



WORKSHOP GUIDELINES

GOAL OF WORKSHOP

The workshop, *Navigating the emergency department*, will provide guidance and direction to people with bleeding disorders on how to prepare and make things go more smoothly for themselves or their child when accessing emergency care.

TARGET AUDIENCE

- People with hemophilia or another bleeding disorder
- Parents or caregivers of a person with a bleeding disorder

WORKSHOP FORMAT

An interactive educational session which could include one or more of the following elements:

- introductory PowerPoint presentation;
- role-playing sessions to help people with bleeding disorders develop new advocacy skills;
- distribution of CHS educational resources relating to accessing emergency care.

The workshop could be offered at:

- chapter family weekends or annual general meetings;
- parent support group meetings;
- HTC information sessions;
- chapter/regional educational sessions.

SUGGESTED SPEAKERS AND/OR FACILITATORS

- Local HTC nurse coordinator or clinic director (see HTC listing on CHS Web site: www.hemophilia.ca)
- Emergency department physician from a hospital that treats people with bleeding disorders
- CHS provincial or regional staff member
- Consumers representing various perspectives (parent, child/adolescent with a bleeding disorder, person with an inhibitor, etc.).

SAMPLE AGENDA

1. Opening remarks (see sample introductory remarks below)
Chapter president or provincial/regional staff
2. Intro skit “How **not** to visit the emergency department” (see guidelines below)
HTC nurse, emergency department physician, consumers
3. PowerPoint presentation
HTC nurse coordinator, clinic director or emergency department physician
4. Role-playing session (see guidelines below)
5. Evaluation of workshop (see sample evaluation below)
6. Closing remarks (see sample closing remarks below)
Chapter president or provincial/regional staff

Sample introductory remarks

“Welcome to the workshop *Navigating the emergency department*. The presentation is one of the modules from the Canadian Hemophilia Society program : *Passport to well-being* designed to empower people with bleeding disorders to maximize their quality of life.

The goal of this workshop is not to provide all the answers. Rather, it is intended to provide information and new skills aimed at improving access to timely emergency care.”

Introduce the speakers and begin with the intro skit *How **not** to visit the emergency department*.

Intro skit *How not to visit the emergency department*

GUIDELINES

Identify, in advance, three or four people to play the roles of the triage nurse, the emergency department physician, a patient and a parent. Develop a scenario about a patient arriving at the emergency department after an injury or trauma. e.g. The players act out the situation using three different approaches.

Example

A young girl, a known von Willebrand disease patient, fell off her skateboard. She was wearing a helmet but loosely and the helmet flew off during her fall. She lost consciousness and her friend ran to the house to get the parents. She also hurt her arm, probably a fracture along with abrasion and bleeding. She is dizzy and vomiting.

1. The parents walk into the emergency department, frantic, screaming at the clerk and insulting her because she is asking them questions while their daughter may be having a life-threatening bleed.
2. The parents come in anxious but very polite, answer all the questions and then sit in the waiting room while their daughter continues to throw up.
3. The third approach will be the proper way to present in the emergency department, by being cooperative yet well informed and assertive.

Begin PowerPoint presentation (distribute handout of slides for note-taking)

ROLE-PLAYING SESSIONS

GUIDELINES

- Prepare cards with 2-3 scenarios in advance (see examples below – other scenarios may be found in the *Navigating the emergency department* booklet).
- Ask for volunteers from audience to participate in a role-playing situation. Allow time for volunteers to prepare role-play scenarios.
- Present role-playing scenarios.
- On a flip chart summarize effective and not effective strategies.

SAMPLE SCENARIOS

The following are a couple of suggestions that can be used for a role-playing segment in an emergency department consumer workshop.

Situation 1

A five-year-old boy with mild hemophilia falls and hits his head. His mother takes him to the emergency department.

