



Autologous Stem Cell Transplant

Patient Education



Autologous Stem Cell Transplantation is a specialized procedure which is only available at a few centres in Ontario. The purpose of this booklet is to help prepare patients and families for their transplant journey at The Ottawa Hospital. The following information provides a general introduction to Autologous transplant.

Disclaimer

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

P1367 ENGLISH (05/2021)

Designed and printed by
The Ottawa Hospital Print Services department

Table of Contents

Mission Statement	1
Program Team Members	1
Introduction to Stem Cell Transplant	2
The Transplant Process	3
An Autologous Transplant Overview	5
Step 1: Consultation.....	5
Step 2: Mobilization	6
Step 3: Stem Cell Collection.....	7
Preparing for Your Transplant.....	8
Step 4: Conditioning	8
Step 5: Transplant Day	9
Step 6: Engraftment.....	9
Step 7: Recovery	10
Do I need to stay in hospital during the transplant?	10
The Transplantation and Cellular Therapy Day Hospital Unit	11
5 West - Inpatient Unit	12
Visitation Policy	13
Module L Outpatient Clinic	14
Central Vascular Access Device (CVAD)	15
Common Side Effects from High-Dose Chemotherapy	17
Effects of Chemotherapy on Blood Cells	17
Preventing Infection.....	18
Infection Prevention Measures	20
Gastrointestinal Side Effects of Chemotherapy	21
Diarrhea	23
Poor Appetite	24
Discharge from the Hospital	25

Signs and Symptoms to Report26

Managing your Health after Transplant27

Potential Long-Term Complications28

Fertility and Sexuality29

 Fertility Preservation29

 Practicing Safe Sex during Treatment30

 Induced Menopause.....30

Appendix I: Information and Support Resources for Patient and Caregiver32

 Coping...with loss of income and other financial issues.....33

 Caregiver Role33

Appendix II: Nutrition Guide35

Appendix III: Granulocyte Colony Stimulating Factor Self-Injection Information40

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 be looked after by many different 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 5 West or Day Hospital TCT nurses are responsible for your daily care needs.

Contact Information:

- **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.
- **For urgent issues** arising after business hours call the hematologist on call at **613-739-6962**.
- **For emergencies call 911** or go to your nearest emergency department.

Please notify your TCT nurse if you go to the Emergency Department or if you are admitted to the hospital.

Introduction to Stem Cell Transplant

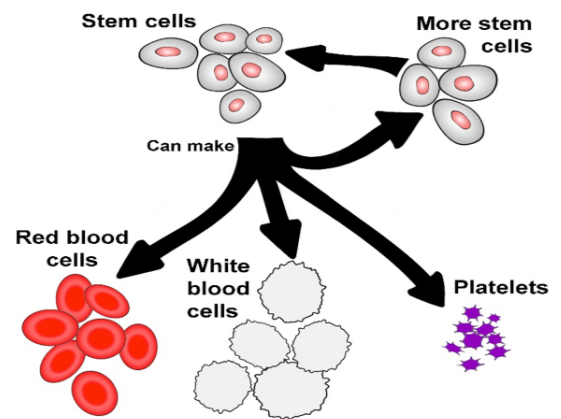
This booklet is a guide to help you better understand the transplant process. Although the term "Bone Marrow Transplant" is widely used, it is more accurate to use the term "Hematopoietic Stem Cell Transplant" when talking about this process. The word hematopoietic means blood-forming. In other words, 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 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 ranging from days to weeks. They must constantly be replenished. The bone marrow is the place where this occurs. It is essentially a factory with many 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:

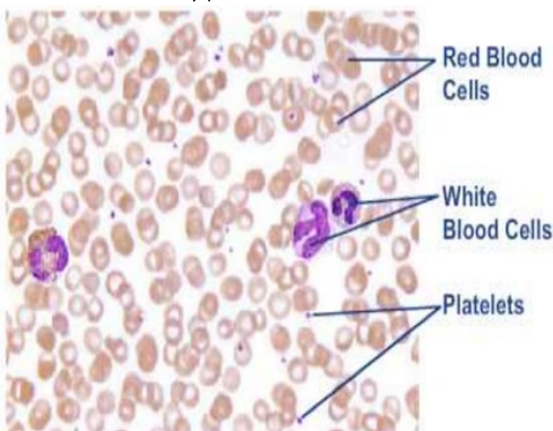


Photo courtesy of Dr. Ruth Padmore, Staff Hematopathologist, The Ottawa Hospital

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

White Blood Cells (WBC) 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 (PLT) 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 you will receive based on your disease.

There are two common types of stem cell transplants:

- **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 autologous transplants.

Some diseases that may require an autologous transplant include:

- Multiple Myeloma
- Lymphoma
- Germ Cell Tumour
- Autoimmune diseases (i.e. multiple sclerosis, scleroderma, stiff-person syndrome)

How Does an Autologous Transplant Work?

