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:

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

The Hematology Apheresis Unit (HAU): 6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 8am - 5pm
604 875 4626

Afterhours Telephone: L/BMT Inpatient Unit, 15th 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 but if they occur, they cannot be managed over the phone.

Table of Contents

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.

Talk to our team or email bmtpatienteducator@vch.ca

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

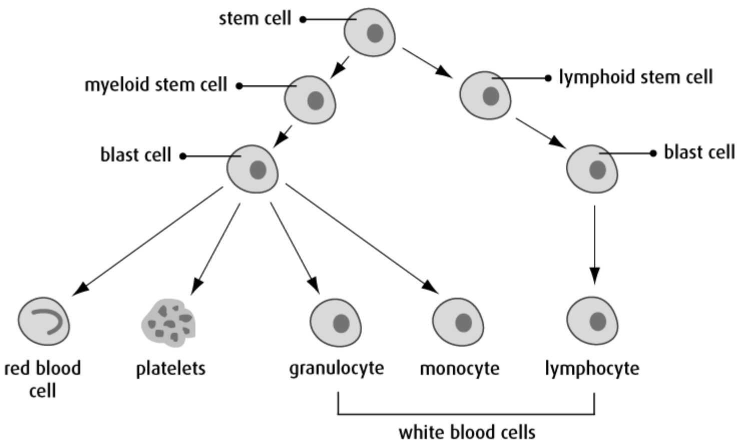
At the end of the booklet there is a section on common medical terms.

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.

Development of Blood Cells in the Bone Marrow



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

(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 80 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 normal. This "high dose chemotherapy" 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 "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?

Until recently, 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.

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
- Social workers
- Dietitians
- Physiotherapists
- 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 Support"* 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'll 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 be given 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 that will be inserted in your chest to help make your treatment more comfortable.
Step 5 High Dose Chemotherapy	You will be given a single high dose of chemotherapy in the Leukemia/BMT Daycare clinic.
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 7 to 12 days. 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. This usually happens 12-14 days after your stem cell transplant. Your tunneled catheter will be removed once engraftment happens.
Step 9 Managing at Home after Transplant	Although It will be safe to finish your daycare clinic appointments, it will take time to resume a normal life. You will have follow-up visits with your hematologist, who will continue to monitor your blood counts.

Step 1: Preparing for Your Transplant

Consultation with Hematologist

4-6 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 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.

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 it is necessary for you to plan ahead and you may call our offices to confirm your tentative transplant date. We are aware you will soon be receiving treatment but it is best if we plan your pre-transplant tests and assessments closer to the 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 BMT Nurse Navigators

5-8 weeks before stem cell transplant

Our BMT Nurse Navigators arrange all the planning, testing and appointments needed in preparation for your stem cell transplant. Roughly 5 to 8 weeks before your transplant date, they will phone you to ask questions on your health history and discuss the tests and appointments you'll need. After this 20-30 minute phone call, they will send you an email with more information on your scheduled appointments and tests.

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 weeks before stem cell transplant

Tests must be done to check how well your heart, lungs and kidneys are working before the transplant. Whenever possible, we will try to arrange 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 54.

These tests include:

- Bloodwork
- Dentist checkup
- 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
All consultations are on 6th Floor Leon Blackmore Pavilion, Vancouver General Hospital

To help you prepare for your upcoming transplant, you will meet with members of your health care team for personalized teaching. A stem cell transplant can affect every part of your normal routine. Knowing what to expect and how to plan for it will help make the transplant process easier for you and your family.

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 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.

If your veins are too small or delicate, we will plan for you to have a “central venous catheter” (CVC) inserted. You may hear this CVC called many different names (see next page). 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 until you have recovered 3-4 weeks later. For more information, please see step 4.

During your visit to the apheresis clinic, you will also receive your prescription for G-CSF. For more information on G-CSF, please see Step 2.

b) **Social Worker**:
Our social worker will 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:** Our dietitian 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 (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 transplant
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-SCF 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-SCF Injections?

We will plan for a nurse to give you your G-CSF in the Hematology Apheresis Unit (HAU) or the Leukemia/BMT Daycare Unit. This unit is on the 6th floor of the Leon Blackmore Pavilion of Vancouver General Hospital. If you prefer, you may have your injections given at your family doctor's office 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 under medical supervision.
- G-CSF will work best when given at the same time every day. The ideal time for injections is between the hours of 1PM and 4PM. This timing ensures you will have the most stem cells at the time of collection.
- **If you choose to have your injections in your home community: you must contact your local clinic or BC Cancer to arrange for this.**

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 stem cell transplant:
Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your stem cells are collected by a procedure called apheresis ("a-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.

