

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
- Where you can find more information



Important Phone Numbers:

The Leukemia/BMT Daycare Unit Hours: 6th Floor Leon Blackmore Pavilion, VGH

****This unit closes every night. Always call before arriving for an unscheduled visit.**

Monday to Friday 7:00am – 7:00pm

Weekends & Holidays 8:00am – 6:00pm

604 875 4073

Afterhours: The Leukemia/BMT Inpatient Unit, 15th Floor Jim Pattison Pavilion, VGH

604 875 4343

Leukemia/BMT Hematology Administration Office:

Monday to Friday 8:30am - 4:30pm

604 875 4863

The Hematology Apheresis Unit (HAU): 6th Floor Leon Blackmore Pavilion, VGH

Monday to Friday 8am - 5pm

604 875 4626

Call Us Immediately If You Have:

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

In Case of Emergency – Call 911

If you or your loved one has severe chest pain, a broken central IV line, can't breathe or requires urgent care – **CALL 911**. An ambulance will take you to the closest hospital.

Tell the staff you are a Leukemia/BMT patient and to contact our doctor on call. These symptoms are rare but if they occur, they cannot be managed over the phone.

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About this book

This book has been developed to help you and your family prepare for an allogeneic stem cell transplant. We hope that reading it 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 given to you about 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.

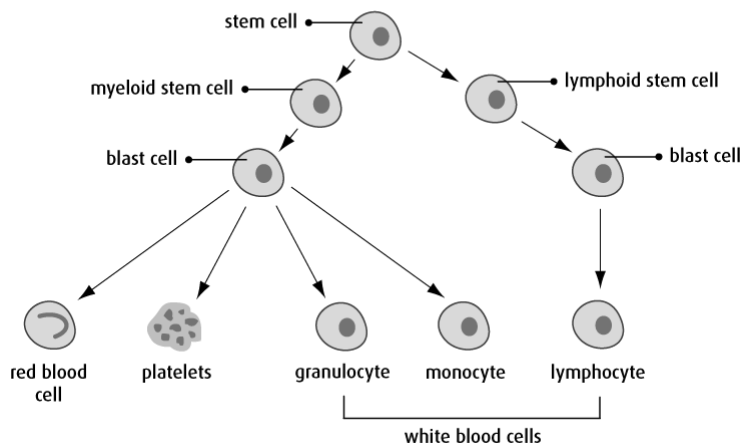
At the end of the book there is a section with descriptions of certain tests and common medical terms.

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. The stem cells that create your blood cells are found in your bone marrow.

Bone marrow is the spongy tissue found inside your bones; it could be called the "factory" where your blood cells are made.

Blood stem cells create lots of different types of blood cells, including white blood cells, red blood cells and platelets. You'll notice that we talk a lot about blood cells or your "blood counts" in particular through your treatment. It's helpful to grow familiar with them and what they do.



Types of Blood Cells

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

White Blood Cells (WBC):

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

Red Blood Cells and Hemoglobin (Hgb)

- Hemoglobin (a protein in 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 may receive a blood transfusion.

Platelets (Plt)

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

What is an 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 high-intensity chemotherapy or radiation.

Before your stem cell transplant date, you are given chemotherapy medications (and sometimes radiation treatment). These “conditioning treatments” kill any remaining diseased or cancerous cells in your body. They also suppress (weaken) 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. They allow your bone marrow to start producing healthy blood cells again.

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

Possible Stem Cell Donors:

“Related” or “Sibling” Stem Cell Transplant: Your best match was stem cells collected from your biological brother or sister.

Haploidentical Stem Cell Transplant: Also a related donor, your best match was stem cells collected from a half-matched family member. Haploidentical transplants are sometimes an option when a full match can’t be found.

Unrelated Donor Stem Cell Transplant: Your best match was stem cells collected from someone unrelated to you. This person joined a registry that matches volunteer stem cell donors with those in need of a stem cell transplant.

Umbilical Cord Stem Cell Transplant: Your best match was stem cells collected from the blood in the umbilical cord and placenta after a baby is delivered.

Types of Allogeneic Transplants

Allogeneic transplants can also vary on their conditioning treatment and where the stem cells are sourced from. Many patients receive a “myeloablative peripheral blood transplant”.

Based on your age, disease, your donor availability, and other factors, your doctor will discuss the best and safest transplant option for you. All of the types of transplants listed below follow the steps in this manual.

