

Autologous Stem Cell Transplant

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Autologous Stem Cell Transplant

This guide will provide information about the process of a stem cell transplant using your own stem cells. We hope that the information in this guide will help you and your family through the transplant process. **Please bring this guide with you every time you come to the hospital.** We will review parts of it with you at certain times and may add information as needed, depending on your situation.

Because some details of each transplant are different for each person, some of this information may be different from what you have been told. Check with your transplant coordinator or doctor if any information is different and whenever you have questions.

It is important that you are given as much transplant information as you need or want during the transplant process. You will get lots of information about procedures and medications — this can feel overwhelming. It is completely normal to not remember everything. Most people have questions and we encourage you to ask.

Although you have agreed to have a transplant and have signed an informed consent, there may be situations that need further discussion about your plan of care. You will be involved in making these decisions.

The members of your transplant team are always working to improve treatments, and lower the risk of complications. There may also be research studies to help improve quality of life. Your doctor may ask if you would like to join a research study. Any research being offered will be fully explained to you. It is completely up to you if you want to take part. If you choose not to participate, it will not affect your care.

About Stem Cell Transplants

What is a stem cell transplant?

- An autologous stem cell transplant is used to treat many blood cancers and other types of cancers. It allows you to have higher doses of chemotherapy, which kills cancer cells. You are able to recover from the high doses of chemotherapy using your own stem cells that were collected ahead of time. The transplanted stem cells will grow to give you a new blood supply and immune system. This may either give you a longer remission than without a transplant or even cure your cancer (depending on the disease). Your transplant doctor will talk with you about the goal of treatment.

- Doctors can get stem cells from peripheral blood (blood in your veins) instead of bone marrow. Sometimes bone marrow is used if the transplant team thinks it is best.
- The goal of an autologous transplant can be different for different people. It may cure you or give you a much longer remission period for your cancer than standard treatment alone. Your transplant doctor will talk with you about the goal of your transplant.
- Before your autologous stem cell transplant can be done, we must collect enough stem cells. You will get medicine(s) to help your body grow more stem cells so they can be collected.

What are stem cells?

Your blood has 3 types of blood cells that each do something different in your body:

- › **white blood cells** protect you from infection
- › **platelets** prevent bleeding by helping with clotting
- › **red blood cells** carry oxygen

Stem cells are “immature” blood cells, or the starting point of cells. A stem cell will turn into a white blood cell, a red blood cell, or a platelet depending on your body’s needs.

Stem cell collection

- Depending on your disease, you may need to have chemotherapy called cyclophosphamide before collecting your stem cells. Your nurse will give you more information about this specific medication.
- You will also need a medication called granulocyte-colony stimulating factor (G-CSF). This medication is given as a daily injection for a certain number of days before the collection. It is used to make your body make more stem cells than you need so they can be collected.
- Your coordinator will arrange these injections to be given by Victorian Order of Nurses (VON) (home care), the Medical Day Unit (MDU), or even by you if you have used this medication before.
- **Once you start the stem cell collection process, do not drink alcohol.** Alcohol can damage your stem cells and lower your stem cell count.

G-CSF side effects

- The main side effects of G-CSF are flu-like symptoms, such as aching bones, feeling tired, and a low fever. **Unless you have been told not to**, you may take acetaminophen (Tylenol® or Tylenol® Extra Strength) following the directions on the package.
- There is often discomfort at the injection site (where the needle goes into your skin). If you have discomfort, you may wish to take acetaminophen 30 minutes before your injections.
- There are no known long-term side effects.

Plerixafor

- You may also need another medication called plerixafor. This medication also helps boost your stem cells. Your BMT (Bone Marrow Transplant) doctor or coordinator will let you know if you need it.
- **Timing when to take plerixafor is important.** Your nurses in the Apheresis Unit will give you more information and specific instructions if you are going to start taking it.

When does stem cell collection start?

- Your stem cell collection will start after you have been taking G-CSF for a few days. Collection will be done in the Apheresis Unit in the Medical Day Unit (MDU).
- Your BMT doctor will decide how many collection visits are needed. You should plan for 2 to 5 days. The length of the collection will depend on how many stem cells were collected the day before. Each day's collection will take from 4 to 5 hours.
- The Apheresis Unit has special machines that are able to draw blood, separate the blood into its parts, pull out and collect the stem cells, and return the rest of the blood back to you. Blood is drawn and returned to you through your Hickman™ line. Stem cells are usually collected through the Hickman™ line, but may also be collected from intravenous (IV) lines in your arms.

Day of stem cell collection

- Report to the Apheresis/Medical Day Unit at 7 a.m. on the day of your first scheduled collection.
- You may want to avoid drinking a lot of liquids on the morning of the collection. Once you are connected to the apheresis machine, you cannot be disconnected to go to the bathroom. If needed, the nurse will help you with a bedpan, commode chair, or urinal.

- You will rest on a hospital bed during your collection.
- A nurse will be there at all times when you are connected to the apheresis machine. A doctor is always close by.
- A family member or friend can stay with you in the Apheresis Unit, but as our space is small, please limit this to only one person.

Will I feel any pain during the collection?

No. Because the collection is done through your Hickman™ line, there is no pain.

Are there any side effects from the collection?

During your collection, you may feel tingling around your mouth and in your fingertips — this is a sign of low calcium. Low calcium is caused by the blood thinner used to keep your blood from clotting when it goes through the apheresis machine. The blood thinner attaches to the calcium in your blood. Tell your nurse if you have tingling. They will give you medication to help.

How will I remember all of this?

Your BMT coordinator will give you all of the information about your appointments and your collection schedule.

Before Your Stem Cell Collection

- Eat regular meals right up to when you come in for the collection. Consider increasing your dietary calcium the week before your collection. Examples of foods high in calcium are: milk, cheese, yogurt, canned salmon, canned sardines, canned baked beans, oatmeal, figs, and broccoli.
- Wear comfortable clothing, such as sweatpants or yoga pants. You will be lying in a bed for most of the collection. Wear a shirt with a front that is easy to open to get to your Hickman™ line.
- The main side effect of stem cell collection is numbness (a tingling feeling) around your mouth or fingertips.

Social work assessment

- Your BMT coordinator will arrange for you to meet the BMT social worker. The social worker will ask questions to learn about you and your family. You will talk about the transplant experience, how you are managing with the transplant process, and different resources that may be available to support you.

- The social worker can help you with coping, decision making, and planning throughout the transplant journey. You can ask any questions about family, work or school, income, and other social or emotional concerns you may have.
- The social worker may be able to help you find ways to manage some of the stresses and concerns that are a normal part of having a transplant.

Care partner

- A care partner is a responsible adult who will come with you to and from the hospital and help you as needed outside of the hospital.
- You must have a care partner throughout the transplant process. This includes when you are an outpatient before the transplant, as well as when you are discharged from the inpatient unit. Once you are settled in the outpatient area each day, your care partner may choose to leave and come back when your care is completed.
- A care partner can be a relative or friend, but they must be an adult. The role can be shared by more than one person. You **MUST** arrange to have a care partner before you can be scheduled for a transplant. Plan for your care partner to be with you for about one week before admission to the hospital. Once you are discharged from the inpatient unit, they must be able to stay with you in the Halifax area for at least 4 weeks.
- A care partner can help you stay on track with taking your medications and checking your temperature. If you are feeling ill, they can help you connect with your doctor or health care team and help you get to the Emergency Department, if needed. They are an extra set of eyes and ears to help you take part in your follow-up care and assessment.

If you have any questions or concerns about the care partner's role, please call the social work office at 902-473-4072.

Dental care

- It is very important to make sure your teeth and gums are healthy before you start the transplant process. Our mouths naturally have many types of germs. When your immune system is damaged or weak, the germs that live in your mouth can cause serious problems like infection. Infections in the mouth can spread to other parts of the body. Your BMT coordinator will arrange for you to see an oral surgeon.

- As soon as you know that you are going to have a transplant, you must see your dentist for a cleaning and to have your mouth and teeth checked. Tell your dentist the type of cancer you have and that you will be having chemotherapy. Also tell your dentist if you are taking drugs to strengthen your bones called bisphosphonates (such as pamidronate, Fosamax[®], Actonel[®], or zoledronic acid). Bring a list of the medications you currently take to your dental appointment. You must also have your teeth cleaned and any oral problems repaired.
- Review the best ways to brush and floss your teeth with the dental hygienist. Ask them how often you should have dental care after your cancer treatment is finished.

If you live in Nova Scotia and do not have a dentist:

- › Visit the Nova Scotia Dental Association website at www.nsdental.org or call 902-420-0088.
- › Look in the Yellow Pages™ or visit www.canada411.ca.
- › If you are having trouble finding a dentist, our BMT social worker may be able to help.

If you live in Nova Scotia and do not have dental insurance or cannot afford care:

- › Ask to talk with the BMT social worker.
- › Most of the care given by the dental surgeon involved in your cancer care will be covered by MSI (provincial health care plan).

If you live in New Brunswick or PEI and do not have dental insurance or cannot afford care:

- › If you do not have a dentist or cannot afford one, talk with the social worker on your health care team in your home province.

Oral surgery care

The Oral Surgery Department is at the Victoria General (VG) site of the QEII, in the basement of the Centennial building. The oral surgeon may contact your dentist to suggest any dental care that needs to be done before your transplant. If a tooth cannot be repaired, the oral surgeon may remove it or recommend that your dentist remove it.

Phases of Autologous Stem Cell Transplant

The stem cell transplant process has 3 phases:

- › pre-transplant phase
- › transplant phase
- › post-transplant phase

Although the experience of these phases may be quite different for each person, this is a general overview.

Pre-transplant phase

- In this phase, all patients will have tests done on their heart, lungs, and kidneys. These tests must be done before you are admitted to the hospital for your transplant. The booking clerk will arrange these tests for you. They may be done at a hospital close to your home, depending on where you live.
- The test on your heart is called a **wall motion study**. It is usually done in the X-ray Department. You will have an injection of dye in your arm. The dye will move through your bloodstream and let the doctors see how well your heart pumps blood.
- The test of your lungs is called a **pulmonary function test (PFT)**. You will be asked to breathe into a tube as hard as you can while the technician measures to see how well your lungs work. Please wear comfortable clothes for this test.
- To test how well your kidneys are working, you will need to collect your urine (pee) for 24 hours. This test is called a **24-hour urine collection for creatinine clearance**. You will need to pick up a jug at your home hospital. You will then be given instructions on how to collect your urine. You will also have a blood sample taken on the day you bring in your urine sample.

Conditioning treatment

- Conditioning is the word used for the high doses of chemotherapy you are given in the days right before the transplant. This is done to kill the cancer and destroy your remaining bone marrow, including your stem cells. The chemotherapy gets your body ready for the stem cells. The destroyed stem cells will then be replaced with new stem cells in the transplant. The stem cells that we collected from you will be returned to you (transplanted) to rebuild your blood and immune system.
- There are different conditioning treatments for different diseases and situations. Your BMT doctor will decide what conditioning treatment is best for you.

- Your conditioning schedule is specific to your diagnosis. The pharmacist and RN will give you information on the specific systemic therapy drugs you will be getting. They will also talk with you about any other medications you will be getting for your transplant. **We suggest you add this information (such as other pamphlets you may be given) to this guide.** Side effects of chemotherapy are described on page 10. Your doctors, nurses, and pharmacist will review them with you during your hospital stay.
- You will get chemotherapy through your Hickman™ line. A nurse will give you this treatment in your room. You will get medications to help with nausea (feeling sick to your stomach) before your chemotherapy. During the conditioning schedule, people are usually encouraged to go out on passes between treatments (preferably with your care partner), as long as their blood counts are OK. **It is important to drink lots of fluids during this time.**
- You may have your conditioning treatment and transplant in a private room on the Hematology Unit instead of on the BMT Unit. Visitors must follow the same handwashing guidelines as if you were in the BMT Unit.
- Your BMT doctor and coordinator will provide you with more information if you need a different conditioning treatment.

