PASSPORT TO WELL-BEING
Empowering people with bleeding disorders to maximize their quality of life

Bon Voyage!
Travelling with a bleeding disorder

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Canadian Hemophilia Society
Help Stop the Bleeding
www.hemophilia.ca
Table of contents

Introduction ........................................................................................................................................... 3
What do you need to prepare before you travel? .................................................................................. 4
What do you need to know about transporting clotting factor concentrates? ..................................... 9
What preparations do you need to make with your treatment team? ................................................ 11
What can you do to arrange for special needs? ................................................................................... 12
What do you need to consider while travelling? ................................................................................ 13
Top 10 travelling tips ......................................................................................................................... 16
Resources ........................................................................................................................................ 17
Emergency numbers .......................................................................................................................... 18
Sample letter from hemophilia treatment centre ............................................................................ 19

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.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and under no circumstances recommends particular treatments for specific individuals. In all cases, it is recommended that individuals consult a physician before pursuing any course of treatment.

The CHS would like to acknowledge those people who contributed to the development of Bon Voyage! Travelling with a bleeding disorder.

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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

Travelling is often an adventure and sometimes a challenge. In today’s world, people with bleeding disorders work in all professions and many practice self-care. Therapies are easily transported, and specialized emergency care is now available in many parts of the world. Due to these major advances in care and treatment, there is no longer any reason to pass up the opportunity to travel.

Having a bleeding disorder does, however, pose added challenges, for example:

- getting through airport security and border crossings with factor products, needles and syringes
- packing bulky clotting factor concentrates
- ensuring you carry medical information in case of a medical emergency
- knowing where to find medical care in a faraway place
- arranging for special travel needs
- obtaining travel insurance.

With the right planning these challenges can usually be overcome. The goal of Bon Voyage!, the sixth in the series of Passport to well-being modules, is to help people with bleeding disorders reduce the risks of travel so they can enjoy their adventure to its fullest.
WHAT DO YOU NEED TO PREPARE BEFORE YOU TRAVEL?

Passport and visas
At the time of writing, you need a valid passport whenever you travel outside of Canada, except for the United States. It is the only proof of your nationality and identity that is accepted in all countries. Unlike a birth certificate or driver’s license, a passport can be replaced if it is lost or stolen on your trip.

When travelling by air to the United States, both children and adults need one of the following documents:
- a passport; or
- a NEXUS card that can be used at designated Canadian airports and at all U.S. airports when returning to Canada.

When travelling by land or water to the United States, adults need one of the following documents:
- a passport; or
- a NEXUS card; or
- a Free and Secure Trade (FAST) card; or
- an enhanced driver’s license (EDL) or enhanced identification card (EIC) from a province where a U.S.- approved EDL/EIC program has been implemented.

Canadian citizens aged 15 years or under are only required to present proof of Canadian citizenship, such as an original or a photocopy of a birth certificate, or an original citizenship card, when entering the United States by land or water. Canadian citizens 18 years of age or under who are travelling with a school or other organized group, under adult supervision with parental/guardian consent, may also present proof of Canadian citizenship alone.

A passport may be required for certain transactions, such as checking into a hotel or renting a car.

All countries have special entry requirements. Some require you obtain a visa before leaving Canada; others provide visas at the country's point of entry. Since those requirements may change, consult the nearest diplomatic embassy of the country you intend to visit. You may also consult Foreign Affairs Canada’s Travel Reports. These provide general information on most countries as well as information on entry requirements.

Travel reports and warnings
Foreign Affairs Canada’s Travel Reports also offer information on safety and security, local laws and customs, entry requirements, health conditions and other important travel issues.

Travelling to a country with a Foreign Affairs Canada’s Travel Warning may negate your health insurance and/or trip cancellation insurance. The decision to travel to these countries is the sole responsibility of the individual.
Medical information

Printed up-to-date medical information comes in several forms and is essential for a person with a bleeding disorder who is planning to travel. Contact your nurse coordinator well in advance of your departure date to ensure you have the following:

- **FactorFirst or TreatFirst card** – Canadian bleeding disorder clinics provide FactorFirst or TreatFirst cards to many of their patients. This card contains basic information on treatment of bleeding disorders, specific information on an individual's particular condition, and contact information for the person's treatment centre. If you don't have one, ask.

