ALLOGENEIC Stem Cell Transplant Handbook

Saskatchewan Stem Cell Transplant and Cellular Therapy Program





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Allogeneic Stem Cell Transplant Information

Welcome to the Saskatchewan Stem Cell Transplant and Cellular Therapy Program

As you begin your allogeneic stem cell transplant journey, we would like to welcome you and introduce our program. An important part of your preparation is to ensure that you have all the information you need to feel well informed.

The purpose of this education manual is to provide you and your family with information about:

- Your health care team and their contact information
- Stem cells and allogeneic stem cell transplant
- Test and procedures you may undergo
- Preparation, collection and recovery during stem cell transplant
- Emotional and practical concerns
- Resources

You may feel overwhelmed by the amount of information in this guide. However, this is a tool for you to use as we help educate you about what to expect at each step of allogeneic stem cell transplant.

Please bring this guide to all appointments



Dr. Mohamed Elemary Director of Stem Cell Transplant



Contact Information

REGULAR BUSINESS HOURS: Saskatoon Cancer Centre 20 Campus Drive Saskatoon, SK S7N 4H4	(306) 655-2662
	to 4:30pm (excluding statutory holidays)
Transplant Physician Your transplant physician is:	
Outpatient Primary Care Nurse	(306) 655
Transplant Coordinator	(306) 655
Social Worker	(306) 655
Clinic Assist	(306) 655

AFTER-HOURS & EMERGENCY CONTACTS:

Hematologist On-Call(306) 655-1000For urgent matters on weekdays after 4:30pm, weekends or statutory holidays call Royal
University Hospital Switchboard and ask to page the Hematologist on call and they will
call you back.

Royal University Hospital

(306) 655-1000

In case of emergency while in Saskatoon, please go to Royal University Hospital Emergency Room.

Out of Town Emergencies

911 or local hospital phone number

In case of emergencies outside of Saskatoon, please visit your local emergency room.



Stem Cell Team

Introducing Your Stem Cell Team

The team that will be caring for you throughout the allogeneic stem cell transplant process consists of many different health care specialties with a focus and/or training in stem cell transplant.

Cellular Therapy/Transplant Coordinator

Responsible for organizing appointments, tests, education, and admission required for your stem cell transplant. The transplant coordinator is your primary contact to help address questions and concerns.

Donor Search Coordinator

Responsible for performing the search for a related and/or unrelated donor. They coordinate donor testing, stem cell collection dates, and the transport of unrelated donor stem cells.

Transplant Physicians

Hematologists with specialized training in stem cell transplantation. A hematologist is a doctor who specializes in diagnosing and treating conditions that arise in the blood and blood-forming tissues including bone marrow.

Clinical Associates

General practitioners (doctors) working in the hematology and transplant field. Working in close partnership with the transplant physician responsible for your care, the clinical associates manage your daily medical care needs during your hospital stay.

Nurse Practitioner

A nurse practitioner is a registered nurse with additional education who may follow you post transplant to provide specialized care along in coordination physician.

Fellows

Physicians who have completed training in internal medicine, hematology or oncology and who are doing further training in the hematology and stem cell transplant.

Social Workers

Dedicated team members of the hematology and stem cell transplant program. They provide support to patients and their loved ones throughout the inpatient and outpatient settings. They provide counselling and support, resources, assistance with practical matters, and facilitate family meetings.

Hematology Pharmacists

Work directly with patients and the stem cell team, and are responsible for providing evidence-based, patient-specific drug information and for identifying, preventing and resolving drug related problems.



Apheresis Nurses

Specially trained RNs skilled in the collection ("apheresis") of stem cells.

Transfusion Medicine Technologists

Responsible for testing and labelling of fresh stem cells following collection and/or arrive at the Transfusion Medicine Laboratory.

Registered Nurses

RNs skilled in stem cell transplant care provide outpatient and inpatient care. An inpatient nurse clinician may be part of your inpatient care, as well as a Nurse Practitioner in the outpatient setting.

Clinical Trials

A clinical trials nurse may contact you if there is a research study for which you may be eligible. Participation is voluntary.

Dietitians

Provide with you with nutritional support during your hospital stay for your stem cell transplant. If you have any difficulty eating or any nutritional concerns pre- or post-transplant, dietitians in the Saskatoon Cancer Centre are also available.

Occupational Therapists

Part of the inpatient team who will follow you during your hospital stay. Occupational therapists provide help with the things you want and need to do including basic activities of daily living, energy management, and access to equipment if needed.

Physiotherapists

Part of the inpatient team who will follow you during your hospital stay. A physiotherapist will see you once you are in hospital, and will design an activity program based on your individual needs.

Spiritual Care

Spiritual care is available upon request to support and encourage you to draw upon your religious and spiritual strengths.

Your Caregiver!

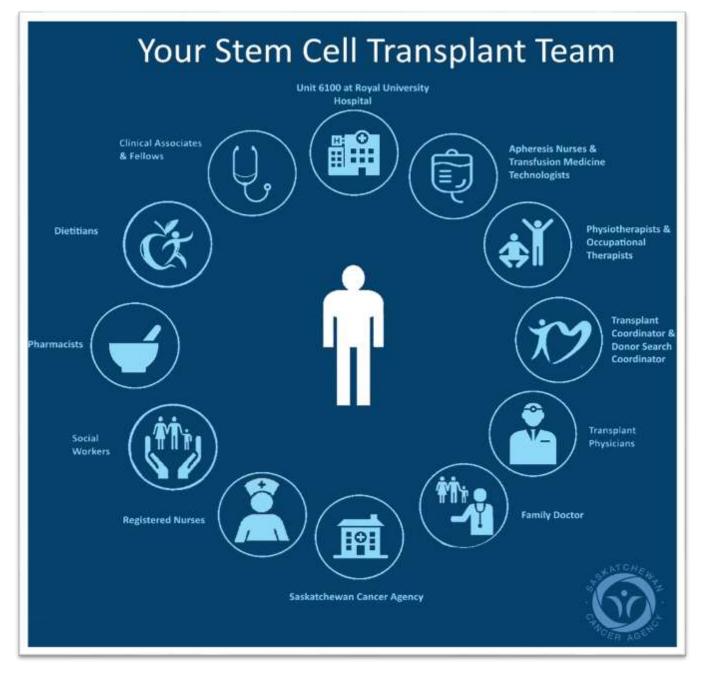
Your caregiver is essential as they help with practical tasks such as helping you get to appointments, keeping track of medications, helping with daily care, as well as serving as an important source of communication between you and your health care team.



You!!

You are an essential part of the team. You will have the most vital role to play in your care and recovery. As you know yourself best, we depend on you to report how you are feeling and how the treatment and other factors are affecting you.







A Committed Partnership

YOUR TRANSPLANT TEAM'S COMMITMENT:

- To provide you with top quality medical care
- To communicate with you and your support network respectfully, openly, and honestly
- To educate and support you and your family/caregivers
- To respect your beliefs and care directives

YOUR COMMITMENT:

- To communicate respectfully, openly, and honestly with your transplant team
- To arrange for a capable and committed caregiver(s)
- To secure appropriate accommodations within 30 minutes of Royal University Hospital, with guidance from your social worker
- To reliably follow the instructions of your transplant teams for appointments, tests, and medications
- To get help to stop smoking, using intravenous drugs, and/or alcohol dependency issues prior to hospitalization
- To ask for help or clarification when you do not understand

YOUR CAREGIVER'S COMMITMENT:

- To be available to provide personal care and assistance to you 24 hours a day, 7 days a week (availability can be shared between more than 1 caregiver)
- To communicate with you and your support network respectfully, openly, and honestly
- To ensure transportation and accompany you during appointments
- To recognize and report signs and symptoms of complications
- ✤ To ensure that you are taking medications correctly, and to ask questions
- To understand and practice infection prevention practices while your immune system is compromised



Stem Cell Basics

What Are Stem Cells?

Hematopoietic (blood) stem cells are the "parent" cells of the blood supply. They are capable of self-renewal and develop into:

- Red blood cells, which carry oxygen throughout our body
- White blood cells, which help fight infections
- Platelets, which help form clots to prevent bleeding

Most stem cells are found in the bone marrow, mainly in the large hip bones and other long and flat bones. Normally there are very few stem cells found in the bloodstream.

What Is Stem Cell Transplant?

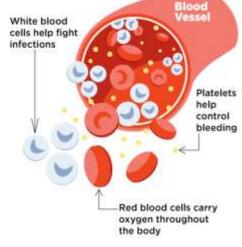
There are different types of stem cell transplants:

- Autologous Stem Cell Transplant. Patients have their own stem cells collected and frozen before treatment, to be returned to the patient ("re-infused") following high dose chemotherapy. This type of transplant is common for patients who have multiple myeloma or certain types of lymphoma.
- 2. Allogeneic Stem Cell Transplant. Stem cells are donated from a suitable donor, usually a sibling or an unrelated donor. This type of transplant is common for patients who have leukemia or some patients who relapse following autologous stem cell transplant.

Before infusing stem cells, patients undergo conditioning treatment with chemotherapy, sometimes with total body irradiation (TBI) to eliminate the underlying disease. This chemotherapy also destroys other cells in the bone marrow. Donor stem cells are then infused into the patient where they make their way to the bone marrow to start producing normal blood cells again.

It is important to understand that the goal of an allogeneic stem cell transplant is to cure the disease.





Is An Allogeneic Transplant Is Right For Me?

Deciding to proceed with an allogeneic stem cell transplant is a personal choice that requires a great deal of thought, preparation, and discussion with loved ones. Undergoing transplant is a major turning point in most patient's lives, often described as an emotional rollercoaster with ongoing feelings of uncertainty even after making the decision.

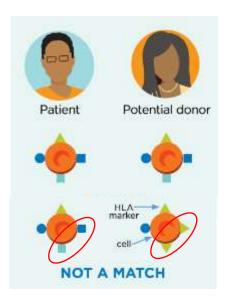
An important role of the stem cell transplant team is to provide you and your family with adequate information to help you make the decision of whether or not to undergo transplant. Some people decide not to have an allogeneic stem cell transplant once they understand all that is involved, even though it may be the last curative option available. It is important to understand that no answer is right for everyone. Regardless of the decision you make, your team will continue to support you.

In addition to this guide, other educational opportunities are available to you and your family prior to making your decision, including:

- An allogeneic stem cell transplant education session for patients and caregivers (offered every other month)
- A repeat discussion with your transplant physician
- A chance to speak with someone who has already undergone an allogeneic stem cell transplant (arranged through your social worker)



Finding a Donor



Looking for a suitable donor in preparation for an allogeneic transplant starts early. This requires a blood test called *HLA typing* (Human Leukocyte Antigen). HLA antigens are like flags located on the surface of cells. Your immune system uses HLA markers to know which cells belong in your body and which do not. Your biological mother contributes half of your HLA markers and the other half are inherited from your biological father, so each brother and sister sharing the same mother and father as you has a 25%, or 1 in 4 chance of being a full match.

Related Donor Search

To begin a related donor search, we ask for your siblings' names and contact information to arrange to have blood

drawn for HLA typing. This blood test can usually be drawn close to your sibling's home and requires no preparation. It is then shipped to the HLA Laboratory in Saskatoon for testing. If there is a matched related donor, additional blood work and tests must then be arranged to ensure that the stem cell collection is safe for the donor as well as for the patient.

A transplant physician at the Saskatoon Cancer Clinic must assess related donors. This evaluation includes an extensive health history, physical examination, electrocardiogram (ECG), chest X-ray (for donors who have a history of smoking), along with other tests as required. Saskatchewan Health covers all medical costs associated with the stem cell donation; however, costs associated with travel and accommodation will not be covered.

Unrelated Donor Search

An unrelated donor search is started through the Canadian Blood Services Stem Cell Registry. This network allows us to search more than 34 million potential adult donors on registries from around the world. A copy of the Canadian Blood Services *Privacy Notice to Patients* will be given to you before an unrelated donor search is started. This notice describes how your personal information will be used and shared. Confidentiality is critical in the unrelated donor search process. As such, any identifying characteristics of



your donor including age, sex, name, and address cannot be disclosed. Likewise, your identifying information will not be shared with the donor.

