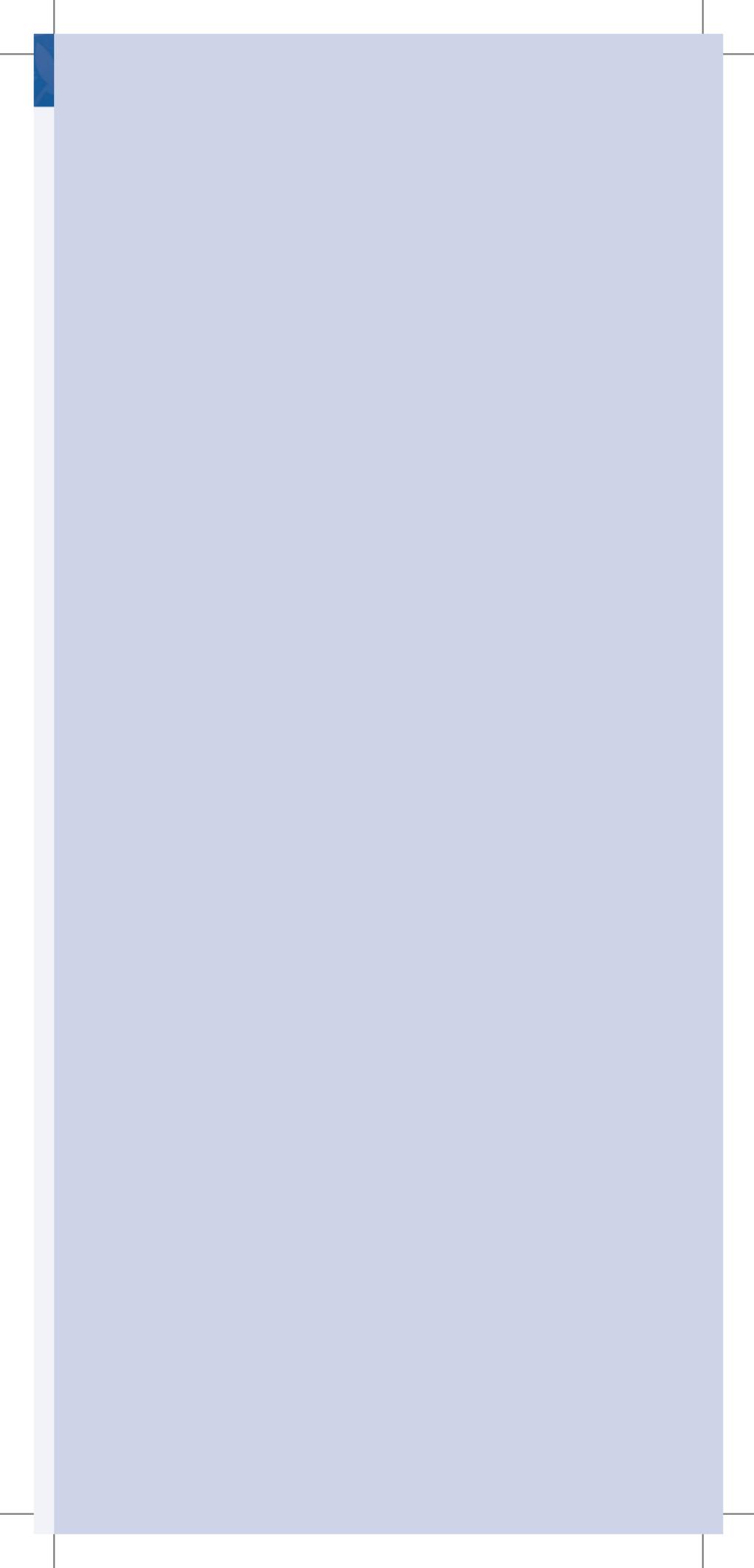
- ✓ Begin to manage your own record keeping, order your own medications and supplies, track your bleeds (including menstrual periods), and communicate directly with your health care providers about any complications or problems.
- ✓ Discuss your treatment plan with your HTC team. Together, you should review which therapy is best for you at this time (on-demand therapy, prophylaxis, or activity-related prophylaxis), including beginning venipuncture and self-infusion, if applicable. Know why it is vital to follow your treatment plan during this stage of your life. Discuss any complications you might have with your health care team.
- ✓ Know and practice the universal precautions recommended for all people handling clotting factor infusion equipment. Practice good hand washing techniques 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 the reach of young children.
- ✓ Learn when to visit the emergency room (ER). Remember always to call your HTC team before you head to the ER so they can notify medical personnel of your arrival. Insist that emergency room staff contact your HTC if they have questions about your treatment plan.

Maintain an Active Life

- ✓ 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 you can participate fully. Understand the importance of starting or continuing on a regular basis home exercise or physical therapy.
- ✓ Know why and how exercise can prevent or reduce complications of your bleeding disorder. Find physical activities that you like to do; continue them on a regular basis.

Understand the Genetics of Your Bleeding Disorder

- ✓ Understand the genetics of your bleeding disorder and if you can pass it on to your children. See whether other family members might benefit from being tested to find out if they are carriers or could be affected by a bleeding disorder.



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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