

Your Inpatient Autologous Stem Cell Transplant

Information for Patients and Caregivers

Read this guide to learn:

- What an autologous stem cell transplant is
- How to prepare for your stay in hospital
- What to expect during your stem cell transplant
- What to expect during your recovery
- Important phone numbers
- Where you can find more information

Important Phone Numbers:

The Leukemia/BMT Daycare Unit Hours:

6th Floor Leon Blackmore Pavilion, VGH

Monday to Friday 7:00am – 7:00pm

Weekends & Holidays 8:00am – 5:00pm

This unit closes every night; always call before arriving for an unscheduled visit.

604 875 4073

Afterhours Telephone:

Leukemia/BMT Inpatient Unit

15th Floor, Jim Pattison Pavilion, VGH

604 875 4343

The Hematology Apheresis Unit (HAU):

6th Floor Leon Blackmore Pavilion, VGH

Monday to Friday 8am - 5pm

604 875 4626

Call Us Immediately If You Have:

- Fever: a temperature of 38°C or higher
- Chills or shaking
- Yellow or green mucus when you cough
- A bad headache
- Diarrhea, nausea or vomiting that doesn't stop
- Flu-like symptoms
- New bad bruising and/or bleeding
- Difficulty taking your pills
- New pain
- Concerns with your IV line
- Unsteadiness when walking or have fallen down
- Rash, blisters, allergic reactions

In Case of Emergency – Call 911

If you or your loved one has severe chest pain, can't breathe or requires urgent care – **CALL 911**. An ambulance will take you to the closest hospital. Tell the staff you are a Leukemia/BMT patient and to contact our doctor on call. These symptoms are rare but if they occur, they cannot be managed over the phone.

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About this booklet

This booklet has been developed to help you and your family prepare for an autologous stem cell transplant. We hope reading will help you feel less anxious about your transplant as you learn about what to expect each step of the way.

We welcome your feedback on how we can improve this book for other patients and families.

Comment cards are found at the front desk in the outpatient clinic.

The amount of information available on a stem cell transplant can be overwhelming. We know you won't be able to remember everything we tell you. This book provides written information to go along with the teaching you'll receive from us, your health care team.

Read each section of these booklets when you are ready. You may think of questions to ask us as you read through it; we encourage you to write them down. Bring your questions and this booklet with you to your appointments.

At the end of the booklet there is a section on common medical terms.

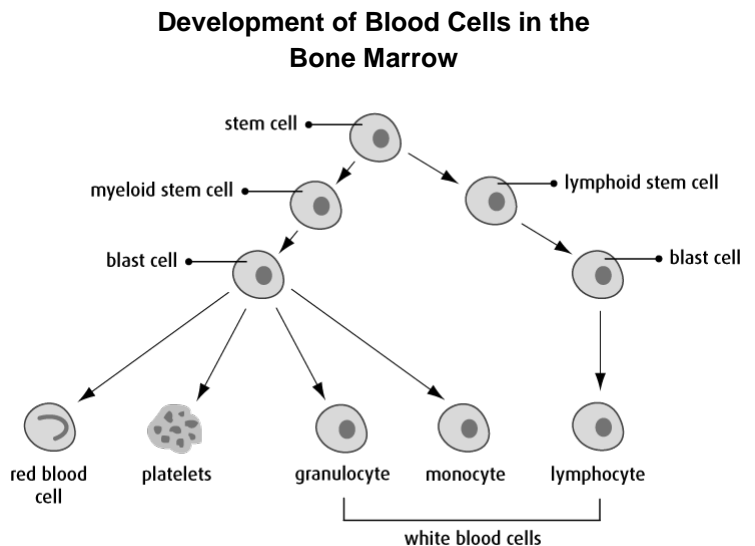
What are Stem Cells?

Stem cells are the body's primary cells. All of your body's cells, tissues, organs and bones are made from stem cells.

Stem cells that develop into blood cells are found in your bone marrow. Bone marrow is the spongy tissue found inside your bones; it could be called the "factory" where your blood cells are made.

Blood stem cells create lots of different types of blood cells, including white blood cells, red blood cells and platelets.

You'll notice that we talk a lot about blood cells (also referred to "blood counts") through your treatment. It's helpful to grow familiar with them and what they do.



Types of Blood Cells

(In Canada, all levels are $\times 10^9/L$. Units from other countries may differ)

White Blood Cells:

- White blood cells help your body fight infection. They are part of your immune system. Normal white blood cell levels are 4 – 11.
- You may be at greater risk for infection when your white blood cell count is low.
- Neutrophils are a type of white blood cell that fight bacterial infections. Normal levels are 2 – 8.
- Lymphocytes are a type of white blood cell that fight viral infections.

Red Blood Cells and Hemoglobin:

- Hemoglobin (attached to red blood cells) carries oxygen from your lungs to other parts of your body. Normal hemoglobin levels are 120 – 180.
- You may feel tired and more easily short of breath when your hemoglobin is low.
- When your hemoglobin falls to 80 or lower, you will receive a blood transfusion.

Platelets:

- Platelets help to clot your blood. Normal platelet levels are 150 – 400.
- You may bleed and bruise more easily when your platelets are low.
When your platelets fall closer to 10-20, you may receive a platelet transfusion

What is an Autologous Stem Cell Transplant?

In some cancers and blood diseases, one of the best treatment options is high doses of chemotherapy and sometimes radiation therapy. This “conditioning treatment”:

- Provides intensive treatment to destroy cancer cells in patients with blood cancers
- Destroys damaged stem cells in patients with diseases such as aplastic anemia.

This “high dose chemotherapy” (and radiation) treatment has the ability to kill more cancer cells than regular chemotherapy. However, this treatment also severely damages your bone marrow and causes it to stop making blood cells. To rebuild your damaged bone marrow after high dose chemotherapy, your collected stem cells are given to you as an intravenous (IV) infusion, similar to a blood transfusion.

This infusion of stem cells is called an autologous stem cell transplant. An **autologous stem cell transplant** uses healthy stem cells from your own body to replace your diseased or damaged bone marrow.

Your stem cells will enter your blood and find their way back to your bone marrow. They allow your bone marrow to start making healthy blood cells again.

The infusion of stem cells is called a stem cell “rescue,” since it is rescuing your normal bone marrow from dying. Without autologous stem cell transplants, we cannot give our patients such intensive treatment.

What’s an “allogeneic” stem cell transplant? What’s the difference?

A **stem cell transplant** is a procedure that:

- Allows doctors to give very high-dose treatment for certain diseases; and/or
- Replaces diseased or ineffective stem cells with healthy new stem cells.

An **autologous transplant** uses a person’s own stem cells.

An **allogeneic transplant** uses stem cells from a donor whose human leukocyte antigens (HLA) are acceptable matches to the patient’s. The recovery period is considerably longer for allogeneic transplants than autologous transplants.

Your Health Care Team:

Your health care team is specially trained to care for patients receiving stem cell transplants.

You and your family are very important members of this team. You know best about your body, your health and your needs. Your health care team counts on you to let them know how you are doing.

The team includes:

- Doctors
- Nurses
- Social workers
- Dietitians
- Physiotherapists
- Occupational Therapists
- Pharmacists
- Administrative clerks
- Support aides

You may meet some or all these health care team members at Vancouver General Hospital. Our doctors rotate through the different areas of the program and you may or may not see your primary hematologist during your treatment. Be assured that all of our doctors are kept up to date on your progress and the whole health care team works together to provide you care.

Please see “*Resources and Supports*” for more information about your health care team and what they do.

We always welcome your comments and questions. Talk to us.

Steps to Transplant

This step by step process is described in more detail in the following pages.

