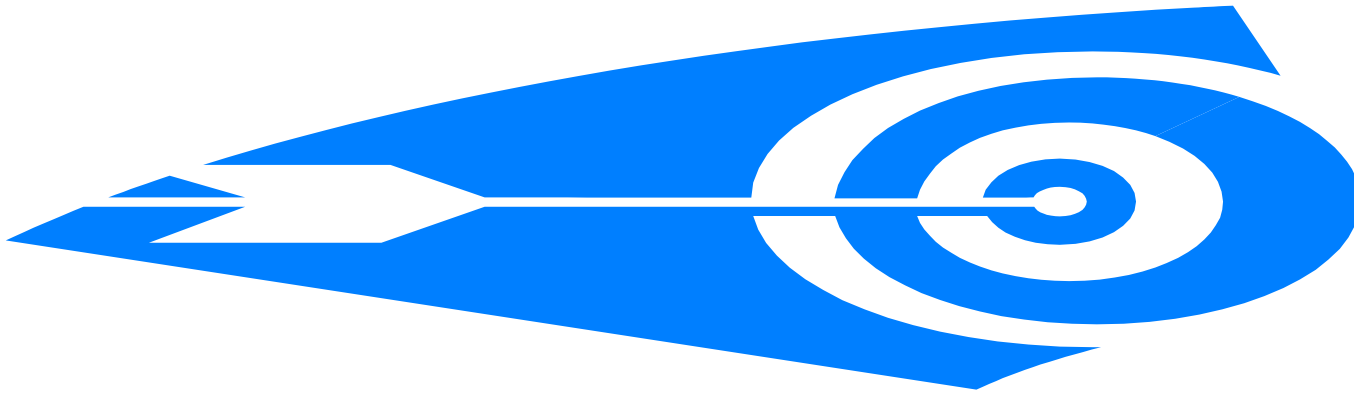


Are You Ready

TO BE

ON TARGET



**ASSESSING READINESS FOR SELF-INFUSION  
REGION VII NURSING/SOCIAL WORK GROUP**

## **HOME TREATMENT LEARNING PACKET\***

**\*ADAPTED FROM “IT’S YOUR HEALTH!!”**

**in Teaching Home Therapy and Infection Control Self-Learning Guide**

Centers for Disease Control and Prevention March 1998

### **INTRODUCTION**

This workbook is to help you understand your bleeding disorder and its treatment. It will probably take you 30 – 45 minutes to complete. After you complete the workbook you should better understand your bleeding disorder, its treatment, and home infusion safety.

You may find areas that you wish to know more about. We encourage you to do so.

### **WHAT YOU KNOW ABOUT BLEEDING DISORDERS**


This workbook contains 24 items, each with several possible responses grouped into 3 columns. For some items you should complete a sentence. Others you may have to show if the item is true or false. Read each item, then circle the one response or group of responses that best describes what you would normally do. When you are done, please follow the instructions at the end of the workbook.

Please use this workbook to help you learn about your bleeding disorder. It is most helpful if you respond based on what you would actually do rather than what you think the “right” response is.


**ARE YOU READY?**  
ASSESSING READINESS FOR SELF-INFUSION  
**CHECKLIST**  
REGION VII

Are you at least 7 years old? ..... 


Can you find and read name of product, dose and expiration date on a label? ..    
(IF YOU HAVE VISITON PROBLEMS OR OTHER DISABILITIES THAT INTERFERE WITH READING, PLEASE LET YOUR BLEEDING DISORDERS TEAM KNOW)

Are you calm during infusions now?..... 

Do you have veins that are easy to find?..... 

Do you have another important job at home that you manage without... your family's help? 

Have you completed the HOME TREATMENT LEARNING PACKET?\*.... 

Do your parents, your doctor, your nurse, your social worker agree..... that you are ready to learn self-infusion? 

