Having an Allogeneic Stem Cell Transplant

Treatment — Blood and Marrow Transplant

Alberta Blood and Marrow Transplant Program

Cancer Care Alberta

There is a lot of information in this book.

- It's a good idea to read this information before your first meeting with the transplant team so you come prepared.
- Write down your questions and bring them with you to your meeting.

You have been referred to the **Alberta Blood and Marrow Transplant (BMT) program** by your oncologist, hematologist, or other specialist to talk about **allogeneic stem cell transplant** and if it is a treatment option for you. If the doctor who referred you is also part of the BMT team, this doctor may also be your transplant doctor.

The goal for transplant is to treat your illness. Once you understand the information and have your questions answered, you can decide if you want to have the transplant.

This booklet will help you, and your family and friends understand basic information about living well through allogeneic stem cell transplant.

Read about:

- what an allogeneic stem cell transplant is and how it's used to treat your illness
- the steps to prepare for transplant
- finding a donor
- possible side effects or complications you may have during and after transplant
- how to recognize the side effects and how to manage them and care for yourself with the help of your care team
- things that may help with your emotional and mental wellbeing

If there is any information you do not understand, ask your health care team to review it with you.

For more information:

Other Alberta cancer care resources are available at your cancer centre or online: www.cancercarealberta.ca > Patients and Families > In Treatment > Stem Cell Transplant

A. What You Need to Know about Allogeneic Stem Cell Transplant

Allogeneic Stem Cell Transplant

What is an allogeneic stem cell transplant?

Allogeneic stem cell transplant is a procedure used to treat people with diseases that affect the bone marrow or blood.

It uses healthy blood stem cells from another person (donor) to help restore and replace the bone marrow after you have high dose treatment.

There are **3 steps to an Allogeneic Stem Cell Transplant**:

1. Stem cells are collected from a donor. The donor may be an immediate family member or someone unrelated to you.
2. You will get high doses of chemotherapy, radiation, or both. The high dose treatment destroys the cancer or diseased cells as well as healthy cells, and stops your bone marrow from making new unhealthy cells.
3. The donor stem cells are infused into your body, much like a blood transfusion. These stem cells find their way into your bone marrow and start making new blood cells.

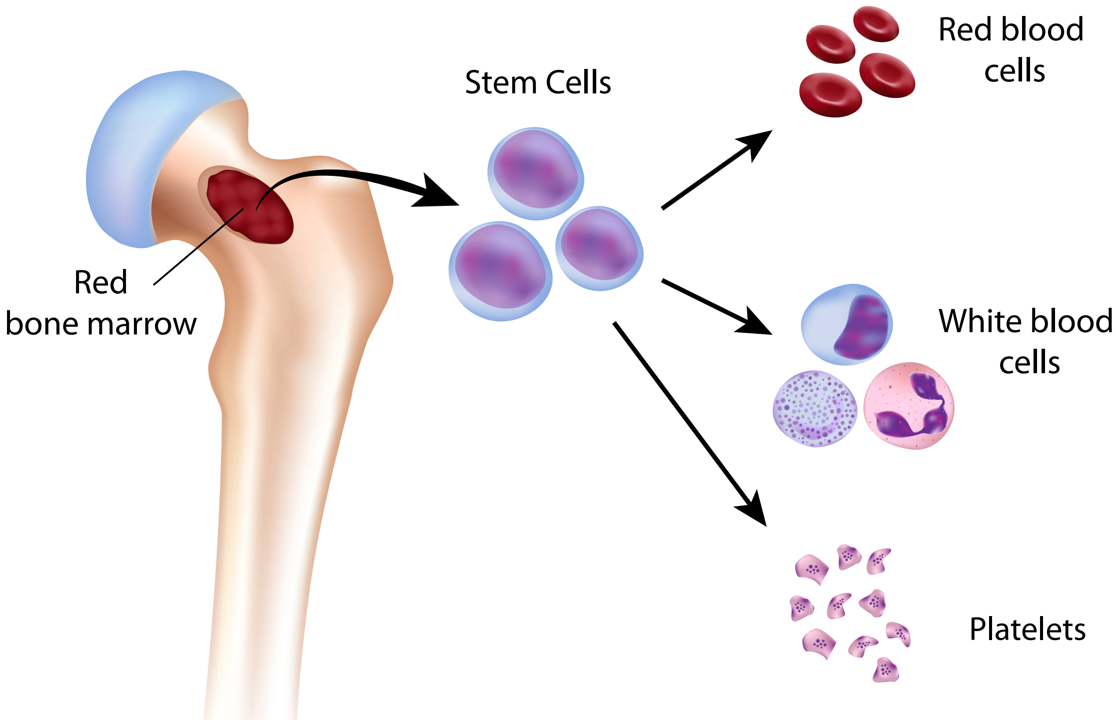
You may hear allogeneic transplant referred to as a bone marrow transplant or a peripheral blood stem cell transplant. In this book, we will use allogeneic or "allo" stem cell transplant.

What are stem cells?

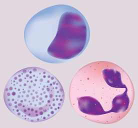
Stem cells are made in the bone marrow. The bone marrow is the soft, spongy part in the middle of your bones. The stem cells grow and mature into other cells like red blood cells, white blood cells, or platelets.

How well does the transplant work?

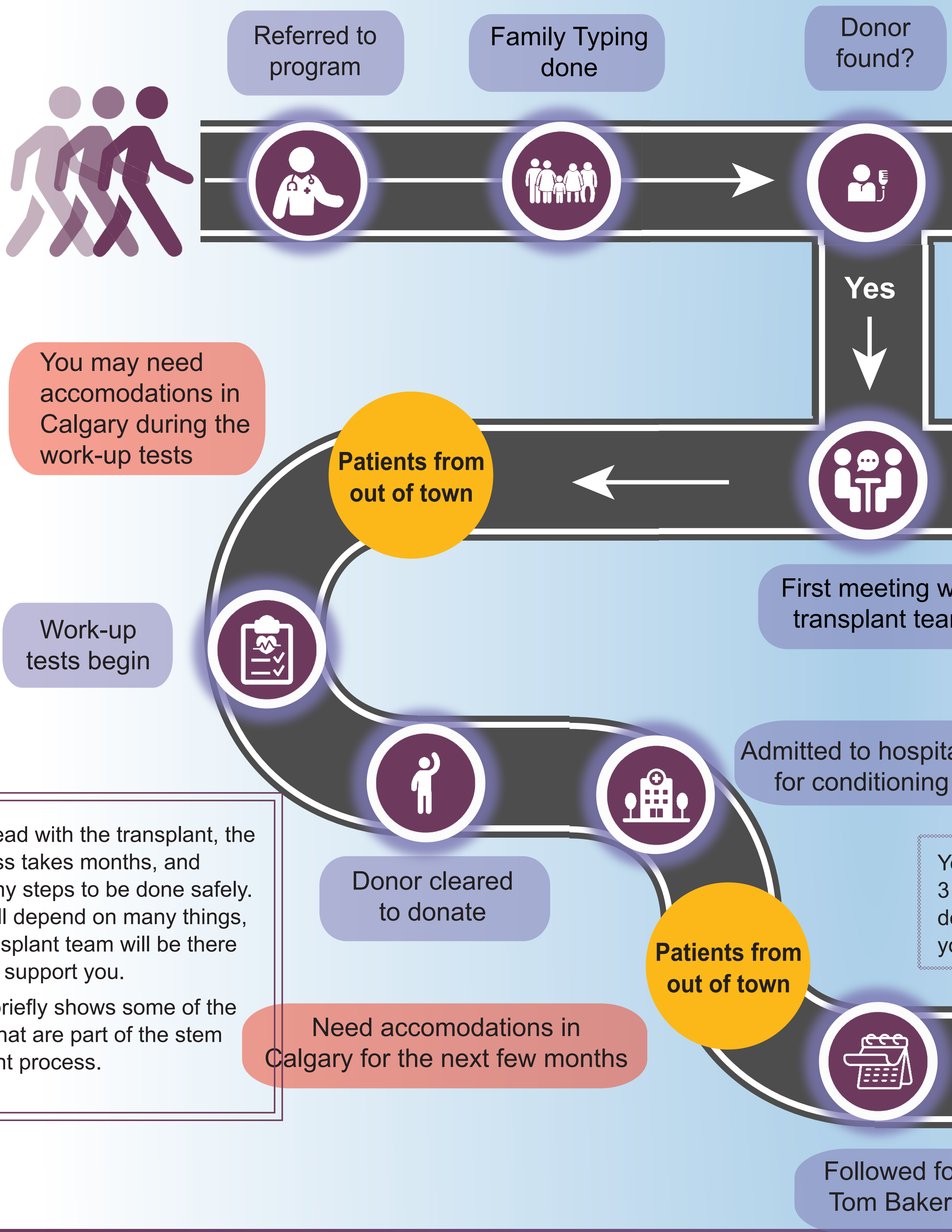
Transplant works differently for everyone and depends on many things — you and your team will talk about this.



Type of blood cell and what it does:

	**White Blood Cells (WBCs):** • help your body fight infection
	**Platelets:** • help your blood to clot and stop bleeding
	**Red Blood Cells (RBCs):** • contain hemoglobin (Hgb), which brings oxygen to all the tissues in your body

Your Journey Through an Allogeneic Stem Cell Transplant (SCT)



Referred to program

Family Typing done

Donor found?

Yes

First meeting w transplant tea

Patients from out of town

You may need accomodations in Calgary during the work-up tests

Work-up tests begin

Donor cleared to donate

Admitted to hospita for conditioning

Patients from out of town

Need accomodations in Calgary for the next few months

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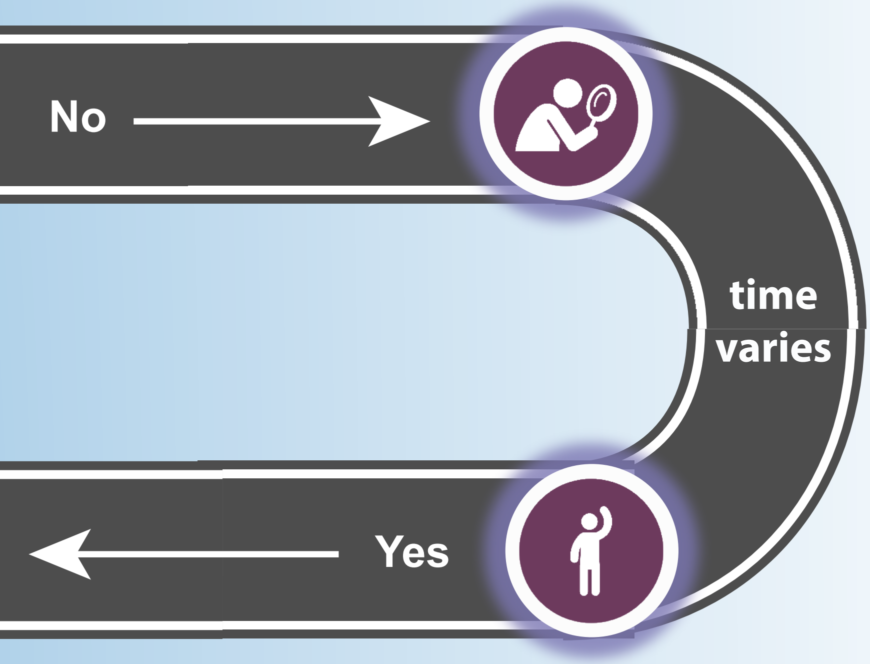
Followed fo Tom Baker

If you go ahead with the transplant, the entire process takes months, and involves many steps to be done safely. Your path will depend on many things, but your transplant team will be there to guide and support you.

This "map" briefly shows some of the main steps that are part of the stem cell transplant process.

Unrelated donor search



ith
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Donor found

al for about 1 month
chemo and SCT

ou are usually followed by TBCC for around
months, but sometimes this can vary. Your
octor will let you know when it is safe for
ou to return home.

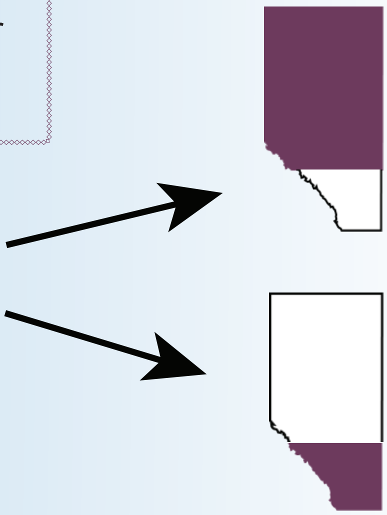
r about 3 months by the
Cancer Centre (TBCC)

All Allogeneic Stem Cell Transplants happen in Calgary.

If you live more than 1 hour outside of Calgary, you will need accommodations at certain points during your treatment. Watch for this yellow symbol in this book. It reminds you when you need to stay in Calgary and for how long.

Patients from out of town

Please be aware that you **cannot drive for 3 months** after transplant.



Northern Albertans - Long-term follow up by referring centre

Southern Albertans - Long-term follow up by the TBCC

Your Health Care Team

It takes many health care professionals working together to help you and your family through transplant. You and your family are an important part of the team, and we want you to ask questions and share information with us.

Doctors

When you are referred to the BMT program, you will have a transplant doctor assigned to you. You will meet this doctor at your consult. This transplant doctor will follow you before and after your transplant while you are in Calgary.

During your time in the hospital, you will have different transplant doctors direct your care. These are the attending transplant doctors. They may change depending on their schedules, but the doctors work together so that each doctor knows about you, and your transplant. A transplant doctor is on call 24 hours a day.

Once you are discharged, your assigned transplant doctor that you started with before transplant will take over your care in the outpatient BMT clinic at TBCC.

Nurses

Nurses will care for you throughout your transplant process.

Before your transplant, a nurse coordinator will work with you and help prepare you for the transplant. Nurse coordinators:

- Arrange all the tests and procedures you (and your donor) need.
- Teach you and your family all you need to know about transplant, and possible complications or side effects.

Nurses also care for you while you are an inpatient and outpatient. They work with the doctors and other health care team members to help you manage the side effects of treatment, and support you and your caregiver to care for you at home.

Radiation Oncologist and Therapists:

The radiation oncologist is a doctor who plans the total body irradiation (TBI) treatment that is part of the transplant treatment before you receive the stem cells. If your transplant doctor decides you need radiation, the radiation oncologist will review the procedure and consent form with you before you sign consent.

The radiation therapists will explain the TBI procedure to you, and deliver the TBI on the day before you receive the stem cells.

Dietitians

Registered dietitians (nutrition experts) are available to help you maintain good nutrition during your transplant recovery. You will see the dietitian before transplant to learn about specific food safety guidelines you must follow after transplant. Dietitians will help manage any concerns while you are in the hospital, and will see you in the BMT clinic after transplant until you are eating well again.

Psychosocial Team — Psychologists and Social Workers

Every transplant recipient sees a social worker or psychologist in the pre-transplant work up. Psychologists and social workers can:

- Provide emotional support to help you and your family cope with your illness and treatment
- Help with making housing or transportation arrangements while in Calgary
- Help with practical things like work-related issues such as disability and leave forms
- Help with reorganizing finances, finding more sources for funding, health insurance or medication coverage

Pharmacists

Pharmacists help teach you about the chemotherapy and other medications you will receive during the transplant process. The pharmacists work with your doctor to decide which medications will best help you, arrange prescriptions, provide medication schedules, and teach you how to manage your medications at home.

Physical Therapists

Physical therapists help with problems related to muscles and bones. They may suggest exercises to help prevent these problems, and can help you rebuild your strength and stamina, as you may feel weak and lose muscle strength during and after transplant.

Physical therapists can help you while you are an inpatient. Your outpatient team can refer you to see the oncology rehabilitation staff if you have concerns with your balance, muscles or bones.

