

Autologous Stem Cell Transplant Handbook

Saskatchewan Stem cell Transplant
and Cellular Therapy Program



Table of Contents

Contact Numbers	5
Stem Cell Team	6
<u>Stem Cell Basics</u>	
What Are Stem Cells?	9
What Is Stem Cell Transplant?	9
<u>An Overview: What To Expect In The Transplant Journey</u>	
What Transplant Involves.....	10
Transplant Timeline	11
<u>Pre-Transplant Work-Up</u>	
Diagnostic Tests	12
Fertility.....	13
<u>Preparing For Transplant</u>	
Choosing a Caregiver.....	14
Physical Preparation.....	14
Emotional Preparation.....	14
Smoking Cessation	14
Accommodations.....	15
Transportation and Parking.....	15
Legal Affairs.....	16
Finances.....	17
<u>Stem Cell Collection</u>	
How Are Stem Cells Collected?	20
Central Venous Catheter Insertion	21
Apheresis: Day(s) of Stem Cell Collection.....	23
After Stem Cell Collection	24
<u>Transplant Admission</u>	
Welcome to 6100.....	26
What to Bring to the Hospital	26
Families and Visitors	27
Conditioning (Preparative Regimen).....	28
Stem Cell Transplant - Day 0.....	29
Engraftment	29

AUTOLOGOUS STEM CELL TRANSPLANT

Early Side Effects of Transplant	30
During Your Hospital Stay	31

Discharge From Hospital

When Will I Be Discharged?	34
Problems to Report	34
When to Call.....	35

Outpatient Care Following Transplant

Follow Up Appointments	38
Preventing Infections.....	38
Medications	38
Home & Environment.....	39
Pets.....	39
Diet & Food Preparation.....	40
Activity/Exercise.....	43
Smoking	43
Plants & Flowers	44
Sun	44
Sexual Intimacy.....	44
Fatigue.....	45
Returning to Work.....	45
Travel.....	45
Immunizations	46
Coping and Support.....	46

<u>Long Term Follow Up</u>	48
----------------------------------	----

Resources

Further Information	50
Patient and Family Resource Centre	50
Support Groups	51
Glossary	53
Blood Work Tracking	56

Autologous Stem Cell Transplant Handbook

Welcome to the Saskatchewan Stem Cell Transplant and Cellular Therapy Program

As you begin your autologous 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 autologous 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 autologous stem cell transplant.



Dr. Mohamed Elemetry
Director of Stem Cell Transplant

Please bring this guide with you to all appointments

Contact Information

Saskatoon Cancer Centre

(306) 655-2662

20 Campus Drive
Saskatoon, SK
S7N 4H4

Regular hours are from 8:00 am to 4:30 pm Mondays through Friday, excluding statutory holidays.

Transplant Physician

Your transplant physician is: _____

Outpatient Primary Care Nurse _____ (306) 655-_____

Your Saskatoon Cancer Centre primary care nurse will follow you after your stem cell transplant. Be sure to call and leave a message with any questions or concerns and a nurse will return your call.

Transplant Coordinator _____ (306) 655-_____

Your transplant coordinator is a registered nurse who will guide you through the donation process and can answer any questions you may have. You may call anytime during office hours, 8:00 am-4:30 pm Monday-Friday, excluding statutory holidays.

Hematologist On-Call _____ (306) 655-1000

For 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.

Social Worker _____ (306) 655-_____

Your social worker is an important part of your health care team, and can assist with practical issues such as travel, accommodations and finances as well as emotional support to you and your family/caregivers.

Clinic Assist _____ (306) 655-6342

Call your clinic assist for information about appointment times or to change any appointments.

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 autologous stem cell transplant process includes 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.

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.

Fellows

Physicians who have completed training in internal medicine, hematology or oncology and who are doing further training in 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”, or “harvest”) of stem cells.

Transfusion Medicine Technologists

AUTOLOGOUS STEM CELL TRANSPLANT

Responsible for processing and freezing your stem cells following apheresis, and for thawing stem cells at the bedside at time of infusion.

Registered Nurses

RNs skilled in stem cell transplant care provide outpatient and inpatient care including assessments, teaching, and administration of chemotherapy, stem cell infusions and other medications.

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

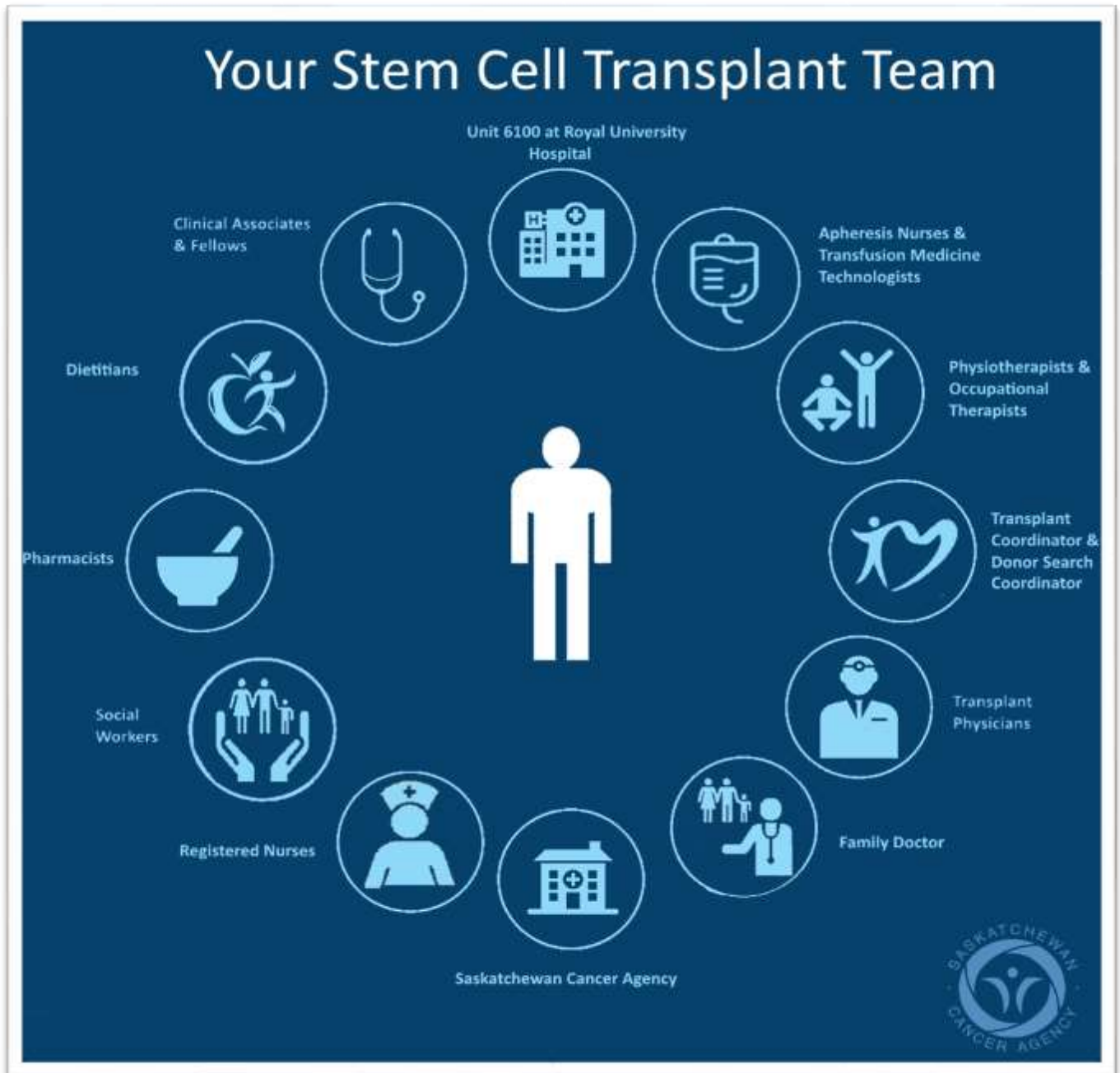
Spiritual care is available upon request to support and encourage you to draw upon your religious and spiritual strengths.