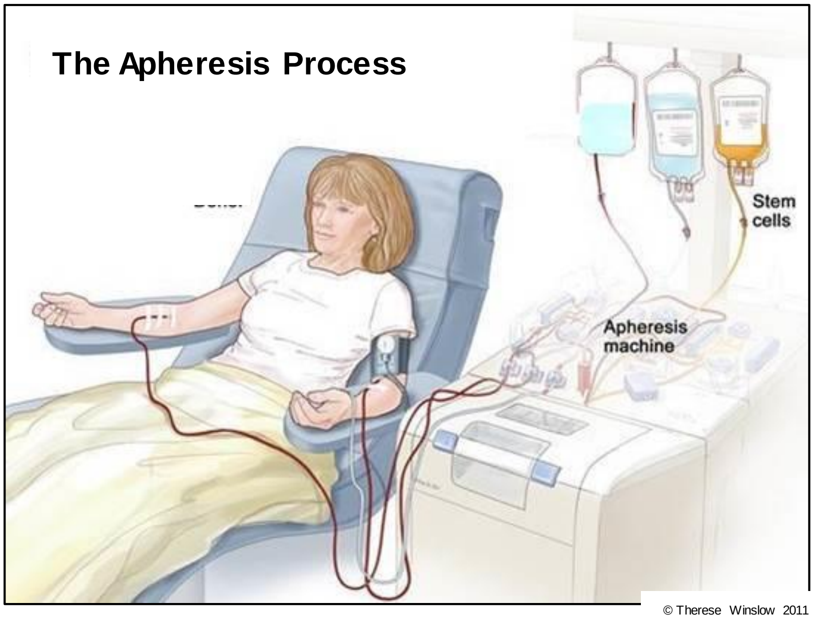
What happens after the stem cells are collected?

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 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 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 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 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;**
    - Inserted before stem cell collection for people with small, delicate veins.
    - Can be used for stem cell collection
    - In some cases, a "Permcath®" CVC is used only for stem cell collection then removed. A Trifusion® or Hickman® line would be inserted later.
- **or a Hickman® Line**
    - Inserted after stem cell collection. Most people have Hickman lines.

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 blood transfusions and medications, as needed.

All these names for the same thing!

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

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

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. 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.

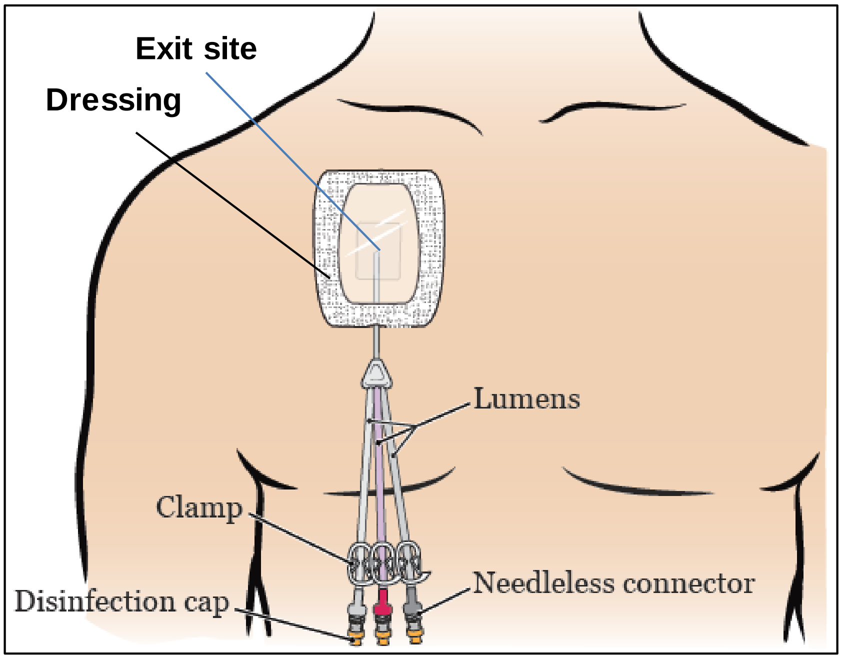
How do I care for my IV line?