## BASIC UNDERSTANDING OF BLEEDING DISORDERS

- |    |  |   |  |  |
|----|--|---|--|--|
| 1. | When you bleed, proteins in your blood work together to form a clot that stops the bleeding. | false                                     | don't know                                   | true                                   |
| 2. | I am missing one of the following clotting proteins...                                       | don't know                                | factor VIII, factor IX, vonWillebrand, other | not sure, but I know where to find out |
| 3. | I have a _____ bleeding disorder.  | not sure, but I know where I can find out | don't know                                   | severe , moderate, mild                |
| 4. | My bleeding disorder may be passed on to my children.  | true                                      | don't know                                   | false                                  |

## TREATMENT ISSUES

5.	My bleeding disorder treatment product is...	don't know	not sure, but I know where to find out	Factor VIII, Factor IX, DDAVP, Other
6.	My dose of product for a bleed...	don't know	depends on my weight and type of bleed	I don't know but I know where to find out
7.	I get my bleeding disorder care from a...	*Hemophilia Treatment Center *Private doctor	Emergency Dept.	Don't have a regular place
8.	In the case of a hard blow to the head, the treatment should be...	*Not sure, but I know where to look *Not sure but HTC, doctor or ED knows	Don't know	Call my HTC or bleeding disorder doctor right away, give 100% dose
9.	When I need more products to treat bleeds, I can get them from...	*Hospital *HTC *Home Care Company *Emergency Dept.	Not sure, but I could call my doctor	Don't know
10.	For joint bleeds, the goal of treatment is to prevent damage to the joint.	True	False	Don't know

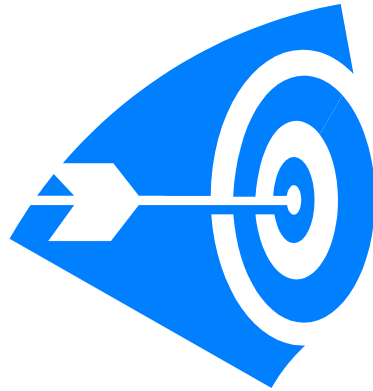
11.	In case of an injury related to my hemophilia I would...	Call 911	*Identify the problem and treat with factor if not life-threatening and then *Call the HTC for advice *If the bleed might be life-threatening, call the HTC immediately	Don't know
12.	In the case of a reaction to treatment (like hives) I would...	Stop the infusion immediately and call the HTC for instructions	Call 911	Don't know
13.	All factor concentrates are free of viruses	True	False	Don't know
14.	Before I begin infusions...	*I wash my hands if there is time and I clean the area with soap	*I clean the area and begin *I clean the needles with alcohol	*I wash my hands with warm soapy water, clean the area with alcohol, * get out a sharps box * set up all supplies
15.	When mixing the factor...	I just do it.	*I check the expiration date * I check the color of the factor before & after mixing *I check the number of units to make sure I have enough	*I wash my hands with warm soapy water

16. When I have found the vein I am going to use I...	Go ahead and stick the needle into the skin	Clean the skin with alcohol or Betadine each time before I put the needle into the vein	Clean the skin when I have time
17. In preparing the butterfly needles...	I clean them with alcohol.	I use a new, sterile one every time.	I use a new one if possible
18. Regarding gloves...	I use them if I have them.	they are used only in the hospital	I always use them if I am infusing another person
19. After the infusion, I do the following with syringes, needles, and butterflies...	*I can't remember, I'm usually in a hurry. * I throw them in the trash.	I use the sharps box when possible, or I throw them in the trash.	I always use the sharps box for needles and other items with blood & factor on them
20. A sharps box is...	*Somewhere in the house *Already full *I'm not sure	*A puncture-resistant box *Always near the infusion area and kept closed and stored away from children and pets *Replaced when it's $\frac{3}{4}$ full.	*I'm not sure what this is

21. When I have nonsharp waste (like gloves or gauze pads) from the infusion that have blood or factor on them I...	*Always use a sharps box *Put them in a plastic bag that is sealed and put in the trash.	Usually put them in a separate plastic bag.	Throw everything in the trash.
22. If someone else was exposed to my blood or factor product...	*I have a plan that I've reviewed with my doctor or HTC and *Wash the exposure site with warm soapy water and *I would call my HTC	*I would not know what to do *It is no big deal as long as its washed off	*I would worry for a while *I would call someone
23. Recording the infusion...	Is something I rarely do.	Is something I do when I have time.	Is something I do every time.
24. The problem with following the rules is...	*If I make a mistake I can't be on home infusion.	It is hard to keep up with all the rules but I try.	They are complicated but necessary so I can protect the people I live with.

CONGRATULATIONS! NOW THAT YOU HAVE CHOSEN YOUR ANSWERS TO ALL THE QUESTIONS YOU CAN MOVE ON TO THE NEXT SECTION. THERE YOU WILL FIND THE "BEST" ANSWERS FOR EACH ITEM ALONG WITH AN EXPLANATION. FOR ITEMS WHERE YOUR RESPONSE MATCHES THE BEST RESPONSE YOUR KNOWLEDGE OF YOUR BLEEDING DISORDER OR YOUR CURRENT PRACTICE ARE ON-TARGET .