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.



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

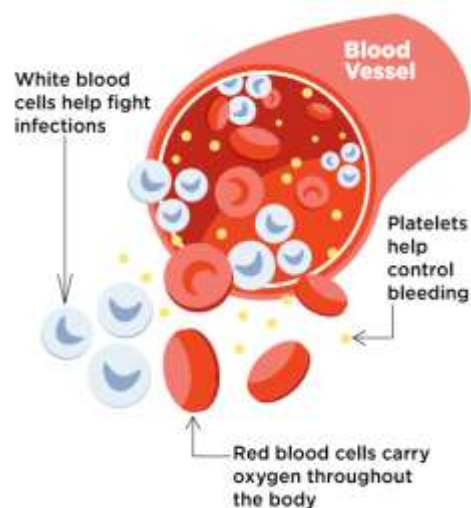
Most stem cells are found in the bone marrow, mainly in the large hip bones and other long and flat bones. Normally there are very few stem cells found in the bloodstream.

There are different types of stem cell transplant:

1. **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 and in some cases some non malignant diseases (ie: scleroderma).
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 transplant, patients undergo conditioning treatment with high dose chemotherapy to eliminate the underlying disease. This chemotherapy also kills the cells in the bone marrow. The collected stem cells are then infused into the patient and they make their way to the bone marrow to start producing normal blood cells again.

It is important to understand what the goal of your stem cell transplant is – sometimes it is to control the disease, while other times it may be to cure the



What Transplant Involves

Here is a quick overview of the steps involved in autologous stem cell transplant:

1

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

Stem Cell Collection

You will receive chemotherapy and/or growth factor injections (also referred to as G-CSF or grastofil) to collect stem cells by using a special machine.

3

Admission For Transplant

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

4

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.

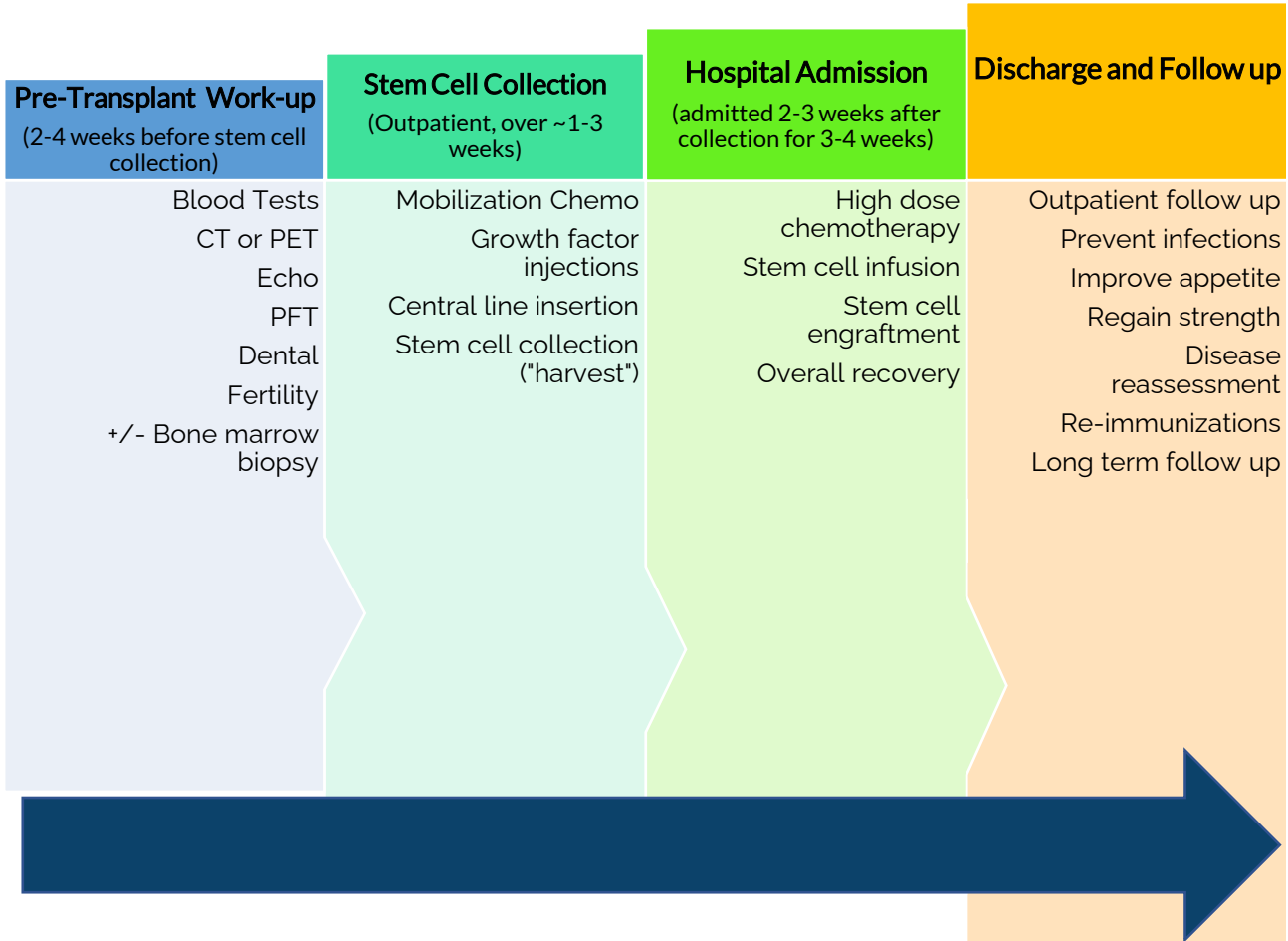
5

Care Following Transplant

Following discharge, you will return home to continue to recover. You will be seen as an outpatient at the Saskatoon Cancer Centre or Allan Blair Cancer Centre.

