Your Allogeneic Stem Cell Transplant

Information for Patients and Caregivers

Read this guide to learn:

- What an allogeneic 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 and contact information
- Where you can find more information

The Leukemia/Bone Marrow Transplant Program of BC

Important Phone Numbers:

The Leukemia/BMT Inpatient Unit:
24-hour care
15th & 16th Floor
Jim Pattison Pavilion, VGH

604 – 875 - 4343

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

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

Leukemia/BMT Daycare closes every night. For issues after hours please call the Leukemia/BMT Inpatient Unit.

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.

Call Us Immediately If You Have:

- Fever: a temperature of 38°C or higher
- Flu-like symptoms, chills or shaking
- Yellow or green mucus when you cough
- Shortness of breath, trouble breathing, or a bad cough
- Diarrhea, nausea or vomiting that doesn't stop
- Impaired speech, memory loss, confusion
- New bad bruising and/or bleeding
- Difficulty taking your pills
- New pain or a bad headache
- Concerns about your Central Venous Catheter (CVC) line
- Dizziness, unsteadiness when walking or have fallen down
- Rash, blisters, allergic reactions

In Case of Emergency – Call 911

If you are having severe chest pain, can't breathe, or require urgent medical care – **You or your caregiver should 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 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 allogeneic stem cell transplant. We hope reading this 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 stem cell transplants can be overwhelming. We know you will not be able to remember everything we tell you. This booklet provides written information to go along with the teaching you will receive from us, your healthcare team.

Read each section of this booklet 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.

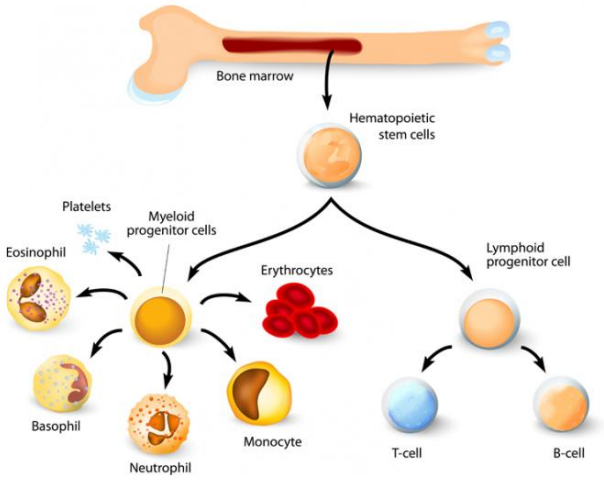
What are Stem Cells?

Stem cells are the body's primary cells. All 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 is 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.

Development of Blood Cells in the Bone Marrow



You will notice that we talk a lot about blood cells (also referred to as "blood counts") through your treatment. It is 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 WBC levels are 4 – 11.
- You are at greater risk for infection when your white blood cell count is low.
- Neutrophils are a type of white blood cell that fights bacterial infections. Normal levels are 2 – 8.
- Lymphocytes are a type of white blood cell that fights viral infections.

Red Blood Cells and Hemoglobin:

- Hemoglobin (inside to red blood cells) carries oxygen from your lungs to other parts of your body. Normal hemoglobin levels are 120 – 170.
- 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 usually 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 to 10 or lower, you will usually receive a platelet transfusion.

What is an Allogeneic Stem Cell Transplant?

An allogeneic stem cell transplant is used for treatment when:

- Your bone marrow or blood cells have become diseased. In this case you need healthy blood stem cells to replace the diseased bone marrow/stem cells.
- Your body cannot make the blood cells it needs because your bone marrow or stem cells have failed.
- Your body requires a new immune system to fight infections or cancer cells.

Allogeneic stem cell transplantation involves transferring the stem cells from a healthy person (the donor) to your body after conditioning treatment.

Before your stem cell transplant date, you are given conditioning treatment (chemotherapy and, for some patients, radiation treatment). Conditioning treatment kills any remaining diseased or cancerous cells in your body. It also suppresses (weakens) your immune system so your body will accept the new donor cells.

After conditioning treatment, donated stem cells are given to you as an intravenous (IV) infusion. The new stem cells enter your blood and find their way to your bone marrow and start producing healthy blood cells again.

Choosing a donor for you is a complex process; our team considers all the options and selects the best match for you:

Possible Stem Cell Donors:

"Related" or "Sibling" Stem Cell Transplant: Stem cells collected from your biological brother or sister. Each pair of siblings has only a 1-in-4 chance of being a full match.

Haploidentical Stem Cell Transplant: Stem cells collected from a half-matched family member. Haploidentical transplants are sometimes an option when a full match cannot be found.

Unrelated Donor Stem Cell Transplant: Stem cells collected from someone unrelated to you who volunteered to donate their stem cells. The unrelated donor will have human leukocyte antigens (HLA) that match your own human leukocyte antigens (HLA). A donor search is completed through stem cell registries around the world.

Double Cord Stem Cell Transplant: Stem cells collected from umbilical cord blood after delivery.

Types of Allogeneic Transplants

Allogeneic transplants can also vary on their conditioning treatment and where the stem cells are sourced from. Based on your age, your disease, your donor availability, and other factors, your Hematologist (Transplant Doctor) will discuss the best and safest transplant option for you.

Different Intensities of Treatment:

Full intensity – "myeloablative" ("MY-low-ah-BLAY-tive")

Most patients receive full intensity high dose chemotherapy (and sometimes radiation therapy). "Myeloablation" means severely suppressing or weakening the immune system.