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”, “mini” or “nonmyeloablative”)

“RIC” transplants use less intense and lowered doses of chemotherapy. These transplants are used for patients who wouldn’t be able to tolerate or don’t require full intensity chemotherapy. Generally, these patients experience milder side effects and are able to be discharged more quickly from hospital than myeloablative transplants.

How the Stem Cells Are Collected:

Peripheral Blood Stem Cell Transplant: Stem cells are collected from blood taken from a donor’s arm veins. “Peripheral blood” is blood that is circulating in the blood vessels. Donors are given medication to move their stem cells from the bone marrow into their bloodstream before they are collected.

Umbilical Cord Stem Cell Transplant: Stem cells are collected from the blood that’s left behind from 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 now used less because it requires an operating room and anesthesia. Peripheral stem cells do not require an operating room.

Your Health Care Team:

Your health care 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 health care team counts on you to let them know how you are doing.

Your team includes:

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

You may meet some or all these health care team members at Vancouver General Hospital. Our doctors rotate through the different areas of the program and you may or may not see your primary hematologist during your treatment. They 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 manual outlines this step by step process is described in more detail.**

Step 1 Preparing for Transplant	You'll meet with different members of your health care team who will help you prepare for transplant. Tests will be performed to ensure a transplant is safe for you.
Step 2 Admission to Hospital	You will be admitted as an inpatient to the Leukemia/BMT inpatient unit on the 15 th floor of VGH.
Step 3 Chemotherapy "Conditioning"	You will be given chemotherapy (and sometimes radiation) to prepare your body for the stem cell transplant.
Step 4 Stem Cell Transplant Day	Donated stem cells will be given to you through your IV catheter. It is similar to a blood transfusion.
Step 5 Waiting for Blood Count Recovery	Chemotherapy and other medications will cause your blood cells or "blood counts" to fall to very low levels for 7 to 12 days. 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 12-14 days 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 Outpatient Clinic	Once you've been cleared for discharge from the hospital, you'll continue to be seen as an outpatient in the Leukemia/BMT Daycare Unit up until 100 days after transplant. In some cases, people need close follow-up beyond 100 days.
Step 8 "Day 100" Tests	100 days after your transplant day, you will repeat many of the tests you had before your transplant. These tests are to check on your disease and any possible side effects from treatment.
Step 9 Managing at Home after Transplant	After 100 days, some people finish their daycare clinic appointments and may return home if from out of town. Others may have to continue until symptoms resolve. 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 and your BMT 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 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 and go over the consent forms you'll sign for treatment.

Phone call with Nurse Navigators

Approximately 6 weeks before transplant

Our BMT Nurse Navigators arrange all the planning, testing and appointments needed when your doctor has recommended a stem cell transplant for you. They are involved with finding a matched donor for you, a process that can take weeks to even months.

Roughly 6 weeks before transplant, your Nurse Navigator will call you to plan the tests and appointments you'll need. After this 20-30 minute phone call, they will send you more information on your scheduled appointments and tests.

Why haven't I heard more about my transplant?

Your doctor may have initially discussed the possibility of needing a transplant with you but there will be a period where you may not receive many updates on its progress. Our team has started your transplant planning but it is best if we 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 how it is necessary for you to plan ahead and you may call our administration offices to confirm your tentative transplant date.

Getting Ready for your Transplant

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

What must I do before my transplant?

- 1. Choose a 24 hour caregiver** – You'll need a 24 hour live-in caregiver for a few weeks once you're discharged from hospital. Your family and friends can share the caregiver role; it does not have to be only one person. Your Nurse Navigator 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. Register for Pharmacare** - If you haven't registered for Fair Pharmacare, call 1-800-663-7100 or visit the web link below to clarify your benefit plan and medication coverage. Your social worker and pharmacist can assist you.
<http://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents/who-we-cover/fair-pharmacare-plan/register-for-fair-pharmacare>
- 3. Plan where you'll stay after discharge** – You will need to be within a 60 minute drive from Vancouver General Hospital through your outpatient treatment. Our team can help you arrange this if necessary. Please see *"Maps, Parking and Places to Stay"* for recommendations and important things to consider when booking accommodations. To plan for unpredictable schedule changes, we recommend booking accommodations with a flexible cancellation policy.
- 4. Get your Flu Shot** – Approaching or during the influenza season (usually October to April), we **strongly suggest** you and your family receive the flu shot; it is offered free at any local clinic and some pharmacies. The flu shot - though not 100% effective - is the best way to prevent the flu and it will lessen the chances of severe complications if you do contract the flu. Ask your doctor when the best time to get your flu shot is.

