Patient Education

Your Outpatient Autologous Stem Cell Transplant

Information for Patients and Caregivers

Read this guide to learn:

- What an autologous stem cell transplant is
- What happens before a stem cell transplant
- What to expect during your stem cell transplant
- What to expect during your recovery
- Important phone numbers
- Where you can find more information

The Leukemia/Bone Marrow
Transplant Program of BC

Important Phone Numbers:

Leukemia/BMT Daycare Unit Hours:
6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 7:00 am – 7:30 pm
Weekends 8:00 am – 6:00 pm
Holidays 7:00 am – 7:30 pm

604 - 875 - 4073

If you do not have a scheduled appointment, please call the unit and speak to a triage nurse prior to showing up to the Leukemia/BMT Daycare Unit.

Hematology Apheresis Unit (HAU):
6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 7:00 am – 7:00 pm
Weekends & Holidays Closed

604 - 875 - 4626

BMT Daycare and Apheresis After Hours:
BMT Daycare and Apheresis units close every night; for issues afterhours please call the Leukemia/BMT Inpatient Unit
Unit, 15th & 16th Floor
Jim Pattison Pavilion, VGH

604 - 875 - 4343

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 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.

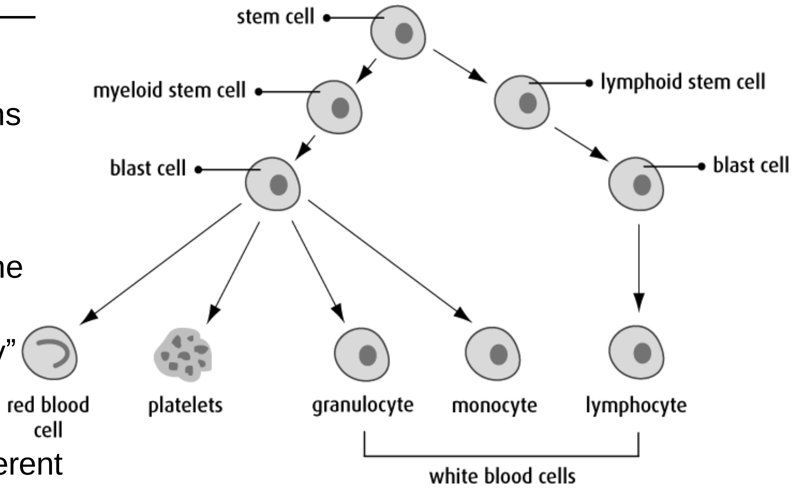
We welcome your feedback on how we can improve this booklet for other patients and families.

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 will 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 down your questions and bring them and this booklet with you to your appointments.

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

Development of Blood Cells in the Bone Marrow



What Are Stem Cells?

Stem cells are the body's primary cells. All 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 will notice we talk a lot about blood cells (also referred to "blood counts") through your treatment. It is helpful to become familiar with them and what they do.

Types of Blood Cells

(all levels are x 10^9/L)

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 are at greater risk for infection when your white blood cell count is low.
- <u>Neutrophils</u> are a type of white blood cell that fight bacterial infections. Normal levels are 2 – 8.
- <u>Lymphocytes</u> 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 70 or lower, you will receive a blood transfusion.

Platelets:

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

What Is an Autologous Stem Cell Transplant?

Some cancers and blood disorders need to be treated with much higher doses of chemotherapy than others. This "high dose chemotherapy" treatment can kill more cancer cells than regular chemotherapy. However, this treatment also 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 "rescue".

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 will allow your bone marrow to grow back and start making 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 high dose chemotherapy.

Certain cancers such as multiple myeloma, lymphoma and other plasma cell disorders like amyloidosis are sometimes treated with autologous stem cell transplants.

I've Heard the Term Bone Marrow Transplant (BMT)? What's the Difference?

Previously, transplants involved stem cells being surgically removed from bone marrow located in the hip bone. This is called a bone marrow transplant, and we still occasionally do them today.

More commonly, stem cells are now collected from blood veins in the arm. This is called a "peripheral blood stem cell transplant" (PBSCT). PBSCTs do not require surgery to collect stem cells. One of the main differences between BMTs and PBSCTs is how the stem cells are collected.

You may still hear this term "BMT" when talking about all types of 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 also includes:

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

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 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 Support and Supporting You Through Treatment 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 is a brief overview of the steps you will take through your stem cell transplant. This step-by-step process is described in more detail in the following pages.

Step 1 Preparing for Transplant	You will meet with different members of your health care team who will help you prepare for your treatment. You will have tests to ensure it is safe for you to have a transplant.
Step 2 Mobilizing your Stem Cells	"Mobilizing" your cells means moving your stem cells from your bone marrow into your blood. You will receive injections and sometimes other drugs 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 Tunneled Catheter Insertion	This is an intravenous ("IV") line. It will be inserted in your chest to help make your treatment more comfortable.
Step 5 High Dose Chemotherapy	You will receive a single high dose of chemotherapy in the Leukemia/BMT Daycare unit.
Step 6 Stem Cell Transplant	Your stem cells will be given back to you through your IV catheter. This process is similar to a blood transfusion.
Step 7 Waiting for Blood Count Recovery	The high dose chemotherapy will cause your blood cells or "blood counts" to fall to very low levels for 2 - 3 weeks. You will generally feel weak and unwell from these and other side effects of the chemotherapy.
Step 8 Engraftment	Engraftment is when your blood cells return to normal levels. Your tunneled catheter will be removed once engraftment happens.
Step 9 Managing at Home after Transplant	Once you have recovered and no longer have Daycare appointments, it will take time to resume a normal life. You will have follow-up visits with your local hematologist/oncologist who will continue to monitor your blood counts.

