

## Navigating the Emergency Department

### Anticipate, Educate, and Advocate

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**W**hile the vast majority of individuals with a bleeding disorder manage their routine infusions of factor at home, there may be times when you or your child may require an emergency department visit. Stories abound about long waits, repeated sticks, and medical staff who do not believe a bleed they cannot see. However, a visit to the emergency department (ED) can be a more positive experience if you -- anticipate, educate, advocate.

### Anticipate- Have a Plan

Emergency rooms can be busy and stressful. If possible, try to have a plan in place before you visit the emergency department. Talk to your treatment center staff about their recommendations which might include:

- A modified treatment plan in place in the ED (how much factor, what type of factor concentrate, etc.)
- A letter from your treatment center physician with details of your treatment that you can give to the staff of the emergency department
- A recommended emergency department in your local community
- A phone number where you can reach a member of your treatment center team after business hours (on-call number)

### Educate

Even if you have a plan, you may encounter difficulties. It is important to understand that health care providers in an emergency room can't be experts in everything and thus may not be experts in the care of bleeding disorders. It is important that you let them know that you or your child has a bleeding disorder and that it needs to be treated quickly. Physicians are accustomed to running tests before they prescribe treatment. Thus, it is critical to stress that when children with bleeding disorders are seen in the ED for a suspected bleed, they should be given factor before any diagnostic tests are administered. In an emergency situation, time is a critical element. If the staff do not seem to know how best to treat, let them know that you or your child is seen by a local treatment center. Give them your center's after-hours (on-call) number so they can talk to your physician. Sometimes you may have to ask more than once. Don't give up. If you feel uncomfortable, insist that someone contact the treatment center, or make the call yourself.

Educate the staff. Stress the importance of having a skilled phlebotomist. A child in an emergency situation, especially a child with a bleeding disorder, is not the patient on whom medical students and residents should learn intravenous techniques. Repeated needle sticks can cause bruising around the vein and soft tissue hematomas—conditions that may cause further trauma and make future attempts at intravenous access problematic.

## **Advocate**

Effective advocacy has two key elements: 1) Getting the information you need about your condition and treatment; and 2) interacting with providers to obtain the best care possible. Both of these elements can be achieved through good communication. Good communication does not mean that everyone always agrees. Sometimes conflict can occur. At times, you may feel that the providers are not treating you or your child appropriately (for example, having to wait for treatment in an emergency room). There are times when you need to speak up about the problem and your concerns.

This can be difficult. However, if you do not speak up about your concerns you will not get the problem solved. The best way to handle conflict is to use assertive statements -- state clearly and specifically what is causing the problem, how you feel about the problem, and what you would like to see happen. For instance, in an emergency department conflict you might say, “When you refuse to give my child factor right away, it worries me because factor is important to immediately stop bleeding in a child with hemophilia. I need you to call my child’s hemophilia physician. Here is the number.”

You will find that most providers want to work with you to resolve problems. Sometimes you may have to state your problem more than once. That’s okay. Be persistent. No one else will be as interested in solving your problem as you are. On those rare occasions when problems are difficult to solve, it can help to involve staff from your center. They can help you find the resources you need or help negotiate an acceptable solution. After an emergency department visit, follow-up with the emergency department director if there are things about your visit that you would like to see changed in the future. Bleeds may be an inevitable part of having a bleeding disorder, but a bad experience in an emergency department doesn’t have to occur. Remember things will not change for the better unless you stand up for yourself or your child. Advocacy is giving a voice to your questions and concerns and following up responsibly.

*This article is adapted with permission from the CDC workbook, Basic Concepts of Hemophilia. This workbook is intended to help families and young adults learn the fundamentals of hemophilia and serve as a catalyst for dialogue with treatment center staff.*

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