

Allogeneic Stem Cell Transplant

Victoria General (VG) Site, QE II

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Allogeneic Stem Cell Transplant

- This pamphlet gives information about having an allogeneic stem cell transplant using stem cells from a donor. **Please bring this pamphlet 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.
- Some of the information in this pamphlet may be different from what you have been told. Some details of each transplant are different for each person. Check with your transplant coordinator or doctor if you have questions.
- You will get a lot of information about the transplant process. We understand that this can feel overwhelming. It is important that you get as much information as you need or want. It is common to forget some of the information you are told. Most people have questions, and we encourage you to ask.
- Although you have agreed to have a transplant and have signed an informed consent form, there may be times when your health care team needs to make more decisions about your 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 the quality of life for transplant patients. A member of your health care team may ask if you would like to join a research study. Any research being offered will be fully explained to you. It is up to you if you want to take part. **If you do not want to take part in a research study, your decision will not affect your care.**

About stem cell transplants

What is an allogeneic stem cell transplant?

- An allogeneic stem cell or bone marrow transplant is used to treat many diseases. It is used to replace bone marrow that does not work as it should with healthy bone marrow.
 - › For example, it can be used to help people with cancer to receive higher doses (amounts) of chemotherapy, which kills cancer cells.

- An allogeneic stem cell transplant allows stem cells to grow into a new blood supply and immune system (cells in your body that fight infection). This may either give you a longer remission (no active disease) than without a transplant or even cure your disease (depending on the disease). Your transplant doctor will talk with you about the goal of your treatment.
- Stem cells can be taken from peripheral blood (blood in your veins) instead of bone marrow. Sometimes bone marrow is used if the transplant team thinks it is best.

What are stem cells?

- Your blood has 3 types of blood cells. These cells each do something different in the body:
 - › **White blood cells** protect you from infection.
 - › **Red blood cells** carry oxygen.
 - › **Platelets** prevent bleeding by helping your blood to clot (stick together).
- All blood cells start out as stem cells. A stem cell can turn into a white blood cell, a red blood cell, or a platelet depending on your body's needs.

Central line

- You will have a central line put in for your transplant. A central line is a type of catheter (a thin, hollow tube put into a large vein near the heart). This gives your health care team a way to give medication and collect blood without doing a lot of needle sticks.

There are 2 types of central lines:

Hickman™ line

- A Hickman™ line is a type of catheter (thin, hollow tube). It is usually placed in a large vein in your chest.
- It is used to give intravenous (I.V.) fluids, blood transfusions, medications, and stem cells. It is also used to take blood samples.
- A doctor in the Interventional Radiology Department will put in your Hickman™ line. You will be given local anesthetic (freezing) to numb the area where the line will be put in, so that you do not feel any pain.
- You will also get sedation (medication to make you relax and fall asleep).
- When you are discharged from the hospital, you will likely still need your Hickman™ line for blood samples, medications, and blood transfusions.

- Your Hickman™ line will be removed when it is no longer needed. This can be done during a regular visit to the Hematology Clinic, or in the Interventional Radiology Department.
- Nursing staff will give you more information about your Hickman™ line before it is put in.

PICC line

- A PICC line is another type of catheter. It is usually placed in a large vein in your arm.
- It is used to give I.V. fluids, blood transfusions, medications, chemotherapy, and stem cells. It is also used to take blood samples.
- A doctor in the X-ray Department will put in your PICC line. You will be given local anesthetic to numb the area where the line will be put in, so that you do not feel any pain.
- Your PICC line will be removed when it is no longer needed. This can be done during a regular visit to the Hematology Clinic.
- Nursing staff will give you more information about your PICC line before it is put in.

Social work assessment

- Your Cell Therapy and Transplant Program (CTTP) coordinator will arrange for you to meet the CTTP social worker. The social worker will ask questions to learn about you and your care partners (see next page). 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, 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 (18 years old or older) who will give you 24-hour support. They must come with you to and from the hospital, and help you as needed when you are not at 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 done.
- A care partner can be a family member or a friend. The role can be shared by more than 1 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 7 days (1 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 100 days after your transplant.
- A care partner can help you stay on track with taking your medications and checking your temperature. If you are not feeling well, they can:
 - › help you connect with your doctor or health care team.
 - › help you get to the Emergency Department, if needed.
- They are there 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, see Appendix A on page 43.

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. An infection in the mouth can spread to other parts of your body.
- If your mouth is sore, be gentle when brushing and flossing your teeth. Brush and floss as well as you can.
- Your CTPP coordinator will arrange for you to visit an oral surgeon. They are located in the basement of the Centennial Building at the VG site of the QE II.

- 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. Bring a list of the medications you currently take to your dental appointment. You must also have your teeth cleaned and any oral problems fixed. Tell your dentist:
 - › The type of disease you have
 - › That you will be having chemotherapy
 - › If you are taking medications to strengthen your bones called bisphosphonates (like pamidronate, Fosamax®, Actonel®, or zoledronic acid)
- 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 done.

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

- Contact the Nova Scotia Dental Association:
 - › Phone: 902-420-0088
 - › www.nsdental.org
 - › Hours: 8 a.m. to 4 p.m. (Monday to Friday)
- Look in the Yellow Pages™:
 - › www.canada411.ca
- If you are having trouble finding a dentist, ask the CTPP social worker for help.

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

- › Ask to talk with the CTPP 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 Prince Edward Island (PEI) and you do not have dental insurance or cannot afford care:

- › Talk with the social worker on your health care team in your home province.

Oral surgery care

- The Oral Surgery Department is at the VG site of the QE II, 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 fixed, the oral surgeon may remove it or recommend that your dentist remove it.

Phases of allogeneic stem cell transplant

- The stem cell transplant or bone marrow transplant (BMT) process has 3 phases:
 - › Phase 1: Pre-transplant phase
 - › Phase 2: Transplant (inpatient) phase
 - › Phase 3: Post-transplant (outpatient) phase
- Although the experience of these phases may be quite different for each person, this is a general overview.

Phase 1: Pre-transplant phase

Workup

In this phase, all patients will have tests done on their heart, lungs, and in some cases 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 (or a MUGA scan)**. It is usually done in the X-ray Department. You will have dye injected in your arm. The dye will move through your bloodstream to 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.

Conditioning treatment

- Conditioning is the word used for the high doses of chemotherapy medication you are given in the days right before the transplant.
- There are different conditioning treatments. Your CTPP doctor will decide what conditioning treatment is right for you.
- Your conditioning schedule depends on your diagnosis. The pharmacist and nurse will give you information on the systemic therapy medications you will get. They will also talk with you about any other medications you will get for your transplant. **We suggest you keep this information (like other pamphlets you may get) with this pamphlet.** Side effects of chemotherapy are described on page 8. Your health care team will review them with you during your hospital stay.
- Usually, conditioning starts as an outpatient in the Systemic Therapy/ Supportive Care Unit (STU), on the 4th floor of the Victoria Building. The length of time it takes to complete the conditioning depends upon the treatment that has been recommended for you. Each day of conditioning is numbered in a countdown until the day of your transplant, which is considered day 0. For example, these days will be referred to as Day -9, -8, -7, -6, -5, -4, -3, -2, -1, 0 (transplant day).
- You will get chemotherapy through your PICC line or 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 their 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 CTPP Unit. Visitors must follow the same handwashing guidelines as if you were in the CTPP Unit.
- Your doctor and coordinator will provide you with more information if you need a different conditioning treatment.
- There are different intensities (levels) of conditioning protocols. The right protocol for you depends on your disease, age, past medical history, and your overall health. The different intensities are:
 - › Myeloablative (high-dose chemotherapy)
 - › Reduced intensity
 - › Nonmyeloablative (low-dose chemotherapy): Non-myeloablative transplants use lower doses of chemotherapy but still have serious side effects and risks.