Getting Ready for Your Transplant:

It is 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 will need a 24-hour live-in caregiver for a few weeks while you are receiving treatment as an outpatient. Your family and friends can share the caregiver role; it does not have to be only one person. Your social worker can assist caregivers with navigating leave from work benefits and requesting visa application letters. For more information on caregiver roles and support, please see the *Resources and Support* booklet.

2. Plan Where You Will Stay

You will need to be within a 45-minute drive from Vancouver General Hospital through your outpatient treatment. Please see *Resources and Support* for recommendations and important things to consider when booking accommodations. To plan for unpredictable changes, we recommend booking accommodations with a flexible cancellation policy.

3. Register for Fair PharmaCare

You can register for BC Fair PharmaCare by searching “BC Fair PharmaCare” on your internet browser. Click on the government www2.gov.bc.ca website. Click the square blue box “Register online for Fair PharmaCare”.

4. Arrange for Care of Any Dependents and/or Pets

Let your nurse navigator and social worker know if there are any concerns regarding people dependent on you for their care.

5. Have a Digital Celsius Thermometer

You can purchase one from your local pharmacy (if you do not already have one). You will use it regularly to monitor your temperature through your treatment and recovery.

6. Inform Your Doctor

If you have seen a doctor in a separate facility or health care program, make sure your transplant doctor is aware. Our doctors are not always informed of all your previous medical records.

7. Get Your Flu Shot

During the influenza season (usually October to April), we strongly suggest you and your family receive the flu shot; it is free at any local clinic and some pharmacies. The flu shot is the best way to prevent the flu and it will lessen the chances of severe complications. Ask your doctor or nurse navigator when is the best time to get your flu shot.

What Are Other Suggestions to Prepare for Transplant?

1. 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 poor nutrition. If you are having trouble eating enough calories, we can refer you to a dietician prior to your autologous stem cell transplant. Ask your nurse navigator for more information.

2. Being physically active is important to build strength and energy prior to treatment and transplant. Follow a regular exercise routine as best as you can. Try gentle exercises like walking every day. Yoga can strengthen muscles and help you relax.

3. Connect with a support program. We strongly recommend our patients use the excellent support services offered by BC Cancer, Canadian Cancer Society, and Leukemia & Lymphoma Society. Please see the *Resources and Support* booklet.

Step 1: Preparing for Your Transplant

Consultation with the BMT Hematologist

3-6 months before stem cell transplant (you may have received this booklet during this appointment). Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor.

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

Why haven't I Heard from My Doctors Yet?

There is a period where you may not receive many updates on the progress of your transplant. We understand how you must plan, and you may call our Hematologists office to confirm your tentative transplant date. We know you will soon be receiving treatment. It is best if we plan your pre-transplant tests and exams closer to your transplant date. This is to make sure we have the most up to date information about your health and how it will be affected by the transplant.

Phone Call with the BMT Nurse Navigators

Initial phone call: *1-3 weeks after Hematologist consultation*

Follow-up phone call: *5-8 weeks before stem cell transplant*

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 stem cell collection dates and your transplant dates so you can begin to plan accordingly. Please note these dates can change.

Our nurse navigators arrange all the planning, testing and appointments needed in preparation for your stem cell transplant. 5 to 8 weeks before your transplant date, they will phone you to ask questions on your health history and review the tests and appointments you will need. After this 30–45-minute phone call, they will send you an email with more information with your scheduled appointments and tests.

Please tell your nurse navigator if you live out of town and if you use any mobility aids, raised toilet seats, bedrails or other assistive devices. They will help you connect with our physiotherapy team to have this type of equipment during your transplant.

Pre-Transplant Tests

Approximately 4 weeks before stem cell transplant

Tests must be done to check how well your heart, lungs and kidneys are working before the transplant. These tests are booked at Vancouver General Hospital during you consultation at the Hematology Apheresis Unit. Depending on appointment availability, we may also arrange for these tests to be done in your local clinic or hospital. More information on these tests can be found under Common Medical Terms on page 44.

These tests can include:

- Blood tests (*bloodwork*)
- Heart tests: *Electrocardiogram (ECG), Radionucleotide Ventriculogram (RVG)*
- Lung tests*: Pulmonary Function Test (PFT), Chest x-ray*
- Kidney tests: *24-hour urine collection*

Pre-Transplant Consultations

Approximately 2 weeks before transplant,

To help you prepare for your transplant, you will meet with members of your health care team for personalized teaching in-person or via phone. Your doctor may refer you for other consultations, depending on the results of certain tests (e.g., cardio-oncologists).

a) **Apheresis Nurse:** you will meet with a nurse who will check your 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 arm veins are suitable, we will use them to collect your stem cells.
b) **Social Worker:** you will meet with a social worker to discuss how having a transplant can affect your family, coping, living arrangements, employment, finances and other practical matters. They can talk with you regarding general steps in creating a will, advance care plan, power of attorney, and temporary substitute decision maker.
c) **Dietitian:** if you have had problems with appetite or weight loss in the past, you will meet with a dietitian. They will discuss how you can prepare for your transplant and manage side effects through your diet and food choices.
d) **Thrombosis Clinic**: this appointment is only needed if you are currently using a blood thinner (e.g., Apixaban, Dalteparin, etc.). Thrombosis Clinic doctor and nurse will teach you how to manage your blood thinner through your treatment.

Step 2: Mobilizing Your Stem Cells

Approximately 1-2 weeks before transplant

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). Moving your stem cells from your bone marrow into your bloodstream is called "**Mobilization.**"

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 slight stinging 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.

How Many G-CSF Injections Will I Need?