Preventing Infection

It is very important that you try to prevent getting an infection before, during, and after your transplant. This next section will talk about some things you can do to help prevent infection.

Clean Your Hands

Cleaning your hands is one of the best ways you can stop germs from spreading and reduce the chance of infection. The main way germs spread is by our hands. You can pick up germs almost everywhere, including phones, doorknobs, and railings. You can spread these germs without even knowing it.

Your hands may look clean, but they can still have germs that cause infections. When you forget to clean your hands or don’t clean them well, you can spread germs to other people. You can also spread germs to yourself if your hands aren’t clean and you touch your eyes, mouth, nose, or a cut on your body.

Encourage your family members, visitors, and health care team to clean their hands whenever they visit you or help you with your care.

When do I need to clean my hands?

Always clean your hands:

- before you prepare and eat food
- before you touch your eyes, nose, or mouth
- after you use the bathroom, blow your nose, or cough or sneeze on your hands
- before you have contact with patients or people who live in a health care facility (residents) and before you go into their room
- after you have any contact with patients or residents and after leaving their room, unit, and the health care facility
- before and after personal hygiene

Should I use hand sanitizer or soap and water?

You can use hand sanitizer (an alcohol-based hand rub) or soap and water to clean your hands. It should have 60% to 95% alcohol in it to work best.

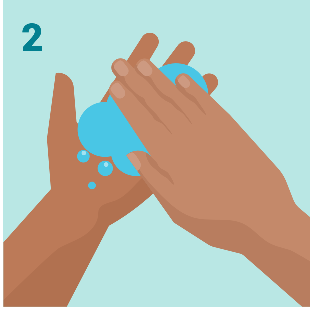
Hand sanitizer is best to use when:

- your hands don’t look or feel dirty
- water and soap aren't available
- you go into or leave a health care centre, or a patient's room

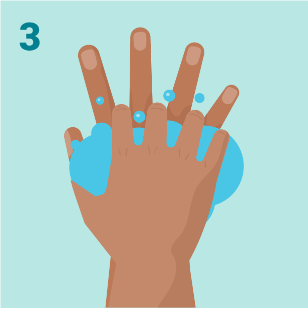
Follow these steps to clean your hands with hand sanitizer:

- Roll up long sleeves and push up your watch, bracelet, and other items on your wrist.
- Put a palm-sized amount of hand sanitizer on your hands.
- Rub the sanitizer all over your hands, wrists, fingers, fingertips, and thumbs.
- Rub until your hands are completely dry.

APPLY THE PRODUCT
ON THE PALM OF ONE HAND



RUB TIPS OF EACH HAND
WITH PALM OF OTHER HAND



RUB BETWEEN THE FINGERS
AND THE BACK OF HAND

RUB HANDS TOGETHER
UNTIL THEY ARE DRY

Soap and water is best to use:

- when your hands look or feel dirty
- before you eat or prepare food
- after you use the bathroom

Follow these steps to clean your hands with soap and water:

- Roll up long sleeves and push up your watch, bracelet, and other items on your wrist.
- Wet your hands with warm water.
- Put enough soap on your hands to cover them.
- Rub the soap all over your hands, wrists, fingers, fingertips, and thumbs.
- Wash and scrub your hands for 30 seconds.
- Rinse your hands under warm running water.
- Pat your hands dry with a paper towel.
- Turn the tap off with the paper towel.

Managing Your Environment

- Stay away from crowded places and avoid large gatherings
- Avoid people who are sick and tell sick family or friends not to visit

- Do not have contact with pets other than the ones you had before transplant. If you have reptiles, birds or rodents in the home, please discuss with your health care team
- It is best not to sleep with, groom, bath or feed your pet
- Avoid contact with pet food, pet feces, saliva, urine or litter box material

- Change dish cloths and kitchen towels often and wash them in hot water with bleach. When you dry them, make sure you use the hottest temperature on the dryer
- If you live in a rural area, you may need to have your well water checked for safety

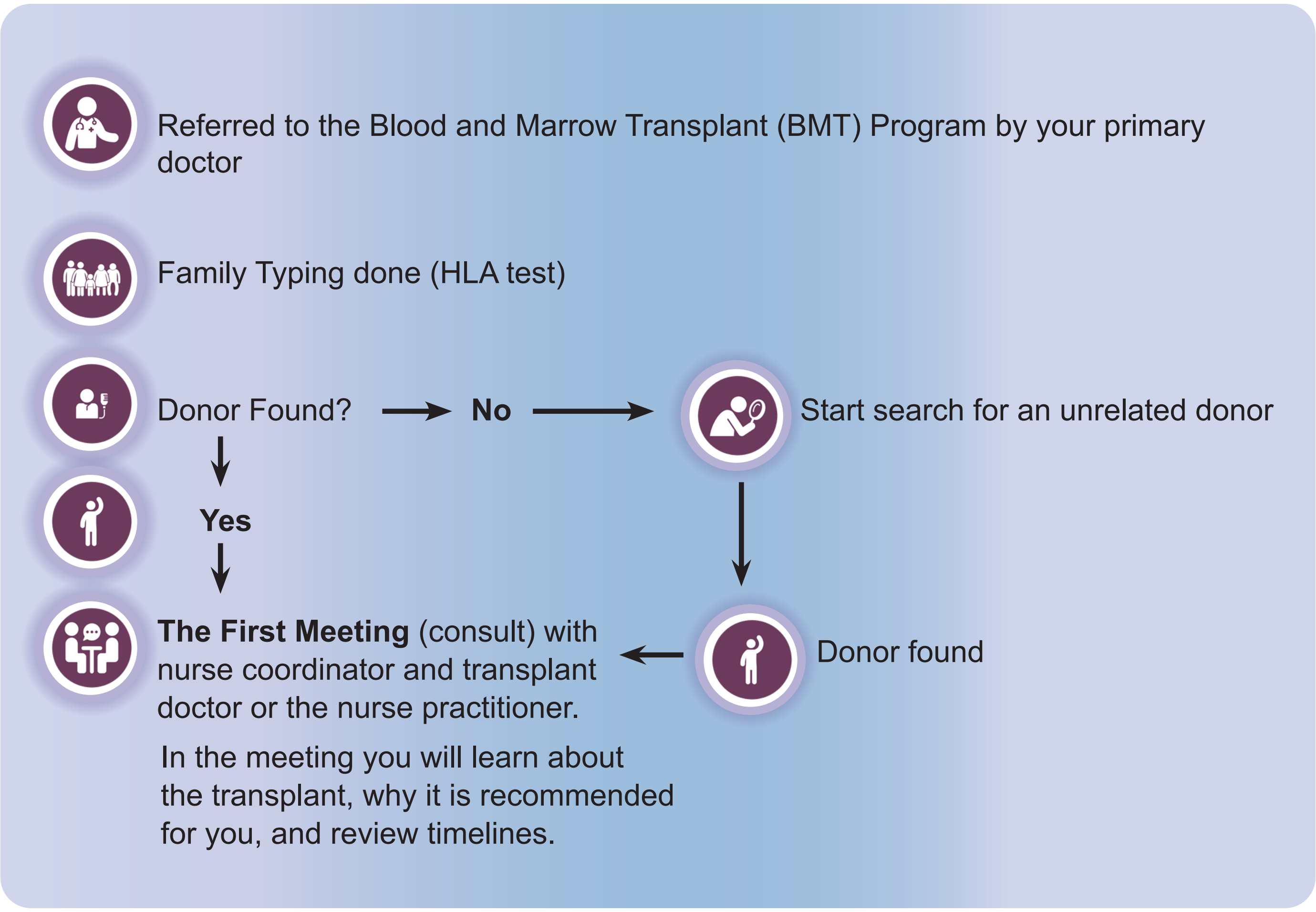
- Plants may remain in the home, but plant care must be done by someone other than you
- Avoid gardening, yard work or digging in dirt

- Do not wade or swim in pools, hot tubs, ponds or lakes

- Stay away from construction sites, dusty places, and home renovations

B. Getting Ready for Your Stem Cell Transplant

Getting ready for your stem cell transplant will be a very busy time for you. Not only will you have many appointments, you may still be getting treatments during this time. Below outlines some of the things to expect during this time.



Referred to the Blood and Marrow Transplant (BMT) Program by your primary doctor

Family Typing done (HLA test)

Donor Found? → **No** → Start search for an unrelated donor

↓ **Yes** ↓

Start search for an unrelated donor ↓ Donor found

The First Meeting (consult) with nurse coordinator and transplant doctor or the nurse practitioner. ← Donor found

In the meeting you will learn about the transplant, why it is recommended for you, and review timelines.

Finding a Donor

We must find a donor before you can have a transplant. The search for your donor begins before your first meeting with the transplant team. When we look for a donor, we are looking for someone who has a compatible immune system to you. To do this, we take blood samples from you and the possible donor(s) to look at proteins called Human Leukocyte Antigens (HLA).

HLA are found on most cells in your body. Your immune system uses these proteins as markers to recognize which cells belong in your body and which don't. Finding a donor can sometimes take a long time.

For more information about how we find a donor, see page 62.

The Meeting (Consult)

Once a donor is found, you, your support person, or your family will meet with your transplant doctor and nurse coordinator to talk more about using stem cell transplant to treat your illness. After the consult, you will have time to talk with your family and decide if an allogeneic stem cell transplant is the best treatment for you. Talk to your nurse coordinator if you have any questions.

Here are some of the questions we will answer during the meeting:

What is the reason for the transplant?	We will talk about: • Why the transplant is an important part of your treatment • How the transplant will benefit you • The expected risks, complications, and possible side effects • What can happen if you choose not to have it
When will I get my transplant?	The decision about when to do the transplant depends on many things that are related to your condition and finding a donor. Dates for transplant can change depending on you or your donor. The Blood and Marrow Transplant (BMT) team will talk to you about your schedule and timelines.
How long will the time commitment be?	It can take quite a long time for the whole transplant journey, and the length of time for each person is different. It can take even longer if it is hard to find a donor for you. Because of this, we can't tell you exactly how long it will take. You will need to stay in Calgary **for at least 3 months with a caregiver(s)** after your transplant. You will stay in the hospital for about 3-5 weeks or longer and then another 2 months in Calgary so you are close to the centre in case you have any complications. For the first 3 months you will have a lot of appointments and will need to get checked often. Once you start to stabilize, you will have less appointments but you will be followed for life.

What tests and procedures will I need before my transplant?

Once you decide to have the transplant, you will begin a lot of tests, procedures and consults. We call this the **work-up phase.** These appointments help to check your overall health, make sure you are a good candidate for transplant, and look for possible problems before transplant. Find more information about this phase on page 14.

Your nurse coordinator will give you a calendar and schedule for your tests. These tests are done over a few days **as an outpatient in Calgary**.

Patients from out of town

If you are from Northern Alberta, some tests may be done in Edmonton. If you live far from the city, you may need a place to stay for that time.

If you are getting tests in Calgary and live more than an hour away, you will need to have accommodations in Calgary during the work up phase.

What about medicine and drug coverage?

There is no cost for the medicine you get while in the hospital. But the cost of the medicine you may need to take when you are not at the hospital (outpatient) can be high. Find out what your drug plan will pay for. A social worker may be able to help with this.

Tip!

If you do not have a drug plan, you can talk to a ***social worker*** *for help. Ask your nurse coordinator for more information.*

What if I live out of town?

Patients from out of town

If you live more than an hour's drive from Calgary, you will have to stay in town with a caregiver before, during and after the transplant — your doctor or nurse coordinator will let you know how long you will need to stay. This time away from home can be financially stressful.

Your nurse coordinator or social worker can provide you with information about accommodations if needed.

Will I need a caregiver?

Yes, you will need a caregiver(s). Caregivers play an important part in your recovery. It must be someone who can commit to the process. How long you will need a caregiver full-time will depend on your condition.

See more information on the caregiver's role on page 16.

What are the financial costs?

- Living expenses if you or your caregiver live an hour or more out of Calgary.
- Any medicines you need not covered by Alberta Health Care.
- Any travelling costs.
- If you need to pay someone to care for your child or children while you are away.
- You will get a dental assessment before transplant. The first visit with the dentist is covered, but if you need more dental work, there may be additional costs. A social worker may be able to help you with these costs.
- If you have a job, you will need to take time off during and after the transplant. When and if you can go back to work depends on how well your body responds to the transplant. Your caregiver may also need to take time off.

Tip!

Helpful tips during stem cell transplant:

"If you are not sure about what you were told, and you are told a lot, then ask questions. I am a retired nurse, my husband was a veterinarian, and even with the background we had, we often were left wondering about all the information we were given. Ask until you get it!! And don't feel bad!

Mary ~ Caregiver

How do I prepare my friends and family?

A transplant will affect everyone in your family, including children, parents or partner. Family routines will be disrupted for several months. Children may have many concerns that can affect their behaviour and emotional well-being.

Before you talk to them about the transplant, learn about your disease, treatment plan, and possible side effects so you can answer your family's questions.

If you need some emotional support during the discussion, the psychosocial team can help you and your family members. (See page 54 for more information).

Clinical Trials and Studies:

You may ask what clinical trials or research studies are available. If any are available, we may ask you if would like to join the trial. If you choose not to take part in the studies, your care will not be affected in any way.

Advance Care Planning:

The booklet Conversations Matter will tell you more about advance care planning. Another booklet, Coming Full Circle, can also help with planning for your care. Your transplant team will discuss your goals of care with you. It is a good idea to have an advance care plan and a personal directive so that your family and your health care team know and carry out your wishes if you cannot speak for yourself. conversationsmatter.ca

Work Up Tests Before Transplant

Once you decide to proceed, we will begin planning your schedule for tests and treatment before your transplant. This will be a very busy time for you as you may have many appointments.

Your schedule depends on:

- your treatment plan
- what transplant dates are available
- how quickly you need treatment
- what times are open for tests and appointments

If you vape, smoke or use tobacco products, your health care team will try to support you quitting or reducing your use. This may help you have:

- A better chance of successful treatment
- Fewer serious side effects
- A faster recovery from treatment
- A decreased risk of the cancer coming back, or getting another cancer diagnosis
- A lower risk of infection
- Easier breathing
- More energy
- A better quality of life

For information or support: www.AlbertaQuits.ca or call1-866-710-QUIT(7848)

Your nurse coordinator will give you a calendar and schedule. Appointments, or transplant dates may change. **Tell your BMT team if you:**

- Cannot go to an appointment. All tests are important steps to get you through the transplant. Missing appointments can affect future scheduled appointments.
- Take or use any over the counter medications, herbal supplements, alcohol, cannabis or tobacco products, vaping or recreational drugs.

During the work up phase, you will have some or all of these tests and procedures:

Blood work:

- Complete blood count (CBC)
- Chemistry
- Blood type
- Iron levels
- Transmissible disease testing like HIV, hepatitis, or syphilis
- Blood clotting time
- Pregnancy test if needed

Physical Examination:
You will have a physical examination to check your overall health and to see if there are other tests you may need.

Other tests may include:

- Electrocardiogram (ECG)
- Lung function — Pulmonary function test (PFT)
- Urine test
- Lumbar puncture
- Bone marrow aspirate and biopsy
- Heart function — Echocardiogram/Cardiac MRI
- X-rays of the jaw and teeth
- CT and PET scans
- Chest X-ray

Continued on next page

Dental Work-Up:
Your nurse coordinator will arrange for you to see the hospital dentist. The dentist makes sure you have no infections or other problems with your mouth or teeth since this can be a source of infection during and after transplant.

If you have a dental infection or other problem, the dentist will decide the best way to treat you or if the problem needs to be fixed before you can have your transplant. If you have a dental procedure done, you need to be fully healed before the transplant.

