

Managing your bleeding disorder



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This booklet has been prepared to help you understand how to manage your bleeding disorder. It contains general educational material and is not intended to constitute medical advice or the rendering of medical care. Accredo is not licensed to practice medicine. The diagnosis and treatment of bleeding disorders should only be undertaken by, or under the direction of, a qualified physician or board certified health care practitioner.



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At Accredo, your specialty pharmacy, our goal is simple — to enhance the quality of life for people affected by bleeding disorders, such as hemophilia or von Willebrand (VWD) disease. You have an Accredo team dedicated to your care — nurses, pharmacists, clinicians, and insurance and field representatives who have been trained on bleeding disorders to support your therapy needs. Our unique support program is built upon our strong history of innovation, and our deep personal commitment to you and the bleeding disorders community. We're here to help you achieve the highest level of health possible.



Lesley
Bleeding Disorders Pharmacist





Your Accredo support

We work closely with you, your health care providers, your insurance company and your community to provide the highest level of individualized care. Your team is available 24 hours a day, every day of the year. You can reach us any time at 866.712.5200.

Telephonic nurses and nurse managers assist with patient issues, help to establish home health nursing, and answer questions you may have.

Nurse educators teach patients, employers, schools, emergency rooms and insurance companies about bleeding disorder care.

Insurance representatives obtain prior approval for your factor order from your insurance company (or payer) before shipping and help explain insurance paperwork.

Pharmacists review your prescriptions, monitor for any drug interactions, and are available for medication counseling while coordinating care with your prescriber.

Home care nurses complete infusions at home, work or school, while educating on care and independence.

Field patient advocates ensure your specific treatment needs are supported by the programs and services offered by Accredo or within the community.

Customer service representatives contact you regularly to ensure you have the clotting factor and supplies you need.

Our services and programs

Since 1990, Accredo has served the needs of individuals (both those diagnosed with a bleeding disorder and caregivers), clinicians and health plan partners with therapy monitoring and support services designed to:

- + Prevent bleeds
- + Minimize number of infusions to treat bleeds
- + Eliminate avoidable ER visits
- + Manage cost by getting the right medication quantity to you
- + Improve satisfaction and quality of life

When to call us

When you begin service with Accredo, your nurse or pharmacist will gather vital information. Keeping records up to date will help us better serve you.

Please contact us if any of the following changes occur:

- + You suspect you are having a reaction to your medication or have developed a new allergy (be sure to contact your doctor first)
- + You have planned a dental, surgical or invasive medical procedure
- + You have been hospitalized
- + Your address changes
- + Your phone number changes
- + You are unavailable to receive an upcoming shipment
- + Your sharps container is three-quarters full
- + Your insurance provider or policy changes
- + Your doctor changes your bleeding disorder prescription or treatment regimen
- + You start attending college away from home
- + You have an infection
- + Your doctor diagnoses an inhibitor
- + You have fewer doses on hand than the number of doses recommended by your hematologist
- + You have to evacuate your home due to severe weather or a natural disaster
- + Your medications have changed or you are taking a new medication

Questions to expect

Your customer service representative will ask you a series of questions to identify potential needs. These questions may include:

- + Have you had any weight changes? Your weight affects accurate dosing.
- + Have you had a bleed since we last spoke or have you used any extra doses in anticipation of increased activity? This information helps us monitor for a target joint or inhibitor development. Many insurance plans will not allow extra doses to be dispensed if all doses are not documented correctly.
- + Have you had any emergency room visits, hospitalizations or unplanned hematologist or nursing visits?

While questions like these may seem unrelated, your answers give us a snapshot of your current health. We can track your medication trends or be on the alert for potential complications, such as a target joint or an inhibitor.



Accredo provides a complete range of services and programs, delivered by people focused exclusively on serving the people in the bleeding disorders community. We can help you with the tools to manage your bleeding disorder and not let the bleeding disorder manage you.

hemophilia.com

Find guidance on recognizing bleeds, understanding treatments and managing your condition at all stages of life, along with other helpful resources.

Educational materials

Our age-specific educational resources provide up-to-date information about living with a bleeding disorder.

Educational programs

Our educational specialists present programs and host workshops tailored to the specific needs of the local and national community. They're available in your area, including our Junior Care ForceSM program that's designed to help children of all ages learn the basics of living with a bleeding disorder through play. Contact your Accredo field patient advocate to find out more.

Medication shipments

Each shipment includes information about your order, as well as a customer comment card where you can provide your feedback.

Inside each order, you will find the following items:

- + Delivery verification record (DVR)
The DVR is a list of all items (factor and supplies) included in your shipment. Please refer to your DVR when unpacking your shipment to make sure your order is complete. Please return a signed copy to our team in the enclosed business reply envelope.
- + Business reply envelope
Use the enclosed business reply envelope to send us your customer comment card, signed DVR, copies of your treatment logs, or other correspondence.

Storing factor and supplies

Store your medication and supplies away from children, pets and household items, avoiding extreme temperature, moisture or light.

Make sure you have adequate injectable medication, Stimat®[®], oral medications and infusion supplies on hand, if applicable, by regularly checking the quantity and expiration dates of your stock. Accredo will call you on a regular basis to verify your home inventory. If you notice you are running short on any supplies or if you only have three doses on hand, then please call your customer service representative at 866.712.5200.

You can keep your medication inventory up to date by following a few simple steps:

- 1 Confirm your shipment is complete, then sign your delivery verification and return it to Accredo.
- 2 Make sure no bottles were broken during shipment. If this occurs, contact your customer service representative about returning and replacing them.
- 3 Most factor products need to be refrigerated. Be sure to check the manufacturer's package insert inside the medication box to confirm storage information. Extreme high or low temperatures can affect medication potency.
- 4 Use infusion supplies with the earliest expiration date first.
- 5 Order medication and any supplies you need at the same time.



