



Allogeneic Stem Cell Transplant

Patient Education



The Ottawa
Hospital

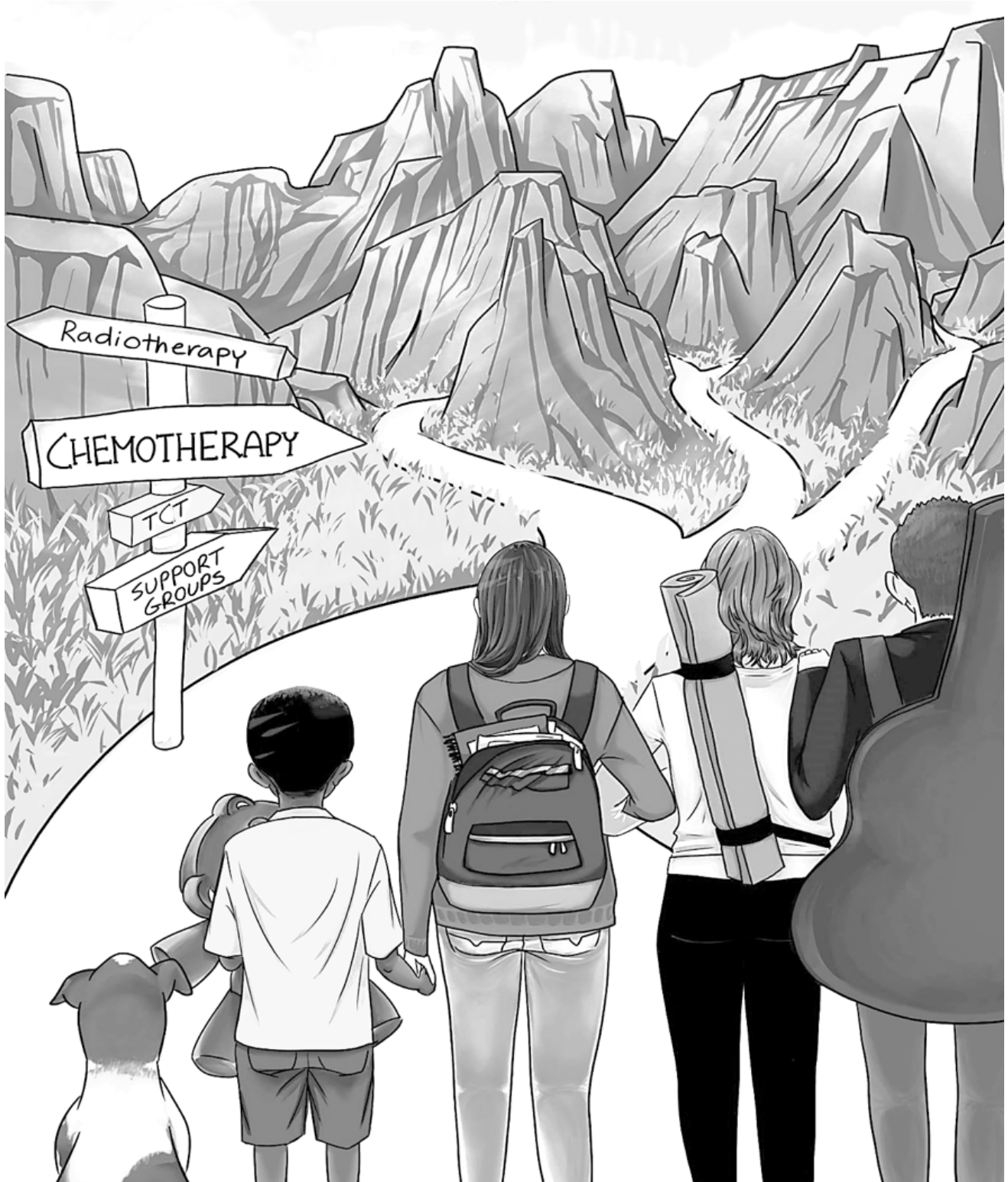
Disclaimer

This is general information developed by The Ottawa Hospital. It is not intended to replace the advice of a qualified health-care provider. Please consult your health-care provider who will be able to determine the appropriateness of the information for your specific situation.

P1342 ENGLISH (REV 05/2021)

Printed at The Ottawa Hospital

Artwork by Sandra Feng
Donated by Stefany Dupont



"Each day is a gift to be shared"

- Emily M., transplant recipient

"The world is an awesome place with endless opportunities, places to see, exciting activities to accomplish, people to meet. Being a marrow recipient has allowed me to carry on doing everything I love to do, and more."

- Trevor F., transplant recipient

Allogeneic Stem Cell Transplantation is a very specialized procedure which is only offered at a few centres in Ontario. The purpose of this booklet is to help prepare patients and families for the transplant journey. The following information provides a general introduction to allogeneic transplant.

Table of Contents

Mission Statement	1
Program Team Members	1
Introduction to Stem Cell Transplant	3
Definitions	3
Steps in the Transplant Process	4
Finding a Donor	5
Collecting Stem Cells	5
Preparing for your Transplant	7
The Transplant Process	11
Conditioning	11
Recovery and Engraftment	13
Areas of Care	13
Discharge from the Hospital	16
Effects of Chemotherapy on Blood Cells	20
Preventing Infection	22
Nausea and Vomiting	25
Mucositis	27
Diarrhea	28
Graft versus Host Disease	29
Potential Long-Term Complications	31
Fertility and Sexuality	33
What if my transplant doesn't work?	35
Appendix I: Information and Support Resources for Patient and Caregiver	36
Appendix II: Nutrition Guide	39

Mission Statement

The Ottawa Hospital Transplantation and Cellular Therapy (TCT) Program includes a team of compassionate professionals that are committed to working together to provide patients undergoing a transplant with the quality care and dignity they would want for their loved ones. This team focuses on the physical, informational, emotional, practical, psychological, social and spiritual needs of transplant patients and their caregivers. Through our research efforts and excellence in care we strive to provide transplant patients the best possible treatment options available.

Program Team Members

Throughout your treatment journey, you will meet many health-care providers. Our interdisciplinary team includes: Registered Nurses, Hematologists, a Nurse Practitioner, Clinical Associates, Clinical Pharmacists, Dieticians, Physiotherapists, Occupational Therapists and Social Workers. Based on your care needs, other specialists may be consulted.

TCT Nurse: Transplantation and Cellular Therapy (TCT) nurses are Registered Nurses (RNs) who organize and manage your care during all phases of your transplant. The TCT clinic nurse will provide you with information about your illness and the plans that will be made for your treatment. He or she will coordinate your care as needed when you are not admitted to the hospital and will communicate with the TCT team to ensure your health care needs are met.

When you are admitted to the hospital and/or during your active treatment and immediate recovery from transplant, the TCT ward nurses on 5W or the TCT Day Hospital are responsible to provide your daily care.

During your admission to Day Hospital: Call the TCT Day Hospital Unit at **613-737-8650** to speak with a TCT nurse Monday to Sunday 7:30am-5:00pm.

Post-Discharge: Call the TCT Office at **613-737-8227** to speak to a clerk or TCT nurse. Please leave a voice message and your call will be returned within one business day (24 hours on weekdays). Phones are answered Monday to Friday 8:00am-4:00pm.

Clinical Associate: This is a doctor who helps manage your care in the clinic and hospital with the Hematologist. You may also receive follow-up care in clinic by a **Nurse Practitioner**.

Social Worker: This is a specialist trained to counsel families on the social and emotional impacts of serious illnesses. You may request to meet with our Social Worker before, during or after your treatment. Your social worker can assist with financial concerns, adjustment counselling, case management, discharge planning, grief and loss as well as other concerns.

Clinical Pharmacist: This is a specialist who provides drug information and assists with monitoring and treatment. Patients will receive regular visits from a pharmacist over the course of their care. Pharmacists are an excellent resource should you have any questions regarding your medications.

Clinical Dietitian: This is a specialist who identifies nutrition problems, assesses your nutritional status, develops a nutrition plan adapted to your medical conditions and food habits, and monitors the effectiveness of dietary changes.

Physiotherapist: This is a specialist who diagnoses and manages physical conditions that may impact your ability to function at full capacity. The goals of physiotherapy are based on the individual. They may include strengthening, mobility, stair assessment, chest care, or help with planning for your discharge home. They can also recommend mobility aids.

Occupational Therapist: This is a specialist that assists you in returning to activities that may be of importance for a successful discharge home from the hospital. This may include encouraging your independence with personal care, recommending home equipment or modifications to ensure your safety, or helping you to find solutions to manage your household or leisure activities when your energy is limited.

Clinical Care Leader, Clinical Manager and Program Manager: These leaders collaborate with the team to oversee nursing care and the day-to-day operations of the inpatient and outpatient units. Their goal is to make sure that you receive excellent care.

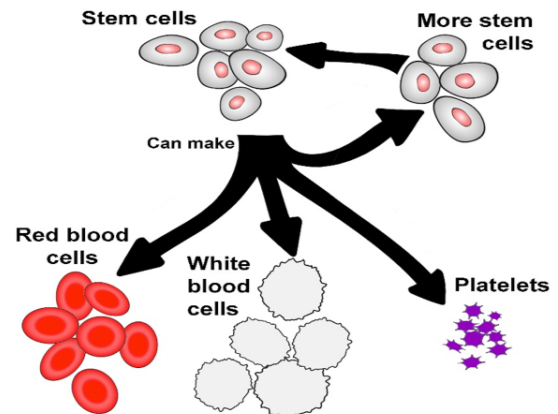
Introduction to Stem Cell Transplant

Definitions

This booklet is a guide to help you better understand the transplant process. Although the term "Bone Marrow Transplant" is widely used, it is more accurate to use the term "Hematopoietic Stem Cell Transplant" when talking about this process. The word hematopoietic means blood-forming. In other words, you will be receiving a transplant of blood-forming stem cells.

What is a Stem Cell?

Hematopoietic stem cells are immature cells that produce all the blood cells in your body. These stem cells are constantly dividing and changing into the different types of blood cells in order to replace old or damaged blood cells. While most stem cells exist in the bone marrow, a small number of stem cells are always circulating within the bloodstream.



What is Bone Marrow?

Bone marrow is the spongy tissue found inside most of the bones of the body where the different types of blood cells are made. In adults, the blood-producing marrow is largely limited to the central skeleton (ribs, spine, and pelvis). Blood cells have a limited lifespan – usually measured in days to weeks. They must constantly be replenished. The bone marrow is the place where this occurs. It is essentially a factory with three different production lines. Cells develop in the marrow and are released into the bloodstream when they are finished maturing.