You will need 4 days of G-SCF injections. Bloodwork will be taken on the 4th day of G-CSF injection. You may need to wait or return for your bloodwork results. The Apheresis staff will let you know if you do.

Where Will I Receive My G-CSF Injections?

A nurse will administer your G-CSF in the Hematology Apheresis Unit (HAU) or the Leukemia/BMT Daycare at Vancouver General Hospital, Leon Blackmore Pavilion, 6th floor.

G-CSF works best when given at the same time every day. Your injection appointments will be between the hours of 4:00 pm and 6:00 pm. This timing ensures you will have the most stem cells at the time of your stem cell collection.

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 your nurse navigator or the Hematology Apheresis Unit. During the G-CSF mobilization you can take Tylenol for discomfort or low fever (less than 38°C).

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

- *Shortness of breath that starts suddenly*
- *Blood in your urine*
- *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 and should be treated as an emergency.

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 depends on the dose required; one course of treatment is between $2,000.00 and $3,000.00. We help you find ways to manage this cost.

Managing the Cost of G-CSF

1. You may be registered for BC Fair PharmaCare. If you have not already been registered, you can register by searching “BC Fair PharmaCare” on your internet browser. Click on the government website www2.gov.bc.ca. Click the square blue box “Register online for Fair PharmaCare”.
2. Contact Fair PharmaCare *(1-800-662-7100)* 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.
3. 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.
4. Ensure you have your extended health benefits identification number and information to provide when asked for this. If you have any extended health benefits through a family member or partner, ensure you also have the identification number and information available.
5. Contact your extended health plan provider directly to determine if G-CSF is covered under your plan. The G-CSF drug we use is called Nypozi® drug ID number is 02520990.
6. 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 with a program that will contact you about your G-CSF coverage. They will help cover some of your out-of-pocket cost.
7. Your nurse navigator will be your contact person regarding any G-CSF drug coverage issues.

Step 3: Collecting Your Stem Cells

Approximately 1-2 weeks before stem cell transplant:
Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your stem cells are collected by a process called apheresis ("a-fur-REE-sis") in the Hematology Apheresis Unit (HAU). During this procedure, your blood will be circulated through an apheresis machine, it will separate and collect your stem cells. The remaining blood is then returned back to you.

- Your apheresis 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 with veins too small to be used, a central intravenous line will be inserted prior to collection. The apheresis process will use two different "ports" on their central venous catheter.
- You will be directly connected to the apheresis machine for 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 two IV lines).

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** to your lips, fingers, toes, or **cramping** in your hands and feet. This is due to a drop in calcium levels in your blood and caused by the anticoagulant used to prevent your blood from clotting in the apheresis machine. Calcium can be added to your intravenous (IV) and these symptoms should fade.

Tell your apheresis nurse at the first sign or any of these side effects, they can help you feel more comfortable.

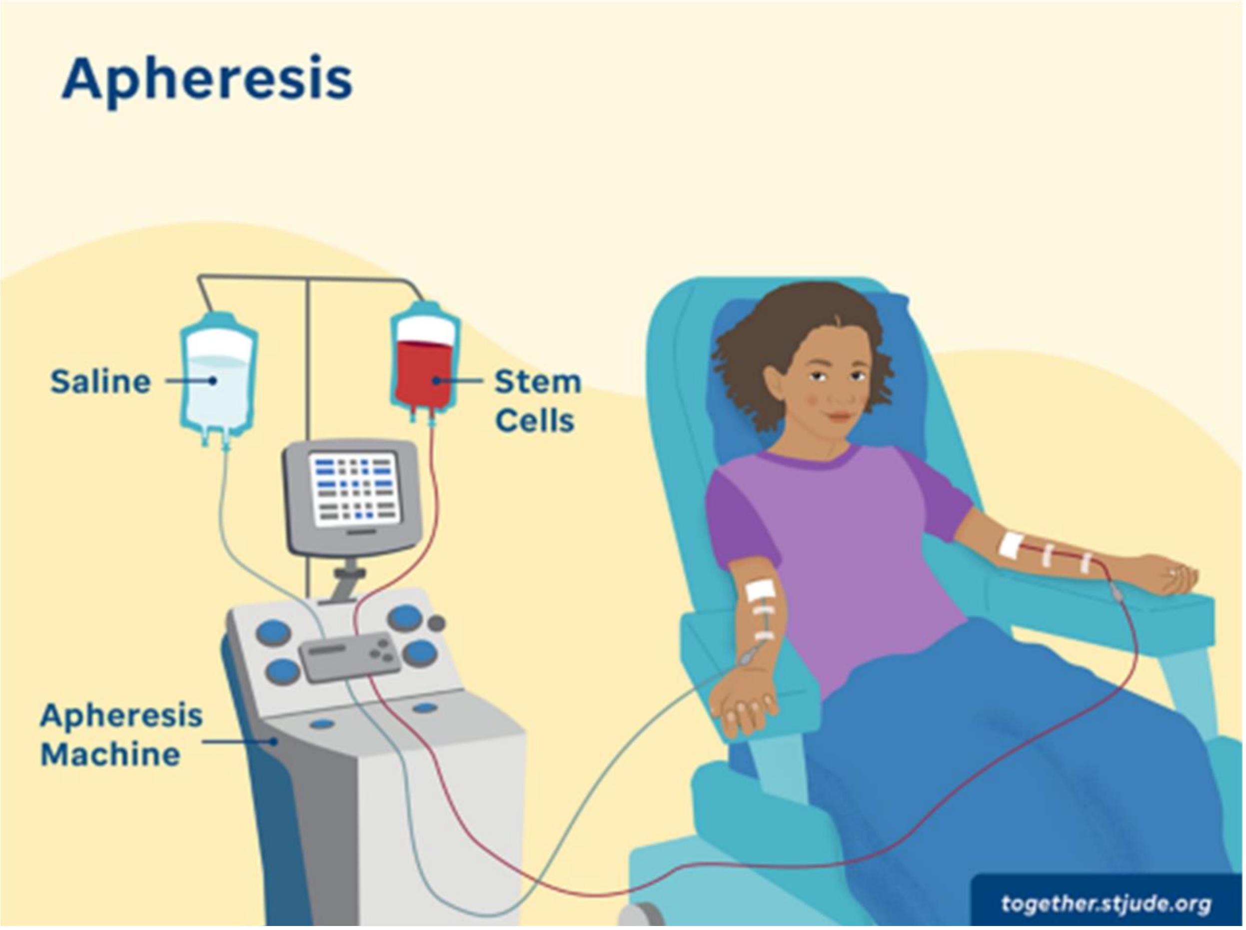
What Happens After the Stem Cells Are Collected?

