

## **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

3-27-06

## **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?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Transition Guidelines for People with Bleeding Disorders

### 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 insure, 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

## Transition Guidelines for People with Bleeding Disorders

### 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

## Transition Guidelines for People with Bleeding Disorders

### Answers to Review Questions

16-18 years old

1. Subjective
2. Subjective
3. a, b, c, d
4. True
5. Subjective
6. Pain, swelling, warmth, tingling, tenderness.
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