- After receiving chemotherapy, you will still have some of your own stem cells left in your bone marrow. Some of your donor's cells may react with your cells after they have had a chance to grow. This can cause a condition called **graft-versus-host disease** (GVHD). GVHD happens when a donor's cells attack the patient's tissues. This is explained on page 20.
- We know that the donor's cells play an important role in attacking the remaining cancer cells in your body. This is called the **graft-versus-tumour effect**. The chemotherapy is given to kill some of the cancer cells and make room for your donor's cells to grow. Eventually, your donor's cells should start killing the rest of the cancer cells. The amount of time it takes for this to happen will be different for everyone but may take weeks or months.

Side effects of chemotherapy

- Chemotherapy harms both cancer cells and normal cells. Common side effects are caused by the damage to your normal cells.

Sore mouth (mucositis)

- Chemotherapy medications 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 look inside your mouth.
- Mucositis can make it very painful to eat and drink. You will get fluids by I.V. to keep you from getting dehydrated (not having enough fluids), and pain medication as needed to help keep you comfortable.

Taste changes

- Chemotherapy can change your sense of taste. 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 ways to cope with taste changes.

Nausea

- The chemotherapy may make you nauseous (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 (like apples, bananas, rice).
 - › Eat and drink small amounts throughout the day instead of a lot at once.
 - › 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 36 or Appendix G on page 57 for tips on improving energy and adding more protein to your meals.

Diarrhea

- Diarrhea may be caused by chemotherapy and other medications. Diarrhea can also be caused by a bacterial infection in your bowel. If you have diarrhea more than 2 or 3 times a day, your nurse may send samples of your stool 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 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.** This is to prevent getting dehydrated.
- The skin around your rectum (bum) can get very red and sore from having diarrhea. It is important to keep this area clean and dry. Your nurse can give you ointment to soothe and protect your skin.

Chemotherapy effects on cells

- Chemotherapy has an effect on your blood cells and on cancer cells. People often feel very tired and sick when their blood cells are low. Your numbers of white blood cells, red blood cells, and platelets (small pieces of cells that help form clots to prevent bleeding) 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 (called neutropenia)

- White blood cells (neutrophils) 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.** This is called **neutropenia**.
- You may be given medications to help prevent certain viral or fungal infections.
- Your white blood cell test will measure your absolute neutrophil count (ANC). Because neutrophils fight 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 3 to 7 days after you have your transplant (between Day +3 and Day +7).

Phase 2: Transplant phase

On the day you are admitted to the hospital, check in at the nursing desk on Unit 8A. Staff will tell you what room you will be in.

Inpatient stay

- You will be admitted to the 8th floor of the Centennial Building at the VG site. 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 patient 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.**

What should I bring to the hospital?

- › Comfortable clothes
- › Pyjamas
- › Slippers or shoes with non-skid soles
- › Framed pictures or other small comfort items
- › Pillow and comforter (optional)
- › Your own tissues and toilet paper, as hospital brands can feel rough (optional)
- › Electronic devices (cell phone, tablet), chargers, and headphones, if needed
- › Books
- › 1 to 2-month supply of your regular medications to start taking as directed when you are discharged

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 is needed. Please leave all valuables (like jewelry, money, cheques, credit cards) at home. **The hospital is not responsible for the loss of any items.**

CTTP policies

There are specific policies that you must follow when you are admitted to the inpatient unit for your transplant. This is to lower your risk of infection. These policies include:

- **Water rules: For your safety, do not drink the tap water or use it to brush your teeth or shower. It is safe to bathe** using the tap water if the basin is prepared by a staff member or your care partner.
- Safe food handling
- Visitor guidelines (including children): Visitors should only visit if they are healthy and do not have flu or cold symptoms.
- Flower rules: Fresh or dried plants are not allowed in patient care areas. **Nova Scotia Health is scent-free.**
- After your transplant (Day 0), you will not be able to leave your room on 8BMT except:
 - › To go for tests
 - › If you need special care, like the Intensive Care Unit (ICU)
- Please read Appendix D on page 49 before your hospital admission for more details on these policies.

Inpatient health care team

- As an inpatient, you will be cared for by a health care team who have been trained to look after patients receiving a stem cell transplant. This team includes:
 - › Doctors
 - › Nurses
 - › Pharmacists
 - › A dietitian
 - › A physiotherapist
 - › An occupational therapist
 - › Care team assistants (CTAs)
 - › A spiritual care provider
 - › A social worker
 - › Others
- The inpatient transplant team will check you every day. There is always a doctor 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 pages 43 and 44 of this pamphlet. Your health care team will depend on you to be involved in your own care:
 - › Follow their advice.
 - › Tell them how you are feeling.
 - › 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 common 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 day shift and a night shift). Shift changes take place at 7 a.m. and 7 p.m. You will be checked often by nursing staff throughout the day and night.
- At the start of each shift, your assigned nurse will check your vital signs (temperature, pulse, blood pressure, breathing), and weight. They will also look for any body changes and ask questions about how you are feeling. This helps your health care team 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 checked often for pain or other discomfort.
- Your nurse will 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 other staff who can help.
- Your nurse is responsible for giving you medications and blood products, and caring for your Hickman™ and I.V. 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, and give important information about many other parts of your blood. You may need more blood tests besides the one done in the early morning.
- Other tests may also be done to check your progress, like:
 - › X-rays
 - › Scans
 - › EKG
- Good hygiene is very important while your immune system is recovering. Many of the infections that can happen are caused by the germs that you already have in and on your body. **Washing your hands often is important, especially after using the washroom.** You may feel tired and not feel like moving around, but it is important to take care of yourself. If you are not able to bathe yourself or brush your own teeth/dentures, your nurse will help you. A Care Team Assistant (CTA) may sometimes help your nurse with your care.

Transplant day (Day 0)

- Your transplant is done in your hospital room 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 move into focusing on recovery.
- The actual stem cell transplant is a straightforward and relatively well tolerated procedure.
 - › You will be hooked up to a blood pressure cuff and an oxygen sensor will be placed on your finger. Before the transplant, your nurse may offer you medication to help with anxiety.
- The whole procedure usually takes up to 1 hour. Our goal is to give you the cells as quickly as you are able to tolerate.
- Most people tolerate the stem cell infusion well, but sometimes people have a reaction to their stem cells. You will be monitored closely by a nurse during the infusion. They will give you other medications, if needed.
- Some patients and their care partners find this day less exciting than they thought it would be. 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.

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 hurts.** Cleaning your mouth often helps 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 given 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 and spit.
 - › If you usually floss your teeth, keep gently flossing at least once a day.

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 to not cut the inside of your mouth 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 ¼ teaspoon salt.
- Once a week, soak your dentures in 100% white vinegar for 10 minutes, then rinse with water before wearing.

Fatigue (tiredness)

- It is not healthy to be in bed for 24 hours a day. This can cause your muscles and heart to weaken, and increase your risk of getting pneumonia (a type of 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 pages 37 and 38 for more information on fatigue.

Signs of an infection

- › Fever (temperature above 38 °C or 100.4 °F)
- › Chills
- › Shaking
- › Sweating
- › Feeling warm
- › Feeling sick
- › Coughing up mucus
- › Burning when you urinate (pee)
- › Red, tender areas on your body
- › Redness, swelling, pain, or discharge from any body opening (like your mouth, rectum, vagina, or penis)
- › **Discomfort, redness, or discharge from your Hickman™ line**

- **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 carries germs, most infections are caused by having too many of your own germs.
- 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 find out what is causing your infection. You will start taking 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 done again. 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 start taking medications to help prevent viral and fungal infections. You may need to take these medications for up to 1 year after your transplant.

