TRANSITION GUIDELINES FOR PEOPLE WITH BLEEDING DISORDERS

REVIEW QUESTIONS

Developed by the Transition Task Force

Linda Belling, MS, RN, CRRN
Hemophilia Center of Western New York

Mavis Harrop, LCSW
Vanderbilt Hemostasis & Thrombosis Clinic

Sherry Herman-Hilker, PT
University of Michigan
Hemophilia & Coagulation Disorders

Susan Kocik, MSW
Puget Sound Blood Center

Lynn Obstein, MSW
Hemophilia Center of Western New York

Susan Zappa, RN, CPN, CPON
Cook Children’s Medical Center

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**Transition Guidelines for People with Bleeding Disorders**

The Transition Task Force developed age-specific review questions to assess patients/parents knowledge as the patient transitions through the age groups.

In addition, the questions are intended to guide the HTC staff regarding their educational goals to help the patient/parents learn about the bleeding disorder, promote health maintenance and plan for the future.

**Recommendations for use of the Review Questions.**

1. Use of the review questions can be adapted to the needs of the Hemophilia Treatment Center (HTC) staff and patient. They may be used to assess the patient’s/parents’ knowledge of the bleeding disorder prior to starting an age-specific section or after the section has been completed.

2. For the younger age-specific sections there are questions for both the patient and parents to complete.

3. Questions may also be administered verbally and discussed with the patient and/or parents.

4. Upon entrance to an adult HTC, staff may wish to use the 16 to 18 year old review questions to assess the transitioning adult’s knowledge of their bleeding disorder. Appropriate learning exercises may be developed as needed.

5. Completion of the review questions provides documentation that the patient/parents have completed the goals and strategies of each age-specific section or defines the objectives and strategies that require further education. Further learning exercises may be developed if needed.

3-27-06
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

Review Questions for Child

Birth – 4 years old

1. Can you say what you have that makes you come to the special doctor? Or get special medicine?
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

2. What is the special medicine called that you get when you are hurt, or you get in the morning to keep you from getting hurt?
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
Transition Guidelines for People with Bleeding Disorders

Answers to Review Questions for Child

Birth – 4 years old

1. Child should be able to say something about his/her disorder; the name would be the best answer.

2. Answer should be “factor” or medicine to make me stop bleeding.
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________
Person completing this test: ______________________________

Review Questions for Parents

Birth – 4 years old

1. What is the name of the national organization for patients and families affected by bleeding disorders? __________________________________________________

2. List the safety measures you would need for your child
   a. In a car:
      ______________________________________________________________
      ______________________________________________________________
   b. Riding a bike:
      ______________________________________________________________
      ______________________________________________________________

3. You are using a babysitter for the evening. What information would you make sure a child care provider had before you left?
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

4. What are the symptoms of a bleed in a joint?
   Check ALL that apply:
   ________ swelling
   ________ warm to the touch
   ________ yellow color to the skin
   ________ range of motion is limited (or child doesn’t move the joint)
   ________ cool to touch

5. What does RICE stand for?
   R __________________
   I __________________
   C __________________
   E __________________

6. Why would your child need a medical alert bracelet or necklace?
   ______________________________________________________________________
   ______________________________________________________________________

7. Where would you obtain a medical alert item?
   ______________________________________________________________________
   ______________________________________________________________________
Transition Guidelines for People with Bleeding Disorders

Answers to Review Questions for Parents

Birth – 4 years old

1. National Hemophilia Foundation or NHF

2. Car: child safety seat
   Bike: helmet, elbow or knee pads

3. Your contact information (cell phone, restaurant, etc.)
   Family member or neighbor contact information
   Emergency room/hospital number
   Hematologist’s emergency number, HTC phone number or whoever the HTC suggests they call

4. Swelling
   Warmth
   Limited ROM

5. R rest
   I ice
   C compression
   E elevation

6. In case the child was not with a parent and an accident occurred, the emergency department would then know about his/her medical condition

7. Medical alert items can be found through information at
   1) a drug store
   2) the internet and
   3) your hemophilia care provider
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