- **MedicAlert® ID** – A MedicAlert® bracelet or necklace is visible to emergency medical care providers. It contains basic information about a person's health condition and a number to call for more details. As the FactorFirst or TreatFirst card is often hidden away in a wallet, the MedicAlert® ID is especially useful if the person is unable to communicate.

- **Letter of authorization to carry concentrates, needles and syringes, contact information for HTC** – Very few people travel with needles and syringes. Even fewer travel with clotting factor concentrates: little vials full of white powder. Border officials and airport security personnel are not accustomed to seeing them.

Airlines can prohibit needles and syringes on board an airplane unless the person carries a document proving medical need. Therefore, it is extremely important to carry a personalized letter from your treatment centre describing what medications and supplies you have to take with you and why you must carry them with you. The letter needs to be up-to-date, in English and should include:

- Name of patient
- Description of medical disorder
- Contact information for treatment centre
- Name of physician
- Type of medication (brand name, generic name)
- Types of supplies (e.g. butterfly needles, syringes)
- Types of implants that might set off security alarms (e.g. knee replacement, port-a-cath...)

See page 19 for a sample letter.

"I believe that many issues regarding travelling with medication can be resolved with strong preparation and working closely with your bleeding disorder clinic."
Taking clotting factor concentrates into the U.S.
Be aware that some clotting factor concentrates, especially those for rare bleeding disorders, are not FDA-approved and you are not permitted to take them into the U.S. Check with your clinic team about your specific product.

Travel insurance
Travel insurance for a person with a bleeding disorder is a complex question.

The first recommendation is to travel with a sufficient supply of clotting factor concentrates or other medication for the duration of your trip. Talk to your clinic team about this.

Within Canada, provinces (with the exception of Quebec) have reciprocal agreements. As a result, a person's health care costs, including clotting factor concentrates, would be paid in full outside his home province.

It is a different story outside Canada. Provincial health care plans may pay the expenses a person incurs abroad up to the amount that would be reimbursed in your home province. In many countries, notably the United States, the cost of health care is higher than in Canada. Without private insurance, you would have to pay the difference between what is charged in the country you visit compared to what is reimbursed in Canada. This could be many thousands of dollars.

Supplemental private travel insurance (for example, Blue Cross) is therefore highly recommended. The key question, however, is whether private travel insurance will reimburse claims for costs related to a pre-existing condition. Bleeding disorders are pre-existing conditions. Answers vary from company to company and person to person.

An insurer may agree to cover a pre-existing condition if, in the last 3 or 6 months, you have not...
- consulted a physician (other than for a regular checkup); or
- been hospitalized; or
- been prescribed or received a new treatment; or
- received a change in an existing treatment; or
- been prescribed or taken a new medication; or
- received a change in existing medication.

Sound advice is therefore to shop around. Just because one company refuses to insure you does not mean that another will do the same.

When applying for insurance, always tell the truth about your bleeding disorder. Failure to provide all health information will void any claim.

You may also be able to obtain automatic coverage if you buy your airline ticket with a credit card that provides travel insurance. A workplace health insurance program may also cover you outside Canada.
“I was travelling in a remote region and had a serious health problem. I had to be evacuated by air ambulance. The travel insurer refused to pay the costs, which were thousands of dollars, because of my pre-existing condition, hemophilia. I eventually won my case, because my health problem was unrelated to my bleeding disorder, but it was a long and difficult fight.”

“I have severe hemophilia. I was travelling in Europe for the summer and applied to three companies for travel insurance. They all turned me down.”

“I visited my family in Florida. My son hit his head on a fence and had to go to the ER for treatment, including FVIII concentrates. He even had a CT scan. My travel insurance paid for everything.”

“If you have travel insurance, NEVER pay medical services before contacting the insurance company. Fees are never the same for non-insured patients. One hospital tried to collect double what they would have charged an insurance company.”

“My health insurance at work pays up to one million dollars in medical costs if I have a health problem outside Canada.”

See the CHS Web site for more information on travel insurance.

List of hemophilia treatment centres on itinerary
It is essential to have a list of all the hemophilia treatment centres (HTCs) on your itinerary. The World Federation of Hemophilia publishes an annual list of the HTCs in over 100 countries. If you run into trouble abroad, these are the best places to seek help. See Resources on page 17.
Emergency contact information
Carry several copies of your emergency contact information. Keep them in different parts of your luggage. This should include:

- Emergency contacts at home
- Your treatment centre contact information
- Contact information for treatment centres on your route
- Travel insurance provider information
- Health insurance provider information

Fill out and take along the CHS Travel Card available at your HTC and from the CHS national office.