Reduced-Intensity Conditioning Transplant ("RIC")

"RIC" transplants use a less intense and lowered doses of chemotherapy. Generally, these patients experience milder side effects.

Types of Allogeneic Stem Cell Transplants:

Stem cells are collected from a donor.

Peripheral Blood Stem Cell Transplant: "Peripheral blood" is blood that is circulating in the blood vessels. Donors are given medication to move their stem cells from their bone marrow into their bloodstream before they are collected.

Umbilical Cord Stem Cell Transplant: Stem cells are collected from the blood that is left behind in the umbilical cord and placenta after a baby is delivered.

Bone Marrow Transplant: Stem cells are collected from a donor's bone marrow (in the hip bone). This technique was once common but is now used less frequently because it requires an operating room and anesthesia. Peripheral stem cells do not require an operating room.

For more information, please see the Donor Manual. Go to www.leukemiabmtprogram.org Click on "Resources". Then select "Education Booklets and Guides". Scroll down and select "Related Donor Guide: Donating Peripheral Blood Stem Cells at Vancouver General Hospital".

Your Healthcare Team:

Your healthcare team is specially trained to care for patients having 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 healthcare team counts on you to let them know how you are doing.

Your healthcare team includes:

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

Before, during, and after your transplant, you may meet different members of your healthcare team. Our Doctors rotate through different areas of the program, and you may or may not see your Hematologist (Transplant Doctor) during your treatment. They are kept up to date on your progress. The whole healthcare team works together to care for you.

Please see *Resources and Support* and *Symptom Management Through Treatment* booklets for more information about your healthcare 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.

Step 1 Preparing for Transplant	You will meet with different members of your healthcare team who will help you prepare for transplant. You will have tests to ensure it is safe for you to have a transplant.
Step 2 Admission to Hospital	You will be admitted to the Leukemia/BMT inpatient unit on the 15th or 16th floor of VGH.
Step 3 Conditioning Treatment	You will be given chemotherapy (and sometimes radiation) to prepare your body for the stem cell transplant.
Step 4 Stem Cell Transplant	Donated stem cells will be given to you through your Central Venous Catheter (CVC). It is similar to a blood transfusion.
Step 5 Low Blood Counts	Chemotherapy and other medications will cause your blood counts to fall to very low levels. You will feel weak and unwell from the side effects from the chemotherapy during this time.
Step 6 Blood Count Recovery (Engraftment)	Engraftment is when your blood cells begin to return towards normal levels. This usually begins around 2.5 to 3 weeks after your stem cell transplant. We will start watching for graft-versus-host disease (GVHD) at this time.
Step 7 Follow-up Visits in the Leukemia/BMT Daycare Unit (Outpatient Clinic)	Once you have been cleared for discharge from the hospital, you will continue to be seen as an outpatient in the Leukemia/BMT Daycare Unit up until 100 days after transplant. In some cases, people need close follow-up beyond 100 days.
Step 8 Day +100 Tests	These tests will be completed in Vancouver and some of them are scheduled after Day 100. Many of the tests you had before your transplant, will need to be completed again after transplant.
Step 9 Managing at Home after Transplant	A week or two after Day 100, your hematologist will meet with you to discuss your results and plan for the future. After this appointment, you can return home if you are not from the Vancouver area. You will continue to have follow-up bloodwork and visits with your hematologist.

Step 1: Preparation for Transplant

Leading up to your transplant, you will have discussions with your Hematologist (Transplant Doctor) and your Nurse Navigator about the process and planning of your stem cell transplant. **You may talk to one before the other but they work together to support you.**

Consultation with Hematologist

Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your Hematologist (Transplant Doctor) will review your health history, do a physical assessment & discuss the stem cell transplant process with you and your family. They will discuss the treatment plan and risks related to having a transplant.

Phone call with a Nurse Navigator

Approximately 4-6 weeks before transplant

Your Nurse Navigator will call you to plan the tests and appointments you will need. After this 20-30 minute phone call, they will send you more information on your scheduled appointments and tests.

Your Nurse Navigator will arrange all the planning, testing, and appointments needed. They are involved with finding a donor for you, a process that can take weeks to even months.

Why have I not heard more about my transplant?

Your Hematologist (Transplant Doctor) may have initially discussed the possibility of needing a transplant with you; however, there will be a period of time where you may not receive many updates. Our team has started your transplant planning. We will schedule 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. We understand you need information to help plan ahead. You may call your Hematologist's (Transplant Doctor) secretary to confirm your tentative transplant date.

Getting Ready for your Transplant

It is helpful to start thinking of the physical, practical, 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 once you are discharged from hospital. Your family and friends can share the caregiver role. Your Nurse Navigator and Social Worker can assist caregivers with requesting compassionate time off work and visa application letters. For more information on caregiver roles and support, please see *Resources and Support.*

2. **Plan Where You Will Stay Before and After Discharge** – You will need to be within a 45-minute drive from Vancouver General Hospital through your outpatient treatment. Our team can help you arrange this if necessary. 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". This helps cover the cost of medications.

4. **Get Your Flu Shot & COVID-19 Vaccine** – During the influenza season (usually October to April), we strongly suggest you and your family receive the flu shot and COVID-19 vaccine. It is free at any local clinic and offered at most pharmacies. While not 100% effective, it is the best way to prevent complications caused by the flu before, during, and after your transplant. Ask your Hematologist (Transplant Doctor) or Nurse Navigator if you are eligible.

5. **Inform Your Doctor** – If you have seen a Doctor in a separate facility or health care program, make sure your Hematologist (Transplant Doctor) is aware. They are not always informed of all your previous medical records.

