

Chimeric Antigen Receptor T-Cell Therapy

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Chimeric Antigen Receptor T-Cell Therapy

This booklet is a guide to help you better understand Chimeric Antigen Receptor T-Cell Therapy (CAR T-Cell Therapy). We hope that the information in this guide will help you and your family through the treatment process. **Please bring this guide with you every time you come to the hospital.** We will review parts of it with you at certain times and may add information as needed, depending on your situation.

This is general information developed by the Nova Scotia Cell Therapy and Transplant Program (CTTP) and is not intended to replace the advice of a qualified healthcare provider. Please check with your coordinator or doctor if any information that has been provided to you is different and whenever you have questions.

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

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

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

ABOUT CAR T-CELL THERAPY

What is CAR T-Cell Therapy?

- CAR T-Cell Therapy is a type of immunotherapy, meaning it involves using your body's own immune system to treat the underlying disease.
- The goal of this procedure is to cure your blood cancer or keep it away as long as possible.
- T-cells from your peripheral blood (blood in your veins) are collected by a process called leukapheresis. This is an outpatient procedure that will be done in one day over 3-6 hours.
- After T-cells are collected, they will be sent to a lab that specializes in manufacturing CAR T-cells.
- Your T-cells will be genetically engineered to produce specific receptors called Chimeric Antigen Receptors (or CARs) that specifically target cancer cells in your body for destruction.
- Your genetically engineered T-cells will be grown in the lab, processed, and shipped back to the hospital that you will receive your CAR T-cell treatment.

What are T-cells?

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

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

T-cells are a type of white blood cell that attack virus infected cells, foreign cells, and cancer cells.

Phases of CAR T-Cell Therapy

The CAR T-Cell Therapy process has up to 7 phases:

1. Enrollment
2. Cell Collection, or Leukapheresis
3. Monitoring/Bridging Therapy
4. Chemotherapy, or Lymphodepletion
5. CAR T-Cell Infusion
6. Monitoring post-cell infusion
7. Long Term Follow-Up

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

ENROLLMENT

All patients will have tests done on their heart, lungs, and kidneys as part of confirming their enrollment into the program. These tests must be done before you proceed with the rest of the CAR T-Cell Therapy process. The booking clerk will arrange these tests for you. They may be done at a hospital close to your home, depending on where you live.

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

You will also be given a blood requisition for some bloodwork that is to be completed before starting leukapheresis.

T-CELL COLLECTION: LEUKAPHERESIS

- CAR T-cells are made from your own T-cells.
- Your blood is removed through your Hickman™ line. The Hickman™ line is attached to a tube that goes into a special machine that draws blood, separate the blood into its parts, pulls out the T-cells, and returns the rest of the blood back to you.
- This procedure is done by nurses with special training on the Apheresis Unit in the Medical Day Unit. This is on the 4th floor of the QEII, Victoria General site.
- This procedure takes 3-6 hours and is completed in one day.
- When the nurses have collected enough T-cells, your T-Cells are then processed by the Tissue Bank and then shipped to an external manufacturing lab, where your T-cells are genetically engineered into CAR T-cells.

When does T-cell collection start?

- Once your enrollment in the CAR T-Cell Therapy Program is confirmed, your CTPP Coordinator will arrange your cell collection with the Apheresis Unit. They will contact you with an appointment date.

Day of T-cell collection

- Avoid alcohol for 24 hours before your appointment. Alcohol may increase your risk for bleeding during the procedure.
- Report to the Apheresis/Medical Day Unit at 7 a.m. on the day of your scheduled collection.
- You may want to avoid drinking a lot of liquids on the morning of the collection. Once you are connected to the apheresis machine, you cannot be disconnected to go to the bathroom. If needed, the nurse will help you with a bedpan, commode chair, or urinal.
- You will rest on a hospital bed during your collection.
- A nurse will always be there when you are connected to the apheresis machine. A doctor or nurse practitioner is always close by.
- If you wish to have a support person stay with you during the procedure, please check with the Apheresis nursing staff as space is limited on the unit.

Will I feel any pain during the collection?

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

Are there any side effects from the collection?

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

How will I remember all of this?

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

Before your T-cell Collection

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

Social Work Assessment

- Your CTTTP coordinator will arrange for you to meet the CTTTP social worker. The social worker will ask questions to learn about you and your family. You will talk about the CAR T-Cell Therapy experience, how you are managing with the treatment 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 CAR T-Cell Therapy journey. You can ask any questions about family, work or school, income, and other social or emotional concerns you may have.
- The social worker may be able to help you find ways to manage some of the stresses and concerns that are a normal part of receiving this type of treatment.

Care Partner

- A care partner is a responsible adult who will come with you to and from the hospital and help you as needed outside of the hospital.
- You must have a care partner throughout the CAR T-Cell Therapy process. This includes when you are an outpatient before the CAR T-Cell infusion, as well as when you are discharged from the inpatient unit. Once you are settled in the outpatient area each day, your care partner may choose to leave and come back when your care is completed.
- The role can be shared by more than one person. You **MUST** arrange to have a care partner before you can be scheduled to proceed with the treatment plan. Plan for your care partner to be with you throughout all phases of the CAR T-Cell Therapy process. Once you are discharged from the inpatient unit, they must be able to stay with you in the Halifax area for at least 8 weeks after your cell infusion.
- A care partner can help you stay on track with taking your medications and checking your temperature. If you are feeling ill, they can help you connect with your doctor or health care team and help you get to the Emergency Department, if needed. They are an extra set of eyes and ears to help you take part in your follow-up care and assessment.
- More information on Care Partner Responsibilities can be found on page 20.

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

› Phone: 902-473-4072

Dental care

- It is very important to make sure your teeth and gums are healthy before you start the CAR T-Cell Therapy process. Our mouths naturally have many types of germs. When your immune system is damaged or weak, the germs that live in your mouth can cause serious problems like infection. Infections in the mouth can spread to other parts of the body. Your CTPP coordinator will arrange for you to see an oral surgeon.
- In addition, as soon as you know that your enrollment is confirmed, you must see your dentist for a cleaning and to have your mouth and teeth checked before you start the chemotherapy phase. Tell your dentist the type of cancer you have and that you will be having chemotherapy. Bring a list of the medications you currently take to your dental appointment.

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

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

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

- Ask a member of your care team 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).

Oral surgery care

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

MONITORING/BRIDGING THERAPY

CAR T-cell manufacturing may take 3 to 4 weeks. Your T-cells are shipped to a laboratory where they are genetically engineered to become CAR T-cells. These CAR T-cells are then expanded to make sure there are enough cells for your therapy. When this process is completed, they are frozen and shipped back to your treatment center in Nova Scotia.