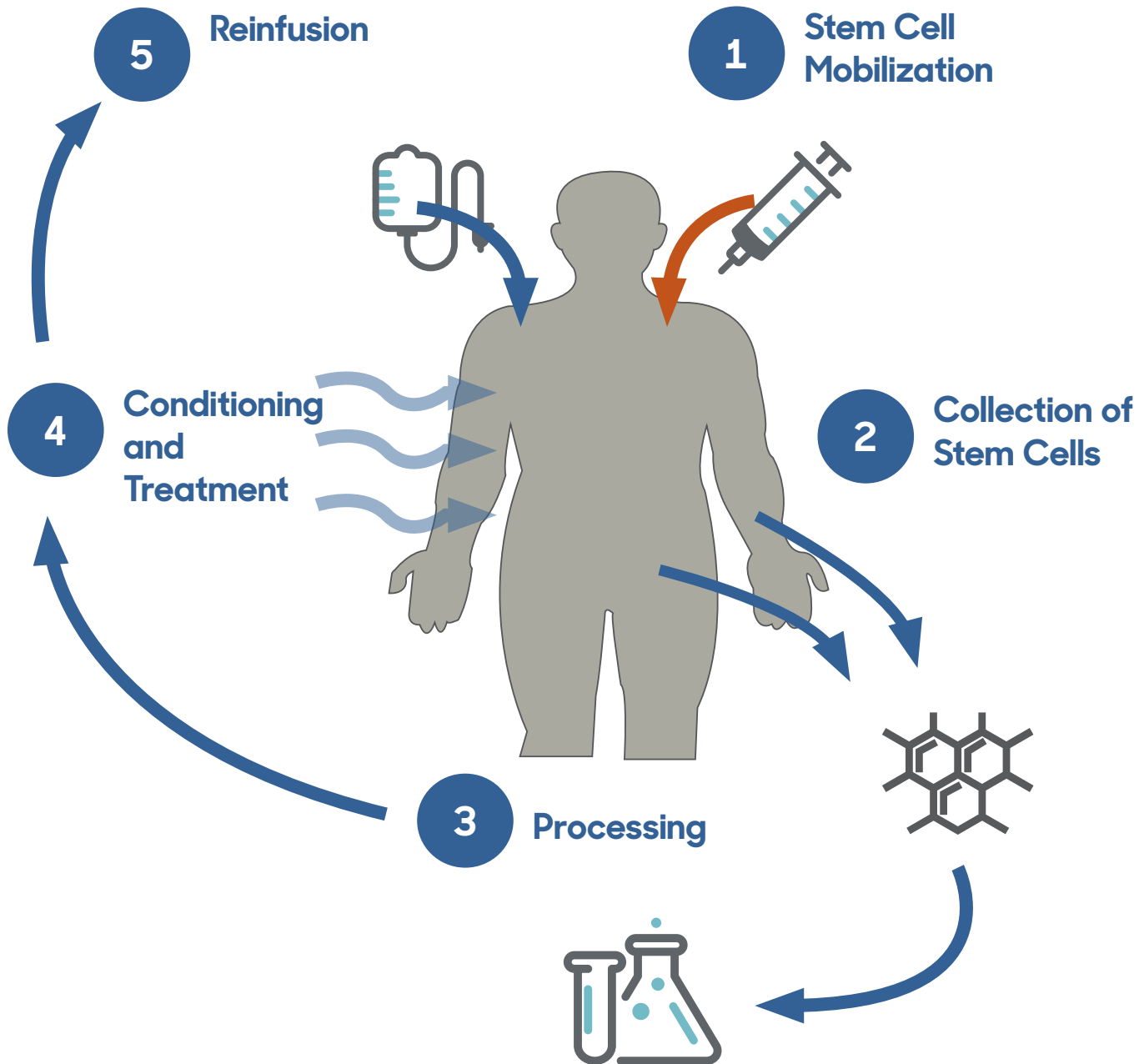
An autologous stem cell transplant involves (1) removing some of your blood stem cells, (2) freezing them, (3) receiving a high dose of chemotherapy with or without radiation, and then (4) re-infusing your stem cells which will replenish your marrow and create new blood cells.

The Transplant Process

The decision to undergo a hematopoietic stem cell transplant is a serious undertaking. A great deal of planning goes into developing a treatment plan that is just for you. The whole transplant process can take many months up to a year.



Autologous Stem Cell Transplantation



Adapted from: <https://www.lls.org/treatment/types-of-treatment/stem-cell-transplantation/autologous-stem-cell-transplantation>

An Autologous Transplant Overview

Step 1 Consultation	You will meet with the transplant team to decide together if a stem cell transplant is right for you. If you decide to proceed, the team will work to prepare your cell collection and transplant schedule. Another appointment will then be scheduled to review your medications and answer questions you may have about your collection and transplant plan.
Step 2 Mobilization	Mobilizing your stem cells involves receiving granulocyte colony stimulating factor (G-CSF) and possibly chemotherapy to help increase the amount of circulating stem cells in your blood.
Step 3 Stem Cell Collection	Stem cells are then collected by a process called apheresis. A special machine removes the stem cells and returns the other blood components back to your blood stream. Your stem cells are then preserved.
Step 4 Conditioning	High dose chemotherapy and possibly radiation is given to control or eliminate your disease and make space for reintroduction of your collected stem cells.
Step 5 Transplant	Your stem cells are infused back into your blood stream.
Step 6 Engraftment	Waiting for your bone marrow to start making new blood cells. This usually takes 10-21 days.
Step 7 Recovery	This stage takes 3-6 months. The effects of your therapy and transplant are monitored in follow-up clinic.

