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TRANSITION GUIDELINES FOR PEOPLE WITH BLEEDING DISORDERS

The following guidelines were approved by the Medical and Scientific Advisory Council (MASAC) on March 8, 2003, and presented to the NHF Board of Directors on March 8, 2003.

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TRANSITION GUIDELINES For People with Bleeding Disorders

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The transition process should start at the time of diagnosis and continue throughout life. A multidisciplinary National Hemophilia Foundation task force was formed because it was recognized that certain aspects of transition may be difficult for individuals with bleeding disorders, as well as for Hemophilia Treatment Center (HTC) staff and the family. The goal of this committee was to develop transition guidelines that could be used by HTC staff with children who have bleeding disorders and with their parents. Nurses, psychosocial professionals and physical therapists worked together to develop guidelines for the transition of the pediatric patient with a bleeding disorder to adult care.

There are many types of transitions for the person with a bleeding disorder. These include acceptance of the bleeding disorder, self care, progressing through school, vocational/career planning, moving to an adult center, starting a family, middle age and retirement. Transitioning is a team effort and it includes the patient, parents and staff. The goal is to proceed through each phase, ensuring that recommendations for each developmental milestone are met.

According to Mary C. Paone, author of *Setting the Trac-A Resource for Health Care Providers*, "The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound prior to and throughout transfer into the adult system." To develop transition guidelines for people with bleeding disorders we used Paone's framework. It was adapted to meet the needs of the bleeding disorders community. Six major components of her framework include: self-advocacy, independent health care behaviors, sexual health, social supports, educational/vocational/financial planning, and health and lifestyle behaviors. Communication and HTC team support are essential for the successful completion of the guidelines. We have attempted to make them user-friendly. Instructions for using the transition guidelines are included.

The Transition Task Force would like to acknowledge Mary C. Paone, RN, MSN, Youth Health/Transition Planning, Children's & Women's Health Centre of British Columbia, Vancouver, B.C. for her encouragement and inspiration in developing these guidelines for people with bleeding disorders. We would like to thank Mary Jane Petruzzi, MD, Hemophilia Center of Western New York for reviewing the guidelines.

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Fairview University Medical Center, Minneapolis, Minnesota

Puget Sound Blood Center Seattle, Washington

Louisiana Center for Bleeding and Clotting Disorders at Tulane University
Health Sciences Center, New Orleans, Louisiana

Vanderbilt Hemostasis & Thrombosis Clinic, Nashville, Tennessee

Cook Children's Medical Center, Fort Worth, Texas

Hemophilia Center of Western New York, Buffalo, New York.

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Linda Belling and Lynn Obstein
Transition Task Force Co-Chairs

INSTRUCTIONS FOR USING THE TRANSITION GUIDELINES

1. The guidelines are designed to be adapted to the needs of each individual HTC.
2. The guidelines were developed for use by physicians, nurses, social workers, physical therapists, and genetic counselors working together as a team. However, some HTC's may not have all three disciplines available to see patients. In that instance, the guidelines can be covered by the available staff.
3. 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.
4. The guidelines are age-specific, with three to four ages grouped together.
5. Strategies should be discussed as appropriate for each age (ie. not all strategies will be discussed at each visit). Some may need to be discussed more than once.
6. Phrases found in bold type within the strategies are intended to act as triggers (quick reminders).
7. 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.
8. 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.
9. The guidelines may be used during an office visit, comprehensive care visit, parent visit, telephone contact or as needed.
10. A list of resources is included for any questions regarding use of the guidelines.

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.					

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 parents re: choice of product/home care companies .					
	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 (disclosure).					
	Discuss continuity of care among HTC and other medical providers, daycare and caregivers.					
	Discuss Medic Alert ID bracelet.					
Family utilizes preventative and supportive health care services in their own community.	Discuss and encourage genetic counseling.					
	Discuss importance of parents educating child re: diagnosis, pain/bleeding episodes requiring notification to responsible adult.					
	Discuss disclosure issues .					
	Discuss importance of services (physical therapy, swimming and exercise programs).					