Conditioning treatment for lymphoma

- You will be given chemotherapy called etoposide (VP-16) and melphalan (Alkeran®). High dose etoposide and melphalan are given to try and put your disease in a long remission or potentially cure you. Your doctor has talked about this with you.
- Your conditioning treatment starts soon after you are admitted to the hospital. Each day of the conditioning is numbered in a countdown until the day of your transplant. For example, these days will be referred to as Day -5, -4, -3, -2, -1 until transplant day, which is Day 0.

Schedule of conditioning treatment for lymphoma	
Day -5	Admit to 8A/BMT Unit
Day -4	IV chemotherapy called etoposide (VP-16)
Day -3	IV chemotherapy called melphalan (Alkeran®)
Day -2	No chemo
Day -1	No chemo
Day 0	Transplant day

- You will get a medication called **allopurinol**. It will be started when you are admitted to the hospital. You must take this pill for 5 days before the stem cells are transplanted. Allopurinol prevents the build-up of uric acid in your body caused by the sudden breakdown of cancer cells.

Conditioning treatment for multiple myeloma

- You will be given chemotherapy called melphalan. High dose melphalan is given to try and put your disease in a long remission. Your doctor has talked about this with you.
- Each day of the conditioning treatment is numbered in a countdown until the day of your transplant. For example, the days leading up to your transplant will be referred to as Day -2, Day -1. Transplant day is Day 0. The conditioning and transplant are both outpatient procedures. **You will be admitted to the inpatient unit on Day +6.** Your coordinator will tell you when to come to the MDU to start the transplant process. You will also see the BMT Nurse Practitioner (NP) in the Hematology Clinic.

Schedule of conditioning and transplant for multiple myeloma	
Day -2	Teaching day in the MDU
Day -1	IV infusion of melphalan in the MDU
Day 0	Day of stem cell transplant in the MDU
Day -1 to +6	Daily visits to the MDU
Day +6	Admit to the Inpatient Unit 8A/8BMT

- You will get chemotherapy through your Hickman™ line. A nurse will give you this in one of the treatment rooms in the MDU. You will also be given anti-nausea medications before your chemotherapy. **It is important to drink lots of fluids while receiving the chemo in the MDU.**
- You will be given prescriptions for **allopurinol, ondansetron, metoclopramide, and valacyclovir (Valtrex®).** You need to have these prescriptions filled before your first visit to the Medical Day Unit on Day -2. **Do not take any of these pills until you receive directions from your nurse or pharmacist during your MDU appointment.**
- **Allopurinol starts on Day -2.** You will take this pill for 5 days. This medication will prevent a build-up of uric acid in your body. This can be caused by the sudden breakdown of cancer cells and/or bone marrow cells.
- **Ondansetron and metoclopramide are anti-nausea medications.** Your nurse will tell you how to take them and when.
- **Valacyclovir is an antiviral medication used to prevent viral infections during your transplant recovery.** You will need to take valacyclovir on Day +1. You must take this medication for at least 28 days. While admitted to the inpatient unit (Day +6), your nurse will give you your dose of valacyclovir.

Side Effects of High Dose Chemotherapy

High dose chemotherapy is harmful to both cancer cells and normal cells. Common side effects are caused by the damage to your normal cells.

Sore mouth (mucositis)

- Chemotherapy drugs can hurt cells in the mucous membrane lining of your mouth. This is called mucositis. It leads to swelling, infection, sores, and bleeding. Your nurse will use a flashlight to examine your mouth.
- Mucositis can make it very painful to eat and drink. You will get fluids by IV to keep you from getting dehydrated, and pain medication as needed to help keep you comfortable.

How can I keep my mouth healthy during the transplant?

It is very important to take care of your mouth during and after transplant, even if it is painful. Cleaning your mouth often is important to help lower the risk of infection.

- Brush your teeth, tongue, and gums after every meal and at bedtime.
Do not use the tap water during your hospital stay. Safe drinking water will be provided to you.
- Use an extra-soft toothbrush and brush **gently** with a fluoride toothpaste.
- **Do not use a whitening toothpaste.**
- If your toothpaste hurts or burns your mouth, try Sensodyne[®], Colgate[®] PreviDent[®], or Biotène[®].
- Rinse your toothbrush well after each use, and store it in a dry place.
- After brushing, rinse with salt water, then swish and spit.
- If you usually floss your teeth, keep gently flossing at least once a day.
- Be gentle, and brush and floss as well as you can.

If you cannot brush your teeth, keep your teeth and gums clean by wiping them carefully:

- Wrap a damp gauze around your finger. Gently rub your teeth and gums to wipe away any food or plaque.
- Rinse your mouth with salt water at least 4 times a day.
- **Do not use toothpicks, as they can cut your mouth.**

If you wear dentures:

- Remove, brush, and rinse your dentures after each meal and at bedtime.
- Use a cleaner recommended by your dentist.
- Take your dentures out and rinse your mouth with salt water at least 4 times a day.
- Be careful when putting in and taking out dentures or partial dentures.
- If your dentures do not fit well, have them adjusted before you start your treatment.
- Leave your dentures out as much as possible.
- Soak your dentures in water with 1/4 teaspoon salt.
- Once a week, soak your dentures in 100% white vinegar for 10 minutes, then rinse with water before wearing.

Taste changes

Chemotherapy can change your sense of taste. Because of this, you may find that food tastes different (metallic, bland, or like cardboard). You may not enjoy foods that you once liked. Salty foods might taste sweet and sweet foods might taste salty. Over time, your sense of taste will go back to normal. Ask your nurse for strategies to cope with taste changes.

Nausea

- The high dose chemotherapy may make you feel sick to your stomach or lead to vomiting (throwing up). Other medications that are part of your treatment may also cause nausea.
- Your nurse will give you medications to help with this, but you may still have some nausea. Medications to treat nausea may be given regularly or just when you ask for them. Your nurse and pharmacist will find a schedule that is best for you. To help lower your risk of nausea:
 - › Eat dry, bland foods.
 - › Eat and drink small amounts throughout the day instead of a lot at the same time.
 - › Avoid very hot and very cold foods.
 - › Practice relaxing and deep breathing.
- Good nutrition is an important part of your recovery. Eat smaller meals more often. Choose foods with more calories. The dietitian on your health care team can suggest ways to improve your nutrition. See page 32 or page 54 for tips on improving energy and adding more protein to your meals.

Diarrhea

- Diarrhea (loose, watery poop) may be caused by chemotherapy and other medications. Diarrhea can also be caused by a bacterial infection in your bowel. If you have a couple of episodes in a day, your nurse may send samples of your diarrhea for testing to help find the cause.
- It is important to tell your nurse how often you are having diarrhea. Your nurse will need to know how much diarrhea you are having and whether there is any blood in it.
- It is important to try to drink fluids to help replace the fluid you lose when you have diarrhea.
- The skin around your rectal (bum) area can get very red and sore from having diarrhea. It is important to keep this area clean and dry. Your nurse can help with this care and give you ointment to soothe and protect your skin.

Fatigue (tiredness)

- Some fatigue is normal with a transplant. It may be caused by the effect of chemotherapy and other medications, low blood cell counts, changes in diet and nutrition, being less active, or interrupted sleep. Fatigue may also have been part of your cancer experience before your transplant.
- It is hard to push yourself to do any activity when you do not feel well, but people who do some physical activity usually have less fatigue.
- After transplant, the way you feel (like pain, nausea, low blood counts) may limit how much and what kind of physical activity you are able to do. It is not healthy to be in bed for 24 hours a day. This will cause your muscles and heart to weaken, and will increase your risk of getting pneumonia (lung infection) and blood clots. Your health care team will encourage you to go for walks, sit in a chair for meals, and practice deep breathing and coughing.

Your energy level will get better over time. See page 33 and 34 for more information on fatigue.

Chemotherapy effects on blood cells

Chemotherapy has an effect on your blood cells, as well as your cancer cells. People often feel very tired and unwell when their blood cells are low. Your numbers of white blood cells, red blood cells, and platelets are measured every day. These are also called your 'counts.' You may like to keep track of these numbers as a way to watch your progress during your recovery.

Low white blood cells (neutropenia)

- White blood cells help protect you from infections caused by different types of bacteria and viruses. **Without enough white blood cells, stem cell transplant patients are at a high risk of getting an infection.**
- You may be given medications to help prevent certain viral or fungal infections.
- Your white blood cell test will include a measure of your absolute neutrophil count (ANC). Because neutrophils are the first line of defense against infection, the lower your ANC, the higher your risk of getting an infection.
- You may have a fever while your ANC is at its lowest. This can be different for each person, but usually happens between three (3) to seven (7) days after you have your transplant. The days after transplant are called plus (+) days. For example, your team will call three (3) days after your transplant “Day +3”.

Signs of an infection

- › Fever
- › Chills
- › Shaking
- › Sweating
- › Feeling warm
- › Feeling unwell

- Tell your nurse right away if you have any signs of an infection. Infections can happen at any time during or after your transplant. Because everyone naturally carries germs in and on their bodies, most infections are caused by having too many of your own germs.
- **Tell your nurse right away if you have any other signs of infection such as:**
 - › Redness, swelling, pain, or discharge from any body opening (like your mouth, rectum, vagina, or penis).
 - › Coughing up mucus, feel burning when you urinate (pee), or notice any red, tender areas on your body.
 - › **Discomfort, redness, or discharge from your Hickman™ line.**
- A break in your skin makes it easy for germs to enter your body. Keeping your skin clean is very important, especially after using the toilet.
- If you have a fever, you will have a chest X-ray, urine tests, and blood tests to look for possible sources of infection. You will also be started on antibiotics right away. You may have a fever off and on for days, or even longer. A fever can make you feel exhausted. Your nurse and care partner will try to make you feel more comfortable. For example, a cool cloth on your forehead may help.
- If your fever does not go away, your blood tests will be repeated. Your antibiotics may be changed and other medications may be added. Although infections can be serious, they can usually be controlled with antibiotics or other medications.

- Starting on Day +1, you will get the medication called valacyclovir. You will take it by mouth unless you cannot swallow a pill (in which case you will get it by IV). Valacyclovir is an antiviral drug given to transplant patients to prevent a herpes infection. The conditioning chemotherapy that you received before your transplant makes your immune system (the cells in your body that fight infection) much weaker. Valacyclovir will help to prevent a herpes infection in your mouth and other areas of your body.

Low red blood cells (anemia)

- Red blood cells have hemoglobin in them. Hemoglobin carries oxygen from your lungs to all parts of your body. **When your red blood cells are low (anemia), you have less hemoglobin to carry oxygen and will feel very tired.** You may have a headache or feel dizzy. You may also feel short of breath with even a small amount of activity. You may be given oxygen by a tube placed in your nostrils, to help with your breathing.
- Low hemoglobin is treated with a transfusion of red blood cells called a ‘unit of blood.’ You may be given 1 or 2 units a day, depending on how low your hemoglobin drops. It is normal to have many transfusions during your recovery.

Low platelets (thrombocytopenia)

Platelets are small pieces of cells that help to form clots to prevent bleeding. **When they are low, you are at a higher risk of bleeding.** You may notice that you bruise more easily, or have bleeding gums, nosebleeds, or blood in your pee or poop. Your pee and poop will be monitored for any signs of bleeding. Some patients may be given medication to prevent menstrual bleeding (periods). Let your nurse know if you notice any signs of bleeding.