Identifying a suitable unrelated donor can be a complicated process. In some cases, it may take just a few weeks or it could take many months to find a suitable match. Once a potential match has been identified, further testing is performed to confirm the match and to ensure that the donor is medically fit and suitable to donate stem cells. Collection of donor stem cell takes place in the donor's country, and are then transported back to our transplant center by one of our program's trained couriers. The stem cell collection is coordinated with the recipient's treatment and planned stem cell infusion day.

Confidentiality and Donor Contact following Transplant

Donor and recipient confidentiality is a requirement of all unrelated donor registries to protect donor and recipient personal information. This confidentiality also extends to social media, where sensitive personal information could potentially be revealed without donor or recipient consent.

If you have an unrelated donor, anonymous communication *may* be possible through Canadian Blood Services, but only after being screened by the Canadian registry to ensure confidentiality. Some donor registries, but not all, permit contact between a donor and recipient one year after transplant but only if both the donor and recipient consent. However, different countries have their own guidelines, and in some cases, the exchange of anonymous correspondence or direct personal contact is never permitted.

If you are interested in contacting your unrelated donor, your request can be directed to the Donor Search Coordinator.

Other Donor Sources

Sometimes there is no matched related or unrelated donor identified. In some of these cases a haploidentical donor, that is, a related donor who is a 50% match to the recipient may be an option. Most often, this is a parent, unmatched sibling, or child of the patient.



Collecting Donor Stem Cells

There are two methods used to collect stem cells, the physician will decide which one of these methods will be used, but most commonly, stem cells are collected through peripheral blood.



Peripheral Blood Stem Cell (PBSC) Collection

Peripheral blood stem cell collection is an outpatient procedure that uses stem cell-stimulating injections and an apheresis machine.





Bone Marrow Harvest

Bone marrow harvest is a procedure performed under anaesthetic in the operating room where bone marrow is removed from the back of the hip bones.



Peripheral Blood Stem Cell Collection

Peripheral blood stem cell collection is the most common way to collect stem cells. Growth factors are naturally occurring special proteins in the human body that stimulate blood cell production and growth. Growth factor medications such as G-CSF

(granulocyte-colony stimulating factor) work in the same way, by stimulating the growth and release of the stem cells from the bone marrow into the blood stream for collection by apheresis. The collection, or "apheresis", of stem cells is accomplished using a machine called a blood cell separator. This machine spins the blood to separate it into different components (red cells, white cells, plasma and platelets). The stem cells, found in the white blood cell



layer, are collected into a bag. All other blood components are then returned back to the donor.

Bone Marrow Harvest

Under certain rare circumstances, obtaining stem cells through a bone marrow harvest is preferred. This procedure is done in the operating room under general anaesthetic. A needle is inserted into the hipbones. Bone marrow is removed using a syringe, and looks very similar to blood. This process is repeated several times until the required number of stem cells are collected. Approximately 1000 mL (or 4 cups) of marrow is removed during the collection. The bone marrow is filtered before being transferred into a large bag where it is ready to be transfused to the patient. In special cases, bone marrow may be frozen for use in the future.

The entire procedure takes about 1-2 hours. Often, this is a day procedure although sometimes an overnight hospital stay is required. Some pain, stiffness, light-headedness and fatigue are common after this procedure.



What Transplant Involves

Here's a quick overview of the steps involved in allogeneic stem cell transplant:

Pre-Transplant Work-Up

This includes evaluation of response to previous treatment, testing to ensure major organs are healthy enough to withstand high dose chemotherapy, arranging for a caregiver, organizing legal and financial affairs, and stopping smoking (if applicable).

2

Admission For Transplant (Timed With Donor Stem Cell Collection)

Once admitted to hospital, you will start high dose chemotherapy and possibly radiation followed by the infusion of stem cells ("transplant"). You will remain in hospital until your stem cells begin to grow and you have recovered from immediate side effects.

3

Discharge From Hospital

Once your blood counts have recovered and you are able to eat, drink and take pills by mouth, you will be discharged from hospital with instructions about what problems you must report.

4

Care Following Transplant

Following discharge, you will be closely monitored as an outpatient at the Saskatoon Cancer Centre. You will be discharged from hospital with instructions about what problems you must report once your blood counts have recovered and you are able to eat, drink and take pills by mouth.



Transplant Timeline

The time to complete pre-transplant treatments and confirm a donor can vary. However once you are ready to proceed with transplant, here is an idea of what the timelines look like. Keep in mind that delays are common and can result from infectious complications, donor issues, or other reasons so this is intended simply as a guide.

Pre-Transplant Work-up (2-4 weeks pre-transplant)	Conditioning Regimen & Stem Cell Transplant (Hospital admission)	Discharge (4-5 weeks after admission)	Long Term Follow up (Beyond 3 months following transplant)
Blood Tests CT or PET Echo PFT Dental Opthalmology Central line insertion +/- Bone marrow biopsy +/-Lumbar puncture * Determine Caregiver* Find accommodations if Saskatoon is not home	Chemotherapy +/- Radiation Therapy Donor stem cell collection Stem cell infusion Engraftment	Outpatient assessments Central line care IV fluids and transfusions Regain strength and appetite Prevent infections Watch for GVHD	Watch for GVHD Reimmunizations Long term monitoring



Pre-Transplant Work Up

Planning your schedule for pre-transplant tests and treatments can begin once your transplant physician has suggested that a stem cell transplant is indicated and you have decided to proceed with the transplant. Your schedule will depend on your treatment plan, how urgently you need a transplant, and the scheduling of tests and appointments.

This is the time to arrange for a caregiver(s). If you live more than 1 hour away from Royal University Hospital, it is also the time to secure temporary accommodations in Saskatoon, as you will be required to stay in Saskatoon for at least 3 months post-transplant. Please refer to the sections on Caregivers and Practical Tips for more information (please see page 26).

Diagnostic Tests

Many tests to evaluate disease status and organ function prior to transplant are required. These tests include:

- Blood Tests
 - Includes looking for viruses studies such as CMV, Hepatitis B, Hepatitis C, HIV, HTLV, Syphilis, and West Nile Virus
- Bone Marrow Aspirate/Biopsy
 - A bone marrow aspirate and biopsy is a procedure in which a small sample of bone marrow and bone is collected. Bone marrow aspirates and biopsies are done to evaluate your disease status prior to transplant and to determine the effectiveness of pre-transplant treatment.
- Dental Assessment and Cleaning
 - All allogeneic transplant patients must have a dental evaluation by Dentistry at Royal University Hospital, which includes a dental cleaning (unless done in the past 6 months), assessment for sources of infection in your mouth, and any necessary dental work or extractions. Dental follow-ups continue every 3 months after transplant for 1 year. After that time, you can return to your regular dentist.
- Echocardiogram (Echo)
 - An echocardiogram is an ultrasound of the heart to measure heart function.
 Gel is placed on your chest and a wand-like device called a transducer is moved over your heart, transmitting painless ultrasound waves into your



chest. A computer converts echoes from the sound waves into pictures of your heart. This test will take about 1 hour.

- Pulmonary Function Test (PFT)
 - A PFT is a breathing test to assess lung function. It measures how much air the lungs can hold, how well air moves through the airways, and how well oxygen penetrates lung tissues in order to enter the blood stream. Results of these tests provide information about how well your lungs work. You may be asked to use an inhaler through which the technician will give you a medication (albuterol, or Ventolin®) to help "open up" the air passages in the lungs making it easier for air to flow through.
- CT scan (Required for some diseases)
 - A CT (computerized axial tomography) scan is a special type of x-ray that takes pictures of different cross-sections of a body part by moving the machine around the patient. Ordinary x-rays, like chest x-rays, give twodimensional pictures while a CT scan provides very detailed threedimensional pictures. A CT scan is not painful, but you must lie very still for up to 15–20 minutes at a time and it does require an IV.
- PET scan (Required for some diseases)
 - A PET (positron emission tomography) scan uses a radioactive dye that is injected into your arm. The PET scanner can detect areas of activity (metabolism or cell growth) in the body. More activity is seen in cancer cells than normal cells. PET scans are not painful, but they do take longer than a CT scan (but you are exposed to less radiation).
- Ophthalmology Consult
 - A detailed eye assessment by an ophthalmologist who follows allogeneic transplant patients is done before stem cell transplant as well as after transplant to monitor for early signs of eye complications.
- Radiation Oncology Consult and Planning CT
 - For patients receiving total body irradiation (TBI) as part of their conditioning treatment, an appointment with a Radiation Oncologist at the Saskatoon Cancer Centre will be arranged prior to being admitted for transplant. The procedure for TBI will be explained, the along with the risks and side effects. A planning CT will also be done in preparation for administration of TBI.

Fertility

Fertility is very often affected by chemotherapy and/or total body irradiation (TBI). Becoming pregnant or fathering a child is uncommon after an allogeneic stem cell



transplant, although some women do recover their ovulation after stem cell transplant. This should be kept in mind when engaging in unprotected sexual intercourse.

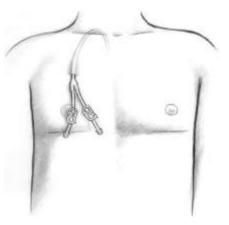
If you would like to be able to have children in the future, please talk to you transplant team. Men may want to consider sperm banking prior to starting conditioning chemotherapy. Women can be referred to a fertility specialist to pursue options about fertility preservation.

Saskatchewan Health does not cover the cost of fertility aid procedures. If costs are a concern, please discuss with your health care team.

Central Venous Catheter Insertion

Before transplant, a central venous catheter (CVC) will be inserted into your chest. The CVC can be used for intravenous fluids, medications, blood products, chemotherapy, nutrition, in addition to infusing stem cells. Nurses must be certified to use CVCs including to draw blood samples.

A tunneled CVC is a long, flexible tube inserted under the skin of your chest with the help of an ultrasound machine. An interventional radiologist at Royal University Hospital performs the insertion. For this procedure, the



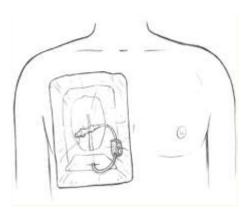
skin around the insertion site is frozen using local anaesthetic. The tip of the CVC is threaded through to a large vessel just outside the heart. The tunneled part of the CVC has a cuff attached that your tissue grows around to help keep the catheter in place. The hub of the catheter hangs outside your body, often with three lumens. Each lumen has a cap and a plastic clamp to keep blood from leaking out while also preventing air from getting in.

A dressing covers the insertion site to help keep the area clean and dry, as well as to minimize the risk of infection. Dressings must be changed within the first 24 hours, then at least once every week. Following the CVC insertion, it is normal to have some redness and discomfort at the site, but this should go away within a few days. There will also be a stitch above the insertion site by your neck. A nurse will remove the stitch 7-10 days after the procedure.

Living With Your Tunneled Central Venous Catheter



Proper care of your catheter is important to prevent infection. CVCs can stay in place safely for weeks, months or even years if cared for properly.



Keep your catheter clean. You should always keep the exit site covered with a sterile dressing or bandage. The dressing needs to be changed once a week or more often if it becomes dirty, wet, or is no longer sticking to your skin.

Keep your catheter dry. Avoid swimming or other activities that may cause your catheter or catheter dressing to become wet. When bathing or showering, the catheter and catheter dressing should be covered by

plastic wrap and tape. Do not submerge the area in water.

Take care not to pull or twist your catheter when getting dressed or undressed or when changing the dressing. Be careful when lifting objects, children or pets.

Avoid using scissors or anything sharp on or near the catheter.

Use caution when doing any activities with your chest muscles. Repetitive motion with your arm on the side of the catheter such as vacuuming can cause damage to the area. Avoid any heavy lifting.

Possible Complications with CVCs

Most people with a tunneled CVC do not experience any of the following problems. With proper care, most of these problems can be prevented and your tunneled CVC should continue to work well for the duration of your treatment.

However, if you do experience issues with your CVC, it is important to know what to do. The following chart provides guidance. If you experience issues not listed in the chart, be sure to call your nurse or physician.