FOR ANY ITEM WHERE YOUR RESPONSE DOES NOT MATCH THE PREFERRED RESPONSE, PLEASE READ THE PREFERRED RESPONSE AND DISCUSS WITH YOUR FAMILY, DOCTOR OR HTC STAFF. YOU MAY NEED TO FOLLOW UP BY CHANGING HOW YOU DO THINGS IN THIS AREA AND BY LEARNING MORE ABOUT THE TOPIC.

1. True            The blood in our body responds to an injury in a blood vessel by starting up its clotting system. This system is made up of different factor proteins working together in a domino effect to form a clot. The clot plugs the hole caused by the injury and stops the bleeding.
2. Factor IX, Factor VIII, vonWillebrands            It is important to know the type of bleeding disorder that you have. In emergency situations or when requiring treatment from a provider who does not know you, if YOU know the type of bleeding disorder it will help you receive the right treatment.
3. Severe \_\_%, Moderate \_\_%, Mild \_\_%            It is important to know how severe your bleeding disorder is. In emergency situations, your best treatment may be decided by disorder severity. If you know your percent of baseline factor, that will help even more.

4. True                      A man with hemophilia has an affected “X” chromosome which he passes on to all his daughters. The daughters are called “obligate carriers” because they will always receive the affected X chromosome.
  
5. Factor IX, Factor VIII, or DDAVP      Knowing the correct treatment product for yourself is very important in emergencies and when on home therapy.
  
6. Depends on my weight and the severity of the bleeding. The dose for factor concentrate products or DDAVP or other bleeding disorder treatment products is based on your weight in kilograms (pounds divided by 2.2). A bleeding episode in the head or neck or abdomen is usually treated with a higher dose than a bleed in joints or muscles
  
7. HTC or physician.              Because bleeding disorders are rare (hemophilia occurs once in every 7500 male births, vonWillebrands in only 1-3% of people) it is important that a person with a bleeding disorder get medical care from someone who is familiar with and knows how to treat their disorder. A system of Hemophilia Treatment Centers (HTC’s) was set up by the Federal government in the late 1970’s to provide expert care to people with bleeding disorders. There are over 125 HTC’s in the USA and they are an excellent choice for providing care for a person with a bleeding disorder.
  
8. Call my HTC right away and give enough factor to raise the factor level to between 80% and 100%. The exact amount will depend on the type of factor and the nature of the injury.  
The right dose for a head injury is one that is high enough to assure that the bleeding in the head will stop. Because the head is a confined space and brain tissue is sensitive to pressure (like pressure from blood during a bleeding episode), it is very important that a big enough dose is given. For an emergency situation, you should know this dose so any bleeding can be minimized. Your HTC or doctor should be notified immediately of this kind of bleed.

9. Hospital, HTC, private physician's office, home care company, emergency department.

People with a bleeding disorder should work with their HTC to set up a system where they can receive products for treatment. If someone needs treatment, few hospitals and emergency departments have factor available. If a person is on home therapy or another plan is in place, a home care company/pharmacy/HTC can supply products to be kept in the home. It is important to know a place where treatment is given before it becomes an emergency.

10. True. The earlier the treatment to stop and lessen the bleeding, the better the situation for maintaining good joint function.

Bleeding in a joint will eventually cause joint damage. The best treatment is to prevent this damage by minimizing the amount of blood oozing into that joint. This can be accomplished by treating each joint bleed early and with the right dose or by treating with prophylaxis which reduces the number of bleeding episodes.

11. Identify the problem & treat with factor if the problem is not life-threatening, and then call the HTC for advice, BUT if the bleed may be life-threatening (such as head, neck, or abdominal injury), call my HTC immediately.

In case of an injury, finding out what has happened and what is injured is the first thing to do. IF the bleed is not life-threatening and you can treat at home, administer the factor. If this is a routine bleeding episode that you have experienced before you may not need to contact your HTC or physician. If you cannot treat at home, call your HTC or physician to let them know you are coming in for treatment. If the bleed is life-threatening, call the HTC, your physician or hospital emergency department. If you can treat at home, either treat with factor as directed or bring the factor to the emergency department to administer as soon as possible. Treat each injury as soon as possible.