You may also see a:

- Pharmacist
- Dietitian
- Psychologist
- Social worker
- Radiation Oncologist
- Palliative Care
- Gynecologist (for women)
- Eye doctor (ophthalmologist)

Consenting to Treatment

It is up to you to decide if you want to have the transplant. Use the information provided to you in this book, your transplant meeting, conversations with your nurse coordinator, transplant doctor, hematologist, family and friends to make this decision. If you have any questions, ask your nurse coordinator or transplant doctor.

Your consent form will be signed by you, the doctor and the nurse coordinator. You will get a copy to keep. Signing the consent form means you plan to go ahead with transplant.

You can use the free AHS **My Care Conversations** app to prepare for your next appointment and to audio record conversations with your health care team. You can listen to your recordings at home and share with family or trusted friends.

Download it from the App Store or Google Play.

Consenting to treatment

You need to understand the treatment plan and risks before you sign the consent forms. Only agree to the procedure and sign the consent when you understand:

- how you will prepare for the transplant
- the transplant procedure and recovery, including the side effects and possible complications
- how it will affect you and your family
- how your life could change because of side effects or complications you may have
- you will need a caregiver to provide support while you go through this process

If you do not understand or have more questions, ask the doctor or nurse coordinator to go over the information with you.

Role of the Caregiver

Will I need a caregiver(s)?

A stem cell transplant is not something you can manage by yourself. You will need a caregiver(s) **during all phases of your transplant** – during the work up phase, while you are in the hospital, and after the transplant while you recover.

Caregivers are very important members of your transplant team and are usually family members or friends who can be with you on your transplant journey. The caregiver(s) must be reliable and agree to commit to the full-time responsibility of this role.

Do I need more than one caregiver?

It really is a good idea to have more than one caregiver if possible. Work out a schedule with your caregivers — they could change week to week for example. The caregiver is a full-time commitment and it's important for them to be able to take some breaks and look after themselves too.

Tip!

Keep a list of your caregivers, their contact information and a schedule of when they will be taking care of you.

How long will I need a full time caregiver(s)?

Plan to have a full-time caregiver(s) for about 3 months after your transplant. You may still need help for several months after that. The length of time you will need a caregiver(s) will depend on your condition and recovery after transplant.

Does my caregiver(s) need to be with me all the time?

Your caregiver(s) should be available when you are not in the hospital. They need to be able to get to you within 10 to 15 minutes in case of an emergency.

Caregivers can go out for short periods of time, like going for a quick run to the grocery store.

What does a caregiver(s) do?

A caregiver(s) can:

- give you emotional support
- help you get information from your health care team
- drive you to and from the hospital
- keep track of appointments
- help give you your medicine or care for your central line
- watch for and tell your health care team about changes in your health
- care for the people you usually care for like children or parents
- help you with your everyday activities like laundry, shopping, or making meals

Tip!

Caregivers need to be prepared to get a lot of information. Make sure you ask questions if you don't understand something. And if you're having trouble coping with anything, contact psychosocial services for help.

C. Your Stem Cell Transplant

Once we have your donor selected and confirmed, workup is completed, and you agree to the transplant, we can go ahead with the next phase:

Admitted to the hospital for transplant

Central line inserted

Conditioning treatment (chemotherapy and radiation)

Stem Cell Transplant:

- Infusion of stem cells
- IV fluids, possible blood products and support medications to help manage side effects
- Stem cells start to work (engraftment)
- You may have passes to leave the hospital if you are well enough
- Prepare for discharge

The Central Line

If you do not already one, you will get a central line inserted. You might hear this called a CVAD or CVC.

Why do I need a central line?

It is used to infuse stem cells, draw blood and to give:

- chemotherapy
- fluids
- medication
- blood products

How long will I have the central line?

The line will stay in as long as you need it. Most people have their central line for about 3 months after transplant.

Picture of a central line called a **Tunnelled CVAD**

How will the line be inserted?	A radiologist or x-ray doctor will freeze the area where the line will be inserted. They will then insert the line in the chest through the skin and into a large vein.
How will I care for my central line?	Your nurse will teach you how to care for your line to help prevent infection, or it may be done at your cancer centre.
Will I still be able to have a shower or bath?	You will still be able to have a shower but the central line needs protection from the water, so a bath is not recommended. You will need to cover your central line site before having a shower or bath. Your nurse will give you more information when you get the central line.

Tell your doctors if you take any of the below. You may need to stop taking them for a while before your central line is inserted:

- blood thinners
- anti-inflammatory pills (such as aspirin, ibuprofen, Advil®)
- herbal supplements
- Ibrutinib

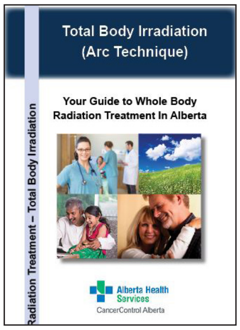
The Conditioning Phase

Before you have your stem cell transplant, we need to give you some strong treatment to help destroy your cancer cells. This is called the **conditioning phase**. You may also hear this called the "preparative regimen".

When we destroy your cancer cells, we make room in your bone marrow for the healthy donor stem cells. It also destroys your immune system so it cannot attack the donor cells after transplant.

It will depend on your diagnosis and treatment plan, but you may get:

- chemotherapy (high-dose chemotherapy)
- total body irradiation (TBI) — the whole body gets radiation treatment



Total Body Irradiation (Arc Technique)

Your Guide to Whole Body Radiation Treatment In Alberta

Radiation Treatment – Total Body Irradiation

Alberta Health Services

CancerControl Alberta

Get more information about TBI from the booklet **"Total Body Irradiation"** at your cancer centre or online.

TBI video:
www.cancercarealberta.ca
Patients & Families >
In Treatment > Radiation Treatment

How long do I need to have conditioning?	This will depend on your diagnosis and treatment plan. Usually, patients will get 4-5 days of high dose chemotherapy. While you're getting your conditioning, you may be able to go out on passes with a caregiver between your chemotherapy doses.
Are there any side effects for conditioning?	Yes, there are some possible side effects. Conditioning destroys cells that divide rapidly. These cells include cancer cells, but also some of your healthy cells like blood cells, cells on your hairline, mouth, stomach, and intestines. When the healthy cells are destroyed, this causes the side effects. The most common side effects are: • low blood counts (page 32) • fever (page 37) • nausea or vomiting (page 40) • fatigue (page 39) • diarrhea (page 38) • sore mouth (mucositis) (page 34) • hair loss (page 41)

Complications of Conditioning Treatment

Some of the chemotherapy, medications and radiation used during conditioning can cause damage to the organs. This damage may be temporary or permanent. Severe damage to major organ(s) can be life-threatening.

Liver Problems

Abnormal liver tests are common after transplant, but most patients do not get liver damage. Resting the liver and avoiding medications that are toxic to the liver usually helps.

Sometimes patients develop **Hepatic Sinusoidal Obstruction Syndrome** (SOS). SOS makes the liver swollen, so it cannot get rid of waste products in the bloodstream properly. We use a drug called defibrotide to help treat patients who develop SOS.

Symptoms of SOS can be:

- Pain in the right side of your stomach
- Sudden weight gain
- Changes to your liver function blood tests
- Swollen stomach or ankles
- Your skin or the whites of your eyes turn yellow (jaundice)

Lung Problems

Damage to the lungs is rare, but sometimes it can cause serious breathing problems.

Day 0 - The Day of Your Transplant

The day of transplant is often called "day zero". This is the day you get your donor stem cells! For some, it’s a celebration of a new beginning, and often considered a second birthday.

The days before Day 0 (conditioning phase) are negative days (Day -7 or Day -1). The days after Day 0 are positive days (Day +1, or Day +10).

Day -2, -1
Conditioning Phase

Day 0
Transplant Day

Day +1, +2, etc.
Days after Transplant

How do the stem cells help?

The stem cells help your bone marrow recover from the effects of the conditioning “high dose” chemotherapy by restoring your bone marrow and immune functions. Stem cells are often called “the rescue”

How do I get the donor cells?

Getting the donor stem cells is almost like having a blood transfusion. The stem cells come in a blood bag and are given to you through your central line. The donated cells will move through your bloodstream to your bone marrow.

How long will it take to infuse the stem cells?

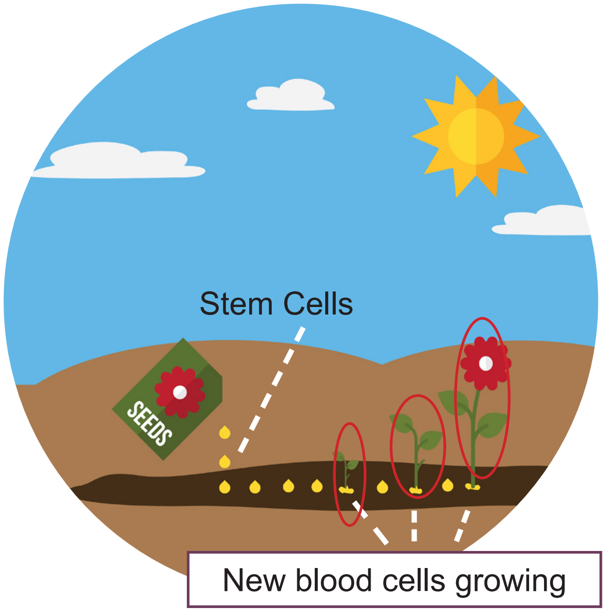
This can take minutes to hours. Your nurse will monitor you closely while you get your new cells. They will explain what to expect and how you might feel.

Days After Your Transplant

Engraftment

When we infuse the donor stem cells into your body, they will enter your bloodstream and move to the bone marrow. Once in the bone marrow, they can grow and make new blood cells. This is called **engraftment**.

Stem Cell Transplant is like planting new seeds (stem cells) in a garden. Engraftment is when the seeds start to grow into plants (new blood cells).



How will I know if the stem cells are engrafting?

Before your stem cells engraft, you will have low blood counts. When blood counts start to rise, we know that the cells are growing and making new blood cells.

How long will it take for the cells to engraft?

It usually takes about 2 to 4 weeks for your blood counts to start to engraft.

While you wait for engraftment, you will have very few cells to protect you from infection or bleeding. As your blood counts begin to go up, your immune system will get stronger. You will be in the hospital for some of this time.

It is important to remember that even when your blood counts are at normal levels you are still at a higher risk of infection. This can be because of the medication you are taking and because these new cells take a while to become “strong”.

How will I feel after my transplant?

After your transplant, you will feel tired and unwell. You will be at risk for:

- fever
- fatigue
- bleeding
- infection
- shortness of breath
- damage to the organs

Most of these problems are worse when the blood counts are very low. This is usually about 1 to 3 weeks after the transplant.

Tip!

We will tell you your blood counts every day to see how your bone marrow is recovering.

You can keep a record of your daily counts so you can watch them as they change.

Will I be in the hospital after my transplant?

You will have a hospital room, but if you are feeling well enough and it is safe, you may be able to leave the hospital on day passes with your caregiver, but stay within 1 hour of the centre. You will need to return to the hospital for blood tests or treatments.

Your Time in the Hospital

Welcome to Unit 57

You will stay on Unit 57 at the Foothills Medical Centre for about 4 weeks from the time conditioning starts, to when you are discharged to the Tom Baker Cancer Centre BMT Clinic. If you have any problems, you may be in the hospital longer.

Unit 57 is made up of units:

- 57A (inpatient)
- 57B (day unit)
- 47D (inpatient)

You and your caregivers are an important part of the team and we want you to ask questions and share information with us to help in your recovery. Many people will care for you during your transplant. This may include (see page 5):

- doctors
- nurse practitioners
- nurses
- health care aides
- psychologists
- dentists
- pharmacists
- dietitians
- physiotherapists
- occupational therapists
- social workers
- spiritual care providers
- palliative care (page 57)

Checklist - Admission to Hospital

Bring some items that will make your stay more comfortable such as:

☐ Loose, comfortable clothing, pajamas, extra underwear. Buttons on the front of shirts make it easier to access your central line.

☐ Comfortable footwear for walking on the unit or doing physiotherapy.

☐ Slippers or sandals with good grip.

☐ Toiletries such as unscented lotions, soap, toothpaste, toothbrush, or electric razor.

☐ Activities to do: reading, simple crafts, computer games, movies (bring earphones if listening to movies or music).

☐ A list of the medications you take.

☐ Personal pillow or blankets (twin size) — avoid linens with similar colours to hospital linens as they may get mixed up and go missing.

☐ Personal laptop, tablet, phone, and don't forget their chargers. Label everything.

☐ If you use a cane or walker for mobility.

☐ Things to decorate your room with like photos or silk plants.

☐ Some food from home is allowed — ask your nurse for more details.

☐ You need to bring your own thermometer.

Remember:

☐ Hospital does not provide laundry service for your personal items.

☐ Put your name on personal items like walkers or tablets.

Your room

- You will have a private room with a private bathroom once your blood counts begin to drop to help protect you from infection.
- **No extra cost for the private room.**
- You can have a cell phone but you may need to put your phone away or on vibrate during assessments and procedures.
- There is free wireless Internet in most of the rooms. It is an unsecured network.
- You may need to move rooms during your stay depending on patient and staff needs.

Tip!

Helpful tips during stem cell transplant:

"Bring a laptop and several movies - this will help to pass the time."

~ Rhonda (caregiver)

Visitors

- Check in at the nursing station first.
- In private rooms, there are no set visiting hours. If you have someone stay overnight in your room, you must get permission from the Unit Manager.
- Must not use the bathroom in your room — this is to help reduce the spread of infection.
- Visitors who are sick will not be allowed on the unit.
- Please be aware that visitation policies may be adjusted for patient safety needs. Your health care team will let you know about any changes to these policies.

Tip!

Remember!

Washing your hands is so important to help reduce infection!

Children

- Children 10 years old and younger are not allowed to visit the transplant unit. This is to help prevent infection.
- If you have young children, you can visit with them on the main floor of the hospital as long as the children are well and have no signs of infection.

Visitors should **not come** if they have:

- a fever
- a sore throat
- vomiting or diarrhea (within the last 48 hours)
- a new or unexplained rash or if they feel sick
- a new cough
- a runny nose
- been exposed to an infectious disease, like chickenpox or the measles
- been in contact with someone who is sick in the past 2 days

To help prevent the spread of infections:

- Patient washrooms (including showers) are only for patients to use. This helps to reduce the risk of either you or your visitor getting an infection.
- Patients and visitors should not visit other patient rooms.
- All visitors must wash their hands well with an alcohol hand rub or soap and water as soon as they arrive on the unit and after visiting you.

Smoking:

- There is no smoking or vaping in or around the hospital. This means you cannot smoke or vape in any of the buildings or on the hospital grounds. This includes cannabis.

Lotions, perfumes and other scented products:

- Ask visitors not to wear anything that has a scent like perfume or lotions.

Flowers, plants and balloons:

- Fresh flowers, plants, dried flowers and fruit baskets are not allowed in your room or on the unit. These can carry germs that cause infection.
- Latex balloons are not allowed on the unit.
- Mylar (non-latex) balloons, silk flowers, cards, and pictures are good choices.

Passes

- If you are well enough to be at your home, or accommodation in Calgary, we may offer you passes with your doctor's approval and following hospital policy.
- Passes may be just for the day, overnight or for more than one day
- You must have a caregiver to go with you for all passes (no exceptions)

Daily Routine

While you are staying with us, there are a few things that are really important for you to do everyday. These are some of the things you can control during this time. They may not seem like much, but they can improve your outcome and experience.

Shower daily. This helps lower your risk of getting an infection from your normal skin bacteria.

Wash your hands or use hand sanitizer often, especially after using the washroom, or when preparing or eating food

Take care of your mouth to help prevent mouth sores or infection (see page 35)

Wear a mask when you leave your room and when you leave and return to the hospital.

Exercise — stay active to help keep you as strong as possible and to prepare for your return home. Walking is a great way to stay active. Physiotherapy will be involved to make an exercise plan that works for you.