Step 1 Preparing for Transplant	You'll meet with different members of your health care team who will help you prepare for your transplant. Tests will be performed to ensure a transplant is safe for you.
Step 2 Mobilizing your Stem Cells	"Mobilizing" your cells means moving your stem cells from your bone marrow into your blood. You will be given medication(s) to mobilize your stem cells.
Step 3 Collecting your Stem Cells	Your stem cells will be collected over 1-2 days using an apheresis machine. This machine safely and painlessly collects stem cells from your blood and then returns the rest of your blood back to you.
Step 4 Central Venous Catheter Insertion	An intravenous ("IV") line will be inserted in your chest to help make your treatment more comfortable.
Step 5 Admission to Hospital	You will be admitted as an inpatient to the L/BMT inpatient unit on the 14 th or 15 th floor of VGH.
Step 6 Chemotherapy Treatment	You will be given chemotherapy and sometimes radiation. This is called your "conditioning treatment."
Step 7 Stem Cell Transplant Day	Your stem cells will be given to you through your IV catheter, similar to a blood transfusion.
Step 8 Waiting for Blood Count Recovery	Chemotherapy will cause your blood cells or "blood counts" to fall to very low levels for roughly 7 days. You will feel weak and unwell from the side effects from the chemotherapy during this time.
Step 9 Blood Count Recovery ("Engraftment")	Engraftment is when your blood cells begin to return to normal levels. This usually begins 10-12 days after your stem cell transplant. Most people are discharged roughly 3 weeks after admission.
Step 10 Follow-up Visits in the Daycare Outpatient Unit	After being cleared for discharge, you'll be followed-up as an outpatient in the L/BMT Daycare Clinic for 7-12 days.
Step 11 Managing at Home	Your IV line will be removed and you'll finish your daycare clinic visits, although it will take time to resume a normal life. Your oncologist will continue with your care.

Getting Ready for your Transplant:

It's helpful to start thinking of the practical physical and emotional preparations before your transplant.

What must I do before my transplant?

- 1. Choose a 24 hour caregiver** – You'll need a caregiver for a few weeks once you're discharged from hospital. Your family and friends can share the caregiver role; it does not have to be only one person. Your Nurse Navigator can assist caregivers with requesting compassionate time off work and visa application letters. For more information on caregiver roles and support, please see *"Resources and Supports"*
- 2. Register for Pharmacare** - If you haven't registered for Fair Pharmacare, call 1-800-663-7100 or visit the web link below to clarify your benefit plan and medication coverage. <https://my.gov.bc.ca/fpcare/registration-status/request-status>
- 3. Plan where you'll stay before and after discharge** – You may not be admitted on your expected admission date, it depends on bed availability. You will need to be within a 60 minute drive from Vancouver General Hospital while waiting to be admitted and again for roughly 1 week after discharge from hospital. Please see *"Maps, Parking and Places to Stay"* for recommendations and important things to consider when booking accommodations. To plan for unpredictable schedule changes, we recommend booking accommodations with a flexible cancellation policy. **Caregivers also need a place to stay** while supporting you in hospital.
- 4. Purchase a digital Celcius thermometer** from your local pharmacy (if you don't already have one). You will use it regularly to monitor your temperature through your treatment and recovery.

5. **Inform your doctor** – If you have seen a doctor in a separate facility or health care program, ensure your transplant doctor is aware. Our doctors are not always informed of all your previous medical records.
6. **Get your Flu Shot** – Approaching or during the influenza season (usually October to April), **we strongly suggest** you and your family receive the flu shot; it is offered free at any local clinic and some pharmacies. The flu shot - though not 100% effective - is the best way to prevent the flu and it **will lessen the chances of severe complications** if you do contract the flu. Ask your doctor or Nurse Navigator when is the best time to get your flu shot is.
7. **Make decisions about your fertility** – If having children after transplant is important for you, talk to your transplant team. They can discuss your options and give you a referral to a fertility specialist.

What are other suggestions to prepare for transplant?

- **Arrange for care of any dependents and/or pets** – Let your Nurse Navigator know if there are any concerns regarding people dependent on you for their care. Pets can stay with you through treatment but some people choose to leave them with friends or family.
- **Connect with a Social Worker and Support Programs** : BC Cancer Agency have patient and family counsellors and social workers available at your regional cancer centre and over the phone. We strongly recommend our patients use the excellent supports services offered by BC Cancer, the Canadian Cancer Society and the Leukemia and Lymphoma Society. They can help you cope with your diagnosis and how it may affect you, your family, your living arrangements, your finances and other practical matters. More information on these services can be found in the *“Resources and Supports”* handout .

- **Proper nutrition** is very important during treatment and transplant:
 - to help heal and repair damaged cells
 - to help produce healthy new marrow cells and
 - to minimize complications related to with poor nutrition.

Eating may be difficult or painful for at time after transplant. Your mouth may become very sore or you may have trouble with taste changes, nausea and vomiting. You may need to be given nutritional replacements through your IV line if you are not eating. For these reasons, try to eat well ahead of time and gain weight if possible. Avoid dieting, and try to add protein and higher calorie foods to every meal if possible. If you are struggling to eat enough calories, try simple things like eating small meals more often. Ask your family for support. We can refer you to a dietitian if you are having difficulties with appetite changes and weight loss, ask you nurse navigator for more details.

- **Being Active** - To build strength and energy, follow your regular exercise routine as best as you can. Or to start, try gentle exercises like walking every day as you are able. Yoga can strengthen muscles and help you relax, which is also good for your mental health.
- **Plan ahead.** Make sure your family and loved ones know your wishes if you can't speak for yourself. Putting one's legal affairs in order does not mean expecting the worst and it can give you the peace of mind to focus on getting better. Talk to your social worker and see page 42 for more information on advance care planning.
- **Make decisions about your hair** - The chemotherapy that kills cancer cells also causes temporary hair loss. Think about if you'd like to cut your hair before transplant. If you're interested in a wig, visit a wig store as soon as you can. That way, you can find one that closely matches your natural hair, if you want to. Hats, scarfs and turbans are also good options to protect your head after hair loss.

Step 1: Preparing for Your Transplant

Consultation with Hematologist

Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your hematologist will review your health history, do a physical assessment & discuss the stem cell transplant process with you and your family. They may ask for additional tests before deciding that a stem cell transplant is safe for you. They will give you instructions and details if this is the case.

Phone call with BMT Nurse Navigators

Initial phone call: 1-2 weeks after Hematologist Consultation

Phone call: 5-8 weeks before stem cell collection

A few weeks after you meet with your Hematologist, you will receive a phone call from one of our Nurse Navigators. They will give you your planned transplant stem cell collection and transplant dates so you can begin to plan accordingly. Please note that these dates can change.

Roughly 5 to 8 weeks before your collection date, they will phone you again to review and discuss what to expect as we help you prepare for transplant, including the tests and appointments that will be scheduled. Our Nurse Navigators have spent years at the bedside in the transplant program; they are an excellent resource to discuss any questions and concerns you may have.

Please tell your Navigator if you are from out of town and use any mobility aids, raised toilet seats, bedrails or other assistive devices. They will help you get in touch with our physiotherapy team to arrange for this type of equipment during your transplant.

Pre Transplant Tests

Approximately 4-6 weeks before your ideal admission date

Tests must be done to check how well your heart, lungs and kidneys are working before the transplant. Whenever possible, we try our best to arrange as many tests and consultations on the same day. **You may not need all of these tests, and your doctor may order extra testing not listed below. It is normal to require extra testing or consultations; we will arrange these appointments for you.**

- **Bloodwork:** These blood tests can tell us many things, including how healthy your organs are and any past exposures to certain viruses.
- **Heart tests:** An electrocardiogram (ECG) and radionucleotide ventriculogram (RVG or MUGA) are done to show us how healthy your heart is and how well it pumps blood through your body.
- **Lung tests:** A Pulmonary Function Test (PFT) and chest x-ray are done to show us how healthy your lungs are and to check your breathing ability.
- **Kidney test:** A blood test or kidney or 24 hour urine collection is done to show how well your kidneys are working.
- **Bone marrow biopsy:** This is done to check how well your bone marrow is making cells and to look for any sign of cancer in the marrow.
- **Lumbar puncture:** This test is used to check for abnormal cells in your cerebrospinal fluid (CSF). We will give chemotherapy into your spinal fluid during this procedure. *Reminder: not everyone requires a lumbar puncture.*
- **Central Venous Catheter:** If you don't already have one, you will need to have a central venous catheter inserted, also known as a Hickman line® or Trifusion® line. This is a flexible plastic intravenous line used to draw blood, give you fluids, medications and your new stem cells. Also see "*All About Your Tunneled Catheter*".
- **CT or PET Scan:** Your doctor may request a computed tomography (CT) scan or PET scan (positron emission tomography) to show a more detailed look at the tissues and bones in a certain area of your body.

