

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
16-18 Years Old**

Social Support

Goals & Objectives	Strategies	16	17	18
Young adult identifies supports.	Discuss sources of support as needed.			
Young adult meets and socializes with others with bleeding disorders.	Recommend Hemophilia Camp/HTC involvement through group or volunteer opportunities.			

Health and Lifestyles

Goals & Objectives	Strategies	16	17	18
Young adult understands concept of healthy lifestyle behaviors, including diet, exercise and problem solving.	Discuss physical fitness /available community resources.			
	Continue to discuss conflict resolution .			
Young adult understands consequences of activities/adaptations related to bleeding disorder.	Discuss consequences of joint, muscle and major bleeds .			
	Discuss appropriate sports/protective equipment .			
Young adult understands impact of alcohol, tobacco and drug use.	Discuss consequences of impaired judgment .			
Young adult understands long-term health goals, including transition to adult care.	Discuss importance of maintaining health care/adherence to treatment regimens.			
	Discuss transfer to primary adult care , staff, location and confidentiality issues.			
Young adult understands the impact of bleeding disorder on body image.	Discuss concerns re: body image .			

Educational/Vocational/Financial Planning

Goals & Objectives	Strategies	16	17	18
Young adult describes interests, aspirations and post high school plans	Review young adults interests/abilities with parental input.			
	Review post-secondary school choices for appropriateness re: bleeding disorder and availability of HTC.			
	Continue to recommend contact with school counselor re: appropriate course work.			
	Provide information/applications re: available resources to assist with post-secondary education including voc/rehab.			
	Suggest summer employment /shadowing in areas of interest.			
Young adult will plan and seek out health care benefits for future.	Recommend young adult/parents explore insurance options for college.			
Young adult describes realistic plans for employment and the future.	Educate re: employment rights (ADA).			
	Provide information/applications etc.			

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Self Advocacy & Self Esteem

Goals & Objectives	Strategies	16	17	18
Young adult expresses medical, physical and social needs to others.	Discuss bleeding disorder/impact on daily living and plans for future.			
	Young adult should demonstrate knowledge of physical abilities .			
	Self-infusion , documentation and interaction with staff expected.			
Young adult will be able to advocate and negotiate for health care.	Ensure young adult has skills to negotiate needs (travel letter, E.R. care, P.T. referral).			
Young adult understands rights and responsibilities for health care.	Discuss what is expected of the young adult and what can be expected from the health care staff.			
	Continue discussion re: problems with peers or awkward situations (i.e. infusions at school).			
Young adult seeks information/services to ensure ongoing health.	Discuss educational support (regional, NHF, WFH, Internet).			
Young adult understands utilization of the adult health care system.	Discuss plans for transition to adult care (primary care/bleeding disorder care). Provide written material as needed.			
	HTC staff should facilitate introductory visit .			
	Pediatric staff support may be offered for the first few months of transition.			

Sexual Health

Goals & Objectives	Strategies	16	17	18
Parents demonstrate understanding of their young adult's bleeding disorder and its relation to sexuality.	Continue to offer assistance to parents re: initiating and continuing discussion about sexual health with their young adult (refusal skills, safe sex, sexual identity and behaviors).			
Young adult understands impact of impending adulthood on his/her bleeding disorder.	Discuss sexual behaviors, contraception, pregnancy, sexual identity and rights as a sexual person . Continue to discuss questions, concerns/fears re: the changes occurring , physically/emotionally;			
Young adult seeks answers to questions about sexual health.	Continue to discussion re: decision making under pressure and safe sex .			
	Continue discussion re: STD's (Hep C transmission), menstruation and impact of bleeding disorder on sexual activity (groin bleeds, joint bleeds) .			
Young adult identifies sexual health services in the community.	Provide information re: sexual health services/providers .			

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**TRANSITION GUIDELINES
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Independent Health Care Behaviors

Goals & Objectives	Strategies	16	17	18
Young adult demonstrates understanding of healthcare needs by participating in treatment/decision-making.	Assess/reinforce young adults understanding of treatment regimen/comprehensive care . Assess adherence.			
	Assess/reinforce young adult's understanding of benefits/adherence with home exercise/PT program and RICE .			
	Reinforce need to contact medical providers if home exercise program causes problems/concerns .			
Young adult participates in health care management by keeping records and communicating with healthcare providers.	Ensure young adult communicates with HTC providers (appointments, prescriptions).			
	Ensure young adult tracks home therapy/medical supplies/medications .			
	Stress reporting complications/problems to HTC.			
	Increase young adults personal time with HTC staff during clinic visits. Encourage young adult to list questions.			
	Ensure females record menstrual bleeding (duration, amount and discomfort) for review at clinic.			
	Discuss who to call for what .			
Young adult, family and healthcare providers negotiate decisions, roles and responsibilities for healthcare.	Ensure young adult completes personal care record/emergency care plan for school/home .			
	Ensure young adult knows address/phone number of treatment center.			
	Continue CVAD/venipuncture transition (if applicable).			
	Continue discussion of developmental tasks re: young adult/disclosure.			
	Discuss changing roles as young adult accepts responsibility for care .			
Family and young adult utilizes preventative and supportive care services in their community.	Encourage youth to consult PT re: bleeds/joint protection or joint protection and fitness.			
	Discuss access to community resources (local fitness center, walking trails, parks, etc.) to promote a health lifestyle.			
Young adult understands genetic implications of his/her bleeding disorders.	Ensure young adult understands genetic variables/implications of his/her diagnosis.			
	Provide written materials (family tree).			
	Offer genetic referral as needed.			
Young adult understands implications of carrier status.	Ensure young adult understands carrier status and its implications . Provide written materials.			
	Educate at risk family members re: carrier testing .			
Young adult understands implications of symptomatic carrier status.	Ensure symptomatic carrier understands the diagnosis, when and where to seek hematological care, refer to GYN care if necessary, etc.			

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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