The three main types of cells in the blood are:

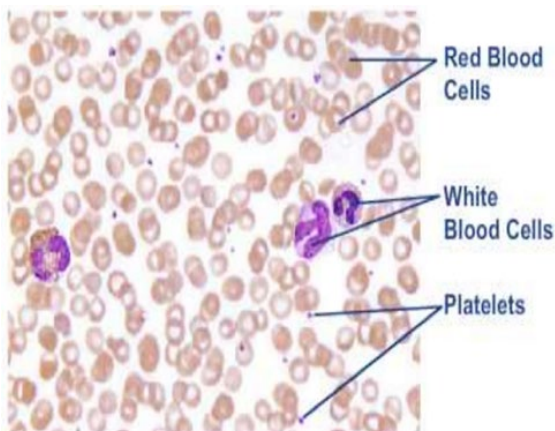


Photo courtesy of Dr. Ruth Padmore, Staff Hematopathologist, The Ottawa Hospital

Red Blood Cells (RBCs) carry oxygen to the tissues in your body.

White Blood Cells (WBCs) help fight infection. Their function is to protect your body against the germs that cause infection. Although there are several kinds of white cells, the most common are lymphocytes and neutrophils.

Platelets (PLTs) are the cells in our bodies that help with the clotting of blood.

Types of Stem Cell Transplantation

Your doctor will recommend the type of transplant based on your disease.

- **Autologous.** The stem cells come from your own body.
- **Allogeneic.** The stem cells are donated by a healthy person (the donor).

This booklet focuses on allogeneic transplants. Some diseases that may require an allogeneic transplant include:

- Acute Leukemia (Myeloid or Lymphoblastic)
- Chronic Leukemia
- Aplastic Anemia
- Myelodysplastic Syndrome
- Lymphoma

Steps in the Transplant Process

The decision to undergo a hematopoietic stem cell transplantation is a serious undertaking. A great deal of planning goes into developing a treatment plan just for you. The process starts with a consultation in the outpatient clinic (Module L) and continues through the path of finding a donor, receiving your transplant, recovery and follow-up. In total, the transplant process can take many months to a few years.

Consultation

At your stem cell transplant consult appointment you and a support person will meet with one of the transplant physicians where your case will be thoroughly reviewed. Blood work and a brief physical examination will be done. The principles of transplant, along with the possible risks and benefits will be discussed in detail.

Your doctors will consider several factors when deciding if you are a candidate for an allogeneic stem cell transplant:

- The likelihood that the disease will respond to the chemotherapy used to prepare your body for transplant (known as the conditioning regimen)
- The availability of a suitable donor
- Your overall health
- Your age and medical condition

The decision to proceed with transplant is sometimes difficult to make. Another appointment can be requested to discuss treatment options.

Planning Rounds

Every week the transplant team meets to review each case, discuss treatment strategies and, based on team recommendations, develop an individualized plan of care for you.

Once the decision is made that a transplant is best for you and you have decided that you wish to proceed, the team will start coordinating the process. Many team members collaborate to coordinate the numerous steps to ensure a safe and effective process.

Finding a Donor

When it has been decided that you require a transplant, the search for your donor begins. Your blood will be taken to test your DNA to determine your human leukocyte antigen (HLA) type, or tissue type. HLA genes code for HLA markers which are presented on the surface of the cells in your body. HLA markers play an important role in infection, immunity and engraftment. In fact, patient and donor HLA matching is most important factor used when choosing the best stem cell donor. If you have siblings who are in good health and willing to donate their stem cells, they will be approached to see if they are an HLA match to you. Their DNA may be tested from a cheek swab or blood sample. Full biological siblings (same parents) have about a 1 in 4 chance to be fully matched to each other.

If a brother or sister doesn't provide a match, the TCT team will search the Canadian Blood Services Stem Cell Registry for an unrelated donor that matches your tissue type. A donor who is not related to you but has a similar tissue type is called a matched unrelated donor (MUD). If there is no ideal match within Canada, the search will be extended to international registries.

Matched Related Donor (MRD): a sibling / relative with the same HLA as the recipient.

Matched Unrelated Donor (MUD): an unrelated donor with the same HLA as the recipient.

Haploidentical Donor (HAPLO): a parent, child, or sibling who is half HLA-matched to the recipient.

Collecting Stem Cells

Stem cells for transplantation can be collected from three sources:

- Blood
- Bone marrow
- Placental and umbilical cord blood

Before stem cells are collected from blood or bone marrow, the donor must undergo a thorough physical exam and blood testing for hepatitis viruses, human immunodeficiency virus (HIV), and other infectious diseases.

Blood

Peripheral blood is the most common source of stem cells for transplant. Peripheral blood is the blood that flows throughout our veins and arteries.

Bone marrow normally releases a small number of peripheral blood stem cells (PBSCs) into the bloodstream. To obtain enough PBSCs for a transplant, the donor takes a white cell growth factor, such as granulocyte-colony stimulating factor (G-CSF), which increases the number of stem cells by drawing them out of the marrow and into the bloodstream.

The blood is removed from the donor and the cells collected using a process called apheresis. This involves placing a needle in the donor's vein, usually in the arm like a blood test. The donor's blood is pumped through an apheresis machine, which separates the blood into four components: red cells, plasma, white cells and platelets. The white cells and platelets, which contain the stem cells, are collected, while the red cells and plasma are returned to the donor. It can take one to two sessions of apheresis ranging from 2 to 6 hours to collect enough blood stem cells for transplantation.

Bone Marrow

Depending on your disease, or the transplant centre or donor preference, bone marrow may be chosen as the best source for your stem cells. This requires the donor to undergo a minor outpatient surgical procedure.

While the donor is under anesthesia, the surgeon inserts a hollow needle into the donor's pelvic bone just below the waist and removes liquid marrow. This is done several times until several pints of marrow are collected. The donor can expect to stay in the hospital for 6 to 8 hours after the procedure to recover from the anesthesia and the pain at the needle insertion site. He or she may feel some lower back soreness for a few days afterward. The donor's body naturally replaces the marrow soon after the procedure.

The marrow that is removed (harvested) is passed through a series of filters and is transferred to a transfusion bag.

Placental and Umbilical Cord Blood

Cord blood provides an alternate source of stem cells for transplant. They are stored frozen and can be made quickly available when a patient needs an urgent transplant. Due to their small volume, cord blood is used more frequently for treatment in children. Cord blood can take much longer to engraft and require multiple units for an adult patient. For these reasons, cord blood transplants for adults are not done at our centre.

Preparing for your Transplant

Once we have found a donor and coordinated donation timing, the transplant can be scheduled. This can take 4 to 6 weeks based on donor and team availability. During this time, you will continue to be followed by your referring physician. The transplant team will continue to review and coordinate your plan at weekly meetings. It is important for you to contact the transplant team if you develop a cold or illness at this stage as they may need to delay the transplant until you are better. Because your immune system will not be working properly when you are undergoing transplant, any infection you have can become life-threatening.

Do I need to stay in hospital during the transplant?

Not necessarily. Years ago transplant patients were kept in special isolation rooms. It has since been learned that most infections come from organisms (bacteria, fungus or viruses) already on or inside the body and that isolation is not helpful in reducing these risks. In fact, it has been shown that patients do better overall if they can be at home as much as possible. They eat better, remain more active and report being generally more comfortable. Sleeping at home during your stem cell transplant, which we call an "outpatient transplant", has been shown to be very safe, if the rules listed below are followed:

1. You must stay within **60 minutes** of the hospital. Patients from outside the Ottawa region need to find local accommodations if they wish to be out of hospital during the transplant. The TCT program social worker may be able to provide some guidance.
2. Caregiver: During your transplant treatment, you will need at least one responsible adult caregiver to provide you with emotional and physical support. Your caregiver can be a family member or a friend. They must be available **24 hours** a day for numerous weeks (approximately 4 to 6 weeks and then be able to stay with you in the area for up to 100 days), but it does not need to be the same person the whole time. Your caregiver will be responsible for your transportation, emotional support, some physical care, medication management, information keeping, preparing food and maintaining a clean home. For more information on the caregiver role and supports refer to the Appendix I of this guide book.
3. You must be brought to the hospital every day for assessment and blood work. You cannot drive yourself to the hospital during transplant.
4. An inpatient bed can quickly be made available to you should your health condition change, requiring you to remain in hospital, (i.e. if you have trouble eating or develop an infection).

If you have your transplant as an outpatient, you will arrive to the TCT unit at a pre-scheduled time each day where you will have your bloodwork drawn and vitals done along with an assessment by the medical team. If you continue to do well during the transplant you may stay outside of the hospital the entire time. You will be given a list of numbers to call if issues arise while you are home, and you and your caregiver will be trained on which symptoms to watch out for. Patients who are not able to meet the above criteria will be cared for as inpatients.

Things to arrange before your transplant

As you are preparing for your transplant there are a few things patients should organize ahead of time to alleviate stress or added worries throughout the process. The TCT social worker is available to patients to assist with these concerns.

- Finance: You should not expect to work during and after transplant (up to a year or longer). If you are currently working, you will need to discuss taking a leave of absence with your employer (if not self-employed) and arrange for a means of compensations such as EI, disability, and employer benefits if applicable. Your caregiver will also be unable to work for some time in order to be available to you 24 hours a day. He/she should also make arrangements for leave of absence with his/her employer or business, if applicable.
- Pets: If you are having your transplant as an inpatient and you are the only one in your household able to care for your pet(s), arrangements should be made with a friend or a kennel to look after them during this period. Be aware that we cannot give you definite discharge dates, and the period you are away from your pets could become lengthy. If you are completing your transplant as an outpatient, you may have lengthy treatment days or require an inpatient stay at some point. Arrangements should be readily available if needed at a moment's notice.
- Accommodations/housing: The TCT social worker can help you find a place to stay if you are relocating to Ottawa for your transplant. Again, definite discharge dates cannot be given, and predicted lengths of stay are an estimate only. Ensure that the terms of your short-term accommodation can be flexible if needed. If you are having your transplant as an inpatient, arrangements should be made to have a family member or friend collect your mail and check on your house.
- Advance care planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself. It means having discussions with family and friends, especially your Substitute Decision Maker – the person who will speak for you if you cannot speak for yourself. It may also include writing down your wishes and talking with healthcare providers and financial or legal professionals. Visit <http://www.advancecareplanning.ca/> for more information.

Family Doctor: It is recommended that your family doctor be aware of your transplant plan. They will be involved in on-going management of any present chronic conditions and will eventually be part of your long-term follow-up care.

Dental Health: Inform the team of any dental health concerns or dental work requirements prior to transplant. Some dental work may need to be completed prior to your clearance for transplant, while other dental work may need to be delayed until after you have recovered from the transplant.