- 5. Inform your doctor** – If you have seen a doctor in a separate facility or health care program, ensure your transplant doctor is aware. Our doctors are not always informed of all your previous medical records.
- 6. Arrange for care of any dependents and/or pets** – Let your Nurse Navigator know if there are any concerns regarding people dependent on you for their care. Pets can stay with you through treatment but some people choose to leave them with friends or family.
- 7. Make decisions about your fertility** – If having children after transplant is important for you, talk to your transplant team. They can discuss your options and give you a referral to a fertility specialist.

What are other suggestions to prepare for transplant?

Proper nutrition is very important during treatment and transplant:

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

Eating may be difficult or painful for after transplant. Your mouth may become very sore or you may have trouble with taste changes, 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 if you have 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 IV or (rarely) through a small flexible feeding tube, until you are able to eat.

Being Active - To build strength and energy, follow your regular exercise routine as best as you can. Or to start, try gentle exercises like walking every day as you are able. Yoga can strengthen muscles and help you relax, which is also good for your mental health.

Learn about your transplant - Information from our team and this manual will learn about the transplant process and help you know what to expect. This can help you feel less anxious through treatment.

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

- **Assign a Power of Attorney (POA).** This person can make your health care decisions for you if you cannot make them yourself. For more information, go to www.nidus.ca/PDFs/Nidus_Guide_EPA.pdf
- **Complete your Advance Plan.** For more information, please see page 40.
- **Make or update your will.** Type "wills and estate planning" at www2.gov.bc.ca/

Make decisions about your hair - The chemotherapy that kills cancer cells also causes temporary hair loss. Think about if you'd like to cut your hair before transplant. If you're interested in a wig, visit a wig store so you can find one that closely matches your natural hair, if you want. You can get a one-time prescription for a wig from your doctor. Hats, scarfs and turbans are also good options to protect your head after hair loss.

Contact your insurance agency - It's a good idea to contact your agency to discuss your extended insurance benefits.

Pre Transplant Tests

Approximately 4-6 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 arrange as many tests and consultations on the same day but this may not always be possible. **You may not need all of these tests, and your doctor may order extra testing not listed below.**

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

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

Pre Transplant Consultations

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.

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

- a) **Social Worker:** Our social worker 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 40.
- b) **Dietitian:** Our dietitian will discuss how you can prepare for your transplant and manage side effects through your diet and food choices.
- c) **Pharmacist:** Our pharmacist will review the medications you'll be taking before and after the transplant and how to take them. Please fill out the questionnaire you will be provided 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 need to be treated before transplant.
- e) **Radiation Oncologist:** If you will be receiving "Total Body Irradiation" (TBI) as a part of treatment before transplant, we will arrange for you to meet with the radiation team at BC Cancer. More information on this process can be found in the booklet "*Understanding Total Body Irradiation.*"
- f) **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: Admission to Hospital

15th floor, Jim Pattison Pavilion, Vancouver General Hospital

On your planned admission day, please check in at the receptionist's desk on the 15th floor (T15A) at 2pm. It will take time for our team to help you settle in, do our assessments 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 for a time while we prepare your room. You will be assigned a shared room with one other patient or a private room. Private rooms cannot be guaranteed as they are required for patients requiring additional isolation precautions or other circumstances.

What will happen on admission day?

- Your nurse will orient you to the unit, 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.
- Your weight and height will be measured.
- Your nurse will draw bloodwork from your tunneled catheter (Hickman[®])
- A baseline ECG (electrocardiogram) will be done at the bedside.
- You will be connected to IV fluids that evening or the following morning.
- Your nurse will teach you how to measure your urine. This is an important way for us to monitor your kidney function. You will be connected to IV fluids and measure your urine the whole time you are in hospital.

For more information on the inpatient unit routine, please see
"The L/BMT Inpatient Unit" booklet.

Step 3: Conditioning Treatment

What is conditioning treatment?