6. **Arrange for Care of Any Dependents and/or Pets** – Let your Nurse Navigator know if there are any concerns regarding people dependent on you for their care.

7. **Make Decisions About Your Fertility** – If having children after transplant is important to you, talk to your Hematologist (Transplant Doctor), Nurse Navigator, or Social Worker. They can discuss your options and refer you to a fertility specialist if needed.

What are other suggestions to prepare for transplant?

Proper nutrition is very important during treatment and transplant**:**

- To help heal and repair damaged cells
- To help produce healthy new marrow cells
- To minimize complications related to poor nutrition

Eating may be difficult or painful for you after transplant. Your mouth may become very sore or you may have changes to taste, nausea or vomiting. For these reasons, try to eat well ahead of time and gain weight if possible. Avoid dieting and try to add protein and higher calorie foods to every meal if possible. If you are struggling to eat enough calories, try simple things like eating small meals more often. Ask your family for support. Your Dietitian will have more suggestions for you during your pre-transplant consultation.

In hospital, if you are underweight or having difficulty eating, your team will start medical nutrition therapy to ensure you get the nutrients your body needs to heal. Nutrients may be temporarily given to you through your Central Venous Catheter (CVC) or (rarely) through a small flexible feeding tube down your nose until you are able to eat.

Being active - To build strength and energy, follow a regular exercise routine as best as you can. Try gentle exercises like walking 30 minutes every day. Yoga can strengthen muscles and help you relax.

Learn about your transplant - Information from your healthcare team and reading this guide will help you learn about the transplant process and to know what to expect. This can help you feel less anxious throughout treatment.

Plan ahead - Make sure your family and loved ones know your wishes if you are unable to speak for yourself. Putting one's legal affairs in order does not mean expecting the worst and it can give you the peace of mind to focus on getting better. Talk to your Social Worker for questions on the 3 legal documents you should consider before treatment:

- **Assign a Power of Attorney (POA).** For more information, go to www.nidus.ca and search "Enduring Power of Attorney". Click on "Enduring Power of Attorney – EPA". Search "Representation Agreement Forms" and select "Section 9 Representation Agreement (RA9)".
- **Complete your Advance Care Plan**. For more information, please see page 38.
- **Make or update your will**. Go to www2.gov.bc.ca and search "wills and estate planning"

Make decisions about your hair - The chemotherapy that kills cancer cells also causes temporary hair loss. Think about if you would like to cut your hair before transplant. You can get a one-time prescription for a wig from your Doctor. Toques, hats, and scarves are also good options to protect your head and to keep your head warm after hair loss. See *Symptom Management Through Treatment* guide for more information.

Pre Transplant Tests

Approximately 2-6 weeks before stem cell transplant at Vancouver General Hospital

Tests must be done to check how well your heart, lungs and kidneys are working before the transplant. We try our best to book tests and consultations on the same day but this may not always be possible. You may not need all of these tests, and your Hematologist (Transplant Doctor) may order extra testing not listed below.

These tests can include:

- Blood tests (bloodwork)
- Heart tests: Electrocardiogram (ECG), Radionucleotide Ventriculogram (RVG), Echocardiogram (Echo)
- Lung tests: Pulmonary Function Test (PFT), Chest x-ray
- Kidney tests: 24-hour urine collection
- Bone Mineral Density test
- Lumbar Puncture
- Bone Marrow Biopsy
- Central Venous Catheter (CVC) insertion: See *All About Your Tunneled Catheter* booklet
- CT Scan

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

Pre Transplant Consultations

To help you prepare for your upcoming transplant, you will meet with members of your healthcare 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.

Please try to have your caregiver at these consultations. It helps to have an extra person to listen and ask questions.

a) **Social Worker:** You will have a booked phone consult with one of our Social Workers. They will discuss how having a transplant can affect your family, living arrangements, finances and other practical matters. Depending on scheduling, this conversation may be done over the phone. Our Social Worker can assist you with organizing a will and an **advance care plan** (see more information on page 38).

b) **Dietitian:** You will have a booked phone consult with one of our Dieticians. They will discuss how you can prepare for your transplant and manage side effects, such as nausea, through your diet.

c) **Pharmacist:** You will have a booked phone consult with one of our Pharmacists. They will review the medications you will be taking before and after the transplant. Please fill out the questionnaire that will be sent to you by your Nurse Navigator before this meeting.

d) **Dentist:** A dental exam must be done at BC Cancer before your transplant. This is to look for any cavities, loose fillings, or gum disease that needs to be treated before transplant.

e) **Radiation Oncologist:** If you are receiving Total Body Irradiation (TBI) as part of treatment before transplant, we will arrange for you to meet with the radiation team at BC Cancer. Please see the *Understanding Total Body Irradiation* booklet.

f) **Thrombosis Clinic**: This appointment may be needed if you have had blood clots in your past, or if you are currently using a blood thinner (e.g., Apixaban®, Dalteparin®, Enoxaparin®, etc.). The Thrombosis Clinic Doctor and Nurses will teach you how to manage your blood thinner throughout your treatment.

Note: There may be other consults booked that are not listed on this page, such as Cardio-Oncologist, Allergist etc.

Step 2: Admission to Hospital

15th floor, Jim Pattison Pavilion, Vancouver General Hospital

On your planned admission day you will receive a phone call from the Patient Care Coordinator (PCC) between 11:00 am and 2:00 pm. After receiving this phone call, please check in at the receptionist's desk on the 15th floor (T15A). It will take time for our team to help you settle in and ensure all the necessary preparations have been done for you to start treatment the next day.

