

## **NHF Transition Guidelines**

The following guidelines were approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) on March 8, 2003, and presented to the NHF Board of Directors on March 8, 2003.

These guidelines were developed by a multidisciplinary task force of nurses, psychosocial professionals and physical therapists. They are intended to be used by hemophilia treatment center (HTC) staff in conjunction with patients and their caregivers. The goal is to proceed through each strategy together to ensure that each milestone is met before proceeding to the patient's next stage of development.

## INSTRUCTIONS FOR USING THE TRANSITION GUIDELINES

1. The guidelines are designed to be adapted to the needs of each individual HTC.
2. The guidelines are for use with people who have bleeding disorders including rare coagulopathies, carriers and symptomatic carriers.
3. The guidelines were developed for use by physicians, nurses, social workers, physical therapists and genetic counselors working together as a team; however, some HTCs may not have all the disciplines available to see patients. In that instance, the guidelines can be covered by the available staff.
4. It is suggested that one staff member coordinate utilization of the guidelines to ensure that each specialty knows which areas they will discuss. Coordination of tasks should be decided before the patient is seen.
5. The guidelines are age-specific with three to four ages grouped together.
6. Strategies should be discussed as appropriate for each age (i.e. not all strategies will be discussed at each visit). Some may need to be discussed more than once.
7. Phrases found in bold type within the strategies are intended to act as triggers (quick reminders).
8. Each strategy should be initialed and dated on the lines at the right after it has been discussed. This will allow the next person using the guidelines to know what has been discussed.
9. It is anticipated that the staff will use only the age-specific set of guidelines during the patient visit; however, it is advisable to file the full set of guidelines in the chart in case they are required for reference.
10. The guidelines may be used during an office visit, comprehensive care visit, parent visit, telephone contact or as needed.
11. There is space at the bottom of each age group to record literature provided and document comments.
12. A list of resources is included for any questions regarding use of the guidelines.

Name:

DOB:

## TRANSITION GUIDELINES 13-15 Years Old

### Social Support

Goals & Objectives	Strategies	13	14	15
Parents/youth identify supports	Discuss <b>sources of support</b> as needed.			
Youth meets/socializes with others with bleeding disorders.	Continue to recommend <b>Hemophilia Camp or HTC involvement</b> through group or volunteer opportunities.			

### Health and Lifestyles

Goals & Objectives	Strategies	13	14	15
Youth understands concept of healthy lifestyle behaviors, including diet, exercise and problem solving.	Discuss <b>physical fitness</b> , sports, and exercise/available community resources.			
	Continue to discuss <b>conflict resolution</b> .			
Youth understands consequences of activities/adaptations related to bleeding disorder.	Discuss appropriate <b>sports/protective equipment</b> .			
	Discuss how to make <b>choices</b> re: sports/physical activities.			
	Discuss <b>consequences of joint, muscle and major bleeds</b> .			
Youth understands impact of alcohol, tobacco and drug use.	Discuss consequences of <b>impaired judgment</b> .			
Youth understands impact of bleeding disorder on body image.	Provide opportunity for youth/family to discuss concerns re: <b>body image</b> .			

### Educational/Vocational/Financial Planning

Goals & Objectives	Strategies	13	14	15
Youth exposed to a variety of career choices	Discuss <b>appropriate jobs, careers</b> re: interests/employment possibilities.			
	Encourage youth to identify mentor.			
	Continue to recommend contact with <b>school/guidance/career development programs</b> .			
Youth describes interests/aspirations.	Review youth's experience with <b>volunteering/clubs/summer jobs/extracurricular courses</b> re: their interests.			
	Explore career <b>choices re: benefits/risks/physical limitations</b> .			
Youth describes realistic plans for employment/the future.	Continue exploring <b>education/vocational interests/college</b> choices.			

### Self Advocacy & Self Esteem

Goals & Objectives	Strategies	13	14	15
Youth expresses medical and physical needs to others.	Ensure youth can <b>describe condition/physical abilities/adaptive devices</b> . (ER, physician's office, etc.)			
	Youth can <b>name/describe the role</b> of those involved in his/her health care.			
	Youth taught to <b>recognize when physical therapy referral is needed</b> .			
	Discuss <b>role of family physician/pediatrician</b> .			