Fertility: In preparation for your body to receive the new stem cells / marrow you will need to receive high-dose chemotherapy and possibly radiation which may affect your ability to conceive. If you are concerned with the impact of treatment on your fertility, please discuss immediately with your doctor. Be sure to notify the transplant team if you are exploring or wish to explore fertility preservation options. For more information refer to the Fertility and Sexuality section of this guide book (page 33).

Central Vascular Access Device (CVAD)

All patients undergoing a hematopoietic stem cell transplant will require a central venous access device (**CVAD**), also known as a central line.

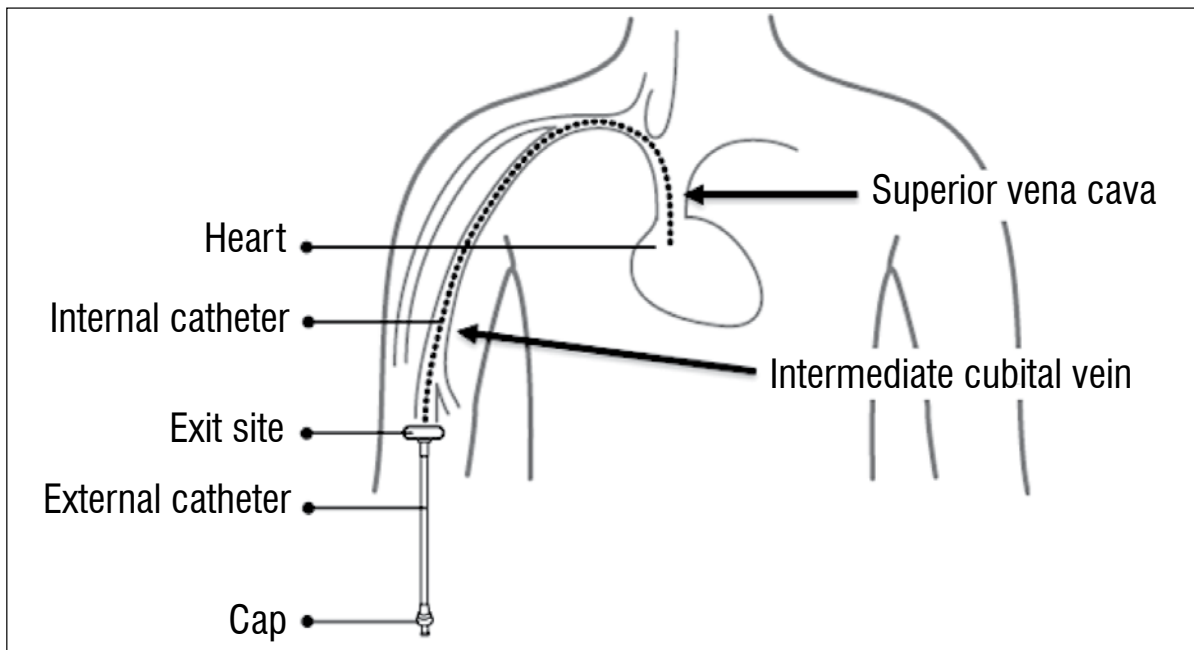
The CVAD is a small, hollow, flexible tube that is inserted into a large vein in your body. This may be either a Peripherally Inserted Central Catheter (**PICC**) or a tunneled Hickman line which can stay in place for several weeks. The line is usually inserted a few days before starting your treatments. During your transplant, it may be used to take blood, as well as to give medications, chemotherapy, blood transfusions and your stem cells.

The **CVAD** will have a transparent dressing cover that will be changed weekly by your nurse. The line must not get wet. The nurse will instruct you how to cover the line for showering.

From the start of your transplant protocol up to your discharge, the CVAD may be used for obtaining blood specimens. Once you have recovered and are attending follow-up appointments in the TCT clinic (Module L) it will not be used for blood work as per practice guidelines.

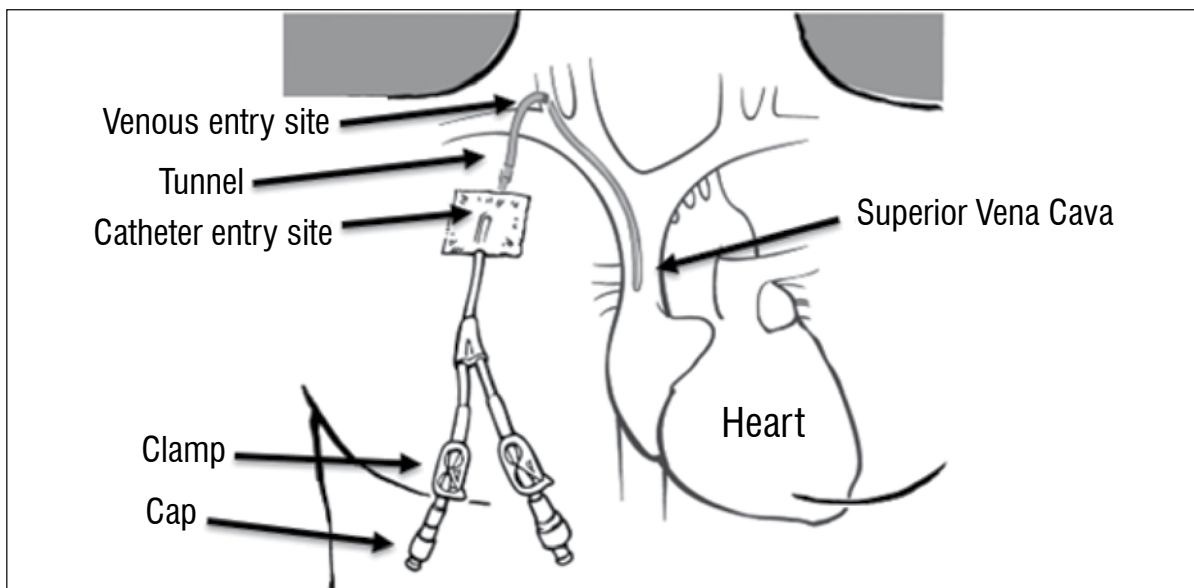
Peripherally Inserted Central Catheter (PICC)

This catheter is inserted through a vein in the upper arm and guided/threaded to a large vein in the chest.



Tunneled Cuffed Catheter (i.e., Hickman line)

This catheter is inserted into a large vein in the chest, then pulled through the skin for approximately 10 to 15 cm and then the end of the tube exits in the upper chest.



The Transplant Process

	Description	Time Period
Phase 1: Conditioning	<ul style="list-style-type: none"> Receive chemo +/- radiation therapy to kill remaining cancer cells and make room for donor cells, as well as suppress the immune system 	Conditioning days- countdown to Day 0 (transplant day)
Phase 2: Transplant Day to Engraftment	<ul style="list-style-type: none"> you will feel the side effects of your conditioning treatment your RBC, WBC & PLT counts will be low, therefore you may need transfusions your risk of developing an infection will be high 	Day 0 to engraftment (blood count recovery) Usually between day +10 and day +30
Phase 3: Engraftment to Day of Discharge	<ul style="list-style-type: none"> your blood counts recover and gradually increase you will begin healing 	Blood count recovery until discharge
Phase 4: Early convalescence	<ul style="list-style-type: none"> your blood counts are recovering but your immune system is still not functioning properly you are still at risk for infection and must remain on certain medications in order to prevent infections you will continue to be closely monitored by the transplant team 	Discharge up to 1 year after transplant (or longer)
Phase 5: Late convalescence	<ul style="list-style-type: none"> your immune system will be almost fully recovered and you may be able to return to normal activities there is still a chance of late complications (i.e., organ dysfunction, or recurrence of original disease) you will begin to receive vaccinations you may have had as a child 	1 year after transplant onward

Adapted from chart published by Memorial Sloan Kettering Cancer Centre: <https://www.mskcc.org/>

Conditioning

Before you undergo stem cell transplantation, you'll need pre-treatment, also called **conditioning** treatment. You will be given high-dose chemotherapy and may also receive radiation therapy to:

- Decrease the risk that your immune cells will reject the donor's transplanted cells.
- Eliminate any disease that might remain at the time of the transplant.
- Eliminate the disordered lymphocytes (white cells) that are attacking your developing blood cells.

The transplant team may decide to use a **myeloablative conditioning regimen**, meaning treatment that will kill your cancer as well as all the stem cells already in your body prior to transplant. The donor stem cells will then replace the ones killed by treatment. This treatment is very intense and not suitable for everyone. Alternatively, the team may decide that a **nonmyeloablative** or **reduced-intensity conditioning (RIC) regimen** is best for you. These methods are less intense and use lower doses of chemotherapy compared to the myeloablative regimens. The goal is to suppress the immune system enough to allow the donor cells to take over and produce a new immune system. Many factors such as disease, prior treatments received, and overall health will determine the conditioning used for your treatment.

Total Body Irradiation

Total body irradiation (TBI) may be used as part of the preparation for your transplant procedure.

What is Total Body Irradiation (TBI)?

Radiation therapy is the use of x-rays to kill cells. TBI is radiation given to the entire body. The purpose of TBI is to kill cancer cells and to suppress the immune system before transplantation. Making your immune system weaker is needed to stop your body from attacking the transplanted cells. The TBI is usually delivered twice a day for **1-4 days** but can also be given as a single treatment.

It is very important to be ON TIME for your TBI treatments. Arriving late will affect your other treatments. If you are going to be late, please call the Radiation Department at 613-737-7700 ext. 70901.

For more information on TBI, refer to the booklet provided by your Radiation therapist.

The Transplant - Cell Infusion Day 0

Each transplant protocol has a specified time frame in which donor stem cells can be given after the conditioning. Receiving the stem cell product is typically uneventful. The donor stem cells will be infused to you through your CVAD line much like a blood transfusion. The infusion time depends on the size of the bag but usually takes between one to two hours. There is a slight risk you will react to the infusion with chills or fevers, and that will be managed by the team if needed. If your donor has a different blood group than you, the transplant team will provide you with a pre-medication (i.e., antihistamine). In some cases (i.e., issues of donor availability or pre-transplant complications), the donated cells may need to be collected and stored in a frozen state (cryopreserved) ahead of time, then thawed when you are ready for transplant.

Recovery and Engraftment

Over the next few days you will start to feel the effects of the conditioning treatment. You may be tired, experience nausea, diarrhea, and mucositis (sore mouth). More information on the effects of chemotherapy can be found starting on page 20 of this guide book.