You may have to wait in the patient lounge while we prepare your room. You will be assigned a shared room with one other patient or a private room. Private rooms cannot be guaranteed as they are required for patients who are severely ill or require increased infection control precautions.

What will happen on admission day?

- Your Nurse will orient you to the unit, take your bloodwork, complete admission forms, and perform a physical assessment.
- A Doctor will discuss the transplant process and treatment with you, perform a physical assessment, and go over any consent forms needed.

For more information on the inpatient unit routine, please see *The Leukemia/Bone Marrow Transplant Inpatient Unit* guide.

Step 3: Conditioning Treatment

What is conditioning treatment?

Your treatment will start on the day after admission. The treatment you are given in the days before your stem cell transplant is called "conditioning treatment." This can be chemotherapy only or both chemotherapy and radiation therapy. Your Hematologist (Transplant Doctor) will choose the best conditioning treatment for you based on several factors, including your disease and age.

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

Conditioning treatment is used to:

- Eliminate the underlying disease.
- Create space for the new stem cells.
- Prevent rejection of the new stem cells.

Your white blood cells usually seek out and kill anything they identify as not belonging in your body. This would normally include your donor's stem cells. In order for your body to accept your donor's stem cells, we have to bring your white blood cell count down to zero. This is called suppressing your immune system or immunosuppression ("ee-MUNE-noh-suh-PRESH-un").

We give you conditioning treatment to eliminate your bone marrow and white blood cells. This allows for your donor's healthy new stem cells to take over and start to rebuild healthy bone marrow and blood cells.

What are the types of conditioning treatment?

1. **Chemotherapy:** All patients receive chemotherapy conditioning. When you are admitted, your healthcare team will teach you about the chemotherapy medications you will be receiving, what days you will receive them and what to expect with each drug.
2. **Total Body Irradiation (TBI):** Some patients will also receive total body irradiation therapy, depending on their diagnosis. For more information on TBI, please see *Understanding Total Body Irradiation* 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 in 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 an upset stomach, hair loss and your blood counts to become very low.

Hazardous Safety

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

Your body fluids are **hazardous every day chemotherapy is given and for 48 hours** from when the last dose finishes.

Your Nurse will tell you what days you are hazardous. While the risk is low, please follow these steps to keep you and your family safe while you are hazardous:

While you are Hazardous:

- Casual contact such as hugging, kissing and sharing a bed is safe.
- Wash your hands well with regular soap and water after any contact with body fluids.
- After using the toilet: Cover the toilet with a blue pad and then flush twice. Replace the blue pad every few days.
- Urine, bowel movements and toilet paper can be flushed down the toilet.
- Vomit, vomit bags, baby wipes and the soft paper towels used as toilet paper “the white roll” go into the red hazardous bins.
- If you are using a commode at the bedside: toilet paper and wipes go into the red hazardous bins.
- Family members who come in contact with your body fluids (e.g., if they are helping to empty and measure urine) need to wear blue gloves to protect themselves.
- Clothing and bedding that is soiled with 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.

Immunosuppressant Medications

Along with conditioning chemotherapy (and sometimes radiation), we use other medications to prevent the donor's immune system cells from attacking your body. You may hear them called "immunosuppressant" drugs or "GVHD prophylaxis."

What immunosuppressant drugs will I receive?

1. **Cyclosporine** ("SYE-clo-SPOR-rin")
   - Cyclosporine is given twice a day as an intravenous (IV) infusion.
   - On discharge from hospital, you will continue to take cyclosporine as an oral pill.
   - You will need to take cyclosporine until your Doctor says it is safe to decrease or "taper" the dose.
   - Depending on any symptoms you have, your Doctor will determine how long you will need to take cyclosporine. Some patients may be able to taper off cyclosporine after 3-6 months, while others may need to continue it for years.
   - Cyclosporine side effects can include increased blood pressure, tremors (shaking), increased hair growth, swelling of the gums, nausea, and reduced kidney function.

2. **ATG** (Rabbit **A**nti-**t**hymocyte **g**lobulin)
   - ATG is given as an intravenous (IV) infusion and runs throughout the day.
   - Common ATG side effects: chills, low blood pressure, fever. Other less common side effects: chest pain, itchy skin, skin rash, sweating, shaking, hypertension, headache.

3. **Methotrexate** ("meth-OH-TREX-ate")
   - Methotrexate is given as an intravenous (IV) infusion; it is a chemotherapy.
   - Methotrexate causes mild to severe mouth sores; this is called mucositis. It can also cause nausea, vomiting, headaches, and liver changes.

Exceptions: Not everyone will receive cyclosporine, methotrexate, and ATG. For example, some patients will receive the immunosuppressant drug tacrolimus instead of cyclosporine. They will also receive different conditioning treatment. Your Doctor will speak with you about which immunosuppressant drugs you will be receiving.

Step 4: Stem Cell Transplant Day

Day 0

The day of your stem cell transplant is referred to as Day 0. From Day 0 onward, your healthcare team will count each day as Day 1, Day 2, Day 3, Day 4 and so on.

Your Doctor will sometimes order pre-medications before your transplant to help your body tolerate the new stem cells.