- Bridging therapy is the use of supportive medications (like steroids), chemotherapy, and/or radiation to ensure you are well enough to receive your CAR T-cells when they arrive.
- You will be monitored very closely by your primary oncologist/hematologist. This phase may require frequent or routine bloodwork and imaging to monitor your disease status.
- The goals of bridging therapy are to:
 - a) Control your disease
 - b) Manage your symptoms
 - c) Optimize your performance status

You may not require any bridging therapy while your cells are being manufactured.

CHEMOTHERAPY: LYMPHODEPLETION

- Lymphodepletion is the word used for the chemotherapy you are given in the days right before CAR T-cell infusion.
- The chemotherapy that you will receive will decrease the number of immune cells in your body to make room for the new CAR T-cells to grow.
- The pharmacist and RN will give you information on the specific drugs you will be getting. We suggest you add this information (such as other pamphlets you may be given) to this guide. Your doctors, nurses, and pharmacists will review the drugs and common side effects of chemotherapy with you during your hospital stay.

Side effects of chemotherapy are described in Appendix A: Common Side Effects of Chemotherapy.

- You will get chemotherapy through your Hickman™ line. A nurse will give you this treatment in the Medical Day Unit. You will get medications to help with nausea (feeling sick to your stomach) before your chemotherapy. It is important to drink lots of fluids during this time.
- Your CTPP coordinator will tell you when to come to the MDU to start the lymphodepletion process. You will also see the CAR T-Cell Therapy nurse practitioner in the Hematology Clinic for an assessment before receiving chemotherapy.
 - › Each day of the lymphodepletion phase is numbered in a countdown until the day of your cell infusion. For example, the days leading up to your cell infusion will be referred to as Day -6, Day -5, Day -4, Day -3, Day -2, Day -1. CAR T-cell infusion day is Day 0.
- If you require lodging during this phase of the CAR T-cell Therapy process, notify your CTPP Coordinator to assist in making accommodation arrangements.

Please see Appendix C for information about the Medical Day Unit.

Admission to the Inpatient Unit

On the morning of your scheduled admission on Day -1, please call the inpatient unit to confirm the time your bed will be available before you leave your home.

- › Phone: 902-473-5173

Inpatient stay

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

What should I bring to the hospital?

- Comfortable clothes and pajamas
- Framed pictures or other small comfort items
- Pillow and comforter (optional)
- Your own tissues and toilet paper, as hospital brands can feel rough (optional)

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

CTTP Program Policies

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

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

Please read Appendix B before your hospital admission for more details on these policies.

Inpatient Health Care Team

- As an inpatient, you will be cared for by a team of health care professionals who have been trained to look after patients receiving cellular therapy. This team includes doctors, registered nurses (RN), pharmacists, a dietitian, a physiotherapist, an occupational therapist, a spiritual care giver, a social worker, and others. The inpatient CTPP team will assess you every day. There is always a doctor in the hospital to help with any care you may need.

Being Admitted and Inpatient Daily Routines

- When you are first admitted to the hospital, you will have assessments by both a nurse and a doctor. You will get information about the unit and what to expect over the coming days and weeks. Your nurse can help you to understand anything that is not clear. It is normal to have questions.

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

CAR T-CELL INFUSION DAY 0

- Your CAR T-cell infusion is done on Day 0 of the CAR T-cell Therapy process.
- You may feel happy but anxious and nervous about what things are going to be like over the next few weeks.
- The infusion phase is the shortest phase. The actual cell infusion takes no more than 30 minutes.
- You will be hooked up to a blood pressure machine and an oxygen sensor will be placed on your finger. Before the cell infusion, the nurse will give you medications to prevent a reaction that may be caused by the preservative that was used when freezing your T-cells.
- Your frozen cells will arrive from the tissue bank. The cells will be thawed at your bedside in a warm water bath, then infused right away through your Hickman™ line. The CAR T-cells are hung much like a blood or platelet transfusion.
- You will be carefully monitored by an RN and Doctor during the infusion. Reactions are rare. Some people will have chest tightness, chills, rashes, or a fast pulse. Reactions will be treated as needed.
- You may notice an unusual smell in the room, like creamed corn or garlic, for up to 24 hours. You may also have a strange taste in your mouth. This smell and taste are caused by the preservative used when freezing your stem cells. Sucking on a lollipop may help.

After Day 0

- We begin to count forward each day from Day 0 (Day +1, Day +2, etc.) to keep track of how far along you are from your infusion.
- Following the CAR T-cell infusion, you will be monitored very closely in the inpatient unit for toxic effects from the chemotherapy you received or CAR T-cells. Expect to be monitored closely for at least 2 weeks after cells are infused.

- The side effects of chemotherapy you may experience include fatigue, nausea, diarrhea, and sore mouth. You are at a higher risk for getting an infection as the chemotherapy would have weakened your immune system. It will be very important to monitor for signs of infection any time after you have received the chemotherapy in Medical Day Unit and while you are admitted to the inpatient unit (e.g., fever).

MONITORING POST-CELL INFUSION

Some toxic effects of CAR T-cell Therapy may occur during, or in the hours/days after infusion.

Cytokine Release Syndrome (CRS)

What is it?

- Cytokines are substances that are released by your immune system when your body is experiencing inflammation.
- The action of the CAR T-cells working to kill your cancer cells activates your immune system, releasing cytokines. This inflammatory process can be serious.

What are the signs and symptoms?

- You may feel like you have the flu, with high fever and/or chills.
- Other symptoms you may experience include low blood pressure, trouble breathing, confusion, nausea, vomiting, diarrhea, muscle or joint pain, dizziness, and headache. Symptoms can be mild to severe.
- In some cases, CRS may be life-threatening or fatal.

How is CRS prevented or treated?

- You will be monitored very closely by your healthcare team to help identify these symptoms.
- You may need oxygen, IV fluids, or medications to manage your symptoms.
- In some cases, you may receive a medication called tocilizumab. This drug helps reduce the effect of cytokines that are being released. Additional medications may also be used to help treat CRS.

Neurologic Toxicity

What is it?

- When CAR T-cells activate the immune system, this may alter the brain and neurological system temporarily causing neurology toxicity.

What are the signs and symptoms?

- Symptoms can include confusion, disorientation, extreme sleepiness, seizure-like activity or seizures, difficulty talking, or memory loss. In severe cases, you may lose consciousness.

How is neurologic toxicity treated?

- Your healthcare team will monitor you frequently during your inpatient stay after your cell infusion. They will ask you a series of questions that will assess your orientation, your ability to follow commands, and ability to write.
- You may receive medications that will help control these symptoms.

Other Side Effects of CAR T-Cell Therapy

Some side effects may be experienced days or weeks after the CAR T-cell infusion.

Tumor Lysis Syndrome

What is it?

- When CAR T-cells target and destroy cancer cells, the contents within these cancer cells are released into your bloodstream which may cause tumor lysis syndrome.