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

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

Conditioning treatment is used to:

- Eliminate the underlying disease;
- Create space for the new stem cells; and
- 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 lower your white blood cells to zero. This is called suppressing your immune system or “**immunosuppression**” (ee-MUNE-noh-suh-PRESH-shun”).

We give you conditioning treatment in order to destroy your bone marrow and white blood cell count. This allows for your donor’s healthy new stem cells to take over and start to rebuild a 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 health care team will teach you about the chemotherapy medications you will be receiving, what days you will receive them and what to expect with each drug.
2. **Total Body Irradiation (TBI):** Some patients will also receive total body irradiation therapy, depending on their diagnosis. For more information on TBI, please see the handout “*Understanding Total Body Irradiation*”

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, hair loss and lowers your “blood counts.”

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



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

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

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

While you are Cytotoxic:

- Casual contact such as hugging, kissing and sharing a bed is safe.
- 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. Wash your hands with soap and water after.
- Vomit, vomit bags, baby wipes and the soft paper towels used as toilet paper (“the white roll”) go into the red cytotoxic bins.
- If you’re using a commode at the bedside: toilet paper and wipes go into the red cytotoxic bins.
- Family members who come in contact with your body fluids (i.e. if they are helping to empty and measure urine) need to wear blue gloves to protect themselves. After removing their gloves, they need to wash their hands with soap & water.

Anti-Rejection 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 "anti-rejection" drugs or "GVHD prophylaxis."

What "anti-rejection" drugs will I receive? How long will I need to take them?

1. Cyclosporine ("SYE-clo-SPOR-rin")

- Cyclosporine is first given as a continuous IV infusion, 24 hours/day.
- On discharge from hospital, you will continue to take cyclosporine as an oral pill.
- You will continue to take cyclosporine until your doctor says it is safe to start to decrease (or "taper") the dose.
- Depending on any symptoms you have, your doctor will determine how long you will continue 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, nausea, swelling of the gums and reduced kidney function.

2. Methotrexate ("meth-OH-TREX-ate")

- Methotrexate is an intravenous (IV) chemotherapy medication you will receive after your transplant.
- You will receive 3 to 4 daily doses of methotrexate, depending on your type of transplant.
- Methotrexate can cause mild to severe mouth sores ("mucositis"). It can occasionally cause nausea, vomiting, headaches and liver changes.

Exceptions: Not everyone will receive cyclosporine and methotrexate:

"Haplo" stem cells transplants patients will receive the anti-rejection drugs tacrolimus, mycophenolate and the chemotherapy cyclophosphamide.

Umbilical cord stem cell transplant patients will receive the anti-rejection drugs tacrolimus and mycophenolate.

You will receive more information about these drugs from your health care team.

Step 4: Stem Cell Transplant Day

“Day 0”

On the day of your transplant, your donor cells will arrive on the unit at a certain time. They will have been delivered from the apheresis collection unit in Vancouver General Hospital (related transplants) or from the collection centre closest where your unrelated matched donor lives.

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

Your doctor may 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. Your family and friends can be in the room to celebrate and support you.
- When we are ready to start the transplant, the bag of stem cells will be connected to your Hickman[®] line and given back to you like a blood transfusion.
- You may receive more than one bag of stem cells. Depending on the size, each stem cell bag will take roughly 15 to 60 minutes to be infused.
- 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.
- A nurse will be with you the entire time. A doctor will be in the room or close by on the unit. Your vital signs will be monitored throughout the transplant.
- You may feel a tickle or a tightness in your throat. This is normal and you will feel better if you take deep breaths and cough.
- Occasionally, some people have an allergic reaction to the stem cells. Sometimes a fever or shakes can develop. Your nurse and doctor are ready if this happens and will give you medications to quickly stop the allergic reaction.

If your stem cells have been cryopreserved (frozen):

Sometimes, in the case of umbilical cord blood transplants and some other instances, stem cells will arrive on the unit “cryopreserved” (frozen). If this is the case, they will be thawed in a warm bath before being 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 that 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 red for a few hours after the transplant. This will stop after 24 hours.
- Your health care team will continue to monitor you.
- You may feel sleepy from any pre-medications that may have been given.

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+. We check your blood regularly to watch for this change.

Step 5: Waiting for Blood Count Recovery

“Days 1 – 14” or later

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

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

What will happen while I’m waiting for engraftment?