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

- You will be awake, sitting up comfortably in a hospital bed. We recommend bringing a caregiver to support you throughout your transplant day.
- When we are ready to start the transplant, the bag of stem cells will be connected to your Central Venous Catheter (CVC) and given back to you like a blood transfusion.
- A Nurse will be there with you the entire time. A Doctor will be on the unit. Your vital signs will be monitored throughout the transplant.
- Some people have a reaction to the stem cells. Sometimes a fever or shakes can develop. Your Nurse and Doctor are ready if this happens and will give you medications to quickly stop the reaction.

If your stem cells have been cryopreserved (frozen):

Sometimes stem cells will arrive on the unit “cryopreserved” (frozen). If this is the case, they will be thawed in a warm bath before they are given to you. You may notice an odd taste in your mouth like canned corn or garlic during your transplant. Those around you may also notice a similar canned corn odour in the room. This is from the DMSO preservative. DMSO was added to the bag of stem cells to protect them while they were frozen.

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

- Your urine may be pink for up to 24 hours after transplant if you received “cryopreserved” (frozen) stem cells.
- Your healthcare team will continue to monitor you.
- You may feel sleepy if you received pre-medications.

Did You Know?

It is possible that your donated cells will not have the same blood type as you. This means that as your new stem cells start to recover in your bone marrow, your blood type will change to match your donors.

For example, if your blood type is A+ and your donor has a blood type of O+, eventually your blood type will become O+.

Step 5: Low Blood Counts

Days 2 – 20 or later

After your transplant day, there will be about three weeks when your blood counts will be very low. During this time, you will feel the most unwell from the side effects of conditioning treatment.

What will happen while I am waiting for engraftment?

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

- **Tests:** You will have daily blood tests and other tests as needed (i.e., CT scan, chest x-ray, etc.) to monitor your progress and watch for infection.
- **Managing side effects of allogeneic stem cell transplant therapy**: You will be given medications to help you manage any side effects. Our healthcare team will also teach you about different things you can do to manage these side effects. See the next page for possible chemotherapy side effects.
- **Blood and platelet transfusions:** Most people need blood and platelet transfusions when their blood counts drop to lower levels. See the *Symptom Management Through Treatment* guide for more information on transfusions.
- **Stay physically active:** Keep moving after your transplant. Staying active is a very important way to prevent lung infections and limit the amount of muscle lost. Even when you are feeling unwell, try to stay out of bed as much as possible. Sit up for all meals and walk around the unit as much as you can each day. Follow recommendations from your physiotherapist.
- **Teaching:** Learning about your medications and how to manage the side effects of transplant is important as you look ahead to being discharged. Your healthcare team is here to support you and answer any questions you may have.

What possible chemotherapy side effects can I expect?

Different people react differently to the stem cell transplant process. Do not feel discouraged if you meet someone who has a different experience than you. Each side effect can vary from mild to severe.

Short-term chemotherapy side effects (the first 3 weeks):

- Fever, chills, and infections (from low white blood cell count)
- Risk of bleeding (from low platelet count)
- Fatigue (feeling tired from low hemoglobin)
- Nausea and vomiting
- Hair loss
- Mouth sores and sore throat (can make it difficult to eat & drink)
- Taste changes and loss of appetite (don't feel like eating)
- Memory and concentration changes "chemo brain"
- Diarrhea (frequent, runny stools)
- Skin changes

Later side effects from chemotherapy (those that can last longer than 3 weeks):

- Fatigue
- Changes in memory/concentration
- Taste changes and poor appetite
- Nausea

Long-term chemotherapy side effects (those that can last longer than 6 months):

- Fatigue
- Infertility (not being able to have children)
- Changes in memory/concentration
- Lower hormone levels (thyroid hormone, testosterone, estrogen)

Alerting your healthcare team

Your healthcare team will assess you often to check for side effects of your treatment. Learning about these side effects yourself can help you recognize when they are occurring and know when to notify your Nurse or Doctor. **It is very important that you always tell your Nurse or Doctor about any side effects or symptoms you are having, as minor as they may seem.** When you mention side effects early, it can often be managed better, and it decreases the chances of complications.

See the *Symptom Management Through Treatment* guide for more information.

Step 6: Blood Count Recovery (Engraftment)

2.5 – 3 weeks or later

The medical term for when your blood cells begin to recover after transplant is '**engraftment**'. Engraftment is when your donor stem cells begin to make new blood cells in your bone marrow. Engraftment usually begins 2 and a half to 3 weeks after your stem cell transplant day. For some patients, engraftment can take longer.

What happens when my blood counts recover (engraftment)?

As your blood counts return to more normal levels, you will notice the side effects and symptoms from conditioning treatment improve. You will still need to stay in hospital as we monitor you for possible complications of your treatment. Complications can happen at any time, before or after engraftment.

What is the difference between a side effect and a complication?

Side effects are generally short-term symptoms that improve quickly. Complications tend to last a long period of time; they can be difficult to treat and are sometimes life-threatening.

What possible complications can happen after transplant?

1. Infection
2. Graft Versus Host Disease (GVHD)
3. Graft Failure (donor cells do not engraft or stop working)
4. Organ, Bone, and Hormonal Dysfunction

When you read about these transplant complications, take your time and **please remember you may not experience a severe complication:**

- Some are more common than others.
- Some are more life threatening than others.
- Most can be treated with medications.
- Each complication can vary from mild to severe.

Transplant Complications

Infection

What is it? An infection is the invasion and spread of harmful bacteria, viruses, parasites, and fungi (a.k.a., a fungal infection) in your body. These germs can come from an external source (outside your body) or from germs that have been living within your body. Prior to transplant, your immune system protected you from these germs. Due to your weakened immune system after transplant, these germs can multiply and cause an infection.