Step 1: Consultation

At your TCT 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. This consultation will take place in Module L (see page 14).

Your doctors will consider several factors when deciding if you are a candidate for an autologous stem cell transplant, such as:

- Your overall health
- Your age and medical condition
- The stage and aggressiveness of your disease



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

Step 2: Mobilization

Since stem cells are normally found in the bloodstream at very low levels, it is necessary to stimulate them to leave the bone marrow and enter the bloodstream where they can be collected for use in your transplant. This process is called mobilization. There are 2 main ways to stimulate your stem cells.

- **Granulocyte-Colony Stimulating Factor (G-CSF)**
- **Chemotherapy**

Granulocyte-Colony Stimulating Factor (G-CSF) is a growth factor for your white blood cells. You may also hear this medication called filgrastim, or by its trade names Neupogen® or Grastofil®. G-CSF is given as an injection into the subcutaneous (SC) tissue. You or your caregiver will be taught how to give this medication to yourself (**see instructions in Appendix III**).

You will give yourself the G-CSF injections once a day for the number of days specified by your doctor (usually 8). You will be given a copy of your "collection protocol" which will include the dates of your chemotherapy, if applicable, and the dates of your G-CSF injections leading up to your stem cell collection, known as day zero.

Chemotherapy may be given to prepare your body for the stem cell collection. It will treat your disease and will cause your blood counts to drop at first. When your body starts to recover, your bone marrow will start producing new blood cells. You will also receive the G-CSF. The combination of chemotherapy and G-CSF will help to maximize your body's stem cell production.

The day before your expected collection date you will have a blood test done that will indicate your CD34+ cell count. CD34 is a marker for stem cells and the test will reveal whether you have enough stem cells circulating in your blood to start the collection process. In the rare case where G-CSF alone does not increase your CD34+ cell count enough for collection, you will need to receive an additional injection (Plerixafor or Mozobil) which will be given at the hospital.

All these dates and instructions will be reviewed with you and detailed on your collection protocol which will be sent home with you. Once your CD34+ cell count is high enough we will know you have enough circulating stem cells and can begin the collection process.

Step 3: Stem Cell Collection

On your collection day you will go to the Apheresis unit at the General Campus. You will receive two Intravenous (IV) catheters, one in each arm. During your consultation your arm veins will be assessed. If the veins in your arms are not suitable you may need to have a temporary central line inserted. Most people will not require a central line for collection.

Your stem cells will be collected by specially trained nurses. They will use an apheresis machine which will be connected to the IVs in both of your arms. Your blood will exit through one IV and travel through the machine. A centrifuge inside the machine will spin your blood and separate out your stem cells. Your blood minus the stem cells will then be reinfused through the second IV, while the stem cells get diverted to a collection bag.

The length of this process varies based on the amount of stem cells. It can last anywhere from 3 to 8 hours. If the target amount of stem cells has not been collected by that time, you will need to come back in the next day.

We recommend you wear comfortable clothing and drink plenty of fluids the day before (limit caffeine). You will remain in bed for the procedure and have limited use of your arms due to the placement of the IVs. Free Wi-Fi is available. If you need to use the washroom you will need to use a bedpan or a urinal, so try to minimize fluids the morning of your collection. Most people tolerate the procedure very well.

One possible side effect is a lowering of calcium in your blood. You might experience shakes, numbness or muscle cramps. This can occur because the apheresis machine uses something called citrate to prevent the blood from clotting while being processed. Citrate binds to calcium which can lead to a decreased supply in your blood. To prevent this side effect, your nurse will give you a calcium replacement through the IV. You will be closely monitored throughout the procedure. If you do begin to feel symptoms of low calcium, your calcium replacement dose can be adjusted. In order to help limit this side effect, it is recommended you increase your calcium intake the night before and the morning of collection (unless lactose intolerant) with foods like yogurt, cheese, milk, sardines with bones, almonds, and/or leafy green vegetables.



The machine primarily removes only stem cells, but sometimes other blood components can be removed as well. For this reason, your blood counts such as your platelets and red blood cells will be monitored, and a transfusion can be arranged if needed.

Preparing for Your Transplant

Once your stem cells have been collected the team will develop a therapy plan and coordinate the timing and preparation for your transplant. During this time, you will continue to be followed by your referring physician. 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. If you do not live in Ottawa, you may return home at this time until it is time for the next step of the transplant. The time between your stem cell collection and stem cell transplant may be a few weeks to several months. This will be decided by the transplant doctors depending on your specific condition and disease. When it is time for your transplant you will have a second meeting in Module L to review the transplant details and ensure you are healthy enough to proceed.

Step 4: Conditioning

The conditioning component of your transplant occurs when you receive high dose chemotherapy and possibly radiation to destroy your disease and make room in your bone marrow for the new stem cells. Specifically, the amount of chemotherapy given to you will destroy your current stem cells to the point where they could not recover on their own. The collected stem cells act as an immune system "rescue", replenishing your body's stem cells after they have been destroyed by the chemotherapy.

Because of this, the side effects you will experience from the chemotherapy may be greater than those you have had in the past. Conditioning treatment side effects are discussed later in the booklet.