Name:

DOB:

**TRANSITION GUIDELINES  
13-15 Years Old**

**Self Advocacy & Self Esteem (continued)**

Goals & Objectives	Strategies	13	14	15
Youth understands rights/responsibilities for health care.	Youth is taught rights/responsibilities for <b>health care/information</b> , such as confidentiality.			
	Youth is involved in <b>decision-making</b> processes.			
Youth seeks information/services to ensure ongoing health.	Continue to discuss <b>information resources</b> (library, internet, NHF, WFH).			
	<b>Continue to discuss questions, concerns and fears re:</b> changes occurring, <b>physically/emotionally</b>			
	Discuss youth’s <b>responsibilities</b> to maintain “good” health (self infusion, prompt treatment, exercise, comprehensive exams.)			
	Discuss <b>transition</b> to adult care.			
	<b>Continue discussion re:</b> problems with peers <b>or awkward situations (i.e. infusions at school).</b>			

**Sexual Health**

Goals & Objectives	Strategies	13	14	15
Parents demonstrate understanding of their child’s bleeding disorder and its relation to sexuality.	Continue to offer assistance to parents re: starting discussions about <b>sexual health</b> with their child (language, refusal skills, safe sex practices, contraception/pregnancy).			
Youth understands impact of puberty re: bleeding disorder.	Continue to discuss <b>puberty changes</b> /possible impact on bleeding disorder, as applicable (menarche, ovulatory pain/bleeding, menorrhagia).			
Youth seeks answers to questions about sexual health.	<b>Provide information re:</b> sexual health services and providers.			
	<b>Discuss information sources re: sexual health.</b>			

**Independent Health Care Behaviors**

Goals & Objectives	Strategies	13	14	15
Youth demonstrates understanding of healthcare needs by participating in treatment and decision-making (home therapy when appropriate).	Assess/reinforce youth’s understanding of <b>treatment regimen</b> , comprehensive care and complications that should be reported to HTC.			
	Assess/reinforce youth’s understanding of benefits/adherence with <b>home exercise/PT program and RICE.</b>			
	Reinforce need to <b>contact medical providers</b> if home exercise program causes problems/concerns.			

Name:

DOB:

**TRANSITION GUIDELINES  
13-15 Years Old**

**Independent Health Care Behaviors (continued)**

Goals & Objectives	Strategies	13	14	15
Youth participates in health care management by keeping records and communicating with healthcare providers.	Encourage youth to increase <b>communication with HTC providers</b> (appointments, prescriptions).			
	Assess youth's participation in <b>tracking home therapy/medical supplies/medications, stress-reporting complications/problems to HTC.</b>			
	Allow youth <b>personal time with HTC staff</b> during clinic visits. Encourage youth to list questions.			
	<b>Encourage females to record menstrual bleeding (duration, amount, and discomfort) for review at clinic.</b>			
	<b>Discuss</b> who to call for what.			
	<b>Encourage youth/family to</b> complete personal care record/emergency care plan <b>for school/home.</b>			
Youth, family and health care providers negotiate decisions, roles and responsibilities for healthcare.	Ensure youth knows <b>address/phone number of treatment center.</b>			
	Continue <b>CVAD/venipuncture transition</b> (if applicable).			
	Continue discussion of <b>developmental tasks</b> re: adolescence/disclosure.			
	Discuss importance of wearing <b>Medic Alert</b> at all times.			
	<b>Discuss</b> changing roles as youth increases <b>responsibility for care.</b>			
Youth will utilize preventative and supportive care services in their community.	Encourage youth to <b>consult PT re: bleeds</b> /joint protection.			
	<b>Discuss access to</b> community resources ( <b>local fitness center, walking trails, parks, etc.</b> ) <b>to promote healthy lifestyle.</b>			
Parents/youth understand genetic component of youth's bleeding disorder.	Educate <b>parents/youth</b> re: <b>inheritance</b> of bleeding disorder (genetic variables, pregnancy risks, etc.)			
	Provide written materials re: <b>inheritance</b> patterns (family tree).			
	Offer <b>genetic</b> referral as needed.			
Parents/youth understand implications of carrier status.	Offer medical and genetic <b>information</b> to all identified carriers as needed.			
	Educate <b>at risk</b> family members re: <b>carrier testing.</b>			
Parents/females understand implications of symptomatic carrier status.	Educate <b>symptomatic carrier</b> re: diagnosis.			

Comments/Literature Provided: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## BIBLIOGRAPHY