Rotating your medication inventory

Medications should have the expiration date printed on the box, or on the container itself. When you receive a factor shipment, put it in your refrigerator as soon as it is unpacked, placing the factor with the earliest expiration date in the front.

If you have any questions about the handling of your medication, please contact your Accredo team at 866.712.5200.





Pain management

Individuals with bleeding disorders can experience pain due to their condition. Pain can be protective and is your body’s way of saying “pay attention to where you hurt.” You can significantly modify how pain affects you by understanding the types of pain and how to manage it.¹

There are two kinds of pain in people with bleeding disorders:

- 1 **Acute** pain is caused by active bleeding into a joint or muscle. Acute pain is a signal that something is wrong. While some individuals may notice a tingling in a joint, pain may be an early sign of a bleed, too. A bleed that is ignored will put pressure on the muscles and other structures, making the pain much worse. While the pain can be severe, acute pain can usually be controlled through treatment products and RICE (rest, ice, compression, elevation).²
- 2 **Chronic** pain is caused by long-term or repeated joint damage. People often have to endure it for a long time, if not a lifetime. Chronic pain usually develops around parts of your body that cannot be fixed – the damage is sometimes permanent.³ As a person with a bleeding disorder ages, chronic pain may increase and may include arthritis.⁴

Describing your pain to your doctor

You may use a pain scale to determine your level of pain. Your doctor may also want to know how your pain felt. Is it shooting, sharp, dull, burning, constant, on-and-off or deep?

Many people find it helpful to keep a pain journal. You can record where you hurt, what the pain feels like, what caused the pain (injury or spontaneous), how long it lasted, steps you took to alleviate the pain and if these steps made you feel better or worse. Also, write down if your pain kept you from sleeping through the night or doing common daily activities.

Stopping pain before it starts

Pain can be avoided by preventing bleeds. Infuse factor as prescribed by your hematologist. Use protective devices, such as helmets, knee and elbow pads, and shin guards when appropriate or as advised by your hematologist. Maintain optimal health by eating properly, exercising regularly and getting plenty of rest.

You can also avoid pain associated with the infusion process by using a topical anesthetic cream before needle sticks, if advised by your hematologist.

Strategies for dealing with pain

Some people may “tough it out” when it comes to pain, but not treating pain can affect your quality of life. Different people need different methods to resolve pain. Some techniques may work for you, while others may not. Some methods you can do for yourself, while others require help from health professionals.



Factor

Pain from a bleed can be controlled by infusing clotting factor to stop the bleeding as soon as a problem is identified. Even if no other obvious signs of bleeding are evident – such as swelling – treatment is recommended. “If in doubt, treat” is the motto used by most experts in bleeding disorder care. Follow your hematologist’s instructions for administering medication.

If your regular dose of medication does not seem to relieve the pain, contact your hematologist immediately. You may have developed an inhibitor, or there may be another reason – besides a bleed – for your pain.⁴



Pain medications

Certain medications can relieve pain; however, do not take any aspirin-containing medication and NSAIDs like ibuprofen, unless approved by your hematologist, since they can prolong bleeding. Be sure to check with your Accredo pharmacist, nurse, or doctor before taking any over-the-counter products. If prescription pain medication is ordered, it should be taken exactly as prescribed and monitored for effectiveness. Follow up with your hematologist if the pain does not go away.

Please refer to the Medication Management section on pages 13-16 for more information.



Exercise

Another key to coping with pain is following an exercise program designed by your hematologist or physical therapist. Physical exercise has an important effect on overall function in people with bleeding disorders. People who are physically active experience fewer health problems than those who are sedentary.⁴

Your program should include special range-of-motion exercises to help keep your joints moveable, as well as general fitness exercises, such as swimming or walking, to help keep your heart, lungs, bones and muscles strong. Be sure to warm up first, and know when to cut back.



Relaxation and stress reduction

Relaxation can help reverse the physical and emotional effects of pain. The best time to use relaxation to manage your pain is before the pain becomes too intense.⁴ Many people find the following relaxation methods helpful: guided imagery, prayer, breathing exercises, biofeedback, hypnosis or relaxation audio tapes.

Assistive devices

Splints or braces can help support damaged joints and prevent further injury. Your doctor may recommend wearing a supportive device during certain activities, all day, or only at night.⁴

RICE (rest, ice, compression and elevation)

These therapeutic measures have been widely recognized by health care professionals as a first step of treatment for many types of injuries. For individuals with a bleeding disorder, these steps have been used to help ease pain and decrease swelling associated with joint bleeds or an injury in a joint.



RICE treatment assists in controlling bleeding; however, it should never be a substitute for factor replacement.^{2,5} As with any injury, always follow your doctor's recommendation on factor replacement.

Rest

To reduce the risk of re-bleeding, protect the joint from repeat injury by resting the affected joint and limiting activity.² Your doctor may recommend immobilizing the joint with elastic bandages, slings or splints, or using crutches.

Ice

Apply ice packs to bruises or swelling to reduce swelling and decrease pain.^{2,4} Put a cloth between the ice pack and your skin, as ice applied directly can cause burns. Don't leave the ice pack on for more than 15–20 minutes at a time. Check your skin frequently to be sure it is not too cold (evident as white or purplish coloring of the skin). Follow your doctor's instructions regarding how often to apply ice packs.

There are many specialty products on the market designed to deliver cold therapy. A sack of frozen peas or a wet washcloth that has been kept in the freezer in a zipper-style plastic bag also make handy ice packs.

Compression

Compression of the affected joint not only helps relieve pain but also helps to improve joint function. Your doctor may recommend compressing the affected joint with some type of bandage, such as an elastic wrap. The bandage should fit snugly enough to provide support without cutting off circulation.