All the dates for your chemotherapy and/or radiation will be included in your "transplant protocol" which will countdown to the day that you will receive your stem cell transplant.

Chemotherapy

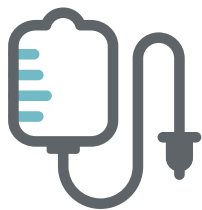
Your chemotherapy will follow a set schedule and be reviewed with you by the physician and pharmacist. It will be administered by a chemotherapy-trained nurse. The chemotherapy you will receive will vary depending on the disease that you have. It will be given intravenously through a central line. This central line will be placed before you start your transplant. See the central line section of this book for more information.

Total Body Irradiation

Total body irradiation (TBI) may be used as part of the preparation for your transplant. 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. For more information on TBI, refer to the booklet provided by your Radiation Therapist.

Step 5: Transplant Day

Transplant day is the day you have your stem cells re-infused, also referred to as **day zero**. It is an exciting day for many patients who have been anticipating this event for some time. The infusion of cells is similar to any other blood product infusion you may have had and is often uneventful.



You will likely receive your stem cell transplant at 1pm but it will depend on when your chemotherapy was finished. You will receive your transplant through your central line by a nurse who has received special training. The nurse will monitor your vital signs and overall well-being throughout the infusion. Your stem cells will arrive in a canister where they are kept cryopreserved (frozen). A technician from the blood bank will thaw the cells in a warm water bath. Each bag of stem cells will be infused in less than 30 minutes. Depending on how many days it took to collect your stem cells you will receive 1-6 bags of cells. If you are receiving more than 3 bags you may receive the additional bags the next morning instead of all at once.

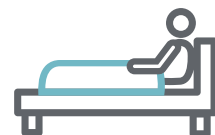
The stem cells you are receiving are preserved with a product known as dimethyl sulfoxide (DMSO). This product is tolerated well by most people. The most common side effect is a cough or tickle in the back of the throat. This occurs because the product is excreted through the lungs. Chewing gum or sucking on a hard candy will usually help. While you may not notice it, caregivers may notice a garlic or cream corn smell on your breath over the next couple of days. This is from the DMSO and will not last long. More serious reactions to DMSO are possible but uncommon. The nurse will remain with you throughout the process and the physician will always be close by should you have any reaction. The stem cells you are receiving are your own, so there is no risk of having an incompatibility reaction as you might experience with the transfusion of a donor blood product.

After your day zero, your transplant progress will be tracked by counting forward each day, (Day +1, +2, etc.).

Step 6: 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/or mucositis (sore mouth). More information on the effects of chemotherapy will be discussed later in this booklet.

Engraftment is the process in which transplanted stem cells migrate to your marrow and start producing new blood cells of all types. It usually takes about 2-3 weeks for this to occur. During your recovery, the team will monitor your blood counts daily. Engraftment is first evident when new white blood cells, red blood cells and platelets begin to appear in your blood following transplantation. Until engraftment, you may have to receive blood products including red blood cells and/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 and inform the team if you develop a fever. If you are an inpatient this will be done for you and if you are an outpatient a number will be provided to report any temperature greater than 38.0 degrees Celsius or other signs of infection. You will remain on medications to prevent infections. The team will monitor you closely during this time.

To speed up the engraftment process you may be given G-CSF injections again, starting on Day +7.

Step 7: Recovery

It generally takes between 3-6 months to recover fully after an autologous transplant. During this time, it is important to look after yourself and to try to focus on the things you can do to help yourself recover both physically and emotionally. You can gradually return to normal activities once your immune system has recovered.

Many patients have questions about how they will feel once they go home. There are some common side effects that last longer, such as:

- Feeling tired. This can last for several months.
- Appetite and taste changes. These changes usually last for 1-3 months.

You will have regular follow-up appointments with the health care team during your recovery from stem cell transplant. These appointments will take place in Module L at the General Campus. They will be weekly at first and will decrease in frequency as you improve.

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 your 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:

- 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 will be able to assist with your accommodation needs.
- Caregiver: During your transplant treatment you will need 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, 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 available supports refer to Appendix I of this booklet.

- You must be brought to the hospital every day. You cannot drive yourself to the hospital during transplant.
- You must have a thermometer at home to monitor your temperature.

If you proceed as an outpatient, an inpatient bed will 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 continue to do well during the transplant, you may stay as an outpatient the entire time. You will be given a list of numbers to call if issues arise while you are home. You and your caregiver will be trained on which symptoms to monitor.

Patients who are not able to meet the above criteria will be cared for as inpatients.

The Transplantation and Cellular Therapy Day Hospital Unit

This unit is located on the 5th floor of the Ottawa Hospital General Campus, just inside the doors to the 5 West unit. This unit provides you care while you undergo the transplant phase of your treatment as an outpatient.



Daily visits are required. The Day Hospital is open from 07:30-19:30 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 replenished as needed.

You will be seen by a member of our transplant 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.

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). Food can also be brought in from home, and staff can microwave items for patients or store food in a fridge upon request. More information, including directions and maps, is available on the Ottawa Hospital website <https://www.ottawahospital.on.ca/en/patients-visitors/>.