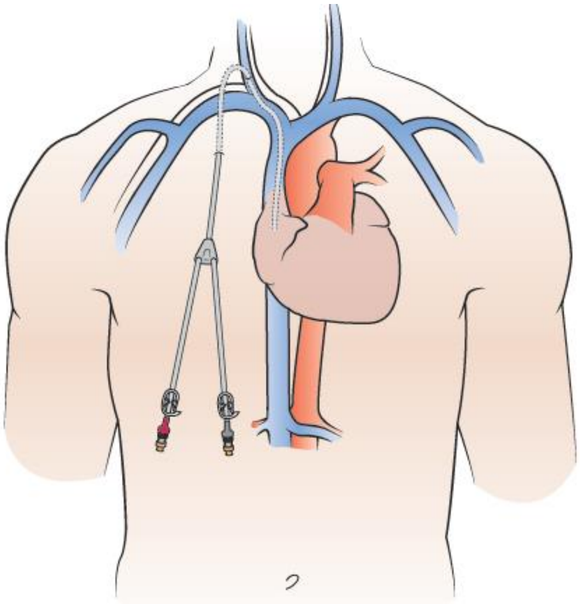
Infection is the biggest risk for any type of IV line. To help avoid infections:

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 CVC 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: Chemotherapy Day

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

This daycare visit is at least 6 hours long so it's helpful to bring some items to items for your comfort (see page 23)

Melphalan ("mell-fa-lan") is the intravenous (IV) high dose chemotherapy you will receive. It is usually divided into 1-2 IV bags that will each run over 30-45 minutes.

When you arrive at the Daycare for your high-dose chemotherapy, the nurses will:

- Connect you to intravenous (IV) fluids. These fluids will run for 2 hours before your high dose chemotherapy is given to protect your kidneys.
- Give you 2 pill medications to prevent feeling sick (nausea and vomiting). They are **Ondansetron 8mg** and **Dexamethasone 12mg.**
- Give you ice chips to suck on before, during and after your chemotherapy. This is to help prevent mouth sores.
- Run your **Melphalan** chemotherapy in 1-2 bags over 30-60 minutes each.
- Run IV fluids for another 2 hours after your Melphalan has completed.
- Begin orienting you to the Daycare unit and routine. See page 23.

Although you may have nausea, you will probably feel fine on your 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. See page 28 for information on chemo side effects and how to manage them. For more detailed information on potential side effects and how to manage them, refer to the "*Supporting You through Treatment*" booklet. Details are on page 56

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 24 hours for Melphalan chemotherapy to slowly leave your body through your urine and stool. Small amounts of the drug can also found in blood, vomit, semen, and vaginal fluids.

After receiving Melphalan, your body fluids are **cytotoxic for 24 hours.** Your chemotherapy will finish at roughly 12pm one day before your stem cell transplant. This means you are cytotoxic until 12pm 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 cytotoxic:

During the 24 hours that you are cytotoxic:

- 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 soap and water after any contact with body fluids.
- 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 significant 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 through treatment are in the Leukemia/Bone Marrow Transplant Daycare Unit. This is called the Daycare Unit or LB6 for short and is located on the 6th floor of the Leon Blackmore Pavilion at Vancouver General Hospital.

Amenities

- 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 during your transplant treatment or while your white blood cell count is low.
- 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 each visit.

Step 6: Stem Cell Transplant Day

"Day 0"
Leukemia/Bone Marrow Transplant 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 (roughly 8 hours) on the unit so it is helpful to bring snacks and materials to occupy your time.

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. After the hydrocortisone is complete, you may choose to rest on the unit or go for a walk until your nurse asks you to return. 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 CVC IV 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 15 to 45 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.
- You may feel nauseated (feeling of having to throw up).
- You may feel cold. This feeling is caused by the thawed stem cells.
- Occasionally, 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 the transplant):

- You will feel sleepy from the IV Benadryl® that was given.
- You will stay in the daycare unit for 2 more hours for monitoring and vital signs.
- 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 7: Waiting for Blood Count Recovery

"Days 1 – 21" or later
Visits to the L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, Vancouver General Hospital every 1-2 days

Waiting for blood count recovery usually takes 2-3 weeks. The chemotherapy you received causes your blood counts (white blood cells, platelets and 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 1-3 days until your blood counts recover.

What will happen during each visit to the Daycare unit?