Elevation

Elevating the joint helps minimize swelling because it aids in the reabsorption of collected fluid. The affected joint should be elevated above the level of the heart for best results. This position can be achieved by placing a few pillows under the affected joint.

Pain in children

As your child grows and matures, the ways he or she deals with pain will change. Listen to your child as pain-coping skills are developing. Encourage your child to express what he or she is feeling. For example, have him or her describe the pain. Is it shooting, sharp, dull, burning, constant, on-and-off or deep?¹

Keep a journal of your child's pain to track the following information: where your child is hurting, what the pain felt like, what caused the pain (injury or spontaneous), how long it lasted, steps taken to alleviate the pain and if these steps made your child feel better or worse. Also, write down if your child's pain kept him or her from sleeping through the night or doing common daily activities. Share this journal with your child's hematologist to help him or her detect any patterns in your child's pain experience.

Use a pain scale to determine your child's level of pain. For younger children, a smiley face scale may be more effective because they simply have to point to the face that best matches the way they feel. Older children may prefer to use a pain scale that uses numbers.

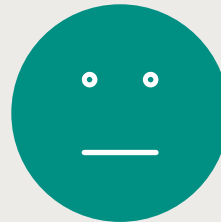
Pain scale



0
No hurt



2
Hurts little bit



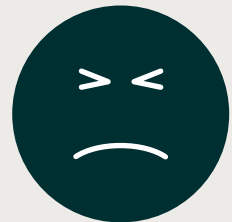
4
Hurts little more



6
Hurts even more



8
Hurts a whole lot



10
Hurts worst

Recognizing your child's pain⁶

Infants ≤12 months	Toddlers 1-5 years	School-age 6-12 years	Teens 13-18 years
<ul style="list-style-type: none"> + Cry harshly or in a high-pitched voice + Whimper or groan quietly + Seem irritable or less playful + Eat less than normal + Bite or squeeze lips + Frown or squeeze eyes tightly shut + Unable to be comforted + Pull knees to chest + Avoid moving or move around trying to find a comfortable spot + Pull the hurting body part away from your touch + Sleep more or less than usual 	<ul style="list-style-type: none"> + Cry intensely or whine + Tell you he/she hurts + Decreased playfulness or activity level + Eat less than normal + Protect where it hurts + Exhibit physical resistance by pushing painful stimuli away from the hurting body part + Sleep more or less than usual 	<ul style="list-style-type: none"> + Tell you he/she hurts + Decreased activity level in a normally active child + Eat less than normal + Limp or avoid using the injured area + Protect the hurting body part + Sleep more or less than usual + Try to conceal the injury or pain from his family, teacher, or nurse 	<ul style="list-style-type: none"> + Tell you he/she hurts + Decreased activity level + Eat less than normal + Limp or avoid using the injured area + Protect the hurting body part + Sleep more or less than usual + Try to conceal the injury or pain from family, teacher or nurse







Medication management

Prescriptions, over-the-counter (OTC) medications and herbal supplements

It's important for your hematologist and specialty pharmacy to know all medications you are taking, including herbs, vitamins, supplements and OTC (non-prescription) medication. Maintaining an accurate and complete medication list will allow health care providers to check for possible interactions. Always keep a list of medications with you. This list should be updated routinely and shared with your health care team, including the Accredo team dedicated to caring for you.

Avoid medications that may affect clotting or cause a bleed.

Manufacturers change the formulas of their brand-name products from time to time so always read the label and consult your doctor or pharmacist before taking any new medicines.



Some medications may prevent your blood from clotting, worsen side effects of other drugs or even prevent other medication from working correctly.

Aspirin (salicylates) and non-steroidal anti-inflammatory drugs (NSAIDs)

Aspirin-containing products and NSAIDs, such as ibuprofen, are used to decrease pain and inflammation. As a person with a bleeding disorder, you should never take medications that contain aspirin unless specifically directed by your hematologist. Taking aspirin can prevent your platelets from functioning correctly, which can keep your blood from clotting. Aspirin and NSAIDs can also irritate your stomach lining, which leads to bleeding.^{2,7}

Aspirin and NSAIDs are found in many cough and cold remedies, fever reducers, and pain relievers. so make sure you read the ingredients list.



Many medications list aspirin by its chemical name, acetylsalicylic acid. Sometimes it is listed as ASA. If you are not sure whether an OTC medication contains aspirin, talk to your specialty pharmacy.^{2,7}

Cox-2 inhibitors

A Cox-2 inhibitor, such as celecoxib, is a type of NSAID that causes fewer bleeding problems than traditional NSAIDs. Cox-2 inhibitors are often used to treat arthritis and, in laboratory tests, have not been associated with platelet malfunction. A prescription from your hematologist is needed before you can take this type of medication.



Acetaminophen is found in more than 600 OTC and prescription medications, including pain relievers, cough suppressants, sleep aids, cold and allergy medication and fever-reducing products.

Acetaminophen⁸

Because aspirin can be harmful to people with bleeding disorders, many hematologists recommend acetaminophen for their patients. Acetaminophen is safe and effective when taken as instructed, but taking too much may lead to severe liver damage. To avoid accidental poisoning with acetaminophen, take NO MORE than the label recommends. You should not take acetaminophen for more days than recommended.

Make sure you take only one product that contains acetaminophen at a time.

Parents should be cautious when giving acetaminophen to children. Make sure you give your child or infant the age-appropriate formula, and follow the proper dosing instructions for that formula and the weight of the child. Do not give a child more than one product that contains acetaminophen. Use the measuring device included with the product, if applicable.