Low red blood cells (called anemia)

- Red blood cells have hemoglobin in them. Hemoglobin carries oxygen from your lungs to all parts of your body. **When you have anemia, you have less hemoglobin to carry oxygen and will feel very tired.** You may have a headache or feel dizzy. You may have trouble breathing even when you are not that active. You may be given oxygen through a tube put 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 common to have many transfusions during your recovery.

Low platelets (called thrombocytopenia)

- **When your platelets are low, you are at a higher risk of bleeding.** You may bruise more easily, or have bleeding gums, nosebleeds, or blood in your pee or poop. Your pee and poop will be checked often for any signs of bleeding. Some people may be given medication to prevent bleeding from their periods. Tell your nurse if you see 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 go back to normal, 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 (like suppositories or enemas) or in your vagina.

Phase 3: Post-transplant phase

- The last phase of the transplant process starts after the stem cell infusion.
- Most people stay in the hospital for 4 to 6 weeks. This will depend on your conditioning plan and if you have any complications.
- While you are waiting for your new immune system to start working, we will treat the complications of the high dose chemotherapy.

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.
- 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.

Fatigue (tiredness)

- Some fatigue is common after a transplant. It may be caused by the chemotherapy and other medications, low blood cell counts, nutrition changes, being less active, or poor sleep.
- It is hard to push yourself to be active when you do not feel well, but people who move their bodies more usually have less fatigue.
- After your transplant, the way you feel (like pain, nausea, fatigue) and low blood counts may limit how much and what kind of activity you are able to do.

Post-transplant complications

Veno-occlusive disease of the liver (VOD)

- VOD can be caused by high dose chemotherapy. In VOD, the blood vessels of the liver become damaged. This causes the liver to not work properly.
- **VOD is serious and may cause death.**
- To help prevent VOD, you will be given a medication called ursodiol and your health care team will check you often. To check how well your liver is working, you will have blood work and your doctor will examine you.
- If you get VOD, you will be given a medication to treat it.

Cytomegalovirus (CMV)

- CMV is a common virus that does not cause problems in people with healthy immune systems. Since your immune system will be weak, we must test you and your donor for CMV before your transplant.
- Your CTPP coordinator will tell you if you are at risk for CMV.
- CMV can cause serious lung infection. If you or your donor has CMV, we will check you for CMV infection after your transplant.
- Once your white blood cell count starts to go up, you will have a blood test every 7 days until Day +100.
- If your tests results show that you have CMV:
 - › You will be treated with an I.V. medication called gancyclovir for several weeks.
 - › You may need to be admitted to the hospital for part of your treatment. The rest of your treatment may be done as an outpatient in the STU or at your home hospital.

Graft-versus-host disease

- Graft-versus-host disease (GVHD) is a condition that can happen when you receive stem cells or bone marrow from a donor.
- GVHD is when the donor's white blood cells attack your tissues. This usually happens after engraftment (see page 18).
- There are 2 types of GVHD:
 - › **Acute:** Happens between engraftment and Day +100
 - › **Chronic:** Happens after Day +100
- A small amount of GVHD may be helpful. As the donor's cells attack your tissues, they are also attacking any cancer cells that are left. This is called the **graft-versus-leukemia effect** or the **graft-versus-tumour effect**.

Symptoms of acute GVHD

- Your health care team will check you closely for symptoms of GVHD, while you are in the hospital and after you are discharged.
- Acute GVHD usually affects the:
 - › **Skin:** Check for redness (especially on the palms of your hands, the soles of your feet, or behind your ears), dryness, itching, tightness, or thickening of the skin.
 - › **Gastrointestinal (GI) tract:** You may have less appetite (not feel as hungry), trouble swallowing, nausea, vomiting, diarrhea that may be green or bloody, stomach cramps, or weight loss.
 - › **Liver:** You will have blood work to check how well your liver is working. It is important to also watch for jaundice (yellowing of the skin and white parts of the eyes).

Symptoms of chronic GVHD

- Your nurse practitioner (NP) and your doctor will check for chronic GVHD. The symptoms may be mild or severe (very bad). If your GVHD does not get better, you may need to be admitted to the hospital or take medication long-term.
- Chronic GVHD can affect any organ in your body.
- Chronic GVHD usually affects the:
 - › **Skin:** Check for redness (especially on the palms of your hands, the soles of your feet, or behind your ears), dryness, itching, tightness, or thickening of the skin.

- › Eyes: Your eyes may be dry, irritated, burning, itchy, or sensitive to light.
- › Mouth: Check for dryness, redness, white patches, sores, or taste changes.
- › Lungs: You may have trouble breathing or fatigue that is getting worse, or while doing an activity.
- › Vagina: Check for dryness, burning, itching, having infections often, or pain during sex.
- › Joints: You may have tenderness, stiffness, or tightness.

Important: Get medical help right away if you have any of these symptoms, especially if you have diarrhea you cannot control (cannot get to the bathroom in time).

- You may need to be admitted to the hospital if your GVHD causes complications.

To prevent GVHD:

- While you are an inpatient, you will be given medication to help prevent GVHD:
 - › Tacrolimus and mycophenolate
 - or**
 - › Cyclosporin
- These medications can be taken by mouth, or by I.V. if you are having trouble swallowing.
- Your pharmacists and nurses will teach you about these medications shortly after you are admitted to the hospital. You will take your medication until at least Day +100.
- If you do not have GVHD, your NP or your doctor will slowly stop the medication. If you develop GVHD, you will start taking the medication again.
- Depending on your conditioning treatment, you may also be given I.V. medication to help prevent GVHD:
 - › Post-transplant cyclophosphamide: chemotherapy given on Day +3 and Day +4. This medication can be hard on your kidneys and bladder. You will get lots of I.V. fluids to help with this.
 - › ATG (anti-thymocyte globulin): given on Day -2, Day -1, and Day +1
 - › Methotrexate: small dose chemotherapy given on certain days after your transplant (this will depend on your conditioning treatment and your condition)
- Your health care team will teach you about your medication.

Moving to the STU

When will I be moved to the outpatient unit?

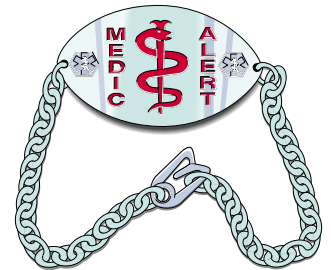
- Discharge day is different for everyone. The average hospital stay after a transplant is between 4 to 6 weeks. Your hospital stay may be longer, depending on the side effects and complications you have and how fast you recover. When you no longer need inpatient care, you will be cared for in the STU, an outpatient area.
- It is important to plan for your discharge when you are first admitted to the hospital. You will be given more information about your discharge and follow-up care closer to that time.
- You are responsible for the cost of any prescriptions given when you are discharged home. Only the cost of your anti-rejection drugs will be covered.
- After your transplant, you may be discharged when:
 - › Your blood cell counts (white blood cells, red blood cells, and platelets) have reached a certain level. You may still need outpatient blood or platelet transfusions.
 - › Your vital signs are stable enough for you to be monitored as an outpatient.
 - › Your appetite is getting better and you are able to drink enough fluids.
 - › You have enough strength and mobility (movement) to attend regular Clinic visits.
 - › You can take your medications by mouth (pill and/or liquid) and keep them down (not throw them up).
 - › You have a care partner 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, give you your medications, and other care as needed. See Appendix A on page 43 for more information.
- Even if your health care team feels that it is safe for you to be discharged and receive outpatient care, it is common for you and your care partners to feel anxious. As an inpatient, you have been closely monitored and cared for at all times. This can be an emotional time, as you become more responsible for your own care. It may help to talk with a member of your health care team.