Do your best to eat and drink something everyday to help your body recover.

Your health care team also has daily duties to help you. They will:

- Check your vital signs every 4 hours to watch for signs of infection or fever
- Get bloodwork from you early in the morning so doctors can review the results first thing in the morning and make adjustments to your care if needed
- Assess you head-to-toe at the start of their shift and when needed.
- Doctors will also assess you daily
- Check your weight. This helps the doctors watch your fluid balance and nutrition
- Come into your room at least once an hour at night to check on you. They will not wake you unless you need an assessment.

To see a timeline for your health care team's daily duties, see page 66.

Activity

It is important to try and get some activity in while you are in the hospital, even if it is just a little bit. Some activities will also help if your feet or legs are swollen.

The physical therapists on the inpatient unit can help you be more active during transplant. They can help you find ways to both increase and save your energy, and keep as much strength as possible.

Tip!

Helpful tips during stem cell transplant:

"Go for a walk....just to get out of your room...get your body moving...it's very, very important."

~Scott (patient)

Here are a few things you can try:

- Change positions often when you are sitting or lying in bed
- Make an effort to do daily activities — get out of bed, take a shower, get dressed, and sit up in a chair when you eat your meals
- Plan activities that last no more than 15 to 20 minutes at a time
- Do regular ankle pumping — point toes up toward your nose and then down as far as possible. Do this 10 times
- Take short walks 4-6 times a day
- Do heel raises a few times a day. Put your hand on a chair or counter for balance. Slowly raise your heels. Hold for 6 seconds and then lower back down. Do this 10 times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Once you are discharged, your health care team can refer you to Oncology Rehabilitation in the community to help you regain strength, balance and stamina if you need help to manage activity at home.

Exercises for People with Cancer: 3 Minute Movement Videos:

The team at the Health & Wellness Lab at the University of Calgary made these videos to help you get moving. They show simple exercises you can do while you're sitting in a chair. These exercises are safe for everyone. **http://bit.ly/cancer-exercise**

Nutrition

Eating well and staying hydrated helps your body recover and build new blood cells. If you eat enough calories (energy), protein, vitamins, and minerals, it will help prevent muscle and weight loss and help you feel better.

People who are well-nourished and do not lose too much weight have fewer side effects and also heal faster after treatment.

A dietitian will meet with you during the transplant process to help make sure you are meeting your nutritional needs.

While in the hospital, choose a food high in protein at each meal. Proteins include things like meat, fish, poultry, eggs, nuts and dairy products like cheese, yogurt, or milk. The kitchen can also provide you with snacks and nutrition supplement drinks like Ensure® that are high-calorie and high in protein. You may also bring in non-perishable snacks to keep in your room.

Problems with Eating

A poor appetite, food that may taste different, feeling tired, and nausea can make it harder to eat or drink. If you lose a lot of weight or are not able to eat or drink enough to get the nutrition you need during transplant, you might get supplemental nutrition through a feeding tube.

If you have very bad diarrhea or your stomach needs to "rest" for a while, you might get supplemental nutrition through your central line.

Tip!

Helpful tips during stem cell transplant:

"Find something to help distract you. I did jigsaw puzzles for distraction and I took a class that was offered at the cancer centre. My husband was a TV lover so he watched that..."

~Mary (caregiver)

D.

Possible Complications of Transplant

During the first few weeks of your recovery, you will probably still be in the hospital, and you may have complications from the treatment. Your health care team will watch you closely and treat you if you have any complications. Complications can be very serious and can be life-threatening.

Some complications that can happen:

- Infection (page 27)
- Graft Versus Host Disease (GVHD) (page 29)
- Graft Failure (page 31)
- Organ Damage (page 31)
- Cytokine Release Syndrome (CRS) (page 31)

Infection

Infection can be a major complication of transplant. There are many viruses, bacteria, and fungi that can cause infection after your transplant. You can get an infection from the germs that may normally be on your body, or from the environment.

Tip! The most important thing you can do to prevent infection is to wash your hands!

Why does it happen?
Your immune system protects you from infection. Since the high dose treatment has damaged all of your white blood cells, you will have no immune system until your blood cells in your bone marrow start to grow again.

Once your stem cells start to grow, your risk for infection is lower, but it still can happen. It takes 6 months to a year after transplant for the immune systems of most patients to work as well as they should. It can take even longer for patients with graft-versus-host disease (GVHD).

What can help?
We will usually give you antibiotics and anti-viral medications to control or prevent infections for 1 to 2 years after transplant.

Types of Infections	
Bacterial	Most common during the first 3 months after transplant and can be anywhere in the body.
Fungal	Can affect the mouth, lungs, and vagina after transplant. Sometimes being treated with antibiotics makes it easier for you to get a fungal infection. We will treat you with anti-fungal medication if needed.

Viral

Viruses that your immune system helped control before transplant can become active after your transplant.

Here are some of the common viruses that could reactivate if you or your donor already had the virus:

Cytomegalovirus (CMV):

- Can make you very sick if your immune system is weak
- We will monitor your blood for the virus and give you medication if needed

Epstein-Barr virus (EBV) (also called "mono"):

- You may have fevers, feel very tired, or have swollen lymph nodes
- We will monitor your blood for the virus and give you medication if needed

Herpes simplex 1 or 2:

- Cold sores or genital herpes
- If it becomes active, we will give you medication to treat it

Varicella Zoster (chickenpox):

- Could cause shingles. Shingles start out as an itchy rash with tiny blisters usually only on one side of your body. The rash can be very painful
- Tell your health care team if you think you have shingles, especially before you come to the hospital or clinic
- If you have not had chickenpox before and think you have been exposed, call your transplant team right away
- Chickenpox is very contagious and you will need to be in an isolation room when you're in the BMT clinic

BK Virus:

- Infects the urinary tract and can cause you to pee more often
- Could cause the bladder lining to become inflamed causing pain and bleeding

Respiratory Viruses:

- Many different types such as influenza A or B, and other common cold viruses
- Can be mild to life-threatening

Continued on next page

Here are some of the things you can watch for that might mean you have an infection:

- a single temperature of 38.3°C (100.9°F), or a temperature of 38.0°C (100.4°F) to 38.2°C (100.8°F) for more than 1 hour
- chills, sweating, or shaking
- feeling light-headed or dizzy
- a cough or a runny nose
- diarrhea
- tenderness, redness, swelling, or drainage where your central line exits your body
- urinating often, it burns when you urinate, or your urine is cloudy
- feel short of breath, have trouble breathing, hurts to breathe, or your chest feels tight
- pain, redness, or swelling in your throat, mouth, eyes, skin, or joints
- pain in your stomach, rectum, vagina, or penis

Tip! Bring your own thermometer so that we can make sure it is accurate.

Graft Versus Host Disease (GVHD)

What is graft versus host disease (GVHD)?

When you get the donor stem cells, you are getting a brand new immune system. If the new immune system sees your body as foreign, it will attack your tissues and organs, and cause side effects. This is called GVHD and it can be a common complication after transplant. The closer you are a match to your donor, the less your risk for developing GVHD.

There are 2 types of GVHD:

Acute GVHD (see page 30)	**Chronic GVHD** (see page 30)
• happens within the first few months after transplant	• starts within the first 2 years after transplant
• usually lasts a short time	• can last a long time

Will I get GVHD?

We do try to prevent GVHD, but you still might get it. You may just get one type, but you might also get both types. Both types of GVHD can be mild, or life-threatening.

To try to prevent GVHD, we will give you medicines during conditioning treatment and after transplant. These medicines will suppress (weaken) the new immune system to try to keep it from attacking your body.

Immunosuppression — when your body's immune system and its ability to fight infections and other diseases is suppressed or weakened.

What happens if I get GVHD?

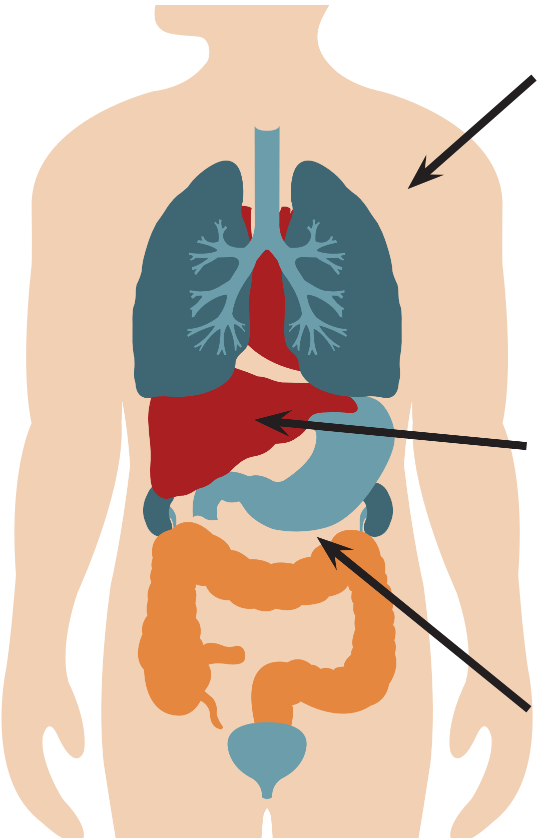
We need to treat GVHD quickly. We will watch you for any signs of GVHD, and you will need to watch for signs of it when at home.

Some GVHD symptoms will respond to treatment or get better on their own. Sometimes, even when treated early, GVHD can progress.

GVHD is serious and can be life-threatening. Treating it early is the best way to control the disease.

Acute GVHD

Acute GVHD can happen in the first few months after transplant. It usually affects the skin, liver and stomach. People with acute GVHD are more likely to develop chronic GVHD later on.



Symptoms:

Skin

The first signs are usually a rash, and redness of the skin that looks like a sunburn on the hands, feet and face. This rash can spread over the entire body and can cause blisters.

If you start to get a rash, tell your health care team right away.

Liver

- Blood work shows elevated liver enzymes
- Tenderness in the upper right stomach
- Jaundice (the skin or the whites of your eyes turn yellow)

Stomach or Bowel

- Diarrhea — watery and sometimes bloody stools, many times per day
- Nausea or vomiting that does not go away with nausea medication
- Stomach cramps
- Very bad heartburn

Chronic GVHD

Chronic GVHD usually develops later than acute GVHD and affects more organs and tissues. It can affect your skin, mucous membranes (eyes and mouth), vagina, the lungs, bowel, liver and blood counts. Chronic GVHD may cause permanent organ damage, and can be life-threatening.

- Can develop within the first 2 years after transplant and can last a long time.
- Usually needs treatment for 1 to 3 years

Symptoms:

- dry eyes and mouth
- changes to skin
- weight loss
- cough or shortness of breath

Treatment of GVHD

Usually the treatment for acute and chronic GVHD involves using immunosuppressive medications like steroids (prednisone), or cyclosporine. Once the GVHD improves, these medications are slowly decreased over a long period of time. If the GVHD does not improve, your health care team will talk to you about other options.

Graft Failure (Graft Rejection) or Poor Graft Function

Sometimes the engraftment does not work or works poorly. Graft failure or poor graft function is rare, but is a serious complication early after transplant. It happens when the new stem cells do not grow in your bone marrow, or they may start to grow at first and then stop. If this happens, your transplant doctor will speak with you about the different treatments for this problem.

Organ Damage

It is rare, but some people get very sick after transplant because of complications that affect their major organs. If you become very sick, you may be admitted to the Intensive Care Unit (ICU). Sometimes your major organs like your lungs, heart or kidneys may be damaged. This can become a life-threatening situation or leave you with an organ that is permanently damaged. If we are concerned that this may happen to you, we will talk to you about this.

Cytokine Release Syndrome (CRS)

One complication that only happens with haploidentical transplants is called **Cytokine Release Syndrome (CRS)**. CRS happens within the first week after transplant, and can cause:

- Fever
- Changes in blood pressure
- Shortness of breath with low oxygen levels
- Neurological symptoms like confusion, trouble finding words and problems with coordination or balance
- Nausea
- Diarrhea

For more information on haploidentical transplants, see page 64.

Medication is available to treat CRS if it happens, but in some cases, CRS is life-threatening.

E. Managing Your Side Effects

You will have side effects throughout the transplant process. This section talks about possible side effects you may have and gives you tips on how to deal with them. Start following these instructions on your first day of treatment, and continue once you are home.

If a side effect is really bothering you and none of the tips help, talk to your transplant team about other things that can help.

Low Blood Counts

When the chemotherapy attacks the cancer cells in your body, it also attacks your blood cells. This is what causes you to have a **low blood cell count**. Having a low blood cell count is the most common and most serious side effect of chemotherapy.

Your blood cell counts will often reach their lowest level about 7 to 10 days **after chemotherapy**.

Low White Blood Cells (WBCs)

Your WBCs will stay low until the stem cells start to grow. When your WBCs are low, your body's immune system becomes weak, which puts you at risk for infection.

WBC Normal Count:
4.0 to 11.0/L

Neutrophil Normal Count:
1.8/L or more

Neutrophils are the type of WBC that we monitor.

You are at high risk for infection if your neutrophils are 0.5/L or less This is called **neutropenia**.

What are the symptoms?

- Infections (viral, bacterial, or fungal)
- Tiredness (fatigue) and weakness

What can help?

- Wash your hands well and often
- Stay away from sick people
- We may need to place you on high risk infection precautions
- We may give you a growth factor (GCSF) to help your WBC count go up
- We may give you medications and antibiotics to prevent or help if you get an infection

Continued on next page

Low Platelets

Your platelet counts drop after chemotherapy. They stay low until the stem cells start to grow. You will be at risk of bleeding until they start to grow and mature.

Normal Platelet Count:
150/L to 440/L

What are the symptoms?

- Bruising
- Red or brown urine
- Nosebleeds
- Bleeding gums
- Fatigue
- Small red or purple spots on the skin caused by bleeding under the skin (petechiae)
- Headaches
- Bleeding from your vagina not from your menstrual cycle (period) or heavier menstrual cycle than usual
- Blood in your stool

What can help?

- We may give you a transfusion of platelets to lower your risk of bleeding until your new bone marrow begins to make platelets.
- If you are constipated, you may need a bowel softener. Bowel movements should be regular and soft.

To help prevent bleeding:

- Do not shave (or use an electric shaver)
- Do not pick your nose or blow it hard
- Do mouth care more often
- Use a soft toothbrush to prevent your gums from bleeding

Low Red Blood Cells (RBCs)

When your RBC count drops after chemotherapy, your hemoglobin (Hgb) also drops and stays low until the stem cells start to grow.

Normal Hgb Count:

Women: 120 to 160 g/L
Men: 137 to 180 g/L

What are the symptoms?

- Feeling cold
- Headache or dizziness
- Feeling short of breath
- Feeling tired (fatigue) and having low or no energy
- Pale appearance (skin, nails, lips)
- Fast heart rate

What can help?

- Try to keep a good balance between activity and rest
- We may give you a blood transfusion of RBCs to increase your Hgb

Mucositis (Example: Mouth Sores)

What is mucositis?

Mucositis is when the mucous membranes become irritated and swollen. Mucous membranes are the moist, inner linings of the body (such as the mouth, throat, tongue, stomach, and vagina).

When the mucous membranes become irritated, it can cause painful sores, bleeding and infection. It most often affects the mouth by causing mouth sores, but it can also affect the lining all the way down to the rectum.

Your mouth may start to get sore **5 to 7 days after transplant**, depending on the type of treatment you had.

It usually starts to get better after about 14 days, but it can take up to 4 weeks for your mouth to heal.

Why does it happen?

Mouth sores can happen when the treatment affects the cells inside the mouth. Many drugs can cause a sore mouth, but it is common when higher doses of drugs are used.

What are the symptoms?

