

TRANSITION GUIDELINES FOR PEOPLE WITH BLEEDING DISORDERS

REVIEW QUESTIONS

Developed by the Transition Task Force

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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?

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