For more information on these tests, please see "Common Medical Terms" on page 44.

Pre Transplant Consultations

Approximately 2 weeks before your stem cell collection (times may vary)
6th Floor Leon Blackmore Pavilion, Vancouver General Hospital

To help you prepare for your upcoming transplant, it is important that you meet with members of your health care team for personalized teaching.

a) **Hematology Apheresis Unit (HAU):**

This appointment must be in Vancouver General Hospital

The nurses in the apheresis unit will meet with you to check your arm veins and teach you about the stem cell collection process. Checking your veins is important because the apheresis machine needs a certain amount of blood flow in order to work properly. If your veins are suitable, we will use them to collect stem cells.

If your veins are too small or delicate, we will plan for you to have a special type of “central venous catheter” inserted. It is an intravenous (IV) line we use not only for collecting your stem cells but also for the rest of your transplant treatment. It will remain in place for 3-4 weeks after your transplant. See Step 4 for details.

During your visit to the apheresis clinic, you will also meet an apheresis doctor. They will review the stem cell collection process with you, obtain your consent to the procedure and give you your prescription for G-CSF medication (see Step 2).

- b) **Dietitian:** If you have had problems with appetite or weight loss in the past, you will meet our dietitian. Our dietitians will discuss how you can prepare for your transplant and manage side effects through your diet and food choices.
- c) **Thrombosis Clinic:** This appointment is only needed if you are currently using a blood thinner (i.e. warfarin, heparin, etc.). The thrombosis clinic doctor and nurses will teach you how to manage your blood thinner through your treatment.

Step 2: Mobilizing your Stem Cells

Approximately 1-2 weeks before your ideal admission date (times may vary)
Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Moving your stem cells from your bone marrow into your bloodstream is called **“mobilization”**.

Your healthy stem cells must be collected from your blood before we can give you high dose chemotherapy. Since stem cells live in your bone marrow, we will give you a medication to move these stem cells into your bloodstream. This is a type of medication called G-CSF (granulocyte-colony stimulating factor). The G-CSF medication we use in our program is called Filgrastim (Grastofil[®] or Neupogen[®]).

What Should I Tell my Doctor before starting G-CSF?

Other drugs may interact with G-CSF. Tell your doctor if you are taking any other medications, even if you only take them sometimes. This includes over-the-counter drugs, naturopath/herbal remedies, vitamins, teas, etc.

How is G-CSF Given?

G-CSF is an injection under the skin using a small needle. You may feel a slight stinging sensation at the injection site while it is being given. Any pain or redness you notice after the injection should go away soon. If you see a “bump” at the injection site, please do not rub it. The bump will often go away within a few hours. If the bump persists for more than a few hours, contact the Hematology Apheresis unit.

How Many G-CSF Injections Will I Need? Where should I keep my G-CSF vials?

You will need 4-5 days of daily G-CSF injections. G-CSF should always be stored in the refrigerator. Do not shake the medication.

How much does G-CSF cost?

G-CSF is a very expensive prescription medication and is not paid for by the Vancouver General Hospital or BC Cancer for the autologous transplant patient. The cost of G-CSF is dependent on the dose required; one course of treatment is between \$2,000.00 and \$3,000.00. We will help you find ways to manage this cost.

Managing the cost of G-CSF

1. You should be registered for BC Fair PharmaCare. You can contact Fair PharmaCare (1-800-663-7100) to clarify your benefit plan and medication coverage. If you have already reached your deductible amount with Fair PharmaCare, in the present calendar year, the cost of your G-CSF may be greatly reduced.
2. If your income has reduced since your diagnosis (more than a 10% change in income in the last 2 years), you may be eligible for an income review and reduced deductible through Fair Pharmacare. Contact them for details.
3. Contact your extended health provider directly to determine if G-CSF is covered under your plan. The Grastofil® drug ID number is 02441489 or 02454548, depending on the dose you receive.
4. Depending on your extended health plan and your Fair PharmaCare deductible, you may need to pay for some of this cost “out-of-pocket”. Your Nurse Navigator will register you for the “Answers Program”. This program will contact regarding your coverage and will help cover some of your out of pocket cost.
5. Your Nurse Navigator will be your contact person regarding any G-CSF drug coverage issues.

Where will I receive my G-CSF Injections?

We can plan for a nurse to give you your G-CSF at VGH. If you prefer, you can arrange to have your injections given at your doctor’s office, pharmacy or a walk-in clinic near your home. Patients, family members or friends in the health care field can deliver these injections if they have been trained to do so (we do not provide this training). Please note:

- The first injection must be given in a medical facility in the rare case of allergic reaction.
- The ideal time for injections is between the hours of 1PM and 4PM.

What are the Side Effects of G-CSF?

Generally, G-CSF is well tolerated. Some people may experience:

- Bone pain, especially in the lower back, hips or leg bones.
- Headache
- Fatigue (feeling tired)
- Flu-like symptoms, like muscles soreness, aches, and a low fever

If you feel uncomfortable or have any concerns with side effects from G-CSF, please contact the HAU Unit. During the G-CSF mobilization you can take Tylenol for discomfort or low fever.

Contact us immediately after mobilization treatment and at any time if you have:

- Shortness of breath that starts suddenly
- Blood in your urine
- Pain or burning when you pass urine after mobilization chemotherapy
- Fever of 38°C or higher
- Chills or shakes
- Yellow or green mucous after you cough

These symptoms may mean a possible infection or side effect from the mobilization therapy that should be treated as an emergency.

Step 3: Collecting Your Stem Cells

Approximately 1-2 weeks before your ideal admission date
Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your stem cells are collected by a procedure called apheresis (“ay-fur-REE-sis”) in the Hematology Apheresis Unit (HAU). During the collection, your blood will be circulated through an apheresis machine that will separate and collect the stem cells. All your remaining blood is then returned back to you.

- Your nurse will connect you to an apheresis machine by an intravenous (IV) line in each arm.
- Your blood will be drawn into the machine through one IV line.
- The machine will collect the stem cells from your blood. The rest of your blood is returned back to your body through the other IV line.
- For patients whose veins were too fragile to be used, the same apheresis process will take place using 2 different “ports” on their central venous catheter.
- You will be directly connected to the apheresis machine for about 4-6 hours. You may want to bring headphones and music to listen to as you will have limited use of your arms (because of the 2 IV lines).
- There will be only a small amount of your blood circulating in the apheresis machine at any one time.

Are there any side effects to stem cell collection?

During the collection, you may feel:

- **Light-headed or dizzy:** This is due to your blood going through the machine.
- **Tingling** in your lips, fingers and toes, **and cramping** in your hands and feet: To prevent your blood from clotting while it circulates in the apheresis machine, a blood thinner is used. Tingling is a side effect from this medication. Calcium can be added to your intravenous (IV) and these symptoms should fade.

Tell the nurse if you feel any of these or any side effects, they can help you feel more comfortable.

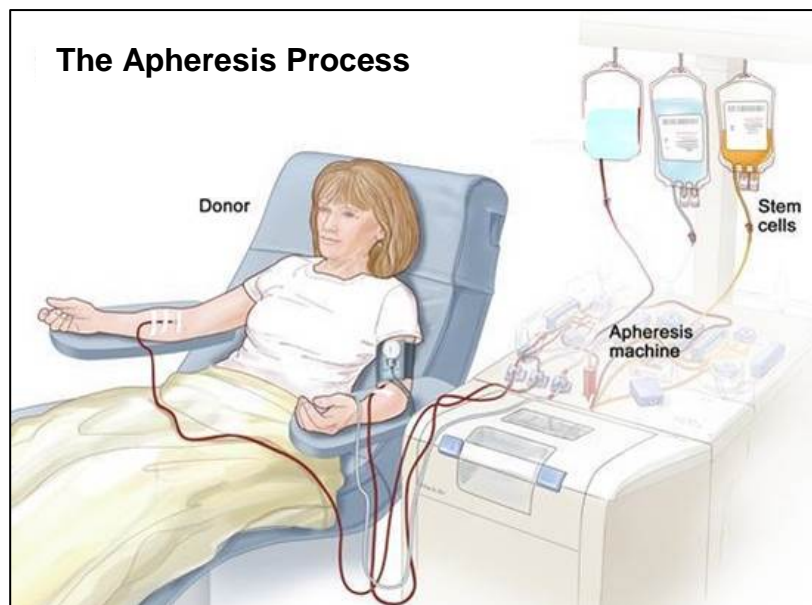
What happens after the stem cells are collected?