What are the signs and symptoms?

- You may experience problems with your kidneys, such as difficulty urinating or fluid retention. You may also experience chest pain, shortness of breath, swelling, or disorientation.

How is this treated?

- You will receive a medication called allopurinol to protect your kidneys.
- The electrolytes in your blood will be closely monitored. You may require electrolyte supplements through an IV or by mouth. You may require other medications to control the fluid and mineral imbalances.

B-cell Aplasia

What is it?

- Some cancers involve the B cells, such as lymphoma. B cells are a type of immune cell that participate in the fight against infection.
- The CAR T-cell Therapy you are receiving targets B-cell cancers, leading to a significant drop in those important immune cells.

What are the signs and symptoms?

- You may be more prone to developing infections.

How is it treated?

- A blood test may be done regularly to monitor your immunoglobulin level, which is an indicator of how many B-cells your body has.
- Depending on those levels, you may need to get an IV product called IV IG (immunoglobulin) to help support your immune system in fighting off infections.
- Monitoring of your immunoglobulin levels will continue with your outpatient care. If you require IVIG, this can be administered in the Medical Day Unit or your local day unit.

MOVING TO THE MEDICAL DAY UNIT (MDU)

When will I be moved to the Outpatient Unit?

- The discharge day is different for everyone. The average hospital stay is between 2-3 weeks. Your hospital stay may be longer, depending on the side effects and complications you have and how quickly you recover. When you no longer need inpatient care, you will be cared for in the Medical Day Unit (MDU), the same outpatient area where you received your chemotherapy.
- Preparing to be discharged from the hospital after receiving your CAR T-cell treatment can bring up a wide range of emotions. Although the health care team has determined that it is safe for you to

be discharged and that you are ready to receive care as an outpatient, it is normal for you and your family to feel hesitant about the leaving the inpatient unit. During this emotional transition time, you may find it helpful to talk with a member of your health care team.

You are getting ready for discharge when:

- Your white blood cell (WBC) counts are recovering. Your WBC counts may not have reached normal levels, but they must be steadily increasing. Your absolute neutrophil count (ANC) will usually be more than 500.
- Your blood product transfusions and IV medications can be given and managed in the MDU.
- Symptoms and side effects have improved, and you no longer need inpatient nursing care. Your appetite is getting better, and you can drink enough fluids.
- You can take your medications by mouth (pill and/or liquid) and keep them down.
- You are physically strong enough to travel to and from the hospital for appointments. When you are first discharged, you will need to visit the MDU every day. These visits may take several hours and can be tiring.
- You have a care partner (family member or friend) who can always stay with you for at least the first 8 weeks. Your care partner will help with travel to and from the outpatient unit, medication administration, and other care as needed.

KEY INPATIENT DISCHARGE INFORMATION

Before you leave the inpatient unit, please confirm:

- The unit has the correct contact information for you and your primary care partner
- You have your CAR T-Cell Therapy Patient Teaching Booklet
- You have the green CAR T-Cell Patient Alert Card
- You have the YESCARTA® Wallet Card
- You have a working thermometer
- You have your prescriptions and understand how to take your medications. Your nurse, doctor, and/or pharmacist may review this with you.
- You have your Medical Day Unit appointment and Hematology Clinic appointment with your CAR T-Cell doctor/nurse practitioner.

Important reminders:

- You must have a care partner stay with you for at least 8 weeks after your CAR T-Cell infusion. They may leave you for no longer than 2 hours at a time. They need to remain with you overnight. Your care partner may be the same person, or a group of people who take shifts.
- You must remain within 1 hour of travel time of the hospital for at least 4 weeks after your cell infusion. Your CAR T-Cell doctor/nurse practitioner may advise you to stay close by for longer than 4 weeks depending on your clinical needs.
- Check and write down your temperature if you don't feel well. **DO NOT TAKE TYLENOL® (acetaminophen), Advil® or Motrin® (ibuprofen), or Aspirin® or Aleve® (naproxen)** unless your doctor tells you it is ok. If you have a fever that is 38°C (100.40F) or higher call 911 or go to the nearest Emergency Department.
- **You must not drive, use machinery, or take part in activities that require alertness for at least 8 weeks after your cell infusion.** You need someone to provide your transportation. Your CAR T-Cell doctor/nurse practitioner may advise you to stay close by for longer than 8 weeks depending on your clinical status.

For each of your outpatient appointments at the Medical Day Unit and Hematology Clinic:

- Bring an up-to-date list of your medications so that the medical team can review this. This includes pills, creams/ointments, inhalers and any other type of medication you may use. Please also list any medications that you buy off the shelf from the pharmacy as well as any vitamins, natural health products or other supplements you may be taking.
- If you are running out of medication, please ask for a refill during your Hematology Clinic appointment.
- Notify your nurse or doctor/nurse practitioner if you are using alcohol, cannabis, or recreational drugs.

LONG TERM FOLLOW-UP CARE

Outpatient Care

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

- 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 (1 hour or more by car), you must stay near the hospital for outpatient care.**

If lodging is required upon discharge because you live 1 hour or more away from the hospital, notify the inpatient Discharge Coordinator or your nurse as soon as possible so that they can help make these arrangements.

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

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

Discharge from the MDU

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

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

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

What care is provided in the Hematology Clinic?

You will be assessed by the CAR T-cell nurse practitioner during your visits. This assessment includes assessing for late CRS and ICANs. You may talk with the CAR T-cell doctor and nurse practitioner about these assessments and lab findings during your clinic appointment. Referrals to other health care professionals may be arranged through the hematology clinic if needed.

Post-Cell Infusion (Day +100 to Day +130 checkup)

You may undergo PET scans around 1 month and 3 months post-cell infusion, but the timing and frequency of this scan is determined by your CAR T-cell Therapy doctor and nurse practitioner based on how you are doing. The purpose of the PET scan is to check how your CAR T-cells are working and how your disease has responded to the CAR T-cell treatment and assess for any complications.

Refer to Appendix C for information about the Medical Day Unit and Hematology Clinic.

When should I call my nurse or doctor?

Although you will be assessed regularly by your primary hematologist after Day +100, there may be times when you have new symptoms or concerns. You may wonder if you should tell someone right away or if you should tell someone in the next 24 hours (1 day) or if you should wait until your next appointment.

If you have any of the following, go directly to the nearest Emergency Department

(DO NOT WAIT FOR YOUR NEXT APPOINTMENT):

- A fever above 38° C/100.4° F (Reminder: Do not take Tylenol®). Remember to show your Yellow Fever Alert Card and Green CAR T-Cell Therapy Alert Card as soon as you arrive. You should also present the drug wallet card to inform Emergency Department staff of the type of CAR T-cell treatment you have received.
- New shivering and chills
- New bleeding that will not stop
- New bright red blood in your vomit, urine, and/or bowel movements (poop)
- A Hickman™ line breaks or comes out
- New shortness of breath (with little or no activity)
- New wheezing
- Not been able to pee
- New rash or blisters. This may mean that you have shingles.