Engraftment Is the process in which transplanted donor stem cells migrate to your marrow and start producing new blood cells of all types. It usually takes about 2 – 4 weeks for this to occur. During your recovery, the team will monitor your blood counts daily. Engraftment is first evident when new white cells, red cells and platelets begin to appear in your blood following transplantation. Until engraftment, you may need to receive blood products including red blood cells or platelets.

Until your blood and immune system fully recover you will be at an increased risk of infection. It will be important to monitor your temperature, report and take medication to prevent infection.

Areas of Care

Where is my care delivered in the hospital?

All your care will be provided at The Ottawa Hospital General Campus. The following is a list of areas in the hospital where your care will be delivered:

Module L Outpatient Clinic

Module L is an ambulatory care clinic located on the second floor of the Ottawa Hospital General Campus. Module L offers various visit types that meet your needs before your transplant and after your discharge from the inpatient unit or Day Hospital. You can reach Module L by phone at 613-737-8131.

MyChart™: Copies of blood results will not be faxed or emailed. To access your TOH test results electronically via myChart™, you can register through the TOH admitting department or Module L in person, or online at <https://www.mychart.ca/>. Otherwise, you can contact the TOH Health Records Department at 613-737-8800. In order to discuss blood test and procedure results, you will need to book a clinic appointment, as our physicians do not discuss results over the phone.

Insurance Forms: A fee may be charged for each insurance form completed by the hematologist if this is not paid for by your insurance company. It may take up to a month to complete the insurance form and it will be mailed directly to the insurance company. Please make sure that you have completed and signed the authorization section.

The Transplantation and Cellular Therapy Day Hospital Program

This unit is located on the 5th floor of the Ottawa Hospital General Campus, just inside the doors to the 5 West unit. The program provides you care while you undergo the transplant phase of your treatment as an outpatient. Patients can remain in the Day Hospital program if they:

- live within one-hour travel time to hospital
- have a full-time caregiver
- are tolerating treatment side effects well

Daily visits are required. The Day Hospital is open from 07:30 a.m. to 7:30 p.m. every day. The timing of appointments is dictated by your treatment scheduled for that day.

Please arrive on time. There is no waiting room for this unit, and it is important to ensure that your medications are given on schedule. There may also be other patients scheduled after you who require the space. You should plan to be at the hospital for a minimum of two hours each day.

The nurse will do an overall assessment and document any concerns. Treatment such as chemotherapy, antibiotics, blood product transfusions and hydration are given as needed.

Medications are reviewed. You must bring all your pills and your medication schedule (provided on admission) to each visit. The hospital supplies all the medications that are prescribed during the transplant. A weekly supply is dispensed on **Thursdays**. In between, medications can be given out as needed.

You will be seen by a member of our medical team at each visit. Blood work results will be reviewed. Your medical concerns and questions will be addressed. Once required treatments are completed an appointment time for the following day will be given to you. If your condition changes during the day prior to 5pm, contact the TCT Day Hospital at **613-737-8650**. If after 5pm, contact the **Hematologist at 613-739-6962** and they will determine if you need to come into the hospital inpatient unit.

Benefits to the Day Hospital Program include:

- Decreased risk for infection
- Routine for eating and sleeping
- Maintaining physical normalcy as much as possible

Meals are not provided by the hospital to patients in the Day Hospital program. There is an on-site cafeteria, Second Cup (near the elevators) and Tim Hortons (near the Eye Institute/Critical Care Wing). More information, including maps and hospital menus, is available on the Ottawa Hospital website (<https://www.ottawahospital.on.ca/en/patients-visitors/>). Food can also be brought in from home. Patient rooms are equipped with small refrigerators, and staff can microwave items for patients upon request.

5 West - Inpatient Unit

5 West is an inpatient unit located on the 5th floor of the Ottawa Hospital General Campus that specializes in the care of transplant patients. Patients are admitted to the inpatient unit for a variety of reasons. Some people start treatment as inpatients for medical or caregiver reasons. However, most patients remain in the Day Hospital program as much as possible.

Many patients who start their transplant in the Day Hospital program get admitted to the inpatient unit because of fever, or difficulties eating and drinking. Sometimes, the inpatient stay is only a couple of days, but it can be much longer if you experience complications. It is common to remain in hospital until blood counts have recovered.

In order to help pass the time, each room is equipped with a television. On the 5 West unit, cable is provided at no cost to the patient. Patients are encouraged to bring in their laptop and/or tablet. Wi-Fi is available at no charge to patients.

Visitation Policies for Inpatient Units

The Ottawa Hospital has unrestricted visitation 24 hours a day in most areas and encourages family presence. However, in order to protect transplant patients who have weakened immune systems, the hematology inpatient units maintain strict visitation policies as described below:

- No one will be permitted to enter the unit with any infectious conditions. This includes but is not limited to the following symptoms: cough, cold, fever, flu-like symptoms, vomiting or diarrhea, and conjunctivitis (pink eye).
- On 5 West, all visitors are required to **use the phone outside the entrance** of the unit in order to gain access with each visit.
- Purell (alcohol-based hand sanitizer) will be used by visitors prior to entering the unit and again prior to entering the patient room. It must also be used by all visitors prior to exiting the room and prior to leaving the unit.
- Visitors are to remain in your room and must comply with all procedures outlined in this document.
- You may only have two visitors at a time, including your caregiver, between the hours of **3:00 p.m. and 8:00 p.m.**
- Children under the age of 12 years are not permitted to visit on the unit.
- Special compassionate exceptions for visitation can be made for a short pre-determined length of time. Please ask your nurse or social worker about requesting a compassionate visitation.
- You are advised against leaving the unit unless deemed medically necessary (i.e., tests, leave of absence home) for your own protection.
- If you do leave the unit, you **MUST** wear a mask at all times to protect against infection. Ask your nurse for a mask. The mask will only protect you as long as it is dry, and it must cover both your mouth and your nose.
- A mask is to be worn anytime you are out of your room.
- The unit kitchen is **only** accessible by hospital staff. If you need something, please ask your nurse or orderly to get it for you.

A **primary caregiver** must be identified by you upon your admission to the unit. Please provide this name to your nurse upon your arrival. Your identified caregiver (usually your spouse, parent, etc.) will be listed on the front of your chart so that all staff can identify them for admittance to the unit **at any time** during your stay. Alternate caregiver arrangements will have to be made if your identified caregiver has any of the infectious symptoms listed above. Please speak to your nurse if you need to change your caregiver due to illness. **Please note that during a time when there is increased infection on the unit or in the community, the visitor policy may be made even more restrictive.**

Other precautions:

- Flowers, potted plants and fresh fruit are **NOT** allowed on the unit.
- The use of humidifiers is prohibited.
- All electrical appliances brought in from home must be cleared by the management team.
- Security may be alerted for non-compliance. Abusive verbal or physical behavior will not be tolerated at any time.

Discharge from the Hospital

Your discharge from the hospital will depend on your blood counts and your general condition. It is important that your bone marrow is working well enough to guard against infections and control bleeding. It is equally as important that you are able to take your medications by mouth, eat and drink well, and carry on with your activities of daily living. The team will continue to monitor your recovery in Module L.

Outpatient guidelines

1. Prescriptions will be provided when you are discharged. It is very important that you take your medications as directed.
2. Keep records of what you are eating and drinking.
3. Weigh yourself each day and keep a record.
4. Before you come to the clinic, check your supply of medications and tell the physician what you need so that prescriptions can be written during your visit.

Central Line Care

The PICC/ Hickman line usually remains in place for 100 days post transplant in case it is required for medication or transfusions. Arrangements will be made with Module L or Homecare for the weekly dressing changes and flushes to be done.

Signs and Symptoms to Report

**TCT Day Hospital (During Transplant): 7:30 a.m. – 5:00 p.m., Mon to Sun.
613-737-8650**

**TCT office (After Discharge): 8:00 a.m. – 4:00 p.m., Mon to Fri (excluding holidays).
613-737-8227**

Hematologist on-call 24hr (outside of office hours): 613-739-6962

1. Increased temperature (fever of 38 degrees or higher for longer than 1 hour) or chills.
2. Breathing problems such as shortness of breath, wheezing, coughing or painful breathing.
3. Strong pain in your mouth, white patches or red/swollen areas in your mouth, trouble swallowing or a choking feeling.
4. Severe nausea that lasts more than 24 hours or if you are weak, dizzy, confused.
5. You are not able to keep any water, food or pills in your stomach.
6. Changes in the appearance of your central line (redness, swelling, pain, discharge).
7. New liquid diarrhea or no bowel movement for longer than 5 days.
8. Painful and/or frequent urination or if you have little or very dark pee.
9. Unexplained bruising and bleeding (nosebleed longer than 1 hour, blood in the urine or stool, vomiting blood / brownish).
10. Worse or new onset of pain.
11. Changes in skin colour such as yellowing, pinpoint purple-red dots, painful blisters or any changes in skin texture.
12. New dizziness, light-headedness or feeling faint.
13. Changes in your vision or eye discomfort such as itchiness, dryness and light sensitivity.
14. Cough or cold lasting longer than 1 week.
15. New swelling in an arm or leg.
16. Loss of appetite or weight loss.
17. Any other major changes in the way you feel.

How to tell if you have a fever?

- You have a fever if your temperature taken by mouth (oral temperature) is 38.0°C (or 100.4°F) at any time.
- Keep a digital thermometer at home and take your temperature if you feel hot or unwell (for example, chills).

- Do not take any medications for your fever, for example, acetaminophen (Tylenol), or ibuprofen (Advil®), as they may hide a fever. You can keep taking other pain medications such as morphine or gabapentin as prescribed by your doctor as they do not affect your temperature.
- Do not eat or drink anything hot or cold right before taking your temperature.

If you have a **fever greater than 38° C** you must contact The Transplant Team immediately using the phone numbers provided earlier in this guide. You will need to come to the hospital for an assessment and intravenous antibiotics.

Family physician

It is very important to keep in contact with your family physician. You should continue with annual physical exams as certain exams will not take place at the TCT Clinic.

Dental care

It is important to follow-up with your dentist, but not necessary to see them until about six months after your transplant. Inform the TCT program team before your first visit to the dentist, as antibiotics may be necessary prior to any treatment.

Sun exposure

As your skin may be more sensitive to the sun it is important to wear protective/reflective clothing (hat and sunglasses) and apply 30 SPF sunscreen.

Returning to work

A reasonable amount of time for recovery post therapy is anywhere from six months to a year; however, each individual case is different. If you require extended leave beyond a year, ensure your doctor has the necessary disability forms to sign.

Cancer-related fatigue is the most common cancer symptom. It can range from mild to severe and may come and go over time. It is a feeling of tiredness that can last a long time and does not go away with rest or sleep. It is different than any fatigue you may have felt before you had cancer.