It's Saturday evening and a young mother and her children are playing in the park. Her five-year-old son, who has mild hemophilia, falls off the play structure and lands on his head. He is conscious but dazed. Since the child has mild hemophilia he is not on home infusion and the family does not have the product

at home. The parents have been told by the HTC nurse to go to the emergency department if they suspect their son may have a bleed. When she arrives at the emergency department with her son she meets with the triage nurse.

Triage nurse “There does not appear to be any obvious injury so this does not require immediate attention. Please wait in the waiting room.”

Possible responses

Mother (passive) You don’t want to argue with the triage nurse so you agree to wait in the waiting room.

Mother (aggressive) You are angry that the triage nurse does not take you seriously regarding the urgency of the situation. You respond, “Hey, you listen to me! You should be aware that a person with hemophilia with any potential injury to his head needs urgent attention. If anything happens to my son I’m holding you personally responsible. You’re not doing your job and I am going to have my son’s hematologist paged immediately. He will set you straight in a hurry.”

Mother (assertive) You take out your son’s *FactorFirst* card and say, “It seems that perhaps you do not understand the urgency of the situation. I’ve been instructed by my bleeding disorder treatment centre to show this card to emergency department staff. My son’s *FactorFirst* card, provided by his hematologist, indicates that hemophiliacs must have prompt triage and assessment and that suspected bleeds to the head should be triaged as **emergent**. It’s extremely important my son receives treatment as soon as possible. His injuries could be serious.”

Situation 2

A 12-year-old girl with Type I von Willebrand disease is having her first period. She is bleeding heavily.

A 12-year old girl with Type I von Willebrand disease is having her first menstrual period. She is bleeding heavily. Her mother takes her to the emergency department at the local rural hospital where she explains that her daughter has a bleeding disorder and needs to receive desmopressin to stop the heavy vaginal bleeding. After a lengthy wait they finally see a physician.

Emergency department physician “How can your daughter have a bleeding disorder? She’s a female. First period can often be heavy. We’ll just observe her and it should improve on its own.”

Possible responses

Mother (passive) You sit there worrying and feeling frustrated that the staff has never heard of VWD before.

Mother (aggressive)

You tell the physician this it is ridiculous that he has never heard of VWD, the most common bleeding disorder that also affects women. “What kind of training do you have? It’s your job to provide treatment for her so where is it? I’m calling the hospital administrator about this immediately.”

Mother (assertive)

You are polite and answer the physician’s questions to the best of your ability. VWD is an inherited bleeding disorder that affects both men and women. VWD patients have low levels of von Willebrand factor in their blood which results in prolonged bleeding. Your daughter has a *FactorFirst* card issued by the bleeding disorder treatment centre physician. It gives a really useful description of her bleeding disorder and the treatments that she may need in case of severe menorrhagia. The phone number for the HTC is also listed there for the physician to call. There is someone on duty who can advise on treatment.

Situation 3

A young man with severe hemophilia has a motor vehicle accident and is brought to the emergency department.

It’s 3 a.m. A young man has been in a car accident and brought to the emergency department by ambulance. He is wearing a *MedicAlert* bracelet which indicates that he has hemophilia and has a copy of his *FactorFirst* card in his wallet. He has had some minor injuries to his legs but no obvious broken bones or other serious injuries. He has been examined by the emergency department physician and is under observation.

Young man with hemophilia

“I have severe FVIII hemophilia and according to my *FactorFirst* card (which is in his wallet) I need to be infused immediately with 3,000 units of recombinant factor VIII product. If you need more information, please contact my bleeding disorder treatment centre at the number on the card or contact the hematologist on call for specific treatment guidelines.

Emergency department physician “I’ll need to run a few tests first before treating you. I refuse to wake anyone up at 3 a.m. if it’s not an emergency.”

Possible responses

Young man (aggressive)

You yell at the doctor demanding that you be infused immediately or you’ll sue. “This could be a life-threatening bleed. If you don’t treat me immediately I could die and you’ll be responsible.”