Each visit will vary in length, depending on what your blood tests and symptoms are that day. Your visit can last from 2-6 hours. You can expect:

- Blood work taken from your CVC IV 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 everyday?

- 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 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. Chemotherapy side effects can make you feel tired (see page 28 on how to manage them) 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, take your temperature, and anything else you need help with.
- Please follow strict infection control guidelines (see page 45).

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

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
- taste changes
- nausea, diarrhea

Long-term side effects (those that can 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 risk 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're 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. For more detailed information on potential side effects and how to manage them, see below or refer to the "Supporting You through Treatment" booklet. Details are on page 56.

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.

What to do:

- Tell your nurse or doctor if you have diarrhea. Depending on how frequent it is, a sample may be taken to test for infection.
- Use soft toilet paper. Clean your bum with mild soap and water after each episode of diarrhea. Rinse well and pat dry with soft toilet paper. Cleaning well will help lessen your risk of infection and skin irritation.
- Do not insert anything into your bum, such as rectal suppositories or enemas.
- Tell/call us immediately if you have any pain or bleeding in your rectal area.
- Drink plenty of fluids to replace lost fluid, at least 8 to 10 large glasses a day. Try water, broth, fruit juices, Jell-O and sport drinks.
- Eat high potassium foods such as bananas, apricots and peach nectars, meats and potatoes.
- Limit the use of irritants such as coffee, chocolate and prune juice.
- Ask your doctor before taking any over-the-counter medications for diarrhea.
- Consider buying a sitz bath, a seat that sits on your toilet (~ $20 at a pharmacy). This allows you to soak your genitals and rectal area to help clean and relieve pain.

Infection and Fever:

The chemotherapy you are given 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 but serious side effect. It’s an important signal that 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 on our unit have weak immune systems (low white blood cells). We take extra care to protect everyone through infection prevention.

What to do:

- Take your antibiotics, antifungals and antivirals as instructed. These medications help protect you from infections while your white blood cells are low.
- Proper handwashing is the best way to prevent infections. You and all of your family members and visitors should wash your/their hands often with soap and water, especially before eating and after using the toilet. Carry a bottle of waterless hand sanitizer for when you are out of your home.
- Check your temperature twice a day in the morning and early evening. Check it more often if you’re 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.).
- Shower daily or every other day. Keep your body clean. Clean your anal area gently but 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 during this time.
- See page 45 for more frequently asked questions on preventing infection.

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 6pm).
- Take your temperature more often if you don't feel well.
- Don't take your temperature after eating or drinking, wait 5 minutes.
- 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.

Fevers and Acetaminophen (Tylenol®)

Acetaminophen (Tylenol®) is used as a pain medication but it also hides or "masks" a fever. Tylenol may bring down your temperature but 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 between 37.5°C – 37.9°C, do not take Tylenol. Recheck your temperature in 20-30 minutes. If you develop a fever, contact us.
- Keep Tylenol in your medicine cabinet. Sometimes fevers may continue after new antibiotics have started. Tylenol can bring you relief by bringing down a high fever and relieving aches. Your doctor or nurse will tell you when it is safe to take Tylenol®.

Nausea and Vomiting:

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

What to do:

- If you are feeling sick, take your "as needed" anti-nausea pills. Tell your nurse or doctor if they are not helping.
- Instead of big meals, eat smaller meals and snacks more often.
- Avoid foods that are very sweet, greasy, fried or spicy or that have a strong smell. Cold or room temperature food smells less than hot food.
- Try bland foods such as soda crackers, congee, rice, applesauce, bananas.
- Save your favourite foods for when you are feeling better. Eating your favourite food when nauseated can make you not like them.
- Sip water and other liquids (flat ginger ale, sports drinks, broth) throughout the day. Cool liquids may be easier to drink than very hot or very cold liquids.
- If you are feeling nauseated, take deep slow breaths through your mouth or place a cool cloth over your eyes and forehead.
- Distract yourself by listening to music, watching a movie or talking to family or friends.

When should I take my Anti-Nausea Medications?

Your doctor will prescribe you anti-nausea medications to take "as needed."

Antinausea medicines often work best if you take them before or as you're starting to feel sick. They may not work well if you take them just as you are about to throw up (vomit). Everyone is different, if one anti-nausea medication doesn't work, try a different one. Tell your doctor or nurse if these medications do not relieve nausea and vomiting. They can make suggestions or prescribe other medicines.