Transplant Timeline

Here is an overview of timing throughout the transplant process, keeping in mind that there can be different timelines for different diseases and treatments. There can also be delays resulting from infections or difficulties collecting stem cells, so use this simply as a guide.



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 quickly you need a transplant and timing for tests and appointments.

Diagnostic Tests

Many tests are necessary prior to stem cell collection and transplant, to assess your cancer as well as how healthy your major organs are. Because autologous stem cell transplant relies on high doses of chemotherapy to work, your physician will be looking for at least some response to the initial chemotherapy in order for you to proceed to stem cell transplant. Tests includes:

- Blood Tests
 - Includes looking for viruses 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 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
 - It is essential that you make an appointment with your dentist as soon as possible. You will be given a letter informing them you are going to have an autologous stem cell transplant. They will need to provide a cleaning if it's been more than 6 months since last done, assess for any source of infection in your mouth, and perform any necessary dental work or extractions.
 - If you are on Zometa (a bone builder), be sure to notify your dentist before having any major dental procedures done.

- Echocardiogram (Echo)
 - An echocardiogram is an ultrasound of the heart to measure heart function. A small amount of gel is placed on your chest so when a wand-like device called a transducer is moved over your heart, ultrasound waves from your

AUTOLOGOUS STEM CELL TRANSPLANT

heart are painlessly transmitted. A computer then 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 the air moves through the airways, and how well the oxygen penetrates the lung tissue in order to enter the blood stream. Results of these tests provide your physician with 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 or PET scan (Required for some diseases)
 - A CT (Computerized Axial Tomography) scan is a special type of x-ray that takes pictures of different body parts by moving a special scanning machine around the patient. Ordinary x-rays, like chest x-rays, give two-dimensional pictures while the CT scan obtains very detailed three-dimensional pictures. The CT scan procedure is not painful, but you must lie very still for up to 15–20 minutes at a time.

 - 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.

- Chest X-Ray (CXR)
 - Usually done once admitted to hospital for your stem cell transplant. A chest x-ray uses a small amount of radiation to take a picture of the chest and lungs. This gives doctors a baseline for comparison of later x-rays.

Fertility

Fertility is very often affected by chemotherapy. Becoming pregnant or fathering a child is uncommon after an autologous 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.

Fertility aid procedures costs are not covered by Saskatchewan Health.

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 is a list of some things you need to do to prepare:

Choosing a Caregiver

Finding a caregiver to support you before and after transplant is very important, as they play a significant role during all stages of the stem cell transplant process. Most often this is a family member or friend. You may have more than one person as your caregiver. Caregivers can help with everyday tasks, transportation to clinic appointments, help with medications, checking your temperature, providing nutritional support or cooking meals, and reporting important information about your health to your health care team.

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 better your physical condition, 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 essential. It is important to ask for help when you need it. Letting family and friends know they can support you is helpful both to you and to 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. Ask family members and friends to help. 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

AUTOLOGOUS STEM CELL TRANSPLANT

You will be strongly encouraged to quit smoking prior to being admitted to hospital for your stem cell transplant. 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:

- SHR Tobacco-free helpline Phone 306-655-7777
- Community pharmacist <https://www.skpharmacists.ca/patients/quit-smoking>
- Canadian Cancer Society Phone 1-877-513-5333 or <https://www.cancer.ca/en/support-and-services/support-services/quit-smoking/?region=on>
- Your family physician

Please speak to a member of the transplant team can if you need support in quitting smoking.

Following your stem cell transplant, we recommend not smoking and avoiding second hand smoke as both can increase your risk for infection or lung complications.

Accommodations

It will be necessary to stay in Saskatoon at certain times during the stem cell collection, possibly for 2-5 days. While you are in hospital for your stem cell transplant, your caregiver or family members may wish to stay in Saskatoon. For shorter stays, popular choices for accommodations include the Saskatoon Cancer Patient Lodge, Laura's Lodge and College Drive Lodge thanks to close proximity to the hospital and economical rates. Other options may be more appropriate for extended stays.

▪ Hotels/Motels

- Certain establishments offer discount rates for patients and visitors
- Please go to the Saskatoon Health Region Visitors Accommodations for more information or use following website:
https://www.saskatoonhealthregion.ca/visitors/Documents/Hotel_lodging-form.pdf

▪ Saskatoon Cancer Patient Lodge

Parkville Manor 625 25th Street East
Phone: (306) 242-4852
Rate: \$40.00/person/night

- Accommodations for a patient and one companion may be available. The daily rate includes three meals per day. Limited parking is available at a small cost. The Lodge is closed Friday at 4:00 p.m. until Sunday 4:00 p.m. Please phone ahead for reservations.

▪ Furnished Suites/Long Term Accommodations

- Furnished suite including cooking utensils, bedding, furniture etc.

AUTOLOGOUS STEM CELL TRANSPLANT

- o 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:

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 – Volunteer Driving Program. These arrangements must be made in advance. Please discuss with your social worker.
- Phone: 1-888-939-3333

Taxi Service (most have taxi 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


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.

AUTOLOGOUS STEM CELL TRANSPLANT

- **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 the 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. It is important to have conversations with your close family, friends and health care provider(s) so that they know the health care treatment you would agree to or refuse, if you become incapable of expressing your own decisions.



Please bring a copy of your health care directive with

Many people name a proxy or decision maker in their health care directive since it can be impossible to predict all future outcomes. This person will help your health care team make medical decisions if you unable to do so.

It is important that you discuss your wishes clearly with those responsible for decisions about your care, particularly in the event that critical care decisions need to be made if you are unable to communicate for yourself. Specific concerns regarding these areas can be discussed with your social worker.

Finances

The costs you incur while having a stem cell transplant will depend on 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 whether you have to pay someone for other tasks such as caring for your children. 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.