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

- Being discharged from the hospital after a transplant can be both exciting and upsetting for you and your care partners. Most people have many thoughts and feelings (like fear, excitement, joy, relief, and nervousness). Your loved ones may feel overwhelmed with the responsibility of being your main care partner. They may worry that you are not ready for discharge.
- Although the health care team has decided that it is safe for you to be discharged and that you are ready to receive care as an outpatient, it is common for you and your care partners to feel unsure about leaving the unit. Until now, you have been closely cared for at all times. It can take time for you to get used to this, as you start to take more responsibility for your own care. You may find it helps to talk with a member of your health care team about this change.
- Most people find that once they start being cared for as an outpatient, they become more comfortable and start to see this as their stepping stone to going home. It helps to remember that you will still be checked often in the STU.
- Just thinking about going to the STU 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)

- We encourage you to wear a MedicAlert® bracelet or necklace after your transplant. This will help first responders give you the best care in an emergency. You can order a MedicAlert® ID online.
- Please include the following information:
 - › Any allergies you have
 - › HSCT (can only receive irradiated blood products)



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 STU 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 STU, but you will also be seen regularly in the Hematology Clinic. You will be monitored very closely and may have frequent follow-up visits, until Day +100 after your transplant. This will depend on your condition. Your next appointment will be given to you at your STU visits.

You may be concerned about:

- › Fatigue
- › Weakness or loss of strength
- › Mood changes (like feeling sad, depressed, overwhelmed, anxious, irritable, frustrated, or angry)
- › Being less able to concentrate, focus, or remember things (brain fog)
- › Changes in roles and relationships
- › Going back to work, school, or other activities
- › Learning to live with the unknown
- › Fear of getting sick again
- › Side effects of treatment
- › Money
- › Getting used 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
- › Becoming active again

Please tell your health care team if you are having these feelings as you get ready to be discharged. See pages 29 to 31 for more information about how you may feel after the transplant process.

STU

4th floor, Victoria Building
Victoria General site

Hours:

- › 7:30 a.m. to 5 p.m. (Monday to Friday)
- › 7:30 a.m. to 3:30 p.m. (weekends and holidays)
- Since everyone is different, it is not possible to know how long or how often you will need care in the STU. For most people, 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 STU 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 STU?

You will be checked by a nurse at every visit. This may include:

- › Physical and emotional assessment
- › Blood work
- › Review of blood test results
- › Talking with the doctor about your lab results and STU visits
- › I.V. medications, blood products, and fluids
- › Hickman™ line care
- › Patient and care partner teaching and support
- › Referrals to other health care providers, as needed

Before coming to the STU

If you will be late, or if you need to cancel or change your appointment:

- › Phone: **902-473-6038**

- Please arrive 10 minutes before your appointment time.
- Register for each visit at the STU 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 clothes and shoes.
- Please tell the STU staff ahead of time if a care partner 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 STU 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 STU.** There is bottled water in the STU kitchen and ice in the freezer. **Remember, do not drink tap water anywhere in the VG.**
- Your care partner is expected to bring you to your appointments, but can come and go while you are at the STU. **If your care partner cannot come with you, you may have to make other plans.**

What should I bring to my appointments in the STU?

- › A list of your medications
- › The medications you need to take during your stay in the STU
- › A list of any questions you or your care partners have
- › Items that may help you pass the time (like books, magazines, music, a craft project, or a laptop. Free Wi-Fi is available. Please bring your own headphones so you will not disturb others).
- **Do not bring any valuables (like jewelry, large amounts of cash, cheques, credit cards).**

Discharge from the STU

- When you are feeling better, your blood counts are stable, and you are able to drink 1.5 to 2 L of fluids each day and are eating well, you will be discharged from the STU. Your Hickman™ line is usually removed at this time. If you have been staying locally, you can go home.
- Once you are discharged, you will still have Hematology Clinic appointments, but not as often.
- You will be asked to have regular blood tests done in your community. These will be monitored by your nurse practitioner. It may take time for your blood counts to get back to a normal range. You will still have access to other team members (like social work) for support as you adjust.
- If you do not live in Nova Scotia, you will still need to return to Halifax for follow-up appointments.

Hematology Clinic

4th floor, Victoria General

Hours:

- › 8:30 a.m. to 4:30 p.m. (Monday to Thursday)
- › 8 a.m. to 4 p.m. (Fridays)
- After you are discharged from the inpatient unit, you will be checked often by a CTPP doctor and/or a CTPP NP in the Hematology Clinic. Your Clinic appointment will usually be coordinated with a STU appointment. Although most tests and procedures are done in the STU, some procedures are also done in the Hematology Clinic (like a bone marrow biopsy).

If you will be late, or if you need to cancel or change your appointment:

- › Phone: **902-473-6605**

- You will be followed by the CTPP for at least 6 years.

When should I call the doctor or nurse?

Although you will be checked often, 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, or wait until your next appointment.

Go to the nearest Emergency Department right away (do not wait for your next appointment) if you have any of these symptoms:

- Fever (temperature above 38 °C or 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, pee, and/or poop
- A Hickman™ line breaks or comes out
- New trouble breathing (with little or no activity)
- New wheezing
- A new rash or blisters
 - › This may mean that you have shingles. See Appendix E on page 53 for more information on shingles.
- Not able to pee

Call your primary health care provider (family doctor or nurse practitioner) in the next 24 hours if you have any of these symptoms:

- Flu-like symptoms (like sneezing, runny nose, and/or a new cough)
- Any new changes or trouble when peeing
- 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 when pooping
- New white patches or sores in your mouth
- Discharge from your vagina or penis
- Not able to take medications by mouth

If you are not able to reach your primary health care provider for urgent symptoms, 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 if you feel depressed, anxious, or nervous, or about any other changes in your mood or thoughts.

Going home

- Many transplant patients find the first months after a transplant full of changes. 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 care partners. Some people say that recovery during the first couple of months at home is the hardest work of their transplant experience. “One day at a time” seems to be the motto for a lot of transplant patients.
- Life after a transplant is different for each person and can change day to day. You may feel pressure that things should go 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 care partners 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 care partners 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.

- 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. This can be especially challenging when you leave the feeling of security that the hospital provides. It is common to have periods of feeling sad or low. As you adjust, you may have thoughts and questions like:
 - › Will I always feel like this?
 - › Will I ever get better?
 - › Nobody told me this part was going to be so hard.

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

- People 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 people 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 enough that I can lead a normal and full day.”
- Relationships may have changed through your 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 others may also need to readjust as you recover.

Going back to work

- Some people start to worry about when they can go back 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 had an allogeneic transplant are able to go back to some level of work and/or activities.
- You may find it helps to talk with other transplant patients who have gone through the process, or with a social worker who has worked with transplant patients.

Fear and worry

- It is common to be scared your disease will come back. Living with this fear can be very hard. For most people, these 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 Appendix F on page 54 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 F on page 54 for more 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 CTPP 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. Keep an up-to-date list of the medications you are taking and carry it with you. If your pharmacist has concerns about your prescriptions, have them contact your doctor.

- **Do not stop taking any medication without first talking to your CTPP 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 CTPP doctor, NP, or pharmacist about what to do.**

Lowering the risk of infection

- To prevent illness after your transplant:
 - › You will need to take a prolonged course of an anti-fungal medication to protect against 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).**
- Although your new bone marrow is working hard to meet the challenges of protecting you, your immune system will still be weak for about 1 year after transplant.
- Check your temperature if you feel hot or do not feel well. Because your new immune system is still getting stronger, 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/patient-education-resources/NSCCP0034

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 (like 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 *Tunneled (Hickman™) Catheter*:
 - › www.nshealth.ca/patient-education-resources/0214
- 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):
 - › www.nshealth.ca/patient-education-resources/NSCCP0036

Care partners 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 STU 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 52 for more information on contact with people who have received live vaccines.**

Public places

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

Sun exposure

Your skin is more sensitive after chemotherapy and transplant. Protect yourself 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 countertops as described in the *Safe Food Handling for Immunocompromised Individuals* booklet given to you by your health care team. See Appendix H on page 58 for more information.