At the end of the day, the bag of stem cells that has been collected is sent to the lab where the stem cells are counted. If not enough cells have been collected, you will be asked to come back the next day to have the process repeated. **This is normal and there is no need for concern.**

Your cells are frozen so they can be used later. A preservative called DMSO is added to protect your cells.

Most people only require G-CSF to mobilize their stem cells for collection. Occasionally, some people may need extra mobilization medications if not enough stem cells can be collected. Your doctor will discuss this option with you if this is the case.

You will be given more information on how to prepare for your collection day during your first apheresis unit visit.



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Step 4: Central Venous Catheter Insertion

Approximately 1-2 days before your ideal admission date
Vancouver General Hospital, Jim Pattison Pavilion, Radiology Unit Ground Floor

Proceed to step 5 if you already have a central venous catheter

Before your transplant, you will need a central venous catheter (**CVC**) inserted. It is a flexible tube that is put into a large vein in your neck. The other end sits outside of your chest. Having an IV line may sound scary but it will make your stem cell transplant experience much more comfortable.

There are 2 CVCs we use in our program. **You will have one of the following:**

- **Trifusion® Line; or a**
 - Inserted before stem cell collection for people with small, delicate veins.
 - Used for stem cell collection, transplant and recovery.
 - In some cases, a “Permcath®” CVC is used only for stem cell collection then removed the same day. A Hickman® line would then be inserted prior to transplant.
- **Hickman® Line**
 - Inserted a few days prior to transplant for people who had suitable veins for collection.
 - Only used for transplant and recovery, not stem cell collection.
 - Most people have Hickman lines.

What will my Trifusion® line or Hickman® line be used for?

- Drawing blood samples
- Giving intravenous (IV) high-dose chemotherapy
- Giving IV fluids to help keep you hydrated.
- Giving back your stem cells on the transplant day.
- Giving blood transfusions and medications, as needed.

How will this IV line be inserted?

A doctor will insert your IV line in the VGH Radiology Department, using a local anaesthetic. You may have some minor pain or stiffness in the neck and shoulder area for a day or two after your line is inserted. You will see a bandage dressing covering your IV line.

What happens after it is inserted?

You will be sent to the Daycare unit (or the Apheresis unit) after the line has been inserted for 1-2 hours of monitoring. You may be sent to the inpatient unit if you are being admitted that day. Your nurse will make sure the bandage (dressing) covering the line is dry. It is normal for a small amount of blood to be on the dressing after insertion. Contact us if there are ever any concerns with your IV line.

You will feel drowsy from the local anaesthetic so it is not safe to drive yourself home from this appointment. Please arrange for someone to take you back home or to your lodgings after your line insertion.

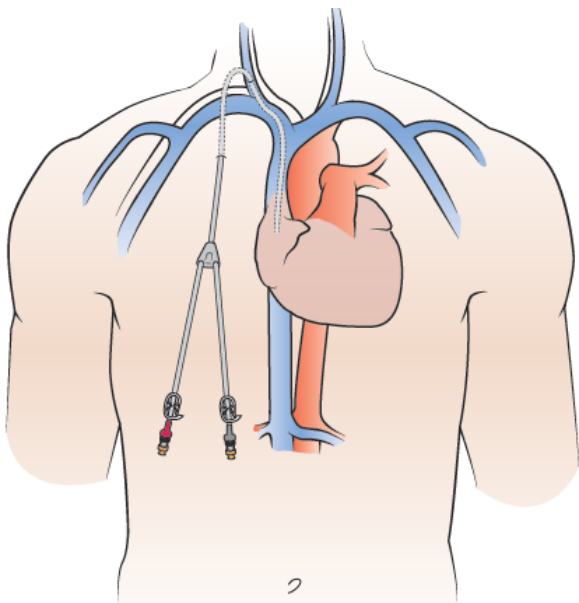
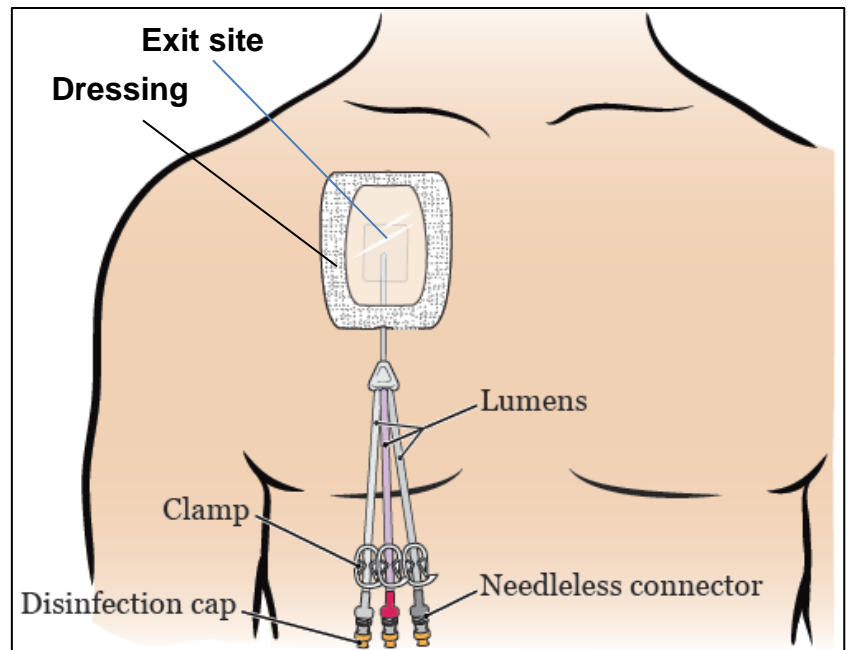
How do I care for my IV line?

Infection is the biggest risk for any type of IV line. To help avoid infections:

1. Avoid getting the dressing wet and do not shower or bathe for 24 hours after it is inserted. Your nurse will show you how to protect it before showering. Steam can cause the bandage to become wet and fall off so it is best to take short showers. Aim the shower nozzle away from the line. Baths are not recommended.
2. Look at your tunneled catheter line every day. That chest area should not be tender, red, swollen or have drainage. Contact us if you notice a problem.
3. Do not remove the dressing. If the dressing peels off, wash your hands well and tape it back into place. Call our unit to set up a dressing change.
4. To prevent tugging on the line, we will give you a necklace to attach your CVC to. Some people find it comfortable to place the ends of their Hickman line in a clean baby sock. Women can tuck the ends of the catheter in their bra.
5. Please refer to the “All About Your Tunneled Catheter” booklet for more information. **You will not have to flush your line, change caps, or change your own dressings as mentioned in the booklet.**

Pictures of Central Venous Catheters

Left: A Hickman® line with three lumens. A Trifusion line is very similar in appearance. A white or clear dressing covers the “exit site” to protect it from infection.



Right: The white plastic catheter enters your bloodstream through a neck vein. The tip of the catheter sits above the heart (not in it).

This picture shows two lumens, most people will have three.

Step 5: Admission to Hospital

14th or 15th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

I've been given an ideal admission date. What does this mean?

Your **ideal admission date** is the date we aim to admit you to hospital. We cannot guarantee that a hospital bed on our unit will be available on this date. We make every effort to admit you as close to your ideal admission date as possible; please see more information on this subject in *"The Leukemia/BMT Inpatient Unit"* booklet.

***Patients receiving radiation (TBI) treatment will be admitted on their ideal admission date. These radiation treatments have been pre-scheduled and cannot be adjusted.

What should I have ready while I'm waiting to be admitted?

From your ideal admission date onwards, have your hospital bag packed and be ready to come to the hospital as soon as you are contacted by our unit charge nurse.

IMPORTANT: Due to the unpredictability of our unit, we are only able to hold your bed for a limited amount of time. For this reason, it is very important that you come to the hospital right away when you are contacted by our nurse. Otherwise, your bed may be offered to another patient. You will rarely be called to be admitted after 3pm.