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 may get admitted to the inpatient unit because of fever or difficulties eating and drinking. Sometimes an inpatient stay lasts a couple of days, but it can be much longer if complications arise. If you are admitted to the inpatient unit, it is common to remain in hospital until your blood counts have recovered.

In order to help pass the time, each room is equipped with a television and cable is provided at no cost. Patients are encouraged to bring in their laptop and/or tablet. Free Wi-Fi is also available. Patient rooms are equipped with small refrigerators and there is a microwave that staff can use to heat up food for patients.

Recommended packing list for your hospital stay

- Soft toilet tissue
- Unscented baby wipes
- Unscented body lotion
- Soft toothbrush
- Soft snacks such as pudding, instant breakfast, apple sauce, yogurt, soups etc.
- Tablet/laptop (Wi-Fi available)
- Earphones and a music listening device
- Whatever you do at home that fills your time (hobbies, puzzles, etc.)
- Your own comforter, blanket and pillows (the hospital supplies bed linens and pillows but you can bring your own in for comfort)
- Walking shoes and outdoor clothing (coats, hat, etc.). We will encourage you to be active.
- Comfy clothes to wear during the day
- Clothes to sleep in
- Shower shoes

Hospital Daily Routine

- Your vitals (temperature, heart rate, blood pressure) will be monitored every 4 hours, day and night.
- Each morning around 5:00 – 6:00 a.m., your nurse will obtain your bloodwork from your central line. This is necessary so that any required infusions can be planned for the day.

- If you wake up or go to the washroom in the middle of the night, ring your call bell so the nurse can come check your vitals or do blood work while you are awake.
- The transplant team will come to assess you daily.

Visitation Policy

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 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).
- All visitors are required to **use the phone outside the entrance** of the unit in order to gain access with each visit.
- 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 have one primary visitor (caregiver) that can visit 24/7 and come and go as needed.
- You may have two visitors (including your caregiver) at a time between the hours of **15h00 to 20h00**.
- Children under the age of 12 years are not permitted to visit 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 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 your chart so that all staff can identify them for admittance to the unit.

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 be aware that visitation rules may change at any time without warning due to a unit outbreak, pandemic or other infection control concerns.

Other precautions:

- Flowers, potted plants and fresh fruit are **NOT** allowed on the unit.
- No latex balloons.
- The use of humidifiers and fans are 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.

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.

Things to Arrange Before Your Transplant



As you are preparing for your transplant there are a few things you 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 for 6 months to a year. 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 compensation 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 plan for a 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. 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. As you will be at increased risk of infection, you will not be allowed to handle pet excrement (i.e., cat litter).
- **Accommodation/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:** This 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 the ongoing 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.

Fertility: In preparation for your body to receive the stem cells 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 this 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 booklet (page 29).

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, in Module L, 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: Fees may apply for insurance forms 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.

Central Vascular Access Device (CVAD)

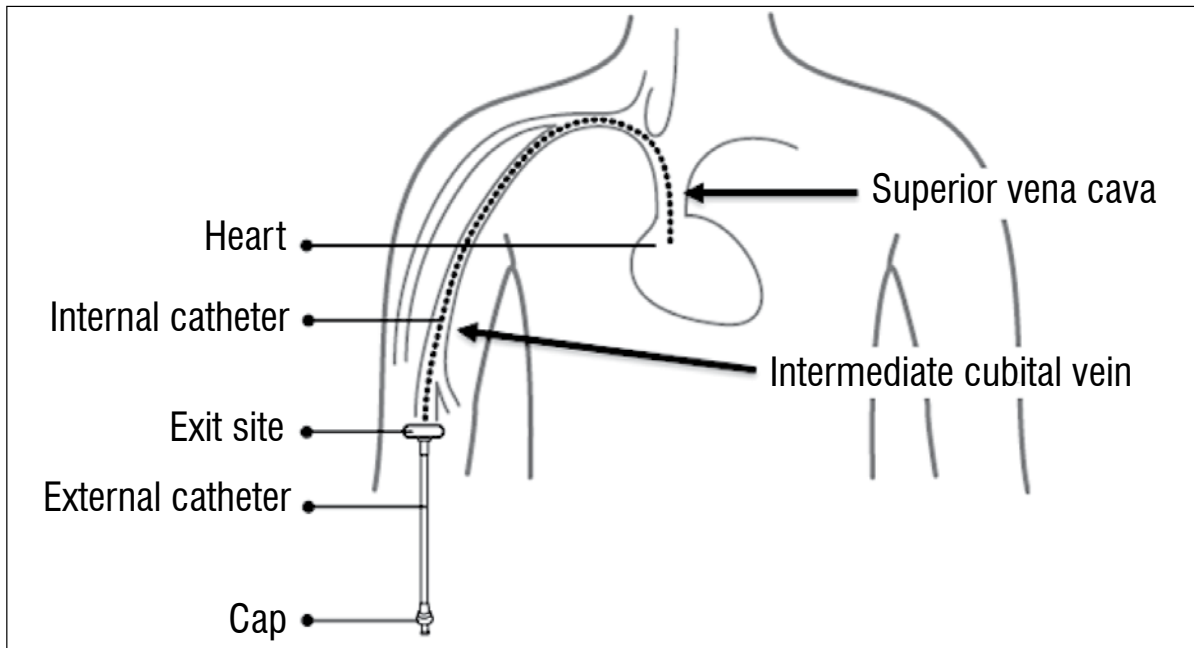
All patients undergoing a stem cell transplant will require a central venous access device (CVAD), also known as a central line. For an autologous transplant a peripherally inserted central catheter (PICC) is usually the type of CVAD inserted.