- Wash your eating utensils well with hot water and soap.
- Wash face cloths and towels at least 2 times 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, be careful around your 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 CTTP doctor or NP says it is safe to do so.
- When your blood counts have recovered and you start to clean up after your pets, remember to wash your hands well afterwards.

Lifestyle changes

- Not smoking, eating healthy, and being active 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 I on page 60 for information on exercise as an outpatient and at home.

Healthy eating

- Try to follow Canada's Food Guide. It is important to handle food safely (see Appendix H on page 58). 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 (have an effect on) 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) who can help with this. There are programs and services available to help you.

Vaccinations after a transplant

High dose chemotherapy destroys the immunity you have built up over the years to diseases and viruses. After your conditioning treatment, you will need to get certain vaccinations to re-immunize you against certain viruses.

These vaccinations will start **6 months** after your transplant. Your CTTP NP will give you a vaccination schedule after discharge to make sure you get these vaccinations on time. Your primary health care provider may give you the vaccinations as needed. Your CTTP 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 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 troubling side effect of a transplant. It can interfere (get in the way) 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 strategies.

- Some people living with moderate to severe (bad) fatigue will work with a doctor from the Nova Scotia Health Cancer Care Program (NSHCCP) to add different strategies into their day, like:
 - › How to start adding exercise after cancer treatments
 - › How to pace and plan your day
 - › How to cope with your thoughts and feelings about being fatigued
- Ask your health care team if you would like help managing your fatigue.

Effects on your fertility, 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 (short-term) or permanent (long-term) 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 avoid getting pregnant after your transplant.**
- If you plan to have children, talk to your doctor **before** stopping birth control.
 - › For your safety and the safety of the fetus, wait at least 1 to 2 years after your last chemotherapy treatment, and only if 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, ask your doctor to do a sperm analysis test 1 year after your transplant.

- 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, you may be able 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 doctor 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, the chances are small. Having some spotting or a period does not always mean you can get pregnant. Sometimes your ovaries start making 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 your transplant is often 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.
- For some couples, the change in fertility can cause strain and tension in their relationship. A single person may question how this issue will have an effect on future 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 provider (like a social worker or a psychologist) to work through the grieving process, move forward in your relationships, and adjust to this information.

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 or desire and not want to have sex after a cancer diagnosis. Being interested in sex and having sex are often pushed to the side while patients and their partners deal with the work of treatment and recovery. You may find that you have too much on your mind, (like 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 sex. Fatigue can affect how you feel and your desire. 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, thinking about sex and wanting to have sex may start to come back. 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 affect getting or keeping an erection, having an orgasm, or ejaculating. 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 you to feel depressed or easily bothered. 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 during sex; they may have changes in arousal and orgasm, or may feel less or no interest in sex.

- GVHD can affect the lining of the vagina, which can cause pain, burning, irritation, and dryness. Scar tissue may develop, which can cause the vagina to narrow. This can make sex difficult or painful. This is called **vaginal stenosis**. A gynecologist (a doctor who specializes in reproductive health) can often help with treatment of vaginal stenosis.

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.
- Beating cancer and staying alive has been your priority as you recover. When 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.
- Communication is important. **Do not** assume your partner knows what you are thinking or feeling. Talk with your partner about:
 - › The changes to your relationship
 - › The changes to your sex life
 - › The changes in how you feel
 - › Ways you can be intimate again
- Some couples may need help to start talking about these things. Couples counselling can be helpful and is available. Ask your health care team how to access counselling resources.
- If your partner has given physical care to you, it can be hard for both of you to adjust and see each other in a sexual way.
- **Do not** underestimate affection and physical touch. Sometimes people are afraid to touch each other after all that has happened since the diagnosis.
- As time passes and life gets back to normal, the sexual part of living usually does too. Be patient with yourself, this process can take weeks to months.

Safer sex

- If you are having sex soon after transplant, **it is important to shower or bathe before and after sex.**
- Use a condom if you are having sex while receiving chemotherapy, to avoid your partner from coming in contact with your body fluids. If you are masturbating, it is not as important to bathe.
- It is also important to have good mouth care before and after, for both you and your partner. Avoid oral sex and French kissing during this time.
- If you are using toys, make sure they are cleaned properly before and after each use. Use water-based lubricant (lube) to lessen any irritation or bleeding.
- If your platelet count is below 50, use a water-based lubricant during sex to prevent vaginal irritation.
- **Do not** have anal or rough sex until your blood counts are nearing normal. It is important to protect your skin, vagina, rectum, and the lining of your mouth from tears or injury during sex. Talk to your partner about this before having sex.
- 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 with the Nova Scotia Health 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 different concerns about changes to their sex life and starting new relationships. Talk with your health care team if you would like more support.

2SLGBTQIA+

- 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 with this part of your life.

Appendix A: Allogeneic Stem Cell Transplant Care Partner Guidelines

- While you are in Halifax for your stem cell transplant, you will need a care partner. **If you have not chosen a care partner, you will not be able to receive treatment.** This is because it would not be safe for you to have a transplant.
- A care partner is a responsible adult (18 years old or older) who can give you 24-hour support. This role may be shared by more than 1 person. We encourage you to have more than 1 person available to help, in case your primary care partner becomes sick or is not able to be with you.
- Your care partner plays an important role in helping you recover, both emotionally and physically. Although they are welcome at any time, they **must** be available when you are being treated as an outpatient.

If your care partner lives outside of Nova Scotia, or outside of Halifax:

- › They should plan to arrive at the hospital on the morning of your discharge. They must be with you for your discharge teaching. If possible, we suggest arriving 24 hours before your expected discharge.
- **Your care partner must be available 24 hours a day, 7 days a week for at least 100 days after your transplant.** This may be longer, depending on your recovery.

Roles and responsibilities

- Your care partners must:
 - › Check for a fever (temperature above 38 °C or 100.4 °F) and/or changes in your condition
 - › Check for signs of GVHD
 - › Help manage your medications (including picking up prescriptions and making sure you take your medications, especially immunosuppressants)
 - › Help prevent infections (like keeping your living area clean)
 - › Do household tasks and prepare meals (encourage you to eat and to drink at least 1.5 to 2 L a day)
 - › Drive you to and from appointments
 - › Stay with you during your appointments
 - › Encourage you to be independent, and to be more active as you regain your strength
 - › Give emotional support

If you or your care partner live more than 40 minutes away from the hospital:

- › Your care partner must stay with you at the lodge or at the hotel until your CTPP doctor or NP discharges you home.

- **Being a care partner is a very important role in the transplant process.** For this reason, your care partner will be asked to sign a document saying that they understand and are comfortable with these responsibilities.

Resources for care partners

Leukemia & Lymphoma Society of Canada®

- › www.llscanada.org

Canadian Cancer Society

- › <https://cancer.ca/en>

Cancer Connections, Canadian Cancer Society

- To register:
 - › Phone (toll-free): 1-888-939-3333

BMT Infonet

- › www.bmtinfonet.org/transplant-article/role-family-caregiver

Appendix B: Accommodations

Staying in Halifax

The following information is for patients who need help finding somewhere to stay during their transplant. These accommodations are:

- › Used by the hospital
- › Partly funded
- › Near the QE II sites

The arrangements and costs for this service is different based on which province you live in. If you plan to stay in one of these accommodations, your CTPP coordinator will book your stay before your stem cell collection appointment.