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

- **Tests:** You’ll have daily blood tests and other tests as needed (i.e. CT scans, chest x-rays, etc.) to monitor your progress and watch for infection.
- **Managing side effects from chemotherapy (and radiation):** Your team will support you with teaching and medications to help you manage any side effects you experience. 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 “*Supporting You through Treatment*” 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’re 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 treatment, how to take care of yourself and your Hickman® line is important as you look ahead to being discharged. Your health care team is here to support you and answer any questions you may have.

What possible chemotherapy side effects can I expect?

Different people react differently to the stem cell transplant process. Don't feel discouraged if you meet someone who has a different experience than you. Each side effect can vary from mild to severe. You may not get a severe case of any side effect.

Short-term chemotherapy side effects (The first 1-2 weeks):

- Fever, chills and infections (from low white blood cell count)
- Risk for 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 (do not feel like eating)
- Memory and concentration changes ("chemo brain")
- Diarrhea (frequent runny stool)
- Skin changes

Later side effects from chemotherapy (those that can last longer than 2 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)

Did you Know?

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

The booklet **"Supporting You through Treatment"** offers advice on managing any side effects you experience.

Step 6: Blood Count Recovery (“Engraftment”)

“Days 10 - 14” or later

The medical term for when your blood cells recover is called ‘engraftment’. Engraftment is when your donor’s stem cells begin to make new blood cells. Engraftment usually starts 10-14 days after your stem cell transplant day but can take longer.

What happens when my blood counts recover (engraftment)?

As your blood counts recover, you will notice the side effects and symptoms from the chemotherapy (and radiation) improve. You will still need to stay in hospital as we monitor and support you for any possible complications from your treatment. Complications can happen at any time, before or after engraftment.

What’s the difference between a side effect and a complication?

Side effects are generally short term symptoms that improve after a medicine or treatment has finished. Complications, also caused by medicine and treatments, tend to be more long lasting. They can be more difficult to treat and sometimes life threatening.

What possible complications can happen?

1. Infection
2. Graft Versus Host Disease (GVHD)
3. Organ and Other Complications in the Body
4. Graft Failure (Donors cells don’t engraft or stop working)

The following pages will outline these complications in more detail. We realize that a stem cell transplant is sometimes the only option for some patients, but it is important to know the potential risks.

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

- Some are more common than others.
- Some are more life threatening than others.
- Most can be treated with medicines.
- The severity of each complication can vary from mild to severe.

Transplant Complications

The following information is based on Toronto's Princess Margaret Hospital's "**Allogeneic Stem Cell Transplant Education Program**" website: <https://pmcancermanagement.ca/>

Although there are some minor differences in our programs, this interactive website is another helpful way to learn about your transplant, side effects and possible complications. Free access requires creating an account. See details on page 44.

Infection

What is it? An infection is the invasion and spread of harmful bacteria, viruses, fungi or parasites in your body. These germs can come from an external source (outside your body) or from germs that you may already be carrying in your body.

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 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. It could be compared to the immune system of a newborn 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, chills, cough, etc.) See more information on preventing infection in "*Supporting You through Treatment.*"

Graft versus Host Disease (GVHD)

What is it? GVHD happens when your new donor cells (the “graft”) attack your body’s cells (the “host”). There are 2 different types of graft versus host disease:

- **Acute GVHD** – Can affect your gut, liver and/or skin
- **Chronic GVHD** – Can affect any part of your body

How common is it? GVHD is very common. It can vary from mild to life threatening. Chronic GVHD can impact your quality of life and increase your risk of infections.

Why is GVHD Helpful? GVHD can be beneficial in mild to moderate cases. This is because of something called the “**graft-versus-leukemia**” (GVL) or “graft-versus-tumour” affect. GVL occurs when new donor cells attack any remaining diseased or cancerous cells in your body. Although this graft-versus-leukemia effect is a form of GVHD, it is helpful because it lowers the chance for your disease to return or “relapse” after the transplant.

What is the timeline? Acute GVHD usually starts in the first few weeks of transplant once your new cells have engrafted, and last up until day 100. Chronic GVHD is typically GVHD occurring any time after the first 100 days of transplant.

What causes it? GVHD occurs when your new donor cells think your own body’s cells are foreign, or don’t belong, and attack them.

What will my health care team do? We give you “anti-rejection” medications (i.e. cyclosporine, methotrexate, etc.) before and after your transplant to prevent GVHD. There are other medication options (i.e. steroids) to treat GVHD if it occurs.