See Appendix D for more information on shingles.

If you develop any other new symptoms, contact your primary health care provider within the next 24 hours. If you are not able to contact your primary health care provider and you feel like the situation is urgent, go to the nearest Emergency Department.

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

If you have non-urgent questions that are directly related to your CAR T-cell treatment, you may get in contact with the CAR T-cell Nurse Practitioner.

- › **Phone: 902-473-6605 (select the appropriate extension)**

GOING HOME

Fear and worry

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

Attending one of the education sessions about ongoing symptoms or the “Living Beyond Cancer” session may also help.

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

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 nurse practitioner.

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 medications or alternative therapies. We suggest you keep an up-to-date list of the medications you are taking and carry it with you. If your pharmacist has concerns about your prescription(s), ask them to contact your doctor.

Remember:

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

Lowering the risk of infection

It can be stressful and disappointing to tell people that they cannot visit because they are sick, or for you to miss an event because it involves being in a large crowd. But until your WBC is up, you need to protect yourself. Remember, most infections come from within your own body.

It is important to keep your body clean, especially your hands, mouth, genitals (vagina, penis), and rectal (bum) area. **It is important to stay away from people who are sick or have any type of infection (like the flu or a cold, an eye infection, a wound infection, etc.).**

Check your temperature if you feel hot or do not feel well. Because the CAR T-cells in your body are attacking both cancer and healthy B-cells, your immune system is not as strong. 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).

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

Handwashing

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

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

Hygiene

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

Mouth care

- Because infections can start in your mouth, it is very important to keep your mouth clean. Brush your teeth after every meal and at bedtime.
- While your blood counts are recovering, follow the instructions in Mouth Care During Cancer Treatment (ask your nurse for a copy).
› Link: <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/nscpp0036.pdf>

Family and visitors

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

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

During the CAR T-cell Therapy and post-cell infusion phases (up to Day +100 to +130), **stay away from (do not be in close contact with) anyone who has received any 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. Other live vaccines include measles, mumps, rubella (MMR); varicella (chickpox); zostavax II (shingles); influenza (nasal spray); and rotavirus.

Stay away from anyone who has been exposed to chicken pox. See Appendix B for more information on contact with people who have received live vaccines.

Public Places

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

Sun exposure

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

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

Home environment

- Keep your home free of dirt and dust as much as possible.
- Keep your bathroom and kitchen clean. Use disinfectant and rinse well.
- Clean cutting boards and kitchen surfaces as described in the Safe Food Handling for Immunocompromised Individuals booklet given to you by your health care team. See 'Safe food handling' section in Appendix G on page 35 for more information.
- Wash your eating utensils well with hot water and soap.
- Wash face cloths and towels at least twice a week.
- Wash sheets once a week in warm soapy water.

Plants

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

Pets

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

- Do not let pets lick your face.
- Always wash your hands after petting your pet.
- Have someone else clean up after your pets (like change the litter box, pick up dog poop, clean up your pet's vomit, clean a birdcage or a fishbowl) until 100 days after your cell infusion OR when your CAR T-cell Therapy doctor or nurse practitioner says it is safe to do so.

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

Lifestyle Changes

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

See Appendix H for information on physical activity as an outpatient and at home.

Healthy eating

In addition to following Canada's Food Guide, it is important to eat healthy foods and to handle food safely. Review the Safe Food Handling for Immunocompromised Individuals booklet provided by your health care team and information on safe food handling found in Appendix B.

During the CAR T-cell 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.

Eating tips can be found in Appendix G.

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

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

Alcohol

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

Smoking

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

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

programs and services available to help you.

Vaccinations After CAR T-Cell Therapy

Vaccinations are recommended for post-CAR T-cell patients. Your CAR T-cell doctor and/or nurse practitioner will talk about this with you.

See the recommended vaccination schedule in Appendix E.

ONGOING SIDE EFFECTS

Cancer-Related Fatigue

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

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 CAR T-cell Therapy, lasting for weeks or months. It can interfere with daily life more than any other side effect. It often interferes with a person's family, social life, work or school life, sex life, and overall quality of life. See page 23 for more information.

Managing cancer-related fatigue

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

Reproductive Health

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

For more information about the effects of CAR T-cell and childbearing, ask your CAR T-cell doctor or nurse practitioner.

Birth control

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

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

You may still have your period after CAR T-cell Therapy, but early menopause is likely. If you have spotting or have your period after CAR T-cell Therapy — this is your chance to try to get pregnant before menopause.

You should NOT try to get pregnant for 1 to 2 years after receiving chemotherapy. Discuss with your CAR T-cell team before trying to conceive. While there is always a chance you could get pregnant, if you are not getting your period or have no spotting at all during the month, it is highly unlikely. Having some spotting or a period does not always mean you can get pregnant. Sometimes your ovaries start producing some hormones but not enough to get pregnant.

Most premenopausal people going into CAR T-cell Therapy will go into menopause (called premature menopause) during the 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 CAR T-cell Therapy is often distressing and upsetting. There is often a great sense of loss at not being able to have children or have more children. Your family and friends may not recognize or acknowledge the loss and grief that you and your partner may experience because their focus is on the cancer and treatment. Many patients also find that there is so much to think about leading up to receiving their CAR T-cells that they do not focus on the reality of not having children until they are home and feeling a bit better.

You and, if applicable, your partner may grieve other losses related to not being able to have children. You may lose meaning in your life, lose your sense of self, or lose your future purpose. For some people, a change in fertility can cause strain and tension in their relationships and some people may question how this issue will impact possible 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 professional to work through the grieving process, move forward in your relationships, and adjust to this new reality.

If you have any further questions about fertility, you may choose to call the Atlantic Assisted Reproductive Therapies (AART).

› Phone: 902-404-8600

Sexual Health

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

Changes in sex and intimate relationships

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

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

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

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

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

Relationships

Going through the complicated process of CAR T-cell Therapy 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 CAR T-cell treatment.

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

Talk, talk, talk!

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

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

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

Safer sex

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

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

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

Getting help

There are health care providers in the Nova Scotia Cancer Care Program and in your community who can help and support you with sexual health and relationship changes. Talk with your doctor or a member of the CAR T-cell Therapy team if you have concerns or questions about sexual changes, starting new relationships, or need help communicating with your partner.