Antinausea drugs can cause side effects, including sleepiness, dry mouth, constipation, or diarrhea. Most people feel that these side effects are worth the benefit of having their nausea and vomiting relieved.

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.

For more tips, find the following pamphlets online or in the Daycare library (room 631):

- Find “Eating When You Have Cancer” on www.cancer.ca under “Publications.”
- Type “food ideas to cope with taste and smell changes” on www.bccancer.bc.ca

How to make every bite count:

- Instead of big meals, eat smaller meals and snacks more often.
- Relax and take your time while eating. Eat when your energy is highest.
- To add calories and protein to meals, try adding: peanut butter, higher fat milk, cream, eggs, cheese, yogurt, tofu, gravies, ice cream, nuts, beans.
- Choose fluids that are higher in nutrients, such as fuller fat milk, smoothies, meal replacement drinks, cream soups, and hot chocolate.

How to manage taste changes:

- Rinse your mouth before and after eating to help clear your taste buds.
- Eat foods cold or at room temperature to reduce strong tastes and smells.
- Use plastic cutlery and glass cooking pots if foods taste metallic.
- Try different foods and seasonings to make food taste better. For example, add spices, try tart foods or add sugar.
- Eat foods that taste good, even if this means eating the same foods for a while.

What should I drink during my transplant?

Try to drink at least 2 liters of fluid every day. Water, juice, soups, sports drinks and even jello are all good fluids to drink. Meal replacement drinks are also a good source of calories and nutrients (Ensure, Boost, Resource, etc.) Some people find it hard to drink 2 liters of fluid but most manage by drinking small amounts (½ cup or even just sips) throughout the day. Everyone will find their own preferences and any fluid is better than nothing, especially if you’re 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.

What to do:

- Tell your nurse or doctor if you have pain or notice sores in your mouth or throat.
- Clean your mouth after every meal and at bedtime.
- Brush your teeth with a soft toothbrush. You will be prescribed a special mouth rinse to use 2-3 times daily. You can add water to it if tastes too strong.
- Use a lip balm to keep lips moist and prevent cracking.
- Try soft foods such as eggs, cream soups, ice cream and ground meats. Gravies, sauces and soups can help soften foods.
- Avoid hot, spicy, acidic, hard or crunchy foods.
- Ice chips, hard candies and popsicles can help relieve dry and sore mouth.

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.

What to do:

- Be extra careful to not bruise, cut or burn yourself.
- Blow your nose gently to prevent a nosebleed. Do not pick your nose.
- If you are female and have bleeding from your vagina (your period), talk to your nurse or doctor.
- Call us immediately if you have any of the following:
  - Vomit that looks like coffee grounds
  - Black, tarry bowel movements
  - Bright red blood in your urine or stool

Fatigue and Malaise (Feeling Tired and Unwell)

Fatigue is the term used to describe lack of energy, feeling weak and tired, and having trouble concentrating or finishing small tasks. It is the most common symptom felt by people with cancer and tends to be the last side effect to go away after treatment. Malaise is the term used for feeling generally unwell. These symptoms are caused by many factors such as low blood counts, infections, eating less food and being less active.

What to do:

- Balance your rest and activity. Take opportunities to rest throughout the day.
- Try to limit the length of visits with family and friends.
- Light exercise such as walking around the block can help boost your energy.
- Plan activities that need concentration or energy when you are more rested.

- To save energy and time involved in meal preparations:
  - **a.** Keep easy to prepare foods and snacks on hand.
  - **b.** Try safe take-out food restaurants. To find a reputable restaurant, click "VCH Inspection Reports website" at: www.vch.ca/public-health/environmental-health-inspections/restaurant-food-safety
  - **c.** Most major grocery stores allow you to enter your grocery list online. You can pick up your order in the store for free (or have it delivered for a fee).

For more information on managing fatigue and energy conservation, search **"fatigue"** in the following websites:

- www.cancercareontario.ca/en/symptom-management
- www.bccancer.bc.ca
- **Cancer Related Fatigue Video:** www.youtube.com/watch?v=YTFPMYGe86s
- Search "**energy conservation**" at www.stjoes.ca/patients-visitors/patient-education

Hair Loss or Thinning

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

What to do:

- Brush your hair gently using a soft hair brush.
- Consider cutting your hair short before treatment starts. Longer hair comes out easier and makes hair loss more noticeable. A family member or salon can help you cut or shave your hair. This is your choice and you will know if and when you feel comfortable to do so.
- Wear soft hats, head scarves or wigs to keep your head warm and protected.
- Type “hair loss” on the BC Cancer website www.bccancer.bc.ca for more information on hair loss resources.