The Dr. Susan K. Roberts Lodge that Gives

5826 South Street, Halifax, NS

- › Phone: 902-420-1849
- The Lodge is located within walking distance of the hospital.
- Parking is free, but it is limited.
 - › If you do not get a parking spot, you can park in the hospital parking lot and ask the social worker for a half-price ticket.
- Free taxi service is provided by Casino Taxi from the Lodge to local hospitals.
 - › Phone: 902-429-6666
 - or**
 - › Phone: 902-425-6666
- If you live in Nova Scotia, there is no cost for the Lodge. Meals **are** included.
- If you live outside of Nova Scotia, please call your provincial liaison nurse:
 - › New Brunswick residents call (toll-free): 1-866-266-3311
 - › PEI residents call (toll-free): 1-866-232-3042
- There is free Wi-Fi. TVs are located in common rooms.

Point Pleasant Lodge

1121 South Park Street, Halifax, NS

- › Phone: 902-421-1599
- › Shuttle service is available (Casino Taxi)
- Point Pleasant Lodge has low-cost accommodations for patients and their care partners. It is within walking distance of the hospital.

- Parking is limited and there is a cost.
- Your accommodation costs are covered.
- Meals are **not** included. If you are from Nova Scotia, you will get meal vouchers to help with your meal costs.
- 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 arrival day to confirm your booking. If you do not call, your room may be booked by another patient.**
- If you miss a mealtime at either lodge, there is a cafeteria on the main floor of the VG.

Halifax Haven Guest Home

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

- › Phone: 902-421-1650
- › Shuttle service is available
- Halifax Haven Guest Home is a non-profit organization with accommodations for patients and their care partners.
- It is fully funded by contributions. The suggested donation is \$60 per night. Please talk about this with the manager, if needed.
- Some rooms have a shared bathroom.
- There are no TVs or electronics available, but you may bring your own electronic devices (like a tablet or a laptop). There is free wi-fi available.

Ronald McDonald House Halifax

1133 Tower Road, Halifax, NS

- › Phone: 902-429-4044
- For patients up to 19 years old 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 whose loved one 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 (Scotia Square), Halifax, NS

› Phone: 902-429-7410

Hotel Halifax

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 C: Parking

- The map below shows available parking at the QE II VG site. It may be hard to find a parking spot near the hospital. Ask your CTTTP 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 VG site for as long as needed. Please ask the CTTTP 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

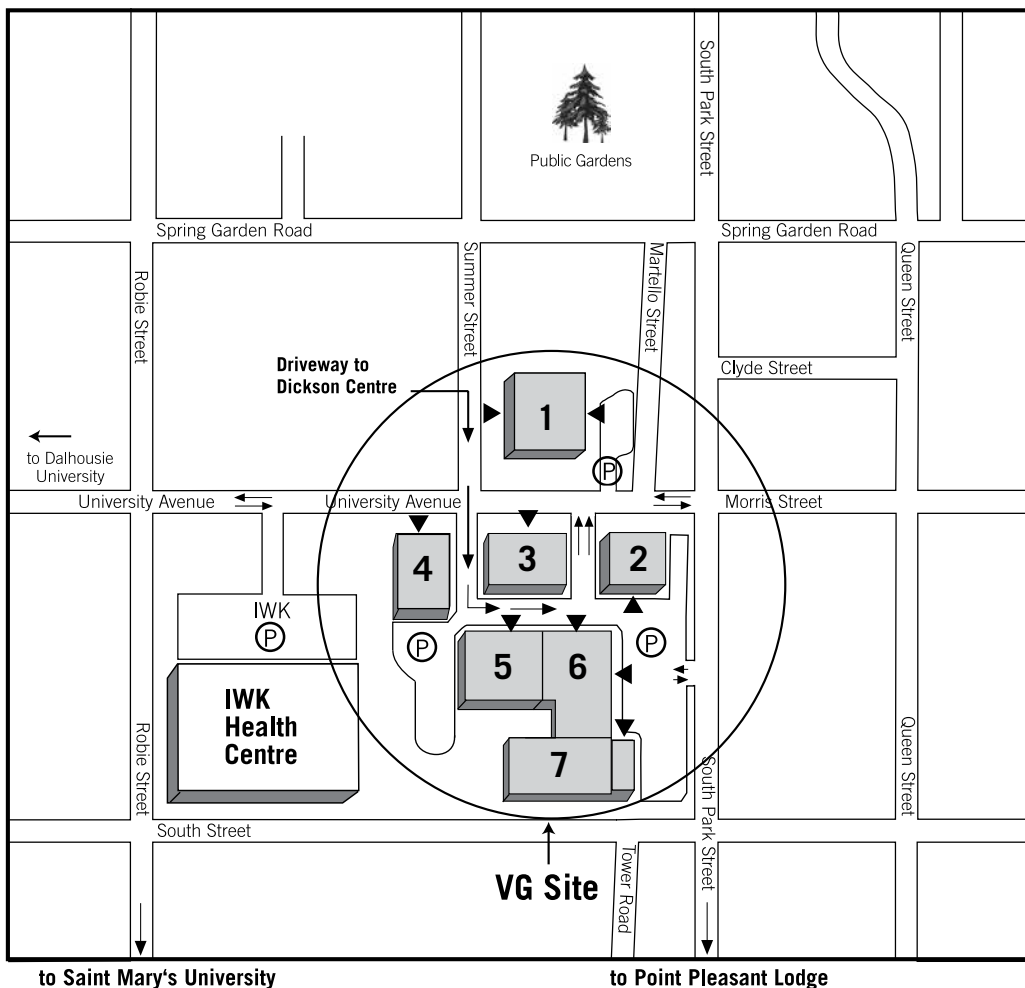
Queen Elizabeth II
Health Sciences Centre

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 products when you come to Nova Scotia Health.



Appendix D: CTPP Policies

Water rules

- Please ask your health care team to give you the pamphlet called *Water Rules*.
 - › www.nshealth.ca/patient-education-resources/0057
- There is bacteria in the water at the VG site that can cause a type of pneumonia in people 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 tap water to brush your teeth.
 - › **Do not** shower or bathe at the sink with the taps running.
 - › **Do not** use the tap water to wash fruits and vegetables. Use bottled water only.
- 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.

Visitors

- Visitors are welcome. We encourage you to talk to your nurse before visitors come to the unit. You may choose to limit the number or length of visits when you are not feeling well. Tell your nurse if you would like to limit visitors. They 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 a person who is not feeling well 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 it 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 I.V. pumps and blood pressure monitors. Please limit the number of personal electronic devices in the room.
- Visitors are **not** allowed to use your bathroom. This can spread germs. Ask your health care team where the nearest public washrooms are located.
- There is a small kitchen outside of the unit for visitors. It has a fridge and a microwave, and is stocked with coffee, tea, and light snacks.
- There is a washer and a dryer on the 7th floor for your care partner to wash any personal clothes you may have.

Children

- We strongly recommend that only children who are close to you 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 wash their hands well before entering the unit.
 - › go directly to your room with the child. The child should not touch walls or equipment, or come into contact with other patients.
 - › keep the child in your 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 the child does not use your washroom.
 - › take the child off of the unit if they need to have their diaper changed.

Coming into contact with people who have recently had a vaccination

- It is OK for you 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 (flu) vaccine (LAIV) for 14 days (2 weeks).
 - › avoid changing diapers of a child who has received the live rotavirus vaccine for 4 weeks (1 month).
 - › avoid contact with anyone who has blisters after receiving the live chickenpox or zoster vaccine until after their symptoms have gone away.
- After your engraftment, ask your CTTP team when it is OK to be in contact with people who have recently received the MMR (measles, mumps, rubella), varicella (including zoster), or yellow fever vaccines.
- After your transplant, you should not be in close contact with people who have received an oral (by mouth) 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 E: 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 1 area.
- You may or may not have a fever, and you may feel tired.
- Over time, a rash will appear. You will likely see raised, itchy spots. **Do not scratch.** Keep your fingernails short. These spots will turn to blisters, which will over time 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 primary health care provider 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 your symptoms.
- Shingles is treated with medication for viral infections (like acyclovir or valacyclovir). This medication may be given as pills or by I.V., depending on how bad the infection is.
- Usually, people do not need to be admitted to the hospital for treatment.
- The doctor will order pills to help control your pain, if needed. The pain will get better over the first week. Shingles can cause a lot of discomfort, pain, and irritation that can last for weeks.
- Placing a cool compress on the painful, itchy areas may help with discomfort.
- Wear loose, breathable clothes (like 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, washcloths, or clothes.
- When the blisters have dried and formed scabs, you are no longer contagious.
- If you think you may have shingles, **call the nurse before going to the STU, the Hematology Clinic, or other areas of the hospital.** You may have to wait to be cared for in a separate area.