Possible Central Venous Catheter Problems and Actions

PROBLEM Broken or cut CVC	SIGN If break is above the clamp, blood may leak or drip from the CVC	WHAT TO DO Clamp the CVC above the cut/broken area and seek medical care as soon as possible.
Infection	Redness, swelling, pain/tenderness, fever or chills	Seek medical care as soon as possible
Clamp open when the end cap is off	Blood is dripping/leaking from end of CVC	Clamp the CVC. Check to make sure the bleeding has stopped. Clean the end of the CVC with alcohol, replace the cap. Call your nurse.
CVC is partially pulled out	CVC may appear longer, and/or cuff that adheres CVC to the skin is visible	If not out all the way, secure with tape. Call your nurse.
CVC is pulled out	CVC is no longer tunneled under the skin	Apply pressure to the exit site until bleeding stops. Seek medical attention as soon as possible.
Blood Clot	Redness, swelling, pain to neck or arm	Seek medical care for assessment as soon as possible.
Stitch around insertion site falls out	Stitch holding tube to the skin is no longer there	If this happens within the first 10 days of insertion – seek medical care immediately – a new stitch will need to be placed. If this happens after 10 days, the skin around the cuff will have time to grow around it and it will be secure without the stitch.



Preparing For Transplant

There are many things to consider before your stem cell transplant. You will need to make practical, physical, and emotional preparations prior to your transplant. Here are some important things you will need to do to get ready:

Choosing a Caregiver

Finding a capable caregiver to support you before and after transplant is essential, since they play a significant role during all stages of the stem cell transplant process. Caregivers can help with everyday tasks, transportation to clinic appointments, help with medications, checking your temperature, providing nutritional support or help with cooking meals, and reporting important information about your health to your health care team.

You are required to have a caregiver(s) in place before your stem cell transplant. Following discharge, you must have a caregiver with you 24 hours a day, 7 days a week for at least the first 3 months and possibly longer.

You MUST have a caregiver with you 24 hours a day, 7 days a week for at least the first 3 months



Who can be a Caregiver

A caregiver is most often an adult family member or friend. Some people have more than one person as a caregiver. It can be challenging for caregivers if they also have small children to care for, or have their own health problems. A caregiver that works outside the home will need to take time off work.

Responsibilities of a Caregiver

It is a recommended that your caregiver attends all appointments with you starting before your transplant. While you are in hospital, caregivers are not required to provide care but spending some time in the hospital can help them become familiar with your care needs.

Caregiver(s) are expected to participate in discharge teaching before you go home. Once discharged from hospital, your caregiver(s) will help with everyday tasks, transportation to clinic appointments, medications, monitoring vital signs such as your temperature, providing nutritional support or help with cooking meals, and gathering information among many other things.



Your caregiver must be there to support you as you continue with your recovery outside of the hospital. While helping you with your day-to-day activities, your caregiver must also watch for any changes in your health. There may be times when you may not recognize a problem. Your caregiver must be able to identify and report changes in your condition such as fevers, nausea, vomiting, problems eating, rashes, confusion, and any other concerns to your healthcare team.

Tips for Caregivers

Being a caregiver is a challenging role. Some things for caregivers to remember are:

- Be kind to yourself. Self-care is very important! It is essential to make and take time away for yourself with the assistance of friends and family as necessary. As a caregiver for a person with a life-threatening illness, you participate in the journey as well. Recognizing this is the first step to good self-care.
- Recognize when you are stressed and identify your stress "triggers." Learn and practice relaxation techniques. Deep breathing, visualization, meditation, and physical exercise can all be helpful for reducing stress.
- Educate yourself and be informed. Ask questions of the health care team and establish your caregiver role with the team. Learn as much as you can about the patient's medical condition and the available community supports and resources. Knowledge is power.
- Confide in someone. Seek support from other caregivers. Talk to one of the transplant social workers. Consider participating in a support group.
- Consider keeping a journal to keep track of important health information for your loved one on a regular basis. You can also write down your thoughts about care giving, your hopes and dreams, disappointments and frustrations.
- Write down questions you have or important phone numbers, names and instructions. Remembering everything that is happening is hard to do.
- Don't underestimate the value of maintaining a good sense of humour.
- Remember that you can plan all you like, but you can't control everything. Laugh, regroup, and make the best of it.

The role that caregivers fulfill is invaluable. Your health care team recognizes how just how deeply challenging and rewarding it can be. As a caregiver, you must ensure that your loved one is taking all medications on time, reporting any new symptoms in a timely fashion, assisting with care at home, and being present at all appointments.



Equally important is the understanding that all allogeneic transplant patients have highrisk disease, and you, as the caregiver, are not responsible for the outcome or complications.

Caregivers may be eligible to apply for the *Compassionate Care Benefit* from the Government of Canada. Speak with your Social Worker for help completing the application.

Accommodations

Saskatoon is the only location in Saskatchewan that performs stem cell transplants. Accommodations within a 30-minute drive of Royal University Hospital are required for at least 3 months following your transplant, and possibly longer, depending on how you are doing.

If you do not have family or a friend to stay with in Saskatoon, it is recommended that you rent a furnished suite.

Furnished Suites/Long Term Accomodations

- Furnished suite including cooking utensils, bedding, furniture etc.
- Your social worker can provide you with a current list of recommended suites/accommodations

If finances are a concern or you need assistance with accommodations, please contact your stem cell transplant social worker.

Transportation and Parking

Royal University Hospital has a parkade on-site, and parking permits are available for Saskatoon Cancer Centre patients to park in spots closest to the Cancer Center. These permits are available from the reception desk at the Saskatoon Cancer Centre. The rates for the parkade can be found at:

https://www.saskatoonhealthregion.ca/locations_services/Services/Parking-Services/Pages/Rates.aspx.

There are also limited metered parking spots available nearby on the University Campus. All metered parking spaces are available on a first come first serve basis.

If you don't mind walking a few blocks, there are times when free street parking may be available across College Drive. Read the street signs carefully to comply with maximum time limits based on time of day and day of the week.

If you require assistance with transportation within Saskatoon, here are some options:



Volunteer Driver Program

- For those who are eligible, rides to and from the Saskatoon Cancer Centre within Saskatoon are available through the Canadian Cancer Society Wheels of Hope – Volunter Driving Program. These arrangements must be made in advance. Please discuss with your social worker.
- Phone: 1-888-939-3333

Taxi Service (most have accessible taxis for disabled)

- Access Transit 306-975-3555 (for physically disabled)
- Accessible Taxi Service 306-220-5444 (for physically disabled)
- Captain Taxi 306-242-0000
- Comfort Cabs 306-242-6666
- Ride Taxi
 306-652-2222

Physical Preparation

Depending on your current activity level and physical condition, you may need to either keep up with your regular exercise program or be as active as possible in preparation for transplant. In general, the more conditioned you are the better you will be able to physically manage transplant and recovery. As well, exercise is a positive way to channel stress and promote general well-being.

Eating healthy and meeting basic nutritional standards pre-transplant are also important.

Emotional Preparation

The emotional impact of treatment and transplant can be significant. Understanding how you and your support network are affected emotionally can help with coping.

Communication with your health care team as well as your family and support network is very important. It is important to ask for help when you need it. Letting family and friends know they can support you is important to both you and them. Your social worker is also available for emotional and practical support, and can help work through any concerns.

Another useful tip is to choose your priorities and let go of less important obligations. You can ask family members and friends to help – they will appreciate having a way to contribute to your recovery! Some people also find it helpful to gather information to help feel more prepared, but ensure you are seeking information from credible sources. Speak to your health care team if you have any questions about where to find reliable information.

Smoking Cessation

We strongly encourage you to quit smoking if you are a smoker, and avoid second-hand smoke as it can lead to infections and lung complications. Smoking includes cigarettes,



cigars, pipes, marijuana, inhaling cocaine and chewing tobacco. Smoking is not permitted in any buildings or on the grounds of the Royal University Hospital.

There are a number of supports available to help you quit smoking through your local health region, family physician, or pharmacist. Check out

https://www.skpharmacists.ca/patients/quit-smoking for information on how your pharmacist can help you quit smoking including prescription medications, over-the-counter nicotine replacement, counseling, and other strategies. Another option is to call the *Canadian Cancer Society*'s Smokers' Helpline at 1-877-513-5333.

We continue to recommend not smoking and avoiding second hand smoke following your stem cell transplant, as both can increase your risk of infection or lung complications.

Legal Affairs

It is advisable to have your legal affairs in order. Discuss your wishes clearly with your family and caregiver(s). This may include:

- Power of Attorney. Refers to a document authorizing someone else to act on your behalf regarding personal and/or financial matters. It can be general or restricted to a specific task, but does not include making health care decisions.
- **Current Will**. A current will is an important financial legal document that helps provide for your loved ones by directing who will care for your minor children, who will get your home and possessions, who will take care of your estate, and any instructions on end of life ceremonies.
- Advanced Health Care Directive (Living Will). This is a legal document that specifically states which forms of treatment an individual agrees to accept and which forms of treatment they wish to refuse. Advance care planning begins by thinking about your beliefs, values and wishes regarding future health care treatment. This is an important conversation to have with close family, friends and health care provider(s) to ensure they are aware of your wishes in the event you become incapable of expressing your own decisions. You can

Please bring a copy of your health care directive with

also name a proxy or decision maker in your health care directive. You should discuss specific concerns with your social worker.

Finances

The costs you incur while having a stem cell transplant will depend on various factors: if you are from out of town, the medications you need to take in the pre- and post-



transplant phase, how much traveling you will have to do for appointments, and other expenses such as childcare. You may also have some costs for necessary dental treatments if you do not have dental coverage. Your social worker can help to find financial support if necessary.

If you are currently employed, you will need to take time off from work. Most patients will be off work for at least 1 year or longer, or you may not be able to return to work at all.

Employment-Related Benefits

Please check with your employer or human resources department for sick leave, short term and long-term disability benefits.

Some other sources of financial help may be available to you from:

- Government of Canada:
 - Employment Insurance (E.I.) Medical Benefits
 - You may qualify for up to 15 weeks of E.I.
 - Contact Human Resources and Skills Development Canada at 1-800-206-7218
 - Website: https://www.canada.ca/en/services/benefits/ei/eisickness.html
 - o Canada Pension Plan (CPP) Disability Benefits
 - You may also qualify for CPP-D benefits.
 - Contact Social Development Canada at 1-800-277-9914
 - Website: https://www.canada.ca/en/services/benefits/publicpensions.html
 - o Income Tax
 - Keep all your travel, food, and accommodation receipts, if you are traveling more than 40 km for your medical care as you may be able to claim them on your income tax return under <u>medical expenses</u> (Note: expenses where you received funding from an outside source cannot be used for income tax purposes).
 - Certain patients may qualify for a <u>disability tax credit</u>, but very strict criteria apply.
 - Website: www.cra-arc.gc.ca/disability/
 - Phone: 1-800-267-6999.
- Saskatchewan Assistance Plan
 - Financial Assistance for living expenses and medically related costs is provided to applicants in need that meet strict eligibility criteria (means no source of income, minimal or no assets, no other available sources).
 - To apply, contact the Ministry of Social Services at 1-866-221-5200 for initial intake and scheduling of an appointment.



- Other Insurance
 - If you have purchased critical illness/disability insurance on mortgages, loans or credit card balances, please check with your financial provider.

Medicine and Drug Coverage

You will be responsible to pay for certain medications when you are an outpatient. If you have private insurance coverage, such as Blue Cross or health coverage through your employer, some of these expenses may be covered. If you do not have private insurance or they do not cover specific medications, you can apply for the *Saskatchewan Health Special Drug Support Program.* You may be eligible for a reduction in your deductible and a decrease in the amount you pay. Applications are available from your pharmacist and will be discussed with you on the day of admission to the hospital for stem cell transplant.

Important Information on Drug Interactions

Certain medications including common over-the-counter drugs such as acetaminophen (Tylenol®), aspirin (ASA®), and ibuprofen (Advil®) may interact with one of the chemotherapy drugs that might be part of your transplant chemotherapy regimen. A pharmacist will notify you by letter before you are admitted to hospital if you need to avoid these and other types of medications.

Admission For Allogeneic Stem Cell Transplant

Welcome to 6100

The next big step of your stem cell transplant journey comes when you are admitted to Royal University Hospital (RUH) Unit 6100: Inpatient Oncology, Hematology and Stem Cell Transplant Unit. You will have an appointment at the Saskatoon Cancer Clinic with a transplant nurse, pharmacist and transplant hematologist either the day before or the day of admission. This is to confirm that there have been no recent changes to your health, and to finalize details pertinent to your admission.