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.

What to do:

- Wear loose, comfortable clothes
- Avoid rubbing or scratching skin
- Use gentle soaps and moisturizing cream on your skin. Use sunscreen every day, even if it is cloudy.
- Wear long sleeves and a hat if you are going outside. You will burn much more easily, even on a cloudy day.
- Petechiae (“puh-TEE-kee-AH”) are small purple or red spots on your skin that usually appear in clusters. They happen with a lower platelet count and although they are not harmful, need to be watched.

Trouble Concentrating and Memory Changes

Chemotherapy and some other drugs can cause memory changes (sometimes called "brain fog" or "chemo brain") You may notice you're 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, but you may notice problems for a few months or longer after your treatment.

What to do:

- Keep track of things using lists and calendars. Set reminder alerts for taking your pills and appointments on your smartphone.
- Do things that don't require a lot of focus (i.e. colouring books, puzzles and TV, movies and light reading).
- Ask your family and friends for help. They can help you remember as well as listen, ask questions and take notes during appointments.
- Balance your rest and activity. Resting and being active will both help your focus.
- Plan activities that need concentration when you are more rested.

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 visits to the Daycare unit will be complete and you may return home if you are not from the Vancouver area. Your central venous catheter will be removed and we will give you a requisition for weekly blood work. You can have this bloodwork drawn in any local clinic.

You will be scheduled to see your hematologist in 2-4 weeks. They will discuss any symptoms you're 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 2-3 weeks after your stem cell transplant. Removing a Hickman® line is a safe and short procedure done at the bedside 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 will 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.

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. Ask your doctor 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.

Do I need vaccination (shots) after my transplant?

Yes. Your hematologist will give you a letter and vaccination schedule in your follow up appointment after treatment is finished. Your immune system has been weakened from the high dose chemotherapy and vaccinations are required to defend your immune system against common infections.

How often will I see my hematologist after transplant?

You and your hematologist will discuss scheduling follow-up visits and blood testing during your visit 2-4 weeks after finishing your transplant. You may continue to see our doctors or it may be best to transfer your care back to your primary cancer doctor.

Step 9: 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

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.
- 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.
- Find more about the booklet "Coping with Cancer" on page 56.

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.

Self-Image and Sexuality

Side effects of treatment (such as hair loss, weight changes, fatigue and emotional changes) can affect your sexuality. Common sexual changes include body image concerns, low sexual desire, difficulties with erections, pain during sexual activity, and relationship changes.

It is safe to have sex once your blood cell counts and immediate treatment side effects have recovered.

Here are some tips to cope with changes in your self-image and sexuality:

- Talk openly about your feelings with your partner. No one can read your mind, not even someone you have lived with for years.
- Being physically active improves self-image and energy.
- There are many ways to express your affection and be intimate with your partner. Long walks, good conversation, hugging, kissing, dancing and touching are important aspects of intimacy.
- Talk with your health care team if you have questions or concerns about sexual or body changes, birth control, periods (menstruation) or fertility.
- Type "*sexuality*" into the BC Cancer website www.bccancer.bc.ca and the Canadian Cancer Society's website www.cancer.ca for more information.
- Learn about the Look Good Feel Better program in *"Resources and Support"*

Suggestions to make sex more comfortable:

- Wash your hands before and after sex or masturbation.
- Use a water or silicone based lubrication to help with comfort and dryness. It should be BPA and Phthalate free, the pharmacist at your local pharmacy can help you find a suitable option. If it smells, tastes or tingles, it shouldn't be used.
- Avoid oral sex if your partner has active cold sores.
- Find positions that are comfortable. Use pillows as extra support.
- Use medical grade silicone or glass vibrators or personal assistive devices. Wash them before and after in hot soapy water. Do not use antibacterial wipes on them.

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,
- or 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. Talk to your social worker about a will. See page 52 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 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.

Frequently Asked Questions:

Am I safe to have this transplant as an outpatient? Shouldn't I be in hospital?

Stem cell transplants for patients with multiple myeloma were once done as an inpatient in the hospital. Advancements in treatment and supports have proved that it is now just as safe (and more comfortable) for these patients to have a transplant as an outpatient. Being outside of hospital allows you to eat better, sleep better and have your loved ones close by during this stressful time. Patients at home are less likely to develop infections related to the hospital and do not have to wait for a hospital bed to open to start the transplant.