At the end of the day, the bag of stem cells that has been collected is sent to a lab where the stem cells are counted. If more cells are needed, you will be asked to come back to the Hematology Apheresis Unit the next day to have the process repeated. **This is normal and there is no need for concern.**

Your cells are then 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 receive more information on how to prepare for your collection day during your first Apheresis visit.



Together by St. Jude, Aug 2022

Step 4: Central Venous Catheter Insertion

Approximately 1 week before stem cell transplant
Vancouver General Hospital, Jim Pattison Pavilion, Radiology Unit Ground Floor

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. It will make your stem cell transplant experience much more comfortable as it can be used to draw blood tests.

There are two CVCs we use. **You will have one of the following:**

- **Trifusion® Line**
  - 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 be inserted later.
- **Hickman® Line**
  - Inserted a few days prior to transplant
  - Only used for transplant and recovery, not stem cell collection
  - Most patients have a Hickman® line

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

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

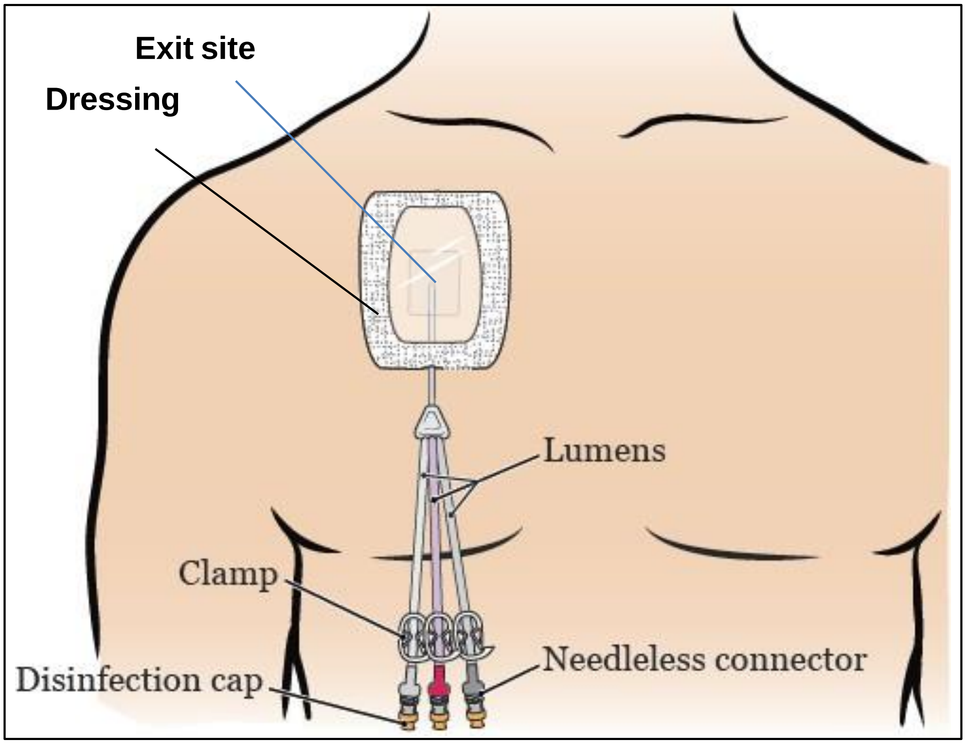
All These Names for the Same Thing!

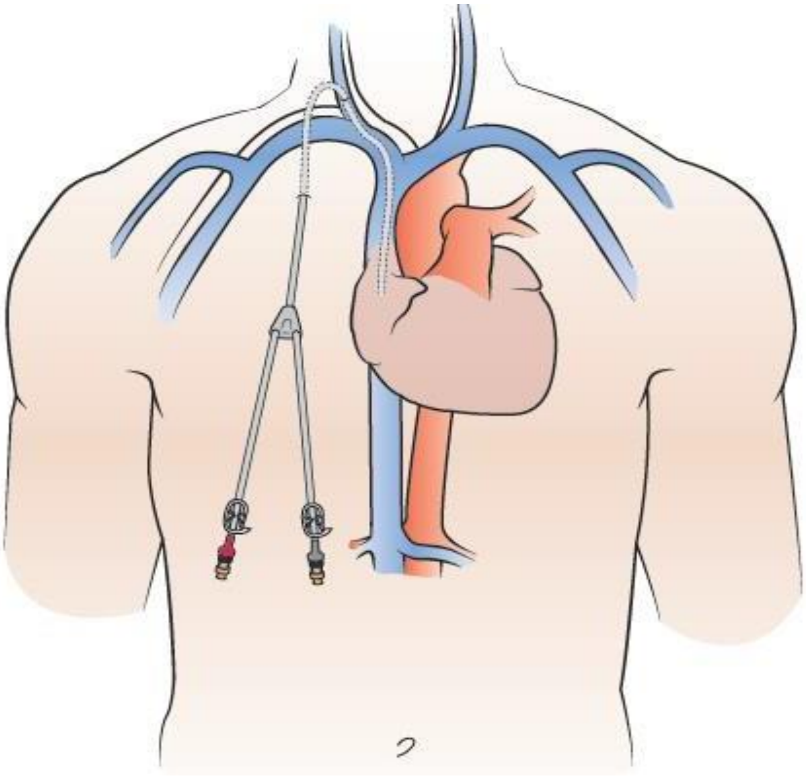
Although there are slight differences between them, all these terms refer to the same Central Venous Catheter line:

- Central venous catheter (CVC)
- Central line
- Hickman® line or Trifusion® line
- Tunneled catheter
- Intravenous "IV line"
- Your line

Pictures of Central Venous Catheters

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.





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.

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 dressing as mentioned in the booklet.**

Step 5: Chemotherapy Day

1 day before stem cell transplant
L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, Vancouver General Hospital

This L/BMT Daycare appointment is at least 6 hours long, so it is helpful to bring some items for your comfort. (*See page 23*).

Melphalan ("mell-fa-lan") is the intravenous (IV) high dose chemotherapy you will receive. Depending on your dose, you will receive either 1 or 2 bags of Melphalan. Each bag will be given over about 30-60 minutes.

What the day of your high-dose chemotherapy looks like:

- You will receive education by your nurse about **Melphalan** chemotherapy, your transplant, and recovery.
- You will receive intravenous fluids for 2 hours before and after your high dose chemotherapy is to protect your kidneys.
- You will receive 3-4 medications to prevent you from feeling sick (nausea and vomiting).
- A pharmacist will meet you to discuss your medications with you. Please do not leave before seeing your pharmacist.

Although you may have nausea, you will probably feel fine on this chemotherapy day. It is common to feel tired after chemotherapy so rest and relax for the rest of the day. Keep your nausea medications handy in case you feel sick to your stomach.

Side effects from this high dose chemotherapy will eventually cause you to feel unwell. For more detailed information on potential side effects and how to manage them, refer to the "*Supporting You through Treatment"* booklet.

How Does Chemotherapy Work?

Chemotherapy is a drug treatment that uses strong medications to kill cancer cells. It targets rapidly dividing cancer cells.

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.”

Hazardous Safety

Chemotherapy is a hazardous medication, meaning it is harmful to cells. It takes 24 hours for Melphalan chemotherapy to slowly leave your body through your urine and stool. Small amounts of the drug can also be found in blood, vomit, semen, and vaginal fluids.

After receiving Melphalan, your body fluids are **hazardous for 24 hours.** Your chemotherapy will finish by 1:00 pm one day before your stem cell transplant. This means you are hazardous until 1:00 pm on your stem cell transplant day. We ensure your stem cells transplant is given more than 24 hours after your chemotherapy.

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

During the 24-Hours That You Are Hazardous:

- Casual contact such as hugging, kissing, and sharing a bed is still safe.
- After using the toilet, put the lid down before flushing. Flush twice.
- Wash your hands well with regular soap and water after any contact with body fluids.
- When cleaning up body fluid spills at home use regular cleaning products and wear disposable gloves.
- Things you cannot flush down the toilet should be placed in a plastic garbage bag, tied tightly and put in another garbage bag.
- Clothing and bedding that is soiled with a <u>significant</u> amount of body fluids should be handled with disposable gloves. Place them in a separate plastic laundry bag and wash them in a separate load from other laundry.

About the L/BMT Daycare Outpatient Unit:

Your regular appointments during treatment are in the Leukemia/Bone Marrow Transplant Daycare. This unit is often called Daycare or LB6 for short and is located on the 6th floor of the Leon Blackmore Pavilion at Vancouver General Hospital.

Amenities

- There are treatment rooms with beds and chairs for patient use.
- Private rooms are used for patients with active infection, symptoms that are infectious, or procedures, such as a bone marrow biopsy or a lumbar puncture. Do not take a private room without talking to your nurse first.
- A small selection of snacks, sandwiches and juices are available for patients who are unable to come prepared. Patients or their visitor may come to the snack kitchen and wait for a staff member who has a spare moment to get them what they need. Due to infection control, only staff can access the kitchen.
- Wi-Fi connection is available throughout the facility.

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).
- A list of the current medications you are taking.
- Any medications you may need to take throughout the day.
- A water bottle or hot drink thermos and snacks.
- Things to occupy your time.
- <u>One</u> family member or friend to keep you company and assist you.
- You will not be able to drive or take public transportation during your transplant treatment or while your white blood cell count is low.

What Can I Expect at the Daycare Unit?

On your first visit, a nurse will give you a tour of the unit. The 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 where to record symptoms you may be having. On average, each visit after your transplant day will be 3 to 4 hours long but sometimes, it can be much longer and 6-10 hours. This is based on what your blood results show that day and any symptoms you may have. At each visit, discuss any side-effects you may be experiencing and questions you have with your nurse and doctor.

Step 6: Stem Cell Transplant Day

“Day 0”

L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, Vancouver General Hospital

The day after your high dose chemotherapy is your stem cell transplant day. We sometimes call it a stem cell “reinfusion” because your own stem cells are being “infused” through the IV line back to you. This is also a long day (8 hours) on the unit, so it is helpful to bring snacks and materials to occupy your time.

What Will Happen on My Stem Cell Transplant Day?