**What are your questions?
Please ask. We are here to help you.**

Appendix F: Resources for Emotional Health

Support groups

- Support groups may be offered at the Cancer Centres in Halifax and Sydney, and in your local community. These groups may be held in person, through virtual care, or online.
- Some cancer support groups are for patients, and others are for the patient's loved ones.
- Groups may be led by:
 - › A health care provider
 - › Cancer patients and/or survivors
- Talk with the person leading the group to find out if the group is right for you. Try to find a group where you feel comfortable talking about what you think and feel.
- If you want to talk to someone who has had the same kind of cancer as you, contact the Canadian Cancer Society and ask to be matched with a Cancer Connection volunteer. They also have information about support groups in your area.
 - › www.cancerconnection.ca
 - › Phone (toll-free): 1-800-939-3333
 - › Email: cancerconnection@cancer.ca

Wellspring Cancer Support

- To see a list of free Well on the Web supportive programs and schedules, visit:
 - › <https://wellspring.ca/virtual-centre/>

Online support groups

The Leukemia & Lymphoma Society of Canada®

- For personalized support, visit:
 - › www.bloodcancers.ca/i-have-blood-cancer/how-we-can-help/access-one-one-personalized-support

or

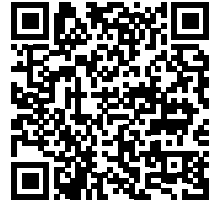
- › Scan the QR code on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears).



Other supports and services

Canadian Cancer Society: One-on-one online peer support program

- Phone (toll-free): 1-888-939-3333
 - › <https://cancerconnection.ca>
- To join the forum, you will need to register at:
 - › <https://cancerconnection.ca/s/login/SelfRegister>
- For other support services in your community:
 - › Phone (toll-free): 1-888-939-333
 - › <https://cancer.ca/en/living-with-cancer/how-we-can-help/community-services-locator>



Myeloma Canada

- › www.myelomacanada.ca

The Leukemia & Lymphoma Society of Canada®

- › www.bloodcancers.ca

Young Adult Cancer Canada

- › <https://youngadultcancer.ca>

Caregivers Nova Scotia

- › <https://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 Program and Services Responsible for Seniors Forum

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



Stand By Me: Lessons Learned from a Family Caregiver and Caregiving Scientist video - BMT Infonet

- › <https://bmtinfonet.org/video/stand-me-lessons-learned-family-caregiver-and-caregiving-scientist>



Appendix G: Healthy Eating

- People having a stem cell transplant have a higher risk of poor nutrition. This is often caused by their disease, and/or the side effects from their treatments. Getting enough calories and protein, and keeping your weight up, can help with your recovery. Let people help you. They could go to the grocery store or cook meals.
- If you have trouble eating enough food, try to eat more foods that are higher in calories and foods higher in protein:
 - › Add extra sauces, gravies, cream, butter, or margarine to your food.
 - › Try not to fill up with ‘light’ 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 have a snack every 2 hours.
 - › Keep quick snacks on hand. Try foods like cheese and crackers, fresh fruit, yogurt, puddings, and nutritional supplements.
 - › Make your meals more attractive. Try adding brightly coloured foods and garnishes.
 - › 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. Local catering companies may offer healthy, frozen meals.
 - › Cook large amounts of food when you feel better. Then you can freeze meals for times when you do not feel like cooking.
- If you are not eating solid foods, try to drink 6 to 8 cups of high calorie, high protein liquids each day, like whole milk, milkshakes, and nutritional supplements.

Appendix H: Safe Food Handling

Some foods have a risk of infection for people who have had a stem cell transplant. This is because of how they are made or stored.

While you are in the hospital

- In the hospital, food is prepared for you using safe food handling practices.
- Safe food handling practices come from Health Canada. They are listed in the booklet *Safe Food Handling for Immunocompromised Individuals*. You will get a copy of this booklet or you can visit:
 - › www.canada.ca/content/dam/hc-sc/documents/services/food-safety-vulnerable-populations/food-safety-vulnerable-populations/immune-immunitaire-eng.pdf



- This booklet includes lists of foods to avoid until:
 - › Day +100
 - › You are told otherwise
- 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.
- Ask for a referral to a dietitian if you have concerns or questions about nutrition, or visit:
 - › <https://food-guide.canada.ca/en/food-guide-snapshot/>

At home

It is important to follow safe food handling practices at home, since some foods have a risk of infection for people who have had a stem cell transplant. This is because of how they are made or stored. **Follow safe handling guidelines for at least 100 days after your transplant.**

Important:

- 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 on page 12 of *Safe Food Handling for Immunocompromised Individuals*) and check foods with a digital thermometer.
- Avoid high-risk foods, like non-dried deli meats, raw or unpasteurized dairy products, soft and semi-soft cheeses, raw hotdogs, patés and meat spreads, raw seafood, raw or undercooked meat or poultry, unpasteurized fruit juice and cider, and raw sprouts.

Appendix I: Exercise

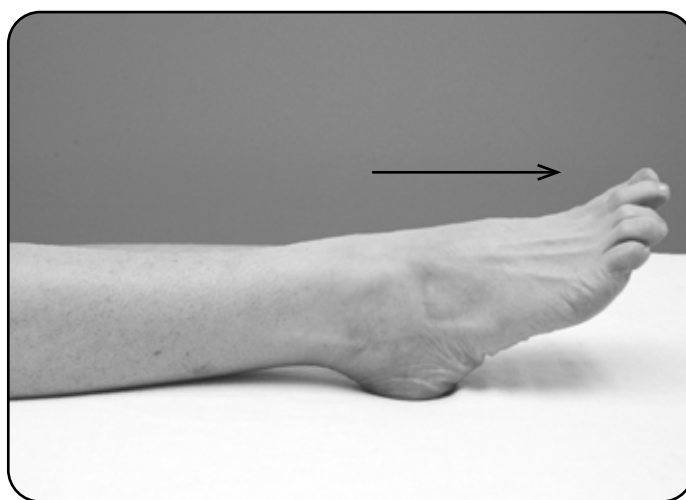
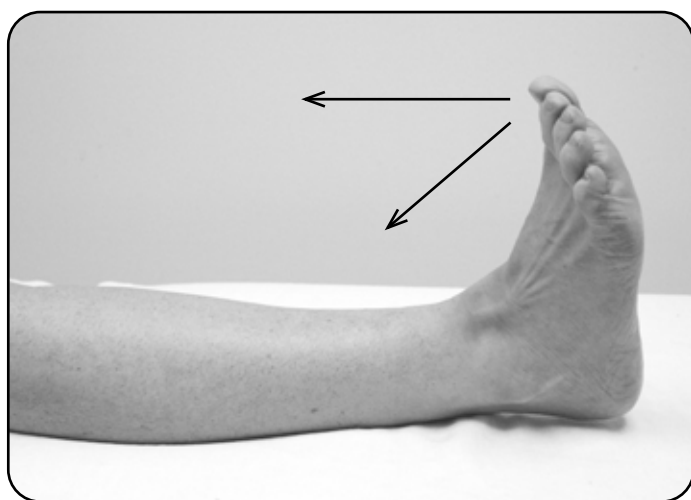
Physical activity as an inpatient

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.

