

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
9-12 Years Old**

Social Support

Goals & Objectives	Strategies	9	10	11	12
Parents/child identify supports.	Discuss benefits of supports /provide contact information.				
Child socializes with others with bleeding disorders.	Continue to recommend child attend HTC activities.				
Child develops a network of friends that support normal social development.	Discuss/encourage social relationships , clubs, scouts, religious groups.				

Health and Lifestyles

Goals & Objectives	Strategies	9	10	11	12
Parents/child understand healthy lifestyle behaviors including diet, exercise and problem solving.	Discuss physical fitness, exercise and available community resources. Suggest choosing at least one sport or activity for participation				
	Discuss conflict resolution and stress management.				
Parents/child understand consequences of activities and necessary adaptations due to bleeding disorder.	Discuss appropriate sports/activities/ safety measures.				
	Discuss consequences of joint, muscle or major bleeds.				
Parents/child understand impact of alcohol, tobacco and drug use.	Discuss impact of alcohol, tobacco and drugs.				
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	9	10	11	12
Youth views self as contributing member of society.	Assist youth in identifying skills, strengths, interests, and goals.				
Youth describes interests and aspirations.	Discuss school, favorite subjects, plans for high school and ideas for careers.				
	Recommend youth make initial contact with guidance counselor /career development at school.				

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9-12 Years Old**

Self Advocacy & Self Esteem

Goals & Objectives	Strategies	9	10	11	12
Parents/youth express and advocate for medical and physical needs.	Review knowledge of bleeding disorder /assess acceptance.				
	Ensure youth can identify acute bleed symptoms and obtain treatment.				
	Ensure youth/ parents communicate special adaptations/accommodations as needed.				
	Ensure youth begins interaction directly with health care team.				
Parents/youth understand their rights and responsibilities for health care.	Continue discussion of patient rights.				
	Discuss with youth when and where bleeding disorder treatment takes place , any problems with peer influence or awkward situations that may arise (i.e. infusions at school).				
	Continue school in-services.				
Parents/youth seek information and services to ensure ongoing health.	Encourage attendance at Hemophilia camp /weekend retreats.				
	Discuss ways to access health information from health care providers, the Internet, community services.				
	Begin discussion about the transition process to adult care.				

Sexual Health

Goals & Objectives	Strategies	9	10	11	12
Parents demonstrate understanding of their child's bleeding disorder and its relation to sexuality.	Offer assistance to parents regarding initiating discussions about sexual health with their youth (language of sexuality, appropriate personal boundaries, sexual behavior, refusal skills).				
Parents/youth understands impact of puberty re: bleeding disorders.	Discuss puberty changes and possible impact on bleeding disorder, as applicable (menarche, ovulatory pain/excessive bleeding).				

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DOB:

**TRANSITION GUIDELINES
9-12 Years Old**

Independent Health Care Behaviors

Goals & Objectives	Strategies	9	10	11	12
Youth demonstrates understanding of his/her healthcare needs by participating in treatments and decision-making	Continue to discuss signs and symptoms of bleeding/pain/poor response to treatment that require medical attention.				
	Continue discussion regarding treatment regimen/medication with youth/parents. (Home therapy when appropriate)				
	Discuss home exercise/PT program benefits/adherence with youth. Review RICE .				
	Educate youth to contact medical providers if a home exercise program causes problems or concerns.				
	Discuss who to call for what.				
Youth participates in health care management by keeping records and communicating with healthcare providers.	Increase youth's involvement with record keeping/communication with HTC providers.				
	Youth starts to track medications/home therapy supplies .				
Parents/youth, and healthcare providers negotiate decisions, roles and responsibilities for healthcare.	Continue CVAD/venipuncture transition if applicable				
	Discuss developmental tasks of adolescence as they relate to family/peer group influences (disclosure, etc.).				
	Discuss feelings on progressing to independence.				
	Discuss importance of wearing Medic Alert at all times.				
Parents/youth utilize preventative and supportive care services in their community.	Educate youth regarding role of PT in assisting with fitness, joint protection, mobility, and treatment of bleeds, appropriate activities.				
	Continue discussion with parent/youth re: importance of utilizing community services available (swimming, fitness centers).				
Parents/youth understand the genetic component of youth's bleeding disorder.	Educate parents/youth re: inheritance of bleeding disorder (genetic variables, pregnancy risks etc.				
	Provide written materials re: inheritance patterns (family tree).				
	Offer genetic referral as indicated.				
Parents/youth understand implications of symptomatic carrier status.	Offer medical and genetic information to all identified carriers as needed.				
	Educate at risk family members re: carrier testing .				
Parents/females understand implications of symptomatic carrier status	Educate symptomatic carrier re: diagnosis.				

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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