How common is it? They are very common and can vary from mild to life-threatening.

What is the timeline? You are at the greatest risk for infection in the first few months after transplant, especially while your white blood cells are low. Infections can also happen in the months and even years it takes for your new immune system to mature.

What causes it? Your immune system is weak in the weeks and months after transplant and you will be taking immunosuppressant medications. It is comparable to the immune system of a newborn baby and needs time (12-18 months) to mature and fully protect your body from invading organisms.

What can I do? Take all your prescribed medications (antibiotics, antivirals, antifungals) as instructed, follow our infection control guidelines and let us know immediately if you have any signs of infection (i.e., fever, headache, chills, feeling sweaty, feeling very hot or cold, cough, etc.) For more information on preventing infection see the *Symptom Management Through Treatment* guide.

Graft Versus Host Disease (GVHD)

What is it? Graft **V**ersus **H**ost **D**isease (**GVHD**) happens when the donor T-cells ("your graft") mistakenly attack your body's cells ("the host"). Your donor T-cells can be beneficial in mild to moderate cases by attacking the last bit of disease in your body. There are two main categories of GVHD:

1. **Acute GVHD** usually occurs within the first 100 days after transplant. It typically affects your skin, liver, and gut.
2. **Chronic GVHD** typically occurs after the first 100 days of transplant. It can affect any part of the body.

How do we prevent GVHD? We give you immunosuppressant medications (e.g., cyclosporine or tacrolimus, methotrexate, ATG) to try and prevent GVHD.

What is the treatment? Acute GVHD is typically treated with steroids. Other treatments may be added depending on response.

What can you do? Take all your prescribed medications as directed, attend all your follow-up appointments, and let your healthcare team know of any symptoms you notice after your transplant. Protect your skin from the sun and avoid smoking.

Please see page 31 for more information on chronic GVHD.

Signs of Acute Graft Versus Host Disease:

- **Stomach or Gut:** Mild to severe diarrhea, stomach cramping, nausea and vomiting, little to no appetite, weight loss.
- **Skin:** A rash that looks like a sunburn. The rash typically develops on the hands, feet, face, chest and back. The rash may be in one of these areas or multiple areas. The rash may spread to other parts of your body and may be accompanied by a fever.
- **Liver**: A large firm tummy, tenderness in upper right stomach, itchy skin, jaundice (skin appears yellow), dark urine.

Graft Failure

Graft failure is a rare but life-threatening complication of transplant. This happens when your new donor stem cells do not successfully grow in your body (i.e., no engraftment occurs or engraftment stops). It usually happens within the first few weeks after transplant but can happen anytime.

Your Doctor will talk to you about options if this happens. In some cases, there is the possibility of having a second stem cell transplant.

Organ, Bone, and Hormonal Dysfunction

Allogeneic stem cell transplant therapy affects your whole body and can cause mild to severe damage to your organs. These symptoms can appear in the months and sometimes years after transplant and are caused by the conditioning treatment you received (e.g., chemotherapy, radiation) and immunosuppressant medications (i.e., cyclosporine or tacrolimus, methotrexate, ATG).

Heart: Tell your healthcare team immediately if you are experiencing chest pain, fast or irregular heartbeat, shortness of breath, or dizziness.

Bladder: Tell your healthcare team immediately if you notice pain with urination, pink or red urine, you are urinating more often than usual. Continue to drink fluids and stay well hydrated.

Lung: Tell your healthcare team immediately if you are experiencing shortness of breath, coughing, or breathing problems.

Liver: **V**eno-**O**cclusive **D**isease (**VOD**), also known as **S**inusoidal **O**bstruction **S**yndrome (**SOS**), happens when the blood vessels to and from your liver become blocked and prevent your liver from working properly. Tell your healthcare team if your tummy feels swollen and firm and/or if you are experiencing pain to your right upper stomach.

Bones: Bone density loss after transplant increases your chances of developing osteoporosis and/or breaking a bone. Regular weight bearing exercise (walking, climbing the stairs) and strength training are things you can do to prevent bone density loss.

Hormones: Reduced hormone levels in the thyroid, pancreas, and sex glands may occur. Tell your healthcare team if you are experiencing chronic fatigue, unexplained weight changes, sexual dysfunction, or mood disturbances.

Step 7: Follow-up Visits in Leukemia/BMT Daycare Unit

Once you are discharge from the hospital, you will continue to be seen as an outpatient in the Leukemia/BMT Daycare Unit up until Day 100 after transplant, or longer if needed. Your appointments will be twice a week. If you are experiencing side effects or complications, your appointments will be more frequent. Sometimes it may be necessary for you to be readmitted to hospital after being discharged.

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. A typical visit can last from 2-6 hours. What you can expect:

- Bloodwork taken from your Central Venous Catheter (CVC).
- Your healthcare team to do an assessment.
- 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 (e.g., X-ray, CT Scan, Ultrasound).

What should I bring to each visit at the L/BMT 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.
- One family member or friend. You will not be able to drive or take public transportation while you are still recovering from your transplant.
- Snacks, drinks, and a reusable water bottle. Bring your own hot water in a thermos. There is no hot water available.
- Things to occupy your time, although you may prefer to rest or watch TV.

What should I do every day after discharge from hospital?

- Check your temperature twice a day. Check it more often if you are feeling unwell. **Call us immediately** if you have a temperature of 38°C or higher.
- Take your medications. If you have questions about your medications, please talk with your Nurse, Pharmacist, or Doctor.
- Write down any questions you have and bring them to your next visit. If you are unsure about a symptom you are having or have an issue that needs attention, contact us.
- Follow infection control guidelines (see *Symptom Management Through Treatment* guide).
- If you feel like it, you can do many of your usual home activities like going for walks, reading, and listening to music.