- You will receive medications 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.
- When we are ready to start the transplant 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 CVC line and given back to you like a blood transfusion.
- A nurse will be by your side during the reinfusion of your stem cells.
- It is a good idea to eat a light lunch to avoid feeling nauseated.

While Your Stem Cells Are Being Given to You (During Transplant):

- You will be sitting up comfortably in a hospital bed. A visitor may 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 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.
- You may feel nauseated (feeling of having to throw up).
- You may feel cold. This feeling is caused by the thawed stem cells.
- Some people have an allergic reaction to the DMSO preservative. 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 Transplant):

- You will feel sleepy from the IV Benadryl®.
- You will stay in the Daycare Unit for 1 hour for monitoring and vital signs.
- Your urine may be pink 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 for 24 hours after the transplant.

Step 7: Waiting for Blood Count Recovery

"Days 1 – 21" or later
L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, Vancouver General Hospital

Waiting for blood count recovery usually takes 2 - 3 weeks. The chemotherapy you received causes your blood counts (white blood cells, platelets, red blood cells) to drop to a very low level. When your blood counts are at their lowest level, you will feel the most unwell from the side effects. As your blood counts return to normal levels, you will start to feel better again.

You will have Daycare visits every 1-2 days until your blood counts recover.

What will happen during each visit at the Daycare Unit?

Each visit will vary in length, depending on what your blood tests and symptoms are that day. A typical visit lasts 3-6 hours. You can expect:

- Blood tests taken from your CVC.
- 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 (e.g., antibiotics, anti-nausea)
- 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**, day or night, if you have a fever (38°C or higher).
- Take your medications. You will receive a list of medications and when to take them.
- Follow strict infection control guidelines (see page 28).
- If you feel like it, you may do many of your usual home activities like going for walks, reading, listening to music, and having healthy family and friends visit you. Chemotherapy side effects can make you feel tired so try not to do too much. On some days, you may want to spend the day resting in bed.
- Your 24-hour caregiver can help prepare your meals, keep track of how much you are drinking and take your temperature.

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

Write down questions you have and bring them to your next Daycare appointment. If you are unsure about a symptom you are having or have an issue that needs attention, call us. A nurse will help with your question over the phone or contact the doctor for instructions. **Refer to page 2 for issues to call us immediately about.**

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 (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) and taste changes.
- Mouth sores and sore throat – this can make it hard for you to eat or drink.
- Abdominal cramping and diarrhea (frequent runny stool).

Later side effects (last longer than 2 weeks):

- Fatigue
- Shortness of breath with physical activity – this will improve with gradual increases in simple exercise such as walking.
- Taste changes
- Nausea, diarrhea

Long-term side effects (last longer than 6 months):

- Fatigue
- Changes in your memory and concentrations (also called "chemo brain").
- Infertility (not being able to have children).
- Lower hormone levels (thyroid hormone, testosterone, estrogen).

Managing Side Effects

While receiving chemotherapy, it is important to look after yourself. This will help reduce the chance of infection and help you feel more comfortable. **Always tell your health care team about any side effects or symptoms you notice, as minor as they may seem.** We count on you to let us know how you are feeling. When you mention a side effect early, it can often be managed better and there is less chance of complications.

Everyone is different – it is normal for some people to have more side effects than others.

Infection and Fever:

The chemotherapy you receive lowers your white blood cells. Normally, your white blood cells protect you from the bacteria, viruses and other harmful organisms you encounter every day. Without your white blood cells, any type of germ can make you very sick with an infection. An infection is the invasion and spread of harmful bacteria, viruses, fungi, etc. that are not normally found in your body.

Having a fever is a common. It is an important signal which tells us your body may be fighting an infection. We act quickly when you have a fever in order to stop an infection from causing serious harm.

Most patients receiving treatment on our units have weak immune systems (low white blood cells). We take extra care to protect everyone through infection prevention.

What to Do:

- Use proper handwashing, it is the best way to prevent infections. You and all of your visitors should wash your hands often with soap and water, especially before eating and after using the toilet. Have hand sanitizer with you when you are out of your home.

- Take your antibiotics, antifungals and antivirals as instructed. These medications help protect you from infections while your white blood cells are low.

- Check your temperature twice a day in the morning and early evening. Check it more often if you are feeling unwell.

- Do not take Tylenol® unless instructed to by your health care team. Tylenol® will “hide” or “mask” your fever without treating an infection.

- **Call us immediately if you have any signs of an infection including:**
    - *A fever. This is a temperature of 38°C (100°F or higher).*
    - *Chills or shaking.*
    - *Burning or pain when you urinate.*

- Family and friends should NOT visit you if they have any signs of illness (i.e., new cough, fever, diarrhea, vomiting, sore throat, runny nose, etc.).
- Keep your body clean. Shower daily or every other day. Clean your anal area gently and thoroughly after a bowel movement. Wipe yourself from the front (genitals) to the back (rectum) to avoid bladder urinary tract infections.
- Avoid touching your face and mouth with your hands.
- Avoid crowded areas such as malls, markets, buses, and movie theatres.
- Do not go swimming or use hot tubs if you have a CVC line or a low white cell count.
- See the "*Food Safety for Patients with Weakened Immune Systems*" booklet for tips on how to prepare food safely and safer food choices to eat.

How and when to take your temperature:

- Take your temperature with a digital thermometer (in °Celsius) twice a day: when you get up in the morning & in the early evening (around 8:00 pm).
- Take your temperature more often if you don't feel well.
- Wait 5 minutes after eating or drinking before taking your temperature.
- Clean your thermometer with warm soapy water and allow to air dry.
- Call us immediately if you have a fever of 38°C (100°F) or higher. We will give you instructions to follow.
- Contact us if you are experiencing any of the following symptoms: dizziness or feeling lightheaded, drowsiness, confusion, headache, shaking, feeling very hot or very cold, sweating, not urinating often despite drinking water, with a temperature between 37.5°C – 37.9°C.