The **more common** symptoms:

- Difficult or painful swallowing
- Redness and swelling of the gums
- Painful, open sores, ulcerations in the mouth and throat
- Pain while eating — caused by a sore esophagus or the mouth sores
- Diarrhea

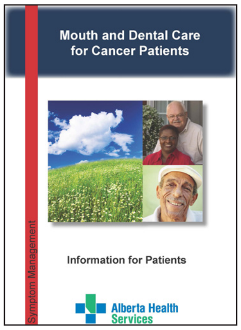
The **less common** symptoms:

- Heartburn or pain to the upper abdomen
- Stomach cramps
- Sore, tender rectum (may have ulcerations)
- Vaginal discharge
- Odor or pain or bleeding from either the rectum or vagina

What can help?

While you may not be able to prevent mucositis, there are things you can do to help manage it as well as the pain.

- Avoid acidic foods like citrus fruits (for example oranges, or tomatoes) — they may make your mouth worse
- Do regular mouth care to reduce your chance of infection — this can help prevent infection and promote healing
- Use special mouth washes and painkillers
- Eat soft foods like mashed potatoes, yogurt, ice cream, soups, oatmeal, scrambled eggs
- Avoid very hot or cold foods
- Sometimes a feeding tube or IV nutrition if necessary



Get more tips from the booklet ***"Mouth and Dental Care for Cancer Patients"*** at your cancer centre or online.

Continued on next page

Caring for Your Mouth

A sore mouth (from mucositis) is common after chemotherapy or radiation treatment. It can be very painful. Good mouth care can help prevent infection and help with healing.

Mucositis increases your risk of infection or bleeding. You may have to take an anti-fungal medication to lower the chance of getting a yeast infection in your mouth.

Mouth Pain

If you have a lot of discomfort or pain, there are medications that can help you manage the pain (such as mouth rinses or pain medication). Pain medication can be delivered in many ways such as by mouth, through an IV, or with a pain pump that the patient can control.

Dry Mouth

A dry mouth is common after transplant. It is often caused by the effects of the chemotherapy or radiation treatment and it can last for many months. If you develop chronic GVHD (see page 30), your dry mouth can last much longer.

When you have a dry mouth, you have a higher risk of cavities and other problems with your teeth. Talk to your health care team if your dry mouth becomes a problem. You may need fluoride treatment for this.

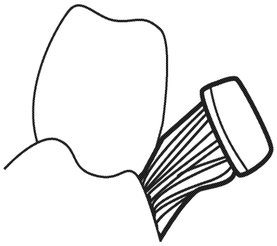
Rinses to help dry mouth, artificial saliva products, and sugar free gum or candies can help. The hospital dentist will see you 3-4 months after transplant and can help if dry mouth is a problem for you.

What can I do to care for my mouth?

Do your mouth care **at least 4 times a day** after the transplant:

Brushing:

- Use an ultra-soft toothbrush. Moisten the brush in hot water before using. Rinse it in hot water while you brush to keep the bristles soft.
- Brush gently and hold your brush at a 45 degree angle.
- Use a mild toothpaste only if it is comfortable. You do not need toothpaste to keep your teeth and gums clean.
- A mild toothpaste, like children's non-mint toothpaste, may be easier on your mouth.



Toothbrush should be at a 45 degree angle against your teeth

Flossing:

- If you do not normally floss your teeth, do not start during the transplant process.
- Do not floss your teeth until your platelet count is higher than 10/L.
- Floss every day if you can do so without hurting your gums and your counts are high enough.

Rinsing:

- Rinse with soda water at least 4 times a day. Do this at least 4 times a day and if you feel up to it, during the night. The hospital supplies soda water.
- Rinsing helps keep your mouth moist and clean. It may help with mouth pain, dryness, and make saliva less sticky.

Appetite (loss of)

Sometimes chemotherapy can affect the way food tastes or it can cause symptoms that make you feel like not eating and lose your appetite.

Why is this important?

If you do not eat enough, you can lose weight. Losing weight can make your immune system weak, affect how you heal, and make you tired and uncomfortable. Proper nutrition helps your body to heal from the effects of the chemotherapy.

What are the symptoms?

- Food tastes “funny”
- Being put off by food smells
- Not liking food you used to enjoy
- Difficulty chewing and swallowing
- Tired of eating and giving up after a few mouthfuls
- Eating only 1 or 2 types of foods
- Feeling full sooner than expected

What can help?

- Medications to prevent or help you with nausea or vomiting
- Dietitians can help you with ideas to get extra calories
- You may need extra fluids by IV
- Nutritional supplements like Ensure®
- You made need a feeding tube if you're not eating enough because you are nauseated or vomiting

What can I do?

- Drink enough fluids to keep your urine pale yellow
- Avoid being near food preparation if smells bother you
- Sip fluids throughout the day. Other ideas for fluids are smoothies, Jello®, soups, and popsicles
- Eat small meals and snacks often
- Eat meals and snacks that are high in protein, fat and calories
- Drink liquid nutrition supplements like Ensure®
- Increasing your activity may help increase your appetite
- Do mouth care often to help with taste, and dry mouth
- Take medications for nausea as suggested

Fever

A fever may be the first or only sign of an infection. Infections can be life-threatening and need to be taken seriously.

A fever is a temperature of:

- 38.3°C (100.9°F) or higher at any time

OR

- 38.0°C (100.4°F) to 38.2 (100.8°F) for at least 1 hour

Why does it happen?

Some chemotherapy treatments can lower your blood counts. One type of blood cell that treatment can affect is your white blood cells, which help fight infection.

If you have a fever, call your health care team right away, or go to your nearest emergency centre.

If you go to emergency, remember to take your emergency letter with you to give to the health care team.

Tip!

You must have a thermometer at home to monitor your temperature. We recommend a **digital thermometer**, which comes in many styles. They give you an accurate temperature reading quickly.

Diarrhea

Diarrhea is when you have loose or watery stools 3 or more times a day.

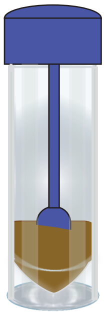
You may also have:

- stomach cramps
- pain, or feeling bloated
- gas, cramping
- dehydration
- weight loss
- bleeding or discharge
- rectal pain

Tip!

Not sure if you have diarrhea?

Diarrhea is very watery and has no formed edges. If you were to put it into a container, it would take on the shape of that container.



What causes it?

It is usually caused by the chemotherapy, radiation, medications, and sometimes infection.

Why is it important?

It is a common side effect and can cause dehydration, which can lead to fatigue and changes in your bloodwork.

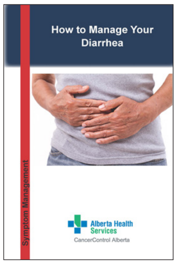
If you are in the hospital and you have diarrhea, we will put you on contact isolation until we know the diarrhea is caused by your treatment, and not by an infection.

This just means that staff and visitors need to follow certain steps when going into or leaving your room. These steps help stop germs from spreading so other people don't get sick.

What can help?

- Good handwashing (see page 6)
- We may need to give you extra fluids and nutrients, usually through an IV
- Medications for pain or discomfort
- Medications to help or prevent diarrhea (only on the advice of your health care team)
- Changes in diet
- Comfort measures such as a warm shower for a sore rectum

Please tell your nurse or doctor if you have diarrhea, so they can help you manage.



How to Manage Your Diarrhea

Symptom Management

Alberta Health Services

CancerControl Alberta

Get more information from the **How to Manage Your Diarrhea** booklet available at your cancer centre or online.

Fatigue

Fatigue (or tiredness) is a very common side effect related to treatment and cancer. It is best treated with regular exercise and good nutrition.

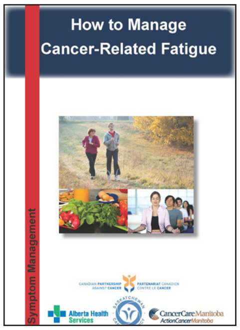
Fatigue may make you feel:

- worn out, tired/sleepy, no energy
- can't concentrate/think
- lack of interest in doing anything with friends or family
- no interest in sex or being intimate with your partner
- depressed, disconnected or not interested in anything
- like you have no energy to do normal daily activities, even self-care like showering
- short of breath

For more information visit: **http://bit.ly/fatigue-videos**

What can cause fatigue?

- low red blood cell count – red blood cells are responsible for carrying oxygen all over your body
- weight loss
- stress
- poor nutrition or not getting enough calories and protein
- changes in your daily schedule or interrupted sleep schedule
- cancer treatment
- depression



How to Manage Cancer-Related Fatigue

Symptom Management

Get more tips from the booklet "How to Manage Cancer-Related Fatigue" at your cancer centre or online.

Fatigue can happen within days after a chemotherapy treatment and can last long after treatment ends, but it usually gets better over time.

What can help?

- Rest — plan your day so you have time to rest in between activities
- Try to get some activity — simple exercises like walks can help help boost your energy
- Get others to help out when you need it
- Try to eat a balanced diet
- Drink lots of fluids - aim for 2 litres a day
- Lower stress, ease your mind and know this is part of the recovery process

Nausea and Vomiting

Nausea and vomiting can last for many weeks. It is important to control nausea and vomiting effectively. Severe nausea and vomiting can cause a loss of fluids and nutrients.

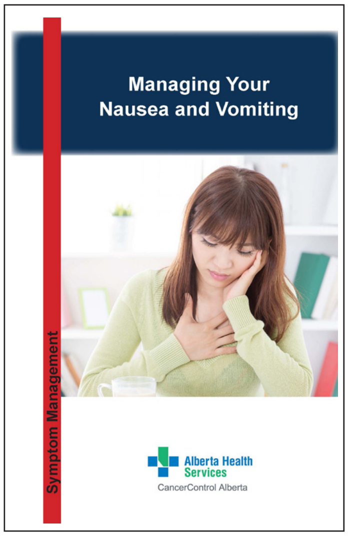
What are the symptoms?

- feeling queasy
- upset stomach
- increased saliva production
- inability to eat or drink without feeling like you need to vomit
- dizziness
- restlessness
- irritability
- lack of appetite

What can help?

The best way to control nausea and vomiting is to prevent them before they happen. Your health care team can prescribe anti-nausea medicine to prevent or reduce nausea and vomiting.

Let your nurse or doctor know if the medicine is not working. We may need to give you extra fluids, medicines, or both using an IV, or supplemental nutrition to manage the effects of nausea and vomiting.



Get more tips from the booklet ***"Managing Your Nausea and Vomiting"*** at your cancer centre or online.

Tip!

Other tips that can help with nausea and vomiting:

- Drink and eat slowly while sitting up
- Avoid lying down 2 hours after you eat
- Try to eat small meals or snacks more often
- Eat foods that are more bland
- Avoid strong-smelling, spicy or greasy foods
- Practice good mouth care
- Take nutritional supplements
- Take slow and deep breaths when you feel nauseated

Hair Loss

Almost everyone who has high dose treatment loses most or all of their hair. The treatment damages cells that grow quickly, and hair is made up of fast growing cells. Hair loss can happen on any part of the body, not just your head — this includes your eyelashes, eyebrows, and anywhere else hair grows.

The hair loss usually starts 1 to 3 weeks after your high dose treatment.

What can I expect?

- You will probably begin to lose your hair between 14 and 21 days after the start of your treatment
- Some people notice an increase in sensitivity to their scalp before losing their hair
- If complete hair loss is expected, it usually takes 3–7 days, but may take up to a few weeks
- Hair may become thinner or may fall out entirely
- It usually starts to thin and falls out in clumps.
- The hair that does not fall out may become dull or dry.
- Some people have scalp discomfort or tenderness 1–2 days before and during hair loss.
- Hair loss may happen gradually or quite quickly.

Your hair will start to grow back 4-6 weeks after treatment is complete.

When the hair grows back, it can be a bit different. Most of the time these changes are just temporary, but it may become:

- finer or coarser in texture
- darker or lighter in colour
- curly or straight

Tip!

Helpful tips during stem cell transplant:

"When my hair was falling out, it felt like it does when you hit your head getting into the car. Definitely get your hair shaved early. It was still tender but less so after the shave."

Christine ~ cancer survivor

What can I do to help manage my hair loss?

Before Treatment:

Be gentle with your hair:

- Do not colour, bleach or perm it.
- Try to limit your use of blow dryers, curling irons, or hot rollers.
- Limit your use of styling products, particularly those with alcohol or heavy perfumes.
- Avoid hair bonding or gluing.

Consider cutting your hair:

- Short hair tends to look fuller
- It may make the transition to total hair loss a little easier

Tip!

Plan ahead and get something to cover your head like a scarf or hat.

During and After Treatment:

Be gentle with your remaining hair:

- Use a satin pillow case to decrease friction (rubbing).
- Use a soft brush or a wide tooth comb.
- Wash hair only when you need to.
- Use a gentle shampoo.

Consider shaving your head:

- This may give you a sense of control during this difficult time.
- It prevents losing your hair bit by bit.
- Your hair will grow back evenly and at the same length. This might allow you to go without a wig sooner.
- This will help decrease scalp tenderness some people have before hair loss.
- Remember to protect your scalp from sun and cold air.

Hair regrowth:

- Your hair may regrow between treatments and this is normal — this hair is usually very fine and soft in texture.
- In most cases, hair loss is temporary. Your hair should start to grow back about 4 to 6 weeks after your treatments stop.
- Most people can expect about 1/4 inch of growth each month. Your hair may take up to 1 or 2 years to grow back completely.

Tip!

Helpful tips during stem cell transplant:

> "I had no idea how cold you can get when you don't have hair. Always have a soft hat for when you go to bed, even in summer!
>
> I had drastic temperature changes so I would tuck it under my pillow if I got too hot. Trust me, later when I woke half asleep and freezing, it was no fun trying to find it. I knew where it was and it was easier to go back to sleep."

Christine ~ cancer survivor

Sexuality and Fertility

Changes in your desire and sexuality may happen as a side effect of the transplant. These changes in sexuality and sexual function may also affect your partner.

You may have to stop all sexual activity if your:

- platelets are low — it puts you at risk of bleeding
- neutrophils are low — it makes it easier for you to get an infection

Pregnancy and Fertility

You may not be able to become pregnant or father a child after transplant. Check with your health care team to find out your options for preserving your fertility.

Both men and women should use some form of birth control before and during treatments.

Women who have not gone through menopause may have symptoms like:

- hot flashes
- vaginal dryness
- mood swings
- less interest in having sex

Hormone replacement therapy or other medication can help with some of these symptoms.

Men may have a lower testosterone level after chemotherapy. They may notice their sex drive is lower or they are having trouble getting or keeping an erection. Speak with your partner or your doctor if you have concerns.

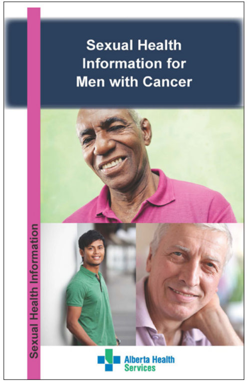
What can I do to help?

- Use water-based lubricants during sexual activity.
- When sexual intercourse is not possible, keep your loving and caring feelings alive with good communication, cuddling, and other activities that create emotional and physical intimacy.

Speak with your health care team if you have any questions or concerns.

The Department of Psychosocial and Rehabilitation Oncology offers sexual health counselling and classes to help you and your partner learn ways to create sexual intimacy.