Step 8: Day 100 Tests

You will have a Bone Marrow Biopsy around 100 days after your transplant (Day 100). After you receive your results from your Bone Marrow Biopsy, your Central Venous Catheter (e.g., Hickman® line) will be removed. You will receive a requisition for follow-up blood work that can be done in any local clinic.

Many of the tests you had before your transplant will be repeated (e.g., Pulmonary Function Test, Bone Mineral Density etc.) to check if you have any transplant-related complications. These tests will be done in Vancouver and some of them are scheduled after Day 100.

A week or two after Day 100, your Hematologist (Transplant Doctor) will meet with you to discuss your results and a plan for the future. They will also discuss your revaccination schedule which starts around 6 to 12 months after transplant. After this appointment, you may be able to return home if you are not from the Vancouver area; some patients may need to continue to receive treatment in the Leukemia/BMT Daycare unit past Day 100 for complications such as infection, low hemoglobin, and GVHD.

After Day 100, you will be referred to our Long Term Follow Up Clinic (LTFU) at VGH. These providers work alongside your Hematologist (Transplant Doctor) to support you through any symptoms and long term side effects you may experience after transplant.

Step 9: Managing at Home after Transplant

Generally, it takes 12-24 months for you to return to a normal lifestyle after transplant. Adjusting to life after your stem cell transplant can feel like a slow recovery. You may still have good days and bad days. It will take time for you to step back into your regular routine. Be patient with yourself as you adjust and recover.

How will I feel after Day 100?

Even after Day 100 you will likely 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 have other side effects and symptoms after the transplant, typically caused by chronic GVHD. See the following pages for more information on:

- *Chronic GVHD*
- *Coping emotionally through treatment*
- *Helping your family cope*
- *Returning to work*
- *Choosing a caregiver*
- *Caregiver responsibilities*
- *Fear of recurrence*
- *Advance care planning*

Chronic GVHD

Chronic GVHD is seen in about half of the patients who have a stem cell transplant. It typically occurs any time after Day 100 and happens when the white blood cells (e.g., T-cells) of your new immune system attack your body's tissues and organs.

Depending on how severe your symptoms are, chronic GVHD can have small to significant impacts on your quality of life after transplant.

How can I manage it?

- **Call your Hematologist's (Transplant Doctor) secretary to report any changes you notice after transplant**, as minor as they may seem. Chronic GVHD can worsen quickly if not treated.
- Take your immunosuppression medications exactly as instructed.
- Complete your lung function testing.
- Stay active, eat a healthy diet, manage fatigue, and try and reduce stress.

General Areas of Chronic GVHD:

Skin: Your skin can become dry, tight, thickened, red, itchy, darker, and/or lighter. This can affect your appearance, your ability to regulate your temperature, and can lead to skin infections.

Stomach/Digestive Tract: Gut GVHD can affect any part of your digestive tract. You could experience difficulty swallowing, nausea, diarrhea, indigestion, cramping, and decreased appetite.

Mouth: GVHD may cause dryness and a sore feeling in your mouth. Good mouth hygiene, staying well hydrated, oral lubricants, and seeing the dentist can help with mouth GVHD.

Eyes: Your eyes may become dry, sore or "gritty". Using eye drops and wearing sunglasses can help.

Lungs: Your lungs may lose some of their flexibility and elasticity. This can cause you to wheeze, cough, and become easily short of breath.

Muscles and Joints: You may experience restricted movement, tension, stiffness or pain to your joints, and taut skin. Staying active and/or seeing a physiotherapist can help with these symptoms.

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, and isolation.
- Feeling 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 healthcare team questions so you will know what to expect.
- Talk to someone who has been through treatment. Connect with one of the many peer support programs available through community cancer centres.
- Manage your energy before, during, and after 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. Try reading, meditation, listening to music/audiobook/podcast, watching a favourite TV show or movie, painting, sketching, knitting, or spending time with family and friends.
- Set realistic, small goals. When you feel overwhelmed or you think what lies ahead will be too long or tiring, try taking it one day, or even one hour at a time. This helps focus on the present.

Scan the QR code: ***Coping with Cancer*** video

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 need to 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. Connect with one of our Social Workers for help.
- 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 a Social Worker.
- Get enough sleep, eat well, be active, or 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 and 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.bcancer.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 assist caregivers who are planning to take time off work, to explore potential financial benefits and request the supporting documentation needed.

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 the Leukemia/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 to communicate with the healthcare team. Translation and interpretation services can be provided.

How many caregivers do I need?

- You need at least one identified caregiver for the duration of your treatment. We understand this can be challenging from a practical and emotional lens for the caregiver. Therefore, rotating caregivers is 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 caregiver to rest, relax and have time away from the hospital, and prevent burnout. *For more information on caregiver burnout please connect with one of our Social Workers.*

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, taking notes, asking questions, keeping track of the patient's schedule.
- Providing emotional support.
- Providing support at home:
    - *Reminding the patient to take oral medications.*
    - *Identifying changes in the patient's condition to the clinical team.*
    - *Calling the BMT triage nursing line or obtaining urgent medical care, if needed.*
- 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.bloodcancers.ca** Search "Caring for a loved one with a blood cancer" or "Learning to be a caregiver" or "Taking care of yourself". Click on the result that matches the title.
- Go to **www.cancer.ca** Search "caregiver". Click on any of the results you feel 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 Hematologist (Transplant Doctor).