Being an outpatient does mean you will need a <u>24-hour</u> caregiver. This is someone, or many people, who will stay with you and help you manage treatment side effects. They can help make your meals, help you manage symptoms, buy groceries and assist/drive you to your frequent Daycare appointments.

Your doctor would not have approved this treatment unless they felt it was safe for you. At every daycare visit, your health care team will monitor your symptoms and help you manage them. Some patients are admitted into the hospital if we feel they need closer monitoring.

Do I need the flu shot? Does my family need the flu shot?

Generally, yes. If necessary, your doctor will recommend that you get a flu vaccine before your treatment starts. Having a flu shot (with a needle) requires your platelets to be above at least 50. Your family members, caregivers, and close household contacts should arrange to get a flu shot every year. For both patients and family members, we recommend the flu shot <u>injection</u>. Nasal spray vaccinations contain a "live" virus that can be passed on to those with weak immune systems and extra precautions need to be taken. Find more information on live vaccines on page 47.

Do I need to have my home or lodgings professionally cleaned?

No professional cleaning is needed. You could perform an initial thorough cleaning of your home in the same way you would do a good “spring cleaning”. There is no evidence that shows the need for intensive cleaning beyond normal day to day chores.

Until your blood counts have fully recovered, general housekeeping is best left for someone else to do. Any commercial cleaning soap or solution can be used. It does not need to be “anti-bacterial”.

The following are suggestions and not strict rules; please use your best judgement.

- Dust and vacuum once a week (Patients should try to avoid entering that room for 30 minutes afterwards.)
- Clean kitchen and bathroom sinks, tubs, shower area, and toilets with a cleaner that kills mildew.
- Regularly wipe down areas that are touched frequently; such as light switches, doorknobs, electronic devices, appliance handles, etc.
- Change bed linens weekly or as needed.
- Consider the last time any filters (air conditioning, heaters, and humidifiers) were checked. Some filters may need to be cleaned or replaced.

Patients receiving active treatment should not renovate your home as this may increase their exposure to moulds. Talk to your doctor before starting any renovations.

Am I safe around children, pets, and other people living with me?

While your immune system is low (i.e. your neutrophils are less than 1.0):

Children are often not careful with their hand-washing and may have infections that could make you sick. We do not want to prevent you from spending time with children but while your immune system is low, you should try not to touch or kiss them if they have a runny nose or cough.

Common Pets such as cats and dogs are fine to handle. Birds, rodents, and reptiles can potentially carry more bacteria and handling is not recommended until your counts have recovered (or longer if you have had a stem cell transplant). Avoid changing litter boxes, cages or picking up your pet’s waste during your treatment and recovery; they can contain harmful organisms such as cytomegalovirus. Pets should not sleep in your bed while your immune system is low. Be sure to wash your hands after petting and handling your pets. Speak with your doctor if you have a job involving animals, such as a veterinarian, farmer, etc.

Other people living in your home need to stay away from you if they are sick with an infection (i.e. new cough, fever, diarrhea, vomiting, sore throat, runny nose, etc).

Should I avoid those who have just received a “live” vaccination (MMR, VZV, chicken pox, rotavirus, etc.)?

In general, your close contacts should receive MMR, MMRV, varicella or herpes zoster vaccines as appropriate for their age. This is the best way to protect you and your loved ones. “Live” vaccines contain a weakened form of a bacteria or virus. These vaccines are safe for the general public but the bacteria or virus can be passed on to those with weakened immune systems. The only time to avoid contact with those receiving live vaccinations is:

- During your first month after a stem transplant (your immune system is severely weakened)
- The person receiving the vaccine has developed a varicella-like rash (rare). Avoid contact until the rash has subsided.
- Contacts have received the live nasal spray influenza (flu) vaccine within the last 2 weeks. We recommend the injection flu vaccine instead, as it contains the inactivated virus that cannot be passed on.
- Ask your doctor about other rare live vaccinations from other countries (i.e. avoid those who have received the live oral polio vaccination within the last month).

Can I garden and care for house plants?

You don’t need to get rid of your houseplants but avoid any gardening until your counts have recovered. This is because soil contains bacteria, fungi and molds. Patients receiving a transplant should wait longer to garden; specific instructions will be given to you. When you are able to return to gardening, be sure to wear gloves for at least 6 months.