ABOUT WORK:

If you are currently employed, you will need to take time off from work

Most patients will be off work for 3-6 months

Some patients will need a gradual return to work program

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/ei-sickness.html>
 - 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>
 - 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 medical expenses (Note: expenses where you received funding from an outside source cannot be used for income tax purposes).
 - Certain patients may qualify for a disability tax credit, but very strict criteria apply.
 - Website: <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>
 - Phone: 1-800-267-6999

AUTOLOGOUS STEM CELL TRANSPLANT

- Saskatchewan Assistance Plan
 - Financial Assistance for living expenses and medically related costs is provided to applicants in need that meet strict eligibility criteria (with 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 you financial provider.

Medicine And Drug Coverage

You will be responsible to pay for certain medications when you are an outpatient. Some of these expenses may be covered if you have private insurance coverage, such as Blue Cross or health coverage through your employer. 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 your admission to the hospital for stem cell transplant.

Stem Cell Collection

Once the pre-transplant assessments and preparations have been completed, you will be scheduled for stem cell collection.

How are Stem Cells Collected?



In the past, stem cells were collected from the bone marrow using a special needle inserted into the hip bone in the operating room. This technique has now been replaced by collecting stem cells from peripheral blood veins, similar to donating blood. To be able to collect enough stem cells from the peripheral blood stream, growth factor injections called “G-CSF” or “grastofil” are given, sometimes on their own and other times in combination with chemotherapy. G-CSF is a naturally occurring special protein in the human body that stimulates blood cell production and growth so these injections increase the growth and release of stem cells from the bone marrow into the blood stream. This moves, or “mobilizes” stem cells from the bone marrow into your peripheral blood stream.

If you are receiving chemotherapy as part of mobilization, it will be given intravenously in the chemotherapy department of the Saskatoon Cancer Center or Allan Blair Cancer Center. You will be taught how to administer the G-CSF injections at home and will be given a calendar instructing when to start these injections. The injections are administered daily through a tiny needle under the skin in the morning.

Common side effects from growth factor injections may include:

- Mild to moderate muscles aches or bone pain
- Headache
- Fatigue
- Flu-like symptoms

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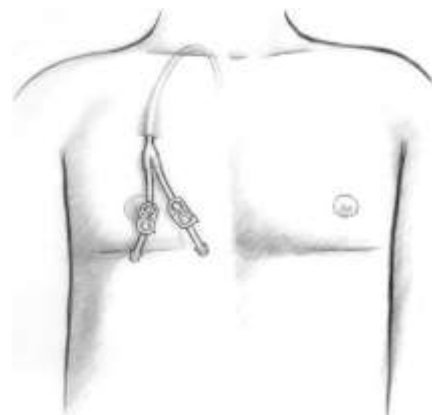
These side effects can be managed using acetaminophen (Tylenol) and usually go away within a few days of stopping growth factor injections. It is important to avoid taking aspirin, ibuprofen or other similar medications because of an increased risk of bleeding. If Tylenol does not control your pain, notify the transplant coordinator.

The collection of stem cells is accomplished with a machine called a blood cell separator. This machine uses a centrifuge to spin and separate the blood into different components (red cells, white cells, plasma and platelets). The stem cells, found in the white blood cell layer, can be collected into a bag. All other blood components are returned back to you.

Stem cell collection usually takes 4-6 hours per day. The number of stem cells collected are counted after each apheresis session to see if the target amount has been reached. Reaching target can sometimes be accomplished in one day, but may require 2-3 days. Sometimes other stimulating agents are used to collect stem cells if the number of stem cells in the blood stream remains low. It is not recommended to drive home if you live out of town or work on the day of apheresis.

Central Venous Catheter Insertion

Before transplant, a central venous catheter (CVC) will be inserted into your chest. The CVC will be used to collect stem cells, and 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.

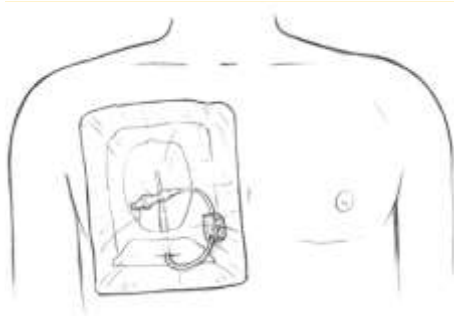
A dressing covers the insertion site to help keep the area clean and dry, as well as to minimize the risk of infection. Dressings must be changed within the first 24 hours, then at least once every week.

AUTOLOGOUS STEM CELL TRANSPLANT

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 CVC

Proper care of your catheter is important to prevent infection. Catheters can stay in place safely for weeks or months 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 per week or 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.

Most people will have their catheter removed before discharge from the hospital following stem cell transplant.

Possible CVC Complications

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

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 Cvc Complications

Broken or cut CVC	If break is above the clamp, blood is leaking/dripping from the CVC	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 or 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 may 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.

Apheresis: Day(s) of Stem Cell Collection

You must arrive at the Admitting Department of Royal University Hospital at 8:00 am on the day of your stem cell collection. You will then be directed to the Apheresis Unit, in the Oncology Day Centre.

AUTOLOGOUS STEM CELL TRANSPLANT

You will have blood work done the morning of the stem cell collection to count the number of stem cells in your blood stream, reported as a CD34 level, as well as to check other blood values.

Your CVC will be connected to the apheresis machine so that blood can flow out of one lumen, through the tubing and into the machine where it is spun at high speed. The spinning separates the different components of the blood into layers based on their weight. The stem cell layer will then be collected and the remaining blood will be returned back to you through the other lumen of your CVC. An anticoagulant is used in the tubing of the machine to keep the blood from clotting. This anticoagulant can also cause the calcium level in your body to drop.

Common side effects during apheresis are:

- Tingling around mouth, tingling of fingertips or vibrations in your chest (from low calcium levels)
- Feeling cold
- Lightheadedness

A registered nurse will be with you throughout the procedure. Be sure to report if you experience any of these symptoms.

As it can feel like a long day sitting/reclining in a large comfortable lazy boy recliner, you are encouraged to bring books, laptop, and so on. There is a TV on the unit as well. Visitors are welcome but please limit the number to 1 or 2 as space is limited. Lunch and snacks are provided, but you are welcome to bring food of your own.

If you have medications that you normally take during the day, please bring them with you. However, DO NOT take any blood pressure medications the morning of stem cell collection. You will be given a calcium infusion to help maintain the calcium level in your body. Bathroom privileges are limited to the use of a commode or urinal while you are connected to the machine.

Your physician will prescribe the number of stem cells to be collected for your transplant based on your weight. When that number of cells has been collected, the cells will be transported to our Transfusion Medicine Laboratory where they will be frozen then stored until you are ready for your transplant.