CAUTION! Fevers and Acetaminophen (Tylenol®)

Acetaminophen (Tylenol®) is used as a pain medication. It also hides or "masks" a fever. Tylenol may bring down your temperature. It will not fight any infection in your body. This is why great caution must be used when taking Tylenol.

- Always check your temperature before taking Tylenol.
- If you have a temperature is between 37.5°C – 37.9°C, do not take Tylenol. Recheck your temperature in 20-30 minutes. If you develop a fever, call us.
- Keep Tylenol in your medicine cabinet. Sometimes fevers may continue after new antibiotics have started, and your health care team may instruct you to take Tylenol®. It can bring your relief by bringing down a high fever and relieving aches. Always consult your doctor or nurse if you are unsure whether to take Tylenol®

Diarrhea

Diarrhea (loose runny stool) can be common. Frequent diarrhea can cause a soreness and irritation to your skin and any hemorrhoids you may have.

Nausea and Vomiting

Nausea is when you are feeling sick to your stomach and feel like you have to throw up (vomit). Feeling nauseated can happen at any time. You usually feel more nauseated in the days after chemotherapy. **Eat whatever you can manage**. Everyone is different and what may work for some people may cause nausea in others.

Appetite Loss and Taste Changes

Many different factors can cause you to lose interest in eating, including chemotherapy, stress, nausea, fatigue, taste changes and depression. Your body needs enough calories and protein to heal and repair tissue. Eating well can help boost your energy levels and recovery. Ask to see a Dietitian if you are having trouble eating.

Mouth Sores (Mucositis)

It is common to develop a sore or painful mouth several days after chemotherapy. The medical term is called mucositis (“mew-co-SYE-tiss”). The first sign of mucositis is a dry, irritated or burning feeling in your mouth. You may also notice small sores on the inside of your cheeks and lips.

Bleeding and Bruising

Chemotherapy will lower your platelets, which help your blood clot normally after an injury (such as a cut). When your blood counts are low you may be more likely to bruise or bleed. You may need a blood or platelet transfusion if your blood counts are low.

Fatigue

Fatigue is the term used to describe lack of energy, feeling weak and tired. It is the most common symptom felt by people with cancer and can be the last side effect to go away after treatment.

Hair Loss or Thinning

High dose chemotherapy will cause your hair to thin and fall out, usually 2 to 3 weeks after treatment. Your hair will grow back 3-6 months after treatment is finished. The texture or colour may be different when it first returns.

Skin Changes

Chemotherapy can cause skin dryness, itching, redness and sometimes a rash. Tell your doctor or nurse if you notice any kind of rashes or skin changes, including petechiae. You will also be much more sensitive to the sun.

Memory Changes and Trouble Concentrating

Chemotherapy and some other drugs can cause memory changes (sometimes called “brain fog” or “chemo brain”) You may notice you are forgetting things more often, having trouble focusing, or having trouble doing more than one thing at once (multi-tasking). Your memory and concentration will get better after treatment is over. You may notice problems for a few months or longer after your treatment.

For detailed information on managing side effects please see Symptom Management Through Your Treatment

Step 8: Blood Count Recovery (“Engraftment”)

The medical term for when your blood cells recover 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?

Once your blood counts have recovered, your line will be removed. You will receive a requisition for weekly bloodwork. Your visits to the Daycare unit will be complete. You may return home if you are not from the Vancouver area. Your bloodwork can be done at a laboratory clinic near your home.

You will be scheduled to see your Hematologist in 2-4 weeks. They will discuss any symptoms you are still having and arrange for follow-up bloodwork and appointments during this visit. They will also discuss your re-vaccination schedule.

How will my IV Line be removed?

Your doctor will remove your line when your blood counts have recovered 3-4 weeks after your stem cell transplant. Removing a Hickman® line is a safe and short procedure done on the Daycare unit. Trifusion® lines are removed in a similar safe and short procedure in the Radiology department.

How will I feel after my blood counts have recovered?

Even after your blood counts recover, you may still feel tired. Feeling tired can persist for many 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.

<u>You may also have other symptoms, such as:</u>

- *Nausea and sometimes vomiting*
- *Changes in taste*
- *Diarrhea*
- *Difficulty sleeping*
- *Poor appetite*

These symptoms are common and will improve slowly. You can get medications that may help settle uncomfortable symptoms. Ask your Hematologist about this at your follow-up clinic visits. You may need to keep taking medications to control your symptoms (such as nausea) until your symptoms get better.

Step 9: Managing at Home After Transplant

Generally, it takes 3-6 months for you to return to a relatively normal lifestyle. Adjusting to life after your stem cell transplant can feel like slow. You may 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 your treatment*
- *Helping your family cope through your treatment*
- *Returning to work*
- *Choosing a caregiver*
- *Caregiver responsibilities*
- *Fear of recurrence*
- *Support groups and community resources*

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 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 you are close to, 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.
- Manage your energy before, during and after the transplant by eating well and being active. 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 a break from your thoughts and feelings. This may include reading, meditation, listening to music/audiobook/podcast, watching a favorite TV show or movie, painting, sketching, knitting, spending time with family and friends.
- 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.

We created a ***Coping with Cancer*** video for you.

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, neighbors 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. For resources on speaking to children about your diagnosis and transplant, connect with social work.
- 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. need to know what is most helpful. Practical things include help with car rides, meals, childcare/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. It is a good idea to work on these in advance. A social worker can help guide you.
- Connect with a 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.