Prior to going to your room on 6100, you will go through "*Registration/Admitting*" on the main floor of RUH. You will receive an identification wristband as well as your admission papers at this time. From this point, take the elevators up to the 6th floor and follow the signs to unit 6100. The clerk will help direct you to your room once you have reached the



unit. If bed available after working hours (after 4:30 p.m.) you will be called and directed directly up to 6100.

Unit 6100 is comprised of 29 beds, including six beds in the BMT unit. The BMT unit is the only one of its type in Saskatchewan. It is located at the back of Unit 6100, with a double door entry system to the BMT unit. Because the BMT unit is a protective isolation unit with specialized air ventilation system that provides high efficiency particulate air (HEPA) filtration under positive pressure, you and visitors will be shown how to "ring" for entrance. Occasionally a room in the BMT unit is not available at time of admission, so you may temporarily be in a room on the regular unit then moved to the BMT unit once a bed becomes available.

You must remain on the BMT unit while your neutrophils are at their lowest unless you need to have essential tests or procedures done elsewhere in the hospital. You will wear a mask at these times.

Personal hygiene is important during this time. Daily baths or showers are encouraged. Each room has a private washroom, for patient use only. You should use fresh towels and clothing daily.

Each BMT room is also equipped with a TV and telephone, which are provided free of charge and free wireless internet is available (find *Patients/Visitors* network on your device).

As regular activity is essential to your recovery and may even help prevent or minimize post-transplant physical complications, a stationary bike is available in each room to help you stay active. You are encouraged to use the bike daily.

What to Bring to the Hospital

Some items you may wish to bring during your hospital stay include:

- Loose, comfortable clothing
- Pajamas or shirts that open in the front for easy access to your CVC
- Slippers and comfortable walking shoes
- Head covering such as scarves, hats, and so on
- Soaps and lotion, but remember to keep them mild or fragrance free
- Soft tooth brush and tooth paste
- Books, magazines, games, lap top, and any other comfort items for diversion
- Pictures of family, friends, pets, etc.
- Blankets and /or pillows



Do not bring fresh flowers, plants or dried flowers as they can carry spores as they may cause infection.

Families and Visitors

Visiting hours on 6100 are not restricted, but visitors should pay attention to how long their visits are to ensure you are able to get enough rest. One caregiver may stay with you during your admission. There is a sleep-chair in each room if they wish to stay overnight.

Important information regarding visitors:

- All visitors must report to the front office of the BMT unit for entry. There are lockers to store bulky items (jackets, boots, etc.) outside of the unit for visitors' use.
- Visitors must ensure that they are healthy before entering the BMT unit by completing a routine screening tool to protect all vulnerable patients on the unit. Visiting is not allowed by visitors with fevers, skin lesions or rashes, nausea, diarrhea, cold or flu symptoms, or recent exposure to contagious disease or live vaccines such as chicken pox, shingles, measles, rubella and whooping cough.
- All visitors must wash their hands with liquid soap and water and/or an alcoholbased hand rub before entering and leaving the room.
- Up to two visitors are allowed at a time during your stay in the BMT unit.
- Visiting by children under 12 years of age is restricted. Please note that arrangements can be made for visiting outside of the BMT unit if your physician permits.
- Visitors must adhere to the scent-free policy.
- Caregivers and visitors are not permitted to use the patient's personal washroom (including shower); public washrooms are available for visitors to use.



Conditioning (Preparative Regimen)



Conditioning (sometimes also called the preparative regimen) is chemotherapy with or without total body irradiation (TBI) used to control your disease and prepare your body to accept the new stem cells. The days that you receive conditioning chemotherapy are referred to as minus days (Day -6, -5, -4 ...) while the day stem cells are infused is called "Day o". The days following infusion of stem cells are Day +1, +2, etc.

There are a variety of conditioning regimens that involve chemotherapy alone, or a combination of chemotherapy and total body irradiation (TBI). The regimen you receive is based on your age, disease, co-morbidities, and type of donor. The conditioning treatment

can be high-dose (myeloablative) or reduced intensity (non-myeloablative):

- **Myeloablative**. Very high doses of chemotherapy, sometimes given in combination with TBI, affects all rapidly dividing cells. This includes cancer cells but also affects other rapidly dividing healthy cells such as bone marrow, hair follicles, mouth, stomach, skin and nails. The dose of chemotherapy is based on your height and weight and is a much higher dose than you would have received for previous treatments. A chemotherapy-certified registered nurse administers this treatment.
- Non-myeloablative. A lower dose of chemotherapy, sometimes given in combination with TBI, works to suppress your immune system so that new stem cells can grow. A chemotherapy-certified registered nurse administers this treatment.





In both myeloablative and non-myeloablative transplants, the new donor stem cells give rise to a new immune system which has an important role in destroying any remaining cancer cells ("graft versus tumor" effect).

Total Body Irradiation (TBI)

If TBI is a part of your conditioning regimen, the Radiation Therapy team will meet with you before you are admitted to hospital. TBI provides benefits of local radiation while minimizing adverse effects on normal tissues and organ function. It has an immunosuppressive effect that helps new stem cells engraft, in addition to destroying cancer cells. It has the additional benefit of reaching sites in your body that chemotherapy may not be able to reach

such as the brain, spinal fluid, and testes.

Depending on your diagnosis, TBI might be a single treatment ("fraction"), or up to six fractions. Once a day TBI is given in the morning, while twice per day TBI is given in the morning and again in the late afternoon. Because all TBI must be given in the Saskatoon Cancer Centre, you will be transferred from the BMT unit to the Cancer Centre for these treatments.

Radiation treatment is not painful. You will receive anti-nausea medications before and after your treatments. You will lie on a stretcher during treatment with a personalized bean bag-like bed to help you stay in one position. Treatments take approximately 30-40 minutes. All metal such as jewelry and glasses will need to be removed prior to the treatment.

Stem Cell Transplant "Day 0"

The day of your stem cell infusion ("transplant") is a significant and often emotional milestone. The infusion of donor stem cells is actually a brief procedure, usually taking less than 1 hour to infuse. The product will be brought to your room by Transfusion Medicine technologists, and is generally infused as a "fresh" (rather than a frozen) product. Stem cells, which look similar to a bag of blood, are infused through your central line. A registered nurse will be with you throughout the infusion, checking your vital signs and watching for any reactions such as nausea, vomiting, flushing, fever, or shortness of



breath. You will receive medications prior to the stem cell infusion to help prevent reactions, which, tend to be mild when stem cells are fresh. Your registered nurse and doctor will be watching closely to manage any symptoms.

Recovery in Hospital

Engraftment

Newly transplanted stem cells travel from your blood stream into your bone marrow where they begin to create new blood cells. This is called "engraftment". It takes a few weeks for new blood cells to be produced and for your blood counts to begin to rise. The wait can be the hardest part! First signs of engraftment are the gradual rise of white blood cell and platelet counts, while red blood cells take a little longer to recover. In most cases, engraftment occurs around 10 to 28 days after the transplant.

Until engraftment occurs, you will be at increased risk of complications such as infections and low blood/platelets. Your health care team will be monitoring you closely during this period, investigating and treating any signs of infection early as well as giving you blood and platelet transfusions as needed.

Early Side Effects of Transplant

A number of side effects are possible throughout allogeneic stem cell transplant. High dose chemotherapy and/or TBI can cause a number of potential side effects. Although cancer cells are sensitive to chemotherapy, so are rapidly dividing normal cells in the body. This means that cells in the bone marrow, mouth, digestive tract, skin, hair, testes, ovaries and lungs may all affected by chemotherapy. Some people become quite ill after receiving chemotherapy, while others experience only mild side effects. Unfortunately, predicting the specific side effects and severity on an individual basis is challenging. Admission to the intensive care unit (ICU) is sometimes necessary to provide temporary advanced support. However if there is severe multi-organ damage or complications occur, there is a risk of death.

Infection

Your white blood cell count will begin to drop in the days following chemotherapy, reaching its lowest level within 10 to 14 days of starting chemotherapy and remaining very low until the newly infused stem cells begin to "home" to your bone marrow and start producing blood cells, or engraft. During this time, the risk of developing an infection remains high until your white count recovers. Infections can be bacterial, viral or fungal.



You will be on medications to prevent viral and fungal infections before and after transplant.

Some signs of infection include fevers, chills, a cough or runny nose, shortness of breath or chest tightness, frequent urination or burning during urination, sore throat, stomach pain, rectal pain, diarrhea, and redness or drainage around the CVC site. Nearly all patients require IV antibiotics during their hospital stay due to infection.

Digestive Tract Symptoms

Mouth sores (mucositis), loss of appetite, nausea, vomiting and diarrhea are all common side effects of chemotherapy. Anti-nausea medications will be given prior to chemotherapy to minimize nausea and vomiting. Good oral care and mouth rinses are important to prevent mouth sores. Dentures must be kept meticulously clean. Rinses containing local anesthetic can minimize the discomfort of mouth sores. If sores become too uncomfortable, stronger medications may be used. Occasionally you may be unable to eat or drink during the transplant period. During this time, nutrition can be provided intravenously. A dietitian will follow you while in hospital to ensure you are getting appropriate nutrition. A dietitian will follow you while in hospital to ensure you are maintaining adequate nutrition.

Fatigue

Fatigue is a very common side effect from chemotherapy and can last for months and sometimes even years after transplant. Many things contribute to fatigue including low blood counts, fighting infections and some medications. Some things you can do to help cope with fatigue are get enough sleep and rest, save and manage your energy, eat and drink appropriately, and stay active.

Additional resources for fatigue are available on the Saskatchewan Cancer Agency website at http://www.saskcancer.ca. Look under the "Patient & Families" tab, then "Managing Side Effects" for "Fatigue".

Hair Loss

Temporary hair loss affects all patients but it will grow back, sometimes a different colour or texture! You can expect to start losing your hair approximately 10-14 days after chemotherapy starts. A prescription for a wig can be provided to you to assist with receiving payments through benefits.

Bleeding & Low Hemoglobin Level

Red blood cells and platelets will be affected by the conditioning chemotherapy, often resulting in a need for red blood cell and platelet transfusions. When your platelets are low, you might bleed and bruise more easily. A soft bristle toothbrush is recommended



when brushing your teeth, and avoid flossing when your platelets are below 20. Use an electric razor only for shaving.

Blood Product Support

Canadian Blood Services (CBS) is the national blood supplier for Canada (excluding Quebec) and looks after the collection, testing, processing and storage of donated blood. Every donation is tested by CBS for known transmissible diseases, including HIV, Hepatitis B and Hepatitis C. Blood components are **not** released by CBS for use until all donor transmissible disease testing is completed. Blood components are produced from blood donated voluntarily by people across Canada.

For more information about blood transfusion and risks associated with please see the Saskatoon Health Authority's *Information for Patients about Blood Transfusion and Tissue Transplantation* handout. You will be required to sign a consent form before receiving any blood products.

Organ Damage

Some of your organs can be affected by chemotherapy and TBI including the liver, lungs, heart and kidneys:

- Liver. *Sinusoidal obstruction syndrome* (*SOS*) is a disorder of the liver in which blood vessels become blocked and swollen. Patients experiencing SOS may be jaundiced (yellow) with swelling in their feet and legs.
- Lungs. May be affected by a number of bacterial, fungal and viral infections, or chemotherapy toxicity.
- Heart. Complications can include cardiac dysfunction due to cardiomyopathy, angina, valve or conduction problems.
- Kidneys. Can be affected by chemotherapy or other medications or infections. In most cases, damage is reversible.
- Bladder. Can be affected by chemotherapy or TBI, sometimes resulting in a condition called *hemorrhagic cystitis*, which is when damage to the bladder causes bleeding. This can also result from a specific viral infection called BK virus.

Acute Graft Versus Host disease (AGVHD)

Graft-versus-host disease is a process whereby donor stem cells (graft) recognize your body (host) as foreign so attack your tissues. GVHD can be either acute or chronic, and can range from mild to severe. Chronic GVHD will be discussed later in this guide. People who develop acute GVHD are more likely to get some form of chronic GVHD later on.