Anticoagulants (oral and injectable) and anti-platelet agents

Anticoagulants, or blood thinners, by their very nature may lead to bleeding complications if not closely monitored. If these medications are needed, monitoring by a doctor is essential. These include heparin, warfarin, low molecular weight heparins, thrombin inhibitors and factor Xa inhibitors.⁷

Bile acid sequestrants

These medications lower cholesterol by decreasing the amount of fat absorbed by the body. While these drugs do not cause bleeding complications directly, continued use may lead to a decreased level of vitamin K in the body. Vitamin K is needed by the liver to produce clotting factor, so when the vitamin K level in the body is low, blood takes longer to clot.⁷

Protease inhibitors (PI)

PIs are used in combination with other antiretroviral medications in the treatment of HIV infection. These medications can be used in people with bleeding disorders under the supervision of a doctor. Some PIs have been reported to cause spontaneous bleeding so be aware of potential complications.⁷

Herbal products and nutritional supplements^{10, 11,12}

You cannot assume that a product is safe because it is “natural.” Herbal products and nutritional supplements are often potent medications. Many herbal products may affect bleeding time, the formation of a clot or the ability of your platelets to stick together to form a clot. Most herbs and supplements have not been studied enough to know their effect on clotting.

Never take an herbal remedy or nutritional supplement without first discussing it with your hematologist or specialty pharmacy.



Although not a comprehensive list, some herbs and supplements known to alter blood clotting include:

- Angelica
- Anise
- Arnica
- Bilberry
- Bromelain
- Dong quai
- Echinacea
- Feverfew
- Fish oils (omega-3 fatty acids)
- Flax seed
- Garlic
- Ginger
- Ginkgo biloba
- Ginseng
- Guarana
- Licorice
- Pennyroyal
- Saw palmetto
- St. John's wort
- Vitamin E
- Willow bark

The information about the effects of individual herbs and supplements on the body, as well as the effect of medications, is frequently updated. It is critical to discuss them with your hematologist or pharmacist PRIOR to taking them.



Medication safety tips

- + Keep an accurate, up-to-date record of all medications you are taking.
- + Make sure to tell your hematologist, and any other doctors you visit, what medications you are taking, including vitamins, herbs and over-the-counter medications.
- + Read the label to be aware of ingredients and possible side effects, especially for OTC medications. The label may also tell you certain things to do or not to do while taking that particular medication.
- + Take only as much medication as your doctor or the label advises.
- + Store medications in the bottle issued by your pharmacist and in a safe place out of reach of children.
- + Never take expired medication.
- + If it seems your medication is not working, do not take an extra dose unless you discuss it with your hematologist.
- + Do not take more than one product containing acetaminophen at a time.

Treatment logs

As an individual with a bleeding disorder, one of your most important responsibilities is to keep accurate treatment records. Everyone with a bleeding disorder should maintain treatment logs, regardless of his/her bleeding disorder, severity and/or treatment plan.

Details to include in your treatment log

Treatment logs record all the measures you use to manage your bleeding disorder. Information recorded on treatment logs may include:

- + Date and time of factor infusion and/or other treatment used
- + Date and time of bleeding episode
- + Cause and location of bleed
- + Level of pain experienced
- + Treatment product used
 - Dose
 - Lot number
 - Expiration date
- + Days missed from school/work
- + Other therapies used, such as RICE

Be sure to use a treatment log that works for you.

Accurate records help you and your doctor manage your health

Treatment logs contain valuable information you should share with your hematologist and Accredo. Access to this information allows your team of bleeding disorder professionals to assist you in proactively managing your health.

Treatment logs are a way to monitor dosage effectiveness, the number of treatments needed to stop a bleeding episode or the number of times you treated with your extra doses in anticipation of an activity. Those caring for you want to be sure the dose you are using adequately treats your needs. Bleeds requiring more than one factor infusion may signal inadequate dosing.^{13,14} Less than optimal dosage can result in joint damage, hospitalization, missed school or work, and higher health care costs.^{13,15}

Tracking your bleeding episodes and treatment can help identify patterns that cause injury or impact your life. Your Accredo team will help you adjust your lifestyle to avoid these complications.

Complete your treatment logs every time you treat.

Take a couple of minutes to record the required information every time you treat (even your prophylactic doses). This includes infused, injected, oral and nasal medications. While a single bleeding episode may not seem important, an overall picture of your treatment provides valuable information to you and your hematologist and helps contribute to the development of an effective treatment plan.

A good rule to remember:

Your treatment logs go wherever your medications go to ensure they will be available following the treatment. Your treatment log is as crucial to your care as a needle and syringe are for infusions.



In the past, manufacturers occasionally recalled product from the marketplace. Your treatment logs will help those caring for you identify if you have used a recalled product.



Many insurance companies now require patients and their pharmacies to submit treatment logs. Treatment logs help monitor the cost and effectiveness of treatment to make the most of each health care dollar spent.



Keeping accurate treatment logs

As an individual with a bleeding disorder, one of your most important responsibilities is to keep accurate treatment records. Everyone with a bleeding disorder should maintain treatment logs, regardless of his/her bleeding disorder, severity and/or treatment plan.

Treatment log example

You'll find additional pages you can use to get started at the back of this book. If you prefer, you could set up an infusion log on your computer using a word processing or spreadsheet program, or use one of the mobile apps that track bleeds and infusions.