Going back to work helps to get you 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 concentrate.

Here are some tips to help you return to work:

- 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 information on what needs to be considered regarding 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, find 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 received, and how long it has been since your last treatment.

If you have a fear of your 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.** 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 38 for more information on advance care planning.
- **Be Informed.** Learn about your cancer. Know what symptoms of relapse 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* booklet 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 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.

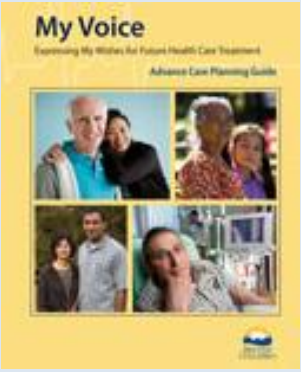
How Do I Start Advance Care Planning?

Advance care planning involves having conversations with your loved ones and healthcare team to make sure they know what your wishes are if you become unable to speak for yourself. Go to www.vch.ca and search “advance care planning”. Select “Advance care planning”.

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. Research shows it can: improve your quality of life, improve the chance your care wishes will be fulfilled, and bring peace of mind to you and your loved ones.

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.

When can I contact my donor?

During the first year after transplant, some donor registries will help connect you with your donor to send emails, cards, letters and one small gift – as long as they are kept anonymous. This means you cannot give away any personal details, such as your name or where you live.

In Canada, you must wait one year after your transplant before you can ask for direct contact. In many other countries the waiting period is longer. If your donor is in a country where the wait is longer, you will have to wait until their waiting period is over.

Whether you or your donor want to connect is a personal decision for each of you. There is no right or wrong choice.

Some countries have laws that say donors and recipients can never have direct contact. If your donor is from one of these countries, you will never know their name or other personal details. You might still be able to send anonymous emails, cards, letters, or a small gift.

If you would like more information about contacting your donor, please ask your Doctor or contact your stem cell transplant Navigator at 604-875-4863.

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.

Antibodies: Proteins produced by white blood cells in response to a foreign substance (antigen) to help eliminate it. Each antibody can bind only to one specific antigen.

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

Bone Marrow Transplant: Bone marrow transplants are procedures to replace damaged or destroyed bone marrow with healthy bone marrow stem cells. They require operating rooms and anesthesia to collect bone marrow from the hip bone. More commonly, stem cells are collected from blood veins in the arm (see Peripheral Blood Stem Cell).

Bone Mineral Density Test: A bone density test uses x-rays to measure how much calcium and other bone minerals are packed into a segment of bone. Bones with lower mineral density are more likely to break.

Chemotherapy: Anticancer drugs or combination of drugs designed to kill cancer cells.

Chest X-Ray: This is a picture of the organs, bones and tissue inside your chest.

Conditioning Treatment: Treatment with high dose chemotherapy and sometimes radiation during allogenic stem cell transplant.

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

Echocardiogram (Echo): An ultrasound that assesses your heart's size, structure, valves, and how well your heart is pumping.

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.

Graft-versus-host disease (GVHD): A condition whereby your transplanted stem cells (graft) view tissues in your body (host) as foreign and attack them.

HLA Typing: The process of identifying the unique immune profile of a person. HLA typing, also known as tissue-typing, is performed to determine whether a donor can be found for a stem cell transplant. A blood sample is used for this test.

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

Immunosuppression: Weakening of the immune response caused by drugs or other means.

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

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

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

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

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

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

Myeloablative: The strongest type of conditioning therapy given for an allogeneic stem cell transplant.

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.

Osteoporosis: A bone disease that occurs when the body loses too much bone, makes too little bone, or both.

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 test to check your lung health. 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.

Refractory: Not responding to treatment.

Relapse: Return of the cancer or disease after treatment remission.

Remission: Complete or partial disappearance of symptoms of a disease in response to treatment. The period during which a disease is under control.

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

Stem cells: The stem cell is the parent cell from which all other blood cells and the immune system are created. Your body is constantly producing the cells that make up your blood and immune systems. They give rise to oxygen-carrying red blood cells, disease-fighting white blood cells, and platelets needed for clotting.

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

T-cell: A type of white blood cell. Donor T-cells help by attacking remaining blood cancer in your body. Donor T-cell can also attack your healthy tissues, causing GVHD.

Testing "positive": A test result that shows that a person has the disease, condition, or biomarker for which the test is being done.

Tunneled catheter: a thin, flexible plastic tube that is inserted into a vein in the body to allow, for example, the flow of fluids, delivery of medications, or drawing of blood.

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

Where Can I Get More Information?

Suggested readings:

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

Find booklets, videos and more information at:

Myeloma Canada: 1-888-798-5771
www.myeloma.ca

The Leukemia & Lymphoma Society of Canada: 1-833-222-4884
www.bloodcancers.ca
Click "I have a blood cancer"

BC Cancer: 1-800-663-3333
www.bccancer.bc.ca

The Canadian Cancer Society: 1-888-939-3333
www.cancer.ca
Click "Living with cancer"

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 healthcare team. Use this as a reference and education guide. Consult your healthcare team if you have any questions or concerns. Creator and Author: Amy Healy 07/2019. Authors and Editors: Sally Moore 08/2026, Patsy Vanee 06/2026, Rebecca St. Jean 07/2026, Jennifer Millar 06/2026, Mona Walia 07/2026, Dr. Brendan Wong 06/2026, Katherine Sawatsky 06/2026.

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