Photocopies of all important documents
Make photocopies of all important documents. Keep them in a separate, but safe, place. These should include: passport, visas, other ID, travel letters and insurance policies. An alternative to paper copies is to scan the documents and e-mail them to your own account.
WHAT DO YOU NEED TO KNOW ABOUT TRANSPORTING CLOTTING FACTOR CONCENTRATES?

Airport security
Going through airport security can be stressful and unpleasant at the best of times. It can be even worse if you are carrying precious medication such as clotting factor concentrates. And, if your connection time is tight, any delay may cause you to miss your flight...

Knowing and following the rules is the best way to ensure easy passage.

Generally, in most countries, people are allowed to carry liquids and gels up to 100 ml in their carry-on baggage. At the security check, these liquids must be removed from the baggage and placed in plastic bags to be checked separately.

Medications, including liquids such as sterile water diluent used to mix factor products, are subject to different rules.

Prescription medication
Transport Canada states, “Liquid prescription medications are exempted from the liquid restrictions and can be carried in carry-on baggage in volumes larger than 100 ml (3.4 oz.). These liquids must be declared to the Screening Officer separately. Ensure the medication is properly labelled (professionally printed label identifying the medication or a manufacturer’s name or pharmaceutical label) and displays a matching name with the name printed on the passenger’s ticket/boarding pass.”

Therefore, it is extremely important to carry a personalized letter from your treatment centre describing what medications you have to take with you and why you must carry them with you. (See Sample letter on page 19)

Needles and syringes
Airlines and airport security can prohibit needles and syringes on board an airplane unless the person carries a document proving medical need.

Transport Canada states, “Hypodermic needles must be for personal medical use, and the needle guard must be in place. The person must possess medication that is to be administered by means of the syringe or needle and biojectors, and the medication must be in a container that bears the name of the medication and the name of either the pharmacy that dispensed the medication or the manufacturer of the medication.”

Therefore, the letter from your treatment centre must also mention the supplies needed for self-infusion, that is, needles and syringes.

Airport security rules change on a regular basis. Visit the Transport Canada Web site (www.tc.gc.ca/eng/air-menu.htm) or your airline’s Web site to find out the latest regulations.
Temperature considerations

In the past, clotting factor concentrates needed to be stored at a temperature between 2 and 8 degrees Celsius. This meant travellers needed to carry bulky coolers and ice at all times. In recent years, many factor products have been approved for storage at room temperature, up to 25 or 28 degrees for periods of 3 to 12 months, depending on the product.

Check the package insert (or product monograph) for precise instructions on the product you use.

NEVER leave factor in the car in the hot sun.

“When I was first planning to travel to India, I had grand plans to travel on to Thailand and Laos, but when I realized that I could not guarantee the safety of the product for such a prolonged time, I instead focused on my stops in India. I travelled for two months in a warm climate and kept my product safe and had an amazing experience.”

Packing

Boxes of clotting factor concentrates can be very bulky. Many travellers remove the vials, syringes and needles from the boxes and re-package them in a neat, compact carrying case designed for this purpose. Some cases are even insulated. Use bubble wrap to avoid breakage.
WHAT PREPARATIONS DO YOU NEED TO MAKE WITH YOUR TREATMENT TEAM?

Discuss your travel plans with your treatment team and inquire if you should make any changes to your usual treatment. (Note that changes to treatment protocols could affect eligibility for travel insurance. (See Travel insurance on page 6.)

These are some of the questions you need to ask:

- Should you take a dose of factor before boarding the plane?
- Should you change your prophylaxis schedule or temporarily adopt a prophylaxis regime?
- How many doses of your treatment (factor concentrate, desmopressin or antifibrinolytic) should you take?
- How should you pack and store your medications?
- How should you keep your infusion records while you are travelling?
- Do you need to carry prescriptions for these medications?
- Should you bring analgesics with you and, if so, which ones?
- Should you bring a First Aid kit with you and, if so, what should you put in it?
- Do you need to see a travel clinic for vaccinations?
- Should you contact the HTC at your destination before leaving home?
- Should you sign a Release of Medical Records form at your HTC so your records can be forwarded to another health care facility if needed?
- What should you do in an emergency?

The Canadian Association of Nurses in Hemophilia Care (CANHC) has published a booklet called Planning Travel: A Guide for People with Bleeding Disorders. You can use this booklet with your treatment centre staff to plan the medical aspects of your trip. Contact your HTC or the Canadian Hemophilia Society for a copy.
WHAT CAN YOU DO TO ARRANGE FOR SPECIAL NEEDS?