Review Questions for Child

5-8 years old

1. Explain in your own words how you report a bleed to an adult.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

2. Explain why it is important to wear a Medic Alert.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

3. If you are on prophylaxis, explain why it is important to receive it.

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
Transition Guidelines for People With Bleeding Disorders

Answers to Review Questions for Child

5-8 years old

1. subjective
2. subjective
3. subjective
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________
Person completing this test: ______________________________

Review Questions for Parents

5-8 years old

1. If a person exercises and is physically active, he will have stronger joints.  
   True  False

2. A parent should begin to assign chores/responsibilities to their child at home.  
   True  False

3. List 3 ways you can help your child become more independent.  
   1. _________________________________________________  
   2. _________________________________________________  
   3. _________________________________________________

4. If you have medical questions regarding your child, who on the team should you contact?  
   a. social worker  
   b. nurse  
   c. doctor  
   d. physical therapist

5. What is a Medic Alert bracelet? Describe the purpose of having one.  
   ____________________________________________________________________  
   ____________________________________________________________________  
   ____________________________________________________________________

6. Does your child need to wear protective gear when playing sports? Why?  
   ____________________________________________________________________  
   ____________________________________________________________________  
   ____________________________________________________________________
Answers to Review Questions for Parents

5-8 years old

1. True

2. True

3. Some examples are: sending your child to camp, letting your child answer questions at clinic, helping and learning how to self insuse, being able to name his bleeding disorder, taking responsibility for chores at home, letting parents know when he has a bleed (helping him become aware of the symptoms)

4. b or c

5. Medic alert bracelet/necklace is associated with a 24 hour response center. The bracelet/necklace lists medical diagnosis, allergies, treatment, and phone number for emergency response. The emergency response center will provide emergency phone contact, physician contact, vital medical information and personal information if unconscious.

6. Yes, it is important to wear protective gear for safety especially to avoid a head bleed, bodily injury or other potentially dangerous situations.
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

Review Questions for Child

9-12 years old

1. I know the names of my hemophilia treatment center staff?
   __________ yes  __________ no
   If yes:
   My doctor is ______________________________________________________
   My nurse is ______________________________________________________
   My social worker is ________________________________________________
   My physical therapist is __________________________________________
   Another important person is __________________________________________

2. My favorite sports and activities are ____________________________________
   The protective gear I use is __________________________________________

3. These are good for me to participate in because
   __________________________________________________________________
   __________________________________________________________________
   __________________________________________________________________

4. If I feel that I am having a bleed I should (check all that apply)
   a. True ____ False ____ Ignore it
   b. True ____ False ____ Tell my parent or other adult immediately
   c. True ____ False ____ Help the adult give me an infusion
   d. True ____ False ____ Give myself the infusion if I have been trained
   e. True ____ False ____ Make a note or keep a record of the infusion

5. My favorite subject in school is _______________________________________
   Special note to boys and girls – Lunch and recess do not count as subjects!!!!

6. I like that subject because __________________________________________

7. When I become an adult, I would like to be ______________________________

8. My diagnosis is ______________________________________________________

9. I treat my bleeding disorder with _______________________________________
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

10. I can do the following (check all that apply)
   Yes ______ No ______ Gather what I need to receive a treatment
   Yes ______ No ______ Mix factor
   Yes ______ No ______ Know when I (or my parents) need to order factor
   Yes ______ No ______ Sit still when my parents give me an infusion
   Yes ______ No ______ Help my parents give me an infusion
   Yes ______ No ______ Give myself an infusion, with my parents watching
   Yes ______ No ______ I can give myself an infusion without any help

11. I can pass along my bleeding disorder to (check all that apply)
    ___________ son
    ___________ daughter
    ___________ grandson
    ___________ granddaughter

12. I can help keep records of my treatments and medications.
    ___________ Yes ___________ No
Answers to Review Questions for Child

9-12 years old

1. Individual names
2. Subjective
3. Subjective
4. a. False
   b. True
   c. True
   d. True
   e. True
5. Subjective
6. Subjective - encourage verbalization of child’s thoughts and feelings.
7. Subjective
8. Subjective
9. Subjective
10. Answer “yes” to all. Provide encouragement on independence with infusions.
11. Depends upon diagnosis.
12. Subjective
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________
Person completing this test: ______________________________