What will happen when I am admitted?

When you arrive at the hospital, please check in at the front desk on the 15th floor (T15A). It will take time for our team to help you settle in, do our assessments and ensure all preparations have been done for you to start treatment the next day.

- You may have to wait in the patient lounge while we prepare your room.
- You will be assigned a shared room with one other patient or a private room.
Private rooms cannot be guaranteed as they are required for patients requiring additional isolation precautions or other circumstances.
- Your nurse will orient you to the unit, draw your bloodwork, complete admission forms and perform a physical assessment.
- A doctor will discuss the transplant process and treatment with you, perform a physical assessment and go over any consent forms needed.
- More information can be found in the *"L/BMT Inpatient Unit"* booklet.

Step 6: Chemotherapy Treatment

14th or 15th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

What is conditioning treatment?

Your treatment will start the day after admission. The treatments you are given in the days before your stem cell transplant is called “**conditioning treatment**.” This can be chemotherapy medication only or both chemotherapy and radiation therapy.

What chemotherapy drugs will I receive?

Different diseases require different types of chemotherapy before transplant. Ask your Nurse Navigator, doctor or medical team on the unit what type of chemotherapy you will be receiving.

Why do I need chemo (and maybe radiation) before a stem cell transplant?

Conditioning treatment is used to:

- Destroy cancer cells in patients with blood cancers
- Destroy damaged stem cells in patients with blood diseases

What are the types of conditioning treatment?

1. **Chemotherapy:** All patients receive chemotherapy conditioning. When you are admitted, your health care team will teach you about the chemotherapy medications you will be receiving, what days you will receive them and what to expect with each drug.
2. **Total Body Irradiation (TBI):** Some patients will also receive total body irradiation therapy, depending on their diagnosis. For more information on TBI, please see the handout “*Understanding Total Body Irradiation*”

See the “***Supporting You through Treatment***” booklet for more information on treatment side effects and how to manage them.

How Does Chemotherapy Work?

Chemotherapy is a drug treatment that uses strong medications to kill cancer cells. It targets cells that grow and divide quickly, as cancer cells do.

Chemotherapy also attacks fast growing healthy cells. The cells that line your stomach, hair, skin and bone marrow are examples of cells that grow quickly.

You will start to feel unwell and experience chemotherapy side effects as your healthy cells are damaged. This is why chemotherapy can cause upset stomach and hair loss, and lowers your “blood counts.”



Cytotoxic Safety (“CYTO” = cell “TOXIC” = harmful)

Chemotherapy is a cytotoxic medication, meaning it is harmful to cells. It takes 48 hours for chemotherapy to slowly leave your body through your urine and poo. Small amounts of the drug can also be found in blood, vomit, semen, and vaginal fluids.

Your body fluids are **cytotoxic every day chemotherapy is given and for 48 hours** from when the last dose finishes. (Melphalan is an exception and you are only cytotoxic for 24 hours after this drug is given).

While the risk is low, please follow these steps to keep you and your family safe while you are cytotoxic:

While you are cytotoxic as an inpatient:

- Casual contact such as hugging, kissing and sharing a bed is still safe.
- Cover the toilet with a blue pad and flush twice. Replace with a new blue pad every few days.
- Urine and stool and toilet paper can be flushed down the toilet. Vomit, vomit bags, baby wipes and the soft paper towels used as toilet paper (“the white roll”) go into the red cytotoxic bins.
- If you’re using a commode at the bedside: toilet paper and wipes go into the red cytotoxic bins.
- Family members who come in contact with your body fluids (i.e. emptying and measuring urine) need to wear blue gloves to protect themselves.

Step 7: Stem Cell Transplant Day:

“Day 0”

14th or 15th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

Your stem cell transplant occurs once your conditioning therapy has completed. You will be given medications 6 hours and 1 hour before your transplant. These medications help your body tolerate the DMSO preservative. DMSO was added to the bag of stem cells to protect them while they were frozen.

The day of your autologous stem cell transplant is called “Day 0”. From “Day 0” onward, your health care team will count each day as “Day 1”, “Day 2”, “Day 3”, and so on.

What will happen on my stem cell transplant day?

- We will give you an IV steroid medication in the morning called **hydrocortisone** over 15-20 minutes.
- Your stem cell transplant will happen in the early afternoon. Eat a light lunch to avoid feeling nauseated.
- One hour before your transplant, you will be given IV **hydrocortisone**, IV **Benadryl**® and 2 **Tylenol**® tablets.
- When we are ready to start the transplant (usually around 2pm), your frozen stem cells will be thawed (unfrozen) in a warm water bath.
- Once your stem cells are thawed, the bag will be connected to your Hickman line and given back to you like a blood transfusion.
- A nurse and doctor will be by your side during the reinfusion of your stem cells.
- Each bag of stem cells will take roughly 20 to 60 minutes to be reinfused.

While your stem cells are being given to you (during your transplant):

- You will be sitting up comfortably in a hospital bed. Your family and friends can be in the room to celebrate and support you.
- You may feel nervous or excited or both. This is normal; you are safe and we are here to support you and can answer any questions you may have.
- You may have an odd taste in your mouth like canned corn or garlic. This is from the DMSO preservative in the bag of stem cells. We will give you a hard candy to suck on through the transplant to help get rid of this odd taste.
- You may feel a tickle or tightness in your throat or chest. This is normal and you will feel better if you breathe deeply and cough. Some people feel more comfortable when they receive a small amount of oxygen.
- You may feel nauseated (feeling of having to throw up).
- You may feel cold. This feeling is caused by the thawed stem cells.
- All these symptoms will go away once the stem cell are finished being infused.
- Occasionally, some people have an allergic reaction to the stem cells. Sometimes a fever or shakes can develop. Your nurse and doctor are ready if this happens and will give you medications to quickly stop the allergic reaction.

After your stem cells have been given back (after the transplant):

- You will feel sleepy from the IV Benadryl[®] that was given.
- Monitoring and vital signs will continue every 15 minutes for the next 2 hours.
- Your urine may be red for a few hours after the transplant. This should stop after 24 hours.
- The canned corn taste from the DMSO may stay on your breath 24 hours after the transplant.

Step 8: Waiting for Blood Count Recovery

“Days 1 – 12” or later

14th or 15th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

After your transplant day, there will be roughly 1-2 weeks where your blood counts will be very low. During this time, you will feel the most unwell from the side effects from chemotherapy (and radiation).

As your blood counts return to more normal levels (“engraftment”), your side effects will improve. **Engraftment** is when your bone marrow is able to begin making healthy new blood cells.

What will happen while I’m waiting for engraftment?

While your white blood cells and other blood counts are low, you will be closely monitored and supported by your health care team. Some things to expect include:

- **Tests:** You’ll have daily blood tests and other tests as needed (i.e. CT scans, chest x-rays, etc.) to monitor your progress and watch for infection.
- **Managing side effects from chemotherapy (and radiation):** You’ll be given medication and teaching to help you manage the side effects and make you more comfortable. See the next page for possible chemotherapy side effects.
- **Blood and platelet transfusions:** Most people need blood and platelet transfusions when their blood counts drop to lower levels.
- **Stay physically active:** Keep moving after your transplant! Staying active is a very important way to prevent lung infections and limit the amount of muscle lost. Even when you’re feeling unwell, try to stay out of bed as much as possible. Sit up for meals and walk around the unit as much as you can each day. Follow recommendations from your physiotherapist.
- **Teaching:** Learning about your treatment and how to take care of yourself is important as you look ahead to being discharged. Your health care team is here to support you and answer any questions you may have.

What are the possible side effects from high-dose chemotherapy?

Different people react differently to the stem cell transplant process; don't feel discouraged if you meet someone who has had a different experience than you.

Short-term side effects (those that you can expect in the first 1-2 weeks after):

- low white blood count – this increases your risk of infection
- low platelet count
- fever, chills and infections
- nausea and vomiting
- fatigue (feeling tired)
- hair loss
- loss of appetite (do not feel like eating)
- taste changes
- mouth sores and sore throat
- diarrhea (frequent runny poo)
- changes in your memory and concentration

The booklet
***“Supporting You
through Treatment”***
offers advice on how to
manage any possible
side effects you may
experience.