If you have any concerns about your family members coping with your diagnosis or transplant, please connect with a social worker

Choosing A Caregiver

When do I need a caregiver?

- It is strongly recommended to have a caregiver when you are receiving treatment as an outpatient.
- There may be times where a caregiver is medically required. This means you need at least one family member or friend who can provide you with physical and emotional support.
- Social workers can help caregivers who are planning time off work to explore financial benefits, and request supporting documentation.

How do I choose my caregiver?

- Caregivers can be family, friends or hired professionals **please note that caregivers cannot be provided by hospitals, health authorities, or L/BMT Program.*
- Caregivers should be someone, 19 years or older, who you are comfortable around, is comfortable around you, who knows you well, and is able to help you through your treatment.
- For us to best care for you, your caregiver must be able and comfortable to communicate with the medical team. Translation and interpretation services can be provided if needed.

How many caregivers do I need?

- It is possible to have one identified caregiver for the duration of your treatment. However, we understand that this can be challenging from a practical and emotional lens for the caregiver. Therefore, rotating caregivers are also an option.
- If one primary caregiver is identified, we suggest arranging visits from family and friends to ensure caregiving tasks do not fall entirely on one person.
- Having rotating caregivers allows each to rest, relax and have time away from the hospital, and prevent burnout.

Caregiver Responsibilities

Caregiver duties and responsibilities depend on what your loved one needs; you can help by:

- Coordinating services, such as transportation to and from the clinic.
- Attending appointments, making notes, asking questions
- Providing emotional support
- Providing support at home:
    - *Reminding you to take oral medications*
    - *Identifying changes in your condition to the clinical team*
    - *Calling the BMT triage nursing line or obtaining urgent medical care, if needed*
    - *Helping you care for your central venous catheter (if applicable)*
- Maintaining the home environment (e.g., household cleaning, pet care, laundry)
- Activities of daily living (e.g., grocery shopping, preparing food, picking up prescriptions)
- Serving as a communication link with other family members and friends

Resources for Caregivers

Go to www.bloodcancer.ca Search "Caring for a loved one with a blood cancer". Click on the second result.

Go to www.cancer.ca Search "caregiver". Select any of the results that you feel may apply to your situation.

If you are experiencing caregiver burnout. Please connect with one of our social workers.

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 and in consultation with your doctor.

Going back to work helps to get you get back into a more “normal” routine. 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*
- *Troubling thoughts about family, relationship issues, 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 considering 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 this.

- 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.

- If you receive disability benefits through employee benefits, please connect with your disability case manager to discuss your return to work plan

- BC Cancer’s Vocational Rehabilitation Program can help you with the return to work/school process, finding new work or new training, explore how to discuss health concerns with those at work/school and more. *1-800-663-333 Ext. 672194.*

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. Talk to your social worker about a will. See page 41 for more information on advance care planning.
- **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 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 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 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 done year after transplant**	**One year or more after transplant**
Taking probiotics	No	No	Ok
Eating raw/undercooked seafood (e.g., 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	Do not sleep in the same bed. Do not clean up litter or waste.	Do not clean up litter or waste.	Ok
Please check with your doctor if you are not off medications or chemotherapy which suppress your immune system at 6 months to one year after transplant, or one year or more after transplant.			

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

Your doctor will discuss your re-vaccination schedule during 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?

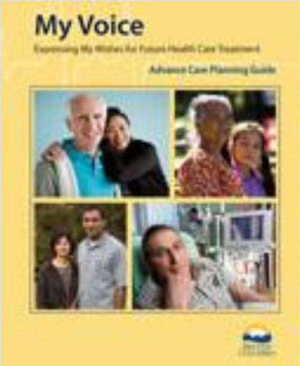
The chance of you facing any life-threatening situations during treatment depends on a lot of factors, such as your type of cancer, your treatment, and your general health. No matter what your age or health, we feel it is important to recommend advance care planning because research shows it can:

- *Improve your quality of life*
- *Improves the chance 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.



Online: Go to www2.gov.bc.ca search "advance care planning". Click on "Advance Care Planning". Scroll down and you will see links to the booklet available in pdf format.

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.

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 tissue (stem cells) infused comes 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 (e.g., kidneys, liver, pancreas), electrolyte imbalances (e.g., potassium, magnesium) and if you have any possible infections.

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

Bone Marrow Transplant: A bone marrow transplant is a procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells.

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. You 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® & Nypozi®.

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

Immunosuppression: Lowering of the body's white blood cells.

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.

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.

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 will 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?

Suggested readings:

- Chemotherapy and Other Drug Therapies (Canadian Cancer Society)
- Coping When You Have Cancer (Canadian Cancer Society)
- Eating Well When You Have Cancer (Canadian Cancer Society)
- Sex, Intimacy and Cancer (Canadian Cancer Society)
- High-dose Therapy & Autologous Stem Cell Transplantation (Myeloma Canada)

Find booklets, videos and more information at:

Myeloma Canada: 1-888-798-5771
www.myeloma.ca
Click Resources → Educational Publications

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

The Leukemia Bone Marrow Transplant Program of BC:
www.leukemiabmtprogram.org

Please note: 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. Authors: Amy Healy 06/2019, Sally Moore 10/2025, Patsy Vanee 10/2025 Co-Authors: Anna Millington 02/2025, Annabel Francis 02/2025, Nikki Stiver 02/2025, Tanisha Bors 02/2025, Nogol Salehi 02/2025, Gretchen Olund 02/2025, Amy Chen 02/2025, Prachi Sony 02/2025, Matthew Bentley, 03/2025, Katie Lecaria 04/2025 Formator: Mimi Gee 04/2025

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