Young man (assertive)

You are entitled to a second opinion. You have the hematologist on call paged. Apologize to the hematologist on call for disturbing him at 3 a.m. but tell him that you feel this is an emergency. Describe your condition, how you feel the bleed is serious and the emergency department physician’s refusal to infuse before conducting tests. Ask for his assistance.

HOW TO SUCCEED AT THE EMERGENCY DEPARTMENT

- Get input from group about emergency department experiences.
- Present *Navigating the emergency department* booklet highlighting major points... *FactorFirst* card, personal emergency plan, updating information, etc.
- Distribute handout *Assertiveness in the emergency department* (see below).
- Bring a fully loaded emergency pack and a personal emergency plan to demonstrate the concept.
- Present documents: *Emergency Care for Patients with Hemophilia* and *Emergency Care for Patients with von Willebrand Disease*
- Present Web site: www.hemophiliaemergencycare.com.
- Emphasize patient responsibility ... we play a key role in receiving effective treatment.

Sample closing remarks

- Thank speakers and participants for attending
- Collect evaluations
- Hand out – *Navigating the emergency department* booklet and copies of the personal emergency plan

ASSERTIVENESS IN THE EMERGENCY DEPARTMENT (handout)

WHAT MAKES IT DIFFICULT TO BE ASSERTIVE?

- Upbringing:** Those inner voices of authority that tell you “not to speak up to people in authority.”
- Your rights:** Each person has the right to be heard and taken seriously, but do you feel that this is true for you?
- Lack of clarity:** Not knowing what you want in yourself, and being unable to express yourself strongly and clearly.
- Being afraid:** Trying to avoid disapproval or punishment from others.
- Being put off:** Allowing another’s reaction or circumstances to weaken or cut off your effort.

Three assertiveness tips:

1. Be empathetic

Deal with nurse’s/receptionist’s/doctor’s feelings. Notice what the other person is dealing with and show you understand their situation.

“I know this must be very frustrating for you...”

“If I were in your situation I would feel the same way...”

“You are dealing with a lot of priorities...”

“How can I make it easier for you to deal with this emergency? My son needs xxx immediately.”

“You are trying to respond to a lot of needs, but I am afraid you don’t understand the urgency here. My son needs xxx immediately.”

2. Be a broken record

Be clear about the point you want to make and **work on it until you resolve the matter**. Use calm repetition, without getting upset. Maintain a low level, relaxed voice and – without getting anxious – stick to your point of view and don’t give in. Keep repeating your point (what you need to have happen) until you get it. Combine this with “be empathetic” (above). Never apologize for asking for what you need, such as *“I am sorry to bother you again, but...”* Only retreat when you have made a rational decision that progress is impossible.

3. Use emotions to best effect

Being very angry and hurt can take your energy away from efforts toward your goal and confuse the issue. But **do** convey your feelings. Let the other person know how strongly you feel about the matter. Stay focused on what you need! Being open and honest makes it difficult for other people to manipulate you.

NAVIGATING THE EMERGENCY DEPARTMENT WORKSHOP EVALUATION

Your feedback helps us to improve the quality of our programs. Please take a few minutes to reply and give your comments.

1. The format of this workshop involved a PowerPoint presentation followed by interactive role-playing sessions and informative presentation about how to prepare for emergency department visits. How would you rate the effectiveness of this format?

1	2	3	4	5
Poor	Fair	Average	Good	Excellent

2. How well do you feel this workshop addressed how to prepare to emergency department visits?

1	2	3	4	5
Poor	Fair	Average	Good	Excellent

3. What part(s) of this workshop were helpful to you?

4. Comments or suggestions for future workshops on this topic.

5. Please indicate your role within the bleeding disorder community:

- a) person with hemophilia: FVIII deficiency ____ FIX deficiency ____
- b) person with von Willebrand disease ____ Type ____
- c) parent/caregiver of a person with hemophilia or VWD ____
- d) HTC health care provider: nurse ____ clinic director ____
emergency department physician ____ other ____
- e) CHS staff: national ____ provincial ____ regional ____