Later side effects (those that can last longer than 2 weeks):

- fatigue
- shortness of breath with physical activity—this will improve with gradual increases in simple exercise such as walking
- changes in your memory and concentrations (also called “chemo brain”)
- taste changes
- nausea, diarrhea

Long-term side effects (those that can last longer than 1 month):

- fatigue
- changes in your memory and concentration (also called “chemo brain”)
- infertility (not being able to have children)

Did you Know?

It is very important for you to always tell your nurse or doctor about any side effects or symptoms you notice, as minor as they may seem. We count on you to let us know how you're feeling. When you mention a side effect early, it can often be managed better and there is less chance of complications.

Step 9: Blood Count Recovery (“Engraftment”)

The medical term for when your blood cells recover after transplant is called ‘engraftment’. Engraftment is when your stem cells begin to make new blood cells. Engraftment usually starts 10-12 days after your stem cell transplant day.

What happens when my blood counts recover?

As your blood counts recover, you will notice the side effects and symptoms from the chemotherapy (and radiation) improve. You will be discharged from hospital when the doctor feels it is safe for you. This usually happens 2-3 weeks after chemotherapy when your blood counts are closer to normal.

Before you are discharged, we consider:

- Your blood cell counts have reached a safe level. Your blood counts do not have to be normal for you to be discharged.
- You are well enough to be monitored as an outpatient.
- You are able to eat and drink enough to maintain your weight.
- You have enough strength and mobility to attend regular clinic visits.
- You are able to take your medications in pill form.

How will I feel after my blood counts have recovered?

Even after your blood counts recover, you will still feel tired. Feeling tired can persist for a few months after the transplant. The best way to fight fatigue and low energy is to slowly increase the amount of activity you do every day.

You may also have other symptoms, such as:

- nausea and sometimes vomiting
- diarrhea
- poor appetite
- changes in taste
- hard time sleeping

These symptoms are common and will improve slowly. You can get medications that may help settle uncomfortable symptoms. You may need to keep taking medications to control your symptoms (such as nausea) until your symptoms get better.

Step 10: Follow-up Visits in Daycare

L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, VGH

Once you've been cleared for discharge from the hospital, you'll continue to be seen as an outpatient in the Leukemia/BMT Daycare Unit for a few weeks after transplant. Your appointments will be 3 times a week or more often, as needed.

About the Daycare Clinic:

- There are 22 treatment rooms with beds and chairs for patient use. Family members/caregivers are welcome to assist you and keep you company.
- Wi-Fi connection and televisions are available for each patient.
- A kitchen with a water machine is available to fill your own bottles with. A small selection of snacks, sandwiches and juice are available for patients who have an unexpected longer stay.
- A patient library where you can find computers, brochures, and other resources.

What should I bring to each visit at the Daycare Unit?

- Your ID card with your name and medical record number (we will give you this).
- Any medications you may need to take during that day.
- A list of the current medications you are taking.
- A family member or friend. You won't be able to drive or take public transportation while you're still recovering from your transplant.
- Snacks, drinks, a reusable water bottle.
- Things to occupy your time, although you may prefer to rest or watch TV.

What Can I Expect in the Daycare Unit?

On your first visit, your nurse will give you a tour to show you where to find water, warm blankets, etc. Our unit has a “self-care” routine which includes your nurse teaching you how to check in for each visit, how to take your own vital signs and when to book your next visit. Each visit following your transplant day will be 2 to 4 hours long, but can sometimes be longer. This is based on what your blood results show that day and any symptoms you may have. Each visit, a nurse and doctor will discuss any side effects you may be experiencing and questions you have.

What will happen during each visit to the Daycare unit?

Each visit may be a bit different, depending on your blood tests and symptoms. You may have a shorter 2 hour visit or you may need to stay longer. You can expect:

- Blood work taken from your Hickman line.
- Your health care team to assess you and help you cope with symptoms.
- Close monitoring for fever, infection and other complications.
- IV fluids, blood and platelet transfusions as needed.
- Medications for treating symptoms as needed (i.e. antibiotics, anti-nausea, etc.)
- Arrangements for extra tests as needed.
- Your health care team is here to support you. Write down questions to ask them.

What should I do every day?

- Check your temperature twice a day. Check it more often if you are feeling unwell. Call us immediately if you have a temperature of 38°C or higher.
- Take your medications. You will be given a list of medications and when to take them.
- If you feel like it, you can do many of your usual home activities like going for walks, reading, listening to music, and having healthy family and friends visit you.
- Your 24-hour caregiver can help prepare your meals, keep track of how much you are drinking, take your temperature, and anything else you need help with.
- Please follow strict infection control guidelines from the *“Supporting You through Treatment”* booklet.

What should I do if I have an issue or questions while at home?

Write down any questions you may have and bring them to your next appointment. If you are unsure about a symptom you're having or have an issue that needs attention, contact us. A nurse can help manage your question over the phone or contact the doctor for further instructions.

Call Us Immediately If You Have:

- Fever: a temperature of 38°C or higher
- Chills or shaking
- Yellow or green mucus when you cough
- A bad headache
- Diarrhea, nausea or vomiting that doesn't stop
- Flu-like symptoms
- New bad bruising and/or bleeding
- Difficulty taking your pills
- New pain
- Concerns with your IV line
- Unsteadiness when walking or have fallen down
- Rash, blisters, allergic reactions

Important Phone Numbers:

The Leukemia/BMT Daycare Unit Hours: 604 875 4073

6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 7:00am – 7:00pm
Weekends & Holidays 8:00am – 6:00pm

Afterhours (T15 Inpatient Unit): 604 875 4343

15th Floor & 14L, Jim Pattison Pavilion, VGH

Step 11: Managing at Home after Transplant

Generally, it will take roughly 3-6 months for you to return to a relatively normal lifestyle. Adjusting to life after your stem cell transplant can feel like a slow recovery. You will likely still have good days and bad days. It will take time for you to step back into your roles, such as being a parent, spouse, employee and friend again. Be patient with yourself as you adjust and recover.

See the following pages for more information on:

- Coping emotionally through treatment
- Helping your family cope through your treatment
- Self-image and sexuality
- Returning to work
- Fear of recurrence
- Support groups and community resources

Do I need vaccination (shots) after my transplant?

After your transplant, you can lose the protection from the infections or the vaccines you got as a child. Your hematologist will give you a letter that will list the vaccinations you will need to receive and when to schedule them with your local clinic. Revaccinations usually start around 6-12 months after your transplant, once your immune system has had time to more fully recover.

You and your hematologist (transplant doctor) will also discuss transferring your care back to your primary cancer doctor during this appointment.

What are shingles? Why should I be aware of the symptoms of shingles?

Shingles is caused by the Herpes Zoster/ Varicella zoster virus (VZV), the virus that causes chickenpox. Most people have been “exposed” to this virus in their lifetime, either by having chickenpox or receiving the varicella vaccine. Once this exposure happens, the virus remains “dormant” (it is inactive but never leaves your body). When your immune system is low (i.e. after a transplant), the dormant VZV virus can become active again and cause shingles. Shingles is contagious and can be passed on to others.

What are the symptoms of shingles?

The symptoms often occur in a strip or band on one side of the body. This is because the infection usually follows the path of a nerve. Lesions are usually in groups of raised, red blisters that may look like clear pimples. They are usually quite sore and itchy. These blisters may break and ooze fluid. This fluid is contagious to others. When the blisters are dried and form a scab, they are no longer contagious.

How can I prevent shingles?

If you have never had chickenpox or the varicella vaccine, you must avoid anyone with chickenpox or shingles. If you are exposed, you must tell your physician as soon as possible so they can determine if additional treatment is necessary. The best way to prevent shingles if you have previously had chickenpox or the varicella vaccine is to take your Valtrex[®] and consider getting vaccinated (Shingrix[™]) when your physician tells you that you are able to.

Coping Emotionally through your Treatment

Undergoing cancer treatment can affect every part of your life, including your body, feelings, relationships, self-image and sexuality. Some patients say that the emotional impact of treatment can be harder to manage than the physical changes.

Your emotions can change from day to day, or minute to minute. Your emotions may also change because of the step of the treatment process you are in.

