

PASSPORT

TO WELL-BEING



Empowering people with bleeding disorders
to maximize their quality of life



Navigating the emergency department

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Canadian Hemophilia Society
Help Stop the Bleeding

www.hemophilia.ca



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The Canadian Hemophilia Society is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

This booklet provides general information only. The Canadian Hemophilia Society does NOT practice medicine and does not suggest specific treatments. In all cases, we suggest that you speak with a doctor before you begin any treatment.

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Note: Bleeding disorders affect both men and women. The use of the masculine in this text refers to both.

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INTRODUCTION

Has this ever happened to you?

It's 10:00 pm. Your child with hemophilia fell earlier in the day and now he has awoken in tears and his ankle is swollen. You have no factor at home to infuse. You rush to the nearest hospital emergency department and sit in the waiting room... and wait, and wait, and wait. When your child is finally examined, the doctor says, "I'm not sure your son's ankle is bleeding. I'll have to run some tests."

Or, does this scene sound familiar?

It's the middle of the night. You have Type 1 von Willebrand disease and you are having a bad nose bleed. You are unable to control it at home and so you go to the emergency department. The waiting room is full and the triage nurse does not seem to think your nose bleed is serious. So you wait. You know that you need an injection of desmopressin (DDAVP). When you finally see the doctor, he/she prescribes packing and refuses to call the hematologist on call. The nose bleed continues.

Unfortunately, stories like these have occurred all too often and many people with bleeding disorders have experienced firsthand the frustrations and anxiety of accessing timely and appropriate care for themselves or their child in the emergency department. This booklet contains practical suggestions of things that can be done to prepare and make things go more smoothly for you or your child. Emergency department visits will be necessary from time to time, despite your best efforts to prevent injury. However, being prepared and well informed about your bleeding disorder, before ever stepping into the emergency department, can pave the way to a successful visit.



PREPARE IN ADVANCE FOR A VISIT TO THE EMERGENCY DEPARTMENT

Obtain and wear a medical identification tag such as MedicAlert®

This is a critical first step in identifying your bleeding disorder. This identification may save your life if you are injured and unable to speak for yourself.

Complete and carry your *FactorFirst* or *TreatFirst* treatment card

The card was developed as a resource for the individual with a bleeding disorder to carry in his wallet for presentation to emergency department staff when accessing emergency care. The card contains important patient information including details on diagnosis and treatment as well as contact names and phone numbers of the patient's bleeding disorder treatment centre. Keep it in a plastic wallet folder next to your health card so that it will be visible in an emergency.



To obtain a *FactorFirst* or *TreatFirst* card, contact your treatment centre.



Develop a personal emergency plan

Prepare a personal emergency plan with the staff at your treatment centre. This will include the phone numbers of people to be contacted during an emergency, 24 hours a day/7 days a week. These emergency instructions vary from one treatment centre to another. Make several copies of the plan and keep one on the fridge or beside your phone, in your car, in your child's schoolbag and anywhere you can find it quickly in an emergency. Be sure to update your plan each year at your annual assessment.

Set up an emergency contingency plan if necessary

If you have other children, set up an emergency babysitting plan with a relative, friend or neighbour in advance.

Be knowledgeable! Be knowledgeable!

Take control of your bleeding disorder. Know more about your personal care than anyone. Remember, these disorders are rare. Many of the health care workers you encounter will have had little or no experience treating a person like you. You may know the signs and the seriousness of a bleed but you cannot assume the health care worker has the same level of understanding.

Know the invasive procedures for which you need to be given clotting factor or other treatment beforehand (e.g. dental work, lumbar puncture, all types of surgeries).

Be familiar with your treatment product, which medication works best for you, your dosage for major and minor bleeds, your maximum dosage (if there is one) and how you respond. For example, with a dose of 1,000 units of factor VIII, you reach 40% of normal levels after 30 minutes, and still have 10% of normal after 24 hours. Know how to prepare your treatment product.