Dosage information	Bleed locations			Reason for treatment
	Key location(s)		Other location(s)	
Date	<input type="checkbox"/> Head	<input type="checkbox"/> Stomach	<input type="checkbox"/> Mouth	<input type="checkbox"/> Prophylaxis
Time	<input type="checkbox"/> L	<input type="checkbox"/> R	<input type="checkbox"/> Thigh	<input type="checkbox"/> Surgery
Factor	<input type="checkbox"/> Hand	<input type="checkbox"/> Elbow	<input type="checkbox"/> GI	<input type="checkbox"/> Physical therapy
Lot #	<input type="checkbox"/> Shoulder	<input type="checkbox"/> Hip	<input type="checkbox"/> Upper arm	<input type="checkbox"/> Injury
Dose	<input type="checkbox"/> Knee	<input type="checkbox"/> Ankle	<input type="checkbox"/> Lower arm	<input type="checkbox"/> Preventative infusion
	<input type="checkbox"/> Foot	<input type="checkbox"/> Other _____		<input type="checkbox"/> Spontaneous bleed
RICE used: <input type="checkbox"/> Rest <input type="checkbox"/> Ice <input type="checkbox"/> Compression <input type="checkbox"/> Elevation			Missed work or school? <input type="checkbox"/> No <input type="checkbox"/> Yes, if yes how many days? Work _____ School _____	
Comments				





Safety practices

Sharps disposal²¹

Accredo will provide a sharps container in a return mail box. Use this container to dispose of your needles in a convenient, cost-effective and environmentally sound manner. Please be sure to read the instruction sheet inside the sharps container box.

Sharps disposal instructions

- + Place all contaminated sharps into the container.
- + Do not put any fluids of any kind into container.
- + Other medical waste, such as used tubing, empty vials and used alcohol swabs, can be put into plastic bags, tied shut, and disposed of in your regular trash can.
- + When your sharps container is three-quarters full, contact your pharmacy team and they will send a new one.



Returning your sharps container

- 1 Close the container, and place it into the enclosed red bag.
- 2 Secure the red bag with the twist-tie attached to the box top.
- 3 Put the red bag into the return mail box.
- 4 Close the box according to the box instructions.
- 5 Once the package is properly secured, you are responsible for sending the filled sharps container to the incinerator through the U.S. postal system. You can hand the box to your mail carrier or drop it off at the local post office.

Do

- + Keep the return box, red bag, and tracking forms in the plastic zipper bag on the inside of the box.
- + Package the container properly before mailing.
- + Store the container out of the reach of children and pets.

Do not

- + Place your contaminated sharps or your sharps container into the trash.
- + Attempt to re-cap or bend needles. Simply drop them into the sharps container.
- + Overfill or stick your hand into the sharps container.



Safety at home

- + Get information about your condition from your doctor, your library, respected websites (like Accredo's hemophilia.com) and support groups.
- + Write down important facts your doctor tells you. Ask your doctor if he or she has any written information you can keep.
- + Read all medical forms, and make sure you understand them before you sign anything. If you don't understand, ask your doctor or nurse to explain them.
- + Make sure you know how to work any equipment that is being used in your care. If you use oxygen at home, do not smoke or let anyone smoke near you.

A safe home environment can help you continue therapy without interruption. Suggestions for keeping your home safe can be found below. Your nurse can assist you in checking your home for potential hazards. If you have been prescribed oxygen, then refer to important safety precautions with its use.²²

Keep emergency numbers clearly posted so everyone in your home can find them.

Most cities, towns and counties recommend calling 911, but know the numbers in your area:

- + Police
- + Fire department
- + EMS
- + Utility company
- + Prescribing doctor
- + Accredo



Prevent falls

- + Put an anti-slip mat or strips in the tub or shower.
- + Install grab bars in the tub and shower and near the toilet.
- + Make sure stairways and walkways are free of clutter.
- + Stairways should be well-lit.
- + Stairways should have stable handrails.
- + Remove or secure area rugs.
- + Use night lights.



Consider preparing an emergency kit so you can be ready as soon as an event occurs. Helpful items for your emergency kit include:

- Flashlight with extra batteries
- Battery-operated radio
- Matches and candles
- First aid kit
- Three-day supply of bottled water for each person
- Non-perishable food
- Change of clothes and footwear
- Diapers (if you have small children)
- Moistened towelettes
- Cash
- Blanket
- Tools (can opener, Swiss army knife)
- Address book with essential phone numbers
- Cell phone and charger
- Hand sanitizer



Prepare for severe weather or natural disaster

For your family's safety, you should establish a plan for inclement weather.

- + Keep your travel bag stocked with number of in-date factor doses and supplies recommended by your hematologist.
- + Make sure everyone in the household knows where to go for safety.
- + Be prepared to evacuate if authorities declare an emergency.
- + Plan for your family to check in with a friend or neighbor in case you are separated.
- + Inform Accredo of your evacuation plans, with information on where we can contact you so your therapy is not interrupted.



Power outage

Medication requiring refrigeration must be stored at the manufacturer's recommended temperature. In the event of a power outage in your home, follow these steps to protect your medication supply:

- + Maintain refrigerator temperature by opening the door as little as possible.
- + Contact your local utility company to be put on a priority service list.

Accredo will make every attempt to contact patients in affected areas so there aren't any disruptions to your service. We also have branches all across the country to ensure delivery, wherever your location.



Stay safe in the car²³

Each year, motor vehicle crashes kill about 32,000 people and cause nearly 2 million disabling injuries. You can protect yourself and others by making sure everyone uses a seat belt or child safety seat at all times.

Child safety seats should be properly installed according to manufacturer instructions.²⁴ You can schedule a free child safety seat inspection by calling 866.732.8243 or visiting seatcheck.org.



Traveling with injectable medications²⁵

Dealing with the Transportation Safety Administration (TSA) at airports can be intimidating, but some simple steps can make it easier. Before traveling, check the TSA website (tsa.gov) for updated information.



Airport security regulations and transporting factor

Clotting factor and the sterile water for dilution are permitted on an aircraft, but the medication prescription label must have a name matching the passenger's ticket. It can be helpful to carry documentation about your bleeding disorder with you, such as a letter from your doctor. This letter should include the following information: your diagnosis, severity level, medication names and your hematologist's phone number.

