

Ages 13-15

# Guidelines for **Growing:**

An action plan for teens  
with bleeding disorders



13 through 15 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*

# 13 through 15 years of age

Teenagers with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and strive for independence while learning to manage their health. As a teen with a bleeding disorder, it is important for you to be aware of the things that will help you begin to live independently and manage your own bleeding disorder. This is the fourth 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 development as they relate to your bleeding disorder. This resource is designed to be used along with your hemophilia treatment center (HTC) provider team to guide you as you grow and develop. Following are some suggestions for what you can do to more effectively manage your bleeding disorder.

## 1. Social Support

- ✓ Attend local and national events for people in the bleeding disorders community throughout the year. Attending these events will help you connect with others and get the support you need. Ask your HTC and local bleeding disorders organization about programs, group sessions and social activities with others affected by bleeding disorders.
- ✓ Connect with others who share similar life experiences at camps designed for youth with bleeding disorders.
- ✓ Explore opportunities for socializing within your community. Extracurricular activities offered by your school, local recreational center or YMCA, parks department, or various clubs and community centers

will give you a chance to create a network of friends.

- ✓ Contact HANDI, NHF's information resource center, to find your local bleeding disorder organization or search the NHF Web site ([www.hemophilia.org](http://www.hemophilia.org)). Search for your local HTC on the Centers for Disease Control and Prevention (CDC) Web site ([www.cdc.gov/ncbddd/hemophilia/HTC.html](http://www.cdc.gov/ncbddd/hemophilia/HTC.html)).

## 2. Health and Lifestyle

- ✓ Discuss the importance of sports and exercise with members of your HTC team. They will be able to help you select safe activities that are good for your physical and emotional well-being. Review NHF's brochure, "Playing it Safe: Bleeding Disorders, Sports, and Exercise", available through HANDI.
- ✓ Learn as much as you can about your bleeding disorder. Discuss with a parent or the social worker at your HTC any concerns about how your bleeding disorder might affect your life and friendships.



- ✓ Teenage years are socially difficult times for any youth. Talk with your parents or a social worker at your HTC to understand how your bleeding disorder might affect your body image and self-esteem. Tell your parents how you feel. They want to help.
- ✓ Have an open discussion with your parents or a school counselor about any peer pressure you might be feeling, especially as it relates to alcohol, tobacco, drugs and sexual conduct. Understand that practicing any of these high-risk behaviors increases your risk for serious health problems because of your bleeding disorder. Role-play what to do and say in an uncomfortable situation so you will know how to handle yourself if the situation does occur.
- ✓ Learn why it is important to wear a medical alert identification tag or emblem at all times. HANDI, your HTC team, and your local bleeding disorders organization can provide you with information about these medical alert programs.

### 3. Educational Planning

- ✓ Make sure you have a 504 plan. If not, work with your parents and school district to develop one. 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](http://www.stepsforliving.hemophilia.org)) for more information or talk with someone in your local bleeding disorder organization or on your HTC team.
- ✓ Think about your career and educational goals. Now is the time to speak with a school guidance or career counselor to further explore your options and the

continued education that is needed to pursue them. Explore volunteering, summer jobs and extracurricular activities that further these interests and potential career choices.

## 4. Self-Advocacy and Self-Esteem

### *Express Medical and Physical Needs*

- ✓ Be able to describe your condition, physical abilities and any adaptive devices you use or need.
- ✓ Treat bleeds promptly by having factor readily available, such as storing it in a refrigerator at school. Discuss with your parents how to handle any awkward treatment-related situations that might arise due to and during treatment, especially at school or during other activities.
- ✓ Be able to name and describe the roles of your medical team. Speak for yourself when you meet with your medical providers and be involved in some of the decision-making processes. Keep a journal of questions or issues to discuss with your health care team.

### *Understand Rights and Responsibilities for Your Health Care*

- ✓ Maintain good health through self-infusion, prompt treatment, exercise and comprehensive examinations.
- ✓ Get ready for the switch from the pediatric care you currently receive to adult care. Talk with your parents about the changes involved and what you can do now to help you start taking charge of your own health care.
- ✓ 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 gives patients control over the use of their health information and regulates the sharing of personal health information. Go online with your parents and research HIPAA information on the U.S. Department of Health and Human Services Web site ([www.hhs.gov](http://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 your bleeding disorder. Speak privately with the doctor if you have concerns about your sexual health. Let your parents know if you would like them to leave the room during your examination.

## 6. Independent Health Care Behaviors

- ✓ Make sure you know the signs and symptoms of a bleed and how to treat it.
- ✓ 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 find and everyone in your family knows where it is located.
- ✓ Become involved in your treatment regimen; start taking on more responsibility for your own care.
- ✓ Continue discussions with your HTC team about your treatment plan. Review with your HTC team which therapy is best for you at this time. Write down any questions that might come up between visits.

- ✓ Be aware of and practice the universal precautions recommended for all people handling clotting factor infusion equipment. 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 never should be recapped. Used needles should be placed in a sharps container out of reach of young children.
- ✓ Know when to visit the emergency room (ER). Remember to always call your HTC before you head to the ER so someone can notify the medical personnel of your arrival. Insist that ER staff contact your HTC if they have any questions about your treatment plan.

### ***Supporting Your Active Life***

- ✓ Spend time with a physical therapist to discuss recommended safe sports or ways to modify activities so that you can participate fully, as well as any home exercise or physical therapy that might be necessary. As a teen with a bleeding disorder, it is important for you to stay active and take part in fitness activities offered through school or community centers.
- ✓ Learn about the benefits of exercise, including preventing or reducing complications of your bleeding disorder. Review NHF's publication "Playing it Safe" with your parents and determine what activities you might find interesting.

### ***Understand the Genetics of Your Bleeding Disorder***

- ✓ Speak with your parents about why you have a bleeding disorder or ask a genetic counselor or other HTC team member for information. See whether other family members might benefit from being tested to find out if they are carriers of 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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