Some companies have programs that can help you return to work gradually by letting you work part-time to ease you back into the job, change your work times so you do not have to commute during rush hour, reduce your work responsibilities, make changes to how you work, where you work or the type of work you do. Make sure to discuss these possibilities with your employer if applicable.

Some things you can do to manage fatigue:

- Be active
- Improve your sleep
- Manage stress and emotions
- Find support
- Pace yourself
- Eat well
- Be patient – feeling better will take time

Visit www.cancer.ca/support or www.cancercare.on.ca/symptoms for more information.

Medical Alert Bracelet

ALL allogenic blood or marrow transplant patients must obtain a Medical Alert bracelet. It needs to indicate:

Stem Cell Transplant Recipient

Date: _____

Irradiated blood products ONLY

In case of emergency call: 613-737-8146

Irradiated Blood Products

Your chemotherapy and stem cell transplant put you at an increased risk to acquire a rare but potentially life-threatening complication of transfusion known as transfusion-associated graft versus host disease. To prevent this, some centres irradiate (treat with radiation) blood components for patients with impaired immune systems. The irradiation impairs the white cells in the product so that they cannot attack your cells.

Immunizations

Once you have had your stem cell transplant, your immune system has been reset, so the benefits of past immunizations you received are no longer present. This means you must receive all vaccines again to provide protection against diseases like measles and mumps. It is very important to follow the vaccine schedule made for you after your transplant. Your immunizations will be coordinated by the transplant program to be given in Module L, with consultation by the Infectious Disease program.

Driving

After your transplant, please consult with your transplant team to determine when it will be safe for you to resume driving. Most patients can start driving again a few weeks after being discharged from the hospital program, depending on their overall health, side effects and medications.

Effects of Chemotherapy on Blood Cells

One of the major side effects of conditioning (chemotherapy/ radiotherapy) is that it temporarily decreases the bone marrow's ability to make blood cells. As a result, you will have a temporary, severe decrease of your circulating blood cells. In order to monitor changes in your blood cell counts, a daily complete blood cell count (CBC) will be ordered by your physician.

Red blood cells

Hemoglobin is a protein in Red Blood Cells (RBCs) that carries oxygen to the tissues in your body. When your red blood cell count is low, your body tissues do not get enough oxygen to do their work. When you do not have enough red blood cells or hemoglobin in your blood, it is called anemia. We can determine if you have anemia by testing your hematocrit, or the percentage of RBCs in your blood by volume, as well by testing your hemoglobin level. A normal hemoglobin level is between 120 to 160 g/L.

If you are anemic, you may feel:

- tired and / or weak
- dizzy
- short of breath
- pounding in your head or ringing in your ears.

Be sure to report any of these symptoms to your nurse or doctor.

Until you start producing new RBCs, an RBC transfusion may be necessary to bring your hemoglobin up. The doctor will establish parameters when a transfusion is required.

You can help manage your fatigue by carefully planning your activities and balancing periods of rest and exercise. As your blood counts rise, your energy level will start to improve. This can take several weeks.

Platelets

A low blood platelet cell count is called thrombocytopenia. Platelets are the cells in our bodies that help with the clotting of blood. Therefore, when your platelet count is low you may bleed more easily and for a longer period. You may notice signs of bleeding such as:

- Nosebleeds
- Easy bruising
- Prolonged bleeding from a cut
- Bleeding from mouth, gums, lips
- Black or bloody stools
- Brown or red urine
- Petechiae (tiny pinpoint-sized, red or purplish spots on your skin)

Be sure to inform your nurse or doctor if you have any of these symptoms.

Use a soft toothbrush when brushing your teeth, and use an electric razor to shave.

Sometimes a platelet transfusion is necessary to stop the bleeding or to prevent bleeding.

A normal platelet count is between 125,000 to 400,000 $\times 10^9/L$.

White blood cells

White blood cells help fight infection. Their function is to protect your body against the germs that cause infection. Although there are several kinds of white cells, the most common are lymphocytes and neutrophils. Most infections occur in the mouth, throat, sinuses, lungs, anal area and skin. A central line may also become a source of infection.

Lymphocytes are the cells that mostly target viral infections.

Neutrophils are the cells that attack and destroy bacteria and are your main defence against infections. When your neutrophil count is low, you are at risk of getting an infection.

The following symptoms can be associated with a low white blood cell count:

- A sore throat
- Shaking or chills
- A cough
- Eye / ear discharge
- Sweating
- Nasal congestion
- Burning while urinating
- Redness / swelling

There is no treatment for low white blood cell counts. Infection prevention is crucial and could be life-saving when your white blood cells are low until your body's new immune system is formed.

Examination of your blood cells

Certain tests need to be done before, during and after your transplant in order check your disease status and guide your ongoing therapy. These include:

- Blood tests: A small amount of blood is taken from your arm with a needle. Blood is collected in tubes and sent to a lab.
- Bone marrow aspiration: A liquid sample of cells is taken from your marrow through a needle. The cells are then looked at under a microscope.
- Bone marrow biopsy: A very small amount of bone filled with marrow cells is removed through a needle. The cells are then looked at under a microscope.

Preventing Infection

After a stem cell transplant, especially in the first 6 weeks until engraftment (when the new stem cells start making white blood cells) you will be at increased risk of infection. You will be given a combination of antibiotics to minimize your risk of developing a bacterial, viral or fungal infection.

It may take up to a year for your new immune system to be working as well as it should, so it is important to continue taking antibiotics as prescribed and to always be on the lookout for signs of infection, like fever or cough.

There are a variety of medications that you will be given to prevent infection during your treatment. Any of the following agents may be prescribed:

1. Septra

Possible Uses: Prevent or treat bacterial infections.

Side Effects: Rash, nausea, vomiting, diarrhea, stomach upset, decreased blood counts, change in kidney or liver function. Signs of an allergy to this medication may include difficulty breathing or swelling of the face, throat or lips.

2. Acyclovir

Possible Uses: Prevent or treat viral infections (i.e., Herpes Simplex Virus, or Varicella Zoster Virus, commonly known as "chickenpox"). Most people have latent virus inside them from past infections which are not active because they are controlled by a healthy immune system. When you receive chemotherapy, your immune system becomes suppressed and these infections may reappear as a result. Again, adequate fluid intake is essential. You will take acyclovir three times a day throughout the treatment period if your blood tests show you have these viruses. You will receive this medication twice a day as preventative therapy if virus not presently detected in your blood.

Side Effects: Diarrhea, dizziness, rash, fatigue, change in kidney function, vein irritation, confusion, change in liver function.

3. Fluconazole

Possible Uses: Prevent or treat fungal infections.

Side Effects: Nausea, vomiting, diarrhea, rash, itching, headache, stomach upset / pain, loss of appetite, dark coloured urine, pale coloured bowel movements, fatigue, yellow skin or eyes, change in liver function.

It is important to report any potential side effects from any of these medications as soon as possible. Prevention of infection is critical during your recovery. Another type of medication may be prescribed.

Infection Prevention Measures

What to avoid:

1. Avoid large crowds. If you go to public places, try to go when the least number of people will be there.
2. Avoid close contact with anyone who has open sores or is feeling unwell. For example, friends or family members with flu-like symptoms, colds, cough, pneumonia or fever.
3. Avoid people with communicable illnesses such as chickenpox or measles.
4. Avoid raw or undercooked meats, chicken, fish or tofu (refer to Nutrition Guide in Appendix II of this guide book).
5. Avoid well water.
6. Avoid rectal suppositories or enemas.
7. Never share drinking glasses or cutlery.

8. You should **NOT** handle animal feces. Avoid cleaning litter boxes or birdcages.
9. Avoid using a razor. Use an electric shaver instead.
10. Avoid tearing or cutting the cuticles of your nails.
11. Do not swim until your Central Line has been removed and the insertion site is well healed.
12. No gardening.

What do to:

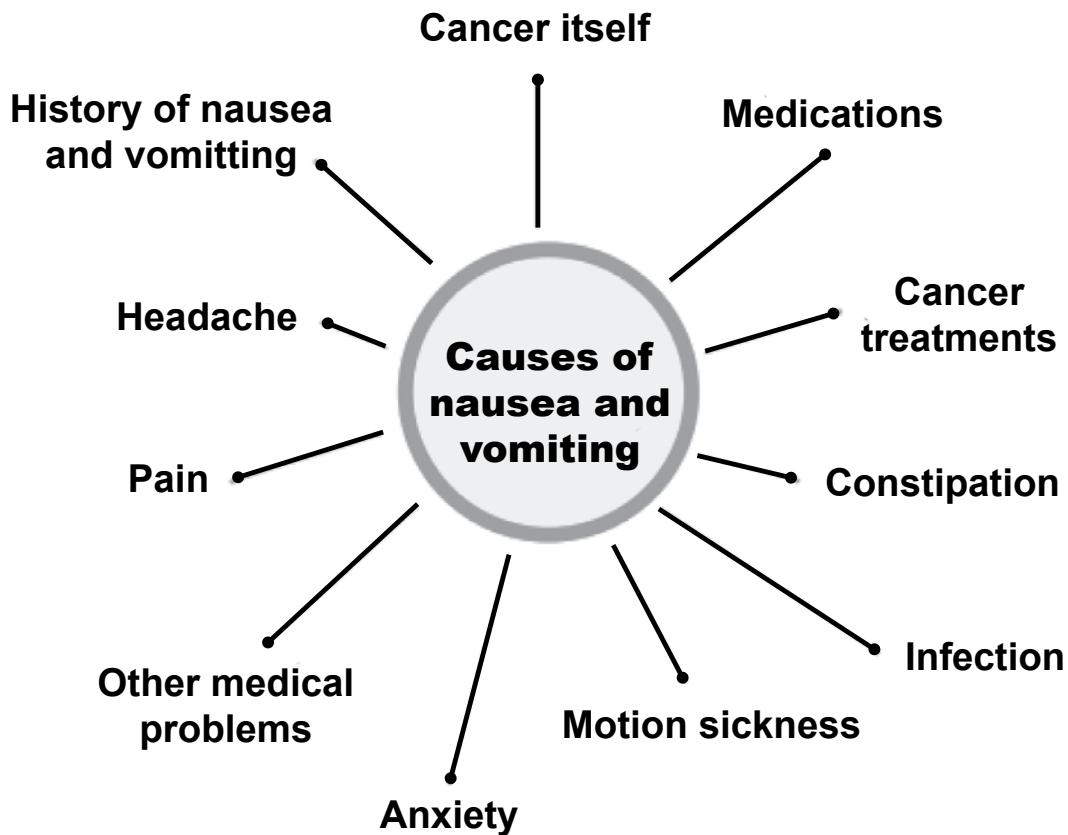
13. Wash your hands often, especially after using the washroom and before eating. Carry a small bottle of hand sanitizer with you.
14. Take your temperature daily (at least 4 times per day), even if you feel well, and especially if you feel warm, have chills or sweats.
15. Pay close attention to signs of infection, such as a new or worse cough or shortness of breath with or without fever.
16. Maintain good body hygiene by bathing or showering every day.
17. Women should use sanitary pads instead of tampons for menstruation and avoid douches.
18. Perform oral hygiene 3 to 4 times daily to help prevent mouth sores.
19. Wash any cuts or scrapes right away and do not squeeze or scratch pimples.
20. Avoid vaccinations unless approved by your Hematologist.
21. Avoid people who have been recently vaccinated with live vaccines (i.e., MMR vaccine), particularly infants 12-15 months old, for at least six weeks. Do not change the diapers of a child who has recently had the rotavirus vaccine.

