

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 5-8 Years Old

Social Support

Goals and Objectives	Strategies	5	6	7	8
Parents/child identify supports.	Continue to discuss benefits of supports /provide contact information (parent support group/NHF).				
	Discuss feelings of preparing to "let go" as child goes to school or camp.				
Child socializes with others with bleeding disorders.	Discuss importance of Hemophilia camp/HTC group activities.				
Child develops network of friends that supports normal social development.	Discuss/encourage social relationships : school, clubs, scouts, religious groups.				

Health and Lifestyles

Goals & Objectives	Strategies	5	6	7	8
Parents/child understand healthy lifestyle behaviors, including diet, exercise and rest.	Discuss physical fitness , appropriate activities and exercise.				
Parents/child understand consequences of activities and necessary adaptations due to bleeding disorder.	Discuss importance of protective equipment .				
	Discuss concept of adapting activities to reduce consequences.				
Parents/child understand the impact of bleeding disorder on body image.	Provide opportunity for child/family to discuss concerns re: body image .				

Educational/Vocational/Financial Planning

Goals & Objectives	Strategies	5	6	7	8
Child views self as a contributing member of society.	Discuss importance of set times for homework, school projects, child's responsibilities at home/chores list and philosophy of allowance .				
Child describes interests and aspirations.	Discuss interests and how bleeding disorder may affect choices .				

Self Advocacy & Self Esteem

Goals & Objective	Strategies	5	6	7	8
Parents/child express and advocate for medical and physical needs.	Ensure child knows name of disorder .				
	Child begins to interact independently with medical team .				
	Ensure parents/child are able to describe problems & contact the correct person to solve the problem.				
	Ensure parents/child are able to communicate physical adaptations/accommodations as needed.				
Parent/child understand rights and responsibilities for health care.	Offer services of financial counselor /business office personnel.				
	Discuss when/where treatment takes place , any problems with peers and awkward situations that may arise (i.e. infusion at school).				
	Provide information on patients' rights .				
	Encourage school in-services by HTC Staff.				
Parents/child seek information/services to ensure ongoing health.	Provide developmentally appropriate educational information .				

Name:

DOB:

**TRANSITION GUIDELINES
5-8 Years Old**

Sexual Health

Goals & Objectives	Strategies	5	6	7	8
Parents demonstrate understanding of child's bleeding disorder and its relation to sexuality.	Prepare parents to answer child's questions as they arise with age appropriate answers.				

Independent Health Care Behaviors

Goals & Objectives	Strategies	5	6	7	8
Parents/child demonstrate understanding of healthcare needs by participating in treatments/decision-making.	Discuss signs and symptoms of bleeding/pain/poor response to treatment that require medical attention.				
	Continue discussion of treatment regimen/medications (home therapy when appropriate)				
	Discuss who to call for what.				
Parents/child participate in health care management by keeping records and communicating with healthcare providers.	Review proper record keeping and encourage continued communication with healthcare providers.				
	Encourage child's involvement with record keeping and interaction with healthcare providers				
Parents/child and healthcare providers negotiate decisions, roles and responsibilities for healthcare.	Develop written emergency plan for home/school. Ensure pertinent family members know where it is.				
	Discuss home therapy responsibilities of child/parents.				
	Discuss continuity of care among providers.				
	If child has CVAD , begin discussion on transitioning to venipuncture .				
	Discuss development tasks of school age child regarding family/peer group influences (disclosure etc.)				
	Discuss importance of Medic Alert ID bracelet with child.				
Parents/child utilize preventative and supportive health care services in their community.	Continue discussion of importance of utilizing PT, exercise programs, swimming.				
Parents/family understand the genetic component of child's bleeding disorder	Review parents understanding of inheritance of bleeding disorder (genetic variables, pregnancy risks etc.)				
	Provide written materials re: inheritance patterns.				
	Offer genetic referral as indicated.				
Parents understand implications of carrier status.	Educate at risk family members re: carrier testing.				
	Offer medical and genetic information to all identified carriers as needed.				
Parents/females understand implications of symptomatic carrier status.	Educate symptomatic carrier re: diagnosis. Refer as necessary.				

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