Some of your feelings may include:

- Hope, anxiety, helplessness, uncertainty, impatience, isolation
- Being out of control and overwhelmed
- Fear of sickness, death or the unknown

All of these feelings are normal.

Here are some things you can try that other patients have found helpful:

- Share your feelings with those who are close to you, such as your family and friends.
- Ask your health care team questions so you will know what to expect.
- Talk to someone who has been through it. Connect with one of the many peer support programs available through community cancer centers. See the booklet *“Resources and Support”* for more on support groups.
- Manage your energy before, during and after the transplant by eating well and being active. Try to take a 10-15 minute walk each day to boost your mood and energy.
- Distract yourself by focusing on or doing an activity you enjoy. This will give you some relief from your thoughts and feelings. This may include things like: reading, meditation, listening to music/audiobook/podcast, watching a favourite TV show or movie, painting, sketching, knitting, spending time with family and friends, etc.
- Set realistic small goals (“Take one day at a time”). When you feel overwhelmed or you think what lays ahead will be too long or tiring, try taking it one day or even one hour at a time. This helps focus you on the here and now and see your progress one step at a time.

Your Family

Family members are also affected by a stem cell transplant, especially your caregiver. Your family members may share the same feelings and worries that you do. For those from out of town, there can be the added stress of being away from familiar surroundings and the support of friends, neighbours and family. Role changes are common and family members may take on more responsibilities. Financial or legal problems are also common concerns.

Here are some things to try:

- As a family, try to openly share your feelings and work together to solve your problems. A social worker can help with this.
- Prepare family members, such as children and grandchildren, by talking with them and giving them information suited to their age and level of understanding.
- As a family member and caregiver, you need to take care of yourself too. Get enough sleep, eat well, be active and find time to do things you enjoy.
- Let extended family members know how they can best help you. Family and friends want to be there for you, but need to know what is most helpful. Practical things include help with car rides, meals, child care/pet care, household chores and daily activities.
- Take care of any financial or legal problems such as Power of Attorney, wills, sick benefits and disability pensions. A social worker can help you with this.
- Talk to your social worker or type “*talking to my family*” and/or “*caregivers*” on the BC Cancer website www.bccancer.bc.ca for more support and information.

Returning to Work

Returning to work is a common source of stress for people after their transplant. When you feel ready to return to work, it is best to do it slowly and over time.

Going back to work helps to get you get back into a more “normal” routine, but you may still be thinking about your transplant experience and will need to balance your work schedule with your post-transplant medical visits. You may also be dealing with side effects, such as:

- low energy;
- feeling anxious or worried about returning to work;
- you may have troubling thoughts about family, relationship issues or financial concerns.

These side effects can affect your ability to focus concentrate.

Here are some tips to help you return to work:

- Talk to your doctor. It is important to talk to your doctor about your return to work plans so you get medical support and guidance. Your doctor can give you advice on when you can consider returning to work. They can also give you and/or your workplace tips on what needs to be considered given your physical needs.
- Be patient with yourself. It is important to pay attention to your body. Each person is different and each person’s return to work plan will look different. It is important to accept that.
- Forcing yourself to move ahead before you are ready may result in needing to take even more time off from work.
- Before you return to work, make a plan. Consider if you want to share information about your illness with your coworkers. How much and how you share this information is fully up to you. Do not feel that your coworkers need to know everything. You have a right to keep your personal situation private.

Fear of Relapse

Many patients are concerned about their cancer coming back (“relapse”) or not being controlled. This is a very common fear. The risk of relapse is different for each person. It depends on many factors, such as your type of cancer, the treatment you had, and how long it has been since your treatment.

If you have a fear of cancer coming back, here are some things you can try:

- **Go to all your medical follow-up appointments.** At these visits, your doctor will look for side effects from treatment and check if your cancer has come back.
- **Ask your doctor** to talk directly about the chances of the cancer coming back. Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions.
- **Plan ahead.** Make sure your family and loved ones know your wishes if you can’t speak for yourself. Putting one’s legal affairs in order does not mean expecting the worst. Dealing with these issues early on in your treatment will give you the peace of mind to focus on getting better.
- **Be informed.** Learn about your cancer. Know what symptoms of recurrence to look out for. Having more knowledge may give you a greater sense of control over your life.
- **Share your feelings.** People often find that when they share strong feelings like fear, anger or sadness, it is easier to let go of them. Some people talk to friends or family, other cancer survivors or a counsellor.

There are programs in your community that offer support for those living with cancer, see “*Resources and Support*” for more information. If you prefer not to talk to others, you can still sort out your feelings by thinking about them or writing them down. If you are having a hard time, talk to your doctor, nurse or a social worker.

Focus on wellness. Try to be hopeful. Sometimes this means looking for the good even during a bad time. Try to use your energy to focus on wellness and doing things that make you happy. Remember that you are never alone. There are people to help and support you. Some of them are in your home and community; others are at your hospital, cancer centre or place of worship.

Common Questions after Autologous Stem Cell Transplant

These are general guidelines as you prepare to return to a more normal routine; your doctor can discuss any concerns you may have. Wash your hands after doing any of these activities.

Am I safe?	Less than 6 months after transplant	6 months to one year after transplant	One year or more after transplant
Taking probiotics	No	No	Ok
Eating raw/undercooked seafood (i.e. sushi), unpasteurized milk/cheese, etc.	No less than 3 months after transplant. Ok 3-6 months after transplant.	Ok	Ok
Work and School	No	Ok	Ok
Traveling	No	Ok	Ok
Hot Tubs	No	Ok	Ok
Swimming (Never swim with an IV catheter)	No	Ok	Ok
Gardening, mowing the lawn, raking leaves	No	Ok. Wear gloves and a mask	Ok
Having plants in the home	Ok. Do not water or handle plants.	Ok	Ok
Kneading/baking bread with yeast	Ok	Ok	Ok
Carpentry or woodworking	No	Ok	Ok
Construction or renovations	No	Ok	Ok
Flu Shot	Ok 3 months after transplant.	Ok	Ok
Bringing new pets to your home	No	Ok	Ok
Cats, dogs, fish	Ok. Do not sleep in same bed, do not touch litter or waste	Ok	Ok

Information adapted from Adult Allogeneic Transplant Manual (©2017). Seattle Cancer Care Alliance.

Your doctor will discuss your re-vaccination schedule in a follow-up appointment.

What is Advance Care Planning?

Advance care planning involves having conversations with your loved ones and health care team to make sure they know what your wishes are if you become unable to speak for yourself. By planning ahead you:

- Make your wishes and instructions for your future health care known;
- Provide your health care team with information to guide them in your care; and
- Ease the burden of your loved ones at a difficult time.

Why should I think about Advance Care Planning?

The chance of you facing any life threatening situations during treatment depends on a lot of factors, such as your type of cancer, your treatment, and your general health. No matter what your age or health, we feel it is important to recommend advance care planning because we know it can:

- Improve your quality of life;
- Improve the chance that your care wishes will be fulfilled;
- Bring peace of mind to you and your loved ones, knowing that you have a plan.

How do I start Advance Care Planning?

- At your own comfort, start with the “**What Matters to Me**” guide (see next page).
- Tell someone close to you, or your health care team, that you want to talk about your future health care. Have as many conversations as you need.
- Use the workbook, *My Voice: Expressing My Wishes for Future Health Care* to guide you and write down your options. Find this guide online:
 - www.advancecareplanning.ca
 - www.healthlinkbc.ca/health-feature/advance-care-planning

Situations change. Even your beliefs, values and wishes can change. As long as you are able to make your own decisions, you can cancel or change any part of your advance care plan.

Make a plan, set it aside and then focus on getting better. You may never need your advance care plan – but if you do, you’ll be glad that it’s there.