Enough stem cells will be collected for 1 or 2 transplants, depending on the type of disease being treated. Collection usually takes 4-6 hours/day. The stem cell collection may take 1 day or can take 2-3 days. The time varies according to your stem cell count (in response to the growth factor injections) and your weight.

AUTOLOGOUS STEM CELL TRANSPLANT

Please have a driver arranged to pick you up from the stem cell collection.

After Stem Cell Collection

You will be discharged home after the stem cell collection with your CVC. This will remain in place until the end of your hospital stay for your stem cell transplant. Your CVC dressing must be changed and lumens flushed once every week. You or a caregiver can be taught how to do this, or arrangements can be made for this to be done at the Saskatoon Cancer Centre, Regina Home Care Treatment Centre or through your local Home Care.

You can expect to be admitted to hospital for the stem cell transplant, usually about 2-3 weeks after the stem cell collection.



- DO NOT take blood pressure medications the morning of stem cell collection
- DO remember to bring all your pills with you!
- Eat a breakfast high in calcium
- Wear loose fitting, comfortable clothing
- Be sure to have a driver available to take you home
- Your CVC will need to be flushed weekly

Admission For Autologous Stem Cell Transplant

The next step of your stem cell transplant journey is when you are admitted to Royal University Hospital (RUH) Unit 6100: Inpatient Oncology, Hematology and Stem Cell Transplant Unit. A transplant nurse, pharmacist and transplant physician will see you in the Cancer Clinic either the day before or the day of admission to hospital. This is to confirm that there have been no new changes to your health, and to finalize details pertinent to this admission. You will also have the opportunity to ask any last minute questions. It may take up to a week or so for a bed to become available for your admission.

Welcome to 6100

Prior to going to your room on 6100, you must go through "Patient Registration" on the main floor of RUH. You will receive an identification wristband as well as admission papers at this time. From this point, take the elevators to the 6th floor then follow the signs to Unit 6100. The clerk will direct you to your room once you have reached the unit. If admission happens after regular hours (after 4:30 pm) then you will be called when bed available and instructed to come directly to 6100.

Unit 6100 is comprised of 29 beds, including six beds within the BMT unit - the only one of its type in Saskatchewan. Autologous transplant patients are typically admitted to a private room on the general unit, while patients having an allogeneic stem cell transplant (stem cells from a donor) are admitted to the BMT unit. On occasion, you may be admitted to a shared room at first, but will be moved to a private room as soon as it is available or it is medically indicated. You will spend about 3-4 weeks on Unit 6100.

What to Bring to the Hospital

When planning what to bring to the hospital, please remember that the rooms are not very large. Below is a checklist of some items you may wish to bring:

- 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

AUTOLOGOUS STEM CELL TRANSPLANT

- Soaps and lotion, but remember to keep them mild or fragrance free
- Soft tooth brush and tooth paste
- Soft tissue and toilet paper
- Books, magazines, games, laptop, and any other comfort items for diversion
- Pictures of family, friends, pets, etc.
- Blankets and/or pillows

Each room has a telephone available for use and there is television available to rent. Payment is due upon activation and can be done directly on the television using VISA credit, VISA debit, MasterCard credit, MasterCard debit, or American Express. You can also visit <https://healthhubsolutions.ca/> and click on 'How to Rent' under the 'Renting' tab, then search for Saskatoon and you will find Royal University Hospital and be able to enter your bed number. There are also frequently asked questions and a contact number for trouble shooting.

Free wireless internet is available. Simply look for <Patients/Visitors> network on your device.

Do Not Bring fresh flowers, plants or dried flowers as they can carry spores that cause infection.

Families and Visitors

Visiting hours on 6100 are not restricted, but visitors should pay attention to how long their visits to ensure that you get enough rest. All visitors must wash their hands upon entering Unit 6100. To help prevent the spread of infections, visitors are not allowed to come if they have:

- Fevers
- Sore throat
- Have recently been exposed to a communicable disease such as chickenpox
- Diarrhea
- A new or unexplained rash
- Any other symptoms that make them feel unwell

Patient washrooms are only for patient use only, but there is a public washroom on the 6th Floor. There are a few sleep chairs on the unit that may be available if you want to have someone stay overnight with you. There are no shower facilities for visitors to use. If you are on the BMT unit, additional visitor screening measures are in place to protect the health of everyone on the unit.

Conditioning (Preparative Regimen)

Conditioning (sometimes also called “preparative regimen”) is high dose chemotherapy used to attack the underlying disease. The days that you receive conditioning chemotherapy are referred to as minusdays (Day -6, -5, -4, and so on) while the day you get your stem cells is called “Day 0”. The days following infusion of stem cells are Day +1, +2, etc.

While the conditioning chemotherapy destroys cancer cells, it also destroys healthy cells including your red blood cells, white blood cells and platelets. Stem cells “rescue” your bone marrow by replacing those destroyed by chemotherapy. Without the stem cell infusion as a rescue, the high doses of chemotherapy would leave you with very low blood counts for a prolonged period and lead to serious infections, low blood and bleeding problems.

Conditioning chemotherapy can either be a combination of chemotherapy drugs given over multiple days or a single chemotherapy drug given over one day, depending on the type of your disease. A chemotherapy-certified registered nurse administers this treatment.



Stem Cell Transplant – Day 0

The day of your stem cell infusion is referred to as “Day 0”, with subsequent days referred to as +1, +2, etc. On Day 0, transfusion medicine technologists will bring your frozen stem cells to your bedside to thaw right before the infusion. A transplant-trained registered nurse will infuse the stem cells through your central line, much like a blood transfusion. This can take anywhere between 20 minutes to a couple of hours. A registered nurse will be in the room the entire time to monitor your vital signs and watch for any side effects. The most common side effects during the infusion of the stem cells result from a preservative called DMSO (dimethyl sulfoxide), an additive used when your stem cells were frozen after collection.



Side effects may include:

- A garlic-like taste
- Flushing
- Chills
- Nausea
- Shortness of breath

You will be given medications prior to the stem cell infusion to help prevent or minimize side effects. You will also receive orange slices on your breakfast tray the day of transplant as holding oranges in your mouth can help with the altered taste during the stem cell infusion.

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 can take a few weeks for new blood cells to be produced and for your blood counts to begin recovering. The wait can be the hardest part! First signs of engraftment are the gradual rise of the white blood cell and platelet counts, while red blood cells take a little longer to recover. Engraftment occurs around 10-14 days after the transplant in most cases.

AUTOLOGOUS STEM CELL TRANSPLANT

Until engraftment, you will be at an increased risk of complications such as infections and low blood/platelets while awaiting engraftment. 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. Growth factor injections are usually given following transplant to help speed up blood cell count recovery.