2SLGBTQIA+

Do not hesitate to speak up and ask your health care team about your concerns around sex and relationship challenges. This is a standard part of your care. Some online resources include:

- › Links: <https://www.rainbowhealthontario.ca/wp-content/uploads/2009/05/Cancer.pdf>
- › <https://www.lgbtcancer.ca/>
- › <https://queeringcancer.ca/>
- › <https://www.grsmontreal.com/en/home.html>

INFORMATION FOR THE CAR T-CELL CARE PARTNER

- Review the CAR T-Cell Patient Alert Card with the patient (“green” alert card)
- Attend the patient’s first consult appointment and all post-treatment clinic visits for about 3 months
- Be available by phone to provide the health care team with patient updates
- Advocate for the patient’s needs and help with decision-making
- Provide emotional and physical care
- Provide transportation for every clinic visit at least 8 weeks post cell infusion
- Stay with the patient all through the night and ensure that there are no more than 2-hour gaps during the day in which the patient is alone. The CAR T-Cell physician or nurse practitioner will advise you when this is no longer required.
- Help administer oral medication if required
- Monitor for signs and symptoms of infections and other complications (CRS and ICANS)
- Help record the patient’s temperature if the patient feels unwell
- Keep records of the patient’s symptoms and report them to the health care team
- Identify changes in the patient’s condition and obtain medical care
- Buy groceries and assist with household tasks
- Gatekeeping visitors
- Keep family and friends informed of the patient’s condition

Tips for the Care Partner

Call	If you are not sure what to do, call the cell therapy team.
Take	Take care of your own health, recognize when you are stressed and need help.
Write down	Write down questions and bring them to the clinic visits.
Find	Find a support system.

APPENDIX A

COMMON SIDE EFFECTS OF CHEMOTHERAPY

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

Sore Mouth (Mucositis)

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

How can I keep my mouth healthy during the treatment process?

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

- Brush your teeth, tongue, and gums after every meal and at bedtime.

Do not use the tap water during your hospital stay. Safe drinking water will be provided to you.

- Use an extra-soft toothbrush and brush gently with a fluoride toothpaste.
- Do not use a whitening toothpaste.
- If your toothpaste hurts or burns your mouth, try Sensodyne®, Colgate® PreviDent®, or Biotène®.
- Rinse your toothbrush well after each use and store it in a dry place.
- After brushing, rinse with salt water, then swish and spit.
- If you usually floss your teeth, keep gently flossing at least once a day.
- Be gentle, and brush and floss as well as you can.

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

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

If you wear dentures:

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

- Once a week, soak your dentures in 100% white vinegar for 10 minutes, then rinse with water before wearing.

Taste Changes

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

Nausea

- Chemotherapy may make you feel sick to your stomach or lead to vomiting (throwing up). Other medications that are part of your treatment may also cause nausea.
- If you feel sick even though you have taken anti-nausea medications, your health care team may add different or new medications to help with this nausea. These medications to treat nausea and vomiting may be taken regularly or you may take them just when they are needed. Your healthcare team will find a schedule that is best for you. To help lower your risk of nausea:
 - › Eat dry, bland foods.
 - › Eat and drink small amounts throughout the day instead of a lot at the same time.
 - › Avoid very hot and very cold foods.
 - › Practice relaxing and deep breathing.
 - › Sip fluids throughout the day and remain hydrated.
- 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 Appendix G on page 35 for tips on improving energy and adding more protein to your meals.

Diarrhea

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

Fatigue

- Some fatigue is normal with this treatment. It may be caused by the effect of chemotherapy and other medications, low blood cell counts, changes in diet and nutrition, being less active, or interrupted sleep. Fatigue may also have already been part of your cancer experience.
- It is hard to push yourself to do any activity when you do not feel well, but people who do some physical activity usually have less fatigue.

- After treatment, the way you feel (like pain, nausea, low blood counts) may limit how much and what kind of physical activity you are able to do. It is not healthy to be in bed for 24 hours a day. This will cause your muscles and heart to weaken and will increase your risk of getting pneumonia (lung infection) and blood clots. Your health care team will encourage you to go for walks, sit in a chair for meals, and practice deep breathing and coughing.

Your energy level will get better over time. See page 17 for more information on fatigue.

CHEMOTHERAPY EFFECTS ON BLOOD CELLS

The administration of chemotherapy in preparation for your cell infusion causes a decrease in the levels of some type of blood cells. The blood cells that are affected are your red blood cells, white blood cells, and/or platelets. Your bloodwork will be monitored closely after you receive your chemotherapy.

Low White Blood Cells (Neutropenia)

- White blood cells help protect you from infections caused by different types of bacteria and viruses. **Patients with low white blood cell counts are at a high risk of getting an infection.**
- You will be given medications to help prevent certain viral or fungal infections.
- Your white blood cell test will include a measure of your absolute neutrophil count (ANC). Because neutrophils are the first line of defense against infection, the lower your ANC, the higher your risk of getting an infection.
- You may have a fever while your ANC is at its lowest.
- 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.

Signs of an infection

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

Tell your nurse right away if you have any signs of an infection. Infections can happen at any time throughout the treatment process. Because everyone naturally carries germs in and on their bodies, most infections are caused by having too many of your own germs.

Tell your nurse right away if you have any other signs of infection such as:

- Redness, swelling, pain, or discharge from any body opening (like your mouth, rectum, vagina, or penis).
- Coughing up mucus, feeling burning or discomfort when you urinate (pee), or if you notice any red, tender areas on your body.
- **Discomfort, redness, or discharge from your Hickman™ line.**

If you have a fever:

- You will have a chest X-ray, urine tests, and blood tests to look for possible sources of infection. You will also be started on antibiotics right away. You may have a fever off and on for days, or even longer. A fever can make you feel exhausted. Your nurse and care partner will try to make you feel more comfortable. For example, a cool cloth on your forehead may help.
- If your fever does not go away, your blood tests will be repeated. Your antibiotics may be changed, and other medications may be added. Although infections can be serious, they can usually be controlled with antibiotics or other medications.
- Starting on Day 0, you will get medications to prevent bacterial, fungal, and viral infections. The pharmacist and/or nurse will review these medications with you.

Low Red Blood Cells (Anemia)

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

Low Platelets (Thrombocytopenia)

- Platelets are small pieces of cells that help to form clots to prevent bleeding. **When they are low, you are at a higher risk of bleeding.** You may notice that you bruise more easily, or have bleeding gums, nosebleeds, or blood in your pee or poop. Your pee and poop will be monitored for any signs of bleeding. Some patients may be given medication to prevent menstrual bleeding (periods). Let your nurse know if you notice any signs of bleeding.
- A low platelet count is treated with a platelet transfusion. Platelets are also given for any signs of bleeding. Platelets may take longer than other parts of your blood to return to normal levels, so it is common to have platelet transfusions regularly while in the hospital and later as an outpatient.