A low platelet count is treated with a platelet transfusion. Platelets are also given for any signs of bleeding. Platelets may take longer than other parts of your blood to return to normal levels, so it is common to have platelet transfusions regularly while in the hospital and later as an outpatient.

To prevent bleeding while your platelets are low:

- Brush your teeth with an extra soft bristle toothbrush.
- Avoid using straight razors to shave (you may use an electric razor).
- Avoid putting anything in your anus (such as suppositories or enemas).

Admission

On the day of admission, please go to the Same Day Admission Department on the 10th floor of the Victoria Building. You will then be directed to the inpatient unit in the Centennial Building.

Inpatient stay

- You will be admitted to the 8th floor of the Centennial Building at the Victoria General Hospital. The floor is divided into 2 units: 8A and 8B. All patient rooms on this floor are private rooms with their own bathrooms.
- 8B is a 6-room stem cell transplant unit with special features that help lower the risk of getting an infection. These include air filtering and positive pressure. This is important for patients whose immune systems are not working well. **Everyone must wash their hands before entering the unit and patients' rooms.** The door to enter the unit is clearly marked. You will get a locker for items that you will not need in your room (like luggage). **You will need to bring your own lock.**
- 8A is a 17-room hematology unit where autologous stem cell transplant patients may spend all or part of their hospital stay. Everyone must wash their hands before entering the unit and patients' rooms. BMT certified nurses also work on 8A and will care for you.

What should I bring to the hospital?

- › comfortable clothes
- › pyjamas
- › framed pictures or other small comfort items
- › pillow and comforter (optional)
- › your own tissues and toilet paper, as hospital brands can feel rough (optional)

Please limit the amount of personal items, especially those that take up lots of space. Hospital rooms are small and a safe working environment for staff should be kept at all times. Please leave all valuables (such as jewelry, money, credit cards) at home. The hospital is not responsible for the loss of any personal items.

BMT Program policies

There are specific policies that you must follow when you are admitted to the inpatient unit for your transplant. These include:

- **Water rules:** For your safety, you must not drink the tap water or use it to brush your teeth or shower. **It is safe to bathe** using the tap water.
- Safe food handling
- Family/visitor (including children) guidelines
- **Flower rules:** Fresh or dried plants are not allowed in patient care areas.

Please read Appendix C on page 44 before your hospital admission for more details on these policies.

Inpatient health care team

- As an inpatient, you will be cared for by a team of health care professionals who have been trained to look after patients receiving a stem cell transplant. This team includes doctors, registered nurses (RN), pharmacists, a dietitian, a physiotherapist, an occupational therapist, a spiritual care giver, a social worker, and others. The inpatient transplant team will assess you every day. There is always a doctor in the hospital to help with any care you may need.
- You and your care partner play a key role in your transplant. For more information on care partners, see page 5 of this guide. Your health care team will depend on you to be involved in your own care: follow their advice, tell them how you are feeling, and tell them about any concerns you have.

Being admitted

- When you are first admitted to the hospital, you will have assessments by both a nurse and a doctor. You will get information about the unit and what to expect over the coming days and weeks. Your nurse can help you to understand anything that is not clear. It is normal to have questions.
- You will get a lot of information about the transplant and schedule, and the medications you will take, their possible side effects, and how these will be managed. You will learn about the effects of the high dose chemotherapy on certain blood cells and what you can expect to happen. It can be a lot of information to take in — your nurse will repeat and explain the information as needed.

Daily routines

- You will always have a nurse assigned to you. Nurses on this unit usually work 12-hour shifts (a dayshift and a nightshift). You will be checked often by nursing staff throughout the day and night.
- At the beginning of each shift, your assigned RN will do a physical assessment that includes checking your vital signs (temperature, pulse, blood pressure, breathing), and weight. The assessment will also include checking different body systems to look for any changes and asking questions about how you are feeling. These assessments are important and help your team to identify the care you need. Please tell your nurse if you notice a change in how you are feeling at any time. You will also be assessed often for pain or other discomfort.
- Your nurse will also help explain procedures, answer your questions, and repeat any information you may have missed. Your nurse will listen to any concerns you may have and help to connect you with specialized staff who can help.
- Your nurse is responsible for giving you medications and blood products, and caring for your Hickman™ line and IV lines. Blood tests are taken between 4 and 5 a.m. so that results are available early in the day. These tests will measure your white blood cells, hemoglobin, and platelets, as well as give important information about many other parts of your blood. More frequent blood tests may be needed. Other tests may also be done to monitor your progress (like X-ray, scans, EKG).
- Good hygiene is very important while your immune system is recovering. Many of the infections that can develop are caused by the germs that are normally present in and on your body. Washing your hands often is important, especially after using the toilet. You may feel tired and have little energy for physical activity, but it is important to try and take part in your care. If you are not able to do your own bathing or mouth care, your nurse will help you. A Care Team Assistant (CTA) who has been trained to help with personal care and checking vital signs may sometimes help your nurse.

Admission to hospital for transplant

Day of admission

Depending on your conditioning and transplant schedule, you will be admitted to unit 8A or 8B. You will be in a private room, but will not have to stay in it all the time. Because you are having an autologous transplant, it is safe for you to be on the 8A Hematology Unit.

Transplant day (Day 0)

- Your transplant is done on Day 0 of the transplant process.
- Many people find this day emotional. You may feel happy for new beginnings, but anxious and nervous about what things are going to be like over the next few weeks. Most people have a mix of fear and excitement as they now move into recovery.
- The transplant phase is the shortest phase of the transplant process. The actual stem cell transplant is a straightforward and relatively easy procedure.
- You will be hooked up to a blood pressure cuff and an oxygen sensor will be placed on your finger. Before the transplant, the nurse will give you medication to help with nausea. You will get medication to prevent a reaction that may be caused by the preservative that was used when freezing your stem cells.
- Your cryopreserved (frozen) stem cells will arrive from the tissue bank, where they have been stored. The stem cells will be thawed at your bedside in a warm water bath, then infused right away through your Hickman™ line. The stem cells are hung much like a blood or platelet transfusion. The whole procedure takes about 1 to 2 hours.
- Most people tolerate the stem cell infusion well. You will be carefully monitored by an RN and doctor during the infusion. Reactions are rare. Some people will have chest tightness, chills, rashes, or a fast pulse. Reactions will be treated as needed.
- You may notice an unusual smell in the room, like creamed corn or garlic, for up to 24 hours. You may also have a strange taste in your mouth. This smell and taste are caused by the preservative used when freezing your stem cells. Sucking on a sucker/lollipop may help.
- Some patients and family members find this day anticlimactic. Much of the focus up to this point has been on getting ready for transplant day. When this day arrives, it can feel like you are getting little more than a blood transfusion. You may feel let down.

Post-transplant phase

- The last phase of the transplant process starts after the stem cell infusion. It starts when you are an inpatient, continues as you move to the outpatient Medical Day Unit (MDU) and Hematology Clinic, and as you return home. This is the longest phase of the transplant process.
- Someone receiving an autologous transplant for lymphoma and myeloma stays in the hospital for 2 to 4 weeks.

Engraftment

- Now you can look forward to seeing signs that the stem cells have ‘taken.’ After the stem cells have been infused, they must travel through your bloodstream to the centre of your large bones, and back to the bone marrow. Once they are in your bone marrow, they can start to make new white blood cells, red blood cells, and platelets. This process is called engraftment.
- Experts are not completely sure how this process works. It takes about 10 to 14 days after the stem cell infusion for engraftment to happen. Sometimes, a medication called G-CSF is used to speed up the process.
- There are different ways for your doctor to tell if engraftment is happening:
 - › Your white blood cell count may slowly rise, usually 10 to 14 days after transplant.
 - › Your absolute neutrophil count (ANC) may rise.
 - › You may need less blood or platelet transfusions.

Moving to the Medical Day Unit (MDU)

When will I be moved to the Outpatient Unit?

- The discharge day is different for everyone. The average hospital stay is between 2 to 4 weeks. Your hospital stay may be longer, depending on the side effects and complications you have and how quickly you recover. When you no longer need inpatient care, you will be cared for in the Medical Day Unit (MDU), an outpatient area.

You are getting ready for discharge when:

- Your white blood cell (WBC) counts are recovering. Your WBC counts may not have reached normal levels, but they must be steadily increasing. Your absolute neutrophil count (ANC) will usually be more than 500. Your ANC shows how well your body is able to fight infection.

- Your blood product transfusions and IV medications can be given and managed in the MDU.
- Symptoms and side effects have gotten better and you no longer need inpatient nursing care. Your appetite is getting better and you are able to drink enough fluids.
- You are able to take your medications by mouth (pill and/or liquid) and keep them down.
- You are physically strong enough to travel to and from the hospital for appointments. When you are first discharged, you will need to visit the MDU every day. These visits may take several hours and can be tiring.
- You have a care partner (family member or friend) who can stay with you at all times for the first few weeks after transplant. Your care partner will help with travel to and from the outpatient unit, medication administration, and other care as needed.

How am I likely to feel about leaving the inpatient unit?

- Being discharged from the hospital after a transplant can be both exciting and unsettling for you and your family. Most people have many thoughts and feelings, such as fear, excitement, joy, relief, and nervousness. Your family may feel overwhelmed with the responsibility of being your main caregiver. They may worry that you are not ready for discharge.
- Although the health care team has determined that it is safe for you to be discharged and that you are ready to receive care as an outpatient, it is normal for you and your family to feel hesitant about leaving the unit. Until now, you have been closely monitored and cared for at all times. This can be a transition time for you emotionally, as you start to take more responsibility for your own care. You may find it helpful to talk with a member of your health care team about this change.
- Most people find that once they start receiving care as an outpatient, they become more comfortable and start to see this as their stepping stone to going home. It is helpful to remember that you will still be assessed regularly in the MDU.
- Just thinking about going to the MDU every day or every second day can feel overwhelming. It may feel like you have to push yourself to get there, but over time your energy will improve. Your effort will help your recovery.

MedicAlert® Identification (ID)

It is optional, but we encourage you to wear a MedicAlert® bracelet or necklace after your transplant. This will help health professionals give you the best care in an emergency. Your nurse will help you fill out an application form before you leave the Transplant Unit.



What information is needed on the MedicAlert®?

- › Any allergies you have
- › That you should only receive irradiated blood products

Please tell the nurse if you have any concerns about getting your MedicAlert® ID.

Outpatient Care

After you are discharged from the inpatient unit, you will be cared for as an outpatient. Before you are discharged, you will get an appointment for your first visit in the MDU and an appointment for the Hematology Clinic.

- If you live near the hospital, you can go home when you are discharged and come back to the hospital each day for outpatient treatment.
- **If you live outside of the Halifax area (45 minutes or more by car), you must stay near the hospital for outpatient care.**

Most of your care will be provided in the MDU, but you will also be seen regularly in the Hematology Clinic. Your next appointment will be given to you at your MDU visits.

You may be concerned about:

- › Fatigue
- › Weakness, loss of strength
- › Mood changes (like sadness, depression, feeling overwhelmed, anxiety, feeling irritable, frustration, or anger)
- › Being less able to concentrate, focus, or remember things (brain fog)
- › Changes in family roles and relationships
- › Returning to work and/or school or other activities
- › Learning to live with uncertainty
- › Fear of getting sick again

- › Side effects of treatment
- › Money
- › Adjusting to the new normal
- › Sexual changes (like less desire and interest, trouble with sex, strain and tension with your partner)
- › Not sleeping well
- › Skin issues
- › Menopausal changes
- › Changes in how you look or feel
- › Returning to physical activity

Please tell your health care team if you are having these feelings as you get ready to be discharged. See pages 26 to 28 for more information about how you may feel after the transplant process.