Early Side Effects of Transplant

High dose chemotherapy 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 are all affected by chemotherapy. Some patients become quite ill after receiving chemotherapy, while others experience only mild side effects. However, predicting which side effects and severity on an individual basis is a challenge. Admission to the intensive care unit (ICU) is sometimes necessary, although not common.

Side effects may include:

Infection

Your white blood cell count begins to drop in the days following chemotherapy, reaching its lowest level within 5 to 14 days of starting chemotherapy and remaining very low until the newly infused stem cells begin to grow ("engraft"). During this time, you are at high risk of developing an infection until the white count comes back. Infections can be bacterial, viral or fungal. Some signs of infection include fevers, chills, a cough or runny nose, shortness of breath or chest tightness, frequent urination or burning when you urinate, pain in your throat, stomach, rectum, diarrhea, and redness or drainage around your CVC site. The inpatient nurses will monitor you closely for infection during your hospital stay by checking your vital signs every four hours when your white blood cell counts are low, and remember to ask your nurse about and concerns you have or changes you notice. Most patients will require IV antibiotics during their hospital stay due to an infection.

Digestive Tract Symptoms

Mouth sores (mucositis), loss of appetite, nausea, vomiting and diarrhea are all common side effects following chemotherapy. Anti-nausea medications are given prior to chemotherapy to minimize nausea and vomiting. Good oral care and mouth rinses are important to prevent mouth sores. Dentures must be 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

AUTOLOGOUS STEM CELL TRANSPLANT

intravenously. 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 or even years after your transplant. There are many things that 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 And Anemia

Your 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 will find that you 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 associated risks, please see the Saskatoon Health Region's [Information for Patients about Blood Transfusion and Tissue Transplantation](#) handout (available on the Saskatoon Health Region website under "Transfusion Essentials" You will be required to sign a consent form before receiving any blood products.

Organ Damage

High dose chemotherapy can have a major effect on your organs, including the liver, lungs, heart and kidneys. The damage is usually reversible.

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 discharged 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. Following transplant, spend as much time out of your bed as possible! Use your bed at night for sleeping or for when you are feeling too unwell to be up. It may help to begin slowly and increase your activity level gradually.

Mouth Care

Following your transplant, it is very important to keep your teeth, gums, and mouth clean. Mouth problems are common side effects of chemo 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)
 - Use: 1 teaspoon baking soda and 1 teaspoon of salt in 4 cups of water
 - 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

AUTOLOGOUS STEM CELL TRANSPLANT

- 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 immune compromised patients. This includes avoiding certain foods, such as deli meat, as they 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 drink) 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 water

- Maintain optimal oral hygiene so mouth bacteria will not cause further changes to taste
- In addition to maintaining excellent mouth care 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 nausea, nutritional intake, 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 clothing 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 3-4 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?

Deciding when you are ready to go home is based on feedback from your physicians, nurses, social worker, dietitian, and physical therapists. In order for you to be safely discharged from hospital after your transplant, you must:

- No fevers or active medical problems
- Satisfactory blood counts
- No intravenous medications
- Able to swallow medications
- Able to eat and drink adequately
- Able to walk
- Strong enough to perform activities of daily living

It is important to remember that discharge from hospital is a transitional process, because you are still recovering. 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. The transplant team will continue to support you during your recovery at home.

Problems to Report & When to Call

It is critical for you and your caregiver to know when to contact your health care team after going home. Many symptoms cannot wait until your next scheduled appointment – if you are not sure, please call and speak to someone from your health care team. Occasionally it is necessary to return to hospital after discharge to deal with a complication.

Problems to Report

URGENT Symptoms to Report Include:

- Temperature of 38.0° C or higher
- Chills, sweats or shakes
- Redness, swelling pain or discharge around central line site
- Bleeding
- Coughing, shortness of breath or chest pain
- Persistent nausea or vomiting
- Frequent or painful urination
- Constant urge to urinate
- Cloudy or foul smelling urine
- New skin rash or painful blisters on skin
- Diarrhea or abdominal cramping
- Yellowing of skin or white of eyes
- Inability to keep medications or fluids down due to nausea

Examples of Emergencies May Include:

- Uncontrolled bleeding
- Choking
- Loss of consciousness
- Difficulty/unable to wake up
- Sudden chest pain
- Severe shortness of breath
- Rapid change in overall condition
- Seizures
- Unable to swallow

When to Call

If...	When...	Where	Contact
Urgent	Weekdays: Call Saskatoon Cancer Centre <ul style="list-style-type: none"> ▪ Monday through Friday 8:00 am to 4:30 pm ▪ Closed statutory holidays 		Call your primary nurse
Urgent	Evenings, weekends and statutory holidays: Call Royal University Hospital <ul style="list-style-type: none"> ▪ Weekends: All day Saturday and Sunday ▪ All Evenings: Monday to Friday 4:30 pm until 8:00 am ▪ Statutory holidays 		Call 306-655-1000 and ask to page the Hematologist on call
Emergency* (See what to bring below)	<ul style="list-style-type: none"> ▪ 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 a current medication list with you.

- **FEVER CARD.** You will be given 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.*

Outpatient Care

Follow Up Appointments

Follow up appointments after discharge depend on your blood counts and how you are feeling. In general, you will have an appointment at the Saskatoon Cancer Centre 2-4 weeks after discharge from the hospital with blood work done once weekly until that appointment.

Central Line Care

In most cases, your central line will be removed the day of or day prior to discharge from hospital. A bandage will be placed over the insertion site. Keep this area clean and covered for 1 week, and try to avoid getting the bandage wet. If it does become damp or soiled, please change the bandage (your nurse will send extra supplies with you when you leave the hospital).

Occasionally the decision is made to leave the central line in place. In this case, arrangements must be in place for your line to be flushed with saline and locked with heparin and the dressing changed once weekly while the line remains in place. This may be done by a trained caregiver or a Home Care nurse.

Preventing Infections

Following autologous stem cell transplant, your risk of infection remains higher than normal for around two to three months. Even though your body has started producing white blood cells again, your immune system still needs more time to recover to a normal level of functioning. If you feel unwell or have a fever, check your temperature, then either call the Cancer Clinic or seek medical attention.

One of the most important ways to prevent infection is **frequent hand washing**: every time you return home, after using the bathroom, before eating, and so on.

Some other recommendations for hygiene 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 3 months post-transplant (if applicable)

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.

Medications

Following autologous stem cell transplant, you will be on several medications to help prevent specific infections and other common complications. Before going home, the transplant pharmacists will explain what each medication is for, when and how to take each medication, and for how long. A personalized medication schedule will be provided to help understand your new medication regimen. Be sure to ask your health care team any medication questions.