To ensure the health and welfare of certain air travelers, the limit of three-ounce bottles that fit in one quart-size bag does not apply to medications. Declare these items for inspection at the checkpoint.

X-rays will not affect your medication or supplies, but you may choose to request a visual inspection instead.



If you need to leave your home, please follow these steps:

- + Take your medication (packed in a cooler if refrigeration is required), supplies and medical paperwork with you.
- + Keep a two-week supply of all prescription medications on hand.
- + Use an antibacterial gel for hand washing in the event of water contamination.
- + Contact Accredo to let them know where you can be reached, including the address, landline and cell phone numbers.



Helpful tips for traveling with factor:

- + Always take enough medication and supplies to meet your prescribed treatment plan or expected bleeding patterns for planned activities, plus two extra doses. If you need additional medication or supplies, contact Accredo.
- + Keep your medication and supplies with you as carry-on baggage to avoid becoming separated from them. Checking your medication and/or supplies with your luggage could cause them to become lost or destroyed.
- + Store factor in a cooler or insulated travel case to maintain manufacturer storage recommendations. Do not leave medication or supplies in a vehicle. Factor products may degrade and be rendered ineffective when they become too hot or too cold.
- + Ask Accredo or your hematologist for the name and phone number of health care professionals and hospitals in your destination area.
- + Ask your doctor if he or she prefers you to carry a current prescription or to be contacted for a prescription for your factor and supplies in case of theft, loss or damage.
- + Be sure to take a sharps container for the safe disposal of medical waste.
- + Wear medical identification jewelry, or carry the medical information card to assist medical personnel in case of emergency.
- + Check with your insurance provider to be sure you will have coverage in your destination area, especially if you will be traveling out of the country.
- + Even if you do not self-infuse, carry factor with you to ensure availability if needed.
- + If traveling outside the United States or a U.S. Territory, contact Accredo at least two months before your scheduled trip to discuss your travel needs abroad.





Self care guidelines

Infection control

Infection control is an important step for proper use of injectable medications. Preventing infection goes beyond wiping down your infusion area; it is done throughout the home. The Joint Commission recommends following these steps to keep your environment clean and free of germs.

Clean your hands

One of the best things you can do for the success of your therapy is to avoid infection. The best way to prevent infection is to practice proper hand washing techniques before touching or eating food or administering your therapy.



If your hands do not look dirty, you can clean them with an alcohol-based hand sanitizer. Rub the sanitizer all over your hands, especially under your nails and between your fingers, until your hands are dry.

For best results, follow these hand washing steps:

- 1 Remove all jewelry on your hands or wrists.
- 2 Turn the water on and adjust the temperature to warm. Leave the water running while washing AND drying your hands, and be sure to keep your hands pointing upward – with fingers higher than wrists – throughout the process to prevent soil from running back over your clean hands.
- 3 Use liquid soap to make a good lather, and scrub your hands for 1-2 minutes, being sure to work the lather under your nails, between your fingers and around your wrists.
- 4 Rinse your hands thoroughly under the running water.
- 5 Dry your hands and forearms thoroughly with a paper towel, starting at the tips of your fingers and working down to your elbows.
- 6 Use the paper towel to turn off the faucet, and dispose of the paper towel.

When to wash your hands

- + Before and after infusing or injecting medication
- + Before preparing food
- + Before you eat
- + After touching raw meat, poultry, fish, or eggs
- + After meals and snacks
- + After using the restroom
- + After changing diapers
- + After smoking (speak to your doctor about a smoking cessation program)
- + After handling animals or animal waste
- + After your hands come in contact with bodily fluids (vomit, saliva, runny noses, feces, urine)

Remember, your cell phone can be a source of many germs.

Cover your mouth and nose

Many diseases are spread through sneezes and coughs. When you sneeze or cough, the germs can travel three feet or more. Cover your mouth and nose to prevent the spread of infection to others.

- + Use a tissue. Keep tissues handy at home, at work and in your pocket. Be sure to throw away used tissues, and clean your hands after coughing or sneezing.
- + If you don't have a tissue, cover your mouth and nose with the bend of your elbow or hands. If you use your hands, clean them right away.

If you are sick, avoid close contact with others

- + If you're sick, stay away from other people, or stay home. Don't shake hands or touch others.
- + When you go for medical treatment, call ahead, and ask if there's anything you can do to avoid infecting people in the waiting room.



Be familiar with the signs and symptoms of infections

Contact your physician if you experience any of these symptoms:

- Fever
- Chills
- Cough
- Sore throat
- Persistent nausea, vomiting, and/or diarrhea
- Ongoing headache, backache, and/or body ache
- Inflammation – an area that is hot, swollen, and/or red
- Painful urination

Keep your household clean. You can reduce the chance of infection by maintaining a clean home.

Get vaccinations to avoid disease and fight the spread of infection

Make sure your vaccinations are current – even for adults. Check with your physician about shots you may need. You can also visit [cdc.gov/vaccines/schedules/](https://www.cdc.gov/vaccines/schedules/) for the recommended vaccination schedules from the Centers for Disease Control and Prevention (CDC).



Help prevent errors in your care

Everyone has a role in making health care safe, including doctors, pharmacists, nurses and other clinicians. As a patient, you can make your care safer by being an active, involved and informed member of your health care team. The following advice has been provided by the Joint Commission as part of its Speak Up™ program,¹⁸ whose efforts to increase patient awareness and involvement are also supported by the Centers for Medicare and Medicaid Services



Speak up if you have questions or concerns

- + Don't worry about being embarrassed if you don't understand something.
- + If you don't understand because you speak another language, ask for someone who speaks your language. You have the right to get free help from someone who speaks your language.
- + Don't be afraid to ask about safety.
- + Don't be afraid to tell the nurse or the doctor if you think you are about to get the wrong medication.
- + Don't be afraid to tell a health care professional if you think he or she has confused you with another patient.