To prevent bleeding while your platelets are low:

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

APPENDIX B

CELL THERAPY TRANSPLANT PROGRAM POLICIES

Water rules

Please ask staff to give you the pamphlet called Water Rules. There is a bacteria in the water at the Victoria General Hospital that can cause a type of pneumonia in patients whose immune systems are not working well. This can happen if water droplets are inhaled (breathed in). Do not drink the tap water.

Do not use the water to brush your teeth.

Do not shower or bathe at the sink with the taps running.

You will get bottled water for drinking and brushing your teeth. Nursing staff will give you a basin with water for bathing. It is safe to wash your hands at the sink after using the toilet.

Safe food handling

Some foods have a risk of infection for immunocompromised patients. This is because of how they are made or stored. In the hospital, food is prepared for you using safe food handling practices.

Safe food handling practices come from Health Canada and are listed in the booklet Safe Food Handling for Immunocompromised Individuals. You will get a copy of this booklet. It includes lists of foods to avoid until you are told otherwise, and specifically for the first 100 days after your treatment.

All fresh fruits and vegetables brought in from outside the hospital must be washed with bottled water (not hospital tap water) unless they were already washed at home.

Visitors

Visitors are welcome. We encourage you to talk to your nurse about this before visitors come to the unit. You may choose to limit the number or length of visits when you are not feeling well. It is OK to tell visitors that you are not feeling good. Talk with your nurse if you would like to limit visitors. Your nurse can put a sign on your door asking visitors to check with staff before entering your room.

Visitors must wash their hands before entering your room. Handwashing is one of the most important things people can do to protect patients from infections. There are hand sanitizer stations along the inpatient hallways for visitors to use before entering the unit and patient rooms. There is also a handwashing station located outside of unit 8B.

People who are not feeling well must not visit. If the person must visit, they should wear a mask.

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

- There is a washer and dryer on the 7th floor for your care partner to wash any personal clothing you may have.

Children

We strongly recommend that only children who are close to the patient visit. Children are often exposed to colds, coughs, and other infections that healthy adults do not usually get. This can increase the risk of infection for all 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 always supervised by a visiting adult who will:

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

Coming in contact with people who have recently had vaccinations

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

- avoid close contact with anyone in your house who has received a live influenza vaccine (LAIV) for 2 weeks.
- avoid changing diapers of a child who has received the live rotavirus vaccine for 4 weeks.
- avoid contact with anyone who has developed blisters after receiving the live chickenpox or zoster vaccine until after their symptoms have gone away.

Discuss with the CTPP team when it is OK to be in contact with people who have recently received the MMR, varicella (including zoster vaccine), or yellow fever vaccines.

After your treatment, you should not be in close contact with people who have received an oral polio vaccine for at least 6 weeks. As Canada does not use oral polio vaccine (OPV), this should not be a common concern.

Flowers

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

APPENDIX C

MEDICAL DAY UNIT AND HEMATOLOGY CLINIC INFORMATION

Medical Day Unit

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

Hours of operation:

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

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

Before coming to the MDU

- Please call **902-473-5492** if you will be late or need to cancel or change your appointment.
- Please arrive 10 minutes before your appointment time.
- Register for each visit at the MDU registration desk across from the Victoria Building elevator on the 4th floor.
- Plan to be at your first appointment for at least an hour.
- Wear comfortable clothing and shoes.
- Please tell the MDU staff ahead of time if a support person will be joining you for your appointment.
- Your care partner is responsible for getting you to and from your appointments. Recovery takes time. **You must not drive for at least 8 weeks post CAR T-cell infusion.**
- The MDU has a kitchen with a microwave, a fridge, coffee, tea, and snacks.
- You will get a sandwich and drink at lunchtime. You can bring your own food and drink if you prefer.
- **Drink only bottled water and ice made from bottled water in the MDU.** There is bottled water in the MDU kitchen and ice in the freezer. **Remember, do not drink tap water while in the Victoria General Hospital.**

What care is provided in the MDU?

You will be assessed by an RN at every visit.

This may include:

- Physical and emotional assessment
- Blood sampling
- Review of blood test results
- IV medications, blood products, and fluids
- Hickman™ line care
- Patient and family teaching and support

What should I bring to my appointments in the MDU?

- A list of your medications

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

Hematology Clinic

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

Hours of operation:

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

APPENDIX D

SHINGLES

What is shingles?

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

What are the symptoms of shingles?

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

APPENDIX E

RECOMMENDED VACCINATION SCHEDULE

6 months after transplant	7 months after transplant	8 months after transplant	12 months after transplant	14 months after transplant	24 months after transplant
Pneumococcal conjugate 13 (Pneumovax® 23) Amount: 0.5 CC IM Date:	Pneumococcal conjugate 13 (Pneumovax® 23) Amount: 0.5 CC IM Date:	Pneumococcal conjugate 13 (Pneumovax® 23) Amount: 0.5 CC IM Date:			Pneumococcal Polysaccharide (Pneumovax® 23) ¹ Amount: 0.5 CC IM/SC Date:
DTaP-IPV-HiB (Pediactel®)* Date:		DTaP-IPV-HiB (Pediactel®)* Date:	DTaP-IPV-HiB (Pediactel®)* Date:		DTaP-IPV-HiB (Pediactel®)* Date:
			Hepatitis B (Engerix-B, Recombivax HB®) ² (double dose) Date:	Hepatitis B (Engerix-B, Recombivax HB®) (double dose) Date:	Hepatitis B (Engerix-B, Recombivax HB®) (double dose) Date:
Meningococcal (groups A, C, Y, and W-135) quadrivalent conjugate (Menactra®, Menveo) Amount: 0.5 CC IM Date:		Meningococcal (groups A, C, Y, and W-135) quadrivalent conjugate (Menactra®, Menveo) Amount: 0.5 CC IM Date:		Meningococcal (groups A, C, Y, and W-135) quadrivalent conjugate (Menactra®, Menveo) Amount: 0.5 CC IM Date:	
Influenza (flu) (after transplant and once a year) (Fluviral, Agriflu®) Amount: 0.5 CC IM ⁶ Date:					MMR (measles, mumps, rubella) ^{3 4} Amount: 0.5 CC SC (2 doses, 6 to 12 mos. apart) Date: Varicella (Varilrix) ^{3 4 5} Amount: 0.5 CC SC (2 doses, 2 mos. apart) Date:

*DTaP-IPV-HiB (Pediactel®) is not officially recommended for patients older than 7 years old. Your health care provider will tell you if you need this vaccine.

