

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

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

Health and Lifestyles

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

Educational/Vocational/Financial Planning

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

Self Advocacy & Self Esteem

Goals & Objectives	Strategies	Birth	1	2	3	4
Parents/child express and advocate for medical and physical needs.	Teach child to express symptoms of bleed/ pain to responsible adult.					
Parents understand their rights/responsibilities for health care.	Give literature/travel letter to parents to take when accessing care outside their HTC.					
	Have financial counselor/insurance expert discuss billing/insurance issues .					
	Describe what the parent can expect from the HTC (comprehensive visits, etc.)					
Parents understand their right to information/decision-making.	Discuss rights pertaining to confidentiality , access to medical information, consents 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: diagnosis/ treatment regimens, medications and RICE. (home therapy when appropriate).					
	Educate re: choice of product/home care company.					
	Educate parents re: signs/symptoms of bleeding or types of bleeding that require treatment or medical attention.					
	Discuss who to call for what.					
Parents participate in child’s healthcare management by keeping records/communicating with healthcare providers.	Discuss record keeping (immunizations, appointments, home infusion logs).					
	Encourage parent to prepare questions for clinic.					
Parents/health care providers will negotiate decisions, roles and responsibilities for health care.	Educate when to call emergency care/911.					
	Discuss how to contact the HTC at all times.					
	Discuss venipuncture vs. central venous access device (CVAD).					
	Discuss developmental tasks of infant/toddler stages.					
	Discuss continuity of care among HTC and other medical providers, daycare and caregivers.					
	Discuss Medic Alert ID bracelet.					
	Discuss importance of parents educating child re: diagnosis, pain/bleeding episodes requiring notification to responsible adult.					
	Discuss disclosure issues.					
Family utilizes preventative and supportive health care services in their own community.	Discuss importance of services (physical therapy, swimming and exercise programs).					
Parents/family understand the genetic component of child’s bleeding disorder	Educate parents/family re: inheritance of bleeding disorder (genetic variables, pregnancy risks, etc.)					
	Provide written materials re: inheritance patterns (family tree).					
	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

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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:

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