Review Questions for Parents

9-12 years old

1. I know about camp and other HTC or chapter activities for children, and encourage my child to attend. __________ Yes __________ No

2. My child’s special interests are:

_________________________________________________________________
_________________________________________________________________

3. I am comfortable talking to my child about sex and reproduction. __________ Yes __________ No

4. I can obtain information on how to talk to my child about sexual health from:

_________________________________________________________________
_________________________________________________________________

5. I am aware that a bleeding disorder may have an effect upon my daughter at puberty: __________ Yes __________ No

If yes, please describe the effect:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

6. My son/daughter can describe his/her bleeding disorder. __________ Yes __________ No

7. My son/daughter knows who to call if he/she needs assistance, whether urgent or not. __________ Yes __________ No
Transition Guidelines for People with Bleeding Disorders

Answers to Review Questions for Parents

9-12 years old

1. If no, provide information and encouragement.

2. Subjective

3. Subjective. Provide encouragement, be aware of parents’ beliefs system.

4. My child’s school, Hemophilia Center, pediatrician, PMD

5. Subjective

6. Subjective

7. Subjective
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

Review Questions for Patient

13-15 years old

1. Fill in the blanks:
I have ____________ (name the bleeding disorder). My severity or level is _______. Describe your disorder in your own words:
__________________________________________________________________
__________________________________________________________________

2. What type of product is used to treat your bleeding disorder? Circle those that apply:

- Factor VIII concentrate
- Factor IX concentrate
- DDAVP
- Stimate
- Other (describe) ________________________________________________

3. After a head injury or trauma I should: (Check all that apply)
   a. ________ Infuse with 100% factor
   b. ________ Wait and see how I feel
   c. ________ Call the Hemophilia Treatment Center or bleeding disorder physician immediately
   d. ________ Tell my parents or teacher immediately

4. I participate in the following sports/activities
   __________________________________________________________________
   __________________________________________________________________
   and use/wear ___________________________________________ for protection.

5. If I noticed one of my joints would not straighten out (extend) to its fullest degree I would seek help from (check appropriate answer):
   a. ________ Lab technician
   b. ________ Physical therapist
   c. ________ Dietitian

6. To maintain my health it is my responsibility to: (Circle those that are correct)
   a. If I think I have a bleed wait a few hours to see if it really is.
   b. Recognize and get a bleed treated as soon as it starts.
   c. Exercise and play sports to maintain good muscle strength.
   d. Attend comprehensive care clinic regularly.
   e. Wear Medical ID only when I play sports.
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

7. Symptoms of a joint bleed are: (Circle all that apply)
   Cold       Heat       Bubbling feeling
   Stiffness   Itching     Pain       Swelling

8. Rice Therapy can be used with factor for treatment of a bleed. Explain what RICE stands for:
   R ______________________________________________________________
   I ______________________________________________________________
   C ______________________________________________________________
   E ______________________________________________________________

9. The person I call when I have a question regarding a bleed is ________________.
The phone number is _______________________________________________.

10. My bleeding disorder might be passed on to my children.
    True       False

11. To become responsible for my care I do the following (put an x by those that you presently do):
    _____ Call and order my own prescriptions or factor when needed
    _____ Fill out my own infusion records
    _____ Infuse myself with factor
    _____ Mix factor but do not infuse myself

12. When I feel the need to talk to someone who understands what it’s like having a bleeding disorder, I can go to or turn to: (check all that are appropriate)
    _____ Treatment center staff (doctor, nurse, or social worker)
    _____ Librarian
    _____ Parents
    _____ School friends
    _____ Hemophilia Camp Friends
    _____ Pharmacist

13. An appropriate career for someone with a moderate to severe bleeding disorder is:
    (check all that apply)
    _____ Computer programmer
    _____ Lawyer
    _____ Construction worker
    _____ Professional football player
    _____ Photographer
    _____ Teacher
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

14. If I have any questions about my sexual health I could get information from:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

15. One goal I would like to work on over the next year with regard to my bleeding disorder is:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

16. I would like more information in the following topic(s) re: my bleeding disorder:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

For Females Only

True or false: Circle the answer for the following statement:

(T) True  (F) False  (U) Unsure

17. T  F  U  It is important to keep a calendar of my menstrual bleeding for my doctor to review with me when I am seen for my regular check-up.

