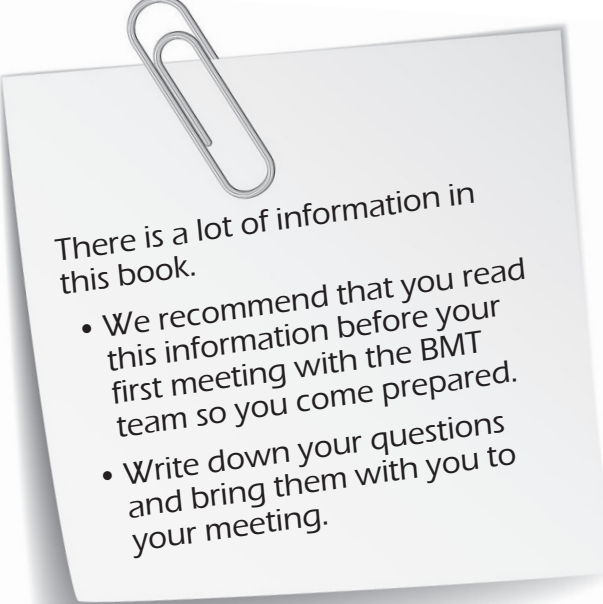


Having an Autologous Stem Cell Transplant



Treatment — Blood and Marrow Transplant

Alberta Blood and Marrow Transplant Program



There is a lot of information in this book.

- We recommend that you read this information before your first meeting with the BMT team so you come prepared.
- Write down your questions and bring them with you to your meeting.

You have been referred to the **Blood and Marrow Transplant (BMT) program** by your oncologist, hematologist, or other specialist to talk about **autologous 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 reason for transplant is to cure your illness or keep your illness from getting worse. 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 your best through autologous stem cell transplant.

Read about:

- what an autologous stem cell transplant is and how it is used to treat your illness
- the steps for stem cell collection and transplant
- possible side effects you may have during treatment
- how to recognize the side effects
- how to manage the possible side effects with the help of your health care team

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.cancercontrolalberta.ca



For an electronic copy of this book or to watch our video series on autologous stem cell transplant, go to: www.cancercontrolalberta.ca > Patients and Families > In Treatment > Stem Cell Transplant

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A. Understanding Autologous Stem Cell Transplant



Autologous Stem Cell Transplant

What is an autologous stem cell transplant?

An autologous stem cell transplant uses healthy blood stem cells from your own body to replace the cells damaged by the high dose chemotherapy. You might hear this called a "rescue".

1. Stem cells are collected from your bloodstream and stored (frozen) for later use.
2. You will get high doses of chemotherapy. The chemotherapy destroys the cancer cells as well as healthy cells, and stops your bone marrow from making new unhealthy cells.
3. The collected stem cells are thawed and put back into your body. This allows your bone marrow to start working and recover so it can produce new blood cells.

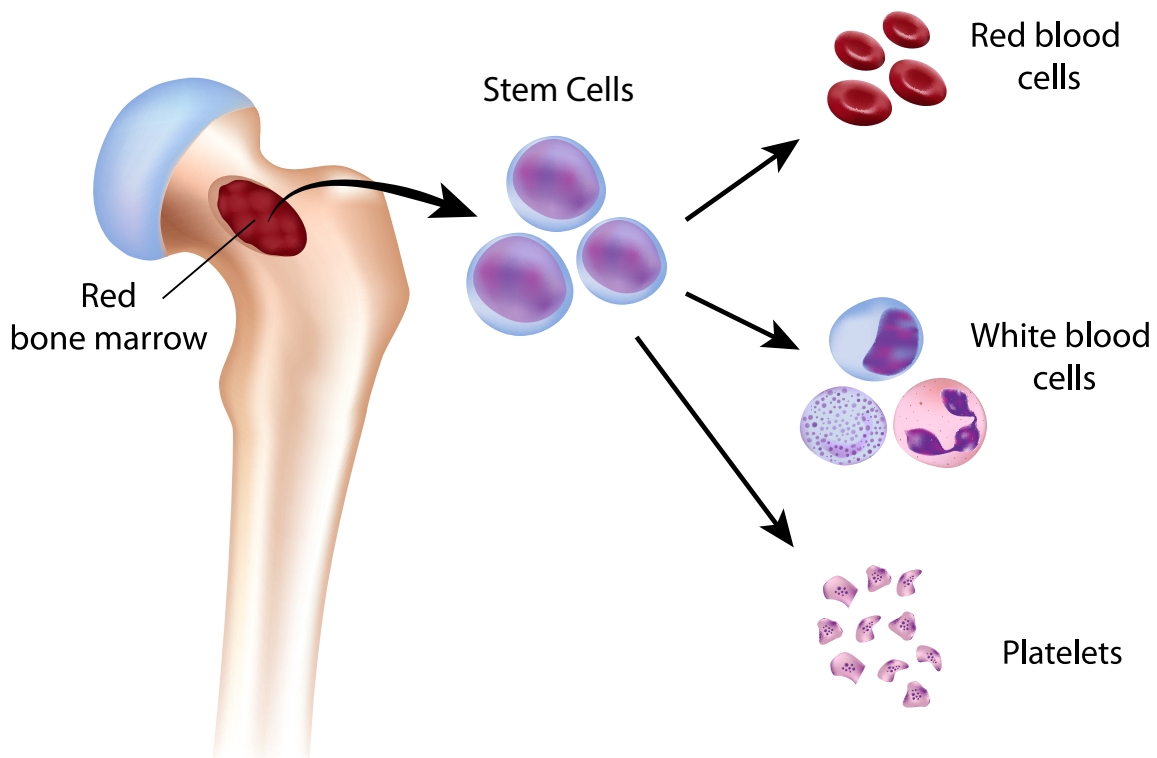


A stem cell transplant is sometimes called a **bone marrow transplant**.

What are stem cells?

Stem cells are made in the bone marrow. The bone marrow is the soft, spongy centre of your bone.

The stem cells grow and mature into other cells like red blood cells, white blood cells, or platelets.

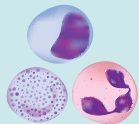




Type of cell and what it does:

Normal blood count:

White Blood Cells (WBCs):



- help you fight infection
- one type of WBC that we monitor is called a **neutrophil**

4.0 to 11.0/L



Platelets:

- help your blood to clot and prevent bleeding

150 to 440/L

Red Blood Cells (RBCs):



- make up the largest part of your blood
- contain hemoglobin (Hgb), which brings oxygen to all the tissues in your body
- it is the Hgb counts that we monitor

Female: 120 to 160 g/L

Male: 137 to 180 g/L

What is a stem cell transplant for?