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

Please see page 33 for more information on chronic GVHD.

Signs of Acute Graft Versus Host Disease:

- **Stomach or Gut:** mild to severe diarrhea, stomach cramping, nausea & vomiting
- **Skin:** a rash that looks like a sunburn on your hands, feet and face. The rash may spread to other parts of your body and may be accompanied by a fever.
- **Liver:** tenderness in upper right stomach, itchy skin, jaundice (skin and/or whites of your eyes turn yellow)

Organ and Other Complications in the Body

A stem cell transplant 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 chemotherapy, radiation and other necessary medications you received. Infection can also cause damage to your organs.

Heart: Severe heart problems are rare but mild heart problems can be common (i.e. blood pressure changes). Tell your health care team immediately if you have any heart symptoms (chest pain, fast heartbeat, dizziness, etc.)

Bladder: Mild kidney and bladder problems can be common, severe kidney problems are rare. Continue to drink fluids and stay hydrated after transplant and tell your health care team if you notice pain with urination or blood in your urine.

Lung: Lung complications can be caused by treatment but are usually related to an infection. Mild breathing problems can be common, such as temporarily needing a small amount of extra oxygen. Severe breathing problems are rare, such as needing a machine to breathe for you. Look after your lungs with deep breathing exercises, staying active through treatment and avoiding smoking, dust and mould.

Liver: “Sinusoidal Obstruction Syndrome” (SOS) happens when the blood vessels to and from your liver become blocked and prevent your liver from working properly. This is a rare but severe complication usually occurring in the first few weeks of transplant.

Bones: Bone density loss can be a common complication and increases your chances of eventually developing osteoporosis and/or breaking a bone. There are medications to prevent and treat this but good nutrition, regular weight bearing exercise (walking, jogging) and strength training are things you can do to prevent bone density loss.

Hormones: Reduced hormones levels, including the thyroid, pancreas and sex glands, can be a mild but common complication. You may need to take medications to balance these hormone changes.

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 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.

Step 7: Follow-up Visits in the Outpatient Clinic

Once you've been cleared for discharge from the hospital, you'll continue to be seen as an outpatient in the Leukemia/BMT Daycare Unit up until 100 days after transplant or longer. Your appointments will be every 1-3 days at first, then gradually less frequent.

Sometimes it may be necessary for you to be readmitted to hospital after being discharged. This is usually related to complications like GVHD and infection. This can feel like a big setback but don't feel discouraged, it can be relatively common.

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 Hickman[®] line.
- Your health care team to assess you and help you cope with symptoms.
- Close monitoring for fever, infection and other complications.
- IV fluids, blood and platelet transfusions as needed.
- Medications for treating symptoms as needed (i.e. antibiotics, anti-nausea, etc.)
- Arrangements for extra tests as needed.

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**, day or night, if you have a fever (38°C or higher).
- Take your medications. We will give you a list of medications and how to take them.
- If you feel like it, you can do many of your usual home activities like going for walks, reading, listening to music, and having healthy family and friends visit you.
- Your 24-hour caregiver can help you prepare your meals, keep track of how much you are drinking, assist with symptoms and support your recovery.
- Follow infection control guidelines (see "*Supporting you Through Treatment*").
- Write down any questions you may have and bring them to your next visit.

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 concerns to call us immediately about.

Step 8: Day 100 Tests

As you approach “day 100” (100 days after your transplant date), you will repeat many of the tests you had before your transplant. These tests are to check on your disease status and any possible side effects from treatment.

After your day 100 tests, your hematologist will meet with you to discuss the results and plan for the future. They will also discuss your re-vaccination schedule. At this point, you will usually be able to complete your Daycare visits and can return home if you are not from the Vancouver area. Your Hickman[®] line will be removed and you will receive a requisition for follow-up blood work that can be done in any local clinic.

Some patients may need to continue to receive treatment in our Daycare unit after day 100 for complications such as infection and GVHD.

After day 100, you'll also be referred to our “Long Term Survivorship Program” at VGH. Working with your hematologist, this program will continue to support you through any symptoms and long term side effects you experience after transplant.

How will my Central Venous Catheter (CVC) be removed?