Acute GVHD may occur early any time following engraftment until approximately 3 months post-transplant. It most commonly affects:

- Skin. Can show up as a rash anywhere but most often found on the hands, feet, abdomen and face. May be itchy and red, or can become a blister-like rash.
- Liver. Most often is detected on bloodwork results, but a yellowish coloring of the skin or eyes be also apparent.
- Gastrointestinal Tract. Often appears as nausea and vomiting or watery diarrhea, sometimes along with abdominal pain or cramps.

Acute GVHD requires rapid intervention with the onset of symptoms, most often with:

- Oral steroids (prednisone), or intravenous steroids in more severe cases
- Other immunosuppressive medications
- Topical immunosuppressive agents

Prevention and Early treatment of GVHD is the best way to control it. However sometimes even when treated early, GVHD does not go away. Severe GVHD can be life threatening.

Graft Failure

Graft failure refers to when donor's stem cells are rejected by your body so donor stem cells are unable to grow or engraft, but graft failure or rejection is rare. In the event of graft failure, a second stem cell transplant from the same or a different donor may be considered.

During Your Hospital Stay

Activity

Staying active before, during and after transplant is very important to your physical and emotional health and recovery! While you are in hospital, a physiotherapist and occupational therapist will assess you and recommend what type of activity you should be doing. You will learn which exercises are safe when your blood counts are very low. Although you will be mostly limited to Unit 6100, we encourage you to go for frequent walks around the unit. Regular exercise will help maintain your strength, and can aid in recovery and an earlier discharge from hospital.

Staying as active as you can is helpful, even on days that your energy feels low. This might mean walking in the hallway several times or marching on the spot. After transplant, spend as much time out of your bed as possible! The bed is for sleeping, or for when you are feeling too unwell to be up. It may help to begin slowly and increase your activity level gradual.



Mouth Care

Following your transplant, it is very important to keep your teeth, gums, and mouth clean. Mouth problems are common side effects of chemotherapy, and may be particularly problematic while your blood counts are low.

Tips for good mouth care:

- Continue with routine mouth care each day
- Brush teeth and gums with a soft toothbrush or toothette to prevent sore gums and bleeding
- Continue flossing as you normally would, unless platelets are under 20
- Rinse your mouth at least 4 times daily (after meals and at bedtime)
 - o Use: 1 teaspoon baking soda and 1 teaspoon of salt in 4 cups of water
 - o Swish, gargle then spit out
 - Keep in a covered container at room temperature
 - Make fresh batch each day
- Brush and rinse dentures after eating and before bed
 - Keep them out as much as possible
 - Soak in a cleansing solution for at least 8 hours
- Remove dentures for sleeping
- Use a moisturizer on your lips that does not contain glycerin or petroleum jelly (these can dry your lips)
- Avoid mouthwash that contains alcohol (can cause more pain and irritation)

Diet

During your stem cell transplant hospitalization, you will be on a diet that is safe for immunocompromised patients. This includes avoidance of certain foods, such as deli meat, that may contain high amounts of harmful organisms. Your dietitian will provide education on foods to avoid during this time. They will also follow you throughout your stay to optimize nutrition and prevent weight loss while providing helpful tips on managing potential symptoms. Helpful tips include:

- High protein/high calorie snack and meal options to manage weight loss
- Nutritional supplement options (e.g. Boost, Ensure, Resource 2.0, high protein/high calorie drinks) to increase calories and protein
- Softer, moist foods for sore mouth and difficulty swallowing



- Small frequent meals for nausea and lack of appetite
- Educating families about foods and fluids that are nutrient dense to make every bite and sip pack a powerful nutritional punch
- Foods with little or no smell to reduce nausea
- Experiment with different flavours/textures for changes in taste
- Add lemon wedges or flavours (Mio, Crystal Lite, etc.) to help flavour the water if it tastes "off"
- Continue with optimal oral hygiene so mouth bacteria will not cause further offflavours in the mouth
- In addition to using mouth sprays, choose tart or sour foods to stimulate saliva for dry mouth (decreased saliva production can also change the way taste is perceived).

Constipation

Regular bowel movements can be a challenge because of poor intake as a result of nausea, lower activity level and medications. If you are having difficulty having a daily bowel movement, medications can help. Be sure to speak to your nurse if you are experiencing constipation.

Diarrhea

Diarrhea can occur as a side effect of chemotherapy or infectious causes. Once infectious causes of diarrhea have been ruled out, medications can be used to manage it. Diarrhea usually resolves as your stem cells engraft.

Personal Hygiene

Daily showers, excellent hand-washing, clean clothes, and bedding changes are important for your health as well as a sense of well-being, even though it is difficult when your energy is low and you are not feeling well.



Discharge

After being in hospital for approximately 4-5 weeks for your transplant, it will be time to get ready to go home and start on your road to recovery. Going home after your transplant is exciting, but may also seem overwhelming. Because every patient and family is unique, please be sure to discuss any questions or concerns with your health care team.

When Will I Be Discharged?

Your multidisciplinary team comprised of physicians, nurses, social workers, dietitians, and physical therapists, will make the decision for discharge. Several conditions must be met in order for you to be safely discharged from hospital after your transplant:

- No fevers or active medical problems
- Satisfactory blood counts (although you may still need blood transfusions as an outpatient)
- Medically stable enough to be monitored on an outpatient basis
- Sufficient strength and mobility to attend frequent outpatient clinic visits
- Able to take required medications with little to no trouble swallowing
- Able to maintain adequate fluid intake and eat a satisfactory diet
- Have accommodations within a 1-hour drive to the Royal University Hospital and the Saskatoon Cancer Centre

It is important to remember that discharge from hospital is a transitional process, because you are still recovering. The transplant team will support you during this transition and recovery at home. While leaving the security of 24-hour a day healthcare providers can feel scary, you will still be assessed frequently on an outpatient basis. It is important to understand that serious complications can arise very quickly at any time, so contact your health care team early with new symptoms or concerns.

You, as well as your family or friends, may expect that you should feel and act as you did prior to your illness and treatment, but the reality is that most patients feel weak and tired. It is common to feel impatient or frustrated while waiting for your energy to recover and get back to feeling "normal".

Give yourself permission to take the time needed for recovery, and know that as you get stronger you will be able to do more.

Prior to leaving hospital, you and your caregiver can expect to have several education sessions with different members of your multidisciplinary care team. You will be taught what signs and symptoms need to be reported, along with tips for practical



considerations and lifestyle modifications. Frequent follow up appointments, often 3 times a week, will be arranged for you at the Cancer Clinic. It is common to feel more fatigued after discharge than while in hospital.

Discharge education sessions provide a significant amount of important information and can leave patients and caregivers feeling overwhelmed. Rest assured that if you have any questions or concerns once you are discharged home, someone is always available to help. You will return to your outpatient care team including your transplant physician, primary care nurse, outpatient hematology pharmacists, and social worker.

Central Line Care

You will still have a tunneled CVC when you are discharged. Because you initially have appointments at the Cancer Centre several times a week, line care (weekly flushes and dressing changes) will be done then. The CVC will be removed once you are no longer requiring IV fluids or medications, usually no earlier than 3 months following your transplant.

REMEMBER!!

- Only trained individuals, like Home Care Nurses, are able take care of your central line
- CVC dressings must be changed at least once every week
- All lumens need to be flushed and caps changed at least once weekly



Problems to Report & When to Call

It is essential that you and your caregiver know when and how to contact your health care team once you have been discharged. Not every problem should wait for your next scheduled appointment. Early intervention is very important to prevent further complications.

Use the following guide to direct who to contact or where to present, depending on the urgency and time of day or day of week. A list of specific signs and symptoms follows on page 44-45 (*"Signs and Symptoms: What to Do"*). If you are unsure, always call your primary nurse or the Hematologist on Call.

lf	When	Where	Contact
Urgent	 Weekdays: Call Saskatoon Cancer Centre Monday through Friday 8:00 am to 4:30 pm Excludes statutory holidays 		Call your primary nurse
	 Evenings, weekends and statutory holidays: Call Royal University Hospital Weekends: All day Saturday and Sunday All Evenings: Monday to Friday 8:00 am to 4:30 pm Statutory holidays 		Call 306-655-1000 and ask to page the Hematologist on Call
Emergency*	 For an emergency AT ANY TIME (Day or night, weekdays or weekends) 	In Saskatoon: Royal University Hospital (RUH) Emergency Department or Nearest local ER	Come to RUH Emergency (by caregiver or ambulance) or Call 9-1-1

In the event of an **EMERGENCY**, you must come to Royal University Hospital for immediate assessment. Please bring the following with you:

• FEVER CARD. This is a wallet card indicating that you are an immunocompromised patient. Present this card immediately to staff at any emergency department. This



indicates that you should be triaged as urgent and placed in isolation. *Carry this card with you at all times.*

• Medication List. A current and complete list of your medications.



Signs and Symptoms: What to Do

Symptom	Emergency	Urgent	Semi-Urgent
	Go To RUH Emergency Or Call 9-1-1 IMMEDIATELY	Call BMT Clinic Or Hematologist On Call IMMEDIATELY	Notify Bmt Physician Or Bmt Clinic Within 24 Hours
Bleeding	Uncontrolled bleeding	 New bleeding Unable to stop nosebleed Blood in vomit, stool, urine or sputum Heavy vaginal bleeding 	 Frequent nosebleeds that stop with pressure New bruising Tiny pinpoint red or purple spots on skin
Breathing	Not breathingChoking	 Shortness of breath Trouble breathing while lying flat Wheezing 	 New onset of shortness of breath with regular activities Chest discomfort
Confusion, change in alertness, consciousness, or behavior	 Unconscious Seizure Difficult to wake up 	 New or increased confusion Change in level of alertness Vision changes Falling or change in balance New numbness or tingling Unable to move limbs 	 Mood swings or behaviour changes Difficulty walking
Cough		 Uncontrolled cough Coughing up bloody, yellow or green sputum (phlegm) 	 New or persistent cough Sneezing or runny nose
Diarrhea		 Constant or uncontrolled diarrhea (watery) Diarrhea with abdominal cramping Bloody, or black stools 	 New onset diarrhea More than 5 watery diarrhea stools/day (>500 mL) Passing whole pills or undigested food Weakness or dizziness with diarrhea



Symptom	Emergency	Urgent	Semi-Urgent
	Go To RUH Emergency Or Call 9-1-1 IMMEDIATELY	Call BMT Clinic Or Hematologist On Call IMMEDIATELY	Notify Bmt Physician Or Bmt Clinic Within 24 Hours
			 Change in color of bowel movements (pale like clay)
Eyes		 White part of your eyes becomes yellow 	 Vision becomes blurred or unclear Dry eyes Eyes feel painful Excessive tearing
Fatigue	Unable to wake up	 Dizziness Too tired to get up or go to the bathroom 	 Increase in fatigue Difficulty performing activities of daily living
Fever		 Fever of 38.0 °C for more than 1 hour <u>OR</u> Fever of 38.3 °C once Shaking chills with or without fever 	 New redness or swelling or drainage at central line site Cold or flu symptoms Difficulty flushing central line catheter or chills after you flush catheter
Mouth Pain		Difficulty breathingUnable to swallow pills	 Bleeding in mouth New mouth sores Pain not controlled
Nausea or vomiting		 Unable to swallow or keep down pills Uncontrolled nausea or vomiting Bloody or "coffee ground" vomit 	 Persistent nausea Weakness or dizziness with nausea/vomiting
Rash (Skin)		Sudden new rash	 Changes in skin rash Itchy rash, especially on the palms of hands or soles of feet Flushed skin Skin redness, swelling or pain around central line site
Swelling	Not breathingNot swallowing	 Sudden swelling Swelling/redness or pain in back of leg/calf 	 New onset of swelling in legs, feet, hands, face with or without pain Swelling at central line site



Symptom	Emergency	Urgent	Semi-Urgent
	Go To RUH Emergency Or Call 9-1-1 IMMEDIATELY	Call BMT Clinic Or Hematologist On Call IMMEDIATELY	Notify Bmt Physician Or Bmt Clinic Within 24 Hours
			 Pain in joints or abdomen with or without swelling
Urination (voiding)		 Unable to void for 8 hours or more Blood in urine Frequent or painful urination 	 Change in or strong odor to urine Change in color of urine

It is important to understand that it is common (and expected) to be readmitted to hospital after being discharged to deal with complications.