Gastrointestinal Side Effects of Chemotherapy

Common gastrointestinal (GI) side effects include nausea and vomiting, mucositis, and diarrhea. While often not life threatening, these complications can cause discomfort and can seriously affect your quality of life.

Nausea and Vomiting

Some chemotherapy agents cause nausea – an unpleasant feeling in the back of your throat and stomach that can make you have more saliva, clammy skin, a fast heart rate or feel light-headed. Vomiting or “throwing-up” may or may not happen with nausea. There are many other things that can cause nausea and vomiting:



Cancer Care Ontario - How to Manage Your Nausea and Vomiting, 2016

The severity and duration of nausea and vomiting after chemotherapy depends on the drug(s) you receive and your personal risk factors. There are a variety of anti-nausea medications that you may be prescribed during and after your treatment. It is easier to prevent nausea with medications than it is to treat it once it starts. Some medications are taken at regular times to prevent or control nausea. Other medications may be taken as you need them, if you feel nauseous in between your regular medications. Most anti-nausea medications take 20 to 60 minutes to start working, so plan to take them ahead of meals.

To help control nausea and vomiting:

- Eat small frequent meals every 2 to 3 hours and take your time when eating. An empty stomach can make feelings of nausea stronger.
- Sip small amounts of liquids often throughout the day even if you do not feel thirsty. Aim for 6 to 8 cups per day (1.5 to 2 Litres).
- Drink liquids and eat foods separately; at least 30 minutes apart.
- Choose cold foods if the smell bothers you.
- Drink clear fluids, such as water, watered down juice or sports drinks, flat ginger ale, lemonade, broths. Cool liquids may be easier to drink than hot or cold liquids.
- Suck on ice chips, popsicles or frozen yogurt.
- Limit caffeine, including coffee and caffeinated soft drinks and avoid alcohol.
- Avoid fatty, fried or spicy foods as well as very sweet foods or foods with a strong odor.
- Eat whatever foods appeal to you.
- Try to choose food/drinks that are high in protein and calories.
- Rest after your meals and sit up for at least 30 to 60 minutes after eating.
- Rinse your mouth with bland rinse before eating to keep it clean and moist.
 - 1 teaspoon salt
 - 1 teaspoon baking soda
 - 4 cups water
- Brush your teeth 30 minutes after eating and before bed. This helps to get rid of tastes in your mouth that make you feel sick.
- If you vomit, stop eating and drinking for 30 to 60 minutes. Then start eating and drinking slowly in this order: 1) clear liquids; 2) dry starchy food (crackers, toast); 3) bland protein rich foods (chicken, fish, eggs); 4) dairy foods (yogurt, milk, cheese).
- If you vomit in between your regular anti-nausea medication doses, take your "as needed" medication.
- It may be helpful to take anti-nausea medication 30 minutes before meals.

It is very important that you do not become dehydrated and stop eating. If you are not able to keep your anti-nausea pills down, speak to your nurse or doctor about other ways to take them (like using dissolving tablets or injections). If you are not able to drink, you may need to get liquids through an intravenous (IV) to keep you hydrated.

Mucositis

Your mouth, throat and entire GI tract are protected by a lining of cells called a mucous membrane. Chemotherapy and / or radiotherapy can cause this lining to become inflamed and damaged. This condition called mucositis usually occurs a few days after treatment and lasts approximately one to two weeks. The first signs are usually a dry, irritated or burning feeling of the tongue and inside of the mouth. Good mouth care is important to decrease the pain and help prevent infections that often occur. Note: most patients will experience mucositis because of the high dose chemotherapy.

To help prevent or treat mucositis:

- Make sure that your mouth is healthy before you start treatment and go to the dentist if needed.
- Keep your teeth, gums and mouth as clean as you can while you are getting treatments.
- Rinse your mouth with your homemade mouth rinse every 1 to 2 hours if your mouth is dry or sore. Otherwise, repeat 4 to 5 times per day and right after eating meals or snacks.
- Do not use mouthwashes with alcohol, as they can dry out your mouth.
- Choose softer foods and chew food well to make swallowing easier. Try minced or blended foods if needed.
- Have room temperature food and drinks instead of hot or cold.
- Avoid hard or crunchy foods (raw fruits/vegetables, nuts), acidic or spicy foods. Avoid foods that are rough, dry or have sharp edges that might scratch.
- Moisten your food by adding olive oil, sauce, broth, sour cream, gravy or cream soup.
- Use an extra soft-bristled toothbrush. You can continue flossing if this was already part of your oral hygiene before starting treatment. Do not start flossing if you never have before. If your platelet count is low, you may need to stop flossing until your platelets return to a safe level, which you will need to verify with the team.
- Avoid cigarettes (smoking can make your mouth sores worse) and alcohol consumption.
- Keep your mouth and lips moist. If you suck on lozenges, make sure they are sugar free (sweeteners like Xylitol are okay). Use animal or plant-based lip balms with bees-wax, lanolin or cocoa butter (do not use petroleum-based lip balm).

Please advise your nurse or doctor if you have any symptoms of mucositis. Mouth rinses, antibiotics and pain medication may be ordered as needed, according to your signs and symptoms.

We recommend bland mouth rinses every 2 to 3 hours starting on the first day of your chemotherapy. This can be increased to every hour if your mucositis worsens.

If your mouth begins to get sore, we have a variety of rinses to help with pain and discomfort. For example, Lidocaine is a topical anesthetic that numbs the mouth and throat.

If pain is severe, narcotics (i.e. Fentanyl or Morphine) will be used to provide relief. They can be delivered in a variety of ways such as through a patch, by injection under the skin, intravenously or orally.

Some mouth pain can be due to oral infections and these will be diagnosed and treated with an appropriate medication.

Diarrhea

Diarrhea is a common side effect of high dose chemotherapy and is characterized by loose, watery stool that might look like many flakes or pieces. It usually happens more than 3 to 4 times a day. It can last for a few hours or become a problem that lasts a long time. Diarrhea may begin during or after chemotherapy. Diarrhea may also cause stomach cramps, bloating, restlessness or agitation, sore skin in the rectal area from going to the bathroom a lot, and dehydration (thirst, dry mouth or tongue, dark yellow pee or a need to pee less often).

Goals:

1. Prevent dehydration
2. Minimize or eliminate diarrhea
3. Treat infections associated with diarrhea
4. Prevent soreness around the rectum

It is important that you monitor the frequency and quantity of your bowel movements, especially if diarrhea occurs. Loss of large quantities of fluid can result in dehydration. Drinking more liquids will not stop your diarrhea, but it will help make up for the liquids you lose.

We will take a stool sample of diarrhea to look for infection. If bacteria or virus is found in your stool, you may be given an antimicrobial drug to help get rid of it.

Anti-diarrheal medications that help decrease the frequency of bowel movements and cramping may be ordered once it is confirmed that the diarrhea is not from an infection. These may include:

- **Loperamide** (Imodium)
- **Diphenoxylate / atropine** (Lomotil) - may cause drowsiness

Frequent diarrhea may cause your rectal area to become irritated, red and painful. It is important to keep your rectal area clean. Often a sitz bath (a warm basin of water that you sit in on the toilet) is the best way to clean and soothe your rectal area. Pat dry with a towel after soaking your rectal area. You can also use zinc oxide cream and Tucks® to protect from skin breakdown. Do not apply petroleum jelly (Vaseline®) to this area, as it may promote infection.

To help control diarrhea:

- Eat small meals and snacks frequently.
- Eat slowly, take small bites and chew food well.
- Drink at least 6 to 8 glasses of liquids each day.
- Drink liquids between meals instead of with them.
- Reduce foods high in soluble fibre (remove peels, seeds and membranes from all fruits and vegetables and avoid whole wheat grain products and legumes, nuts and seeds).
- Include foods high in soluble fibre (white rice, tapioca pudding, bananas, apple sauce, oatmeal).
- Eat foods that are high in potassium, like bananas, spinach, orange juice, and potatoes.
- If you have cramps, avoid foods that may cause gas, like soft drinks, cabbage, broccoli, spicy foods, excessive sweets and sugar-free chewing gum.
- Use lactose-free milk and milk products, as needed.
- Avoid stimulants such as caffeine, alcohol, and prune juice.
- Check with your team before taking probiotics or eating foods with probiotics.

Graft versus Host Disease

Graft versus host disease (GVHD) is a complication that may occur following an allogeneic stem cell transplant. GVHD develops when the donor's immune cells attack the patient's normal cells. The cells responsible for this function are called T-lymphocytes. There are two types of GVHD: acute and chronic. The severity depends on the differences in tissue type between patient and donor, and it may be worse in older patients.

Acute GVHD symptoms can occur 10 to 90 days post-transplant and affects approximately 1 in 3 transplant patients.

Signs and Symptoms:

- Rash, burning, and redness of the skin (initially on palms and soles)
- Nausea
- Vomiting
- Diarrhea (watery and sometimes bloody)
- Yellowing of skin and eyes (jaundice)
- Abdominal Pain
- Weight gain

Chronic GVHD symptoms can occur anytime post-transplant. You are more likely to get chronic GVHD if you have had acute GVHD already.

Signs and Symptoms:

- Rash, itching, scaly skin which peels
- Scarring of skin leading to contractures, mouth ulcers
- Drying of eyes, vagina, lung tissue
- Yellowing of skin and eyes (jaundice)
- Liver failure

It is important to report any symptoms to your health care team so they can monitor and treat this complication.

Preventing GVHD

A few days before your transplant you will start receiving medication to lower your risk of developing GVHD.