The line is usually inserted a few days before starting your conditioning treatment. This will be done as an outpatient procedure with a local anaesthetic. It will be inserted by a specially-trained nurse and its placement will be verified by an ultrasound and chest x-ray.

During your transplant it will be used to take blood, as well as to give medications, chemotherapy, blood transfusions and your stem cells.

Peripherally Inserted Central Catheter (PICC)

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



The PICC will have a transparent dressing covering 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 until your discharge, the PICC may be used for obtaining blood specimens. Once you have recovered and are attending follow-up appointments in the outpatient clinic (Module L) it will not be used for blood work as per practice guidelines. Based on your recovery the doctor will direct the nurses as to when your PICC can be removed.



Common Side Effects from High-Dose Chemotherapy

Effects of Chemotherapy on Blood Cells

One of the major side effects of **conditioning** (chemotherapy/ radiotherapy) is that it decreases the bone marrow's ability to make blood cells. As a result, you will have a temporary, severe decrease in 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

When you do not have enough red blood cells or hemoglobin in your blood it is called anemia. Hemoglobin is a protein in red blood cells (RBCs) that carries oxygen to the tissues in your body. When your red cell count is low, your body's tissues do not get enough oxygen to do their work. 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.

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 for 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 cells in the body 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 and an electric razor to shave to minimize bleeding risk.

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

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. A low neutrophil count is called neutropenia.

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

- Sore throat
- Shaking or chills, fever
- Cough
- Eye / ear discharge
- Sweating
- Nasal congestion
- Burning while urinating
- Redness / swelling



Infection prevention is crucial and could be lifesaving when your white blood cells are low and until your body's new immune system is formed. When your white blood cells are low, the only sign or symptom of infection may be a fever. This is why we monitor your temperature very closely. If you develop a fever or other signs of infection you will be started on antibiotics.

Preventing Infection

In the 2-3 week period between receiving your stem cells and your stem cell engraftment in your bone marrow, you will be at an increased risk of developing an infection. You will be given a combination of medications 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 medications 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. You may be given different versions of these medications depending on specific risks, prior infection or allergy specific to you. The following medications will likely be prescribed.

Acyclovir

Use: Prevent and 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 come back. You will need to take this medication twice a day to try to prevent it from coming back.

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

Timeline: You will begin this medication the day you receive your stem cells and take it for at least a year.

Fluconazole

Use: This medication is given to help protect you from fungal infections while your immune system is impaired.

Potential 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.

Timeline: You will begin this medication the day you receive your stem cells and take it until your blood counts have recovered.

Septra

Use: Prevents a specific type of pneumonia.

Potential Side Effects: Rash, nausea, vomiting, diarrhea, stomach upset, decreased blood counts, change in kidney or liver function.

Timeline: You will begin this medication when your blood counts have recovered and take it for at least six months.



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:

- Avoid large crowds. If you go to public places, try go when the least number of people will be there.
- 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.
- Avoid people with communicable illnesses such as chickenpox or measles.
- Avoid raw or undercooked meats, chicken, fish or tofu (refer to Nutrition Guide in Appendix II of this booklet).
- Avoid well water.
- Avoid rectal suppositories or enemas.
- Never share drinking glasses or cutlery.
- You should NOT handle animal feces. Avoid cleaning litter boxes or birdcages.
- Avoid using a razor. Use an electric shaver instead.
- Avoid tearing or cutting the cuticles of your nails.
- Do not swim until your central line has been removed and the insertion site is well healed.
- No gardening.

What to do:

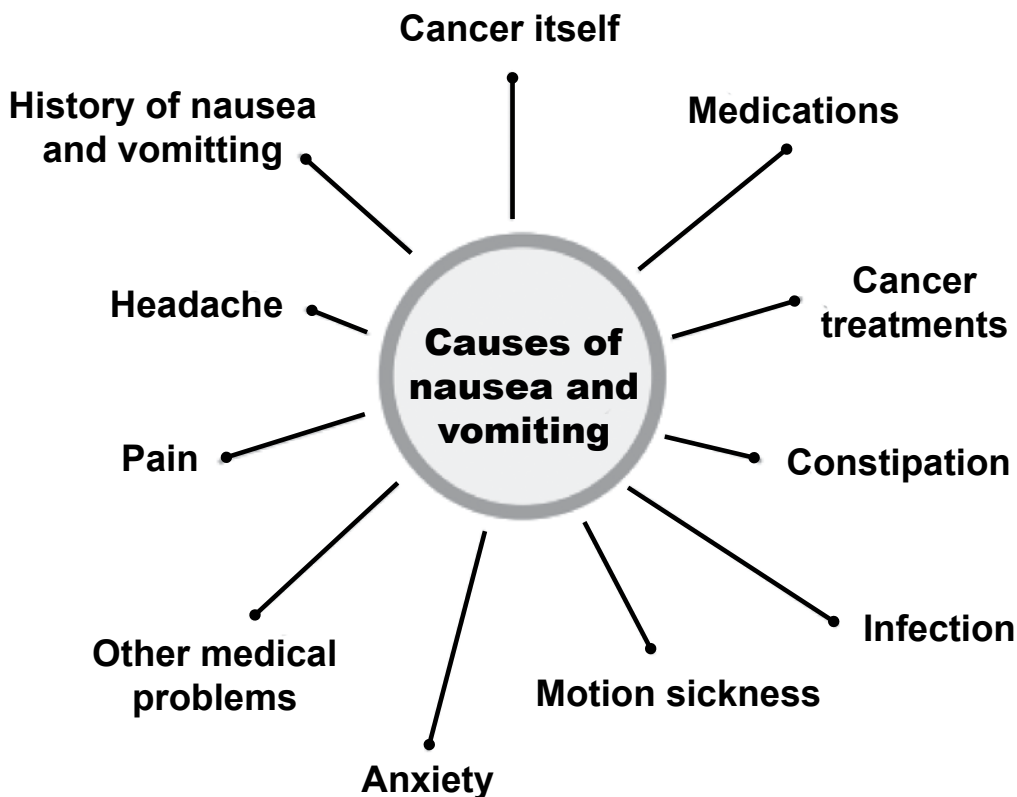
- Wash your hands often, especially after using the washroom and before eating. Carry a small bottle of hand sanitizer with you.
- Take your temperature every four hours even if you feel well, and especially if you feel warm, have chills or sweats.
- Pay close attention to signs of infection, such as a new or worse cough or shortness of breath with or without fever.
- Maintain good body hygiene by showering every day.
- Women should use sanitary pads instead of tampons for menstruation and avoid douches.
- Perform oral hygiene 3 to 4 times daily to help prevent mouth sores.
- Wash any cuts or scrapes right away and do not squeeze or scratch pimples.
- Avoid vaccinations unless approved by your hematologist.
- 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 will 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 before they start to work. Some patients find it helpful to take them before meals.

To help control nausea and vomiting:

- An empty stomach can make feelings of nausea stronger. Eat small frequent meals every 2-3 hours.
- 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 or foods at room temperature if the smell bothers you.
- Drink clear fluids such as water, watered down juice or sports drinks, flat ginger ale, lemonade and 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 and drink whatever appeals to you.
- Try to choose foods/drinks that are high in protein and calories.
- Rest after your meals and sit up for at least 30 to 60 minutes after eating.
- 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 or feel nauseous in between your regular anti-nausea medication doses, take your "as needed" medication.

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 can occur.

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 saline 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. This saline solution will be provided to you. Ask your nurse for more when you are running low.
- 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.
- 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 beeswax, 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 saline 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 to protect from skin breakdown. Your physician can order this for you. 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. Sip fluids slowly.
- Drink liquids between meals instead of with them. Limit high fibre foods such as whole grain breads, high fibre cereals, legumes, nuts and seeds.
- Remove skins, peels, seeds and membranes from fruits and vegetables.
- Avoid raw vegetables.
- Use lactose-free milk and milk products, as needed.
- Avoid stimulants such as caffeine, alcohol, and prune juice.
- Limit sugary drinks such as soda pop.
- If you drink juice, dilute it half and half with water.
- Avoid deep fried, greasy foods.
- Avoid eating or drinking anything with artificial sweetener.
- Check with your team before taking probiotics or eating foods with probiotics.

Poor Appetite

Almost all patients will experience some degree of poor appetite. Nausea, diarrhea and mucositis will contribute to this as well as taste changes that often accompany chemotherapy. As much as possible we will strive to control these side effects, so they impact your intake as little as possible.

While it is often difficult to consume an adequate amount of food and fluids, it is also vital to helping your body recover from this difficult treatment.

Your team will work with you each day to ensure you are receiving the proper nutrition. A dietician will speak with you at the start of your transplant and be available to talk with you as needed throughout. Your physician will monitor your weight, intake and electrolytes (tested in

your morning bloodwork) daily.

Your doctor may prescribe IV fluids to be given through your PICC line if you are finding it difficult to drink enough fluids. Your diet may be changed to a minced or fluid diet if you are finding it difficult to chew or swallow. Liquid nutritional supplements are available on the unit.

If you are unable to meet your nutritional needs the team may recommend you receive a feeding tube. This is a small, plastic tube that will be inserted by your nurse through your nose, past the back of your throat and down into your stomach. The insertion process is somewhat unpleasant but quick. An x-ray will be done to confirm the tube is in your stomach. We can then use this tube to give you nutritional supplements without you having to eat or swallow (mucositis can often make swallowing painful). We can also use the tube to administer your medications.

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. Also, it is important that you are able take your medications by mouth, eat and drink adequately, and carry on with your activities of daily living. Once you are discharged, 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.



Signs and Symptoms to Report

TCT Day Hospital (During Transplant): 7:30am – 5:00pm, Mon to Sun. 613-737-8650.



TCT office (After Discharge): 8:00am – 4:00pm, 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. New or worse 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. Cough or cold lasting longer than 1 week.
14. New swelling in an arm or leg.
15. Loss of appetite or weight loss.
16. Any other major changes in the way you feel.