A stem cell transplant may cure your illness, or keep your disease from getting worse.

What does autologous mean?

Autologous means that your own stem cells are used. You do not need to have someone else donate their stem cells for you to use.

How well does the transplant work?

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

Steps to the Autologous Stem Cell Transplant

Going through the stem cell collection and transplant process is an important part of your treatment. It requires a big commitment and involves many steps to be done safely and successfully.

The "map" on the next page will help you understand the process more easily.



1

Getting Ready for Your Stem Cell Collection

Page 5

4 - 8 weeks or more



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



- Continue with current treatment
- Nurse coordinator contacts you and gives some information about the transplant and a date for your consult



The First Meeting (consult) with nurse coordinator and transplant doctor or the Nurse Practitioner. This may include:

- Learn about the transplant and why it is recommended for you
- Review timeline for the whole process
- Consents
- Workup tests

2

Collecting the Stem Cells

Page 10

2-4 weeks



- Review dates for mobilization
- GCSF (pg. 11) and other teaching



- Meet with the apheresis nurse for assessment
- Central line inserted



Mobilization chemotherapy (if needed). Given as an outpatient or inpatient



Stem cell collection week:

- Could take 1-4 days



Rest period:

- getting ready for transplant
- maintain activity



3

Stem Cell Transplant

2-4 weeks

Page 17

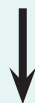


Admitted to the hospital for transplant



High dose chemotherapy (conditioning)

- may be given as an inpatient or outpatient



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

4

After the Stem Cell Transplant

3 months to a year

Page 24



You may be discharged from hospital and followed as an outpatient (after 2-4 weeks)



Follow Up (1-3 months)



- You may need to stay close to the transplant centre until you are well enough to return home
- How often you will come for follow up appointments will be decided by your doctor



Rest and recovery (3 months to 1 year)



- Nutrition
- Increase activity to help regain strength
- Prepare to return to regular activities like work or school
- Immunizations will start 6 months after transplant with approval from your doctor

B.

Getting Ready for Your Stem Cell Transplant



Your First Meeting — Consultation

You, your support person, and/or your family will meet with your transplant doctor and nurse coordinator to talk about using stem cell transplant to treat your illness. 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
- Why it is the best choice for you
- The expected risks
- What can happen if you choose not to have it and discuss other options


When will I get my transplant?

The decision about when to do the transplant depends on many things like the response to your current treatment.

Some people need to have the transplant done quickly. Dates for transplant can change depending on your condition or the condition of other patients waiting for transplants.

The BMT team will talk to you about your schedule and timelines.

How long will the time commitment be?

It can take around 3-4 months from the time of your first appointment to the time you are discharged from hospital after transplant. You will likely stay in the hospital for 2 to 4 weeks for the transplant.

Recovery at home from the transplant will take 3-12 months.

See [page 3](#) for more information.

What tests and procedures will I need before my transplant?

Once you consent to transplant, you will begin a lot of tests and procedures.

You may get a **central line** if you do not already have one. We collect your stem cells using this line, and can also give you your chemotherapy, stem cells, antibiotics, blood transfusions, and extra fluids using the central line.

What is a central line? →



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, please contact the social worker for help.



What are the financial costs?

- Living expenses if you or your caregiver live an hour or more out of the city (Calgary or Edmonton)
- Any medicines as an outpatient not covered under your drug plan
- Any travelling costs and if you have 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 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 the stem cell collection and after the transplant. When 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.

What if I live out of town?

During the time your stem cells are being collected you need to be no more than 1 hour away from the hospital.

If you live more than 1 hour's drive from the city, you may have to stay in town 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.

Helpful tips during stem cell transplant:

Tip!

"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



Will I need a caregiver?

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

A caregiver can:

- give you emotional support
- drive you to and from the hospital
- make or remind you 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

Clinical Trials and Studies:

You may ask what clinical trials or research studies are available. If any are available, we may ask if you 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. Your transplant team will discuss this further with you. For more information, go to: 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. **Tests can take up to 4 weeks.**

Your schedule depends on:

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



If you 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 call 1-866-710-QUIT(7848)

Your nurse coordinator will give you a calendar and schedule. Stem cell collection, 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.
- you take or use any over the counter medications, herbal supplements, alcohol or cannabis products, as these can all affect a stem cell collection.

Tip!

It is a good idea to have an answering machine, or voice mail so we can leave messages for you.

Please remember to identify yourself in your recorded voice message, or we cannot leave a message.



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



Blood work:

- Complete blood count (CBC)
- Chemistry
- Blood type
- Virology (including testing for hepatitis, HIV, West Nile virus, chickenpox, syphilis, cytomegalovirus)
- Blood clotting time
- Pregnancy test



Other tests may include:

- Electrocardiogram (ECG)
- Pulmonary function test (PFT-lung function)
- Urine test
- Lumbar puncture
- Bone marrow aspirate, biopsy or both
- Echocardiogram/MUGA scan (heart function)/ cardiac MRI
- X-rays, CT and PET scans, and an MRI



You may also see a:

- Dentist
- Dietitian
- Pharmacist
- Social worker
- Psychologist
- Cardio - oncologist



Physical examination:

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



Dental work-up:

The dentist makes sure you have no infections or other problems with your mouth or teeth. The BMT clinic may arrange for you to see one of the hospital dentists before the 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.

Consenting to Treatment

Your transplant doctor will explain everything you need to know about your treatment plan, but **you need to decide** if you want to have the treatment. You will get more information and consent forms to read after you meet with the transplant team.

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



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.



You can use the free AHS **My Care Conversations** app to prepare for your next appointment and to 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.

C. Collecting the Stem Cells



After you decide to go ahead with the stem cell collection and transplant, you will start the process to prepare for your stem cell collection. There are 3 main steps:

1. Getting your central line
2. Moving the stem cells from the bone marrow to the bloodstream (mobilization phase)
3. Collecting the stem cells. This can also be called "harvesting" the stem cells (apheresis phase)



Harvest – collecting the stem cells.

Infuse – putting the stem cells back into the bloodstream.

The Central Line

You will need a type of central line for a while (from collection of stem cells to after transplant). You might hear this called a CVAD or CVC. It is a long tube that is inserted through your skin into a large vein.

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

- chemotherapy
- medication
- fluids
- blood products

Why do I need a central line?

The benefits of the central line is that you will not always need to be poked for blood samples and you can get medications and chemotherapy using the line instead of starting an IV (intravenous).

How will the line be inserted?