Removing a CVC (i.e. Hickman[®] line) is a short, safe procedure done by a doctor in the Daycare unit. Rarely, it requires a small incision (cut) in your skin where your skin has grown around the plastic tube. Trifusion[®] lines are removed in a similar short, safe procedure in the Radiology department. Firm pressure and a small dressing is placed on the area after the line is removed. Please keep this dressing dry and in place for 48 hours after removal.

Will I need to be revaccinated?

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

What are 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 appear in a strip or band on one side of the body. Lesions are usually in groups of raised, red blisters that may look like clear pimples. They are usually quite sore and itchy and can the blisters can break and ooze fluid. This fluid is contagious to others. When the blisters are dried and form a scab, they are no longer contagious.

How can I prevent shingles?

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

When can I contact my donor?

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

In Canada, you must wait 1 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.

You may not want to connect with your donor after your transplant. Or, your donor may not want to connect. 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 patients can never have direct contact. If your donor is from one of these countries, you will never know their name or other personal details about them. But you might still be able to send anonymous emails, cards, letters, or a small gift.

Step 9: Managing at Home after Transplant

Generally, it can take roughly 12-24 months for you to return to a relatively normal lifestyle after transplant. 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.

How will I feel after Day 100?

Even after day 100 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, most commonly from chronic GVHD. Please see the following pages for more information on:

- Chronic GVHD
- Disease Relapse
- Coping emotionally through treatment
- Helping your family cope through your treatment
- Self-image and sexuality
- Returning to work

For more detailed descriptions on coping and complications after a transplant, talk to your health care team and/or refer to the following websites. They are from international programs but contain helpful information. **Differences do occur between programs.**

www.fredhutch.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/Transplant%20Patient%20Care%20Manual.pdf

www.anthonynolan.org/patients-and-families

www.anthonynolan.org/sites/default/files/Next_Steps_Digital.pdf

Chronic GVHD

Chronic GVHD is seen in about half of the patients who have an allogeneic (donor) transplant. It typically occurs any time after day 100 and happens when your new blood cells 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. In some cases, chronic GVHD can prevent you from returning to your job.

How can I manage it?

- **Call us to report any changes you notice after transplant**, as minor as they may seem. GVHD can worsen quickly if not treated.
- Take your immunosuppression medications exactly as instructed.
- Look after yourself. Stay active, eat a healthy diet, manage fatigue and prevent weight loss and stress.

How is it treated?

Treatment for GVHD can vary, depending on the symptom and severity. Some treatments involve taking oral pill medications or using creams. For more moderate to severe symptoms you may need to be an inpatient in hospital for IV medications.

In some cases, your doctor will refer you to a specialist who can better help you manage your symptoms (i.e. dentist, lung doctor, eye doctor, etc.). Another treatment option is called extracorporeal photophoresis (ECP). ECP involves coming to clinic every 2 weeks to have some of your blood removed and treated with light in a machine. These visits can last for 6-12 months.

This section on GVHD has been adapted from:

<https://www.anthonynolan.org/patients-and-families/recovery-body> (2019)

For more information on GVHD and how it can affect you, talk to your health care team and/or refer to this website.

Symptoms of Chronic GVHD Include:

Chronic GVHD is different for everyone, and **you will not experience all of the following symptoms**. Many people have very few symptoms of GVHD and are able to return to their work and relatively regular routine. Some people's experience with GVHD symptoms has a much greater effect on their everyday life. Our team will support you through these symptoms and will suggest coping strategies.

Skin:

Your skin can become dry, red, itchy, darker or lighter. This can affect your hands, feet, face or different areas of your body. This can affect your appearance, your ability to regulate your temperature and can lead to skin infections if the skin is broken.

Stomach/Bowels:

Gut GVHD can affect your esophagus (food pipe), stomach and bowels. You could have difficulties swallowing, nausea, diarrhea, indigestion, cramping and decreased appetite. Medications to treat these symptoms can help make you feel more comfortable.

Mouth:

GVHD may affect your mouth and can leave your mouth sore and dry. Good mouth hygiene and regular trips to the dentist help with mouth GVHD.

Eyes:

Your eyes may become dry, sore or "gritty". Even when they are dry, they may water a lot. Using eye drops, seeing the eye doctor and wearing sunglasses can help.

Lungs:

Your lungs may lose some of their flexibility and elasticity. This can cause you to become more easily short of breath, wheezy and more prone to coughs. Contact our team right away if you experience any of these symptoms.