If you are experiencing any one of the above symptoms, contact the transplant team immediately.

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) or higher.

- 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 **temperature of 38°C or greater** you must contact the Transplant Team immediately using the phone numbers provided above. You will need to come to the hospital for an assessment and intravenous antibiotics.

Managing your Health after Transplant

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 required beforehand.

Exercise



Being physically active, as you are able, will help you manage fatigue, feel better and build strength. However, you may have to modify your old activities. Ask your nurse or doctor if there are any restrictions on your physical activity.

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(or greater).

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.
<https://www.cancerandwork.ca/>

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 in consultation with 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.

Potential Long-Term Complications

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. Patients should see their eye specialist if they have any issues and have a yearly follow-up after their transplant.

Secondary Cancer

Following transplant, you have a slightly higher chance of developing a secondary 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. 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.

What if my transplant doesn't work?

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.

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 males 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. This chemotherapy 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?

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
- Lifestyle 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.

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.

Myeloma Canada

<https://www.myelomacanada.ca/>

Lymphoma Canada

<https://www.lymphoma.ca/>

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.

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".
- Please visit <https://www.ottawahospital.on.ca/en/clinical-services/deptpgrmcs/programs/cancer-program/what-we-offer-our-programs-and-services/patient-education-information-and-resources/> for links to many additional caregiver 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 the 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. It is also important 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
Fruit 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 non dried deli meats heated through to steaming hot Commercially packaged dried and salted meats such as salami and pepperoni Canned or shelf-stable pâtés Cooked tofu Roasted nuts Commercial peanut butter or nut butter 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 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

Appendix III: Granulocyte Colony Stimulating Factor Self-Injection Information



How is this medication given?

This drug is given daily by injection under the skin. The injection should be given only on the days specified by your doctor. If you miss your dose, check with your health care team before taking the missed dose.

How should I safely store this medication?

Keep in the refrigerator, but do not freeze. Keep out of sight and reach of children and pets. Never re-use needles. Always dispose of needles and pre-filled syringes in a puncture-proof sharps disposal container and return to your pharmacy for proper disposal.

What are the side effects of this medication?

The most common side effect of G-CSF is pain in the joints, muscles and bones, most commonly in the lower back, legs and arms. Acetaminophen (Tylenol) tablets may be used. Take 1-2 tablets every 4 hours as needed for mild aches and pains. If the pain does not improve or worsens after 24 to 48 hours, talk to your health care team to discuss if a stronger pain reliever is needed. Do not take ibuprofen (Advil) or naproxen (Aleve), since these may increase your risk of bleeding. Take your temperature before using any of these drugs as they may mask fever. If you develop signs or symptoms of a fever call your health care team.

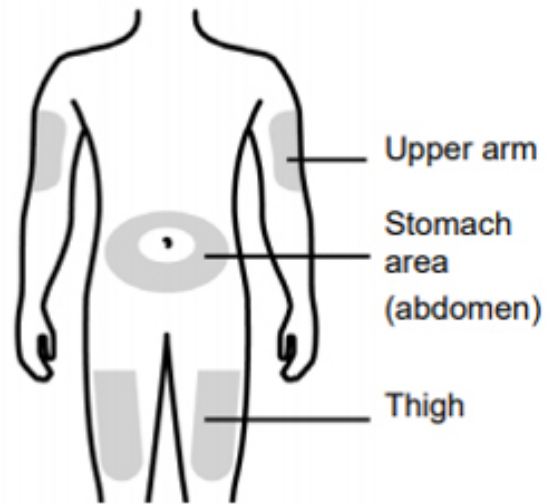
Less common side effects effects of G-CSF include: liver changes, headaches, fatigue, elevated white blood cell counts, bruising, bleeding gums and nosebleeds, diarrhea, nausea, abdominal pain, pain when urinating, rash, and, rarely, allergic reaction.

Contact your health care team if you have severe side effects.

Patient's Guide to Subcutaneous Self-Injection

- Wash your hands thoroughly with soap and water.
- On a clean, well-lit work surface place the pre-filled syringe, alcohol wipe, gauze pad or adhesive bandage and sharps disposal container (these will be provided to you).
- Choose your injection site. You should use the upper arm, thigh or stomach area (see diagram below). If using the abdomen, do not inject within two inches of the umbilicus. Choose a different injection site each time to avoid soreness at any site. Do not inject into areas where the skin is tender, bruised, red, or hard. Avoid injecting into areas with scars or stretch marks.

- Clean your injection site with an alcohol wipe. Let your skin dry. Do not touch this area again before injecting.
- Pinch your chosen injection site to create a firm surface. Important: Keep skin pinched while injecting.
- With your other hand, insert the needle into the skin at a 45 to 90 degree angle. Using slow and constant pressure, push the plunger rod until it reaches the bottom. Do not pull back the plunger rod while the needle is inserted.
- When done, gently pull the syringe out of your skin and place the gauze pad or adhesive bandage over injection site if needed.
- Dispose of the used syringe into the puncture-proof sharps disposal container right away.



(Amgen Inc. 2016 and and Cancer Care Ontario: <https://www.cancercareontario.ca/en/drugformulary/drugs/infosheet/43826>).



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