Once you are out of the hospital, it is important that you are a willing and active participant in your recovery and care. You must:

- Have access to a telephone (voicemail is beneficial)
- Take steps to avoid infection
- Watch for and report new symptoms in a timely manner
- Eat well and follow food safety guidelines
- Take medications as directed and report side effects
- Get adequate activity and rest
- Accept help and support from others
- Follow recommendations for follow-up care
- Attend all appointments



Outpatient Care

Follow Up Appointments

Following discharge, you will have frequent follow up appointments. A registered nurse at the Saskatoon Cancer Centre will assess you three times per week initially. Expect to see your transplant physician once a week, or more often as needed. As you recover, your follow up appointments will become less frequent.

Appointments will be first thing in the morning to allow for blood tests. You will have blood work drawn, and a nurse will assess you. Once blood work results are back (usually about 1 hour), you can expect to receive intravenous (IV) infusions such as magnesium or transfusions that same day. Fluid and electrolyte infusions are routine following transplant as some of the medications you will be on cause your body to lose electrolytes.

Infusions take place at the **Oncology Day Centre**, an outpatient unit located in Royal University Hospital. Most infusions take between 1 to 3 hours, and sometimes longer if multiple treatments are needed (for example: blood transfusions, IV medications, etc.). You will need to register at Royal University Hospital Admitting prior to receiving treatments.

Graft Versus Host Disease

A common complication of allogeneic transplant is graft-versus-host disease (GVHD), the result of donor stem cells recognizing the patient's body as foreign. There can be a benefit to GVHD. The same immune response responsible for attacking your normal cells can also destroy surviving cancer cells, known as graft-versus-tumor effect. GVHD can affect your quality of life.

GVHD may be acute or chronic. Acute GVHD often presents in the first 3 months after transplant and can affect the skin, gastrointestinal tract and liver. Chronic GVHD can present at any time, though more commonly is after 3 months and can persist for a lifetime. It may develop as a continuation of acute GVHD or can occur without prior history of GVHD and can affect skin, eyes, hair, nails, genitalia, mouth, liver, lung, gastrointestinal tract, joints and muscles.

The following chart describes some of the sites and symptoms related to GVHD:



Site	Symptoms
Eyes	Dry or gritty eyesBlurry vision
Liver	 Abnormal blood tests Abdominal pain Yellow discoloration of skin/eyes
Skin and nails	 Rash or discolored areas Skin tightening or thickening Nail changes
Gastrointestinal Tract	 Persistent nausea Vomiting Abdominal cramps with diarrhea Poor appetite
Mouth	Dry mouth with soresPain or irritation in mouth
Joints and Muscles	 Pain and stiffness Muscle pain Cramps Weakness
Lungs	 Shortness of breath Cough that doesn't go away Trouble breathing
Vagina/Vulva (Female Genitals)	 Dryness or irritation Rash or open areas Painful intercourse

GVHD can be challenging to diagnose in some cases. Investigations may include:

- Physical exam
- Blood work
- Biopsy
- Other tests, such as a colonoscopy or imaging tests

Some symptoms are vague, which can make the diagnosis possible only after excluding other causes.

Following transplant, immunosuppressive, or anti-rejection drugs such as cyclosporine or tacrolimus are given to help reduce the risk (or severity) of GVHD.



The goal is to slowly taper the dose of these medications before stopping them completely a few months after transplant. It is sometimes necessary to restart these drugs if there are symptoms of GVHD. Similarly, more immunosuppression are added if you develop signs of GVHD while already on these medications.

GVHD is most commonly treated with:

- Steroids such as prednisone
- Other immunosuppressive medications
- Topical creams/solutions
- Extracorporeal photopheresis (ECP)

The effectiveness of GVHD treatment is influenced by the site and severity of GVHD. Patients will also be at risk for infections while on immunosuppressive therapy.

Some things you can do to reduce your risk of GVHD are:

- Take all your medications as directed
 - Let your nurse know if you are unable to take your medication for any reason
- Watch for early warning signs
 - Early treatment of GVHD can make a big difference
- Protect yourself from the sun
 - Exposing yourself to the sun's ultraviolet rays increases your risk of GVHD
 - o Avoid the sun as much as possible
 - Wear a hat, long sleeves and pants when you go outside
 - Apply a sunscreen with SPF 30 or higher
 - Remember that the sun can be harmful on cloudy days as well!

Medications

Following allogeneic stem cell transplant, there are many medications prescribed to help prevent infections, GVHD, and other common post-transplant complications. Prior to discharge, a transplant pharmacist will explain the purpose of each medication, how and when to take each medication, and for how long. A personalized medication calendar will be provided to help follow your new medication regimen. It is vital to have a current list of your medications with you at all times! This list will be reviewed at **each** visit. If you require an updated medication calendar, please ask your primary nurse or transplant pharmacist. It is important for you and your caregiver to be familiar with your medications.

Please do not stop any medication without specific direction to do so from your doctor, nurse or pharmacist. Also, do not take any medication without consulting your pharmacist, physician or nurse, as certain medications may not be recommended (for example, any nonsteroidal anti-inflammatory drugs such as ibuprofen).

Please bring ALL of your medication bottles to your first outpatient appointment so the pharmacist or primary nurse may review everything once again in detail.



Common immunosuppressant medications used to prevent GVHD are cyclosporine or tacrolimus. Blood levels for these medications are monitored frequently and the doses of medication often need to be adjusted based on the blood results. In order to get an accurate level, you must take your cyclosporine or tacrolimus after your blood work is drawn. Please bring these pills with you to the clinic. Results are usually received by the end of day or the next morning, so you may get a phone call to change your dose.

DO NOT take your cyclosporine or tacrolimus pills before blood work



A community pharmacy of your choice will be needed to fill your oral medications. Some pharmacies do not carry all of the drugs you will be prescribed, so they may need to be ordered which often takes at least one business day. Please discuss options with pharmacist to avoid any delays in receiving your medications.

Bring a list of required medication refills to your appointments to avoid delays, as requests for refills by phone often take more than1 day.

Preventing Infections

Following allogeneic stem cell transplant, your risk of infection remains higher than normal for up to 2 years (and even longer if you have GVHD and are on immunosuppressant medications), even if your blood counts are normal. Even though your body has started to produce white blood cells again, your new immune system needs time to mature, just like when you were a child. This includes repeating childhood vaccinations once directed.

One of the most important ways to prevent infection is frequent **hand washing**: every time you return home, after using the bathroom, before eating as examples. If you feel unwell or have a fever, you will need to check your temperature and either call the Cancer Clinic or seek medical attention.

Some other hygienic recommendations include:

- Shower daily, and perform regular mouth care.
- For dry skin, use a mild moisturizer or baby oil after showering.
- Avoid lotions with alcohol and fragrances
- Use your own clean towel and face cloth every day
- Avoid close contact with people who are ill or coughing
- Avoid crowded areas where close contact with persons with respiratory illnesses is likely; instead try visiting public places at times when they are less busy
- Do not use tampons for the first 12 months post-transplant



Be sure to notify your health care team if you will be in contact with children that have been immunized with live virus vaccines who has developed a rash or fever, or a child who has chicken pox, measles or other viruses.

Special blood work following transplant can detect specific viral levels. These common viruses do not cause illness in a healthy person, but can reactivate in your body after stem cell transplant because of your weakened immune system. Here is additional information on specific viruses that are closely monitored:

Cytomegalovirus (CMV)

- Many adults have been exposed to CMV in their lifetime, usually without knowing it
- Following exposure the virus remains asleep in your body without causing symptoms
- CMV status of patients and donors is checked before transplant; CMV-negative donors are preferred for CMV-negative recipients if this an option
- Blood work is checked regularly after transplant to monitor for increased CMV levels
- Medications are started if there is a rise in CMV levels, even without symptoms
- If there is progression to CMV disease, symptoms can be present in the lungs (CMV pneumonitis), colon (CMV colitis), liver (CMV hepatitis) and eyes (CMV retinitis)
- Admission to hospital may be required to treat CMV reactivation
- Early intervention is important

Epstein Barr Virus (EBV) and Post-Transplant Lymphoproliferative Disorder (PTLD)

- Many adults have been exposed to EBV in their lifetime without realizing it; only a minority will have been diagnosed with mononucleosis (usually as an adolescent)
- Following exposure, the virus remains asleep in your body without causing symptoms
- Following allogeneic stem cell transplant, EBV-infected white blood cells can result in post-transplant lymphoproliferative disease (PTLD)
- PTLD is a serious complication following stem cell transplant
- Blood work is regularly monitored following transplant for detection of EBV reactivation
- Symptoms of PTLD can be vague (such as fever, weight loss, fatigue) and vary depending on the type and location of PTLD
- Intravenous medications are started with a rise in EBV levels, even without symptoms
- Highest risk is the first year following stem cell transplant

Home & Environment

Before returning home from hospital, it may be helpful to have your home thoroughly cleaned including cleaning and replacing all filters (air conditioning, heaters, and



humidifiers). Exposure to molds and dusts can be risky while your immune system is weakened.

In order to protect yourself:

- Avoid yard work, gardening, and farming until your doctor says it's okay
- Avoid construction areas
- Avoid activities that expose you to dust or dirt; when near a construction site, wear a mask

You can do things such as:

- Clear dishes from the table
- Wash dishes
- Make beds

Someone else should:

- Dust and vacuum
- Clean bathrooms with a disinfectant regularly, especially the tub and toilet

Pets

It is okay to return home to your pets, with some limitations. Dogs, cats, and fish do not pose a great risk of infection to you if you follow the guidelines below. If you have any other animals at home, please discuss it with your physician. It may be best to let someone else care for them for a while. If you do not have a pet, now is <u>not</u> the time to get a new pet.

- Have someone else clean your pet's cage, litter box, pen or fish tank until for the first 3 months or until you are off immunosuppression medications
- Have your pet sleep in another room
- Be sure to wash your hands after petting and handling your pet
- Avoid being scratched by your cat
- Do not have your pet's litter box or cage in kitchen where food is prepared and eaten
- Do not let your pets lick you keep them away from your face
- Only feed your pet food that has been bought from a store
- Ensure your pet's vaccinations are up to date
- Take pet to veterinarian at the first sign of illness

Diet & Food Safety

While food safety is important to everyone, chemotherapy and stem cell transplant patients are at an increased risk of developing a serious illness from eating foods with bacteria, viruses, or parasites. Refer to the *Food Safety for Patient's with Weakened Immune System* booklet for more information on what foods to avoid for the first 2 months after autologous stem cell transplant.



It is common for your appetite to remain lower than normal when you leave hospital. Good nutrition is important to help prevent infections, maintain and rebuild your muscles, and restore energy. Your dietitian can help you with strategies to get the calories you need and provide teaching on safe food preparation and storage.