18. T  F  U  If I have vonWillebrand Disease –I may experience heavy menstrual bleeding (menorrhagia)

19. T  F  U  If I am a hemophilia symptomatic carrier, I should call my Hemophilia Treatment Center before I have a tooth pulled
Transition Guidelines for People with Bleeding Disorders

Answer to Review Questions – Patient

13-15 Years Old

1. Subjective

2. Subjective

3. a, c, d

4. Subjective

5. Physical Therapist

6. b, c, d

7. stiffness, heat, bubbling feeling, pain, swelling

8. R Rest the affected area or stay off of it
   I Ice the injury for 15-20 mins every 1-2 hours
   C Compression wrap the area in an ace bandage
   E Elevation raise the area to decrease swelling

9. Subjective

10. True

11. Subjective

12. Could be 1 or all of the following: treatment center staff, parents, Hemophilia camp friends

13. Computer programmer, lawyer, photographer, teacher

14. My school nurse, my parents, Hemophilia Center staff, my private doctor

15. Subjective (may review #11 to develop a goal)

16. Subjective

17. True

18. True

19. True
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

Review Questions for Patient

16-18 years old

1. I am a patient of ____________________________ (hematologist) at ____________________________ (address of treatment center). The phone contact number is ____________________________.

2. My health care insurance carrier is ____________________________ and I carry my insurance cards at all times _____yes _____no.

3. Physical activity/exercise is important to me for the following reasons (circle all that apply)
   a. Strengthen muscles to provide better joint support
   b. To help me maintain a healthy weight
   c. To help me manage stress
   d. To help me maintain strong heart and lungs

4. ADA stands for the American’s with Disabilities Act. 
   __________ True __________ False

5. My target joints are 
   __________________________________________
   __________________________________________
   __________________________________________

6. I recognize when I am having a bleed because I experience the following:
   __________________________________________
   __________________________________________
   __________________________________________

7. Life threatening bleeds include:
   __________________________________________
   __________________________________________
   __________________________________________

8. List in order the steps you will take when you experience a bleed
   a. __________________________________________
   b. __________________________________________
   c. __________________________________________
   d. __________________________________________
   e. __________________________________________
   f. __________________________________________
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

9. I am planning my senior trip to Florida. Because of my bleeding disorder I will need to take
   a. _______________________________________________________________
   b. _______________________________________________________________
   c. _______________________________________________________________
   d. _______________________________________________________________
   e. _______________________________________________________________
   f. _______________________________________________________________

10. My plans relating to educational or vocational training after high school are (please explain):
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________
    _________________

11. I will obtain care for my bleeding disorder from:
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________

12. After age 18 years old my Insurance will be:
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________

13. Based on my particular condition I know that I am able to participate in the following sports/physical activities:
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________
    However, I should avoid
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________

14. The factor product that I use is ____________________ and my infusion schedule is
    __________________________________________________________________
    __________________________________________________________________
    __________________________________________________________________
Transition Guidelines for People with Bleeding Disorders

Name: ______________________________
DOB: ______________________________
Date: ______________________________

15. My bleeding disorder will affect my children in the following way:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

16. If I have questions about safe sex, Hepatitis C or sexually transmitted diseases I could talk to: (circle all that apply)
a. My private doctor
b. Hemophilia Center staff
c. My school nurse
d. Planned Parenthood

17. Now that I am 18 years old I must sign a release of information for my parents to discuss my medical information with my doctors.
______________________ yes ____________________ no
Answers to Review Questions

16-18 years old

1. Subjective
2. Subjective
3. a, b, c, d
4. True
5. Subjective
7. Head, neck/throat, spinal cord, intra-abdominal.
8. Subjective
9. Subjective
10. Subjective
11. Subjective
12. Subjective
13. Subjective
14. Subjective
15. subjective
16. a, b, c, d
17. Yes