Pay attention to the care you get

- + Tell your nurse or doctor if something doesn't seem right.
- + Expect health care workers to introduce themselves. Ask to see their identification (ID) badges.
- + Notice whether your caregivers have washed their hands.
- + Make sure your nurse or doctor checks your ID. Make sure he or she asks your name before giving you your medication or treatment.
- + Ask about the health care organization's experience in taking care of individuals with bleeding disorders.



Ask a trusted family member or friend to be your advocate

- + Your advocate can ask questions you may not think about when you are stressed.
- + Ask this person to stay with you, even overnight, when you are hospitalized. You will be able to rest better.
- + Your advocate can also help remember answers to questions you have and make sure you get the right medications and treatments.
- + Make sure this person understands the kind of care you want. Make sure he or she knows what you want done about life support and other life-saving efforts if you are unconscious and not likely to get better.
- + Go over the consents for treatment with your advocate before you sign them. Make sure you both understand exactly what you are about to agree to.
- + Make sure your advocate understands the type of care you will need when you get home. Your advocate should know what to look for if your condition is getting worse. He or she should also know who to call for help.



Know what medications you take and why you take them. Medication errors are the most common health care mistakes.

- + Ask for written information about the medication, including its brand and generic names. Also ask about the side effects of all medication.
- + If you do not recognize a medication, make sure it is for you.
- + Whenever you get a new medication, tell your doctors and nurses about allergies you have or negative reactions you have had to other medications.
- + If you are taking several different medications, including OTC medications, vitamins or supplements, be sure to ask your doctor or pharmacist if it is safe to take those medications together.
- + Make sure you can read the handwriting on prescriptions written by your doctor. If you can't read it, the pharmacist may not be able to either.
- + Carry an up-to-date list of the medication you are taking in your purse or wallet.
- + If you start a new medication or stop taking a medication, or if the dose of medication or the frequency of your medication dose should change, make sure to update your hematologist and your Accredo pharmacy team on these changes.



Educate yourself about your bleeding disorder.

Learn how to feel your best every day at hemophilia.com.

- + Good places to get information about your disorder are from your doctor, your library, respected websites and support groups.
- + Write down important facts your doctor tells you. Ask your doctor if he or she has any written information you can keep.
- + Read all medical forms, and make sure you understand them before you sign anything. If you don't understand, ask your doctor or nurse to explain them.
- + Make sure you know how to work any equipment that is being used in your care. If you use oxygen at home, do not smoke or let anyone smoke near you.



You are the center of the health care team.

- + You and your hematologist should agree on exactly what will be done during each step of your care.
- + Know who will be taking care of you. Know how long the treatment will last. Know how you should feel.
- + Understand more tests or medications may not always be better for you. Ask your doctor how a new test or medication will help.
- + Keep copies of your medical records from previous hospital stays, and share them with your health care team.
- + Don't be afraid to ask for a second opinion. If you are unsure about the best treatment for your illness, talk with one or two additional doctors. The more information you have about all the kinds of treatment available to you, the better you will feel about the decisions made.
- + Ask to speak with others who have had the same treatment or operation you may need to have. They may be able to tell you what to expect and what worked best for them.
- + Talk to your doctor and your family about your wishes regarding resuscitation and other life-saving actions.



Nutrition¹⁹

A report from the CDC showed teens with hemophilia and von Willebrand disease are almost twice as likely to be overweight as children of the same age in the general population. Weight management is especially important for people with bleeding disorders. Extra weight adds stress on joints, which increases joint pain and frequency of joint bleeds. Extra weight also makes it harder to find veins for infusion and requires more factor since doses are based on weight.

Helpful tips for maintaining a healthy lifestyle:

- + Eat and exercise as a family.
Children will follow parents' examples.
- + Do not eat meals or snacks in front of the TV.
- + Read nutritional labels. Ingredients are listed in order of the amount in the product.
- + Avoid foods that contain high amounts of sugar, fat, sodium and cholesterol.
- + Eat from all food groups every day for a well-balanced diet. Eat more vegetables, fruits and lean meats.
- + Limit sweets, pastries and other foods that are high in calories and low in nutrition.
- + Avoid fried foods. Instead, bake or grill meats and steam or grill vegetables. Replace animal fats and vegetable oil with olive oil.
- + Keep nutritious snacks available, like dried fruits, vegetables and pretzels.
- + Choose healthy beverages. Drink plenty of water. Choose water, juice or calorie-free beverages instead of soft drinks. Replace whole milk with low-fat or skim milk.
- + Don't skip meals. Eat smaller meals and healthy snacks instead.



Planning for the future

Advance directives²⁰

Although it is an important issue, no one likes to talk about illness and death. Imagine you were in a coma or could not communicate. Would your family or health care professionals know what treatments you want?

Advance directives communicate what you want if you cannot speak for yourself, taking the burden off your family. When you have advance directives, your family and health care professionals know what treatments you do and do not want.

For more information on advance directives, visit caringinfo.org or free-living-will.org.

Facts about advance directives:

- + Advance directives are easy to fill out. Accredo, your hematologist or a hospital can help you get the necessary forms.
- + You do not need a lawyer.
- + You can always change your mind.
- + They will only be used when you cannot speak for yourself.



Living will²⁰

A living will only takes effect if you are dying and cannot speak for yourself. It clarifies the types of care you do or do not want. You have a right to accept or refuse medical care.