1. Repeat the dose in 5 years.
2. Six (6) months after your third dose of hepatitis B vaccine, your health care team will test for hepatitis B antibodies. Your health care team will decide if the vaccine needs to be repeated based on your test results. You will be tested again one (1) month after getting the second set of vaccines, if required.
NOTE: Nova Scotia's provincial health care plan (MSI) does not cover the cost of hepatitis A vaccine for people who have had a bone marrow transplant. You may get the hepatitis A vaccine with the hepatitis B vaccine as TWINRIX.
3. You cannot have a live, attenuated vaccine (like MMR or varicella) for 12 months (1 year) after transplant. This type of vaccine will only be given with the **approval of your hematologist** if: You do not have severe (very bad), chronic (on-going) graft-versus-host disease (cGVHD) **AND** you have not been taking any immunosuppressant medication(s) for 3 months. These vaccines can be given together or separately (at least 4 weeks [1 month] apart).
4. Your health care team will check to see if these vaccines need to be administered (given) by checking your antibody status 24 months (2 years) after your transplant. These vaccines are only given if: Your antibody status is seronegative, it is confirmed that you do not have graft-versus-host disease (GVHD), **AND** you are not taking any immunosuppressant medication(s).
5. You will be tested for the Varicella-Zoster virus (VZU) antibody one (1) month after getting your second Varilrix dose.
6. You may start getting a yearly flu shot (as needed) 3 months after your transplant. If you get a flu shot less than 6 months after your transplant, you will need a second dose 28 days later.
NOTE: Do not get FluMist®, as it is a live, attenuated vaccine.

APPENDIX F

EMOTIONAL SUPPORT RESOURCES

Support Groups

Living Beyond Cancer

Cancer Care Program education sessions have moved online. See our education resource for more information about how to access Living Beyond Cancer and other helpful patient education sessions.

- › Link: <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/nshccp4025.pdf>

Wellspring Nova Scotia

Wellspring Cancer Canada offers free Well on the Web supportive programs.

To see a list of these programs and schedules visit their website.

- › Link: <https://wellspring.ca/online-programs/>

Halifax area

Living Well with/after Leukemia & Lymphoma

Held on the last Tuesday of each month in room 138, 8B Centennial Building, QEII, VG site.

For more information contact Janice Spencer.

- › Phone: 902-473-4072

Multiple Myeloma

Held on the fourth Saturday of each month at the Larry Uteck Sobeys.

For more information contact Trish or Julie.

- › Phone: 902-678-9378

- › Phone: 902-462-8670

Online support groups

Cancer Chat Canada

This is a professional-led online support group for people affected by cancer. It is free for Canadians affected by cancer. Different groups run at different times.

To sign up for a group visit their website.

- › Link: cancerchat.desouzainstitute.com

Click on 'Sign Up' to identify what you are looking for in a group. You will be contacted when a group that fits your needs is scheduled.

Leukemia & Lymphoma Society of Canada®

This is a friendly forum to share experiences and chat with others about anything from initial diagnosis to treatment and survivorship. The chat sessions are moderated by an oncology social worker who gives support and guides conversation.

To access weekly online chats visit their website.

- › Link: llscanada.org/support/online-chats

Other supports and services

Canadian Cancer Society

To reach the one-to-one peer support program visit their website.

- › Link: cancerconnection.ca
- › Phone: 888-939-3333 (toll-free)

To join this online forum, you will need to register.

- › Link: cancerconnection.ca/registration

Call (toll-free) 1-888-939-333 To access a variety of other support services in your community visit their website.

- › Link: cancer.ca
- › Phone: 888-939-3333

Go to Support & services then click on 'Find services in your community'. Click on 'community services locator (CSL)'. Type in your city or postal code to see the services available in your community.

Lymphoma Canada

- › Link: www.lymphoma.ca

Leukemia & Lymphoma Society of Canada®

- › Link: www.llscanada.org

Young Adult Cancer Canada

- › Link: www.youngadultcancer.ca

Caregivers Nova Scotia

- › Link: www.caregiversns.org

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

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

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

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

Books

After You Ring the Bell...10 Challenges for the Cancer Survivor by Anne Katz (2012)

Picking up the Pieces: Moving Forward After Surviving Cancer by Sherri Magee and Kathy Scalzo (2007)

Life after Cancer in Adolescence and Young Adulthood: The Experience of Survivorship by Anne Grinyer (2009)

Feeling Good: The New Mood Therapy by David D. Burns (1999)

Chicken Soup for the Surviving Soul by Jack Canfield, Mark Victor Hansen, Patty Aubery, and Nancy Mitchell (1998)

Chicken Soup for the Cancer Survivor's Soul by Jack Canfield, Mark Victor Hansen, Patty Aubery, Nancy Mitchell and Beverly Kirkhart (1996)

Other recommended resources

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

APPENDIX G

EATING TIPS

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

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

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

APPENDIX H

PHYSICAL ACTIVITY

Physical activity while in hospital

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

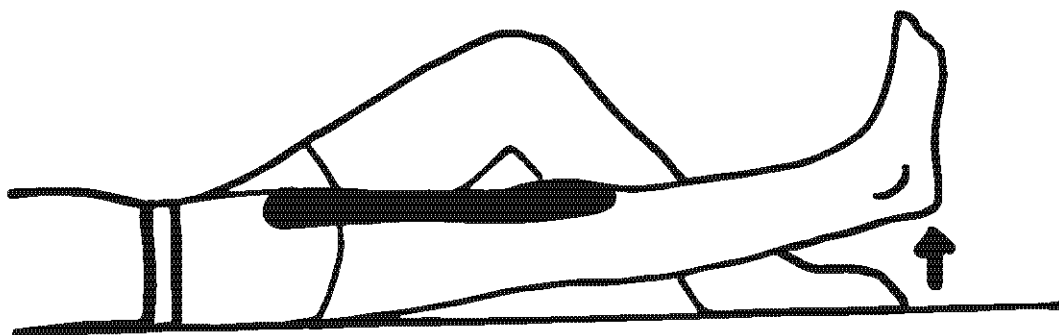
- Stay as active as you can.
- Do more physical activity over time.
- Try setting a goal of sitting up in your chair 3 times a day. Aim to sit for 30 minutes (or more) each time. Just sitting at the edge of your bed will not give you the back or arm support you need. It can be more tiring than sitting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

Bed exercises

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

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

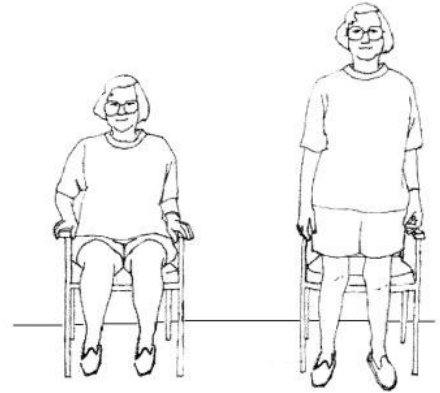
1. **Ankle pumping:** Point your toes down, then bring them back up.
2. **Knee flexion:** Slide your heel towards your buttocks (bum). Keep your heel and buttocks on the bed. Hold for 5 seconds. Relax and repeat 10 times.
3. **Hip abduction:** Slide your leg out to the side. Keep your toes pointed at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