Mobility assistance at airport
The world’s airports are getting larger and larger. Some airports have up to five separate terminals with long distances between them to be covered on foot, by bus or by train.

To help travellers with mobility problems, airlines and airports offer mobility assistance. This can take the form of a wheelchair or electric cart, or a combination of the two. In Canada, the airline has responsibility for helping its customers. In European Union countries, it is also the responsibility of the airport operator to provide assistance to anyone with a disability during his time at the airport.

If you expect to need assistance at any airport on your itinerary, contact your airline, when possible at least 24 hours in advance, so it may provide the airport operator with any required advance information.

Beware! Quality of service varies. While mobility assistance in airports can be a godsend, it can also be a nightmare. Often, the wheelchair is not waiting when the flight arrives at its destination. There can be delays in moving through the airport, especially the larger ones. You may not always be treated with dignity.

“I was flying from Canada to Ireland through Heathrow in London. I knew I had to change terminals in Heathrow and that it was a very long walk. I requested a wheelchair. It wasn’t there when the plane landed so I had to wait on the plane. In the end, to make my connection, I rode four wheelchairs, two electric carts and a bus. Seven times I was told, ‘Sit here and wait!’ In all, it took two and a half hours to get to my next gate. I made it with five minutes to spare.”

“I asked for a wheelchair when arriving in Cairo. It was ready when the plane arrived. The driver was pleasant and he whisked me through customs and immigration ahead of everybody. I was like a VIP.”

“I was travelling through Toronto and was on crutches. I asked for a wheelchair at check-in. They stuck me in a corner with three other people in wheelchairs and said somebody would come to get us. When it was almost time for my flight to depart, and no one had appeared, I got up and hobbled to my gate.”

Special seating on planes
By contacting your airline, it is possible to request a seat:

- with movable armrests
- close to the washrooms and exits
- with extra legroom.

Express lines
At some tourist attractions, you can request a special pass so as not to have to wait in line.
WHAT DO YOU NEED TO CONSIDER WHILE TRAVELLING?

Treatment before departure
It is often a good idea to take a treatment just before departure, especially if the trip is to be long and arduous.

Getting through airport security
You have every right to carry medication and supplies through airport security. (See What do you need to know about transporting clotting factor concentrates? on page 9.)

Security scanning machines are more and more sophisticated. Nowadays, vials of clotting factor concentrates and diluent rarely alarm security personnel. If they do, and staff ask to inspect the bag carrying your medication, agree and explain that you are carrying prescription medication for your own use and you have a letter of authorization from your physician.

"When the security person opens my bag with my factor, I explain that each vial is worth a thousand dollars. When I tell them this, they usually decide not to touch anything."

"Before I started travelling I thought that carrying my products on board would bring me a lot of frustration... but it almost always went smoothly. It's very surprising how often, even in the United States, they do not even notice the products in my bag. It seems to me they are better at finding toothpaste tubes than my needles and factor."

"The first time I took a plane, I had a letter from my physician explaining why I needed to carry my products. This letter was only in French. The security in Edmonton found my product and I only had this letter in French to explain the reason. Since it was in Canada, the person at the security faked knowing how to read French and let me through. I think it is always better to have a letter at least in English and even better in the language of the country you are going to."

If the security person insists on touching the vials, explain that the vials are sterile and request that he changes gloves. If he insists on testing them for controlled substances, request that he use a fresh swab.

If he threatens to take action that puts your medication at risk (e.g. wanting to open a vial to test it), stay as calm as you can and explain that the medication is vital and must not be tampered with. If he persists, immediately request to speak to his supervisor.
Infusing en route
The stress and strain of travel can often be the cause of bleeds. Finding a suitable place to infuse is not always easy.

If you need to infuse on a train or plane, explain your situation to the conductor or flight attendant and ask for a place where you have sufficient room and can concentrate.

In an airport, if you cannot find a quiet, suitable location to infuse, ask for help in finding a First Aid station. Your own airline is likely to be most helpful as you are its customer.

If none of these suggestions work, find a table (as secluded as possible), lay out your supplies and give your infusion. There is no reason to be shy!

See What to do with “sharps” on next page for tips on how to dispose of needles safely.

Carrying and storing medication
Never keep your medication in your checked luggage!
Always keep it with you. Checked luggage can be lost for days, or even forever.

