

## **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**  
**Birth – 4 Years Old**

**Social Support**

| <b>Goals &amp; Objectives</b>                                   | <b>Strategies</b>  | <b>Birth</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
|---|--|--------------|----------|----------|----------|----------|
| Family identifies supports                                      | Discuss benefits of <b>contact with other parents/support groups</b> .                       |              |          |          |          |          |
|   | <b>Provide information</b> re: internet resources, local hemophilia organizations, NHF, WFH. |              |          |          |          |          |
| Child meets and socializes with others with bleeding disorders. | Recommend <b>child attend chapter parties, picnics and play groups</b> .                     |              |          |          |          |          |

**Health and Lifestyles**

| <b>Goals &amp; Objectives</b>                              | <b>Strategies</b>  | <b>Birth</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
|--|--|--------------|----------|----------|----------|----------|
| Parents understand importance of safe environment.         | Discuss <b>safety measures/car seat/childproofing home</b> .                                 |              |          |          |          |          |
| Parents understand concept of healthy lifestyle behaviors. | Discuss <b>safety gear</b> : helmets, knee/elbow pads.                                       |              |          |          |          |          |
|  | Discuss <b>teething/oral hygiene</b> .   |              |          |          |          |          |
|  | Discuss <b>separation</b> re: day care, babysitters, and alternative childcare arrangements. |              |          |          |          |          |
|  | Review with parent/child <b>feelings re: helmet, kneepads</b> .                              |              |          |          |          |          |
|  | Discuss <b>hygiene for uncircumcised males</b> .   |              |          |          |          |          |
|  | Stress physical <b>abilities</b> .   |              |          |          |          |          |

**Educational/Vocational/Financial Planning**

| <b>Goals &amp; Objectives</b>                         | <b>Strategies</b>   | <b>Birth</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
|---|---|--------------|----------|----------|----------|----------|
| Parents view child as contributing member of society. | Discuss <b>pre-school programs</b> , day care, etc.                               |              |          |          |          |          |
|   | Provide assistance with <b>resources, questions to ask child care providers</b> . |              |          |          |          |          |

**Self Advocacy & Self Esteem**

| <b>Goals &amp; Objectives</b>                                      | <b>Strategies</b>   | <b>Birth</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
|--|---|--------------|----------|----------|----------|----------|
| Parents/child express and advocate for medical and physical needs. | Teach child to <b>express symptoms of bleed/ pain</b> to responsible adult.   |              |          |          |          |          |
| Parents understand their rights/responsibilities for health care.  | Give literature/travel <b>letter to parents</b> to take when accessing care outside their HTC.                                    |              |          |          |          |          |
|  | Have financial counselor/insurance expert discuss <b>billing/insurance issues</b> .   |              |          |          |          |          |
|  | Describe what the parent can <b>expect from the HTC</b> (comprehensive visits, etc.)  |              |          |          |          |          |
| Parents understand their right to information/decision-making.     | Discuss rights pertaining to <b>confidentiality</b> , access to <b>medical information, consents</b> and decision-making process. |              |          |          |          |          |

Name:

DOB:

**TRANSITION GUIDELINES  
Birth – 4 Years Old**

**Independent Health Care Behaviors**

| Goals & Objectives   | Strategies  | Birth | 1 | 2 | 3 | 4 |
|--|---|-------|---|---|---|---|
| Parents demonstrate understanding of child’s health care needs by participating in treatments/decision-making.   | Educate parents re: <b>diagnosis/ treatment</b> regimens, medications and RICE. (home therapy when appropriate).                        |       |   |   |   |   |
|  | Educate re: <b>choice of product/home care company.</b>   |       |   |   |   |   |
|  | Educate parents re: <b>signs/symptoms of bleeding</b> or types of bleeding that require treatment or medical attention.                 |       |   |   |   |   |
|  | Discuss <b>who to call</b> for what.  |       |   |   |   |   |
| Parents participate in child’s healthcare management by keeping records/communicating with healthcare providers. | Discuss <b>record keeping</b> (immunizations, appointments, home infusion logs).  |       |   |   |   |   |
|  | Encourage parent to prepare <b>questions for clinic.</b>  |       |   |   |   |   |
| Parents/health care providers will negotiate decisions, roles and responsibilities for health care.              | Educate when to call <b>emergency care/911.</b>   |       |   |   |   |   |
|  | Discuss <b>how to contact the HTC</b> at all times.   |       |   |   |   |   |
|  | Discuss <b>venipuncture vs. central venous access device (CVAD).</b>  |       |   |   |   |   |
|  | Discuss <b>developmental tasks</b> of infant/toddler stages.  |       |   |   |   |   |
|  | Discuss <b>continuity of care</b> among HTC and other medical providers, daycare and caregivers.  |       |   |   |   |   |
|  | Discuss <b>Medic Alert ID</b> bracelet.   |       |   |   |   |   |
|  | Discuss importance of <b>parents educating child</b> re: diagnosis, pain/bleeding episodes requiring notification to responsible adult. |       |   |   |   |   |
|  | Discuss <b>disclosure issues.</b>   |       |   |   |   |   |
| Family utilizes preventative and supportive health care services in their own community.                         | Discuss <b>importance of services</b> (physical therapy, swimming and exercise programs).   |       |   |   |   |   |
| Parents/family understand the genetic component of child’s bleeding disorder                                     | Educate <b>parents/family re: inheritance</b> of bleeding disorder (genetic variables, pregnancy risks, etc.)                           |       |   |   |   |   |
|  | Provide <b>written materials</b> re: inheritance patterns (family tree).  |       |   |   |   |   |
|  | Offer <b>genetic referral</b> as indicated.   |       |   |   |   |   |
| Parents understand implications of carrier status  | Educate <b>at risk</b> family members re: <b>carrier testing.</b>   |       |   |   |   |   |
|  | Offer medical and genetic <b>information</b> to all identified carriers as needed.  |       |   |   |   |   |
| Parents/females understand implications of symptomatic carrier status  | Educate <b>symptomatic carrier</b> re: diagnosis<br>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