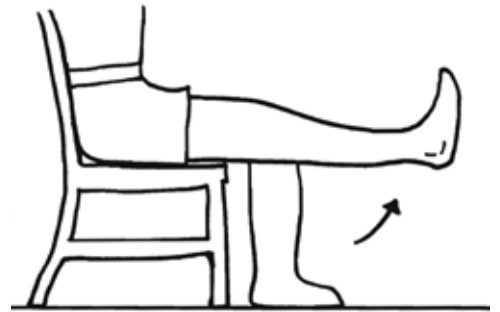
When you are out of bed

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

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



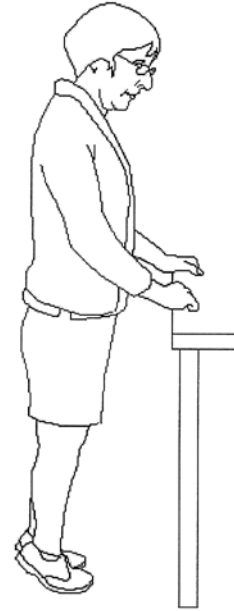
2. **Quadriceps:** Sit in a chair and slowly straighten your right leg. Hold for 5 seconds, then slowly lower. Repeat with your left leg.



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



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



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



Physical activity as an outpatient and at home

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

Cardio activity

- Cardio (endurance) activity makes your heart pump harder for a period of time. It helps to strengthen your heart and lungs. It also improves blood circulation throughout your body.
- Cardio activity can be something you enjoy doing, like brisk walking or cycling. Choose an activity that gets your heart rate up and **keeps it up**.
- Start out slowly. You may only be able to manage 2 or 3 minutes of slow walking as you start to recover. Some people start by walking around in their house for 2 minutes without stopping, then increase to 3, then 4, then 5 minutes. As you feel stronger, increase your activity 1 or 2 minutes each day. Once you feel strong enough, try walking outside and add a little more time each day or every few days.
- You can add to your activity level in different ways. For example, you can work up to three 10-minute walks each day. Over time, you can increase two of your walks so that you are doing two 15-minute walks each day. From there, aim for one 20-minute walk.

- Some people may be able to start their physical activity sooner, with more speed and strength, and for a longer period of time. Remember to take breaks and do not push yourself so hard that you are exhausted for the rest of the day.
- The Canadian Society of Exercise Physiology (CSEP) says that people with cancer can safely take part in moderate exercise during active treatment and after their treatment is finished. CSEP recommends 30 minutes of **moderate** cardio exercise 5 days a week. Moderate activity is described as being able to carry on a conversation while doing the activity, where you may be winded at times. It may take you weeks or months to reach this goal and this is OK. While your blood counts are low, try to exercise at home or outside so that you are not in close contact with other people.

Strengthening activity

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

Exercises after Cellular Therapy and Transplant

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

Warm-up

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

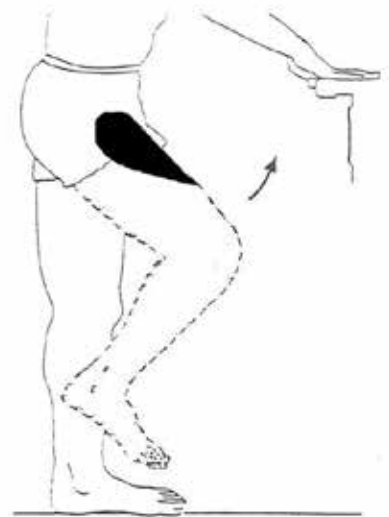
Bridging: Lie on your back with both knees bent and both feet flat on the bed. Push through your heels and raise your hips up off the bed. Do this 10 times (one set). Over time, work up to 2 sets or more.



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



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



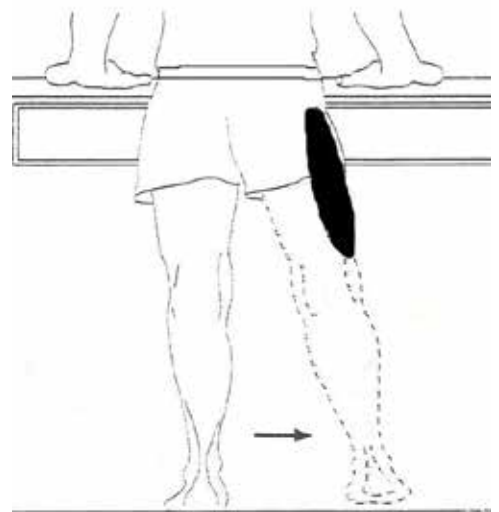
Standing hip abduction: Stand up straight. Lift your leg out towards the side. Do not lean to either side. Hold for 5 seconds. You should feel the muscles on the side of your thigh and hip working. Relax and repeat 10 times each leg.



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



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



Cool-down

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

Do these stretches after you exercise.

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

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



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

Or

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



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

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



APPENDIX I

PARKING

Below is a map of available parking at the QEII VG site. It may be hard to find a parking spot near the hospital. If you are an inpatient, speak with the social worker or inpatient charge nurse about half price parking vouchers.

As an outpatient, if you are required to visit the hospital for at least 2 weeks and require financial assistance for parking, the Medical Day Unit and Hematology Clinic can provide you with a form that you can bring Parking Services located on the main floor Centennial Building (by the service elevators) to obtain vouchers,

You may wish to get a temporary Nova Scotia motor vehicle accessibility parking permit. This will let you park in the accessible parking spots or the 2-hour parking spots at the Victoria General Hospital site for as long as needed. Please ask the CTP social worker or Access Nova Scotia about applying for this permit. Your doctor will need to sign the application. See the map on page 44.

QEII Health Sciences Centre Map

Victoria General Site

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

- Ⓟ Patient Parking
- ▶ Entrance Doors

Please do not wear scented product when you come to Nova Scotia Health locations.



to Saint Mary's University

to Point Pleasant Lodge

Patient and family feedback is very important to us.

We would like to invite you to send any comments or suggestions on how to improve this booklet to education.cancercare@nshealth.ca or feel free to call us at 1-866-599-2267.

Looking for more health information?

Find this brochure and all our patient resources here: <http://library.nshealth.ca/cancer>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Nova Scotia Health promotes a smoke-free, vape-free, and scent-free environment.

Please do not use perfumed products. Thank you!

Nova Scotia Health
www.nshealth.ca

Prepared by: Nova Scotia Cell Therapy and Transplant Program

Approved by: Nova Scotia Cancer Patient Education Committee

Designed by: Cancer Care Program Staff

The information in this brochure is for informational and educational purposes only.

The information is not intended to be and does not constitute health care or medical advice.

If you have any questions, please ask your health care provider. The information in this pamphlet is to be updated every 3 years or as needed.