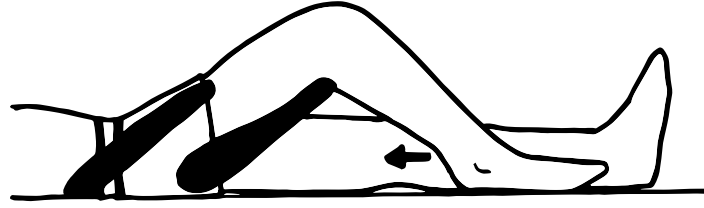
- Stay as active as you can.
- Do more over time.
- Try setting a goal of sitting up in your chair 3 times a day. Try to sit for 30 minutes (or more) each time.
 - › Just sitting at the edge of your bed will not give you the back or arm support you need. It can be more tiring than sitting in a chair.
- 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 your care partner or a staff member to help you.

Bed exercises

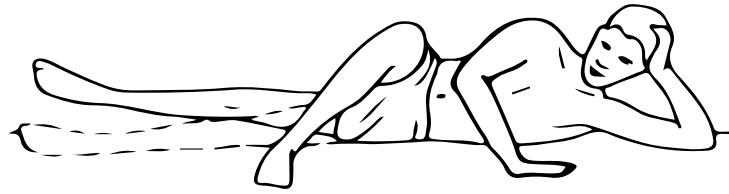
- Try doing these exercises on days when it is too hard to get out of bed. Remember not to hold your breath during these exercises.
 - Try to work up to doing each exercise 10 times, 2 to 3 times a day:
1. **Ankle pumping:** Point your toes down, then bring them back up.



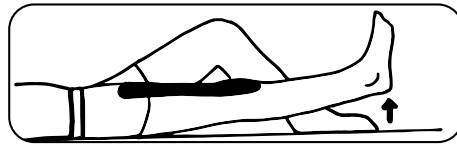
2. **Knee flexion:** Slide your heel towards your buttocks (bum). Keep your heel and buttocks on the bed. Hold for 5 seconds. Relax and repeat 10 times.



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.



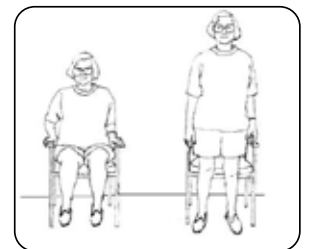
4. **Straight leg raise:** Lie on your back, with your right leg straight and your left knee bent. Keep your left foot flat on the bed. Lift your right leg while keeping it as straight as possible, about 6 inches off of the bed. Hold for 5 seconds, then slowly lower your leg. Repeat with your other leg.



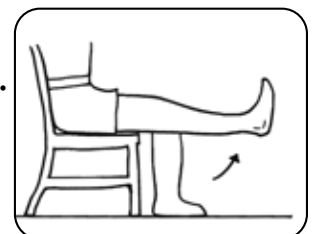
When you are out of bed

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 standing 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.

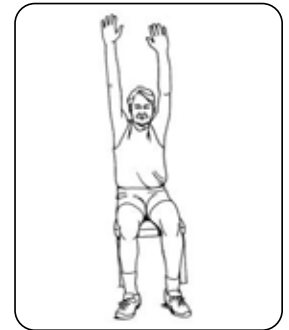


3. **Knee raises:** Sit in a chair with your back straight. Raise your right leg and bend your knee. Hold for 5 seconds, then lower your leg. Repeat with the other leg.



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 both arms straight up, then bring them back down.



Physical activity as an outpatient

- Moderate activity is described as being able to carry on a conversation while doing the activity, where you may be winded at times. Moderate exercise can improve tiredness, quality of life, and mood. It can also improve muscle strength, and strengthen your heart as you recover.

Cardio activity

- Cardio (endurance) activity makes your heart pump harder. It helps to strengthen your heart and lungs. It also improves blood circulation throughout your body.
- Choose a cardio activity that you enjoy doing, like brisk walking or cycling. Choose an activity that gets your heart rate up and **keeps it up**.
- Start slowly. At first, you may only be able to manage 2 or 3 minutes of slow walking. Some people start by walking around in their house for 2 minutes without stopping. Then they slowly increase to 3 minutes, then 4 minutes, 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 2 of your walks so that you are doing two 15-minute walks each day. From there, try for one 20-minute walk.

- **Remember to take breaks and do not push yourself so hard that you are exhausted for the rest of the day.**
- People with cancer can safely take part in moderate exercise during active treatment and after their treatment is finished. Try for 30 minutes of **moderate** cardio exercise 5 days a week. It may take weeks or months to reach this goal and that 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 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 2 to 3 times a week once you are doing cardio 4 or 5 times a week.
- **Do not start strenuous (hard) strengthening exercises until your platelets are above 50,000.** If you want to talk with a physiotherapist, ask for a referral from a CTPP team member.

Exercises after transplant

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

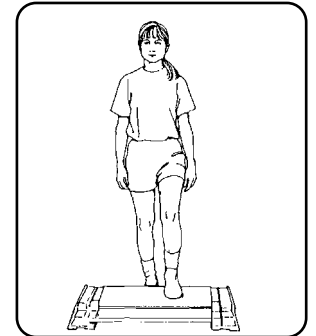
Warm-up

Start with a 5 to 10-minute warm-up, including easy movement. 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 (1 set). Over time, work up to 2 sets or more.



Step-ups: Stand in front of a step. Hold on to the rail as needed. Place 1 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 (1 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.



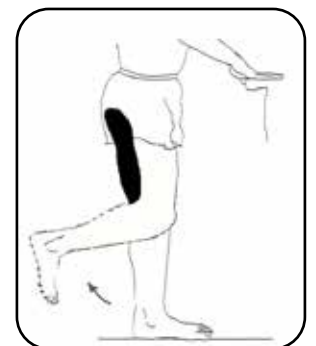
Standing hip and knee flexion: Stand up straight. Lift 1 knee upwards. **Do not** lean forward. Hold for 5 seconds. You should feel the muscle on the front of your hip working. Relax and repeat 10 times with each leg.



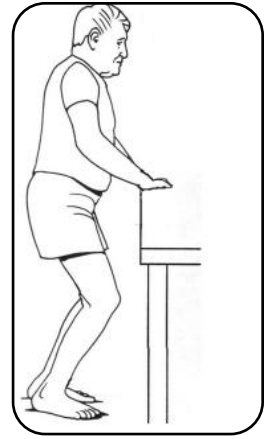
Standing hip abduction: Stand up straight. Lift 1 leg out towards the side. **Do not** lean to either side. Hold for 5 seconds. You should feel the muscles on the side of your thigh and hip working. Relax and repeat 10 times with each leg.



Standing knee flexion: Stand up straight. Bend 1 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 also feel a stretch on the front of your thigh. Relax and repeat 10 times with each leg.



Knee bends: Hold onto a counter for balance. Stand up straight. Place your feet shoulder-width apart. Bend your knees slightly, about $\frac{1}{4}$ 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.
- Stretch slowly and **do not bounce**. Hold each stretch for 30 seconds. Repeat each stretch 2 to 3 times.
- Remember: a stretch will feel like tension in your muscles, but it should not cause any pain.

Do these stretches after you exercise

Calves: You will feel this stretch in your calf muscles. Stand up straight, holding onto a chair for balance. Place one foot in front of the other. Keep your back leg 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 1 foot, holding onto 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 1 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 on the floor, so you can place your feet 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 1 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 for 20 to 30 seconds. Repeat 3 times. Repeat with the other foot.



It may help to talk with someone from the CTP team about an activity plan that is realistic for you.

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

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