Medical Day Unit (MDU)

The MDU is on the 4th floor of the Victoria Building, at the Victoria General Hospital. The MDU is open:

- › Monday to Friday: 7:30 a.m. to 5 p.m.
- › Weekends and holidays: 7:30 a.m. to 3:30 p.m.

Since everyone is different, it is not possible to know how long or how often you will need care in the MDU. For most patients, outpatient care is every day or every other day, and lasts for 3 to 8 weeks. Over time, you will have appointments less often. The length of your MDU appointment time will change, but it may be 30 minutes to several hours, depending on the care you need.

What care is provided in the MDU?

You will be assessed by an RN at every visit. This may include:

- › Physical and emotional assessment
- › Blood sampling
- › Review of blood test results
- › Talking with the doctor about your assessment and lab findings
- › IV medications, blood products, and fluids
- › Hickman™ line care
- › Patient and family teaching and support
- › Referrals to other health professionals, as needed

Before coming to the MDU

- Please call **902-473-5492** if you will be late, or need to cancel or change your appointment.
- Please arrive 10 minutes before your appointment time.
- Register for each visit at the MDU registration desk across from the Victoria Building elevator on the 4th floor.
- Plan to be at your first appointment for at least an hour.
- Wear comfortable clothing and shoes.
- Please tell the MDU staff ahead of time if a support person will be joining you for your appointment.
- Your care partner is responsible for getting you to and from your appointments. Recovery takes time. **You should not drive while you are recovering from your transplant.**
- The MDU has a kitchen with a microwave, a fridge, coffee, tea, and snacks.
- You will get a sandwich and drink at lunchtime. You can bring your own food and drink if you prefer.
- **Drink only bottled water and ice made from bottled water in the MDU.** There is bottled water in the MDU kitchen and ice in the freezer. **Remember, do not drink tap water while in the Victoria General Hospital.**

What should I bring to my appointments in the MDU?

- › A list of your medications
- › The medications you need to take during your stay in the MDU
- › A list of any questions you or your family members have
- › Items that may help you pass the time, such as books, magazines, music, a craft project, or a laptop. Free Wi-Fi is available. Music, movies, and audio books are available (check with the BMT social worker). Please bring your own headphones so you will not disturb others.
- › Do not bring any valuables (like jewelry, large amounts of cash, credit cards).

Your care partner is expected to bring you to your appointments, but can come and go while you are at the MDU. **If your care partner cannot come with you, you may have to make other arrangements.**

Discharge from the MDU

When you are feeling better, are able to drink 1.5 to 2 L of fluids per day, and are eating well, you will be discharged from the MDU and able to go home. Your Hickman™ line is usually removed at this time. Once you are discharged from the MDU, your care shifts from the BMT team back to your local care team.

- Patients from NB and PEI:
 - › Your care shifts back to your hematologist or oncologist.
- Patients from mainland NS:
 - › Your care shifts back to your hematologist after Day +100.
- Patients from Cape Breton, NS:
 - › Your care shifts back to your hematologist once you go home.

Once you are discharged from the MDU, you will still have Hematology Clinic appointments, but not as often. You will also be asked to have regular blood tests done in your community. It may take time for your blood counts to get back to a normal range. You will still have access to other team members for support as you adjust (like social work).

Hematology Clinic

The Hematology Clinic is on the 4th floor of the Victoria General Hospital. It is on the same floor as the MDU.

Hours:

- › Monday to Thursday: 8:30 a.m. to 4:30 p.m.
- › Friday: 8 a.m. to 4 p.m.
- After you are discharged from the inpatient unit, you will be assessed regularly by a BMT doctor and/or BMT NP in the Hematology Clinic. Your Clinic appointment will usually be coordinated with an MDU appointment. Although most tests and procedures are done in the MDU, some procedures are also done in the Hematology Clinic (such as a bone marrow biopsy).
- If you are going to be late, or need to cancel or change your appointment, please call **902-473-6605**.

Post-Transplant (Day +100 to Day +130 checkup)

- You will have a post-transplant checkup between your 3rd and 4th month (between Day +100 to Day +130). You may have a bone marrow biopsy and other tests. Your doctors and health care team will check how your bone marrow is working and how your disease has responded to the transplant, and assess for any complications.

When should I call the doctor or nurse?

Although you will be assessed regularly, there may be times when you have new symptoms or concerns. You may wonder if you should tell someone right away or in the next 24 hours (1 day), or wait until your next appointment.

Go directly to the nearest Emergency Department (DO NOT WAIT FOR YOUR NEXT APPOINTMENT) if you have:

- › A fever above 38° C/100.4° F
Do not take Tylenol®. Remember to show your *Yellow Fever Card* as soon as you arrive.
- › New shivering and chills
- › New bleeding that will not stop
- › New bright red blood in your vomit, urine, and/or bowel movements (poop)
- › A Hickman™ line breaks or comes out
- › New shortness of breath (with little or no activity)
- › New wheezing
- › New rash or blisters. This may mean that you have shingles. See page 47 for more information on shingles.
- › Not been able to pee.

Contact your primary health care provider in the next 24 hours if you have:

- › Flu-like symptoms such as sneezing, runny nose, and/or new cough
- › Any new changes or trouble when passing urine
- › New bleeding from your gums
- › New bruising
- › New pain or pain that is getting worse (including a headache)
- › New muscle weakness, numbness, or tingling
- › New dizziness or lightheadedness
- › New diarrhea or new nausea and/or vomiting
- › New pain with a bowel movement
- › New white patches or sores in your mouth
- › Discharge from your vagina or penis
- › Not been able to take medications by mouth

If you are not able to contact your primary health care provider and you feel like the situation is urgent, go to the nearest Emergency Department.

Wait until your next Hematology Clinic appointment to talk about:

- › Changes in appetite
- › Noticeable weight loss or gain
- › New pain during sex

Talk with your primary health care provider about feelings of depression, anxiety, or nervousness, and any other changes in your mood or thoughts.

Going Home

Life after transplant can change a lot from person to person and day to day. You may feel pressure that things should be back to normal when the transplant is over. Getting back to a new normal takes time and patience. Some people recover quickly and are back to work and their usual daily activities within months. For others, recovering is slower and can take many months, depending on fatigue and other side effects. How you feel and how you look may be very different. It may help to tell your family what you can do for yourself, and what you need help with. This will change as you recover and you may need to keep telling your family as your needs change.

The recovery period has been described as a mind game. Even though your brain is saying “go”, you just are not ready physically, mentally, or socially. You are still healing. Let yourself heal before looking too far ahead. You may find it helps to think about this phase as a rehabilitation period rather than recovery.

Remember: this is a marathon, not a sprint.

Many transplant patients find the first months after transplant full of adjustments. Some things may be the same, while many are different. This can be very hard emotionally and can be very stressful for you and your family. Some people say that recovery during the first couple of months at home is the hardest work of their transplant experience. They are fed up and want to move on with their life, but they still have times when they are feeling lousy and just want things back to normal. They want this to be over. “One day at a time” seems to be the motto for a lot of transplant patients.

You will likely have many thoughts and feelings as you start your recovery at home. One minute you may feel excited that you are finally returning home and the next minute you may feel overwhelmed, scared, angry, and unsure of how things are going. This can be especially challenging when you leave the feeling of security that the hospital provides. It is normal to have periods of feeling sad or low. As you adjust, you may have thoughts and questions such as:

- › Will I always feel like this?
- › Will I ever get better?
- › Nobody told me this part was going to be so hard.

The social worker and other team members can help to support you as an outpatient.

Patients often feel pressure to be back to normal once they are home because they worry that is what the world expects. People may say how well you look, but you may not feel well at all. They may congratulate you for the transplant being over, when you may still feel like it is not. How you look is not how you feel, and you may worry that everyone assumes you are fine when you know you still have a long road ahead.

You may find that some family members and friends do not understand what you have been through. Some people will expect you to be at 100% because you have had the transplant. They may say, “Why aren’t you back to normal – haven’t you had a transplant?” They may not understand that the recovery period takes longer. Helping others to understand this can lessen their comments and expectations. You may want to say: “I have had a transplant, but my recovery can take months. I have to build up my body’s immune system (defense) against infection. It can take a year or so before my energy level is up so that I can lead a normal and full day.”

Relationships with family and friends may have changed through your cancer experience. Some have changed for the good, and some may have been damaged or lost. As there have been many adjustments along the way, your relationships with family and friends may also need to readjust as you recover.

Returning to work

Some people start to worry about when they can return to work and spend a lot of time thinking about this. We suggest giving yourself a few months to focus on recovery before thinking about this. Over time, most people who have received an autologous transplant are able to return to some level of work and/or activities. You may find it helpful to talk with other transplant patients who have gone through the process, or with a social worker who has experience helping people with this transition.

Fear and worry

It is normal to have fear of the disease coming back. Living with the unknown can be very challenging. For most people, these disruptive thoughts fade over time. If you are finding your worry is taking up too much of your time and energy, this may be a good time to reach out for help.

See the “Resources for Emotional Health” section (Appendix E) on page 50 for examples of support groups, websites, books, and other resources that offer emotional and practical support.

Attending one of the education sessions about ongoing symptoms or the “Living Beyond Cancer” session may also help. See Appendix E for further information.

Caring for Yourself

Blood work

Once you are home, you will continue to have blood tests. The reports will be sent to the Hematology Clinic to be reviewed by the BMT doctor or NP.

It is your responsibility to get blood work done as recommended, and attend appointments for ongoing care.

Taking your medications

It is important that anyone caring for you knows which medications you are taking. This includes any over-the-counter and alternative treatments. We suggest you keep an up-to-date list of the medications you are taking and carry it with you. If your pharmacist has concerns about your prescription(s), have them contact your doctor.

Remember:

- Do not stop taking any medication without first talking to your BMT doctor or NP.
- Some over-the-counter medications can interact with your medications. Do not take over-the-counter medications without asking your doctor, NP, or pharmacist.
- **If you miss a dose, do not double the next dose. Ask your BMT doctor, NP, or pharmacist about what to do.**

Lowering the risk of infection

It can be stressful and disappointing to tell people that they cannot visit because they are sick, or for you to miss an event because it involves being in a large crowd. But until your WBC is up, you need to protect yourself. Remember, most infections come from within your own body. It is important to keep your body clean, especially your hands, mouth, genitals (vagina, penis), and rectal (bum) area. **It is important to stay away from people who are sick or have any type of infection (like the flu or a cold, an eye infection, a wound infection, etc.).**

Although your new bone marrow is working hard to meet the challenges of protecting you, your immune system will still be weak for about one year after transplant. Check your temperature if you feel hot or do not feel well. Because your new immune system is still maturing, a fever may be the only sign of an infection. If you have a fever, follow the instructions the Hematology Clinic team gave you, or the instructions on your *Yellow Fever Card*. You can also follow the instructions (ask your nurse for a copy) in the pamphlet called *Neutropenia (Low White Blood Count)*:

› www.nshealth.ca/sites/nshealth.ca/files/patientinformation/nscpp0034.pdf

Handwashing

The best way to stop the spread of infection is to wash your hands.