- American Academy of Pediatrics. (1996). Transition of care provided for adolescents with special health care needs. *Pediatrics*, 98 (6) Part 1 of 2, 1203-1206.
- Anderson, A., Holtzman, R.S. & Masley, J. (2002). Physical therapy in bleeding disorders. New York.
- Betz, C. (1998). Adolescent Transitions: A Nursing Concern. *Pediatric Nursing*, 24:1, 23-28.
- Blum, R.W. (1995). Transition to adult health care: setting the stage. *Journal of Adolescent Health*, 17:1, 3-5.
- Butler, R., Crudder, S., Riske, B. & Toal, S. (2001). *Basic Concepts of Hemophilia: A Self-Study and Planning Workbook for Families with a New Diagnosis of Hemophilia*. Centers for Disease Control and Prevention.
- Carroll, B. (Nov. 16, 2001). Empowering your child: lessons for medical transition. Presentation at the National Hemophilia Foundation, Nashville, TN.
- Daria-Wiener, I. (2002). School days: an issues advisory. *Hemalog*, 13 :3, 27-31.
- Green, K. (1999). Treatment strategies for adolescents with hemophilia: Opportunities to enhance development. *Adolescent Medicine: State of the Art Review*, 10, 369-375.
- Information for parents and families*. Giving your child an active role in his or her health care. (n.d.). Retrieved December 26, 2001, from <http://depts.washington.edu/healthtr/Families/role.htm>
- Information for parents and families*. Transition timeline 3 to 5 years old, 6 to 11 years old, 12 to 18 years old. (n.d.). Retrieved December 26, 2001 from <http://depts.washington.edu/healthtr/Timeline>
- Issues, challenges & strategies of health care transition for youth and young adults with special health care needs. Conference Call sponsored by The Consortium for Children with Disabilities and Special Health Care Needs. March 20, 2002.
- Kelton, S. (1999). Sexuality education for youth with chronic conditions. *Pediatric Nursing*, 25:5, 491-495.
- MacReady, N. (May, 2002). How to move a patient to adult care. *ePediatric News*, 36 (5), 58. Retrieved May 22, 2002 from <http://www.epediatricnews.com/>
- Merritt, D. & Joseph, S. (2001). Session two, child development. In Parent's manual, Parents Empowering Parents (pp.39-69). Bayer Corporation and the Children's Hospital of Michigan/Detroit Medical Center.

- National Hemophilia Foundation & American Red Cross. (1996). *Hemophilia, Sports and Exercise*. New York.
- O'Connell, D. (2001). Making the transition: pediatric to adult care. *Hemalog*, April, 13-16.
- Paone, M.C. (2000). *Setting the Trac-A Resource for Health Care Providers*. Vancouver, BC: Children's & Women's Health Centre of British Columbia.
- Parish, K.L. (2002). Sexuality and haemophilia: connections across the life span. *Haemophilia*, 8, 353-359.
- Rosen, D. (1995). Between two worlds: bridging the cultures of child health and adult medicine. *Journal of Adolescent Health*, 17:1, 10-16.
- Scal,P., Evans, T., Blozis, S., Okinow, N. & Blum, R. (1999). Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health*, 24, 259-264.
- Schidlow, D. V. & Fiel, S. B. (1990). Life beyond pediatrics, transition of chronically ill adolescents from pediatric to adult health care systems. *Medical Clinics of North America*, 74:5 1113-1120.
- Shapiro, J., Merritt, D. (1998). Letting go. *HemAware*, 3:3, 54-58.
- Whitehouse, S. & Paone, M. C. (1998). Patients in transition: bridging the health care gap from youth to adulthood. *Contemporary Pediatrics, A Canadian Journal Dedicated to the Care of Children*. Retrieved April 9, 2002 from <http://www3/bc.sympatico.ca/steeksma/Medical/transition.htm>

#### TRANSITION TOOLS

"Driving to the Future" (a game developed from the Transition Guidelines to address transition issues with youth). For information, contact Susan Kocik, LICSW & Renee Killian, RN, MPH, Puget Sound Blood Center, 921 Terry Ave. Seattle, Washington 98104, 206-292-2548

## Transition Guidelines for People with Bleeding Disorders

For questions regarding the guidelines including use of the guidelines, the following people can be contacted:

Linda Belling, MS, RN, CRRN  
Hemophilia Center of Western New York  
462 Grider St.  
Buffalo, NY 14215  
Phone: 716-896-2470  
lbelling@wnyhemoctr.org

Mavis Harrop, LCSW  
Vanderbilt Hemostasis & Thrombosis Clinic  
2220 Pierce Ave., 525 PRB II  
Nashville, TN 37232-6310  
Phone 615-343-6509  
mavis.harrop@vanderbilt.edu

Susan Kocik, MSW  
Puget Sound Blood Center  
Hemophilia Program  
921 Terry Ave.  
Seattle, WA 98104  
Phone 206-292-2548  
susank@psbc.org

Lynn Obstein, MSW  
Hemophilia Center of Western New York  
462 Grider St.  
Buffalo, NY 14215  
Phone 716-896-2470  
lobstein@wnyhemoctr.org

Diane Standish, LSW  
Hemophilia Center of Western PA  
3636 Blvd. of Allies  
Pittsburgh, PA 15213  
Phone 412-209-7280  
dstandish@itxm.org

Susan Zappa, RN, CPN, CPON  
Hematology/Oncology Clinic  
Cook Children's Medical Center  
901 7th Ave. Suite 220  
Fort Worth, TX 76104-2796  
Phone 817-810-2587  
susanz@cookchildrens.org

Kim Baumann, PT  
Fairview University Medical Center  
University Campus  
420 Delaware St. SE  
Minneapolis, MN 55455  
Phone 612-273-3944  
kbauman1@fairview.org

Sherry Herman-Hilker, PT  
University of Michigan  
Hemophilia and Coagulation Disorders  
F2480 Mott Hospital Box 0235  
1500 East Medical Center Drive  
Ann Arbor, MI 48109  
Phone: (734) 936-6393  
shhilker@umich.edu