12. Stop the infusion right away and call the HTC for further instructions.

Factor concentrate contains proteins. Proteins can cause an allergic reaction. With the new, purified factor concentrates, there is a low risk of this occurring, but some people have allergic reactions even to the new products. If you have hives during the administration of the factor, this is a sign of an allergic reaction and should be reported. Most times, giving oral benadryl will eliminate the symptoms. However, hives could be an early sign of a stronger, more serious reaction so they should always be reported.

13. False.

While the current manufacturing techniques for factor concentrates have reduced the risk for transmitting viruses, some products are still made from some part of human blood and have some risk of carrying certain viruses. The factor concentrates have not been shown to carry HIV since 1987, but other viruses are not killed as easily by heat and can survive the manufacturing process.

14. I wash my hands with warm soapy water AND I clean the area and get out a sharps container AND I set up all the equipment.

Hand washing with warm soapy water for 10 – 15 seconds (about the time it takes to sing the alphabet song) is the best way to keep germs away. Cleaning the area that will be used for infusions is important to reduce any dirt and germs. Setting up the equipment before starting the infusion is a good way to organize and find out if there are enough alcohol pads, syringes, etc. It is better to prepare ahead of time than to start the infusion process then finding out later you don't have something you need.

15. I wash my hands with warm soapy water before and after mixing AND I check the expiration date and number of units to be given to make sure I have enough.

Hand washing with warm soapy water (for 10 – 15 seconds) is the easiest and most effective way to get rid of germs. Factor products or DDAVP should not be given after the expiration date. Because each factor vial size is different, it is important to check the number of units so you give the correct dose.

16. Clean the skin with alcohol or betadine each time before I insert the needle into the vein.

Using alcohol or betadine on the skin reduces germs on the skin and decreases the chance of getting skin bacteria onto the needle or into the vein, which can cause infection.

17. I use a new, sterile butterfly needle every time.

Butterfly needles are packaged to be sterile. Once they are opened and touch an unsterile surface, they are no longer sterile. Therefore, anytime a butterfly is touches a non-sterile surface like the counter top or your hand, a new one should be opened and used. Butterflies should never be re used.

18. I always use them if I am infusing another person.

Gloves should be worn by a person giving someone else factor concentrates or DDAVP. Gloves provide protection from any blood or body fluids including any fluid from the factor bottle. They will help protect the infuser from exposure to viruses that are in the factor or carried by the person being infused. Gloves will also help protect the person being infused from exposure to viruses carried by the infuser.

19. I always use the sharps container for throwing away needles and other items that have touched blood or factor.

A puncture resistant box should be used for throwing away all used infusion equipment as well as any item that touches the blood or body fluids of the person being infused. This will stop people getting these viruses by accident. The sharps box should be disposed of according to state disposal rules. Your HTC or home care company will know these rules and help you dispose of your box properly.

20. Resistant to puncture by needles AND always near the infusion area AND kept closed and stored away from small children and pets AND replaced when it is  $\frac{3}{4}$  full.

A puncture resistant box should be used for throwing away all used infusion equipment as well as any item that comes in contact with blood or body fluid. It should be close to the infusion area so needles can be placed into it without being recapped and risking a needle stick injury. When not in use, the box should be closed and stored in an area that children or pets can't get to. The box should be replaced when  $\frac{3}{4}$  full.

21. Always use a sharps box OR put them in a plastic bag that is then sealed and put in the trash.

22. I have a plan that I have reviewed with my HTC AND I would immediately wash the exposure site with warm soapy water AND I would call my HTC.

23. Is something I do every time.

Recording infusions is an important part of home therapy. It is a document of each time a prescribed treatment is given. It is a prescribed medical practice and your HTC requires it. Because factor concentrate can be a blood product, it is important to have a recording of each time it is administered. Factor is expensive and many insurance companies require logs for each infusion. In reviewing records of infusions, a picture of the frequency of joint or muscle bleeding is painted. This gives you and your health care provider an opportunity to see trends in bleeding and use other treatments to minimize the bleeding, strengthen the area, and promote good joint and muscle function. It may also point out the development of an inhibitor to factor.

24. They are complicated but necessary so I can best protect my family.

Infection control in the home takes a little extra work, but preventing exposure of a virus from one person to another is worth the time. Some of the viruses that can be transmitted have serious consequences.