- Keep your hands clean.
- Wash your hands well with soap and water for 1 minute. Dry with a clean towel.
- Wash your hands before eating.
- Wash your hands after going to the bathroom, blowing your nose, and handling pets. If you are in a public bathroom, use a paper towel to turn off the taps and to open the bathroom door after you wash your hands.
- Remind family members to wash their hands more often when they are home.
- Use hand sanitizer to clean your hands when you are away from home.

Hygiene

- Bathe or shower regularly using a mild soap such as Ivory, Dove, or Johnson's® baby bar soap. If you use bar soap, do not let it sit in a container of water.
- Wash and dry your underarms and groin areas well.
- Wash your genitals and rectal area well. Always wipe from front to back. Clean under the foreskin of your penis, if you have a foreskin.
- Do not share your towels or face cloths. Replace your towels with clean ones every few days.
- If you take a bath and have a Hickman™ line, do not let the line soak in the water. Cover it with plastic wrap secured with waterproof tape before showering or bathing.
- Change your dressing if it gets wet. Your nurse will show you how to do this. They may also give you a pamphlet called *Care of a Hickman™ Line*:
 - › www.nshealth.ca/sites/nshealth.ca/files/patientinformation/0214.pdf
- If you have diarrhea, wash your rectal area well after going to the bathroom. If your skin gets red and irritated, talk with the Hematology Clinic nurse about what you should use to protect your skin.
- Keep your nails trimmed and clean.
- Use a skin moisturizer to prevent dry skin and cracking.

Mouth care

- Because infections can start in your mouth, it is very important to keep your mouth clean. Brush your teeth after every meal and at bedtime.

While your blood counts are recovering, follow the instructions in *Mouth Care During Cancer Treatment* (ask your nurse for a copy):

- › <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/nscpp0036.pdf>

Hickman™ line care

Care of your Hickman™ line will be done by the nurses in the MDU or by VON (Victorian Order of Nurses). These nurses may teach you how to care for your Hickman™ line.

Family and visitors

- Until your blood counts are within normal range, stay away from anyone who has a cold, an infection, or the flu.

- When coming to the MDU or Hematology Clinic, staff will make every effort to protect you from anyone with a possible infection.
- If someone in your home is sick, keep the rooms very well aired out.
- Everyone in your house, sick or healthy, should wash their hands 4 or 5 times a day and every time they use the bathroom.

- **During the transplant and post-transplant phases (up to Day +100 to +130), stay away from (do not be in close contact with) anyone who has received a live vaccine. In Nova Scotia, these include the Oral Polio Vaccine, which is rarely given, and the Yellow Fever Vaccine, which might be given when someone is travelling abroad.**
- **Stay away from anyone who has been exposed to chicken pox. See page 46 for more information on contact with people who have received live vaccines.**

Public places

Stay away from crowded places such as grocery stores, movie theatres, or shopping malls for 100 days after your transplant. If you must go, go at less busy times.

Sun exposure

We all need to protect ourselves from the sun's harmful rays.

- Whenever possible, stay out of the sun from 11 a.m. to 3 p.m.
- Wear a hat, long-sleeved shirt, and cotton pants (UV-protected clothing is preferred).
- Use a sunscreen with a sun protection factor (SPF) of 30 or higher on your hands, face, neck, and any other exposed areas. Apply it often.
- Wear UV-filtering sunglasses, as your eyes may be much more sensitive to light.
- Sun protection should be a lifelong practice.

Home environment

- Keep your home free of dirt and dust as much as possible.
- Keep your bathroom and kitchen clean. Use disinfectant and rinse well.
- Clean cutting boards and kitchen surfaces as described in the *Safe Food Handling for Immunocompromised Individuals* booklet given to you by your health care team. See 'Safe food handling' section in Appendix C on page 44 for more information.

- Wash your eating utensils well with hot water and soap.
- Wash face cloths and towels at least twice a week.
- Wash sheets once a week in warm soapy water.

Plants

Do not start to do any gardening until your blood counts are in a normal range. Use gardening and/or rubber gloves to care for indoor plants. While gardening or doing yard work, avoid touching your face. Wash your hands well after taking off your gloves.

Pets

It is OK for pets to stay in your house as you recover. Because animals can pass some diseases to humans, avoid close physical contact with pets until your immune system is in a normal range. For example:

- Do not let pets lick your face.
- Always wash your hands after petting your pet.
- Have someone else clean up after your pets (like change the litter box, pick up dog poop, clean up your pet's vomit, clean a birdcage or a fish bowl) until 100 days after your transplant OR when your BMT doctor or NP says it is safe to do so.

When your blood counts have recovered and you start to clean up after your pet(s), remember to wash your hands well after this activity.

Lifestyle Changes

Not smoking, eating healthy, and doing regular physical activity will help with your recovery. If you have any concerns or need extra support with making lifestyle changes, tell your health care team.

See Appendix G on page 56 for information on physical activity as an outpatient and at home.

Healthy eating

In addition to following Canada's Food Guide, it is important to eat healthy foods and to handle food safely (see Appendix F on page 54). Review the Safe Food Handling for Immunocompromised Individuals booklet provided by your health care team.

During the transplant process, you may have lost your appetite. Getting your appetite back may take some time. If you struggle with appetite issues and are not eating as much as usual, try to focus on eating foods high in protein and calories. Some people who do not have their usual appetite find that 4 to 5 small meals works better than 3 big meals.

Stay hydrated and drink as much fluid as possible (not just water) – unless you have been told by the health care team to limit your fluids.

Weigh yourself once a week and tell your doctor or nurse if you are losing weight.

Alcohol

Alcohol can interact with your medications. Talk about this with your health care team.

Smoking

If you are a smoker, it must have been hard to get through the transplant and recovery without smoking. Congratulations, you did it! Please consider yourself a quitter and keep up the good work.

If you are still struggling to not smoke and would like help, talk to your health care team— it may be your primary health care provider, social worker, nurse, or specialist, etc. who can help with this. There are programs and services available to help you.

Vaccinations After a Transplant

Vaccinations are recommended for post-autologous transplant patients. Your transplant doctor and/or NP will talk about this with you.

Ongoing Side Effects

Cancer-related fatigue

Cancer-related fatigue is whole body tiredness or whole body exhaustion. Many people say it is a tiredness and weakness that they have never experienced before. Cancer-related fatigue is different from other fatigue because you can be fatigued without doing any physical or strenuous (hard) activity. With cancer-related fatigue, it is common to wake up feeling tired even after a full night's sleep. It is one of the most common side effects after a transplant.

Each person's experience with fatigue is different. No one can predict how severe (bad) it will be or how long it will last. You may have mild to severe fatigue after your transplant, lasting for weeks or months.

At home, cancer-related fatigue is often the most bothersome side effect of a transplant. It can interfere with daily life more than any other side effect. It often interferes with a person's family, social life, work or school life, sex life, and overall quality of life.

Managing cancer-related fatigue

To learn more about cancer-related fatigue and how to manage it, ask your nurse or social worker. There is written information available, monthly classes on fatigue management, and videos that you can watch online (search 'cancer related fatigue Mike Evans') to learn helpful strategies. Some people living with moderate to severe fatigue will work with a doctor at the Nova Scotia Cancer Care Program to add different strategies into their day. Such strategies may involve how to start doing physical activity after cancer treatments, how to pace and plan your day, and how to cope with your thoughts and feelings about being fatigued. Ask your health care team if you would like help managing your fatigue.

Reproductive effects, birth control, and early menopause

Most people receiving a transplant have had previous treatment for their cancer. You may have learned about the possible damage to your reproductive organs (like testicles or ovaries) caused by chemotherapy. Depending on the type of chemotherapy you received, you will have been told whether it could cause temporary or permanent damage that could interfere with your ability to have children.

With a transplant, you are given very high doses of chemotherapy. This causes you to be at a high risk for permanent damage to your testicles or ovaries. **This means that after a transplant, it is highly unlikely that you will be able to have children.** However, there is a small group of younger adults who have had a transplant and have gone on to have children.

Birth control

It is important to remember that **you should not get pregnant and/or should not have a child for 1 to 2 years after your last chemotherapy - AND only when your doctor says it is safe to do so.** There is a small chance that your reproductive organs may start working again, so it is important that you **use birth control for the first 2 years after transplant** (if you are of child-bearing age).

If you want to know if you have working sperm 1 year after your transplant, ask your doctor to do a sperm analysis test. Your doctor can do this test regularly.

You may still have your period after your transplant, but early menopause is likely. If you have spotting or have your period after your transplant — this is your chance to try to get pregnant before menopause. **Remember, you should NOT try to get pregnant for 1 to 2 years after your transplant, and only when your health care team says it is safe to do so.** While there is always a chance you could get pregnant, if you are not getting your period or have no spotting at all during the month, it is highly unlikely. Having some spotting or a period does not always mean you can get pregnant. Sometimes your ovaries start producing some hormones but not enough to get pregnant.

Most premenopausal people going into transplant will go into menopause (called premature menopause) during the transplant process. This means you will not have a period again, and you cannot get pregnant. Talk with your doctor about keeping good bone health and managing other menopause symptoms.

If you are planning on having children:

Learning that it is unlikely that you will be able to have children after transplant is often distressing and upsetting. There is often a great sense of loss at not being able to have children or have more children. Your family and friends may not recognize or acknowledge the loss and grief that you and your partner may experience because their focus is on the cancer and treatment. Many patients also find that there is so much to think about leading up to their transplant that they do not focus on the reality of not having children until they are home and feeling a bit better.

You and your partner may grieve other losses related to not being able to have children. You may lose meaning in your life, lose your sense of self, or lose your future purpose. For some couples, the change in fertility can cause strain and tension in their relationship. A single person may question how this issue will impact possible relationships. These feelings can lead to anxiety and/or depression.

You may not have the focus and energy to work through this loss and grief until you are well into your recovery. It may help to talk with a health care professional to work through the grieving process, move forward in your relationships, and adjust to this new reality.

Sexual health changes during recovery

Almost all people recovering from cancer treatment, as well as their partners, have sexual health changes for part or much of this process.

For example, you may:

- › lose your sexual interest or desire for a period of time
- › not be able to get aroused or have an orgasm
- › feel differently about yourself and your body (you may feel less desirable and/or less attractive)
- › worry about how things will work if you have not been sexually active for a while

Changes in sex and intimate relationships

You may have much less sexual interest/desire and sexual activity with a cancer diagnosis, or even none at all. Sexual interest and sexual activity are often pushed to the side while patients and their partners deal with the physical, practical, and emotional work of treatment and recovery. You may find that you have too much on your mind, such as worries about money, children, child care, work, and fears about the future, treatment, and recovery. Patients often say, “Sex is the last thing on my mind.”

Fatigue plays a huge role in sexual activity. Fatigue can affect how you feel and your desire to be intimate. For some people, the desire is there, but they do not have the energy to act on it. Talk to your partner about how you are feeling.

When you are no longer living with day-to-day fatigue and are generally feeling well, sexual thoughts and interests may start to return and you may want to be sexually active again. This can take weeks or months after your transplant.

There are many reasons why a person may not be interested in sex, get excited, have an erection, or have an orgasm. Most people find that their sexual interest and ability to get and keep an erection returns when they feel better and have more energy. Not having working sperm does not change your ability to get or keep an erection, have an orgasm, or ejaculate. It only means that there are no working sperm in the fluid that comes out of your penis.

Symptoms of menopause can affect your mood and may cause depression or irritability. They can also cause physical changes which may affect your sexual activities and satisfaction. Common physical changes include fatigue, pain with sex, and vaginal dryness, itching, or tightness. Menopause often changes how people respond sexually; they may have changes in arousal and orgasm, or may feel less or no sexual interest.