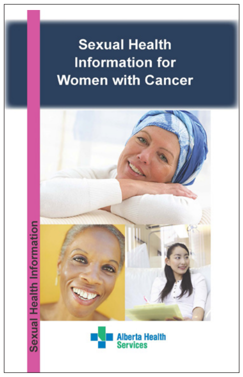
Ask your health care provider for any of the booklets below for more information or go online:


Sexual Health Information for Men with Cancer

Sexual Health Information

Alberta Health Services

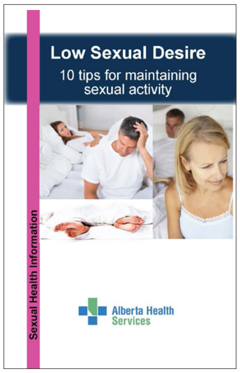
“Sexual Health Information for Men with Cancer”


Sexual Health Information for Women with Cancer

Sexual Health Information

Alberta Health Services

“Sexual Health Information for Women with Cancer”

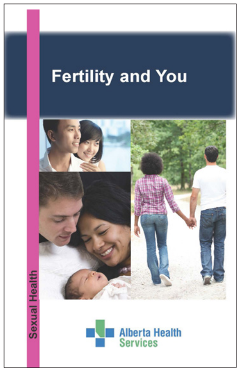

Low Sexual Desire

10 tips for maintaining sexual activity

Sexual Health Information

Alberta Health Services

“Low Sexual Desire"


Fertility and You

Sexual Health

Alberta Health Services

"Fertility and You"

Skin Changes

Your skin may change because of the conditioning treatment, or because of GVHD. It is important to care for your skin during and after transplant to help prevent infection.

Check your skin regularly for:

- Rashes
- Areas that are dry or peeling
- Tender or red areas
- Breaks in the skin or open sores
- Bruises

Tell your health care team right away if you have skin changes you are concerned about.

What can I do to help?

- Clean and treat any cracks or breaks in the skin right away. Your health care team will tell you how to do this
- Take a bath or shower every day
- Do not douche if you are female
- Avoid shaving
- If you have diarrhea, the skin around your rectum may become sore. Clean this area carefully with water and wipe gently after bowel movements. Tell your health care team if you have a sore rectum, bleeding from your rectum or hemorrhoids that are bothering you.

Tip! *Use soaps or lotions that are unscented — these are less irritating to your skin.*

Tip! *Dry skin is normal after transplant. Keep your hands and feet well moisturized with unscented lotion. Watch for cracks in your skin — they can be a way for germs to enter your body.*

Nails

It is normal for your nails to split or peel after a transplant. This does not happen right away.

- Do not try to peel any nail that splits.
- Keep your nails clean and short.
- Do not put on false nails until your nail beds and blood counts are back to normal.
- Some people find it helpful to cover splitting nails with band-aids.

Sun Safety

Even if it is not really sunny out, it is important you protect your skin from the sun. Your skin is sensitive to the sun for 2-3 months after transplant. You can trigger GVHD skin rash even from a slight sunburn.

- Use sunscreen with sun protection factor SPF 50 when you are outside even in winter, and apply it to all exposed skin areas.
- Wear a hat and cover up with long sleeves and long pants.

There is an increased risk of skin cancer after a transplant, so you must continue to use sunscreen for the rest of your life.

F. After the Stem Cell Transplant

Now that you have had your stem cell transplant, it is time for you to heal. Remember, recovery can take a long time, so do not be too hard on yourself. During this time you will:

1. Be **discharged** and leave the hospital (page 45)
2. Have frequent **follow-up** care for the next 3 months (but you will be followed for life at either the Tom Baker Cancer Centre or Cross Cancer Institute) (page 47)
3. **Recover** for a year or longer — (page 48)

Discharge from the Hospital

When will I be able to leave the hospital?

Everyone is different so it varies from person to person. Once the blood tests show that your blood cell counts are rising and you have no major complications, your team will discharge you from the hospital. You will continue to come to the TBCC BMT outpatient clinic for follow-up care. If you have complications at any time after transplant, you may need to be re-admitted to the hospital. This may feel like a setback, but it is part of the recovery process.

Patients from out of town

You will need to stay close to the hospital for **around 3 months (no more than 1 hour away).** The reason for this is so that if you have any serious complications, we have specialists who know a lot about transplant and can treat you quickly.

Checklist - Leaving the Hospital

Before you are discharged from Unit 57 you must:

- ☐ Have a caregiver
- ☐ Have a thermometer — we will make sure it's accurate before you leave the unit
- ☐ Have reliable transportation to the outpatient clinic (you may not drive for 3 months after transplant). You may need a ride many times a week.
- ☐ Be able to care for yourself with help from your caregiver
- ☐ Be able to take your medications by mouth
- ☐ Be able to eat and drink small amounts
- ☐ Have a place to stay within 1 hour of the hospital
- ☐ Meet with a pharmacist to review medications you will need to take at home

What do I need before I leave the hospital?

Before you leave the hospital, we will give you your follow-up appointments. Appointments may include lab work, clinic appointments or appointments with specialists.

We will also go over any instructions with you and your caregiver(s) about how to care for yourself at home such as:

- important phone numbers and when to call
- what you can do to prevent infection
- caring for your mouth and teeth
- what to eat
- exercise

Checklist - Leaving the Hospital -what you need to know

☐ List of important contacts

☐ Know serious symptoms and side effects to watch for and what to do

☐ Get any prescriptions you need, and a medication schedule so you know when to take them

☐ Get a list of important things to report to your health care team

☐ Get lab work and follow-up appointments with doctor

☐ Any specialist appointments, like with a psychologist

Checklist - After Discharge

BMT Clinic
Monday–Friday 7am-7pm
Saturday/Sunday 8am-4:30pm
403-521-3463

After Hours – Urgent Concerns only
403-944-1110
Ask for the Blood and Marrow Transplant doctor on call

Call when you:

☐ are not feeling well (feeling worse than usual)

☐ have a fever 38.3ºC (100.9°F) or higher OR 38.0ºC (100.4°F) to 38.2ºC (100.8°F) for 1 hour. **Call as soon as you notice that you have a fever.** You will need treatment right away

☐ have uncontrolled shivering or have chills

☐ have any new bleeding

☐ feel light-headed or dizzy

☐ have diarrhea 3 times or more in 24 hours (page 38)

☐ have new skin rashes

☐ are unable to take your medications especially cyclosporine

Remember:

☐ Call the clinic as **early as possible** in the day to allow time to care for you during open hours at the clinic.

☐ The on-call BMT doctor manages **urgent concerns only**. Do not call the on-call BMT doctor to ask about your appointment times or other general questions.

Call 911 if you have chest pain or problems breathing.

Follow-Up Care

You will have a lot of different appointments and treatments after your transplant. The next couple of pages talk about what kinds of appointments and treatments you might have. You may need further treatment if you have any complications after transplant.

1 Clinic Visits:

You will have a visit with your transplant doctor **at least once a week for about 3 months** after transplant. Other visits to the outpatient clinic for treatments or other care will depend on your blood counts and how you feel. After about 3 months, you may start to see your doctor less often, but you may also have appointments with other members of the BMT team, like a nurse practitioner.

Checklist - What to Bring to Your Clinic Visits

- ☐ AHS-TBCC card or Alberta Health Care card (to each visit). You will need it when you check in for every visit, and before any treatment or procedure.
- ☐ All your medications in their original containers (to your first clinic visit).
- ☐ Medication schedule (bring to all clinic visits). A pharmacist will review your medication schedule and arrange prescriptions for you.

Patients from out of town

If you are not from Calgary, your outpatient visits will still be at the TBCC BMT clinic for **at least 3 months after transplant**. Remember to find a place to live for you and your caregiver that is within a 1 hour drive from the hospital for the next 3 months. You may also need to stay in Calgary longer than 3 months after transplant if you have complications.

Precautions in the TBCC BMT clinic:

Most patients at the BMT clinic have a weak immune system. To protect them from infection when you come to the clinic, we will ask you and your caregiver if either of you has:

- A new rash
- A new cough
- A fever
- A sore throat
- A runny nose
- Diarrhea or vomiting

If you or your caregiver has any of these symptoms:

- Wear a mask if you have one
- Clean hands with alcohol-based rub when you arrive at the clinic and before you leave
- We will put you on isolation precautions in a room, or seated away from other people
- Someone else should come with you to the clinic if your caregiver is not well
- We may ask you to wear a mask for your own protection or to protect other people

2 Treatments, Blood Counts and Transfusions:

You may still need to get blood transfusions or platelets after discharge from the hospital. You can get these in the outpatient clinic. Let your transplant team know if you have ever had a reaction to blood products. You may also need other IV treatment after discharge including hydration (fluid), especially if you are not able to eat and drink well.

3

Day 100 (3 month) Evaluation

Day 100 usually marks the end of the early recovery phase after transplant.

At this time you will have a follow-up bone marrow aspirate and a bone marrow biopsy done. Results take 1-2 weeks, and will be reviewed at your clinic visit. If you still have your central line, it may be removed at this time.

The transplant team will decide if you are well enough to return to your home community after your bone marrow test results are reviewed.

Patients from out of town

If you are from Northern Alberta, arrangements are made for you to be followed at the BMT outpatient clinic in Edmonton. The BMT coordinator at the Cross Cancer Institute will become your contact nurse once you have had your initial visit back in Edmonton.

4

Other Follow–Up Appointments and Tests after Transplant:

- You will need other follow-up appointments even 1-2 years after transplant with specialists like the eye doctor, dentist or gynecologist. These are separate from your regular BMT clinic visit.
- Pulmonary function tests (PFT) every 3 months for the first year, and after that, once a year for 5 years — helps us monitor your lungs (conditioning treatment, infections, or GVHD can all affect the lungs).
- Other possible tests depending on how you are doing after transplant.

Recovery

How long will it take me to recover?	Recovery time is different for everyone. You may feel very tired until your blood counts slowly get back to normal. It may take you anywhere from months to years, and you may never feel the same as you did before your transplant.
Will I still have appointments during this time?	Yes, you will still have routine appointments. Your doctor will decide how often.
What if I am having problems adjusting emotionally?	Tell your transplant team if you are having a hard time emotionally. They can help connect you with the supports you may need.
When can I go back to work or school?	Check with your doctor when it is safe for you to return to work or school. We usually recommend not to return until at least 1 year after your transplant.
When is it safe to travel?	Talk to your doctor before you make any travel plans.

When is it safe to do outdoor adventure pursuits?	Some outdoor adventure pursuits can be unsafe while you're immunocompromised. Please talk with your health care team before planning anything.
Is it safe for me to be around other people?	Once your counts have recovered, you can be around other people, but you should avoid people who are sick. Remember to wash your hands well and take care of yourself. You are at increased risk for infection during your first year after transplant because your new immune system has not fully formed but especially if you are on immunosuppressive medications.

Caring for Your Skin (see page 44)

To protect your skin and help prevent infection:

- Stay out of the sun as much as possible. Wear a hat, protective clothing, and always use sunscreen with SPF 50 or greater
- Do not share your toothbrush, towels, shavers, or other personal hygiene products
- Wash your bed sheets and bath or hand towels regularly using hot, soapy water
- Use unscented lotions

Caring for Your Central Line

Your transplant team will decide when to remove your central line. We will take out your central line once you are eating and drinking well, and your blood counts have returned to a safe level. You will have your central line as long as you need it but it's usually removed around 3 months.

You or your caregiver need to take good care of your central line to help prevent infection. We may show you and your caregiver(s) how to care for your central line, or we may care for it when you are here for appointments, or we may help you make other arrangements for its care.

Activity

You may still feel tired for many months after your treatment is done. Some days you may find your energy level is low and you feel like doing nothing. Regular exercise is a goal that can lead to feeling better, being able to do more.

Walking is one of the best ways to improve the strength in your legs. Increase your exercise as you can, but remember to also get enough rest. The less active you are, the more risk you have for falls, poor sleep, appetite, or feeling worse.

While you should get up and move each day, listen to your body and find balance between activity and rest. Let your family help you with some of your responsibilities for a while. You can expect gradual improvement in your energy 3-6 months after transplant.

Once we discharge you, we can refer you to Oncology Rehabilitation to help you regain strength, balance and energy if you need help to manage activity at home.

Nutrition

It can be hard to eat a well-balanced diet when you feel unwell — a poor appetite, food that may taste different for weeks after transplant, feeling tired, and nausea can make it harder to eat or drink.

You may need to continue working with a dietitian to help you get enough nutrition for recovery after transplant. Once you are eating a regular diet and regaining energy and strength, your dietitian can review other important topics such as bone health, heart health, and nutrition guidelines for cancer survivorship.

Tip!

Here are some tips to help improve your diet:

Fluids:

- Drink enough fluids to keep your urine pale yellow. Most people need about 2-3 litres of fluids a day.
- Fluids may include water, milk, juice, Jello®, soups and others.

Food:

- Eat small meals and snacks often.
- Eat meals and snacks that are high in protein and calories.
- If liquids work better for you, try smoothies or nutrition supplement drinks such as Ensure®, Boost®, or Carnation® Breakfast Essentials®.

Medications

You may have to take many medications after your transplant, and you may have to take some of them for a long time.

Be sure you know:

- what medications you take
- why you take them
- the amount (dose) you take
- how and when to take them
- when your prescription needs to be refilled or renewed

Tip!

Remember to bring:

- *All of your medications in their original containers to your first clinic visit.*
- *Your medication schedule with you to all your clinic visits.*

Immunosuppressive Medications

Immunosuppressive medications are used after transplant to prevent or treat GVHD.

The most common immunosuppressive medications we use are:

- cyclosporine
- tacrolimus
- sirolimus
- mycophenolate mofetil
- prednisone

The BMT program covers the cost of the immunosuppressive medications (except prednisone), so make sure you fill the prescription at the hospital outpatient pharmacy so that you do not have to pay for them.

Continued on next page

Patients from out of town

Where to Pick up Your Prescriptions

While in Southern Alberta:

- Foothills Medical Centre outpatient pharmacy (Rexall)

While in Northern Alberta:

- University of Alberta Hospital outpatient pharmacy (Rexall)
- Kaye Edmonton Clinic (Rexall)

You will have a blood test done 1-2 times a week for the immunosuppressive medications (except prednisone). This is done to make sure you are getting the right amount. The goal is to maintain a level that is effective without causing harm to you.

Do not take your morning dose of immunosupressive medications before the blood test and bring your morning dose to the clinic with you so you can take it after your blood work has been done.

Other Transplant Medications

There are medications to help you maintain your health after transplant.
Please take them as prescribed.

- Sulfamethoxazole-trimethoprim (Septra®) and Valacyclovir (Valtrex®) — antibiotics to prevent pneumocystis pneumonia and certain types of bacterial infections for example, Streptococcus pneumonia. You will take this medication if prescribed for at least 12 months after transplant, or longer if you are on immunosuppressive medications.
- Valtrex (Valacyclovir) — an antiviral medication used to prevent shingles (varicella zoster). You will take this medication for 2 years after transplant, or longer if you are on immunosupressive medications.
- Fluconazole — a medication used to prevent certain types of fungal infections like Candida
- Ursodiol — a medication used to prevent liver complications

Prescriptions

- Most pharmacies can fill your other prescriptions other than the immunosuppressive medications.
- Make a list of any medications you need. Make sure you ask for prescriptions you need at your clinic visits.
- Prescription requests over the phone are usually done if you have medication changes or if it is urgent.
- Ask your family doctor or specialist for medications for pre-existing conditions like diabetes.

Preventing Infection

After transplant, you will be at risk for infection. You need to protect yourself against infection for 1-2 years after your transplant, and longer if you develop GVHD. The transplant team will give you guidelines to help prevent infections until your immune system recovers.