A living will may address the following topics:

- + DNR (do not resuscitate) orders – not being revived if heartbeat and breathing stop
- + Being connected to machines to be kept alive
- + Having surgery
- + Donating organs

Durable power of attorney for health care (health care proxy)²⁰

You name a person as your agent to make health care choices for you if you cannot speak for yourself. Your agent should be someone you trust and know well. Tell your agent what care you would want if you were sick or hurt so he or she can make the right choices for you.

Provide a copy of your advance directives to your doctor, your agent, and the hospital if applicable.







Important contacts

If you have any unresolved safety or quality issues, please contact Accredo so we can correct the problem.



Call:

866.712.5200 (24/7/365)

Upon receipt of any complaint or issue, we will respond within 24 hours and follow up to provide resolution within 72 hours.



Write:

Customer Service
Accredo by Evernorth
730 Cool Springs Blvd
Suite 301
Franklin, TN 37067

If you still have concerns after discussing your issue with us, a complaint can be sent to one of the following outside organizations:

+ The Joint Commission
jointcommission.org/contact-us
The Office of Quality & Patient Safety
The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, IL 60181



Email:

BleedingDisorders@accredo.com

+ Your state's board of pharmacy
A complete list of state pharmacy boards can be found on the National Association of Boards of Pharmacy (NABP)
Website: nabp.net
Phone: 847.391.4406
Fax: 847.391.4502



Comment:

Complete and return the customer comment card that's included in all medication shipments. Pharmacy and clinical services personnel review all issues and concerns. They investigate all situations and work to resolve any issues to your satisfaction.

+ Your state's board of nursing
A complete list of state nursing boards can be found on the National Council of State Boards of Nursing
Website: ncsbn.org
Phone: 312.525.3600
Fax: 312.279.1032

The filing of any complaint will not disrupt your service.

Understanding home infusion care checklist

There are many things to remember when starting home infusion. If you are not able to check off any items on this list, please contact Accredo at 866.712.5200.

- ☐ I know what items can be safely placed in a sharps container.
- ☐ I store my sharps container away from children and pets.
- ☐ I know when to call my customer experience specialists to order a new sharps container.
- ☐ I know the proper way to return my filled sharps container.
- ☐ I know the correct way to wash my hands.
- ☐ I know when I should wash my hands.
- ☐ I know the recommended storage temperature for my medication.
- ☐ I know how to contact Accredo if I ever have to evacuate my home.
- ☐ My family has established a severe weather/natural disaster plan.
- ☐ I verify my medication order using the delivery verification report enclosed in each shipment and return it to Accredo in the envelope provided.
- ☐ I have room in my refrigerator – away from food – to store my boxes of factor.
- ☐ I keep factor with the earliest expiration date forward when I place a new order of factor in my refrigerator.
- ☐ I check my supply inventory before placing my medication order to ensure I will have everything on hand for treatment.
- ☐ I have a storage area in my home for all my medical supplies, located away from children and pets and protected from extreme temperature, moisture or light.
- ☐ I check all over-the-counter medications to see if they contain aspirin (also listed as ASA or acetylsalicylic acid) and contact my specialty pharmacy if I have any questions.
- ☐ When traveling, I keep my medication and supplies in my carry-on luggage.
- ☐ I wear medical identification jewelry at all times.
- ☐ I carry a letter from my hematologist that details my diagnosis, severity level and treatment products.
- ☐ I know the importance of RICE (rest, ice, compression, elevation) to treat a bleed.
- ☐ I understand the importance of completing my treatment log after every treatment.
- ☐ I understand when to treat and how to administer my medication according to my prescription.
- ☐ I have given Accredo a way to contact me by phone (home phone or cell phone).
- ☐ I understand Accredo has a product recall procedure and will assist me in the event of a manufacturer recall.
- ☐ If I am using factor for treatment, but do not currently perform home infusions, I know when an infusion is necessary and when to call my doctor or treatment center.
- ☐ I understand how to file a complaint.
- ☐ I understand that I need to provide updates to changes in my medications.



Accredo at a glance

Our bleeding disorder-trained team is focused on treating you and understands how to help manage your condition.



16
Pharmacists &
pharmacy techs



14
Patient care
representatives



600+
Field nurses



Nationwide
Field patient advocates



24/7
Clinician access



30
Insurance representatives

We're here for you: hemophilia.com or 866.712.5200

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Treatment log

Dosage information	Bleed locations		Reason for treatment
	Key location(s)	Other location(s)	
Date	<input type="checkbox"/> Head <input type="checkbox"/> Stomach	<input type="checkbox"/> Mouth	<input type="checkbox"/> Prophylaxis
Time	L R	<input type="checkbox"/> Thigh	<input type="checkbox"/> Surgery
Factor	Hand	<input type="checkbox"/> GI	<input type="checkbox"/> Physical therapy
	Elbow	<input type="checkbox"/> Upper arm	<input type="checkbox"/> Injury
	Shoulder	<input type="checkbox"/> Lower arm	<input type="checkbox"/> Preventative infusion
Lot #	Hip	<input type="checkbox"/> Other _____	<input type="checkbox"/> Spontaneous bleed
	Knee		
Dose	Ankle		
	Foot		
RICE used: <input type="checkbox"/> Rest <input type="checkbox"/> Ice <input type="checkbox"/> Compression <input type="checkbox"/> Elevation		Missed work or school? <input type="checkbox"/> No <input type="checkbox"/> Yes, if yes how many days? Work _____ School _____	
Comments			

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Comments			

At Accredo, we are dedicated to providing you with quality care and look for ways to enhance the level of service we offer. With this focus in mind, we are proud to be accredited by Joint Commission, whose mission is “to continuously improve the safety and quality of care provided to the public.” For more information on Joint Commission accreditation, visit [jointcommission.org](https://www.jointcommission.org).

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By **EVERNORTH**