Some suggestions for safe foods and foods to avoid include:

Sask cancer

Type of Food	Foods to Avoid	Safer Food Choices
Deli Meats and	Non-dried meats such as	Dried and salted deli meats such as salami and
Hot Dogs	bologna, roast beef and	pepperoni. Non-dried deli meats heated until
	turkey breast. Cold hot	steaming hot. Hot dogs cooked to a safe
	dogs straight from package	internal temperature - 74°C (165°F).
Other	Any foods/fluids with	Canned goods commercially made and
	probiotics added (ex	processed
	Activia/Danactive yogurt, Kefir, Yakult and Good Belly	Commercially fermented foods that have been pasteurized after fermentation
	drinks). Home canned	pastednzed alter reimentation
	goods (jam, preserved	
	pickled foods). Fresh	
	, fermented foods	
Meat, Poultry	Raw or undercooked meat	Meat and poultry cooked to a safe internal
and Pâtés	or poultry, such as rare	temperature. Pates and meat spreads sold in
	steak or steak tartare. Fresh	cans
	pâtés and meat spreads.	
Seafood	Raw or undercooked	Seafood cooked to a safe internal temperature $f = f \left(\frac{1}{2} - \frac{1}{2} \right)$
	seafood such as sushi, poke	of 74 C (165 F). Cook until the shell has opened. Canned seafood (smoked salmon, canned
	bowels. Raw oysters, clams and mussels. Refrigerated	tuna, etc)
	smoked seafood.	
Eggs and Egg	Raw or undercooked eggs	Egg dishes thoroughly cooked to a safe
Products	or egg products including	internal temperature. Eggs should be cooked
	salad dressings, cookie	until the yolk is firm. Homemade eggnog must
	dough, or cake batter,	be heated to 71°C (160°F). Pasteurized egg
	homemade mayonnaise,	products in a carton. Commercially made
	aioli and homemade	mayonnaise and salad dressings
Dairy Products	eggnog. Raw or unpasteurized dairy	Pasteurized dairy products, and hard cheeses,
Daily Troducts	products including	such as Colby, Cheddar, Swiss and Parmesan.
	unpasteurized milk, soft and	
	semi-soft cheese such as	
	Brie, Camembert and blue-	
	veined cheese.	
Sprouts	Raw sprouts such as alfalfa,	Thoroughly cooked sprouts.
-	and bean sprouts.	
Beverages	Unpasteurized fruit juice,	Unpasteurized fruit/vegetable juice, cider or
	cider, beer or other unpasteurized alcohol,	beer. Check with a doctor before consuming any
	kombucha tea.	alcohol
Water	Well water that has not	Municipal tap water, bottled water, well water
	passed safety tests	that has passed a safety test, boiled well water
	-	



Source: Health Canada and the Canadian Food Inspection Agency

Even though you may not feel like eating, good nutrition during and after transplant is important to maintain your strength and help your body recover.

Make every bite count	Eat high calorie, high protein foods, such as ice cream/non-dairy frozen dessert, yogurt, sour cream, nut butters, smoothies, milkshakes, dried fruit, nuts, eggs, fish, meat, cheese, dried beans, peas and lentils Drink homogenized milk instead of 2%, and try cream- based soups instead of clear soups
Make every sip count	Drink a high protein high calorie supplement drink throughout the day such as Ensure or Boost, or make your own high protein high calorie drink by mixing 1 tablespoon of skim milk powder, 1 cup of cow or soy milk, 1 banana (or ½ cup of your favourite fruit) and ½ cup of ice-cream. Blend all of these ingredients and serve chilled.
Eat often	Aim to eat 6–8 small meals daily instead of 2–3 large meals. Ideas include granola bars and milk, cheese and crackers, toast and peanut butter, bagel and cream cheese, pita bread and hummus or tzatziki, chips and dip, dried fruit, trail mix, pudding (rice, tapioca), cookies, fruit custard.
AND	Eat in a pleasant atmosphere with family or friends to raise your spirits

Here are some more helpful tips:

Temporary changes to your sense of taste may last several weeks. Food may taste bitter or metallic. Some ways you can try to cope with these taste changes are:

- Eat when you are hungry rather than just at meal times
- Rinse your mouth before and after eating to help clear taste buds
- Keep trying different foods keep a list of foods that taste good to you
- Citrus fruits, such as oranges or lemons, can help stimulate the taste buds, but avoid citrus fruits if they irritate your mouth or if you have mouth sores
- Use seasonings to make foods taste better, but be cautious with spices and seasonings as they can irritate a sore mouth and bother an upset stomach.
- Try marinating meats; if red meats don't taste good, try other sources of protein such as chicken, eggs, fish, peanut butter, beans or dairy products
- If food tastes metallic, use plastic utensils instead of metal



 Suck on sugar-free lemon candies or mints, or chew gum, to help get rid of unpleasant after-tastes

The Saskatoon Cancer Centre and Allan Blair Cancer Centre have outpatient dietitians that are available for ongoing support. If you have further questions or concerns after you leave hospital, please discuss these with your primary nurse who can initiate an outpatient dietitian referral.

Chemotherapy and some medications can affect the liver. Do not drink alcoholic beverages during treatment and for 3 months post-transplant, and in some cases longer. Check with your physician before consuming alcoholic beverages.

Activity/Exercise

Staying active before, during, and after transplant is very important towards your health and recovery! While you are in hospital, a physiotherapist and occupational therapist will assess and advise you on the type of activity you should be doing. When your blood counts are very low, they will let you know what type of exercises are safe. Although you will be mostly limited to Unit 6100, we encourage you to go for frequent walks around the unit. Regular exercise will help maintain your strength, and can aid in recovery and an earlier discharge from hospital.

Staying as active as you can is helpful, even on days that your energy feels low. This might mean walking in the hallway several times or marching on the spot. After transplant, spend as much time out of your bed as possible! The bed is for sleeping or when you are feeling too unwell to be up. It may help to begin slowly and increase your activity level gradual.

It is important to continue activity and exercise as tolerated. Some benefits of exercise following stem cell transplant include:

- Decreased incidence of chest infections and blood clots
- Improved mental and emotional well-being
- Improved sleep
- Decreased need for pain medication
- Improved heart function
- Increased appetite

After you are discharged from hospital, it is important to get out and do things you enjoy. However, do try to stay away from crowded areas while you are on immunosuppression medications such as malls, buses and movie theatres where you have a higher likelihood of coming into contact with people who could give you an illness. It is better to visit these areas during less busy times, usually between 9:30 am and 11:30 am. Continue strict hand washing after such activities.



Fatigue tends to last for some time after transplant. Increase activity over time and take frequent rest breaks. Before starting any strenuous activity, check with your health care team. If your hemoglobin is quite low, you may experience fatigue, shortness of breath, lightheadedness and rapid heart rate. When your platelets are low, you may bruise and bleed easier so should avoid high impact activities such as running to prevent injury to muscles and joints.

Avoid swimming in lakes, rivers, swimming pools and hot tubs while you are on immunosuppression medications.

Have someone else drive you until otherwise told by your doctor. Many patients find that they feel too weak or too tired to drive. To be safe, please check with your transplant physician before driving.

Plants & Flowers

Soil contains bacteria, fungi and molds that can cause serious infections. It is not necessary for you to get rid of all your houseplants, but we do recommend that you do not re-pot plants or flowers, and avoid farming, gardening, raking leaves and mowing the lawn until your doctor says that it is safe to do so. Once your doctor says its okay, be sure to wear gloves and a mask for at least 3-months to limit your exposure.

Sun

Chemotherapy can make your skin more sensitive to the sun and can also activate GVHD, so avoid direct sun exposure to the skin. Use SPF 30 or higher and wear a wig, scarf or hat when outside. Sunscreen should be used along with shade, clothing and hats, not instead of them. It is particularly important to avoid sun exposure between the hours of 10:00 am and 3:00 pm. be particularly careful in areas that reflect sun/UV rays such as the beach, water and swimming pools. All of these recommendations should be followed for life.

Sexual Intimacy

The extent to which transplant affects ones' sexual life varies, but it is normal to feel a decrease in sexual desire following transplant. Contributing factors include hormone changes, fatigue, pain, and changes in self-image.

Resuming intimate relationships takes patience and time. While it is safe to resume intercourse once your blood counts have recovered (platelets >50,000 and neutrophils >1500), it can take several months or more for interest in intimacy to return so open communication with your partner is key. You should feel free to kiss, hug and sleep in the same bed as your partner unless they are ill. Touching and caressing take much less energy than sexual intercourse and can provide an ongoing sense of intimacy.

It is unlikely that you will be able to become pregnant or father a child after transplant, although pregnancies have happened after stem cell transplant. Men and women should



continue on birth control following transplant for at least 12 months; then discuss with your physician.

Women who were pre-menopausal may experience some symptoms of menopause such as:

- Hot flashes
- Loss of bone mass
- Vaginal dryness
- Mood swings
- Decreased interest

These can occur because of the lack of ovarian hormone production. Using lubricants, gels or other vaginal creams such as K-Y jelly may help to relieve some of the vaginal discomfort. Consult your physician with concerns as they can refer you to a specialist to help with some of these issues. Please feel open to discuss any questions and concerns with your health care providers at any time.

Fatigue

Fatigue is one of the most common concerns following stem cell transplant, and can significantly affect your quality of life. One of the most common causes of fatigue is side effects of chemotherapy. Other factors that can contribute to fatigue are disruption of eating and sleeping habits, often due to nausea, pain, and/or changes in routines. It may be helpful to know that everyone feels and deals with fatigue differently.

Here are some helpful tips to assist you in dealing with fatigue:

- Be active: Research shows that exercise is the best way to improve your energy.
- Improve your sleep: Try waking up at the same time each morning. At night, relax before going to bed by doing activities such as reading, listening to music or taking a warm bath.
- Manage stress and emotions: Talking to someone about your feelings or doing activities to relieve stress and anxiety can help your fatigue.
- **Pace yourself**: Use your energy wisely in order to be able to do the things that are most important to you. Rest between activities. Try easier or shorter versions of the activities you enjoy.
- Eat and drink well: Eat as well as you can, and drink plenty of fluids.
- Accept help: Ask your family or friends to help you with tasks you find difficult or taxing.



- Journal: Keep a diary of how you feel each day to help you with planning your daily activities.
- **Pastimes**: Nurture an interest in less strenuous activities such as listening to music or reading.

Returning to Work or School

It generally takes at least one year following transplant before returning to work or school in order to allow adequate time for recovery of blood counts, immunity, and overall wellbeing. Some people may never be able to return to work or school, or only return part time. This timeline can vary based on individual tolerance of the transplant procedure, work environment, and other factors. It is important to start this discussion early with your health care team following discharge from hospital to ensure that expectations are realistic.

Travel

All allogeneic transplant patients are required to stay in Saskatoon for **at least** the first three months after transplant. Depending on your health status, it may be necessary to stay in Saskatoon beyond three months in order to continue monitoring your health closely.

For at least the first twelve months following stem cell transplant and while you are on immunosuppression medications, it is important to discuss travel plans with your physician. Activities that increase potentially dangerous environmental exposures such as camping, hunting and fishing should be avoided during the early post-transplant period. If your travel plans involve travel by air, you are encouraged to discuss the potential concerns with your health care team. In general, short trips in which you have control over the environment are safe, particularly to locations where a full-service health care center is located in case complications arise. Be sure to check with your insurance provider(s) prior to booking travel, as there may be insurance implications.

Driving

For the first three months following transplant, it is important to have someone drive you for both your safety and the safety of others. Depending on your recovery and medications, you should discuss when it is safe to return to driving with your doctor.

Immunizations

Because immunity is impaired following stem cell transplant, you will need to repeat your childhood immunizations. You will receive a letter by mail with instructions advising you begin re-immunizations approximately six months post-transplant. This letter will advise you to contact your local public health nurse, along with a list of the immunizations due.



One-year post-transplant another letter will instruct you to contact your local public health nurse again to book the next immunizations.

Starting two years post-transplant, the transplant coordinator will review your current medications to see if/when you are eligible for the next set of immunizations that include live vaccines. You will be notified by letter once you are able to receive live vaccines. It is important to note that these vaccinations may not start on schedule if you are still on immunosuppression medications. Some people may not ever receive live vaccines if on immunosuppression medications.

In addition, all stem cell transplant patients should receive a flu shot each year at least 4 months post-transplant. You will receive a letter in the mail during flu season encouraging you to attend a flu clinic. Household members and close contacts are also encouraged to receive the flu vaccine. Please discuss any questions or concerns with your health care team.

Shingles

Shingles is a painful blister-like rash, often on one side of the chest or back, but it can also affect other areas including the face. You may feel burning, itching or tingling up to a couple of days before the rash appears. It is very important to seek medical attention as soon as possible once the rash appears to start on treatment if you think you have shingles.

Shingles are caused by the same virus that causes chickenpox (called Varicella zoster). Once you have had chickenpox, the virus remains asleep in the body but can be reactivated when your immune system is weakened. You will be on an antiviral medication to prevent shingles for some time after your stem cell transplant.

Because these viruses are highly contagious, they can easily be passed on to others who have never had chickenpox or not been vaccinated. It is important to avoid contact with anyone who has been exposed or has an active infection, and report any exposure to chickenpox or shingles to your health care team early.

Be sure to report blister-like rashes, or exposure to chickenpox or shingles to your health care team as soon as possible

Shingles vaccinations are not recommended post-transplant for at least 2 years, and should be first discussed with your transplant physician.