Assume a lifelong role as a teacher. You will continually find yourself in situations where you have to explain your condition. With your disorder being rare, you are your own best resource.

Obtain a copy of your CHARMS individual treatment protocol form

This form contains all of the information regarding the management of your bleeding disorder. Be sure that it is updated at your annual visit to the treatment centre or if there are any changes to your treatment plan (e.g. dosage levels, clotting products). Discuss with your treatment centre nurse how to have it kept on file at the emergency department in the hospital where your clinic is located. If you go to a different hospital, such as your local community hospital for emergency treatment, ask your treatment centre team to facilitate having this on file at your local emergency department.

Visit your local emergency department

If your local emergency department is in a different hospital than your treatment centre, call and set up an appointment to meet with an **emergency department** staff person, such as the nurse in charge, before a crisis occurs. Bring along any educational materials you have with regard to your condition such as:

- your *FactorFirst* or *TreatFirst* treatment card
- a copy of the instructional manual for health care providers: *Emergency Care for Patients with Hemophilia* or *Emergency Care for Patients with von Willebrand Disease* that can be obtained from the CHS or your treatment centre
- your treatment product including the package insert.



Emergency Care for Patients with von Willebrand Disease
An instructional manual for health care providers



Ask questions about how the **emergency department** works and what you can do to receive prompt, effective treatment there, in an emergency. It may be possible to have a “flag” on your name in the computer system so that when you appear in the **emergency department** and your name is entered, the staff is informed of your condition and directed to a chart containing information about hemophilia, VWD or other bleeding disorder.

Find out if your clotting factor concentrate is stocked in the blood bank of the hospital. If you use desmopressin (DDAVP injection, Octostim® injection or spray) or anti-fibrinolytics (Cyklokapron®), ask if these medications are normally stocked in the hospital pharmacy.



Cyklokapron
A Guide for Patients
and their Caregivers

Desmopressin
A Guide for Patients
and their Caregivers

If they are not, discuss with the staff at your treatment centre the possibility of putting a small quantity of your factor product (or other medication) in the blood bank or pharmacy of your local hospital. You must ensure that:

- the product is labeled for your use only;
- you replace the product well before it expires; and that
- you use the exchanged product to prevent wastage.

Prepare an emergency pack

Keep ready a cooler bag or backpack that contains everything you need to treat a bleed when you are away from home, or for an unexpected visit to the **emergency department**.

Leave the bag somewhere handy and take it with you as you would your purse or car keys on long trips, day excursions or any other place a long distance from home.

Keep the bag in the front seat of the car with you where it will be visible and accessible in an emergency. (It's not much good to you stuck in a smashed-in trunk.)

Place a label of some kind on the outside of the bag or backpack stating *Emergency Medical Supplies and Information*. That way, if you are in an accident, it is clearly identified for emergency personnel who will send the pack with you to the hospital.

Don't forget the pack in the car if it contains factor products. You are responsible for protecting them from freezing and overheating.



What to include in your emergency pack

- A copy of your personal emergency plan with contacts and phone numbers and a *FactorFirst* or *TreatFirst* treatment card.
- An empty Ziploc® bag for your treatment product. Pop in the treatment product along with a flexible ice pack, just before you leave the house. Be sure your name, address and phone number are boldly displayed inside the bag just in case it is ever lost or for quick reference by emergency personnel.
- Another Ziploc® bag already stocked with everything you need for an emergency infusion including:

- tourniquet	- butterfly needles	- adhesive tape & bandages
- gloves	- saline	- port needles*
- alcohol wipes	- Emla cream	- betadine and heparin*
- syringe	- gauze dressings	* if your child has a port
- An entertainment pouch filled with items to pass the time for you or your child such as books, crayons, hand-held video games and iPod. Be sure to include any "special" items for children such as a blanket, stuffed toy or small pillow.
- A utility pouch containing money for parking, snacks and change for telephones. Other important things to include are pen and paper/notepad, and a notebook with important phone numbers such as the school, neighbours and friends. Numbers that are normally familiar to you can be forgotten when you find yourself in a stressful situation.
- A first-aid pouch containing tissues, acetaminophen, thermometer, adhesive bandages, instant cold pack, alcohol swabs, anti-bacterial wet wipes or hand washing lotion.
- A clean towel that can be used as a surface on which to prepare treatment products or in which to wrap an ice pack or ice cubes to treat a bleed.