Even if your products can be kept at room temperature, in hot climates you may need to pack them in a bag with ice. Room temperature is defined as 25 or 28 degrees Celsius. Above this temperature, your products are at risk of slowly losing potency. The temperatures in hot countries, or even hot vehicles, often exceed these limits. If that is the case, you will need to carry ice packs with your supplies.

Infusion records
It is just as important to keep good infusion records while travelling as when at home.

If you use a paper-based infusion record, take your forms along with you.

If you use an electronic or Web-based device, and can’t take it with you, make your own paper log. Record:

- Date and time of infusion
- Lot number
- Number of units infused
- Reason for infusion: Bleed (indicate site), prophylaxis or immune tolerance induction therapy

See the Passport to well-being module Charting your course for more about why keeping infusion records is so important for you.
What to do with “sharps”

It is critical that “sharps”, that is, needles, be disposed of safely after use.

If you don’t have a “sharps” container, carefully replace the plastic guards on the needles and store them together inside another secure container. Carry these in a safe place such as a special compartment of a suitcase or backpack. If your trip is relatively short, bring them home to dispose of in your “sharps” container.

If your trip is longer, find a medical facility that will accept to dispose of them for you. Some airports have “sharps” containers in washrooms.

Vials and syringes can be discarded in the regular waste disposal.

Air Canada states: “Passengers needing to dispose of a used syringe while onboard the aircraft are required to advise a member of the cabin crew. A sharps/syringe disposal container will then be made available to the passenger for safe disposal. Seat pockets must not be used to dispose of used syringes.”
TOP 10 TRAVELLING TIPS

1. Discuss your travel plans with your treatment team.
2. Carry a personalized letter from your treatment centre describing what supplies you have and why you must carry them with you.
3. Carry an up-to-date FactorFirst or TreatFirst card.
4. Wear a MedicAlert® necklace or bracelet.
5. Have a list of all the hemophilia treatment centres on your itinerary.
6. Carry several copies of your emergency contact information.
7. Obtain travel insurance, if possible.
8. Check the package insert (or product monograph) for precise instructions on the storage conditions of the product you use.
9. Never keep your medication in your checked luggage! Always keep it with you.
10. Keep good infusion records while travelling.
RESOURCES

Transportation
Transport Canada: Air Transportation
www.tc.gc.ca/eng/air-menu.htm

Air Canada: Customers with special needs

WestJet: Special Needs Guests

Customs and Borders
Foreign Affairs and International Trade Canada: Travel Reports and Warnings
www.voyage.gc.ca/countries_pays/menu-eng.asp

Foreign Affairs and International Trade Canada: Before You Go
www.voyage.gc.ca/preparation_information/menu-eng

Foreign Affairs and International Trade Canada: Canadian Consular Services
www.voyage.gc.ca/about-a-propos/role-eng.asp

U.S. Customs and Border Protection
www.cbp.gov

Health resources
Canadian hemophilia treatment centres
www.hemophilia.ca/en/treatment-centres

International hemophilia treatment centres
www.wfh.org
Click on Find a Treatment Centre

Canadian MedicAlert Foundation
www.medicalert.ca

Public Health Agency of Canada
EMERGENCY NUMBERS

Emergency contact at home
Name .........................................................................................................................

Phone 1 ......................................................................................................................
Phone 2 ......................................................................................................................

Hemophilia treatment centre at home
Name .........................................................................................................................

Phone 1 ......................................................................................................................
Phone 2 ......................................................................................................................

Hemophilia treatment centres on itinerary
Destination 1

..............................................................................................................................

Phone ......................................................................................................................

Destination 2

..............................................................................................................................

Phone ......................................................................................................................

Destination 3

..............................................................................................................................

Phone ......................................................................................................................

Travel insurance provider ..........................................................................................

Health insurance provider .........................................................................................

Other ........................................................................................................................
(Name of hospital)
(Name of hemophilia treatment centre)
(Date)

To whom it may concern,
(Name and address of patient)
(brand and generic names of product, lot number)

I hereby confirm that this patient is a person with (type of bleeding disorder). He is authorized to carry the above-mentioned coagulation products and to inject them in case of hemorrhage. He is also authorized to carry the needles and syringes required for this treatment.

For asepsis and safety reasons, these vials must remain sealed until preparation.

The patient must carry this medication with him at all times.

Sincerely,

(Physician signature)