Coping and Support



Having a serious illness is an experience that permanently changes you and the relationships you have with those around you, although this is not necessarily negative. It is common to be anxious for things to "get back to normal" and it can be frustrating if this does not happen as expected. Understanding that you can create a new normal can help with the frustration. In fact, some people find the experience quite positive. Many patients and family members come through treatment with a new appreciation for life, sometimes taking on different roles within family and community, and seeing their lives and futures in a different light. This transition period is a process and is something that your social worker and help with and support you through if you choose.

A resilient attitude is essential. Your emotions may go up and down - try not to be too hard on yourself, and accept what you are feeling. Try to take one day at a time, knowing that some days will be easier while others are tough. The effects of chemotherapy and transplant can be hard, and recovery after some treatments can be a very slow and difficult process. Be patient with yourself.

Recognizing and acknowledging feelings and concerns is important for both you and your family in order to develop physical, mental, emotional, and spiritual resilience.

Life After Transplant

It can take 1 to 2 years to return to a relatively normal lifestyle. This is in part because it takes this long for your new immune system to function fully. In some cases, ongoing medical treatments will be required for the rest of your life.

There are certain times post-transplant when tests are necessary to evaluate response to the transplant, as well as to identify problems early. Additional tests may be necessary, depending on your health and complications. If you have GVHD, for example, you may require more frequent testing.

Organ function and disease status will be checked at different time points post-transplant. Special eye and dental follow up will also be scheduled following transplant. Annual assessment tests will include extensive work-up to assess organ functions and disease status.

It is difficult to predict with certainty when side effects will occur. Everyone responds differently and symptoms are specific to each individual. Some side effects may not be apparent until long after the transplant.

Your family physician remains an essential part of your health care team following transplant for management of non-transplant related issues.



If you had an unrelated donor for your transplant, you may request to contact your donor one year following your transplant. Contact the Donor Search Coordinator if you are interested in contacting your unrelated donor (refer to Contact Information).

Depression

Some people may feel sad, upset or angry because of their illness and treatment. These feelings are a natural response to stress and usually lessen overtime. If these feelings interfere with your daily life, you should talk to your doctor. Persistent sad feelings and lack of interest in things you normally enjoy could be signs of depression

Cataracts

There is a possibility of developing cataracts after stem cell transplant, particularly if you received TBI and/or large doses of steroids. Cataracts can be successfully treated with a minor surgical procedure. An ophthalmologist (eye specialist) will follow you regularly and advise how often you require follow up assessments.

Bone Complications

Regular risk factors for osteoporosis include older age, family history, smoking, physical inactivity as well as a diet low in calcium or vitamin D. Stem cell transplant increases the risk for developing osteoporosis for many reasons including prolonged use of steroids and other immunosuppressive medications. Bone density scans are done post-transplant to determine your risk.

Secondary Malignancies

Chemotherapy can increase the risk of developing a new cancer, known as a secondary cancer, particularly as a late complication of high-dose chemotherapy. It is important to be aware of the risk of a secondary cancer following high-dose chemotherapy treatment, and to discuss with your transplant physician.

Disease Relapse

It is important to understand that the goal of transplant is to cure your disease. However, there are times that the stem cell transplant does not work and the disease still comes back. Talk to your transplant physician about the likelihood of this happening.

GVHD Effects

While chronic GVHD has been discussed previously, it is important to understand that chronic GVHD can last a lifetime, and can affect many body systems including the skin,



mouth, and eyes. Depending on the severity of GVHD, it can affect your daily activities and quality of life.

Hypothyroidism

Hypothyroidism refers to when the thyroid gland is underactive. It can be a long-term side effect of TBI, usually occurring a few years later. If this condition develops, it is easily treated with medication.

Infection

Infections can be bacterial, viral or fungal. While most infections occur within the first 100 days post-transplant, your immune system does not return to functioning normally for one to two years, even if the numbers for your blood counts are normal. Some people will need to stay on immunosuppression medications long term.



"I had a great friend who I was able to talk

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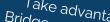
to about my rears and we would go for long walks and talk. It was exercise and a

"Words Of Wisdom"

From others who have experienced this journey:



"...the best tip I would have for a patient and caregiver is being positive even when you're feeling down. It always was great to see (my partner) come in smiling and happy, not sure how she was feeling inside, but it made things a lot easier"



"Take advantage of a site like Caring Bridge so that you can keep your family and friends updated as to how things are going. It saves having to call/text/email everyone and then you know everyone who cares has the same information.

"I also had a very clever social worker who, when I was worried about leaving (my partner) to go for my regular swim, advised me that it was important to take care of myself so I could take care of him. It was very good advice that I believe helped me get through the stressful times. The hospital stay is a long one and if you can get out, either with a friend/family or on your own, even just for a walk it is so good for you. You have to remember that your loved one is being cared for by the best so take advantage of it and don't feel like you need to be there every minute."

"Listen to the doctor and nurses"



Resources

Further Information

Some patients wish to access further information regarding their particular disease and the stem cell transplant process. Sources of information include:

- Cancer Information Services (Canadian Cancer Society) 1-888-939-3333
- Saskatoon Cancer Centre and Allan Blair Cancer Centre Patient and Family Resource Centres (Patient Library)
- Internet Sites (Note: these sites are provided as reference only the BMT Program does not endorse specific information provided by these sites)
 - Blood and Marrow Transplant Information Network. 1-888-597-7674, <u>http://www.bmtinfonet.org/</u>
 - National Bone Marrow Transplant Link. 1-800-546-5268, <u>http://www.nbmtlink.org</u>
 - o Lymphoma Foundation Canada. <u>www.lymphoma.ca</u>
 - o Leukemia and Lymphoma Society (LLS). <u>www.leukemia-lymphoma.org</u>
 - o LLS- Young Adults (18-39). <u>www.LLS.org/YAconnect</u>
 - o Lymphoma Information Network. <u>www.lymphomainfo.net</u>
 - o National Marrow Donor Program. <u>www.marrow.org</u>
 - The Canadian Cancer Society. <u>www.cancer.ca</u>
 - People Living With Cancer. <u>http://www.plwc.org</u>
 - o Medline. <u>www.nlm.nih.gov</u>
 - o Memorial Sloan Kettering Cancer Centre. <u>www.mskcc.org</u>
 - o Young Adult Cancer Canada. <u>www.youngadultcancer.ca</u>
 - o Caringbridge. <u>www.caringbridge.org</u>
 - o Lotsa Helping Hands: A site to coordinate care. <u>www.lotsahelpinghands.com</u>
 - o Cancerchat Canada. <u>www.cancerchatcanada.ca</u>
 - o STEM (Saskatchewan Stem Cell Transplant Advocacy Group). <u>www.stemsask.ca</u>

Please remember not everything you read about cancer will apply to you, and not all information on the internet is reliable. The best source of information for your individual case is your transplant physician and the health care team. While it is important to be informed, some patients find too much information overwhelming - you are the best judge of how much is right for you.



Patient and Family Resource Centre

Located on the main floor at Royal University Hospital, the Patient and Family Resource Centre provides comfortable seating, five computer stations with internet access, a printer and, books and magazines. There is access to information on local accommodations and amenities. The Centre can connect patients and their families with library resources, patient education materials and additional resources within Saskatoon Health Region, including access to translation services, spiritual care, social work services, client representatives and other services.

Support Groups

Look Good Feel Better

This popular workshop is held the second Thursday of the month for *women only*, providing tips on looking your best while going through your treatments. A professional cosmetologist leads the sessions. Space is limited and sessions fill quickly.

First Connection Program (Leukemia & Lymphoma Society of Canada)

Connects patients, families, and caregivers with individuals who have personally experienced the challenges of dealing with a diagnosis of leukemia, lymphoma, myeloma or myelodysplastic syndrome.

o Phone: 1-866-547-5433, press 2, extension 8

CancerConnection

CancerConnection is a one-to-one telephone-based support service that matches people who are living through an experience with cancer with trained volunteers who recently have had cancer.

Every effort is made to match you with a cancer survivor with a similar diagnosis and treatment. Caregiver support and connecting caregivers is also offered.

• To access *CancerConnection*, call the *Canadian Cancer Society* toll free at 1-800-263-6750.

Emotional Support and Counselling

The emotional impact of treatment and transplant can be very significant. Understanding how you and your caregivers/family are affected emotionally can help with coping. Counselling is available to you and your family – please ask for help when you need it. Social workers on the Malignant Hematology/BMT team are available to meet with you to discuss any concerns.



• To contact your assigned social worker, please refer to page 7 for contact information.

Glossary



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Term	Definition
Absolute Neutrophil Count (ANC)	The total number of neutrophils (infection-fighting cells) in your blood; a very low ANC means the risk of infection is very high
Activities of Daily Living (ADL)	Activities of everyday living such as bathing, dressing, eating, and using the toilet
Allogeneic Stem Cell Transplant	A transplant in which hematopoietic stem cells are obtained from a suitably matched related or unrelated donor
Apheresis	A procedure in which peripheral blood stem cells are collected from the blood stream
Autologous Stem Cell Transplant	A transplant in which the patient receives his or her own stem cells
Bone Marrow	The tissue found in the soft center of bones where blood cells (red blood cells, white blood cells and platelets) are produced
Central Venous Catheter (CVC)	A small tube inserted into a large vein leading to the heart that can be used to collect stem cells as well as to draw blood and infuse intravenous fluids, medications, and stem cells
Collection	The process of collecting stem cells through peripheral blood stem cell apheresis; also called harvest
Conditioning Regimen	Treatments of chemotherapy, monoclonal antibodies, and or radiation to the whole body used before infusion of stem cells in order to destroy cancer cells and prepare for newly transplanted donor stem cells
Cryopreservation	The process of freezing stem cells in order to preserve them for use at time of transplant



Term	Definition
Cytomegalovirus (CMV)	A relatively common virus carried in an inactive state by healthy individuals but that can cause serious complications in immunocompromised patients
Day o	Day of stem cell infusion; "transplant day"
Engraftment	The process by which re-infused stem cells grow in the bone marrow and produce new blood cells. After stem cells are re-infused, engraftment is the rise in blood counts once the new stem cells begin working
Graft Failure	When transplanted bone marrow does not produce new blood cells, or stops producing blood cells after initially functioning
Graft Rejection	When the recipient's cells reject the transplanted donor cells
Graft Versus Host Disease	A condition in which transplanted donor cells recognize organs of the recipient as foreign and attacks them
Growth factor	Injection medication given to increase the number of stem cells in preparation for stem cell collection; similar to a naturally occurring substance in the body. Also called filgrastim or G-SCF®
Harvest	The process of collecting stem cells through peripheral blood stem cell apheresis; also called apheresis
Hematopoietic Stem Cells (HPCs)	See "Stem Cells"
Hemorrhagic Cystitis	Blood in the urine as a result of damage to the bladder caused by chemotherapy and/or TBI
Human Leukocyte Antigen (HLA)	Markers on the surface of white blood cells used to determine degree of match between a recipient and donor; blood test is called HLA typing
Infectious Diseases Markers (IDMs)	Blood tests that indicate whether a person has been exposed to specific viruses such as cytomegalovirus (CMV), hepatitis, HIV, HTLV, syphilis, varicella, etc.)



Term	Definition
Mobilization	For donors, the process of moving stem cells from the bone marrow into the blood stream using growth factors alone
Neutrophils	A type of white blood cells that fights bacterial infections
Peripheral Blood Stem Cells (PBSCs)	Stem cells that have moved from the bone marrow into the peripheral blood stream
Platelets	A type of blood cell that helps control bleeding by causing the blood to clot
Sinusoidal Obstructive Syndrome (SOS)	A serious complication of high dose chemotherapy in which some of the veins in the liver become blocked and lead to liver damage.
Stem Cells	Immature blood cells capable of becoming white blood cells (infection-fighting cells), red blood cells (oxygen-carrying cells) and platelets (cells that help stop bleeding); mainly found in the bone marrow but can be moved into the blood stream using medications for stem cell collection
Total Body Irradiation (TBI)	Radiation therapy treatments used as part of the conditioning regimen to remove cancer cells from the body and prepare the body for stem cell infusion



Blood Work Tracking

Month/Dat e	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
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Blood Work Tracking

Month/ Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
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