Contact your transplant team right away if you have symptoms like:

- fever
- difficulty breathing
- pain
- chills
- severe diarrhea
- rash
- coughing
- severe vomiting

Hand Washing

The best way to prevent infection is to wash your hands well with soap and water before and after:

- eating or preparing food
- using the bathroom
- going outdoors or to a public place
- taking medications
- touching animals
- before and after touching central lines and wounds

Managing Your Environment

For at least 6 months after transplant, and longer if you are still taking immunosuppressive medication, follow these guidelines:

- Stay away from crowded places and avoid large gatherings
- Avoid people who are sick and tell sick family or friends not to visit

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- Do not have contact with pets except for the ones you had before transplant. If you have reptiles, birds or rodents in the home, please tell your health care team
- It is best not to sleep with or groom, bathe or feed your pets
- Avoid contact with pet food, pet feces, saliva, urine or litter box material

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- Change dish cloths and kitchen towels often and wash them in hot water with bleach. When you dry them, make sure you use the hottest temperature on the dryer
- If you live in a rural area, you may need to have your well water checked for safety

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- Plants may remain in the home, but plant care must be done by someone else
- Avoid gardening or digging in the dirt

- Do not wade or swim in pools, hot tubs, ponds or lakes

- Stay away from construction sites, dusty places, and home renovations

Immunizations

Since you have a whole new immune system, you may have lost your immunity to preventable illnesses. This means that any immunizations you received as a child or adult may no longer work. You will need to get these immunizations again.

Stem cell transplant patients can **usually** start getting re-immunized about 6 months after the transplant, but the transplant team will let you know when you can start.

If you are approved to start immunizations, you should get your flu shot during flu season. Your caregivers and family members should also get their flu shot every year to help protect you.

Your health care team will let you know where you can get your immunizations.

G. Emotional and Mental Wellbeing

Emotional Adjustment and Support

You may have many emotions and feelings during and after the transplant. These can include hope, fear, anger, confusion, frustration, guilt, and anxiety. Some days you may feel powerful, strong, and in control. Other days you may feel powerless and out of control.

You may feel a bit lost once you are discharged from hospital. Some people feel down or anxious as they go through the change from staying in the hospital to leaving the hospital. These feelings are normal when going through intense treatment for a life-threatening illness.

You may need to be re-admitted to the hospital if any problems come up. This can be disappointing, but it is not uncommon after transplant.

Everyone deals with stress in their own way. You and your family must find what works best for you. Family members can also struggle to deal with their own stress.

Family and friends may be the first to notice that you are struggling to cope and may need help. They can be very supportive and they may be able to remind you of the ways you dealt with stress successfully in the past.

Social workers, spiritual care providers, and psychologists are available to support you and your family through every phase of the transplant.

Ask your doctor or nurse for contact information or go online at www.cancercarealberta.ca > Patients and Families > Supportive Care & Living Well

Tip!

Below are some tips that may reduce stress. These may help you cope and feel more calm and relaxed:

- listen to recorded relaxation meditations or music
- talk to someone who will listen without “fixing” or giving advice
- attend to your spirituality as you explore your emerging sense of meaning, purpose and hope
- pray, speak to your religious leader, or meditate
- watch a funny movie or tv show
- practice deep breathing exercises or yoga
- seek out local support groups

Your health care team can help you learn other ways to reduce your stress.

After transplant, some people expect to recover completely and feel as well as they did before they got sick. This is not usually possible right away. Your body will need weeks to many months to rebuild and recover from the intense stem cell transplant process.

You will still need help from your family after the transplant. Family members who support you during your treatment may not understand how long it takes to recover and that you still need help. This can cause relationship struggles.

Children

Parents often want to protect their children from the impact of cancer or other diseases. One way to do this is to give children clear and honest information using words they understand rather than keep your illness a secret. You can explain your illness, how you are being treated, and any changes they can expect because of the illness or treatment.

Listen to your children, answer their questions, and share your feelings as well as the facts. Let them know you will tell them if anything changes and that it is okay to talk about their thoughts, feelings and questions.

Tell them you and the care team are doing what you can to get better, that they will continue to be loved and cared for, and that you will try to keep things as normal and routine as possible for them.

Feeling Depressed

It is common to feel down or depressed during and after your treatment. Depression is when feelings of sadness, hopelessness, despair and lack of purpose are strong and will not go away for weeks or months. A person who is feeling depressed cannot just “snap out of it” or “cheer up”.

Depression can cause physical and emotional symptoms and may make it harder to cope and enjoy other areas of your life. Speak with your partner or family members if you find your mood is low and does not get better.

If you feel depressed, let your health care team know. With professional counselling, you can learn about different ways to help you cope.

If your depression does not get better or gets worse, you may need medications to feel better.

Sometimes depression can affect your sleep. You may find you wake up more often, have trouble staying asleep, sleep longer or stay in bed for many more hours than you usually need. Speak with your care team if you are having difficulty with sleep.

Late Effects of Conditioning Treatment and Transplant

Different side effects can happen depending on which chemotherapy you received. These are long-term effects that may take many months to get better. Sometimes it is hard to know if the effects are from the conditioning chemotherapy, the transplant, or the medicines used to help you feel better.

Concentration and Problems with Memory ("Chemo brain")

"Chemo brain" includes fuzzy thinking, foggy memory, and an overall feeling of "brain drain" — like you are unable to think clearly anymore.

Chemo brain happens to many patients during treatment but it can also continue after treatment is finished. Your concentration and memory can be affected by your illness, the treatment, fatigue, or an infection.

You may find:

- The amount of new information you can learn at a time is less.
- Things you knew before may be harder to remember.
- It is difficult to focus on one thing or do more than one thing at a time (multi-tasking).

Things you can do that can help improve your memory:

To manage your energy:	To help with your memory:
• do tasks that need a lot of energy when you have the most energy • try relaxation, breathing or meditation exercises • try to do light exercises to rebuild your muscle mass and endurance • take short breaks often • get enough sleep	• use notes, reminders, and a daily planner • keep your things in the same place — for example, keep your keys in the same drawer or on the same hook all the time • pay attention to new information you want to remember — review it in your mind and make a note of it • ask your family or friends to gently remind or cue you to information you may have forgotten

Most people treated with chemotherapy find that the problems with memory and concentration get better over time.

Ask to see the psychologist on your health care team for more tips and tools to make the most of your memory.

Palliative Care

Palliative care is often misunderstood and can be seen as a negative or scary thing. In fact, it can provide many benefits to both patients and families.

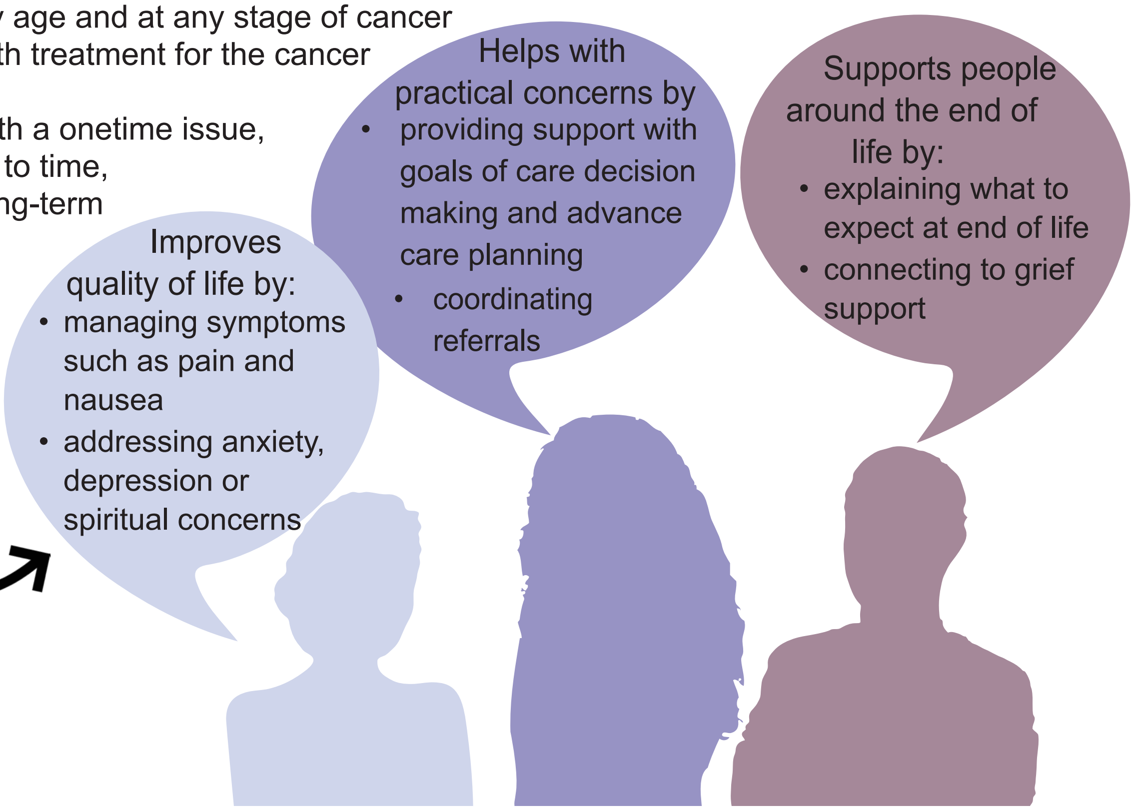
Palliative care can be:

- an added layer of support for you and your family
- appropriate at any age and at any stage of cancer
- provided along with treatment for the cancer or by itself
- needed to help with a onetime issue, needed from time to time, or needed as a long-term form of support

What can palliative care do?

Palliative care can help patients and families live life to the fullest.

Palliative care:



Improves quality of life by:

- managing symptoms such as pain and nausea
- addressing anxiety, depression or spiritual concerns

Helps with practical concerns by

- providing support with goals of care decision making and advance care planning
- coordinating referrals

Supports people around the end of life by:

- explaining what to expect at end of life
- connecting to grief support

Who provides palliative care?

Your current care team can provide some palliative care. There are also specialized palliative care teams (doctors, nurses, pharmacists, social workers and other professionals) who work together with you, your cancer doctor and your family doctor to focus on issues important to you. This team works with you to make care plans based on your values, preferences and wishes.

How do I get palliative care?

Palliative care is available in the home, community, nursing homes, outpatient clinics and hospitals. If you think palliative care may help you, ask your care team for more information.

For more information:

- Talk to your health care team
- Find out more about palliative care in Alberta or find programs and services in your community - https://myhealth.alberta.ca/palliative-care (ALBERTA)
- Check out www.virtualhospice.ca and livingmyculture.ca (CANADA)

The BMT team is available to help you get through all parts of your treatment program.

Adjusting to a new normal after transplant

Transplant survivors and their loved ones have been through a lot. Going through a stem cell transplant involved many important steps and was a huge time commitment for both you and your support system (family or friends).

As you move through the recovery process, you may find yourself feeling different than your former self. While you may experience physical side effects for months after transplant, you may also discover a new appreciation for life, interests, or priorities.

Figuring out how to incorporate the physical, emotional, mental and spiritual changes into your life after transplant is complex and will take time. You may need to adjust your goals and expectations. Over time, most people are able to adapt to the changes of transplant, and a new normal emerges.

We hope the information in this book has helped you understand the steps and the importance of an allogeneic stem cell transplant as a part of your treatment program.

Please contact us if you have any questions or concerns or if there are any changes to your condition during or after this treatment. We have a team of people to help you with any concerns. To help you have the best outcomes, it is important to try to stay as active, engaged and as positive as you can through this treatment while following the directions and steps your transplant team gives you.

H. Common Words Used

A

Acute: New and sudden symptoms that are severe, usually over a short period of time

AHS: Alberta Health Services

Analgesic: Medication that helps with pain such as Tylenol®, ibuprofen, or Morphine®

Anemia: A decrease of red blood cells in your blood. Causes a low hemoglobin

Antiemetic: Medicine that controls nausea or vomiting. It may come as a pill or intravenous (IV)

Anxiety: A feeling of deep nervousness or worry, often about future events

Allogeneic Stem Cell Transplant: A transplant that uses another person's stem cells

Apheresis: A medical procedure used to collect stem cells

Autologous Stem Cell Transplant: A transplant that uses the patient's own stem cells

B

Bone Marrow: Spongy tissue found in the bones, especially in the sternum and pelvis (hips). Bone marrow produces stem cells. These cells mature to become white blood cells, red blood cells and platelets, before they go into the bloodstream.

BMT: Blood and Marrow Transplant

C

CBC: Complete Blood Count (white blood cells, hemoglobin, and platelets)

CCI: Cross Cancer Institute (Edmonton)

Central Venous Access Device (CVAD): Also called a tunnelled CVAD, CVC or central line. It is a small, flexible, plastic tube that is inserted into a large vein near the heart. The CVAD is used for giving fluid, medications, blood products or nutrition. It is also used for getting samples of your blood without a needle poke and for stem cell collection (see page 17)

Chemotherapy: Medication(s) given to kill cancer cells. Usually given orally (by mouth) or by intravenous (IV)

Conditioning: High dose chemotherapy treatment that prepares the body for stem cell transplant by destroying the bone marrow, so it can be replaced by new stem cells. (see page 18)

D

Depression: A feeling of strong sadness that will not go away

E

Echocardiogram (Echo): Ultrasound of the heart that shows heart function

ECG (Electrocardiogram): A test that looks at the electrical currents and rhythm of your heart beat

Engraftment: Happens when the stem cells begin to grow in the patient's bone marrow and produce blood cells (white blood cells, red blood cells and platelets)

G

GVHD (Graft Versus Host Disease)**:** can happen after an allogeneic stem cell transplant where the donated stem cells or bone marrow sees the body as foreign and attack the body

H

Harvest: Extraction of stem cells from the body

Hemoglobin (Hgb): The part of the red blood cell which carries oxygen to the body cells

I

Inpatient: A person who is admitted to a hospital or clinic for treatment and needs to stay at least one night

M

MRI: (Magnetic Resonance Imaging) A test that uses magnets to scan the inside of your body

N

Nausea: A feeling of sickness in the stomach that may cause an urge to vomit

Neutrophil: A type of white blood cell that is monitored. Chemotherapy can cause your neutrophils to drop. A low neutrophil count puts you at risk for infections

O

Outpatient: A person who is admitted to a hospital or clinic for treatment but does not need to stay overnight

P

Packed Red Blood Cells (PRBCs): A blood product of many red blood cells packed into a small bag for transfusion

Peripheral Blood: Blood circulating in blood vessels throughout the body such as those in arms, neck and legs

PET: (Positron Emission Tomography) — an imaging test that shows how your tissues and organs are working. A PET scan uses a radioactive drug to show this activity.

Prescription: An order for a medication from a qualified professional

Platelets: a type of blood cell that helps blood clot and prevent bleeding. Some symptoms of a low platelet count are the presence of tiny red spots on the skin (petechiae), easy bruising and bleeding from the gums, nose, or other areas

Protocol: A medical treatment plan

Psychosocial Oncology – A team of psychologists, psychiatrists, social workers and spiritual care specialists available to support patients, donors and family members with their mental, emotional, social and spiritual well-being

Pulmonary function test: (PFT) A breathing test that shows us the health of your lungs

R

Red Blood Cells (RBCs): a type of blood cell that carries oxygen in the blood. Hemoglobin (Hgb) is the substance in this cell which carries oxygen to all the body tissues. Anemia can happen when there are not enough red blood cells in the body, which causes a low Hgb count

Relapse: The cancer returns after a period where there was a decrease, or no sign of cancer in your body (remission)

Remission: A decrease of the cancer, or no sign of cancer in your body. This may be partial or complete. Partial remission happens when at least half (50%) of the disease has been destroyed with treatment. Complete remission happens when there are no signs of disease after treatment. Remission does not mean cured

S

Stem Cell: blood stem cells are immature blood cells produced in the bone marrow that grow into white blood cells, platelets, or red blood cells and released into the bloodstream

Stem Cell Transplant: The bone marrow is destroyed by high dose chemotherapy and radiation and then the stem cells are infused. This helps the bone marrow recover more quickly

T

TBCC: Tom Baker Cancer Centre (Calgary)

V

Virus: Tiny organisms which invade body cells, multiply and cause disease. Viruses often move easily between people allowing spread of disease from person to person

W

White Blood Cells (WBCs): Also called leukocytes. There are many different types. They are mostly responsible for controlling infection by destroying microorganisms such as bacteria

I. More Information

HLA Typing

How do we find you a donor?