Tacrolimus

Side Effects: increased blood sugar, nausea, diarrhea, difficulty sleeping

OR

Cyclosporine

Side Effects: headache, diarrhea, heartburn, tingling hands and feet, difficulty sleeping

OR

Mycophenolate Mofetil (MMF) and Antithymocyte globulin (ATG)

Side Effects: fever, chills, increased heart rate or blood pressure, nausea, diarrhea

Post-Transplant

Methotrexate: low dose Day 1, 3, 6, 11

Side Effect: low risk for side effects related to the dose, but may include nausea, vomiting or headache.

You will continue to take tacrolimus or cyclosporine for a few months. The pharmacist will monitor the drug level in your blood.

The team will be monitoring you for symptoms of GVHD. If GVHD is suspected, a biopsy may be needed to confirm the diagnosis. You will receive medications and treatments to decrease the effects of GVHD.

Extracorporeal Photopheresis

If you develop chronic GVHD, your doctor may decide you could benefit from a treatment known as extracorporeal photopheresis, or ECP. In this procedure, some white blood cells are removed from your bloodstream via apheresis and treated with a chemical that sensitizes them to UV irradiation. Once irradiated, the now damaged cells are reinfused back into your bloodstream. Your body recognizes these cells as dysfunctional and destroys them. This process is thought to improve tolerance of the grafted cells by reducing the problematic lymphocyte cells and inflammatory molecules in your body that are causing your GVHD.

If you would like to know more about GVHD, refer to the **Leukemia and Lymphoma Society website** or **the Canadian Cancer Society website**.

Potential Long-Term Complications

Eyes

Dry Eye Disease (DED): Many patients will experience DED; a disorder where there is a lack of tearing or excessive evaporation. Symptoms can include redness, a dry, gritty, sandy feeling or irritation of the eyes, sensitivity to light, excessive tearing, discharge, blurring of vision and pain. You may wish to discuss the use of preservative-free ocular lubricants with your doctor. He/she can determine if additional treatment is needed.

Cataracts: Some patients will develop cataracts about a year or more after transplant. Cataracts cause cloudiness that occurs over the lens of the eye. This is more frequent in patients who have received total body radiation therapy before the transplant and in patients that have received prolonged high doses of steroids (such as Prednisone or Decadron for GVHD). Patients should see their eye specialist if they have any issues and have a yearly follow-up after their transplant.

Musculoskeletal

As a result of transplant conditioning (chemotherapy / TBI), steroid use, and immunosuppressant drugs (i.e., tacrolimus), you could be at an increased risk for loss of bone mass. The transplant team will arrange a bone density scan approximately a year after your transplant. Loss of bone density could put you at risk for fractures or avascular necrosis (death of bone tissue due to interruption of the blood supply). It is important to report bone pain to your doctor. Exercising and quitting smoking are a few things you can do to decrease your risk of bone loss. Discuss whether you would benefit from calcium, vitamin D and hormone supplements with your doctor.

Lung Issues

Transplant patients may be at increased risk of lung infections, especially if GVHD is present. To monitor your lung function, Pulmonary Function Tests (PFTs) will be arranged routinely. Please report any shortness of breath, cough and wheezing to your doctor. Some patients may develop restrictive lung disease that prevents the lungs from fully expanding with air. This restriction makes breathing difficult.

Iron Overload

As a result of receiving multiple blood product transfusions, you may be at risk of iron overload. Your iron (ferritin level) will be monitored routinely. If your ferritin level is elevated, your hematologist might recommend phlebotomy treatments which involves removal of a unit of blood periodically in order to reduce your iron levels.

Cancer Relapse

Unfortunately, in some cases, the transplant does not cure the disease and the cancer comes back. The risk of recurrence is typically highest in the first 6 months after your transplant and decreases as more time passes.

Secondary Cancer

Following transplant, you have a slightly higher chance of developing a second cancer. It is important for your family doctor to be aware of your transplant history and monitor you more closely.

Thyroid / Hormone function

Thyroid function and gonadal testing are recommended at one year and then annually with replacement if needed. Up to 25% of patients who receive total body irradiation will have some thyroid dysfunction.

Cognitive Effects

Some patients experience problems with memory, concentration or other cognitive functions after this intensive therapy program. Commonly referred to as "chemo brain" or "chemo fog", this impairment could be caused by chemotherapy, radiation, medications, fatigue, stress, anemia or nutritional deficiency among other things. This impairment is often temporary but can be long-lasting or permanent to varying degrees. Report to your doctor if you have cognitive issues which are affecting your ability to care for yourself.

Fertility and Sexuality

Fertility Preservation

It is important that you discuss fertility preservation options with your doctor/health team BEFORE starting chemotherapy. Some chemotherapy drugs can cause sterility in male and females and induce premature ovarian failure. For more information on fertility preservation, visit the website: <http://fertilefuture.ca/>.

Fertility Preservation Options for Women:

- Embryo Cryopreservation
- Egg Cryopreservation
- In Vitro Maturation
- Ovarian Tissue Cryopreservation

Fertility Preservation Options for Men:

- Sperm Banking

Practicing safe sex during treatment

The risks from high doses of chemotherapy and / or radiation to an unborn baby are significant. A pregnancy test will be required before starting your treatment protocol. If you are able to have children, a doctor and / or nurse from the TCT Program will discuss appropriate birth control options with you. You must be using an effective method of birth control.

It is also important for your sexual partner to be aware that chemotherapy can be present in body fluids; this includes both vaginal and seminal secretions. Your partner should wear a condom in addition to any other birth control methods being used.

Induced menopause

If you are a woman who has not yet reached menopause naturally, induced menopause is likely to occur as a result of the high dose chemotherapy (with or without radiation) that you will receive as part of your treatment.

What is menopause?

Menopause is a natural process that results when the ovaries stop working and when menstruation ends. Menopause is confirmed once a woman has not had a menstrual period for one year (12 consecutive months). The average age is approximately 51.

Women who enter menopause naturally will experience physical and emotional changes gradually over several years. These changes may include hot flashes, mood swings, sleep disturbances, loss of fertility, decreased libido, vaginal dryness, fatigue, and various aches and pains.

What is induced menopause?

The high dose chemotherapy you are going to receive, as part of your treatment, is known to cause permanent damage to the function of ovaries. This can occur at any age before natural menopause occurs. Women that experience induced menopause will begin to experience menopausal symptoms suddenly. Sometimes these symptoms can be severe. The most disturbing symptoms that are often reported are associated with hot flashes. Hot flashes can cause night sweats and sleep disturbances, which can lead to headaches, fatigue, anxiety and tension. It is important to recognize these signs and symptoms and discuss them with the medical team.

A woman has approximately 200,000 ovarian follicles when she first starts menstruating. The follicles are the functioning units of the ovaries and are a major source of estrogen in a women's body. Estrogen is associated with many functions like fertility, reproduction, bone growth and bone thickness, lipid levels, tissue thickness, moistness and elasticity. There are long-term risks related to decreased levels of estrogen. These risks include heart disease, thinning of the bones, bladder symptoms, sexual dysfunction, emotional upset, and infertility.

Is there a treatment for managing my symptoms?

Yes. There are several known treatments and therapies that are successful in treating menopausal symptoms. Lifestyle changes, natural remedies and pharmaceutical agents, both hormonal and non-hormonal, are available to help treat and ease symptoms associated with menopause. Some long-term management options include:

- Routine clinic visits with your health-care professional team
- Specialist consultation when necessary
- Life style changes including healthy diet, adequate exercise, and weight management
- Routine blood work and diagnostic tests (bone mineral density scans)
- Herbal remedies
- Prescription therapies

Speak to your nurse or doctor if you have any questions or concerns about how treatment may impact your sexuality at any point before, during or after your treatment.

What if my transplant doesn't work?

Not every transplant is a success. **Failed engraftment** is not common but can occur, whereby the donor cells fail to take over and produce blood cells in your body as expected. In this case, a second transplant may or may not be an option. There is also a chance that your disease will return. This is called a **relapse**. Your doctor will discuss next steps or other potential treatment options available to you if your transplant has failed.

It is normal to feel emotions such as anger, sadness, anxiety and fear when you hear that your transplant didn't work. Please know that it is not your fault. If you are having trouble coping with your emotions, the Psychosocial Oncology Program at the Ottawa Hospital can help: 613-737-7700 ext. 70516.

Appendix I: Information and Support Resources for Patient and Caregiver

Going through a transplant can be a frightening and overwhelming experience. It is important that you have access to accurate information and supportive resources during this time. For more information on community resources or counseling, please discuss with the TCT social worker.

Leukemia & Lymphoma Society of Canada

www.llscanada.org

Canadian Cancer Society (CCS)

<http://www.cancer.ca/en/?region=on>

Cancer Connections, Canadian Cancer Society

Call 1-888-939-3333 to register.

The Ottawa Hospital Patient Learning Links

www.ottawahospital.on.ca/cancer

Fondation québécoise du cancer

1-800-363-0063 (Monday to Friday 9 a.m. to 5 p.m.)

Support and Counselling:

- The Ottawa Hospital Cancer Centre (TOHCC) Psychosocial Oncology Program (PSOP). PSOP services are all OHIP funded. Self-referrals are accepted. 613-737-7700 ext. 70516.
- Ottawa Regional Cancer Foundation (ORCF) Maplesoft Centre. 1500 Alta Vista Dr., Ottawa, ON K1G 3Y9. Tel: 613-247-3527.

Other Electronic Media:

- If you have a smartphone or tablet, you may wish to download the Transplant (HCT) Guidelines by the National Marrow Donor Program® for free from the app store. It includes patient and caregiver checklists as well as screening recommendations, a GVHD symptom checker, and reminder tools.
- If you would like to learn more about the Canadian volunteer stem cell donor registry and the process of finding an unrelated stem cell donor, visit www.blood.ca/en/stem-cells/information-patients and download the OneMatch Patient Guide.

Coping...with loss of income and other financial issues

Whether you are living with cancer or acting as a caregiver to a person with cancer, your income can be affected through unexpected expenses or time away from work. This section discusses options patients and caregivers can explore to replace lost income and deal with costs related to medication.

Replacing lost income

When you are undergoing a transplant, you will not be able to work. The resulting loss of income can cause additional stress to an already stressful situation. Options you and your caregiver can explore to replace lost income are discussed below.

1. Taking leave from your place of employment

Talk to Human Resources personnel at your place of employment about your coverage for sick leave, vacation leave, and short or long-term disability.

2. Employment Insurance Sickness Benefit (E.I.)

This is a federal program accessed through Service Canada. Sickness benefits may be paid for up to 15 weeks to a person who is unable to work because of sickness, injury or quarantine. A medical certificate must be obtained to confirm the duration of your incapacity. Application forms are available online at: <https://www.canada.ca/en/services/benefits/ei.html>.