WHEN TO GO TO THE EMERGENCY DEPARTMENT

Go to the emergency department if you or your child:

- might have a head, neck or abdominal bleed (even without prior injury)
- feels a lack of sensation in an arm or leg
- has had an accident with trauma
- is experiencing uncontrollable vaginal bleeding
- experiences an uncontrollable nose bleed (more than 30 minutes)
- passes blood in the stool or vomits blood
- has any kind of unusual bleeding, such as in the groin
- is not on home infusion and you suspect a bleed
- is on home infusion but you can't access a vein



BEFORE GOING TO THE EMERGENCY DEPARTMENT

Follow instructions in your personal emergency plan

Call your treatment centre or the hematologist on call depending on the procedure in place at your clinic. Give the nurse/doctor details about you or your child:

- name
- health and hospital card numbers
- type of bleeding disorder
- severity
- type of bleed
- the treatment product used and current dosage
- the presence of an inhibitor or a port-a-cath
- other medication
- other complications or adverse reactions

Have a pen and paper ready to write down:

- the name of the nurse/doctor with whom you are speaking;
- any instructions he /she gives with regard to treatment.



IMPORTANT!

Ask the nurse/doctor at your treatment centre, or the hematologist on call, to phone ahead to the **emergency department**. This will let the staff know you are coming, and provide them with instructions on your treatment. If this is not possible, call ahead to the **emergency department** yourself.

Infuse first before you go to the emergency department

If you feel that the emergency is not life threatening and you or your child are on home infusion and able to access a vein quickly, infuse first before you go to the **emergency department**. Be sure to bring the empty factor vials and boxes with you to show the doctor which product you have infused.



IMPORTANT!

If you are on home infusion and are having trouble accessing a vein and your only option is to go to the **emergency department**, be sure to call ahead to your treatment centre and explain the situation. As your factor will already be mixed at this point, bring it with you but also bring along the empty vials, boxes and package inserts. Also be sure to have your *FactorFirst* or *TreatFirst* treatment card and any information describing your bleeding disorder.

Many health care workers will not infuse anything they have not prepared themselves. Assure them that you are on home treatment and that you only need someone to access a vein for you and that you will administer the product.

Bring along your emergency pack

Don't forget to pack your factor or other treatment product.

WHO'S WHO AT THE EMERGENCY DEPARTMENT

It's crowded, you're nervous, the **emergency department** staff are working as best they can. Everyone there wants to be seen... now! Luckily you're prepared... or are you?

Present your *FactorFirst* or *TreatFirst* treatment card along with your health card and/or hospital card to the first person you meet. This may be the **receptionist** or the **triage nurse**.

Receptionist/registration clerk

In some hospitals, this person does some triage* of patients. If you called ahead to the *emergency department*, or your treatment centre or hematologist called ahead for you, inform the person of this. This person will record information such as your name, health or hospital card numbers, address, etc. If this is the first person you meet, show your *FactorFirst* or *TreatFirst* treatment card. Make sure that your bleeding disorder is highlighted on your chart.

Triage* - The evaluation of cases according to urgency, from most urgent to least urgent. The Canadian Emergency Department Triage and Acuity Scale (CTAS) has now classified triage for major or moderate bleeds as LEVEL II or EMERGENT, which indicates emergent care is needed. Mild or moderate bleeds are assigned a CTAS LEVEL III, which indicates urgent care is needed.