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.				
	Offer services of financial counselor/business office personnel.				
Parents/child understand rights and responsibilities for health care.	Provide information on patients' rights .				

TRANSITION GUIDELINES

5-8 Years Old

Self Advocacy & Self Esteem (continue)

Goals & Objectives	Strategies	5	6	7	8
	Encourage school in-services by HTC Staff.				
Parents/child seek information/services to ensure ongoing health.	Provide developmentally appropriate educational information.				

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 health care needs by participating in treatments/decision-making. <i>(home therapy when appropriate)</i>	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.	Discuss when/where treatment takes place , any problems with peers and awkward situations that may arise (i.e. infusion at school).				
	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 developmental 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.				

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.				
	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.	Suggest choosing at least one sport or activity for participation.				
	Assist youth in identifying skills, strengths, interests, 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 .				

TRANSITION GUIDELINES

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 .				
	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.				
	Discuss youth's responsibilities to maintain wellness (self infusion, prompt treatment, exercise, comprehensive exams).				
	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/bleeding).				

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 (home therapy when appropriate).	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.				
	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.	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 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.				
	Educate youth regarding role of PT in assisting with fitness, joint protection, mobility, treatment of bleeds, appropriate activities.				
Parents/youth utilize preventative and supportive care services in their community.	Continue discussion with parent/youth re: importance of utilizing community services available (swimming, fitness centers).				

TRANSITION GUIDELINES

13-15 Years Old

Social Support

Goals & Objectives	Strategies	13	14	15
Parents/youth identify supports	Discuss sources of support as needed (scouts and clubs).			
Youth meets/socializes with others with bleeding disorders.	Continue to recommend Hemophilia Camp or HTC involvement through group or volunteer opportunities.			

Health and Lifestyles

Goals & Objectives	Strategies	13	14	15
Youth understands concept of healthy lifestyle behaviors, including diet, exercise and problem solving.	Discuss physical fitness , sports, exercise/available community resources.			
	Continue to discuss conflict resolution .			
Youth understands consequences of activities/adaptations related to bleeding disorder.	Discuss appropriate sports/protective equipment .			
	Discuss how to make choices re: sports/physical activities.			
	Discuss consequences of joint, muscle and major bleeds.			
Youth understands impact of alcohol, tobacco and drug use.	Discuss consequences of impaired judgment .			
Youth understands impact of bleeding disorder on body image.	Provide opportunity for youth/family to discuss concerns re: body image .			

Educational/Vocational/Financial Planning

Goals & Objectives	Strategies	13	14	15
Youth exposed to a variety of career choices	Discuss appropriate jobs, careers re: interests/employment possibilities.			
	Encourage youth to identify mentor .			
	Continue to recommend contact with school/guidance/career development programs.			
Youth describes interests/aspirations.	Review youth's experience with volunteering/clubs/summer jobs/ extracurricular courses re: their interests.			
	Explore career choices re: benefits/risks/physical limitations .			
Youth describes realistic plans for employment/the future.	Continue exploring education/vocational interests/college choices .			

Self Advocacy & Self Esteem

Goals & Objectives	Strategies	13	14	15
Youth expresses medical and physical needs to others.	Ensure youth can describe condition/physical abilities/adaptive devices . (ER, physician's office, etc.)			
	Youth can name/describe the role of those involved in his/her health care.			
	Youth taught to recognize when physical therapy referral is needed .			
	Discuss role of family physician/pediatrician .			