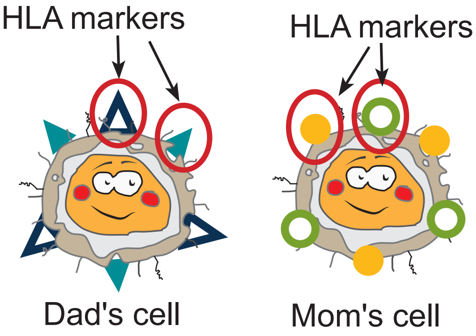
There are a few steps we do to find you a donor:

1. **HLA typing** (do a blood test)
2. **Finding a related donor** (test your family to find a match)
3. **Finding an unrelated donor** (send your HLA results to a worldwide registry for an unrelated donor if we do not find a donor in your family)
4. **Finding a donor when it's difficult** (related or unrelated)
5. **Collecting the stem cells**

1 HLA Typing (or HLA Matching)

We use HLA typing to match you and a donor. To find out your HLA type, we do a blood test. The blood is tested in a lab to figure out your HLA type.

HLA's (human leukocyte antigens) are proteins or markers found on your white blood cells and other tissues in your body. You get half your HLA markers from your father and half from your mother.

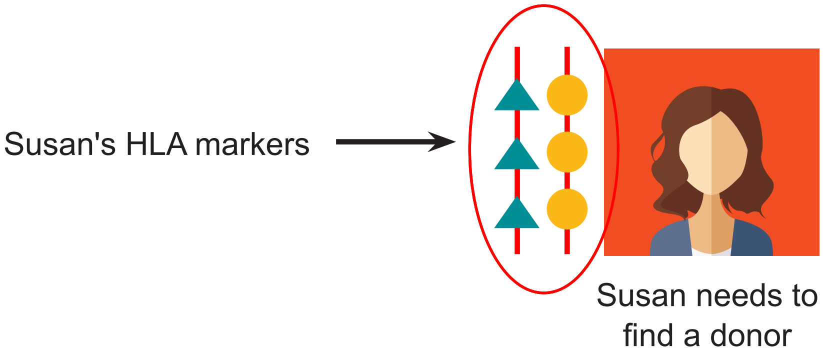


Why is HLA typing so important?

HLA typing helps:

- increase the success of the transplant
- lower your risk for complications like graft-versus-host disease (GVHD). GVHD happens when the immune cells from the donor attack your cells (host) (page 29)
- your donor’s healthy stem cells grow and make new blood cells in your body (called **engraftment**). (page 21)

Let's use Susan to explore related and unrelated donors.



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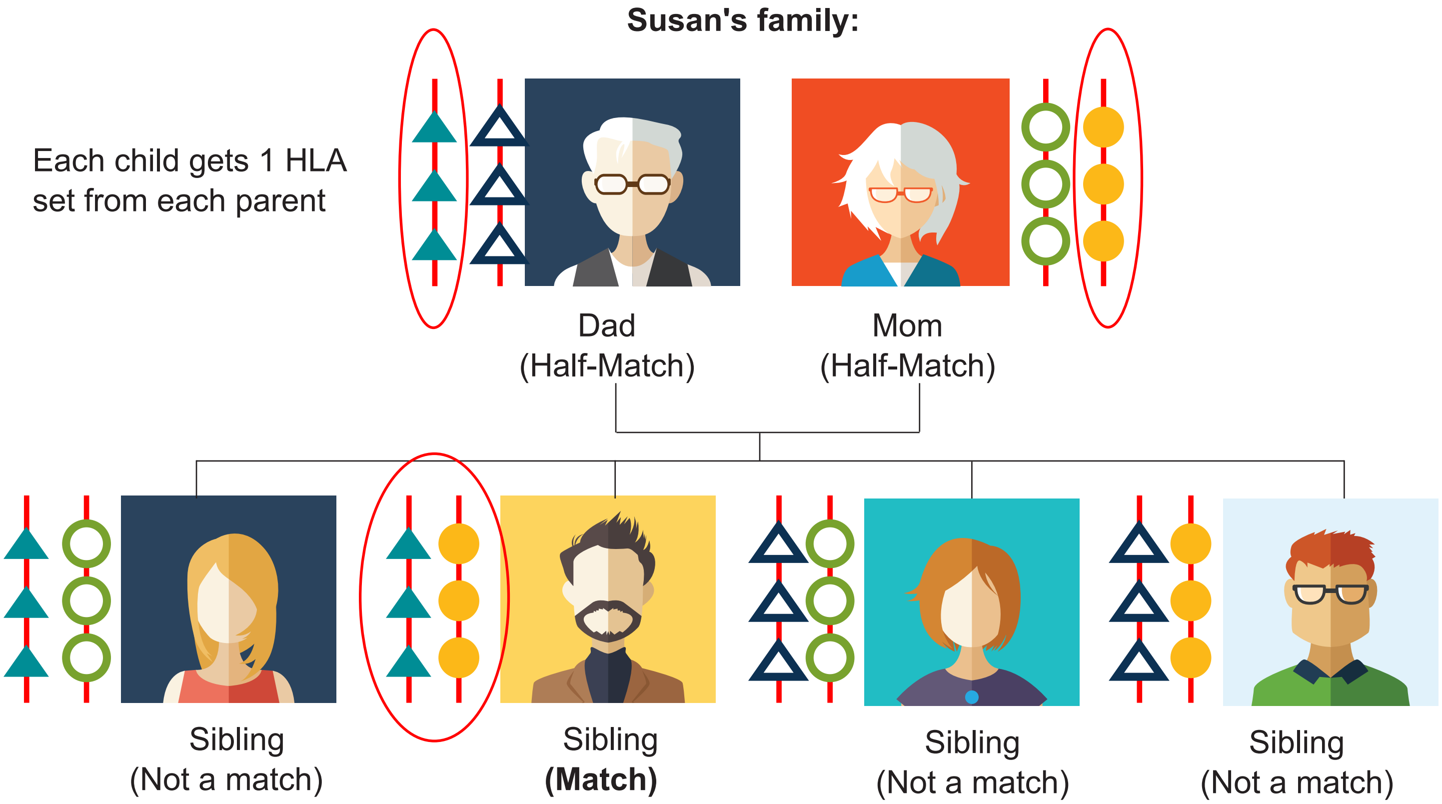
Finding a Related Donor

Once we have tested your HLA's, we want to see if anyone in your family is a match. We will first have to draw blood from your siblings to find out their HLA type.

Sometimes a brother or sister (sibling) who share the same parents will be a match but it does not always happen. Since you get half your DNA from your mother and half from your father, there is a 1 in 4 (25%) chance that your brother or sister will be your match.



Children inherit 1 in 4 **possible** combinations. **A full match only happens** if the **same set of HLA** is inherited by another sibling.

If a related donor is found and the donor agrees to have their stem cells collected, more tests are done to make sure the donation process is safe for the donor, and that the donor has no infections or health conditions that can be passed on to you.

3 Finding an Unrelated Donor

If you do not have a fully matched, related donor, we will use your your HLA typing to search the worldwide registry to try to find an unrelated donor.

Worldwide Registry

More testing is done on possible unrelated donors to see if they would be a good donor for you. Finding an unrelated donor can sometimes take a long time.

What happens when we find a match?

The transplant team will make a request for the donor once a match is found. The donor registry will contact the donor to make sure that they are still willing and eligible to donate, and can donate at the requested time.

Will I be able to contact my donor?

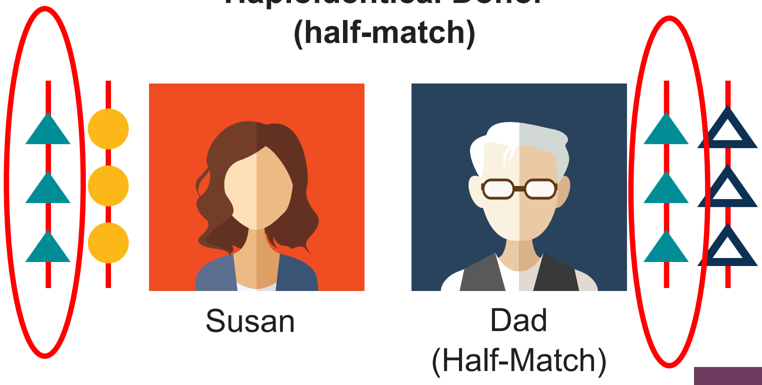
It depends — the donor registry has laws or policies to protect the privacy of donors and patients. Over time, if both you and the donor consent to know more about each other, we can make arrangements to share contact information. Ask your nurse coordinator for more information.

4 Finding a Donor when it's Difficult

If we are unable to find a related or unrelated donor for you, your transplant doctor may choose to use a **haploidentical donor.**

A haploidentical donor is a donor who is related to you but only matches **half** your HLA type. A haploidentical donor can be your mom, your dad, siblings or your child. Parents are always a half-match for their children.

Haploidentical Donor (half-match)

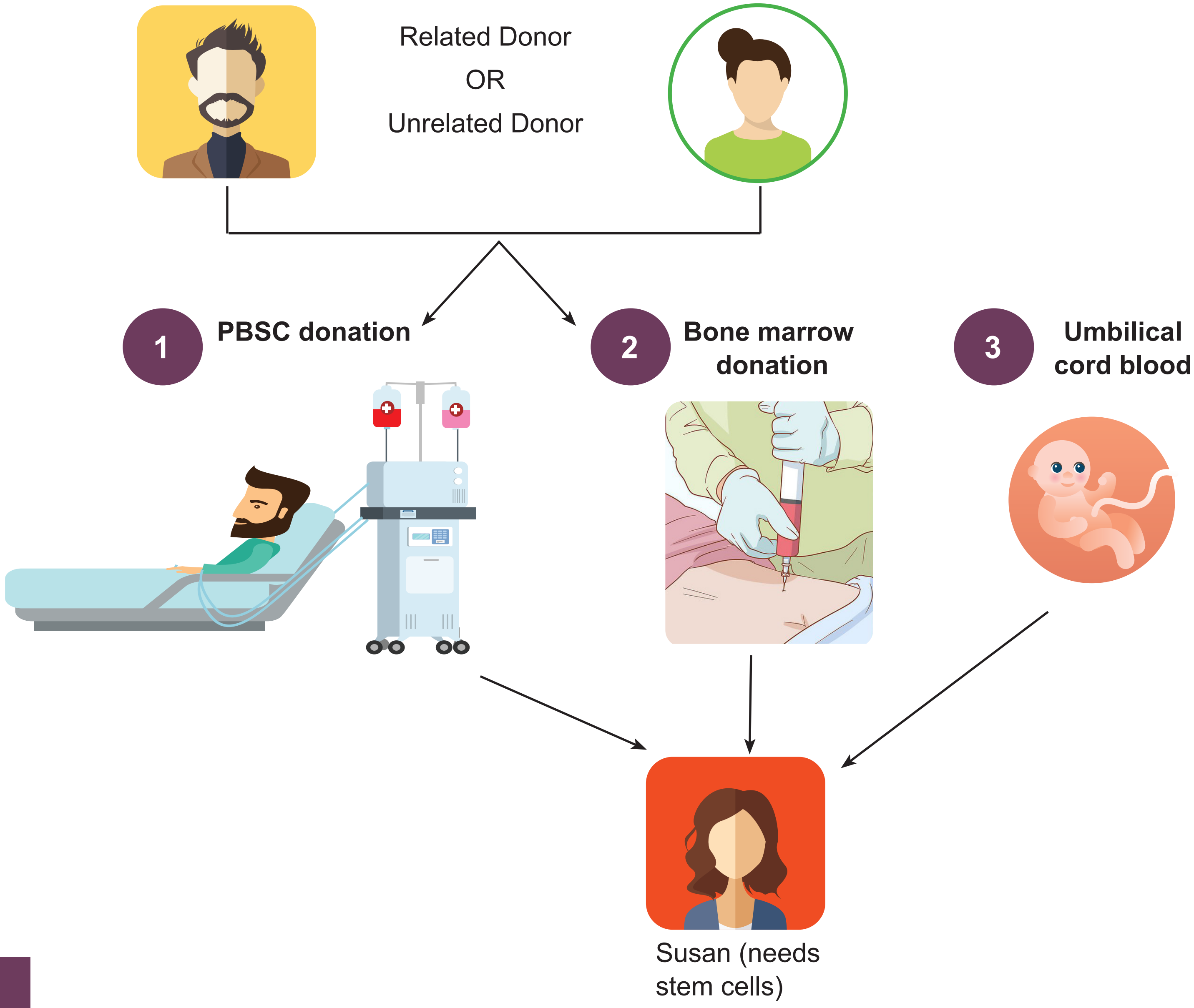


5 Collecting the Stem Cells

Stem cells are collected in 3 possible ways. They can come from:

1. The donor's blood (peripheral blood stem cells). This is the most common source for stem cells, called a PBSC donation
2. Bone marrow from the donor
3. The umbilical cord of a newborn baby (cord blood stem cells)

3 Possible Ways to Collect Stem Cells



Daily Routine Unit 57

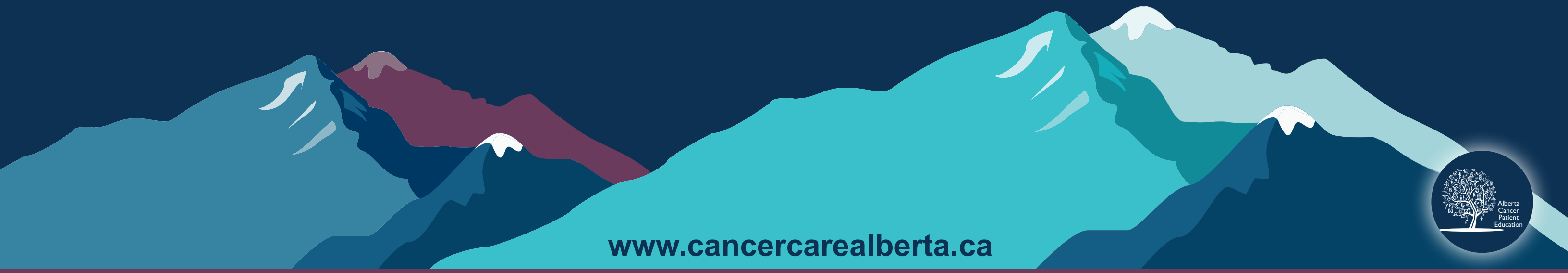
Time of Day	**Activities**
Early Morning	
4am	• Vital Signs • Daily blood draw for central line — we do early morning testing so results are available for the doctors to review first thing in the morning. This allows them to adjust your care if needed
Morning	
7am	• Nursing Shift Change
8am	• Vital Signs (are routinely checked every 4 hours or more often if needed)
	• Daily weight (measured on the scale in patient's room) • Breakfast • Daily shower recommended • Nursing Assessment (nurses do a full assessment of the patient's condition in the morning) • Physicians' Rounds (usually completed some time in the morning) • Patients are encouraged to be up and walking daily (if the patient is on isolation please check with the nursing staff prior to leaving the room)
Afternoon	
12pm	• Vital signs • Lunch • Evening Nurse Assessment (some time after 3:00pm)
3pm	• Nursing Shift Change
4pm	• Vital Signs
Night	
11pm	• Nursing Shift Change
12am	• Vital Signs • Nursing staff will do hourly rounds of patients throughout the night

The information is to be updated every 3 years, or as new clinical evidence emerges. If there are any concerns or updates with this information, please email **cancerpatienteducation@ahs.ca**.

This book is meant to support the information your health care team gives you. It does not replace any information that your health care team gives you.

Cancer Care Alberta

Leading care through compassion, courage, learning and discovery



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