Triage nurse

The triage nurse will ask you a few questions in order to assess your condition and determine how quickly you need to receive care. If the triage nurse feels your condition is urgent she may send you directly for treatment or she/he may send you to the waiting area.

Remember that in the **emergency department** patients are not seen on a first-come, first-served basis but on the urgency of their need for treatment.

If you are sent to the waiting room, ask the triage nurse if he/she can give you an estimate of how long you can expect to wait before receiving treatment. If the answer is much longer than you are comfortable with, once again, contact the hematologist on call for a second opinion.

Be sure to give the triage nurse all the pertinent information with regard to your bleeding disorder such as:

- type of bleeding disorder
- severity
- type of bleed
- the treatment product you use and the current dosage
- the presence of an inhibitor or a port-a-cath
- other medication
- other complications

Emergency department nurse

The nurse may assess you or your child's condition, record vital signs (heart rate, blood pressure, breathing, temperature) and provide basic treatment. She/he can answer any questions you may have and is the person to call on during your visit should you require any assistance. Remember the nurse's name and use it when speaking to her/him.

Tell her/him of your *FactorFirst* or *TreatFirst* rule and show her/him your *FactorFirst* or *TreatFirst* treatment card.

Make sure she/he knows the bleeding disorder you have, the type of bleed, the treatment product you use and if you or your child has an inhibitor or a port-a-cath.

State any concerns you have about your condition and treatment, such as the need for prompt infusion, the best needle size to use, and the easiest veins to access.

Know how to calculate your factor dosage. Offer to mix and prepare the factor for the nurse. Don't mix the factor without her/his consent, as she/he will probably want to be present to supervise. Generally nurses can only infuse a medication that they have prepared or for which they have supervised the preparation.

Remember, if the normal dosage is 500 units and the vial contains 1,000 units, the **emergency department** staff may want to infuse only half.

Refer them to your *FactorFirst* or *TreatFirst* treatment card. For many treatment products, there is no "overdose." The entire vial should be infused. Never waste factor!

Emergency department doctor

The **emergency department** doctor will conduct an examination and determine what treatment is necessary.

If you have asked your treatment centre or hematologist on call to phone ahead to the **emergency department**, make sure the doctor is aware of this call. Make sure he/she reviews any directions given by the hematologist about your treatment.

Tell him/her of your *FactorFirst* or *TreatFirst* rule and show him/her your *FactorFirst* or *TreatFirst* treatment card. If necessary, inform the doctor of the need for prompt infusion to stop any bleeding prior to doing any tests.

Make sure he/she knows the bleeding disorder you have, the type of bleed, the treatment product you use, and if you have an inhibitor or port-a-cath.

Make sure your treatment is fully explained to you. Don't be afraid to disagree if you feel that the treatment suggested is not the best one for your condition. Remember that you may be more informed with regard to your own bleeding disorder than either the **emergency department** physician or the hematologist on call.

If you feel you are not getting the right care, phone your treatment centre or the hematologist on call from the **emergency department** and explain the situation.

Remember to address the doctor by his/her name.



When talking to the emergency department staff

Speak up and say exactly what your concerns are. You need to be precise about your condition and your concerns. Make sure your bleeding disorder – for example, severe factor VIII deficiency hemophilia or Type 1 VWD – is clearly indicated on the triage form. It is not enough to simply write your symptoms – for example, a sore leg.

DON'T SAY: "My son has fallen and hurt his elbow."

DO SAY: "My son has severe hemophilia – factor VIII deficiency – and he is bleeding into his elbow joint. He will continue to bleed until he receives treatment. He needs to be seen and treated quickly with factor VIII."

If you feel that your condition is potentially life threatening, say so. Otherwise you could be sent to the waiting room to wait.

DON'T: Sit there worrying and feeling frustrated that you aren't being seen as quickly as you would like.

DO SAY: "I am bleeding. I may have had a miscarriage. I also have Type 2 von Willebrand disease, a bleeding disorder. This could be life threatening. I must see a hematologist. He knows what treatment I need. This is urgent."