Can I take public transport during treatment?

While your immune system is recovering, please avoid public transit such as the train or buses. Public transit is very crowded and you could pick up an infection easily. If you need to use the ferries, avoid the more crowded areas. If you are concerned about picking up an infection, wear a mask.

Can I drive while receiving treatment?

Most patients find they feel too weak or tired to drive. To be safe, we recommend not driving at any time before, during and after treatment, until you feel you have fully recovered. <u>Please do not drive yourself to clinic appointments</u> as you may need a blood transfusion or other medications that will sedate you. You might also be taking medications that could make you feel drowsy, (i.e. Ativan®, Benadryl®, Gravol®). Please arrange for someone to drive you to the hospital.

Volunteer driver programs may be able to transport you to your cancer appointments at no charge, you may be sharing a ride. P**lease book two days ahead if possible:**

1. **Freemasons Volunteer Drivers 604 872 2034 or 1- 800-663-2524**
   Covers Vancouver, Burnaby, New Westminster, Richmond

   Operates Monday – Friday

2. **Volunteer Cancer Drivers Society 604 515 5400**
   Covers North Shore, Coquitlam, Port Coquitlam, Port Moody, Surrey, Delta, Langley, White Rock

   Operates Monday – Friday

Can I go swimming? Is tap water safe?

In general, while you have a central line in place (Hickman®, Trifusion®, PICC) you should not wade or swim in any pool or body of water. While your immune system is low, do not drink water from a well, especially a private well. Drinking or swimming in these bodies of water can lead to serious infections such as cryptosporidium. Municipal tap water is safe to drink and bottled water is not required. Local health departments will issue warnings about water safety. If such a warning is issued in your area, it is important to follow the instructions for boiling water.

Can I drink alcohol?

Chemotherapy and other medications can greatly stress and damage the liver. Some treatments, like a stem cell transplant can cause your liver to be sensitive and unable to fully function. All alcoholic beverages should be avoided during treatment and for at least 3 months for those people who have received a stem cell transplant. This period may be longer for some patients. Check with your doctor before having beer, wine and other alcoholic beverages.

Can I smoke?

If you smoke, we suggest that you quit immediately. Smoking includes cigarettes, cigars, pipes, marijuana, inhaling cocaine and chewing tobacco. Stopping these activities is important to prevent serious respiratory infections (i.e. pneumonia, fungal infections) when your immune system is low. No one should smoke inside your home. Avoid second hand smoke in public.

VGH is a smoke free environment. This includes the grounds at the hospital. There are many effective aids to help you stop smoking. If you need assistance with quitting smoking, please talk to your health care team, or see www.quitnow.ca 1 877 455 2233.

When can I travel after treatment?

Please check with your doctor before making any travel plans, We usually recommend waiting 6 months from recovery before air travel and travelling to other countries, longer for underdeveloped countries. It is important for your neutrophil and platelet counts to be at a safe level for travel.

Are herbal supplements and traditional Chinese medicines safe?

Tell your doctor or pharmacist about any herbal supplements or therapies you may be taking. We generally recommend not taking any supplements during your treatment. Although research in this area is limited, we do know that some herbal remedies, such as St. John’s Wort and Echinacea, may be quite harmful to recovering patients. Most common herbal teas are safe.

What are shingles? Why should I watch for 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, tell your physician as soon as possible. If you have previously had chickenpox or the varicella vaccine, take your Valtrex® tablets.

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 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 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
- 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. This guide and more information can be found with your social worker or 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.

For more copies, go online at **http://vch.eduhealth.ca** or
email **phem@vch.ca** and quote Catalogue No. **GV.175.W59**

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.

Excellent guides created by Myeloma Canada are available online at:

- www.myelomacanada.ca/en/resources/myeloma-canada-patient-and-caregiver-educational-publications

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)

Please contact bmtpatienteducator@vch.ca to offer feedback and to report any website that are no longer working.

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 (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 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® & Grastofil®.

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'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 Ventriculogulam 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 public washrooms 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)
- 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 these 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 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 06/2019

Adapted from *Your Autologous Stem Cell Transplant* (© 2016) with permission from South East Regional Cancer Program.
Adapted from *Your Guide to Having an Outpatient Autologous Stem Cell Transplant* (© 2017) with permission from University Health Network Patient Education.