- Do not stop any medication without specific direction from your doctor, nurse or pharmacist
- Do not take any medication without consulting your physician or nurse as certain medications are not recommended (such as ibuprofen)

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). Keep your home as clean as possible. Until your blood counts have fully recovered, general housekeeping is best left for someone else to do. You may help in clearing the dishes from the table, washing dishes and making beds. Remember to wash your hands after doing these activities.

Exposure to molds and dusts can be risky while your immune system is weakened. In order to protect yourself for approximately 3 months post-transplant:

- Avoid yard work or gardening
- Do not shovel grain, or work with hay or manure
- Avoid construction areas or wear a mask
- Avoid activities that expose you to dust or dirt

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 not the time to get a new pet.

AUTOLOGOUS STEM CELL TRANSPLANT

- Have someone else clean your pet's cage, litter box, pen or fish tank for the first 3 months
- 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 Preparation

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:

Type of Food	Foods to Avoid	Safer Food Choices
Deli Meats and Hot Dogs	Non-dried meats such as bologna, roast beef and turkey breast. Cold hot dogs straight from package	Dried and salted deli meats such as salami and pepperoni. Non-dried deli meats heated until steaming hot. Hot dogs cooked to a safe internal temperature - 74°C (165°F).
Other	Any foods/fluids with probiotics added (ex Activia/Danactive yogurt, Kefir, Yakult and Good Belly drinks). Home canned goods (jam, preserved pickled foods). Fresh fermented foods	Canned goods commercially made and processed Commercially fermented foods that have been pasteurized after fermentation
Meat, Poultry and Pâtés	Raw or undercooked meat or poultry, such as rare steak or steak tartare. Fresh pâtés and meat spreads.	Meat and poultry cooked to a safe internal temperature. Pates and meat spreads sold in cans
Seafood	Raw or undercooked seafood such as sushi, poke bowls. Raw oysters, clams and mussels. Refrigerated smoked seafood.	Seafood cooked to a safe internal temperature of 74 C (165 F). Cook until the shell has opened. Canned seafood (smoked salmon, canned tuna, etc)
Eggs and Egg Products	Raw or undercooked eggs or egg products including salad dressings, cookie dough, or cake batter, homemade mayonnaise, aioli and homemade eggnog.	Egg dishes thoroughly cooked to a safe internal temperature. Eggs should be cooked until the yolk is firm. Homemade eggnog must be heated to 71°C (160°F). Pasteurized egg products in a carton. Commercially made mayonnaise and salad dressings
Dairy Products	Raw or unpasteurized dairy products including unpasteurized milk, soft and semi-soft cheese such as Brie, Camembert and blue-veined cheese.	Pasteurized dairy products, and hard cheeses, such as Colby, Cheddar, Swiss and Parmesan.
Sprouts	Raw sprouts such as alfalfa, and bean sprouts.	Thoroughly cooked sprouts.
Beverages	Unpasteurized fruit juice, cider, beer or other unpasteurized alcohol, kombucha tea.	Unpasteurized fruit/vegetable juice, cider or beer. Check with a doctor before consuming any alcohol

AUTOLOGOUS STEM CELL TRANSPLANT

Water Well water that has not passed safety tests Municipal tap water, bottled water, well water 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.

Here are some more helpful tips:

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

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.

AUTOLOGOUS STEM CELL TRANSPLANT

- 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

It is important to continue activity and exercise as tolerated after leaving hospital. Some benefits of exercise after 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 for the first 3 months after transplant, 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 for 3 months post-transplant.

AUTOLOGOUS STEM CELL TRANSPLANT

Have someone else drive you until complete recovery, which usually takes up to 3 months. To be safe, please check with your transplant physician before driving.

Smoking

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. If you need assistance with quitting smoking, please talk to your health care team.

Plants & Flowers

Soil contains bacteria, fungi and molds that have potential to cause 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 gardening, raking leaves and mowing the lawn until your doctor says that it is safe to do so. When you get the okay to go back to gardening, be sure to wear gloves for at least 3 months.

Sun

Chemotherapy can make your skin more sensitive to the sun so avoid direct sun exposure on the skin especially for the first 3 months after transplant. Use SPF 30 or higher and wear a wig, scarf or cap when outside. Sunscreen should be used along with shade, clothing and hats, not instead of them. Try to avoid direct and prolonged exposure to sunlight especially between the hours of 1:00 pm and 3:00 pm. Be especially careful of areas that can reflect sun/UV rays such as the beach, water and swimming pools.

Sexual Intimacy

The extent to which transplant affects ones' sexual life varies, but it is normal to feel a decrease in sexual desire after a transplant. Contributing factors include hormone changes, fatigue, pain, and changes in self-image. Please discuss questions and concerns with your health care providers at any time.

Resuming intimate relationships will take 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. Feel free to kiss, hug and sleep in the same bed as your partner unless he or she is 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

AUTOLOGOUS STEM CELL TRANSPLANT

continue on birth control following transplant for at least 3 months, then consult 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 symptoms 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 with 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 as well as you can, and drink plenty of fluids
- Ask your family or friends to help you with tasks you find difficult or taxing
- Keep a diary of how you feel each day to help you with planning your daily activities
- Cultivate an interest in less strenuous activities such as listening to music or reading

Returning to Work

In general, you should expect to be off work for at least 3 to 6 months following transplant in order to allow adequate time for recovery of blood counts, immunity, and overall well-being. This timeline may vary based on your tolerance of the transplant procedure, your work environment and other factors. It is important to begin this discussion with your health care team following your discharge from hospital to ensure that expectations are realistic.

Travel

For at least the first 3 months following your stem cell transplant, you should talk to your physician before planning travel. Activities that increase potentially dangerous environmental exposures such as gardening, camping, hunting and fishing are discouraged during this early post-transplant period.

If your travel plans involve travel by air, you should discuss the potential concerns and complications with your health care team before booking your trip. Certain destinations require vaccinations before traveling there; however because your immune system is still new, it may not be strong enough to react well enough to the vaccinations to protect you.

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.

Immunizations

Following stem cell transplant, your immune system is less capable of fighting off common infections for months. All childhood vaccinations will need to be repeated after transplant. Approximately 6 months after transplant, you will receive a letter from the transplant coordinator with instructions to begin immunizations. Approximately one year after transplant, you will receive another letter outlining the process for further re-immunization, which you can then arrange through your public health office. "Killed" vaccines can only be given one year after transplant, and "live" vaccines after two years. If you are receiving certain medications as maintenance therapy for your disease, you will not be able to receive live vaccines.

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 for some time after your stem cell transplant to prevent shingles.