TIPS FOR SUCCEEDING AT THE EMERGENCY DEPARTMENT

Stay calm

The emergency department can be a noisy, hectic place. You may feel stress because of your or your child's condition. Staying calm can be difficult, but it is important. The emergency department staff will find it easier to understand you.



Listen

Listen carefully to what the **emergency department** staff say so that you understand what they propose to do. Don't be afraid to ask them to explain if you're not sure you understand.

Speak up! Be assertive!

Tell the staff what you need and why you need it. State what the problem is and what concerns you have. If you don't understand something or disagree with a treatment, say so!

DO SAY: "My son has had a bad fall on to his head. He has hemophilia and I'm concerned that he may be bleeding internally in his brain. He needs to be seen right away."

DO SAY: "My daughter has von Willebrand disease. She is having her first period and is bleeding heavily. She has lost a lot of blood. She needs to be seen by a hematologist right away. Please call one now."

DON'T: Sit there worrying and feeling frustrated that you have to wait. The staff has probably heard of hemophilia or VWD before, but you can help them by reminding them that people with bleeding disorders suffer from prolonged bleeding if not given prompt, effective treatment.

Use positive, proactive ways of communicating with the emergency department doctor

DO SAY: "Have you read my *FactorFirst* (or *TreatFirst*) treatment card? It gives a really useful description of my bleeding disorder and the treatments that I need. The phone number for my bleeding disorder treatment centre is also listed in there for you to call."

DO SAY: "I see that the hematologist on call has prescribed Octostim® Nasal Spray for me but I find that the subcutaneous injections of Octostim® injectable work better for me."

Be knowledgeable about your bleeding disorder

Emergency department staff cannot possibly know everything about your bleeding disorder. Provide information to the best of your ability.

DO SAY: "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. I am under the care of Dr. _____ at the _____ Bleeding Disorder Treatment Centre. Here is the phone number. There is someone on duty who can advise you on my treatment."

Or perhaps you are a symptomatic carrier. Explain your low factor levels and once again urge the doctor to call your treatment centre for assistance.

Repeat yourself, if necessary

If you find you are not getting prompt treatment, approach the triage nurse again and calmly repeat your problem.

DO SAY: "I have hemophilia and I am bleeding into the calf muscle of my leg. I need to be seen and receive treatment right away."

DON'T SAY: "Hey, I'm a hemophiliac here and I need to see a doctor right away. You can't keep on making me wait!"

Be polite and courteous

The health care professionals are trying to do their jobs to the best of their abilities. Remember that patients with bleeding disorders such as hemophilia, von Willebrand disease or other even rarer bleeding disorders are not often seen at **emergency departments**. The person you meet may never have had the opportunity to treat anyone with your condition. It is unfair to expect them to know a lot about it.

Focus on the problem, not the people

You are there to receive treatment for a bleed and that is the problem at hand. If necessary, repeat to staff why you are there and why prompt treatment is important.

DO SAY: "I need to receive prompt treatment for this knee bleed. If not, there could be serious damage to the joint."

DON'T SAY: "This is ridiculous how long I have been waiting here. What are you people doing back there? It's your job to provide treatment for me so where is it? I'm calling the hospital administrator about this."

Use "I-statements" not "you-statements"

Don't tell the staff what to do. It is more effective to focus on your own needs. Don't get caught up in an argument about how long it is taking:

DO SAY: "I understand that you are very busy but I have hemophilia and I am bleeding internally. I need to be seen and receive treatment with factor concentrates quickly."

DON'T SAY: "You have to infuse me now before you do any X-rays."

Try rewording the request, using "I," to give the doctor useful information about your treatment.

DO SAY: "What I have been taught by my hematologist is to give factor first to control any possible bleeding, then to do X-rays for further diagnosis."

DO SAY: "I am concerned that this is a bleed and I feel that my son needs an infusion right away to stop the bleeding before he undergoes any X-rays or tests."