Relationships

Going through a transplant can put strain and tension on an intimate relationship. If sex was an enjoyable part of your life before your cancer diagnosis, it most likely can be an enjoyable part of your life after your transplant.

Survival may overshadow sexuality and intimacy for some time. You may feel like just being alive is the most important thing. When the intense time of treatment and recovery is over, and you and your partner both start feeling better, the desire to be close and have sex usually comes back.

Talk, talk, talk!

Talk about changes in your relationship, in your sex life, and in how you feel. Talk with your partner about ways you may enjoy intimacy at that time. Do not assume your partner knows what you are thinking or experiencing, and do not underestimate affection and touch. Sometimes people are afraid to touch each other after all that has happened since the diagnosis. Talk with your partner about this.

If your partner has given physical care to you, it can be hard for both of you to readjust and see each other in a sexual way. Talk to each other about what you are thinking and feeling. These thoughts and feelings usually lessen and go away over time and with more sexual activity. Some couples may need help to start the conversation. Couples counselling can be helpful and is available. Ask your health care team how to access counselling resources.

As time passes and life gets back to normal, the sexual part of living usually does too. Remember that this may take months.

Safer sex

If you are having sex soon after transplant, it is important to shower or bathe before and after sex. We also recommend good mouth care before and after, for both you and your partner. If you are having solo sex (masturbating), it is not as important to bathe. If you are using toys, make sure they are cleaned properly before and after each use. Use water-based lubricant to lessen any irritation or bleeding.

Until your blood counts are nearing normal, have only gentle sex (no anal sex, and nothing that will risk tearing your skin or the lining of your mouth, vagina, rectum, or anal area).

Protect yourself and your partner from sexually transmitted infections (STIs). For more information on STI prevention, talk with your health care team.

Getting help

There are health care providers in the Nova Scotia Cancer Care Program and in your community who can help and support you with sexual health and relationship changes. Talk with your doctor or a member of the BMT team if you are worried, have questions, or need help communicating with your partner.

Being single

People who are single often have unique concerns about sexual changes and starting new relationships. Talk with your health care team if you would like more support.

LGBTIQ+

Do not hesitate to speak up and ask your health care team about your concerns around sex and relationship challenges. This is a standard part of your care. Resources are available that can help you move forward in your relationships.

Appendix A — Lodging

Halifax accommodations

While you are in Halifax to have your stem cell collection done, you can stay with family or friends in the Halifax area or make other arrangements (like a hotel).

The following information is for patients who need help with accommodations during their transplant process. These accommodations are used by the hospital, are near the QEII sites, and are partly funded.

The arrangements and coverage for these services are different depending on the province in which you live. If you plan to stay in one of these accommodations, your BMT coordinator will book your stay before your collection appointment.

The Dr Susan K. Roberts Lodge that Gives

5826 South Street, Halifax, NS

Phone: 902-420-1849

Open 7 days a week, no shuttle service

- The Dr Susan K. Roberts Lodge That Gives is run by the Nova Scotia division of the Canadian Cancer Society and is located within walking distance of the Victoria General (VG) Hospital. Space is limited and is first come, first served.
- There are only a few parking spots available. There is no charge for parking. If you do not have a space, you can park at the hospital. The social worker can give you half-price parking vouchers.
- If you live in Nova Scotia, lodging is free and meals are included. Anyone staying with you for the stem cell collection will have to pay for their lodging (meals are included in the fee).
- If you live outside of Nova Scotia, you may have to pay in advance and be reimbursed by your province. This varies from province to province and must be approved in advance. Talk with your provincial liaison or the social worker about these details, as these guidelines change often.
- There is free Wi-Fi. TVs are located in common rooms.

Point Pleasant Lodge

1121 South Park Street, Halifax, NS

Phone: 902-421-1599

Open 7 days a week, shuttle service (Casino Taxi)

- Point Pleasant Lodge provides low-cost accommodations for patients and their family members and/or friends. It is within walking distance of the hospital. Your BMT coordinator will make the booking for you.
- Parking is limited and there is a cost. If you would rather park at the hospital, the social worker can give you half-price parking vouchers.
- Your accommodation costs are covered, but meals are not included.
- If you are from Nova Scotia or Newfoundland, you will get meal vouchers to help offset your meal costs. Anyone staying with you for the stem cell collection will have to pay for their stay. They will be given meal vouchers.
- If you are from PEI or New Brunswick, please contact your provincial liaison to ask about meal allowances and any further questions.
 - › PEI residents call (toll-free): 1-866-232-3042
 - › New Brunswick residents call (toll-free): 1-866-266-3311

You must call Point Pleasant Lodge before 10 a.m. on your day of arrival to confirm your booking. If you do not call, your room may be booked by another patient.

If you miss mealtimes at either lodge, there is a cafeteria on the main floor of the hospital.

Halifax Haven Guest Home

5897 Inglis Street (across from Saint Mary's University), Halifax, NS

Phone: 902-421-1650

Shuttle service available

- Halifax Haven Guest Home is a non-profit organization providing accommodations for patients and families.
- It is completely funded by contributions (suggested donation is \$45 per person, but you can talk about this with the manager).
- Some rooms have a shared bathroom.
- There are no TVs or electronics available. You may bring your own electronic devices such as a portable DVD player, tablet, or laptop with pre-loaded entertainment.

Waverley Inn

1266 Barrington Street, Halifax, NS

Phone: 902-423-9346 or (toll-free) 1-800-565-9346

- Free parking
- Call for rates. Rates differ between off-season (Nov. 1st to May. 14th) and high-season (May. 15th to Oct. 31st).
- Second and third-floor rooms are only accessible by stairs.

Garden South Park Inn

1265 South Park Street, Halifax, NS (directly across from the VG)

Phone: 902-492-8577 or (toll-free) 1-877-414-8577

- For rate information, please visit:
 - › www.gardensouthparkinn.com

Dalhousie University

6299 South Street, Halifax, NS

Phone: 902-494-8840

- Mid-May to mid-August: residence-style accommodations available at lower rates for long and short-term stays. Call for services, rates, and availability.
- Two wheelchair accessible rooms are available.
- Parking costs \$12 extra per day.

Saint Mary's University

923 Robie Street, Halifax, NS

Phone: 902-420-5486

Ronald McDonald House Halifax

1133 Tower Road, Halifax, NS

Phone: 902-429-4044

- For patients up to the age of 19 and their families.
- For your first stay, you will need a referral from your clinic and/or doctor's office.

Hotels

Some hotels have special rates for people who have a family member who is a patient at the hospital. Ask if there is a hospital rate available. These include:

Lord Nelson Hotel & Suites

1515 South Park Street, Halifax, NS

Phone: 902-423-6331

Atlantica Hotel Halifax

1980 Robie Street, Halifax, NS

Phone: 902-423-1161 or (toll-free) 1-888-810-7288

The Barrington Hotel

1875 Barrington Street, Halifax, NS

Phone: 902-429-7410

Hotel Halifax

Scotia Square, 1990 Barrington Street, Halifax, NS

Phone: 902-425-6700

- Furnished apartments (for extended stays)

Premiere Suites, Paramount Apartments

1545 South Park Street, Halifax, NS

Phone: 902-420-1333 or (toll-free) 1-866-844-1333

- The area close to the hospital is called the South End or the peninsula.

Appendix B – Parking

Below is a map of available parking at the QEII VG site. It may be hard to find a parking spot near the hospital. Ask your BMT health care team about half price parking vouchers. You may wish to get a temporary Nova Scotia motor vehicle accessibility parking permit. This will let you park in the accessible parking spots or the 2-hour parking spots at the Victoria General Hospital site for as long as needed. Please ask the BMT social worker or Access Nova Scotia about applying for this permit. Your doctor will need to sign the application.

QEII Health Sciences Centre Map Victoria General Site

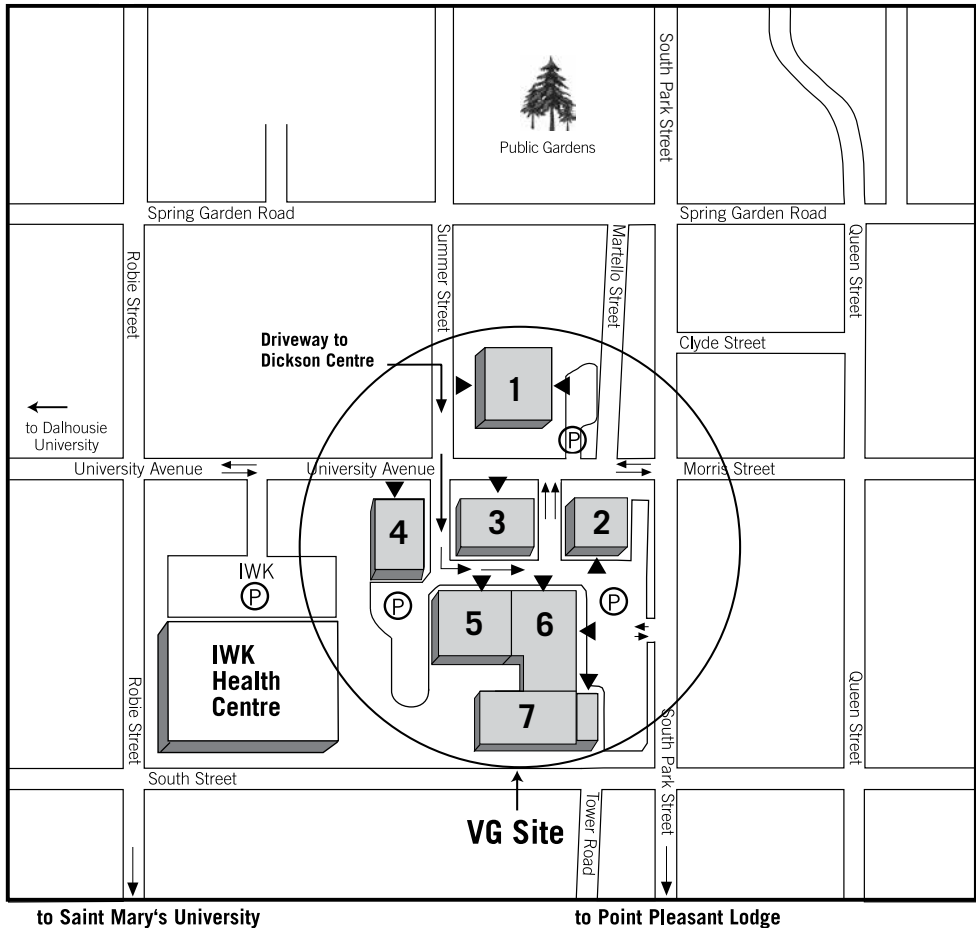
Queen Elizabeth II
Health Sciences Centre

VG Site		
1. Nova Scotia Rehabilitation Centre	4. Centre for Clinical Research	7. Centennial Building
2. Bethune Building	5. Dickson Building	
3. MacKenzie Building Laboratories	6. Victoria Building	

Ⓟ Patient Parking

▶ Entrance Doors

Please do not wear scented product when you come to Capital Health



Appendix C — BMT Program Policies

Water rules

- Please ask staff to give you the pamphlet called *Water Rules*. There is a bacteria in the water at the Victoria General Hospital that can cause a type of pneumonia in patients whose immune systems are not working well. This can happen if water droplets are inhaled (breathed in).
 - › Do not drink the tap water.
 - › Do not use the water to brush your teeth.
 - › Do not shower or bathe at the sink with the taps running.
- You will get bottled water for drinking and brushing your teeth. Nursing staff will give you a basin with water for bathing. It is safe to wash your hands at the sink after using the toilet.