Muscles and Joints:

Physiotherapy, keeping active and using creams can help with restricted movement, tightness, stiffness or pain in your joints and skin. These symptoms can make driving and climbing stairs more difficult.

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. More information on support groups is in *“Supporting You through Treatment”*
- 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 TV show or favorite 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 45.

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. Use water-based lubricants during sexual activity to increase comfort and reduce the risk of small tears that can sometimes happen.

Hormone changes after transplant may cause some women (who have not been through menopause) to have some of the symptoms of menopause. These can include hot flashes, vaginal dryness, loss of bone mass and less interest in having sex.

Men may have a lower testosterone level after chemotherapy. They may notice their sex drive is lower or have difficulty getting an erection.

Your doctor can help prescribe hormone replacement therapy or other medications that can help these symptoms.

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.
- The Look Good Feel Better program helps women manage the physical and emotional effects of cancer treatment. Call 1 800 914 5665 or www.lgfb.ca

Returning to Work

Returning to work is a common source of stress for people coping 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; and/or
- you may have troubling thoughts about family, relationship issues or financial concerns.

These side effects can affect your ability to focus and concentrate. It is not usually recommended that you try returning to work for at least 12 months after transplantation.

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.

Disease Relapse

Many patients are concerned about their cancer coming back (“relapse”) after transplant. 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 health care team and see page 40 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.
- **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 the *“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 a loved one and your health care team. We want to help.

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.

What is Advance Care Planning?

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

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

Why should I think about Advance Care Planning?

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

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

How do I start Advance Care Planning?

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

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

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



What Matters Most to Me

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

Wishes of: _____

Written by: _____

Date: _____

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

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

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

☐ Yes ☐ No

Some questions I have about my health condition include:

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

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

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



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

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

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

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

I have documented my wishes in an advance care planning document

- ☐ Representation Agreement
☐ Advance Directive
☐ Other: _____

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



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



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

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). Each antibody can bind only to one specific antigen and help destroy it.

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: Our program also performs transplants 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.

Bone Mineral Density Test: A bone density test is an x-rays that measured how much calcium and other bone minerals are packed into a segment of bone. It measures how easily your bones are able to break. This scan takes 10-30 minutes

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

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

Conditioning: Treatment with high dose chemotherapy and sometimes radiation to prepare a patient for stem cell transplant.

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.

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

Graft-versus-Leukemia (GVL): A beneficial effect where transplanted immune cells attack leftover leukemia or diseased cells.

HLA Typing: The process of identifying the genetic structure of circulating white blood cells. 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: An extreme 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.

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

Myeloablative: suppressing or weakening of the immune system

Neutrophils: A type of white blood cell that protects you from infections. They make up 40 to 60% of the white blood cells in our bodies, and 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 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.

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 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: 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.

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 to allow 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.

Allogeneic Transplant Resources

Disclaimer:

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.

Contact bmtpatienteducator@vch.ca to offer feedback on this booklet and to report any websites that are no longer working.

The following websites offer overviews on allogeneic stem cell transplant and recovery information:

- www.mskcc.org/cancer-care/patient-education/allogeneic-stem-cell-transplantation (American)
- www.fredhutch.org/en/treatment/long-term-follow-up/information-for-patients.html (American)
- www.anthonynolan.org/patients-and-families (United Kingdom)

A helpful resource is Toronto's Princess Margaret Hospital's "**Allogeneic Stem Cell Transplant Education Program**" website: <https://pmcancermanagement.ca>

Free access requires creating an account. **Relevant modules are:**

- Transplant Process
- Donor Match
- Complications and Side Effects
- Infections
- Hand Hygiene
- Financial Impacts (please note drug coverage policies differ between Ontario and British Columbia).

Please note there are differences in all stem cell transplant programs; this information does not replace advice given to you by your health care team.

Where Can I Get More Information?

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

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

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

Find these booklets, videos and more information at:

The Leukemia Bone Marrow Transplant Program of BC:

www.leukemiabmtprogram.org/

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

www.llscanada.org/

Click Patients & Caregivers → Free Information Booklets

BC Cancer: 1-800-663-3333

www.bccancer.bc.ca/

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

www.cancer.ca

Click Support and Services → Publications

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Please note that the information contained in this manual is not intended to replace the advice of your health care team. Use this as a reference and education guide. Consult your health care team if you have any questions or concerns. Author: Amy Healy 07/2019

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