Be prepared for difficult situations

At times you may find yourself in the difficult situation where medical staff fail to understand your need for prompt treatment. They may refuse to follow your advice.

This can be very frustrating. Read the following statements, many of which may be familiar to people with bleeding disorders. Prepare responses to these statements in advance. If necessary, ask the nurse coordinator at your treatment centre for help in formulating responses. Then, if you are faced with these situations, you will be better able to answer.

Emergency department doctor: "How do you know your son has hemophilia?"

YOUR RESPONSE:
.....

Emergency department doctor: "I can't infuse this child until I have determined the cause of the bleeding. I'll need to order some blood work and a few X-rays first to be sure."

YOUR RESPONSE:
.....

Emergency department doctor: "I think this bleed in your leg will just resolve itself over time. It's probably just a pulled muscle. I really don't see the need for any treatment now."

YOUR RESPONSE:
.....

Emergency department doctor: "It's 3 a.m. I'm not going to call your treatment centre and get someone out of bed for advice. I'll just run some tests and we'll figure things out. Don't worry."

YOUR RESPONSE:
.....

Hematologist on call: "When you get to the emergency department, have them call me."

YOUR RESPONSE:
.....

Emergency department doctor: "How can you have a bleeding disorder? You're a woman."

YOUR RESPONSE:
.....

Phone your treatment centre again, if necessary

If you feel you are not getting the right care, phone your treatment centre or the hematologist on call once again from the **emergency department** and explain the situation. Feel free to contact the Patient Advocate or Patient Representative of the hospital to discuss your concerns.

Know your rights as a patient!

You have the right...

- to be treated in a respectful, courteous manner;
- to participate in decisions with respect to your health care;
- to be informed about any treatment proposed;
- to consult with another person before you consent to any procedure; and
- to refuse to consent to treatment.

HEADING HOME

Before you leave the emergency department

Be sure you are given follow-up instructions detailing what you are to do after you leave the **emergency department**.

These instructions could be...

- what medication to take: when, how much and possible side effects;
- what follow-up treatment products are needed;
- what signs or symptoms to look for indicating that the bleed has not stopped or has started again; and
- whom to contact for advice.

Before leaving the **emergency department** make sure that all of your questions and concerns have been addressed, that you understand the follow-up instructions fully and that you agree with them. If you still have concerns, contact your treatment centre or the hematologist on call once again.

Say thank you!

Usually the **emergency department** staff will be attentive to your particular needs and your visit will go well. When you have received prompt treatment and the staff have listened to your concerns, remember to say thank you. Remember! You may need the **emergency department** staff to work with you again in the near future.

DO SAY: "Thank you so much for your care today/tonight. I really appreciate that you saw me so quickly and that you listened to my ideas. You really did a great job."

You may also want to call/write the hospital directly and tell them of your visit and all the things the **emergency department** staff did right!

After a visit to the emergency department

After a visit to the **emergency department**, call your treatment centre the next day. Let them know the details of your visit and follow-up instructions. Keeping them up to date allows them to better manage your bleeding disorder.

Call the local chapter office or the national office of the Canadian Hemophilia Society to voice your concerns or to share stories of successful **emergency department** visits. Input from the bleeding disorder community is crucial in our efforts to promote better health care for our members.

CONCLUSION

Many **emergency department** visits go extremely well. You or your child are seen quickly, the staff listen to your concerns, treatment is prompt and effective and you go home with appropriate follow-up instructions and the peace of mind that things have been taken care of.

On the other hand, you must be prepared for the times when things do not go so smoothly. You may be confronted with a long line-up, staff that may not understand your need for prompt treatment or that refuse to follow your advice.

So, what will you do?

Remember!

- Prepare in advance.
- Stay calm.
- Be assertive.
- Use positive, proactive ways of communicating.
- Be knowledgeable.
- Show your *FactorFirst* or *TreatFirst* treatment card.
- Call your treatment centre for assistance if necessary.