What Matters Most to Me

Preparing for **Conversations** About **My Health**

Wishes of: _____

Written by: _____

Date: _____

Vancouver Coastal Health (VCH) and Providence Health Care (PHC) encourage people, particularly those living with a serious illness, to voice their wishes in conversations with their health care providers about their care. We provide these questions below for you to think about and share with your primary care provider or discuss with the health care team if you visit a hospital for care. You are also encouraged to consider completing your advance care plan.*

This is my understanding of my current health condition(s):

I want more information about what is likely ahead with my health condition:

☐ Yes ☐ No

Some questions I have about my health condition include:

These are my most important goals as I live with my health condition:

These are my biggest fears and worries about the future with my health:

This is what gives me strength as I think about my future with my illness:



These are abilities in my daily life that are critical to me and that I cannot imagine living without:

If my health were to worsen, this is what I would be willing to go through for the possibility of more time (for example: tests, treatments, hospital stay, etc.):

It is important to share these thoughts with your loved ones, family and/or friends, so your wishes are known by others. These family members/friends are aware of my wishes:

These questions are intended to help you prepare for conversations with your health care provider and/or family members and friends. These questions are also an important part of advance care planning - thinking about and sharing your wishes for care in the future if you can no longer speak for yourself.

I have documented my wishes in an advance care planning document

- ☐ Representation Agreement
☐ Advance Directive
☐ Other: _____

You are invited to provide a copy of this, and your other advance care planning documents, to your care team.



*For information about Representation Agreements, Advance Directives and other aspects of advance care planning please visit www.vch.ca/acp.



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The information in this document is intended solely for the person to whom it was given by the health care team.
www.vch.ca

Autologous Transplant Resources

Please Note:

The websites listed in this manual are created by organizations outside our program. They are meant to be used as information only and should not replace the advice given to you by your health care team. Information and policies change frequently and we cannot guarantee any websites contain the most up to date information. We do not endorse the content on any third party websites.

The following websites offer overviews on autologous stem cell transplant and recovery information. Please remember you're receiving an *autologous* transplant. Some information on these sites may mention "*allogeneic*" transplants and "GVHD". These types of transplants use healthy stem cells collected from a matched donor and do not pertain to you.

- www.mskcc.org/cancer-care/patient-education/autologous-stem-cell-transplant-guide-patients-caregivers (American)
- www.anthonynolan.org/patients-and-families (United Kingdom)

Common Medical Terms

Anemia: A condition in which the blood has too few red blood cells, or not enough hemoglobin in these cells.

Antibiotics: Medications used to fight bacterial infections.

Apheresis: A painless procedure where blood is run through a machine that removes the stem cells and then returns remaining cells back to the bloodstream.

Autologous Transplantation: A transplant in which the stem cells infused come from the individual receiving it.

Allogeneic Transplantation: A transplant where stem cells are donated to a patient from another matched person.

Biopsy: Removal of small piece of tissue for microscopic examination.

Blood Tests: You will have many blood tests before and throughout your treatment.

Blood tests tell us about your blood cells levels (white blood cells, hemoglobin, platelets). They can also tell us about your general health, how well your organs are working (i.e. kidneys, liver, pancreas), electrolyte imbalances (i.e. potassium, magnesium) and if you have any possible infections.

Bone Marrow: Spongy tissue inside the bones where the blood cells are produced.

Bone Marrow Biopsy and Aspirate: In this procedure, a needle is used to remove a small amount of bone marrow tissue (aspirate) and bone fragment (biopsy) from the pelvic bone. Doctors use these samples to diagnose and monitor blood and marrow diseases and cancers.

Bone Marrow Transplant: Bone marrow transplants are procedures to replace damaged or destroyed bone marrow with healthy bone marrow stem cells. They require operating rooms and anesthesia to collect stem cells from bone marrow located in the hip bone. Now more commonly, stem cells are collected from blood veins in the arm. One of the main differences between BMTs and PBSCTs is how the stem cells are collected.

Chemotherapy: Anticancer drugs or combination of drugs designed to kill cancer cells. High-dose Chemotherapy is higher than standard doses of anticancer drugs.

Chest X-Ray: This is a picture of the organs, bones and tissue inside your chest. It takes about 30 minutes to complete. Your doctor will decide if you need other x-rays.

DMSO (dimethyl sulfoxide): A drug used to protect frozen stem cells.

Electrocardiogram (ECG): A heart test to check your heart's electrical activity.

Electrode stickers are placed on your chest to measure your heart's rhythm.

Engraftment: The process in which reinfused stem cells begin to grow in the bone marrow and make new blood cells.

Filgrastim: A medication (G-CSF) given by needle injection that moves stem cells from the bone marrow into the bloodstream. Brand names are Neupogen® & Grastofil®.

Hematologic: Relating to blood and blood forming tissues. A hematologist is a doctor that treats diseases and disorders related to the blood.

Infusion: The introduction of a liquid into the body through a vein.

Intravenous (IV): A therapy that delivers liquid substance directly into a vein.

Infection: The invasion and spread of harmful organisms (bacteria, viruses, fungi, parasites) that are not normally present in your body.

L/BMT: Leukemia/Bone Marrow Transplant Program of BC, formed in 1981.

Lumbar Puncture: In this procedure, a needle is used to remove a small amount of cerebrospinal fluid (CSF) from between the lower back bones (vertebrae). CSF is the fluid that surrounds and cushions the brain and spinal cord and can sometimes contain cancer cells. Chemotherapy is administered into the spinal cord to treat and prevent any cancer cells in the CSF.

Mobilization: Using a medication to move stem cells from the bone marrow into the bloodstream. This is used to prepare for apheresis.

Neutrophils: A type of white blood cell that protects you from infections. They are the first cells to arrive on the scene when you have a bacterial infection.

Peripheral Blood Stem Cell: A stem cell that has left the bone marrow and is circulating in the blood stream.

PET Scan (Positron Emission Tomography): A PET scan uses a form of radioactive contrast to create 3D colour images to see how your body's cells are working. It is often combined with a CT scan to provide a more complete picture of the location and growth of any diseased cells.

Platelets: Cells that are needed for blood to clot.

Pulmonary Function Test (PFT): A lung test to check your breathing ability. A clip will be placed on your nose and you'll be asked to breathe in and out of a mouthpiece.

Red Blood Cells: Cells that carry oxygen from the lungs to the rest of your body.

Reinfusion: The return of your stem cells to your bloodstream.

Remission: Complete or partial disappearance of symptoms of a disease in response to treatment.

Radionucleotide Ventriculogram Scan (RVG or MUGA): A type of x-ray used to look at how well your heart is pumping. A series of images of the heart are taken after 2 injections of radioactive solution are given in your arm. The scan takes about 90 minutes.

Stem cells: Basic cells in the bone marrow that can become almost any type of cell in the body, including blood cells, muscle cells, organ cells, etc.

Stem cell collection (Harvest): The process of taking stem cells out of the blood; see apheresis.

White Blood cells (WBC): The blood cells that fight infection. Also see neutrophils.

Where Can I Get More Information?

Ask a member of your health care team for any of the materials listed below. You can read or order them online. They can also be found on the inpatient unit (near the patient lounge, room 15020) or on the Daycare Unit patient library (room 631).

- Supporting You through Treatment (Leukemia/BMT Program of BC)
- Resources and Support (Leukemia/BMT Program of BC)
- Coping When You Have Cancer (Canadian Cancer Society)
- Eating Well When You Have Cancer (Canadian Cancer Society)
- Sex, Intimacy and Cancer (Canadian Cancer Society)
- Blood and Marrow Stem Cell Transplantation (Leukemia/Lymphoma Society)

If you have questions or concerns about your treatment or coping with your diagnosis, let your health care team know.

Find these booklets, videos and more information at:

The Leukemia Bone Marrow Transplant Program of BC:

www.leukemiabmtprogram.org/

The Leukemia & Lymphoma Society of Canada: 1-833-222-4884

www.llscanada.org/

Click Patients & Caregivers → Free Information Booklets

BC Cancer: 1-800-663-3333

www.bccancer.bc.ca/

The Canadian Cancer Society: 1-888-939-3333

www.cancer.ca

Click Support and Services → Publications

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Please note that the information contained in this manual is not intended to replace the advice of your health care team. Use this as a reference and education guide. Consult your health care team if you have any questions or concerns. Author: Amy Healy 02/2020

Adapted from *Your Autologous Stem Cell Transplant* (© 2016) with permission from South East Regional Cancer Program.

Adapted from *Your Guide to Having an Inpatient Autologous Stem Cell Transplant* (© 2017) with permission from University Health Network Patient Education.