Safe food handling

- Some foods have a risk of infection for patients having a stem cell transplant. This is because of how they are made or stored. In the hospital, food is prepared for you using safe food handling practices.
- Safe food handling practices come from Health Canada and are listed in the booklet *Safe Food Handling for Immunocompromised Individuals*. You will get a copy of this booklet. It includes lists of foods to avoid until you are told otherwise, and specifically for the first 100 days after your transplant.
- All fresh fruits and vegetables brought in from outside the hospital must be washed with bottled water (not hospital tap water), unless they were already washed at home.

Visitors

- Visitors are welcome. We encourage you to talk to your nurse about this before visitors come to the unit. You may choose to limit the number or length of visits when you are not feeling well. It is OK to tell visitors that you are not feeling good. Talk with your nurse if you would like to limit visitors. Your nurse can put a sign on your door asking visitors to check with staff before entering your room.
- **Visitors must wash their hands before entering your room.** Handwashing is one of the most important things people can do to protect patients from infections. There are hand sanitizer stations along the inpatient hallways for visitors to use before entering the unit and patient rooms. There is also a handwashing station located outside of unit 8B.

- **People who are not feeling well must not visit. If the person must visit, they should wear a mask.**
- When you are admitted to the hospital, both you and your visitors must wash their hands before entering the transplant unit and your room. Visitors should **NOT** visit if they have any signs of an infection (like a cold, sore throat, eye infection, sinus infection, flu symptoms, diarrhea).
- You may wish to have your care partner, family member, or friend stay overnight with you. Talk to the nurses on the unit about this first. A cot can be placed in the room for overnight stays, but should be folded up and moved out of the way by 8 a.m. to give staff room to work. Your nurse must be able to move easily around the room to care for you. Other staff members will also need space for cleaning and restocking supplies.
- Nursing staff must have enough electrical outlets and room for IV pumps and blood pressure monitors. Please limit the number of personal electronic devices in the room.
- Visitors are not allowed to use the patient's bathroom as this can spread germs. Staff will direct visitors to bathrooms for their use.
- There is a small kitchen outside of the unit for visitors. It has a fridge and microwave, and is stocked with coffee, tea, and light snacks.
- There is a washer and dryer on the 7th floor for your care partner to wash any personal clothing you may have.

Children

We strongly recommend that only children who are close to the patient visit. Children are often exposed to colds, coughs, and other infections that healthy adults do not usually get. This can increase the risk of infection for all of the patients on the unit.

Children who visit must:

- › not visit if they are sick or have been around people who are sick.
- › be up to date on all vaccinations.
- › not have received the FluMist® nasal spray vaccine.

Children who visit must be supervised by a visiting adult at all times who will:

- › help the child to thoroughly wash their hands before entering the unit.
- › go directly to the patient's room with the child. The child should not touch walls or equipment, or come into contact with other patients.
- › keep the child in the patient's room while visiting.
- › make sure the child does not play in the hallway, kitchen, or family room.
- › make sure the child does not play with, sit on, or pick up items from the floor. If this happens, the child must wash their hands again.
- › make sure that the child does not use the patient's washroom.
- › take the child off of the unit if they need to have their diaper changed.

Coming in contact with people who have recently had vaccinations

It is OK for BMT patients to be in contact with people who have received a live vaccine, but you should:

- › avoid close contact with anyone in your house who has received a live influenza vaccine (LAIV) for 2 weeks.
- › avoid changing diapers of a child who has received the live rotavirus vaccine for 4 weeks.
- › avoid contact with anyone who has developed blisters after receiving the live chickenpox or zoster vaccine until after their symptoms have gone away.
- After your engraftment, ask your BMT team when it is OK to be in contact with people who have recently received the MMR, varicella (including zoster vaccine), or yellow fever vaccines.
- After your transplant, you should not be in close contact with people who have received an oral polio vaccine for at least 6 weeks. As Canada does not use oral polio vaccine (OPV), this should not be a common concern.

Flowers

Flowers (fresh or dried) and potted plants carry germs. They are not allowed in patient areas on the 8th floor.

Appendix D — Shingles

What is shingles?

Shingles is a type of infection caused by a virus. It happens when the virus that caused chicken pox becomes active again. It is also called the “adult version of chicken pox.” You may get shingles after a transplant because your immune system is weak.

What are the symptoms of shingles?

- Shingles can be on any part of your body.
- It starts as pain, tingling, burning, or an irritation on your skin, usually in one area.
- You may or may not have a fever, and you may feel tired.
- Over time, red, raised, itchy spots will appear. **Do not scratch.** Keep your fingernails short. These spots will turn to blisters, which will eventually break and drain fluid for a few days. With treatment, the blisters will dry up in a couple of days and the spots will go away over time.
- If you have a fever, it will get better when the rash turns to red patches.

How is shingles treated?

- If you think you may have shingles, or have been in contact with someone who has chicken pox or shingles, **call your doctor or the Hematology Clinic within 24 hours (1 day), or go to the nearest walk-in clinic.** Early treatment can lower the severity (how bad it is) and discomfort of the infection.
- Shingles is treated with medication for viral infections (like acyclovir or valacyclovir). This medication may be given as pills or by IV, depending on how bad the infection is.
- Usually, people do not have to be admitted to the hospital for treatment.
- The doctor will order pills to help control the pain, if needed. The pain will get better over the first week. Shingles can be very uncomfortable, painful, and irritating. It can cause weeks of pain, soreness, and distress.
- Placing a cool compress on the painful, itchy areas may relieve some of the discomfort.
- Wear loose, breathable clothing, such as cotton, over the affected area. If your groins are affected, wear cotton underwear or boxer shorts. Do not wear pantyhose, as it does not let the area heal as fast.

How do I prevent spreading shingles?

- Avoid young children and pregnant people until you are no longer contagious.
- Wash all of your clothes, bedsheets, and towels separately with regular soap.
- Do not share towels, face cloths, or clothes.
- When the blisters have dried and formed scabs, you are no longer contagious.
- If you think you may have shingles, contact the nurse before going to the Medical Day Unit, Hematology Clinic, or other areas of the hospital. You may have to wait to receive care in a separate area.

What are your questions?

Please ask. We are here to help you.

Appendix E — Resources for Emotional Health

Support Groups

Living Beyond Cancer

- This class gives information about what to expect after your cancer treatment. It is also a chance for you to connect with other cancer survivors.
- Held on the last Wednesday of each month in community locations across Nova Scotia:
 - › Amherst
 - › Antigonish
 - › Baddeck
 - › Bridgewater
 - › Cheticamp
 - › Halifax
 - › Inverness
 - › Kentville
 - › Neil’s Harbour
 - › New Glasgow
 - › Port Hawkesbury
 - › Sydney
 - › Yarmouth
- To register, call (toll-free) **1-866-599-2267 (option 3)** and leave a message, and your call will be returned.

Wellspring Nova Scotia

- Wellspring Cancer Canada offers free Well on the Web supportive programs.
- To see a list of these programs and schedules, visit:
 - › <https://wellspring.ca/online-programs/>

Halifax area

Living Well with/after Leukemia & Lymphoma

- Held on the last Tuesday of each month in room 138, 8B Centennial Building, QEII, VG site.
- Call Janice Spencer at 902-473-4072 for more information.

Multiple Myeloma

- Held on the fourth Saturday of each month at the Larry Uteck Sobeys.
- Call Trish at 902-678-9378 or Julie at 902-462-8670 for more information.

Online support groups

Cancer Chat Canada

- This is a professional-led online support group for people affected by cancer. It is free for Canadians affected by cancer. Different groups run at different times.
- To sign up for a group, visit:
 - › cancerchat.desouzainstitute.com
 - › Click on ‘Sign Up’ to identify what you are looking for in a group. You will be contacted when a group that fits your needs is scheduled.

Leukemia & Lymphoma Society of Canada®

- This is a friendly forum to share experiences and chat with others about anything from initial diagnosis to treatment and survivorship. The chat sessions are moderated by an oncology social worker who gives support and guides conversation.
- To access weekly online chats, visit:
 - › llscanada.org/support/online-chats

Other supports and services

Canadian Cancer Society

- Call 1-888-939-3333 (toll-free) for a one-to-one peer support program, or visit:
 - › cancerconnection.ca
- To join this online forum, you will need to register at:
 - › cancerconnection.ca/registration
- Call (toll-free) 1-888-939-333 to access a variety of other support services in your community or visit:
 - › cancer.ca
 - › Go to Support & services then click on ‘Find services in your community’.
 - › Click on ‘community services locator (CSL)’
 - › Type in your city or postal code to see the services available in your community.

Myeloma Canada

› www.myelomacanada.ca

Leukemia & Lymphoma Society of Canada®

› www.llscanada.org

Young Adult Cancer Canada

› www.youngadultcancer.ca

Caregivers Nova Scotia

› www.caregiversns.org

Caregivers' Guide: Practical Information for Caregivers of Older Adults, from the government of New Brunswick

› www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Seniors/CaregiversGuide.pdf

Government of Canada's Federal/Provincial/Territorial Ministers Responsible for Seniors Forum, provides information for caregivers

› www.canada.ca/en/employment-social-development/campaigns/seniors.html

Books

- After You Ring the Bell...10 Challenges for the Cancer Survivor by Anne Katz (2012)
- Picking up the Pieces: Moving Forward After Surviving Cancer by Sherri Magee and Kathy Scalzo (2007)
- Life after Cancer in Adolescence and Young Adulthood: The Experience of Survivorship by Anne Grinyer (2009)
- Feeling Good: The New Mood Therapy by David D. Burns (1999)
- Chicken Soup for the Surviving Soul by Jack Canfield, Mark Victor Hansen, Patty Aubery, and Nancy Mitchell (1998)
- Chicken Soup for the Cancer Survivor's Soul by Jack Canfield, Mark Victor Hansen, Patty Aubery, Nancy Mitchell and Beverly Kirkhart (1996)

Other recommended resources

Please use this space to add any other resources or notes that may be helpful to you and your family:

Appendix F — Healthy Eating

Proper nutrition is an important part of cancer treatment and recovery. Patients who are having a stem cell transplant are at a higher risk of poor nutrition. This is because of their underlying disease, as well as the side effects from their treatments. Getting enough calories and protein, and keeping up your weight, can help with your recovery.

If you have trouble eating enough food at meals, try to eat more calorie-rich foods and foods higher in protein. You can:

- › add extra sauces, gravies, cream, or margarine to your food.
 - › try not to fill up with ‘light’ and/or diet products, like tea, coffee, broth soups, and diet pop. Choose higher calorie versions of these foods, like cream soups and milk.
 - › eat small meals and snacks often. Try to snack every 2 hours.
 - › keep quick snacks on hand. Try foods like cheese and crackers, fresh fruit, yogurt, puddings, and nutritional supplements.
 - › if you are not eating solid foods, aim for 6 to 8 cups of high energy, high protein liquids each day. Try whole milk, milkshakes, and nutritional supplements.
 - › keep frozen, canned, or ready-to-use foods available for when you do not feel like cooking. There are many frozen meals available at your local grocery store and local catering companies offer healthy frozen meals.
 - › cook large amounts of food when you feel better. Then you can freeze your favourite meals for times when you do not feel like cooking.
 - › let your family and friends help you. They could go to the grocery store or cook meals.
- Make your meals more attractive. Try adding brightly coloured foods and garnishes.