TRANSITION GUIDELINES

13-15 Years Old

Self Advocacy & Self Esteem (continue)

Goals & Objectives	Strategies	13	14	15
Youth understands rights/responsibilities for health care.	Youth is taught rights/responsibilities for health care/information , such as confidentiality.			
	Youth is involved in decision-making processes.			
Youth seeks information/services to ensure ongoing health.	Continue to discuss information resources (library, internet, NHF, WFH).			
	Encourage attendance at camp/weekend retreats for youths with bleeding disorders.			
	Discuss youth's responsibilities to maintain "good" health (self infusion, prompt treatment, exercise, comprehensive exams.)			
	Discuss transition to adult care.			

Sexual Health

Goals & Objectives	Strategies	13	14	15
Parents demonstrate understanding of their child's bleeding disorder and its relation to sexuality.	Continue to offer assistance to parents re: starting discussions about sexual health with their child (language, refusal skills, safe sex practices, contraception/pregnancy).			
Youth understands impact of puberty re: bleeding disorder.	Continue to discuss puberty changes /possible impact on bleeding disorder, as applicable (menarche, ovulatory pain/bleeding, menorrhagia).			
Youth seeks answers to questions about sexual health.	Continue to discuss questions, concerns and fears re: changes occurring , physically/emotionally.			
	Offer opportunities to discuss sexual health re: bleeding disorder .			
Youth understands genetic implications of bleeding disorder.	Genetic counselor meets with youth/family to discuss genetic variables and implications of diagnosis .			
	Genetic counselor provides written information/resources for youth/family .			
	Provide information re: sexual health services and providers .			
	Discuss information sources re: sexual health .			

Independent Health Care Behaviors

Goals & Objectives	Strategies	13	14	15
Youth demonstrates understanding of healthcare needs by participating in treatment and decision-making (home therapy when appropriate).	Assess/reinforce youth's understanding of treatment regimen , comprehensive care and complications that should be reported to HTC.			
	Assess/reinforce youth'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.			

TRANSITION GUIDELINES

13-15 Years Old

Independent Health Care Behaviors (continue)

Goals & Objectives	Strategies	13	14	15
Youth participates in health care management by keeping records and communicating with healthcare providers.	Encourage youth to increase communication with HTC providers (appointments, prescriptions).			
	Assess youth's participation in tracking home therapy/medical supplies/medications, stress reporting complications/problems to HTC.			
	Allow youth personal time with HTC staff during clinic visits. Encourage youth to list questions.			
	Encourage females to record menstrual bleeding (duration, amount, and discomfort) for review at clinic.			
	Discuss who to call for what.			
Youth, family and health care providers negotiate decisions, roles and responsibilities for healthcare.	Encourage youth/family to complete personal care record/emergency care plan for school/home.			
	Ensure youth knows address/phone number of treatment center.			
	Continue discussion re: problems with peers or awkward situations (i.e. infusions at school).			
	Continue CVAD/venipuncture transition (if applicable).			
	Continue discussion of developmental tasks re: adolescence/disclosure.			
	Discuss importance of wearing Medic Alert at all times.			
	Discuss changing roles as youth increases responsibility for care.			
Youth will utilize preventative and supportive care services in their community.	Encourage youth to consult PT re: bleeds/joint protection.			
	Discuss access to community resources (local fitness center, walking trails, parks, etc.) to promote healthy lifestyle.			

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.			

TRANSITION GUIDELINES

16-18 Years Old

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.			
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.			
Young adult seeks answers to questions about sexual health.	Continue to discuss questions, concerns/fears re: the changes occurring , physically/emotionally;			
	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 understands genetic implications of bleeding disorder.	Genetic counselor ensures youth/family understand genetic variables/implications of youth's diagnosis.			
	Genetic counselor provides written information/resources.			
Young adult identifies sexual health services in the community.	Provide information re: sexual health services/providers.			

TRANSITION GUIDELINES

16-18 Years Old

Independent Health Care Behaviors

Goals & Objectives	Strategies	16	17	18
Young adult demonstrates understanding of healthcare needs by participating in treatment/decision-making (home therapy when appropriate).	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 discussion re: problems with peers or awkward situations (i.e. infusions at school).			
	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.			

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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

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