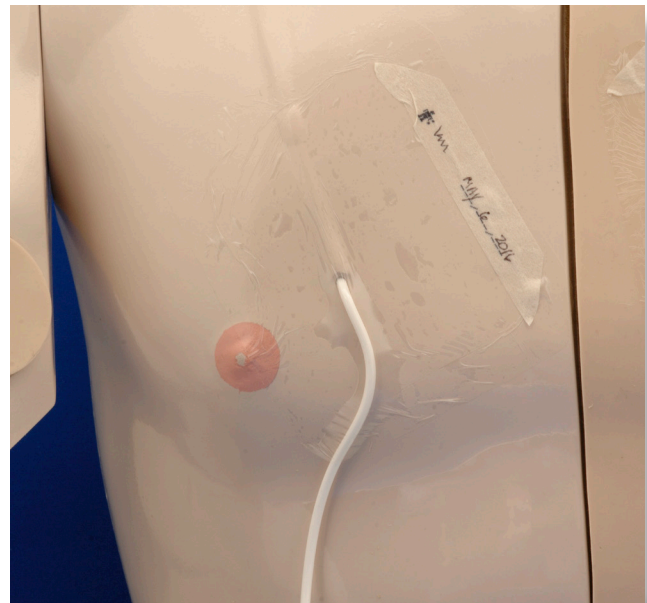
A radiologist or x-ray doctor will insert the line in the arm or chest through the skin into a large vein. We will freeze the area where the line is inserted so you will feel no pain.

How will I care for my central line?

Your nurse will teach you how to care for your line to help prevent infection. You may also be referred to Home care for line care, 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. Your nurse will give you more information when you get the central line.



Picture of a central line called a **long term tunnelled line**



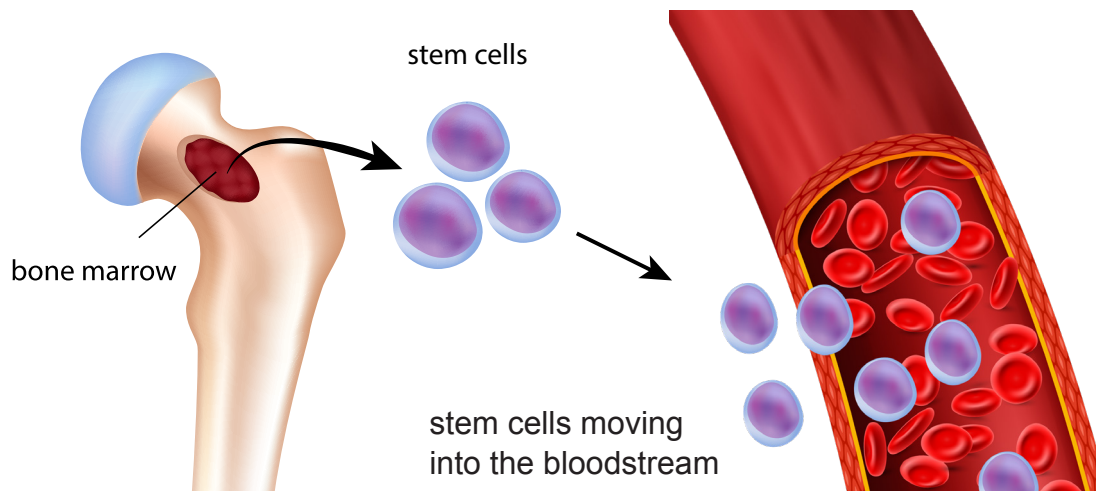
Tell your doctors if you take any of the below. You may need to stop taking them for a while before your central line is inserted:

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



The Mobilization Phase

Blood forming stem cells normally live in the bone marrow. The mobilizing phase is when certain drugs are used to help the stem cells move from the bone marrow into the bloodstream so we can collect them.



To help move the stem cells into your bloodstream, you may get either:

- mobilization chemotherapy with GCSF or
- just GCSF alone

GCSF (granulocyte colony stimulating factor)



What is GCSF (granulocyte colony stimulating factor)?

GCSF is a type of growth factor. It is a medication that causes the bone marrow to produce stem cells and release them into the bloodstream where they can be collected.

How do I take the GCSF?

You inject the GCSF (such as Grastofil® or Neupogen®) under your skin with a needle. We will teach you and your caregiver how to give the injection and make sure you are comfortable giving the injections.

How often will I take the GCSF?

We will give you a schedule for taking the GCSF. You will inject the GCSF daily and start 4 or more days before your stem cell collection. You need to inject the GCSF until we finish collecting your stem cells. We will tell you when you can stop your GCSF.

Is there any cost to the GCSF?

There is no cost for the GCSF — it is covered by Alberta Health Care.

Will the injection hurt?

It may sting a bit at the injection site. Try to inject the GCSF slowly to help reduce the sting. You may have a little redness, pain or a small lump at the injection site — these should all go away within a few hours of giving the injection.

Are there any side effects with GCSF?

Some side effects are possible and are listed below.

Some of the possible side effects of GCSF:

Common:

- Bones and muscles "ache"
- Bone pain - especially lower back pain. You may also have pain in your sternum (breastbone)
- Headache
- Fatigue
- Fever
- Chills

We may give you a prescription for Codeine™ or other pain medicine to help relieve these symptoms.

Less Common:

- Pressure in your chest
- Feels like your heart is fluttering (palpitations)
- Being short of breath
- Feeling very tired
- Spleen gets bigger (which may cause pain in your stomach)
- Nausea and vomiting
- Flu like symptoms such as: sweating, low grade fever, and chills
- Skin reactions at the injection site
- Allergic reaction



When will the side effects stop?

The side effects will stop about 1 to 2 days after you are done all the injections.



While you are taking the GCSF, it is very important to **call your nurse coordinator** if you develop a fever, or have concerns or questions.

Is there anything I should not do while I am taking GCSF?

Yes, there are a few things you should avoid while you are taking GCSF such as:

- vigorous exercise like jogging, weight lifting, swimming, biking, or contact sports
- anti-inflammatory pills like Aspirin®, Ibuprofen, or Advil® during the collection
- herbal supplements, alcohol or cannabis for at least 1 week before starting your GCSF and during the collection

Tip!

- Store GCSF in the fridge
 - Do not freeze it.
- Bring a small cooler with you the day you are bringing the GCSF home.

Mobilizing Chemotherapy



Mobilizing chemotherapy can help move stem cells from the bone marrow to the blood. The type of chemotherapy depends on your treatment plan. If you do get chemotherapy, it will take 1 to several days and you may get it as an inpatient or outpatient. Your nurse coordinator will give you more information specific to you.

What are the side effects for the mobilizing chemotherapy?

The most common side effects are:

- nausea or vomiting (p. 36)
- diarrhea (p. 28)
- sore mouth (mucositis) (p. 34)
- hair loss (p. 31)
- low blood counts (p. 32)
- fever (p. 30)



We will give you medications to help with the side effects. Please tell us if they are not working — there may be something else that can help.

Preparing for your stem cell collection (consenting to apheresis)

To help prepare for your stem cell collection, you will meet with an apheresis nurse, who is a nurse with special training on how to collect the stem cells. If you can, bring someone with you to the meeting — they can help listen, ask questions and take notes.

What is covered in the apheresis consult:

- The nurse will explain the procedure, review how you can prepare, and answer your questions
- You will sign a separate consent for the apheresis procedure
- Most of the time, we collect stem cells using your central line. If we need to collect them a different way, your nurse coordinator will let you know
- If you take medication for blood pressure, your nurse will tell you what medications you may or may not take the day of the procedure
- You will get to see the machines used to collect the stem cells and you might be able to see someone getting a stem cell collection



Remember to use the free **My Care Conversations** app to prepare for your next appointment and to record conversations with your health care team.

Download it from the App Store or Google Play.

What can I do to prepare for the collection?

- Rest well the evening and night before
- Drink lots of fluids the night before
- Arrange to have someone drive you to and from the hospital

What happens if we do not get enough stem cells?

This does not happen very often, but if it does, your doctor will discuss a plan with you.

What can affect a successful stem cell collection?

Some risk factors can be age (60 or older), radiation to the pelvic area, types of chemotherapy you have had in the past, use of herbal medications, alcohol or cannabis.

Collecting the Stem Cells

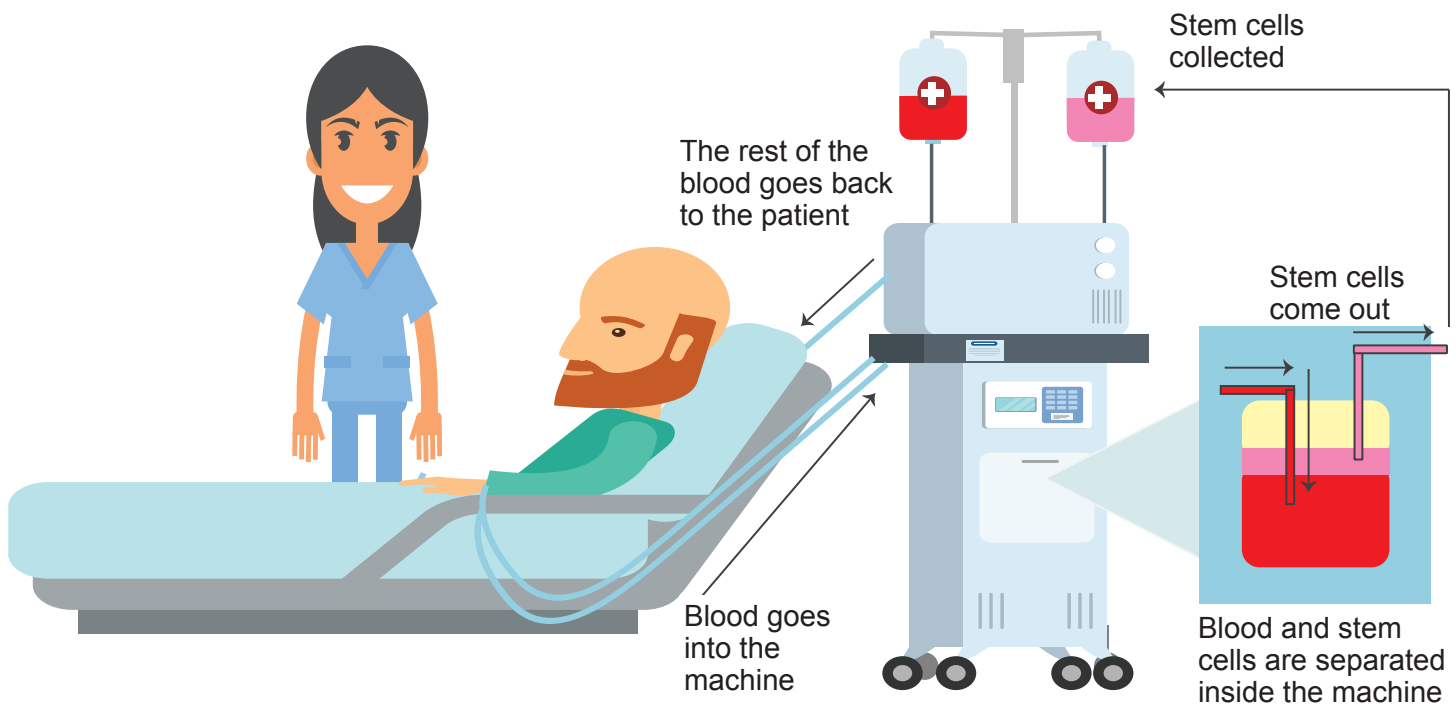
When can you collect my stem cells?

Before we can collect your stem cells, we need to make sure you have enough of them in your blood. To find out how many you have, we do blood tests that tell us the **CD34 count** (stem cell count). Once there is the right level of stem cells in your blood, we can start to collect them.

How do you collect the stem cells?

To collect the stem cells, we use a process called **apheresis**. Apheresis means “withdraw” or to “take away”.

1. The blood parts (red blood cells, white blood cells, platelets) go into a special machine.
2. The machine spins the blood and separates them into layers.
3. The stem cells move from the machine and into a collection bag.
4. The remaining blood is returned to you.



How does the blood get into the machine?

Collecting the blood is almost like giving blood, except you get your blood back. We connect your central line to the **cell separator machine**. The blood will move to the machine through one IV tube, and the remaining blood will be returned to you through a different IV tube.

Each day you come in for collection, we will check the central line to make sure it is working. If there is a problem, we will give you medication through the line to help it work better.

What happens to the stem cells after the collection?

The stem cells are frozen in a special lab until your transplant date. This is called **cryopreservation**. The lab staff add a special preservative called DMSO to protect the cells until they are ready for use.




What to Expect During Your Collection

The apheresis nurse will stay with you during the collection, so if you have any questions or concerns, just ask — they will be happy to help.

Will the collection hurt?

The procedure is not painful. You may have some side effects but we can help you manage them to make you more comfortable.

Side effect:	Cause:
Feeling dizzy or light-headed	Caused by the blood leaving your body — extra fluids are given by IV to help with this
Lower calcium levels in your blood may cause: <ul style="list-style-type: none"> • a sour taste in your mouth • a tingling feeling around your lips, eyes, hands or feet • nausea • muscle cramps • stomach cramps 	We mix a blood thinner with your blood so the blood will not clot when it moves through the machine. This medication affects your levels of calcium, magnesium and potassium. We will give you calcium during the procedure. <div style="text-align: right; margin-top: 20px;">  <p>Tell your nurse right away if you feel side effects.</p> </div>



How long will it take to collect the stem cells?

It may take between **4 to 6 hours**. We may also need more than 1 day to collect all the stem cells to get the amount we need (target amount).

At the end of the collection day, your team will tell you if they collected enough stem cells or if you need to come in for another day. You will need to keep taking the GCSF until we collect enough stem cells for your transplant.



What can I do during the collection?

When your central line is attached to the machine, you will be able to use your arms and you can read, knit, or use electronic devices.



Will I be able to go to the bathroom during the procedure?

You must stay in a bed as your central line will be connected to the machine. If you need to use the washroom during the procedure, you will need to use a portable toilet chair, bedpan or urinal bottle.



What should I wear?

Wear clothing that is comfortable and loose fitting, with easy access to your central line.



Can I have visitors?

We welcome family and friends, but it is a good idea not to bring young children since you will be unable to care for them during the collection.



Can I eat during the procedure?

Yes! Bring food and your favourite snacks and eat often throughout the day of your collection.



Can I drive after the collection?

You will need someone to drive you to and from the hospital on collection day(s).



Do I bring my medications?

Bring any medications you need to take in the day with you – this includes medications for pain or diabetes. Please follow your usual routine for food and insulin or other diabetes medications and bring your diabetic supplies.

Checklist - Day of Collection

- wear clothing that is comfortable and loose with easy access to your central line
- arrange a ride to and from the hospital
- bring snacks, lunch, something to drink
- bring things to do — electronic devices, reading, knitting, movies (bring earphones if listening to movies or music)
- bring any medications you need
- arrange childcare if needed



After the Collection and Follow-up

Make sure to eat enough food and drink lots of fluids after your collection. You may also need to rest a little more than usual for 1-2 days after the procedure.

Are there any side effects I should watch for?

The side effects are usually minimal, but you may feel weaker, or light-headed. This should only last 1-2 days. Watch for fever, sore throat, cough, congestion, new onset of diarrhea, or a rash that is new or getting worse.



Contact your nurse coordinator during regular hours, or call the after hours number provided to you with any urgent concerns you may have after your collection.

What happens next?

Once your cells are collected, you will usually have a break from treatment for about 2-4 weeks. You should feel well during your break but it is very important to call us if you notice any changes or illnesses, such as cold and flu symptoms. It's important for you to go into transplant healthy.

You may still need some tests, teaching, dental work, as well as blood work and care of your central line. We will give you a schedule for appointment dates and times. You may get a transplant date and schedule. Your nurse coordinator will review your schedule and plans after your stem cells are collected.

D. Your Stem Cell Transplant



Now that we have collected your stem cells and you have had a bit of a break to recover, we will start the next step of transplant. During this phase you will get:

1. High dose chemotherapy (the conditioning phase)
2. Your stem cells back

High Dose Chemotherapy (The Conditioning Phase)

Before you have your stem cell transplant, we need to give you stronger chemotherapy. This is called the **conditioning phase**.

Why do I need so much chemotherapy?

We use a lot of chemotherapy to try and destroy any remaining cancer cells left in your body.

How long do I need to have the high dose chemotherapy?

This depends on your diagnosis and treatment plan. You may get 1 day, or up to several days of high dose chemotherapy.

During this time you may get admitted to hospital for this phase or sometimes it can be given as an outpatient.

Are there any side effects for the high dose chemotherapy?

Yes, there are some possible side effects. Chemotherapy 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 short-term side effects are:

- low blood counts (p. 32)
- fever (p. 30)
- nausea or vomiting (p. 36)
- fatigue (p. 29)
- diarrhea (p. 28)
- sore mouth (mucositis) (p. 34)
- hair loss (p. 31)

You will be in the hospital for about **2 to 4 weeks after conditioning starts**. If you have any problems, you may have to stay in the hospital longer.

To see how you are doing, your care team will give you a medical assessment everyday.

- If you have any medical issues, you will need to stay overnight in the hospital.
- If you are doing well, you may be able to go out on short or overnight passes. This will also depend on your treatment plan, if you feel up to it, and if your doctor feels it is safe.



Day 0 - The Day of Your Transplant

What is "Day 0"?

Day 0 is the day you get your stem cells back. 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).



When will I get my stem cells back?

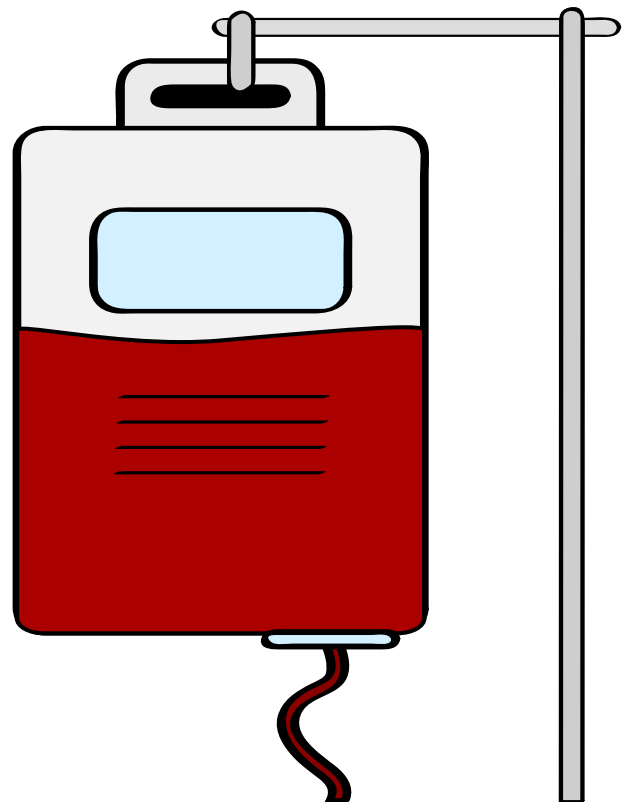
You will get your stem cells back on day 0 after you finish getting your high dose chemotherapy.

How do the stem cells help?

The stem cells help restore or "rescue" your bone marrow function from the effects of the high dose chemotherapy.

How do I get my stem cells back?

Getting your stem cells back is almost like having a blood transfusion. The stem cells arrive still frozen and are thawed in warm water at your bedside right before they are given through your central line.



Are there any side effects?

Most people have very little side effects when getting their stem cells back.

The **more common** side effects: Many patients feel flushed — cold cloths to the forehead help

The preservative found in the frozen stem cells can cause the following:

- An unpleasant taste in your mouth during the infusion — to help with the taste, try sucking on a mint or sliced oranges
- A smell for about 24 to 48 hours. The preservative comes out through your sweat and breath. People describe it as smelling like garlic, cream of corn, or oysters.

The less common side effects:

- Feeling cold
- Fever or chills
- Feeling sick to your stomach (nausea or vomiting)
- A dry cough or a tickle in your throat
- Chest feels heavy or tight
- An allergic reaction to the preservative (DSMO) used to protect the frozen stem cells. We will give you medications before the infusion to try to prevent this and we will monitor you



Tell your doctor or nurse if you have any of these less common side effects.

How long will it take to infuse my stem cells?

It depends on the amount of stem cells you are getting back. It may take from a few minutes to an hour. If you have to get a lot of stem cells back, you may also need to get them over 2 days.

Days After Your Transplant

How will I feel after my transplant?

You should feel well after you get your stem cells back, but you will start to have side effects from the chemotherapy a few days later.

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 until your blood counts start to fall. You will need to return to the hospital each day for blood tests or treatments.

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.

How will I know if the transplant is working?

When the transplanted stem cells begin to grow and make new blood cells in your bone marrow, we know the transplant is starting to work. This is called **engraftment**.

It usually starts 10 to 14 days after your transplant (Day 0). Each morning we will do a blood test so we can monitor your blood counts. Your blood counts will be low and will take a while to go back up.

Possible Problems After Transplant

General side effects

Are there any side effects after the transplant? Most of the possible side effects come from the high dose chemotherapy you had before your transplant (see side effects listed on [pg. 17](#)).

What can help with the side effects? We may need to give you blood products, such as platelets or red blood cells to help increase your blood counts.

You may also need medications like antibiotics, fluids, or electrolytes, pain medications or anti nausea medication to help manage the side effects from the chemotherapy until your blood counts recover.

Infection

It is common to develop some sort of infection during your recovery after transplant. You may get an infection from germs you already carry in your body or you could get an infection from food, plants, or other people.

Infections can happen anywhere in your body but the most common areas are your central line, lungs, sinuses, bowels, urinary tract and mouth.

Why does it happen? Your immune system protects you from infection. Since the chemotherapy 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.

What can help? We may give you GCSF ([pg 11](#)) after your transplant until your white blood cells start to grow again. GCSF can lessen the time that you are most open to infection.

We will monitor you very closely during this time for any signs of infection. If we think you have an infection, we will do some tests to look for the type and source of infection so we can treat it with the right medications. We will usually give you antibiotics or other medications during and after transplant to help control or prevent infections.

Signs you may have an infection:

- a core temperature of 38.0°C (100.4°F)
- chills, sweating, or shaking
- a cough or a runny nose
- feel short of breath, have trouble breathing, hurts to breathe, or your chest feels tight
- a new rash
- pain, redness, or swelling in your throat, mouth, eyes, skin, or joints
- urinating often, it burns when you urinate, or your urine is cloudy
- pain in your stomach, rectum, vagina, or penis
- diarrhea
- tenderness, redness, swelling, or drainage where your central line exits your body



If the engraftment does not work

Sometimes the engraftment does not work but this is very rare. It happens when the new stem cells do not make the new blood cells you need. Your blood counts may start to increase at first but then may fall. If this happens, your transplant doctor will speak with you about the different treatments for this problem.

Organ damage

It is rare (less than 5 people out of 100), 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) because you may need to have a machine to help you with your breathing. Sometimes your major organs like your 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.



Your Time in the Hospital

Many people will care for you during your transplant. This may include:

- doctors
- nurse practitioners
- nurses
- pharmacists
- dietitians
- psychologists
- social workers
- physiotherapists
- occupational therapists
- spiritual care providers
- health care aides
- dentists

You and your family are an important part of the team and we want you to ask questions and share information with us to help in your recovery.

Checklist - Admission to Hospital

- loose, comfortable clothing, pajamas, extra underwear
- comfortable footwear for walking and non-slip slippers
- toiletry items such as unscented lotions, toothpaste, toothbrush, or electric razor
- activities to do: reading, simple crafts, computer games, movies (bring earphones if listening to movies or music)
- bring a list of the medications you take
- personal pillow or blankets (hospital does not provide laundry service)
- personal laptop, tablet, phone



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.

Helpful tips during stem cell transplant:

Tip!

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

~ Rhonda (caregiver)



Visitors

- In private rooms, there are no set visiting hours. If your loved one or caregiver would like to stay the night, speak to management.
- Your visitors or caregivers must not use the bathroom in your room — this is to help reduce the spread of infection.
- Visitors check in at the nursing station first.
- Visitors who are sick will not be allowed on the unit.
- Check with the nursing unit if children are allowed to visit.



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

- a fever
- a new cough
- a sore throat
- a runny nose
- diarrhea (within the last 48 hours)
- been exposed to an infectious disease, like chickenpox
- a new or unexplained rash or if they feel sick



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.





Lotions, perfumes and other scented products:

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



Flowers and plants:

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

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. 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
- Make sure you get enough rest
- 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

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)



© Healthwise, Incorporated



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 from treatment and also heal faster after treatment.

A dietitian will help you meet your nutritional needs during the transplant.

E. 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 while, so do not be too hard on yourself. During this time you will:

1. Be **discharged** and leave the hospital
2. Have **follow up** care for the next 1 to 3 months
3. **Rest and recover** for 3 months to a year

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 problems, you may be allowed to go home.

How does the care team decide when I am ready to leave the hospital?

When your blood counts recover to a safe level and you have no serious problems or infections. Your care team will decide when it is safe to discharge you.

Usually patients are able to leave the hospital 2 to 4 weeks after their transplant. Some people may need to stay longer if problems develop.

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 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

Checklist - Leaving the Hospital

- List of important contacts
- Know serious symptoms and side effects to watch for and what to do
- Get 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



Follow Up Care

You will have many checkups and tests for 1 to 3 months after your transplant. Your checkups will be with your transplant doctor or your referring doctor.

If you live out of town, you may need to stay close to the transplant centre for appointments and tests until you are well enough to return home. Your doctor will decide when it is safe for you to travel home.

Recovery

How long will it take for me to recover?

Recovery time is different for everyone. In the first month, you are still going to feel really tired until your blood counts slowly get back to normal. Recovery time could take anywhere from 3 months to a year.

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 the nurse or your doctor if you are having a hard time emotionally. They can help connect you with the supports you need.

What are the most common side effects during recovery?

Fatigue and low energy are the most common side effects. You may also find that food tastes funny or different than it used to. Poor appetite can also happen.

Are there any side effects I should watch for?

If you have any of the following symptoms, contact your health care provider at the numbers they gave you:

- fever
- chills
- sore throat
- cough
- congestion
- sweating or shaking
- new onset of diarrhea or large amounts
- nausea or vomiting not controlled by medications, or unable to take medications as prescribed
- new or progressing rash
- tenderness, redness, swelling or drainage to your central line site

When can I go back to work?

Check with your doctor when it is safe to go back to work.

When is it safe to travel?

Talk to your doctor before you make any travel plans.



Is it safe for me to be around other people?

Once your counts have recovered, you can be around other people, but you should still avoid people who are sick. Remember to wash your hands well and take care of yourself.

Immunizations

You may have lost immunity to vaccine preventable illnesses in the transplant process. You will need to be immunized 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.



Caring for Your Central Line

Your transplant team will decide when to remove your central line. You or your caregiver need to take good care of your central line to help prevent infection. We may show you how to care for your central line, or we may set up home care appointments, or appointments at your local cancer centre to help care for your line until it is removed.

We will take out your central line once you are eating and drinking well, and your blood counts have returned to a safe level.

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 and reduce the risk of some other cancers. 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 and stamina 3-6 months after transplant.

What can help?

- 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.
- Eat a well-balanced diet and drink plenty of fluids to help your energy level.



Caring for Your Skin

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

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.

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.

- Other ideas for fluids are Jello[®], soups, and popsicles.

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[®].



Tip!

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

Diarrhea

Diarrhea is when you have frequent loose stools. You may also have cramps, pain, or feel bloated.

What causes it?

It is usually caused by the chemotherapy or sometimes an infection. Finding out the cause is important so we can treat the diarrhea with the best medications.

Why is it important?

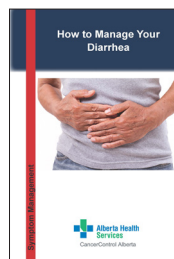
It is a common side effect and can cause dehydration, which can lead to fatigue and changes in your bloodwork. Diarrhea needs to be managed quickly and effectively for comfort, and to prevent dehydration and damage to the skin around the rectum.

What are the symptoms?

- loose or watery stools 3 or more times a day
- stomach cramps
- pain, or feeling bloated
- gas, cramping
- dehydration
- weight loss
- rectal pain
- bleeding or discharge

What can help?

- We may need to give you extra fluids and nutrients, usually through an IV
- Changes in diet
- Medications for pain or discomfort
- We may give you medications to help or prevent diarrhea
- Good handwashing (see [pg 30](#))
- Comfort measures such as a warm bath for a sore rectum



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

<https://www.albertahealthservices.ca/assets/info/cca/if-cca-how-to-manage-your-diarrhea.pdf>



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:

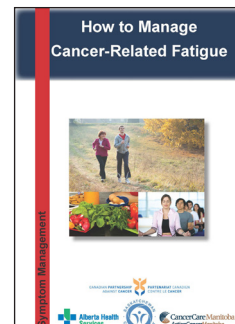
- worn out, tired/sleepy, no energy
- can't concentrate/think
- lack of interest in doing anything with friends or family
- no interest in sex or being intimate with your partner
- depressed, disconnected or not interested in anything
- like you have no energy to do normal daily activities, even self-care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

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



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



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
- Save your energy when you feel too fatigued
- 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

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?

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.

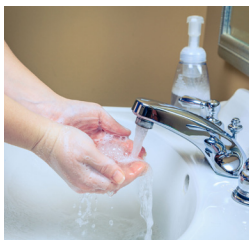
Tip!

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



Washing your hands

Washing your hands well is the most important thing you can do to reduce the chance of infection.



Wash your hands with soap and plain water:

1. Wet your hands with running water.
2. Put soap on and thoroughly spread over your hands.
3. Rub your hands together for 15 to 30 seconds and make lots of bubbles.
4. Rinse your hands.
5. Dry your hands with a paper towel or clean hand towel.
6. Use the towel to turn off the water taps.



You can also use alcohol-based hand rub. It must contain at least 60% alcohol.

How to use alcohol-based hand rub:

1. Use the amount it says in the directions.
2. Put it in the palm of your hand.
3. Rub your hands together. Make sure you cover the front and backs of your hands and in between your fingers.



Hair Loss

Almost everyone who has conditioning chemotherapy loses most or all of their hair. 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 2 weeks after chemotherapy.



What causes it?

The chemotherapy damages cells that grow quickly, and hair is made up of fast growing cells.

What are the symptoms?

- 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.

What can help?

- Think about cutting your hair short or shaving it before your high dose chemotherapy.
- Be gentle when you wash or style your hair.
- Think about scarves, hats or wigs to use temporarily. Touques will keep your head warm.
- Protect your scalp from the sun with sunscreen and a hat.
- Wear something to cover your head at night to keep your head warm and protected from rubbing on your pillow (a silk pillow case can help).

Will my hair grow back?

Yes, your hair will start to grow back about 4-6 weeks after treatment is complete. It may grow back with a different texture (it might be finer, coarser, straight or curly) and the colour may change (may be darker or lighter).



Loss of Appetite

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
- We may need to give you extra fluids by IV
- Nutritional supplements like Ensure®
- Sometimes a feeding tube is needed if a lot of weight loss happens from nausea and vomiting

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 14 days **after chemotherapy**.

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

Continued on next page



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.

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

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**.

Low Platelets

Your platelets 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 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



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, stomach, and vagina).

When the mucous membranes become irritated, this can lead to 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. It often gets better on its own a few weeks after treatment is finished.

Your mouth may become sore anywhere from **5 to 10 days after chemotherapy** starts.

Why does it happen?

Mouth sores can happen when the chemotherapy affects the cells inside the mouth. Many drugs can cause a sore mouth, but it happens more often 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.

- Eating ice chips will help during some chemotherapies — this keeps your mouth cold and will help reduce the mucositis in the mouth
- 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
- Use special mouth washes and painkillers
- Eat food that is easier to swallow (soft or cold foods)
- Sometimes a feeding tube or IV nutrition if necessary

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.

It may start 5 to 7 days after transplant, depending on the type of chemotherapy you had. It usually starts to get better after about 10 days. It can take up to 3 weeks for your mouth to heal. Good mouth care can help decrease how bad the mucositis gets.

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 treatments and medications that can help you manage the pain (such as mouth rinses or pain medication).

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.

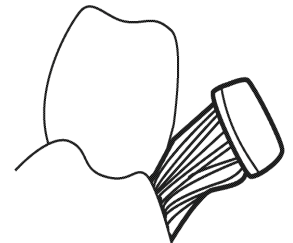
When you have a dry mouth, you have a higher risk of cavities and other problems with your teeth. Talk to your health care team if your dry mouth becomes a problem. The hospital dentist may see you for a follow-up after your transplant.

What can I do to care for my mouth?



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.
- Brush 3 to 4 times a day after the transplant. Use 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 at 45 degree angle



Flossing:

- Do not floss your teeth until your platelet count is higher than 20.
- Floss every day if you can do so without hurting your gums.
- If you do not normally floss your teeth, do not start during the transplant process.



Rinsing:

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

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.

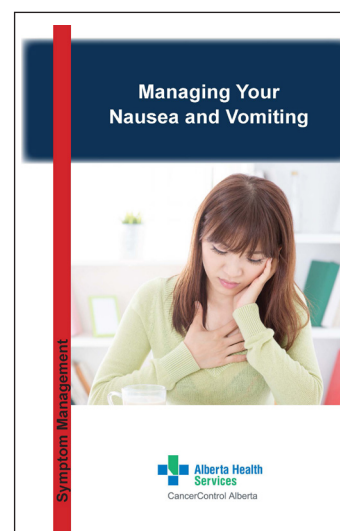
What are the symptoms?

- 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 medications to prevent or reduce nausea and vomiting.

Let your nurse or doctor know if the medications are not working. We may need to give you extra fluids, medications, 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 dry or bland
- Avoid strong smelling, spicy or greasy foods
- Practice good mouth care
- Take nutritional supplements
- Take slow and deep breaths when you feel nauseated



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

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

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

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.



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.

Make sure you use precautions if you do not want a pregnancy.



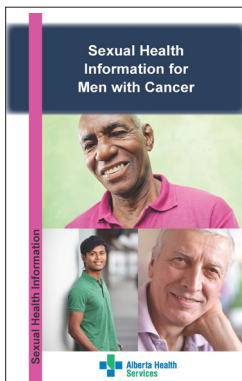
Hormone replacement therapy or other medication can help with some of these symptoms.



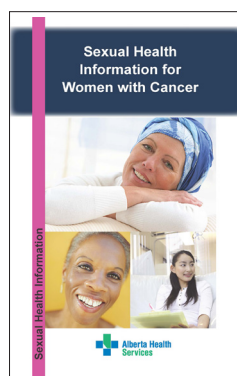
Speak with your health care team if you have any questions or concerns.

The Psychosocial Resources Department can 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:



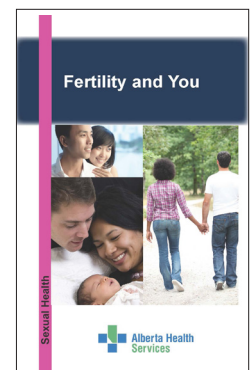
“Sexual Health Information for Men with Cancer”



“Sexual Health Information for Women with Cancer”



“Low Sexual Desire:



“Fertility and You”

Skin Changes

Skin care is important during and after transplant. Your skin may change because of the treatment you had in the conditioning phase of transplant.

Check your skin regularly for:

- Rashes
- Areas that are dry or peeling
- Tender or red areas
- 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

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.

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.

Tip!

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



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.

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

Tip!

- 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.

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.



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.



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.

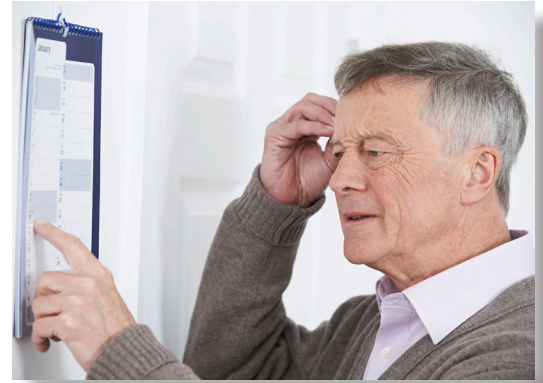
Concentration and Problems with Memory (“Chemo brain”)

“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:

- 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

To help with your memory:

- use notes, reminders, and a daily planner
- keep your things in the same place — for example, put your keys on a hook by the front door
- 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



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

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





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 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 assist 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 health care team gives you.



H.

Common Words Used



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. This includes drugs such as Tylenol®, ibuprofen, or Morphine®

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

Antiemetic: Medication 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

Apheresis: A medical procedure used to collect stem cells (see page 13)

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

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

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

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

CCI: Cross Cancer Institute (Edmonton)

CD34 Count: CD34 is a protein marker on the outside of stem cells and is used to find out the number of stem cells in the blood. We need a certain amount of blood cells in your bloodstream before we can collect them

Central Venous Access Device (CVAD): Also called a long term tunnelled device, 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 10)

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

Collection Days: The days you have your stem cells collected on the apheresis machine



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 17)

CVC: Central Venous Catheter. Also known as CVAD, long term tunnelled device, or central line

Cryopreservation: A process where stem cells where stem cells are preserved using very low temperatures to safely store them

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

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)

DMSO: Dimethyl sulfoxide — the preservative used in the freezing process to prevent damage to the stem cells

GCSF: Granulocyte Colony Stimulating Factor is a growth factor. When GCSF is injected, the bone marrow increases stem cell production and moves the stem cells from the bone marrow into the bloodstream so that stem cells can be collected

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

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

Mobilization: The process of moving the blood cells from the bone marrow into the bloodstream

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

MUGA: (Multiple Gated Acquisition) A test that uses radioactive elements to show how much blood your heart can pump

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

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

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

Stem Cell Harvest: The use of an apheresis machine to collect stem cells from the blood.

Stem Cell Transplant: The bone marrow is destroyed by high dose chemotherapy followed by the infusion of stem cells. This helps the bone marrow recover more quickly.

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 Department – 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: A breathing test that shows us the health of your lungs

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

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

TBCC: Tom Baker Cancer Centre (Calgary)

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

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



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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.

CancerControl Alberta

Leading care through compassion, courage, learning and discovery

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