Safe food handling

- It is important to follow safe food handling practices after your transplant. You will get a copy of *Safe Food Handling for People with Weakened Immune Systems* or you can visit
 - › www.canada.ca/en/health-canada/services/food-safety-vulnerable-populations/food-safety-people-with-weakened-immune-system.html
- Certain foods and how they are prepared may increase your risk of infection. These safe handling guidelines should be followed for at least 100 days after your transplant. Important points to remember are:
 - › Keep meat, poultry, fish, and seafood separate from fresh or ready-to-eat foods during shopping, storage, and food preparation.
 - › Wash your hands, fresh fruits and vegetables, and kitchen surfaces and utensils well.
 - › Keep hot foods hot and cold foods cold.
 - › Always cook foods to the correct internal temperature (see chart listed on page 12 of the *Safe Food Handling for People with Weakened Immune Systems*) and check foods with a digital thermometer.
 - › Avoid high-risk foods, such as non-dried deli meats, raw or unpasteurized dairy products, soft and semi-soft cheeses, hotdogs (uncooked), patés and meat spreads, raw seafood, raw or undercooked meat or poultry, unpasteurized fruit juice and cider, and raw sprouts.

Ask for a referral to a registered dietitian if you have concerns or questions about nutrition or visit:

- › <https://food-guide.canada.ca/en/food-guide-snapshot/>

Appendix G — Physical Activity

Physical activity while in hospital

Exercise does not have to be hard to make a difference. Try your best to do some light activity during your hospital stay. Light exercise will help you return to your regular daily activities.

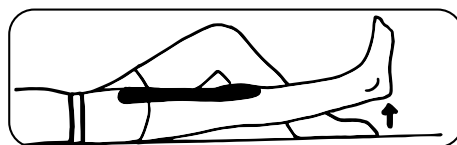
- Stay as active as you can.
- Do more physical activity over time.
- Try setting a goal of sitting up in your chair 3 times a day. Aim to sit for 30 minutes (or more) each time. Just sitting at the edge of your bed will not give you the back or arm support you need. It can be more tiring than sitting in a chair.
- When you are feeling a bit better, try walking around your bed.
- Take deep breaths every hour while you are awake.
- If you are not steady on your feet, ask a family member or staff member to help you.

Bed exercises

Try doing these exercises on days when it is too hard to get out of bed to exercise. Remember not to hold your breath during these exercises.

Try to work up to doing each exercise 10 times, 2 to 3 times a day:

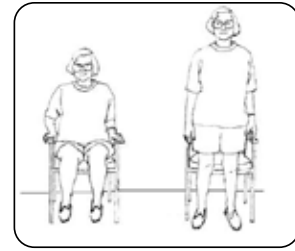
1. **Ankle pumping:** Point your toes down, then bring them back up.
2. **Knee flexion:** Slide your heel towards your buttocks (bum). Keep your heel and buttocks on the bed. Hold for 5 seconds. Relax and repeat 10 times.
3. **Hip abduction:** Slide your leg out to the side. Keep your toes pointed at the ceiling. Hold for 5 seconds. Bring your leg back towards your other leg. Relax and repeat 10 times.
4. **Straight leg raise:** Lie on your back, with your left leg straight and your right knee bent. Keep your right foot flat on the bed. Lift your left leg while keeping it as straight as possible, about 6 inches off of the bed. Hold for 5 seconds, then slowly lower your leg. Repeat with the right leg.



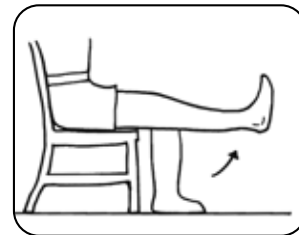
When you are out of bed

Try to work up to doing each exercise 10 times, 2 to 3 times a day. Remember not to hold your breath during these exercises.

1. **Sit to stand:** Sit in a chair and practice rising up and out of the chair. You may use your arms, if needed. When your legs are strong enough, cross your arms across your chest and do the same exercise without using your arms.



2. **Quadriceps:** Sit in a chair and slowly straighten your right leg. Hold for 5 seconds, then slowly lower. Repeat with your left leg.



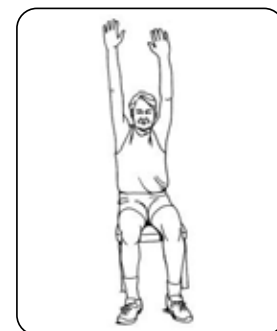
3. **Knee raises:** Sit in a chair with your back straight. Hold for 5 seconds then lower your knee. Repeat with the other leg.



4. **Heel lifts:** Sit in a chair with both feet flat on the floor. Lift your heels off the floor, then slowly lower them back down.



5. **Shoulder press:** Sit in a chair with your elbows bent and your hands by your chest, with or without weights. Lift one arm straight up, then bring it back down. Repeat with the other arm.



Physical activity as an outpatient and at home

Moderate exercise can improve tiredness, quality of life, and mood. It can also improve muscle strength and strengthen your heart when recovering from treatment.

Cardio activity

- Cardio (endurance) activity makes your heart pump harder for a period of time. It helps to strengthen your heart and lungs. It also improves blood circulation throughout your body.
- Cardio activity can be something you enjoy doing, like brisk walking or cycling. Choose an activity that gets your heart rate up and **keeps it up**.
- Start out slowly. You may only be able to manage 2 or 3 minutes of slow walking as you start to recover. Some people start by walking around in their house for 2 minutes without stopping, then increase to 3, then 4, then 5 minutes. As you feel stronger, increase your activity 1 or 2 minutes each day. Once you feel strong enough, try walking outside and add a little more time each day or every few days.
- You can add to your activity level in different ways. For example, you can work up to three 10-minute walks each day. Over time, you can increase two of your walks so that you are doing two 15-minute walks each day. From there, aim for one 20-minute walk.
- Some people may be able to start their physical activity sooner, with more speed and strength, and for a longer period of time. Remember to take breaks and do not push yourself so hard that you are exhausted for the rest of the day.
- The Canadian Society of Exercise Physiology (CSEP) says that people with cancer can safely take part in moderate exercise during active treatment and after their treatment is finished. CSEP recommends 30 minutes of **moderate** cardio exercise 5 days a week. Moderate activity is described as being able to carry on a conversation while doing the activity, where you may be winded at times. It may take you weeks or months to reach this goal and this is OK. While your blood counts are low, try to exercise at home or outside so that you are not in close contact with other people.

Strengthening activity

- Strengthening (resistance) exercises help your muscles get and stay strong. They improve your muscle strength, power, and endurance.
- Strengthening activities make your muscles work harder than usual by using your body weight or working against a resistance.
- Examples of muscle-strengthening activities include:
 - › Lifting weights (or cans of soup)
 - › Moving in a swimming pool
 - › Working with elastic bands
 - › Climbing stairs or hills
 - › Biking
 - › Dancing
 - › Yoga
 - › Squats
 - › Other activities that use your own body weight as resistance
- Add strengthening activities a couple of times a week once you are doing cardio 4 or 5 times a week. CSEP recommends that you strengthen major muscle groups 2 to 3 times a week.
- **Do not start strenuous (hard) strengthening exercises until your platelets are above 50,000.** If you want to meet with a physiotherapist to learn more, ask for a referral from a BMT team member.

This pamphlet is just a guide. If you have questions, please talk to your health care provider. We are here to help you.

Exercises after transplant

After you are home, you may be able to add some more challenging exercises to the exercise program you started in the hospital.

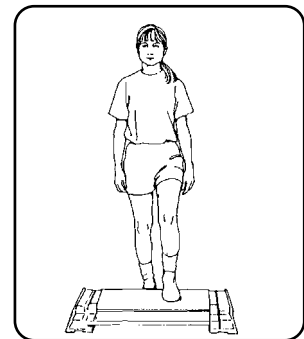
Warm-up

Start with a 5 to 10-minute warm-up, including easy movement of your joints. This will help your body get ready for the rest of your exercise. Examples of warm-up exercises include shoulder shrugging, lifting your arms overhead, toe tapping while sitting in a chair, knee lifts, and marching on the spot.

Bridging: Lie on your back with both knees bent and both feet flat on the bed. Push through your heels and raise your hips up off the bed. Do this 10 times (one set). Over time, work up to 2 sets or more.



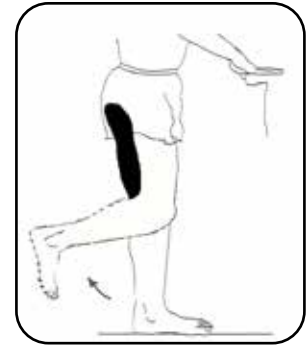
Step-ups: Stand in front of a set of stairs. Hold on to the rail as needed. Place one foot on the bottom step. Then bring your other foot onto the step. Lower your first foot back down, then lower your other foot (like right foot up, left foot up, right foot down, left foot down). Do this 10 times (one set). Then repeat starting with the opposite foot (like left foot up, right foot up, left foot down, right foot down). Over time, work up to 2 sets of 10 repetitions or more.



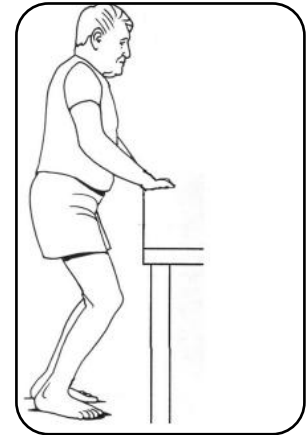
Standing hip and knee flexion: Stand up straight. Lift your knee upwards. Do not lean forward. Hold for 5 seconds. You should feel the muscle on the front of your hip working. Relax and repeat 10 times each leg.



Standing hip abduction: Stand up straight. Lift your leg out towards the side. Do not lean to either side. Hold for 5 seconds. You should feel the muscles on the side of your thigh and hip working. Relax and repeat 10 times each leg.



Standing knee flexion: Stand up straight. Bend your knee by bringing your heel toward your buttocks. Do not move your hip. Hold for 5 seconds. You should feel the muscle on the back of your thigh working. You may feel a stretch on the front of your thigh. Relax and repeat 10 times each leg.



Knee bends: Hold onto a counter for balance. Stand up tall and straight. Place your feet should-width apart. Bend your knees slightly, about 1/4 of a squat (**do not do a full squat**). Hold for 5 seconds. Straighten your knees.



Cool-down

Stretching after exercising helps to lessen muscle stiffness and soreness, and increase flexibility. Hold each stretch for 30 seconds. Stretch slowly and **do not bounce**. Repeat each stretch 2 to 3 times. Remember: a stretch will feel like tension in your muscles, but should not cause any pain.

Do these stretches after you exercise

For each stretch, hold for 20 to 30 seconds. Repeat 3 times.

Calves: You will feel this stretch in your calf muscles. Stand a couple of feet away from a wall. Place one foot in front of the other. Keep your back knee straight with your heel on the floor. Slowly move your hips forward. Repeat on the other side.



Quadriceps (thighs): This exercise stretches the muscles in the front of the thigh. Stand on one foot using a chair for balance. Bend your other knee and grasp your ankle. Pull your ankle backwards until you feel a stretch in the front of your thigh. It is important to stand straight during this exercise. Do not do this exercise if you have balance problems.



Or

Lying on your side, slightly bend your bottom leg for balance. Grasp the ankle of your top leg and pull backwards until you feel a stretch on the front of your thigh.



Hamstring stretch: Lie on a bed or the floor so that you can place your foot on the wall. Note: If your bed does not work and you are not able to easily get off the floor, do not do this exercise at home. Place a towel under your foot so that your foot will slide more easily. Slide your foot down the wall so that you feel a mild to moderate stretch. Hold 20 to 30 seconds. Repeat 3 times.



It may be helpful to talk with someone from the BMT team about what a realistic activity plan may look like for you.