There are many other financial supports that may be available to you. The TCT social worker can assist you in applying to one or more of the following programs where eligible:

- Ontario Works
- Ontario Disability Support Program (ODSP)
- Trillium Drug Plan (TDP)
- Disability Tax Credit Certificate
- Employment Insurance
- Canada Pension Plan (CPP) Disability Benefits
- Quebec Pension Plan (QPP) Disability Benefit

Caregiver Role

While you are in the hospital, your caregiver will be responsible for:

- Telling the medical team about any changes in your condition
- Providing you with emotional support
- Advocating for your needs and helping with decision-making
- Communicating with family and friends

After you have been discharged from the hospital, your caregiver will assume additional duties including:

- Transporting you to the outpatient clinic daily or weekly
- Keeping track of your medical appointments
- Making sure you take your many medications according to the schedule
- Reporting changes in your condition to the medical team
- Monitoring you for signs of infection and other complications
- Encouraging you to eat

In addition, your caregiver will need to ensure your home environment is safe. This includes:

- Cooking and cleaning
- Protecting you from sources of infection, such as visitors with colds or those who have been around sick people
- Helping you move safely, if you need help

Additional Caregiver Resources:

- BMT Infonet: <https://www.bmtinfonet.org/transplant-article/role-family-caregiver>. This caregiver webpage has an excellent navigational video titled "What's involved in being a caregiver for a transplant patient".
- <https://www.ottawahospital.on.ca/en/clinical-services/deptpgrmcs/programs/cancer-program/what-we-offer-our-programs-and-services/patient-education-information-and-resources/>.

Appendix II: Nutrition Guide

It is very important to have a well-balanced diet during and after your treatment. The foods that you eat will help give you strength and energy. Patients who eat well are better able to cope with side effects of treatment.

Side effects from your chemotherapy can make it hard for you to eat well. The following guidelines to increase your energy and protein intake will help you meet your nutritional needs. We will also talk about precautions you should take to keep the level of bacteria in food to a minimum.

General Guidelines

- Make sure every mouthful counts!
- Choose high energy, high protein foods and drinks as part of every meal and snack.
- Eat several small meals and snacks during the day instead of three large meals. Aim to have a meal or a snack approximately every two hours. Have a few mouthfuls even if you do not feel hungry.
- Drink often. Choose liquids that have calories such as milk beverages, juices and soft drinks more often than water, tea or coffee. Drink fluids after your meals and snacks.
- Take nutritional supplements if you have difficulty eating and maintaining your weight. If you drink only these supplements, you may need to drink six or more per day to meet your nutritional needs. A variety of nutritional supplements will be offered to you at no cost during your hospital stay.
- Do not take vitamin and mineral pills or natural supplements without talking to the medical team as they can interact with your chemotherapy treatment.

Don't forget about fluids!

Drink at least eight to ten glasses of fluids daily (one glass = 250 mL or eight ounces). This will help your body get the fluid it needs and prevent dehydration. Juice, milk, milkshakes, yogurt beverages, oral nutritional supplements, ginger ale, Gatorade, broth, water, jello and popsicles are all good sources of fluid. Limit caffeinated products such as coffee, tea, cola products etc.

Tips to increase protein

Protein is a major building block of the body's cells and is an important part of your diet. Make a special effort to include high protein foods at each meal and at snack times.

• Skim milk powder

Add 1 cup of skim milk powder to 4 cups of homogenized milk to make fortified milk.

Use the fortified milk to prepare cream soups, milk puddings, hot cereal, sauces, pancake batter and milkshakes. Add skim milk powder to casseroles, meatloaf and baked goods.

- **Eggs**

Add finely chopped boiled eggs to casseroles, sauces and béchamel. Prepare entrees and desserts that contain eggs, such as omelettes, quiche, soufflés, rice pudding and angel food cake. Add extra eggs to recipes.

- **Cheese**

Add grated cheese to the following dishes: soups, sauces, hot vegetables, casseroles and egg dishes. Melt cheese on sandwiches, hot-dogs and hamburgers.

- **Cottage cheese**

Use to stuff crepes or noodles. Mix it with fruits.

- **Peanut butter**

Spread generously on toast, crackers, muffins or English muffins. Use in milkshakes or in baked goods such as muffins, cookies and bread. Mix it with ice cream or yogurt.

- **Meat, fish and poultry**

Add diced meat, chicken, shrimp, canned tuna or salmon to soups, omelettes, quiche, pasta and casseroles.

- **Legumes**

Add beans, peas and lentils to soups and casseroles.

- **Nuts**

Add to muffins, cookies and salads.

Tips to increase calories

- **Butter or margarine**

Use generously on hot items such as toast, pancakes, waffles, French toast, and vegetables. Stir into soups, mashed potatoes, rice and hot cereal.

- **Honey, jam, and jelly**

Spoon onto toast or crackers. Use on pancakes, waffles, French toast or muffins.

- **Table cream**

Add to hot beverages, milkshakes and milk beverages. Use half-milk half-cream in your recipes for pudding, cream soup and sauces.

Safe handling of food

Following your chemotherapy, you will be able to eat most of the foods you are presently eating; however, when your immune system is weak it is very important to be careful about what you eat and to handle, cook and store food in a safe manner.

- Wash your hands thoroughly with soapy warm water for at least 20 seconds before you prepare any food and before eating. A hand sanitizer can be used if soap and water are not available.
- Keep all working surfaces clean (counters, cutting boards). Use separate cutting boards for ready-to-eat foods and raw meat, poultry, fish and shellfish.
- Do not leave perishable food at room temperature for more than two hours (1 hour during summer outdoor activities). Discard leftovers after 48 hours.
- Always cook raw meat, poultry, fish, shellfish and eggs to a safe internal temperature. Refer to "Safe Internal Cooking Temperature Chart" from Health Canada.
- Keep hot foods at a temperature above 60°C and cold foods at a temperature below 4°C. Between 4°C and 60°C, bacteria can grow quickly and cause food poisoning.
- Only eat fresh fruits and vegetables that are easy to wash or peel. Avoid buying items that are bruised or damaged. Gently wash them under cool, running, drinkable water (even the ones you will peel). You do not have to use anything other than water to wash fruits and vegetables.
- At the grocery store, do not buy packages that are damaged or leaking.
- Do not buy food from self-serve containers (as in bulk food stores). Avoid testing free food samples.
- Wash the top of cans thoroughly before opening.
- Check the best before date on products before eating them.
- Replace dish cloths and dish towels daily. Avoid using sponges as they are hard to keep bacteria-free.
- Avoid restaurants. If you must eat out, choose a restaurant that has a good reputation for cleanliness. Eat early to avoid crowds. Stay away from salad bars, buffet meals and street vendors, delis and pot-luck meals.
- You cannot always tell if food is safe by its look, smell or taste. When in doubt, throw it out!

Items	Foods Allowed	Foods to Avoid
Fruits and Vegetables	<ul style="list-style-type: none"> • Raw fruits and vegetables that can be properly washed (wash well under cool running drinkable water) • Cooked or canned fruits and vegetables • Dried fruits • Pasteurized juice and frozen juice from concentrate 	<ul style="list-style-type: none"> • Unwashed raw fruits, vegetables and herbs • Raw fruits and vegetables that are difficult to wash (i.e., raspberries, blackberries, mushrooms) • Raw sprouts • Unpasteurized fruit and vegetable juice
Milk and Alternatives	<ul style="list-style-type: none"> • Pasteurized milk and milk products • All commercial yogurts without added probiotics • Pasteurized cheeses such as Cheddar, Ricotta, Swiss, Mozzarella, Gouda, cheese curds, cottage cheese • Pasteurized processed/ spreadable cheeses, such as cream cheese 	<ul style="list-style-type: none"> • Unpasteurized milk and milk products • Moldy blue-veined cheeses (Roquefort, Gorgonzola, Blue) • Unpasteurized and pasteurized soft cheeses such as Brie, Camembert and Feta • Unpasteurized and pasteurized semi-soft cheeses such as Havarti and Monterey Jack Cheeses from delicatessens
Meats and Alternatives	<ul style="list-style-type: none"> • Well cooked meat, poultry, fish or shellfish • Well cooked eggs (yolk should be firm) • Commercially packaged cold cuts heated through to steaming hot • Canned or shelf-stable pâtés • Cooked tofu • Roasted nuts • Commercial peanut butter or nut butter • Dried and salted deli meats such as salami and pepperoni • Hot dogs that are well cooked 	<ul style="list-style-type: none"> • Raw or undercooked meat, poultry, fish, shellfish or eggs • Cold smoked fish products • Cold cuts from deli counters • Refrigerated pâtés and meat spreads • Uncooked tofu • Raw nuts, roasted nuts in a shell • Non-dried deli meats such as bologna, roast beef and turkey breast • Hot dogs straight from the package

Items	Foods Allowed	Foods to Avoid
Others	<ul style="list-style-type: none"> • Tap water • Well water that has been boiled for at least 1 minute • Bottled water • All canned, bottled or powdered juices • Candies • Pasteurized honey 	<ul style="list-style-type: none"> • Well water (not boiled) • Fountain beverages • Salad dressings made with raw eggs • Natural herbal supplements • Unpasteurized honey • Cream and custard-containing desserts and pastries that are not refrigerated or frozen

SAFE INTERNAL COOKING TEMPERATURES CHART

MEAT, POULTRY, EGGS AND FISH	TEMPERATURE
Beef, veal and lamb (pieces and whole cuts)	
Medium-rare	63 °C (145 °F)
Medium	71 °C (160 °F)
Well-done	77 °C (170 °F)
Mechanically tenderized beef (solid cut)	
Beef and veal	63 °C (145 °F)
Steak (turn over at least twice during cooking)	63 °C (145 °F)
Pork (ham, pork loin and ribs)	
Pork (pieces and whole cuts)	71 °C (160 °F)
Ground meat and meat mixtures (burgers, sausages, meatballs, meatloaf and casseroles)	
Beef, veal, lamb and pork	71 °C (160 °F)
Poultry (chicken and turkey)	74 °C (165 °F)
Poultry (chicken, turkey and duck)	
Pieces	74 °C (165 °F)
Whole	82 °C (180 °F)
Eggs	
Egg dishes	74 °C (165 °F)
Seafood	
Fish	70 °C (158 °F)
Shellfish* (shrimp, lobster, crab, scallops, clams, mussels and oysters)	74 °C (165 °F)
Other foods	
Other foods (hot dogs, stuffing and leftovers)	74 °C (165 °F)

* Checking the temperature of shellfish with a food thermometer can be hard. Because of this, eat only the shellfish that have opened after being cooked. Discard the rest.

From "Safe Food Handling for Immuno-compromised Individuals", Health Canada, 2015



The Ottawa
Hospital