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.

Shingles vaccinations are not recommended until at least 6 months post transplant. Ask your transplant team for more information.

Be sure to report blister-like rashes and exposure to chickenpox or shingles to your health care team

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 you will have good days and bad days. The after-effects of chemotherapy and transplant can be hard, and recovery can be a very slow and difficult process. Be patient

AUTOLOGOUS STEM CELL TRANSPLANT

with yourself. For both you and your family, recognizing and acknowledging feelings and concerns is the starting point to developing physical, mental, emotional and spiritual strengths in the face of your diagnosis and treatment.

Long Term Follow Up

Approximately 3 months following transplant, tests such as CT scans or blood tests will be done to evaluate the response to transplant. Typically, you will also be referred back to your original physician at the Allan Blair Cancer Center (ABCC) or Saskatoon Cancer Center (SCC) at this time as well. This will be discussed with you to address any questions you may have. Your doctor will decide how often follow up needs to be done. Because there can be long-term effects following transplant, regular follow-up with your doctor continues to be important.

Autologous transplant patients usually return to a relatively normal lifestyle about 3 to 6 months after transplant. Many patients with multiple myeloma may require certain medical treatments post-transplant.

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. Patients who need to receive large doses of steroids will have an increased risk of developing cataracts. Regular follow up with your optometrist will be helpful in identifying issues early on.

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 and discuss with your transplant physician.

Disease Relapse

It is important to understand the goal of doing a stem cell transplant in your situation. Sometimes the goal is to get your disease into remission for as long as possible. Other times the goal is to achieve lifelong remission or cure of the disease. In this situation, even

AUTOLOGOUS STEM CELL TRANSPLANT

after going through stem cell transplant there is a chance the disease could return. Talk to your transplant physician about the likelihood of this happening.

Regular Health Screening

It is very important to keep in contact with your family doctor or nurse practitioner. Your health care team will be very involved for the first 3 months; however, your family doctor or nurse practitioner will ensure that you have age-recommended health screening including mammograms, pap smears, FIT tests, colonoscopies, and others as appropriate.



It is important to keep in touch with your family physician or nurse practitioner for non-transplant related concerns and health screening

Resources

Further Information

If you wish to access further information regarding your particular disease and the stem cell transplant process, some reliable 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**
 - www.saskcancer.ca <<Patient and Families>> Managing Side Effects
 - 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, <http://www.bmtinfonet.org/>
 - National Bone Marrow Transplant Link, 1-800-546-5268, <http://www.nbmtlink.org>
 - Lymphoma Foundation Canada, www.lymphoma.ca
 - Leukemia and Lymphoma Society (LLS), www.leukemia-lymphoma.org
 - LLS- Young Adults (18-39), www.LLS.org/YAconnect
 - Lymphoma Information Network, www.lymphomainfo.net
 - Multiple Myeloma Research Foundation, www.multiplemyeloma.org
 - International Myeloma Foundation, www.myeloma.org
 - Myeloma Canada, (514) 570-9769, www.myelomacanada.ca
 - National Marrow Donor Program, www.marrow.org
 - The Canadian Cancer Society, www.cancer.ca
 - People Living With Cancer, <http://www.plwc.org>
 - Medline, www.nlm.nih.gov
 - Memorial Sloan - Kettering Cancer Centre, www.mskcc.org
 - Young Adult Cancer Canada, www.youngadultcancer.ca
 - Caringbridge, www.caringbridge.org
 - Lotsa Helping Hands: A site to coordinate care, www.lotsahelpinghands.com
 - Cancerchat Canada, www.cancerchatcanada.ca
 - STEM (Saskatchewan Stem Cell Transplant Advocacy Group), www.stemsask.ca

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 hematologist 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

AUTOLOGOUS STEM CELL TRANSPLANT

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, 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 2nd Thursday of the month for *women only*, providing tips on looking your best while going through your treatments. The sessions are led by a professional cosmetologist. Please note that space is limited and sessions tend to fill quickly.

- **Saskatchewan Multiple Myeloma Support Groups**

The Saskatchewan Myeloma Support Groups welcome all multiple myeloma patients, caregivers and family to join in a sharing, caring and positive environment, centered around mutual support and keeping up with the latest developments in treatment and care.

- Website www.myelomacanada.ca
- Regina email: reginasupport@myeloma.ca
- Saskatoon email: saskatoonsupport@myeloma.ca
- Facebook Saskatoon Myeloma Support Group

- **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.

- 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 are available to meet with you to discuss any concerns.

- To contact your assigned social worker, please refer to page 5.

- **Young Adult Support Group**

Our Young Adult Program (YAP) provides emotional and practical support to anyone aged 18-39 who has had a cancer diagnosis.

YAP aims to help those facing the challenges surrounding a cancer diagnosis by providing a safe place where young adults can find peer and professional supports to help them as they go through diagnosis, treatment and recovery.

More information is available at www.saskcancer.ca <Patients and Families> <Support Services> <Young Adult Program>.

Glossary



TERM	DESCRIPTION
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 (ADLs)	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	This is the tissue found in the soft center of bones. It creates blood cells (red blood cells, white blood cells and platelets)
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 referred to as "harvest"
Conditioning Chemotherapy	High dose chemotherapy drug(s) given to destroy cancer cells before receiving the stem cells as a rescue
Cryopreservation	The process of freezing stem cells in order to preserve them for use at time of transplant
Cytomegalovirus (CMV)	A relatively common herpes virus that can cause complications in immunocompromised patients
Graft-Versus-Host Disease (GVHD)	A process whereby transplanted donor stem cells ("graft") recognize the recipient ("host") as foreign and cause damage to major organs such as the skin, gut and liver
Day 0	Day of stem cell infusion; "transplant day"
Debulking Chemotherapy	Chemotherapy given prior to mobilization to reduce the burden of disease and demonstrate chemosensitivity

AUTOLOGOUS STEM CELL TRANSPLANT

TERM	DESCRIPTION
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
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 referred to as G-SCF [®] , filgrastim, or grastofil
Harvest	The process of collecting stem cells through peripheral blood stem cell apheresis; also called apheresis
Hematopoietic Stem Cells (HPCs)	See "Stem Cells"
Infectious Disease 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.)
Mobilization	The process of using medications called growth factors to cause the movement of stem cells from the bone marrow into the blood stream
Peripheral Blood Stem Cells (PBSC)	Stem cells that have moved from the bone marrow into the peripheral blood stream
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

AUTOLOGOUS STEM CELL TRANSPLANT

Notes:

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	
Hemogl obin																																
Platelets																																
WBC																																
Neutrophils																																
Magnesium																																
Potassium																																

Notes: