

Chimeric Antigen Receptor T-Cell Therapy

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Chimeric Antigen Receptor T-Cell Therapy

Overview

This guide is designed to help you and your family understand CAR T-Cell therapy and what to expect during treatment. It provides general information and does not replace advice from your healthcare team. Always speak with your doctor or coordinator if you have questions.

Receiving a lot of information during this process can feel overwhelming. This is normal—please ask questions at any time. Your healthcare team is here to support you and involve you in decisions about your care.

What is CAR T-Cell Therapy?

CAR T-Cell therapy is a type of immunotherapy that uses your own immune system to fight cancer.

- Your T-Cells (a type of white blood cell) are collected from your blood.
- These cells are sent to a lab where they are modified to recognize and attack cancer cells.
- The modified cells (CAR T-Cells) are grown and returned to your body through an infusion.

The goal of treatment is to eliminate your cancer or keep it under control for as long as possible.

Understanding T-Cells

Your blood contains:

- White blood cells – fight infection.
- Red blood cells – carry oxygen.
- Platelets – help stop bleeding.

T-Cells are a type of white blood cell that help destroy infected or cancerous cells.

Preparing for Treatment

Medical Testing

Before treatment, you may need:

- Heart test (to check how well your heart pumps).
- Lung function test.
- Bloodwork.
- Possible imaging (such as PET scan).

Social Work Support

You will meet with a social worker who can help with:

- Emotional support.
- Planning and coping strategies.
- Financial or family concerns.

Dental Care

Healthy teeth and gums are important before treatment:

- Visit your dentist for a checkup if possible.
- Your Cell Therapy Transplant Program (CTTP) coordinator will arrange for you to see an oral surgeon before your treatment starts. There is no charge for this service.
- Follow recommendations from the oral surgeon.

Care Partner Requirement

You must have a care partner (a responsible adult) who will:

- Support you during treatment.
- Help with medications, appointments, and symptoms.
- Stay with you after discharge for at least 30 days (24 hours a day).

T-Cell Collection (Leukapheresis)

- CAR T-cells are made from your own T-cells.
- Your blood is removed by either an IV inserted in your arm or a special IV line called a vascath. Your CTTP coordinator will give you more instructions about this if it is needed.
- Your blood then goes into a special machine (called an apheresis machine) that draws blood, separates the blood into parts, pulls out the T-cells and then returns the rest of the blood back to you.
- This procedure is done by nurses with special training on the Apheresis Unit in Supportive Care Unit which is located on the 4th floor of the QEII Health Sciences Centre – Victoria General Site.
- This procedure will take 3-6 hours and is completed in 1 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.

During the Waiting Period

You may receive bridging therapy (e.g., chemotherapy, radiation or steroids) in order to:

- Control your disease.
- Manage symptoms.
- Maintain your health while cells are prepared.

Chemotherapy: Before CAR T-Cell Infusion (Lymphodepletion)

You will receive chemotherapy shortly before infusion to:

- Reduce your existing immune cells.
- Help the CAR T-Cells work more effectively.

The days leading up to your CAR T-Cell Infusion are counted as:

- Day -6, -5, -4 . . . leading to Day 0 (infusion day).
- Please see chart below for more details.

Day	-6	-5	-4	-3	-2	-1	0
Actions	Teaching	Fludarabine cycloPHOSPHAMIDE			Assessment Ambulatory	Admit to Inpatient	Car-T-Cell Infusion

CAR T-Cell Infusion (Day 0)

- The infusion typically takes less than 30 minutes.
- Given through your IV line.
- You are closely monitored during and after.

You may notice unusual taste or smell due to the cell preservation solution—this is normal.

After Infusion (Monitoring Phase)

You will be closely monitored in hospital for about 2 weeks to monitor for the following side effects.

Side Effects

Some toxic effects of CAR T-cell Therapy may occur during, or in the hours/days after infusion. This is a result of a rapid breakdown of cancer cells which release toxins into your blood stream.

You will be monitored by your cancer care team to help identify these symptoms.

EFFECT	SYMPTOMS	MANAGEMENT
Cytokine Release Syndrome (CRS) • Symptoms range from mild to severe. • Can sometimes be serious and need immediate attention/ transfer to ICU/etc.	• You may feel like you have the flu, with high fever and/or chills. • Low blood pressure • Trouble breathing • Confusion • Nausea • Vomiting • Diarrhea • Muscle or joint pain • Dizziness • Headache	• You may be given oxygen, IV fluids, or medications if needed to help manage symptoms.

EFFECT	SYMPTOMS	MANAGEMENT
Neurologic Toxicity - Symptoms range from mild to severe. - Can sometimes be serious and need immediate attention/transfer to ICU/etc.	- Confusion - Disorientation - Extreme sleepiness - Seizure-like activity or seizures - Difficulty talking - Memory loss - In severe cases, you may lose consciousness.	- Your healthcare team will monitor you closely (including a special assessment every 8 hours) during your inpatient stay after your cell infusion. - You may receive medications that will help control these symptoms.
Tumor Lysis Syndrome	- You may experience problems with your kidneys, such as difficulty urinating or fluid retention. - Chest pain - Shortness of breath - Swelling - Disorientation	- You will receive medications to protect your kidneys. - You may require electrolyte supplements through an IV or by mouth. - You may require medications to control fluid and mineral imbalances.

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.

EFFECT	SYMPTOMS	MANAGEMENT
Sore Mouth (Mucositis)	- Swelling, bleeding, sores or an infection in your mouth. - It may be painful to eat and/or drink.	- Brush your teeth, tongue, and gums after every meal and at bedtime. - Use an extra-soft toothbrush and brush gently with fluoride toothpaste. - Do not use 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.

EFFECT	SYMPTOMS	MANAGEMENT
Sore Mouth (Mucositis) (Con't)		• 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. • You will get fluids by IV to keep you from getting dehydrated. • Pain medication as needed to help keep you comfortable. • For more information on this side effect please read the NSH patient education pamphlet titled "Mouth Care During Cancer Treatment": https://www.nshealth.ca/patient-education-resources/NSHCCP4094

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

EFFECT	SYMPTOMS	MANAGEMENT
Nausea	• Feeling ill • Stomach sickness • Possible vomiting	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. • Your cancer care team may prescribe anti-nausea medications that can help. • For more information on this side effect please read the NSH patient education pamphlet titled “Nausea and Vomiting”: https://www.nshealth.ca/patient-education-resources/NSHCCP4086.
Taste Changes	• Food may taste 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.

EFFECT	SYMPTOMS	MANAGEMENT
Diarrhea	Loose, watery stools	- 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. - For more information on this side effect please read the NSH patient education pamphlet titled “Diarrhea”: https://www.nshealth.ca/patient-education-resources/NSHCCP4064

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.

EFFECT	SYMPTOMS	MANAGEMENT
Low White Blood Cells (Neutropenia)	- At greater risk of an infection when white blood cells low. - Signs of an infection include fever, chills, shaking, sweating	- You will be given medications to help prevent certain viral or fungal infections. - Be careful not to scratch or tear your skin. - For more information on this side effect please read the NSH patient education pamphlet titled “Neutropenia (Low White Blood Count)”: https://www.nshealth.ca/patient-education-resources/NSHCCP4092 - Contact your cancer care team immediately if you have a fever and any other listed symptoms of an infection.

EFFECT	SYMPTOMS	MANAGEMENT
Low Red Blood Cells (Anemia)	• Headache or feeling dizzy • Shortness of breath	• You may also receive a blood transfusion. • For more information on this side effect please read the NSH patient education pamphlet titled “Low Red Blood Cells/Anemia”: https://www.nshealth.ca/patient-education-resources/NSHCCP4080
Low Platelets (Thrombocytopenia)	• Bleed easily • Bruise easily • Bleeding gums or nosebleeds • Blood in pee or stool	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). • 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. • For more information on this side effect please read the NSH patient education pamphlet titled “Low Platelets/Thrombocytopenia”: https://www.nshealth.ca/patient-education-resources/nshccp4090

Discharge and Recovery

The typical hospital stay is 2-3 weeks, depending on your recovery.

After discharge, you will:

- Attend frequent outpatient appointments (Supportive Care Clinic, Clinic visits with a Nurse Practitioner).
- Stay near the hospital initially (within a 40–45 minute drive to the Hospital).
- Have a care partner with you.

Care Partner Role

Your care partner will:

- Monitor symptoms.
- Help with medications.
- Drive you to appointments.
- Provide emotional support.
- Stay with you for at least 30 days after infusion.

Important Safety Instructions

- Stay within 40-45 minute drive of the hospital for first few weeks
- Do not drive or operate machinery for at least 8 weeks
- Please go directly to your closest emergency department if you have:
 - › A fever that is greater than 38°C.
 - › Trouble or difficulty breathing.
 - › Bleeding.
 - › Confusion.

Follow-up Care

- Regular clinic visits and blood tests at the Supportive Care Unit.
- Scans to monitor treatment response.
- Care gradually transitions back to your primary hematologist (around Day 100).
- CAR T-Cell therapy is a complex treatment, but your healthcare team will guide you through each step. You are not expected to remember everything—ask questions whenever needed.

Long Term Side Effects

B-cell Aplasia

Some cancers involve 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.

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 IVIG (immunoglobulin) to help support your immune system in fighting off infections.

Monitoring your immunoglobulin levels will continue with your outpatient care. If you require IVIG, this can be administered at the Supportive Care Unit or your local day unit.

Cancer-Related Fatigue

Cancer-related fatigue is whole body tiredness or whole-body exhaustion. It is one of the most common side effects of cancer treatment.

For more information on this side effect please read the NSH patient education pamphlet titled “Managing Cancer-Related fatigue: <https://www.nshealth.ca/patient-education-resources/nshccp4030>

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

For more information on sexual health, please read the Canadian Cancer Society booklet titled Sex, Intimacy and Cancer: <https://cancer.ca/en/cancer-information/resources/publications/sex-intimacy-and-cancer>

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). Remain on birth control and if you plan on getting pregnant please talk to your health care team.

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.

Reproductive Health and Fertility

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.

If you have any further questions about fertility, you may choose to call the Atlantic Assisted Reproductive Therapies (AART) at 902-404-8600.

Care Partner Information

Why You Need a Care Partner

While you are in Halifax receiving CAR-T-Cell therapy, you must have a care partner. If you do not have one, it is not safe to continue with the transplant, and treatment cannot go ahead. Care partners are a key part of your care team.

What Is a Care Partner?

Your care partner is someone who helps support you during your recovery. They may be asked to sign a form to confirm they understand their role and responsibilities.

Your care partner must be:

- 18 years of age or older.
- Responsible and reliable.
- At the hospital on the morning you are discharged.
- Able to provide care 24 hours a day, 7 days a week.

Care Partner Time Commitment

- A care partner is needed for at least 30 days after treatment.
- This may be longer depending on your recovery.
- Care must be available 24 hours a day, 7 days a week.

Where You Stay After Discharge

- If accommodations are not already arranged, the discharge nurse can help to arrange this for you.
- You can return home when the doctor or nurse practitioner says it is safe.

Sharing the Role

- More than one person can share caregiving.
- It is best to have a backup care partner in case your main care partner needs help or support.

Care Partner Responsibilities

- Watch for fever or changes in your condition.
- Help with medications (including picking up prescriptions).
- Help prevent infection by keeping your space clean.
- Help with cooking and housekeeping.
- Encourage you to eat and drink (1.5–2 L per day).
- Drive you to appointments (you cannot drive for about 60 days).
- Go with you to your appointments.
- Encourage activity as you regain strength.
- Provide emotional support.

Tips for Care Partners

Call: Contact the care team if you are unsure what to do

Take care: Look after your own health and ask for help when needed

Write it down: Keep a list of questions for appointments

Find support: Build a support system for yourself

Helpful Resources

- Leukemia & Lymphoma Society of Canada: www.llscanada.org
- Canadian Cancer Society: www.cancer.ca
- Cancer Connections: Call 1-888-939-3333
- BMT Infonet: www.bmtinfonet.org

Going Home & Caring for Yourself

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 find your worry is taking up too much of your time and energy, this may be a good time to reach out for help.
- Talk with your primary health care provider about feelings of depression, anxiety, or nervousness, and any other changes in your mood or thoughts.

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 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.).

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.

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) which can be found here:

<https://www.nshealth.ca/patient-education-resources/NSHCCP4092>

Infection Risk

The chart below outlines things you can do to prevent infection.

TOPIC	DETAILS
Handwashing The best way to stop the spread of infection is to wash your hands.	- 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.
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) or follow this link: https://www.nshealth.ca/patient-education-resources/NSHCCP4094

TOPIC	DETAILS
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 PICC 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 PICC line dressing if it gets wet. Your nurse will show you how to do this. • 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 non-scented or gentle moisturizer to prevent dry skin and cracking.
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 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.
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. • Wear a mask if possible.

TOPIC	DETAILS
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 Supportive Care Unit or the 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 (chickenpox); zostavax II (shingles); influenza (nasal spray); and rotavirus. Stay away from anyone who has been exposed to chicken pox.

Overall Health Recommendations

TOPIC	DETAILS
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. • 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. • The Government of Canada has a book titled Safe Food Handling for Immunocompromised Individuals. You can view it online at download it by following this link: https://www.canada.ca/en/health-canada/services/publications/food-nutrition/safe-food-handling-immunocompromised-individuals.html. Your cancer care team can provide you with a hard copy of this booklet. • 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.

TOPIC	DETAILS
Lifestyle Changes	• Not smoking, eating a healthy diet 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. • For more information on quitting smoking, please read the NS Health patient education pamphlet titled “The Benefits of Quitting Smoking for People with Cancer”: https://www.nshealth.ca/patient-education-resources/NSCCP0067 • Feel free to visit the Tobacco Free Nova Scotia website at: https://tobaccofree.novascotia.ca/
Alcohol	• Alcohol can interact with your medications. Talk about this with your health care team.
Vaccinations	• Vaccinations are recommended for post CAR T-cell patients. Your doctor or nurse practitioner will talk about this with you. • All patients who have received CAR T-cell therapy are recommended to be revaccinated. Revaccination is important to rebuild the immune system and protect them against infections, which can be serious and potentially life-threatening. • The Cell Therapy and Transplant team have developed a Vaccination Schedule based on Public Health Guidelines. You will be provided with a vaccine schedule by your CTPP Nurse Practitioner after you are discharged from the hospital. • Revaccination is usually performed by your primary care provider. If you do not have a primary care provider, please let your CTPP nurse practitioner know. • Select pharmacies in Nova Scotia can provide revaccination services to patients who do not currently have a primary care provider and this can be arranged for you.

TOPIC	DETAILS
Healthy Eating	• 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. • Please follow guidelines outlined in the Canadian Food Guide: https://food-guide.canada.ca/en/. • The Canadian Cancer Society also has a booklet titled “Eating Well When You Have Cancer” that can be found on their publications section of their website: https://cancer.ca/en/cancer-information/resources/publications • For more information about this topic, please read the NS Health patient education pamphlet titled Healthy Eating: https://www.nshealth.ca/patient-education-resources/NSHCCP4083
Appetite Issues	• 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 work better than 3 big meals. Eating tips can be found in Appendix B. • 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.
Pets	• It is OK for pets to stay in your house as you recover. Because animals can pass on 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

TOPIC	DETAILS
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.

Units Section

Admission to Inpatient Unit (8AB, Centennial Bldg., VG)

- The Charge Nurse will call you to let you know what time to come to the unit on the morning of your scheduled admission (Day -1).
- You will be admitted to the 8th floor of the Centennial Building at the Victoria General Hospital.
- This is a hematology/oncology floor which consists of patients undergoing chemotherapy, along with CAR-T, Autologous and Allogeneic Stem Cell Transplants

What should I bring to the hospital?

You should bring the following:

- Comfortable clothes and pajamas.
- Framed pictures or other small comfort items.
- Pillow and comforter (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.

Inpatient Admission

- 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.
- There will be a nurse assigned to you 24/7 who will routinely check on you.
- Your nurse can help you to understand anything that is not clear. If you have any questions, please ask.

Inpatient Daily Routines

- Each day will consist of but not limited to, the following:
 - › Physical assessment at the beginning of each shift.
 - › Vitals, sometimes these are done every 4 hours throughout your admission.
 - › Bloodwork every day, usually around 4-5AM to ensure results are back early in the day.
 - › Maintaining good hygiene to help prevent infection (bathing, washing).

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 Supportive Care Unit.
- 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 Supportive Care Unit. 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 30 days. Your care partner will help with travel to and from the outpatient unit, medication administration, and other care as needed.

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 (this booklet).
- › You have the green CAR T-Cell Patient Alert Card.
- › You have the CAR-T Specific Wallet Card.
- › You have a working thermometer (If you don't have a thermometer and need help with the cost speak to your coordinator or social worker).
- › 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 Supportive Care Unit appointment and Hematology Clinic appointment dates / time scheduled.

Infection / Temperature

- 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 (100.40°F) or higher, go to the nearest Emergency Department.

Moving to the Supportive Care Unit / Outpatient (4th Floor, Victoria Bldg., VG)

When will I be moved to the Supportive Care 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 Supportive Care Unit, the same outpatient area where you received your chemotherapy.

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 Supportive Care Unit.

- 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 (40 minutes or more by car) you must stay near the hospital for outpatient care.

If lodging is required upon discharge, because you live 40 to 45 minutes 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 Supportive Care Unit but you will also be seen regularly in the Hematology Clinic by your Doctor / Nurse Practitioner. Your next appointment will be given to you at your Supportive Care Unit visits.

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

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 Supportive Care 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 PICC 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.
- 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.

- › 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 into 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.

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.

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 at 902-473-6605 (select the appropriate extension).

Supportive Care Unit

The Supportive Care Unit is located on the 4th floor of the Victoria Building at the VG Hospital.

Since everyone is different, it is not possible to know how long or how often you will need care in the Supportive Care Unit. 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 Supportive Care Unit appointment time will change but it may be 30 minutes to several hours, depending on the care you need.

What care is provided in the Supportive Care Unit?

You will be assessed by a registered nurse at every visit.

This may include:

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

Before coming to the Supportive Care Unit

- Please arrive 10 minutes before your appointment time.
- Plan to be at your first appointment for at least an hour.
- Register for each visit at the registration desk across from the Victoria Building elevator on the 4th floor.
- Please call 902-473-5492 if you will be late or need to cancel or change 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.
- Wear comfortable clothing and shoes.

What should I bring to my appointments in the Supportive Care Unit?

- A list of your medications.
- The medications you need to take during your time on the unit.
- A list of any questions you or your family members may 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 CTP 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).

Discharge from the Supportive Care Unit

- When you are feeling better, you can drink 1.5 to 2 L of fluids per day, and are eating well, you will be discharged from the Supportive Care Unit and able to go home. Your PICC line is usually removed at this time. Once discharged, your care shifts from the CAR T-Cell team back to your primary Hematologist.
- Your care will be transferred back to your hematologist around day 100. In some situations, care may be transferred sooner.
- Once discharged, you will still have Hematology Clinic appointments, but not as often. You will also be asked to have regular blood tests done in your community. It may take time for your blood counts to get back to a normal range. You will still have access to other team members for support as you adjust (like social work).

Hematology Clinic

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

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.

Although most tests and procedures are done in the Supportive Care Unit, some procedures are also done in the Hematology Clinic (such as a bone marrow biopsy).

If you are going to be late, or need to cancel or change your appointment, please call 902-473-6605.

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.
- Some appointments may be over the phone, but you may be asked to attend in person appointments as requested by the nurse practitioner or medical doctor.

For each of your outpatient appointments at the Supportive Care 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.

Supports and Resources Section

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 at

<https://www.bloodcancers.ca/i-have-blood-cancer/how-we-can-help/access-one-one-personalized-support>

Let's Chat CAR T

Link: <https://www.letschatcart.ca/en-ca/>

Lymphoma Canada

Link: www.lymphoma.ca

Support Groups

Living Beyond Cancer

The NS Health Cancer Care Program has a patient education pamphlet and video resource library that you can access by going to <https://www.nshealth.ca/patient-education-resources/NSHCCP4025>

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 at <https://wellspring.ca/online-programs/>.

Online support groups

Canadian Cancer Society – CancerConnection.ca

CancerConnection.ca is an online community through the Canadian Cancer Society. It helps people with cancer and cancer survivors, as well as their loved ones and caregivers, connect with others who know what they are going through.

You can visit their website at: <https://www.cancerconnection.ca/s/> or call 888-939-3333 (toll-free).

Other Support and Services

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: <https://www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Seniors/CaregiversGuide.pdf>

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.lgbtcancer.ca/>
- <https://queeringcancer.ca/>
- <https://www.grsmontreal.com/en/home.html>

Appendices Section

Appendix A

Cell Therapy Transplant Program Policies

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.
- 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.
- For more information on this topic, please read the NSH patient education pamphlet titled “Water Rules”: <https://www.nshealth.ca/patient-education-resources/0057>

Visitors

- Visitors are welcome. Before inviting visitors to the unit, please talk with your nurse. If you are not feeling well, you may choose to limit the number of visitors or shorten the length of visits. Anyone who is feeling unwell should not visit. If a visit is essential, the visitor should wear a mask.
- It is okay to let visitors know that you are not feeling up to a visit. If you would like help managing visitors, speak with your nurse. A sign can be placed on your door asking visitors to check with staff before entering your room.
- To help prevent the spread of infection, all visitors must clean their hands before entering your room. Hand sanitizer is located in the hallways throughout the unit.
- If you would like a care partner, family member, or friend to stay overnight, please speak with the nursing staff first. A cot can be provided; however, it must be folded and moved out of the way by 8:00 a.m. so staff have enough space to provide care, clean the room, and restock supplies.
- Visitors must not use the patient bathroom, as this can increase the risk of spreading germs. Staff can direct visitors to designated public washrooms.

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 that the child does not use the patient's washroom.
- Take the child off the unit if they need to have their diaper changed.

Contact with people who have recently had vaccinations

It is OK for 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 contact with anyone who has developed blisters after receiving the live chickenpox or zoster vaccine until after their symptoms have gone away.

Discuss with your care 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.

Appendix B

Eating Tips

Proper nutrition is an important part of cancer treatment and recovery. 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.

Different things you can do to help:

- 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.
- 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 by adding brightly colored foods and garnishes.

Safe food handling

- Health Canada has created a booklet that outlines safe food alternatives for immunocompromised people. You can read it by clicking on this link: <https://www.canada.ca/en/health-canada/services/publications/food-nutrition/safe-food-handling-immunocompromised-individuals.html> or you can ask hospital staff for a copy.
- This booklet 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.
- In the hospital, food is prepared for you using safe food handling practices outlined by Health Canada.

Healthy Eating Resources

- Canadian Food Guide: <https://www.canada.ca/en/health-canada/services/food-guide.html>
- Canadian Cancer Society booklet titled “Eating Well When You Have Cancer” : <https://cancer.ca/en/cancer-information/resources/publications/eating-well-when-you-have-cancer>
- Nova Scotia Health pamphlet titled “Healthy Eating”: <https://www.nshealth.ca/patient-education-resources/NSHCCP4083>

Appendix C

Physical Activity

You will be seen by a physiotherapist who will provide you with a mobility assessment and can provide you with small exercises you can do to help stay active.

Physical activity is very important to your health and recovery. 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.

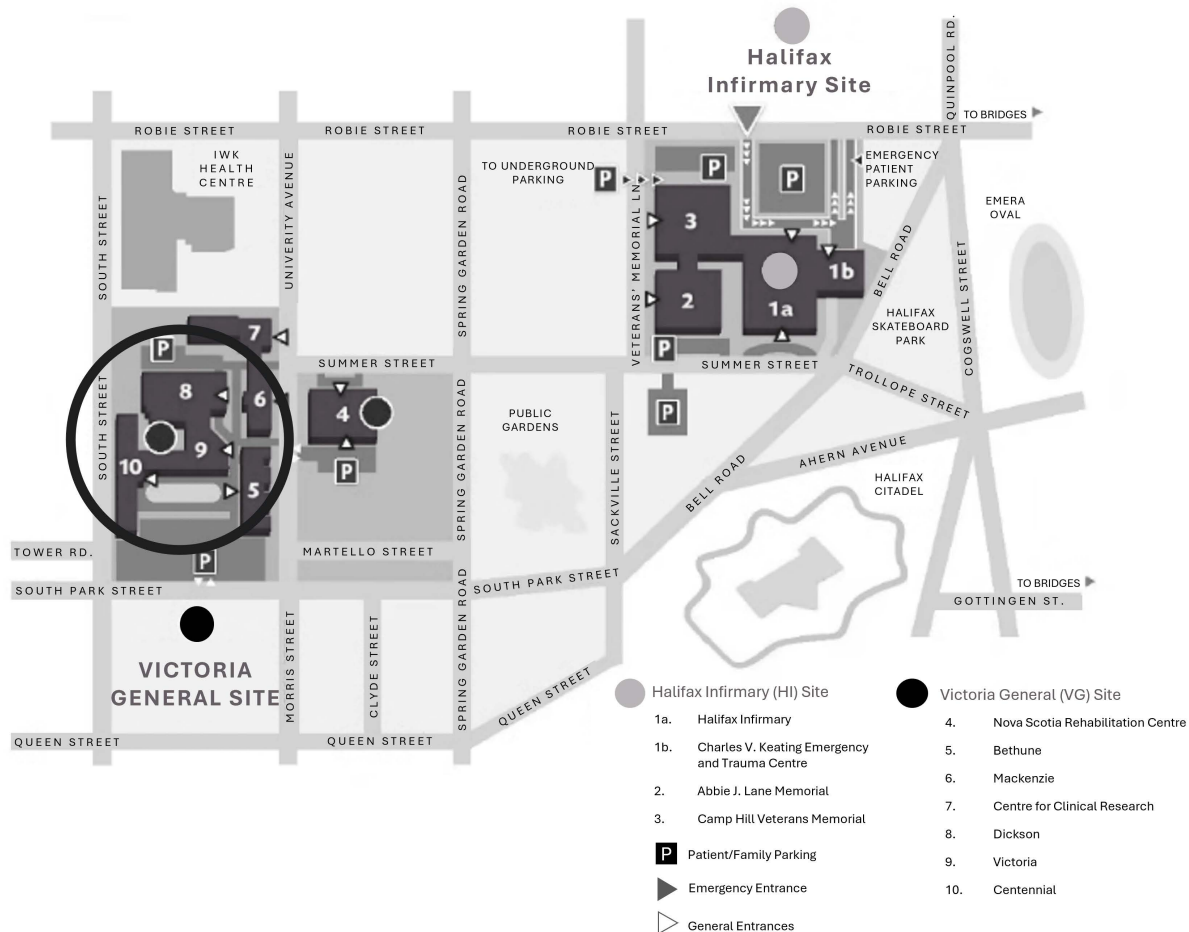
- Take deep breaths every hour while you are awake.
- If you are not steady on your feet, ask a family member or staff member to help you.

Physical Activity Resources

- An individualized exercise plan can be created for you with the help of our EXCEL Program through the (Physical Activity and Cancer) PAC Lab:
 - › <https://www.thepaclab.com/>
- Health and Wellness programs are also available; you can view by clicking this link:
 - › <https://cht.cdha.nshealth.ca/selectCourse.aspx>
- HealthyNS provides free online health and wellness classes plus one-on-one support for residents of Nova Scotia. You can view these classes by clicking here:
 - › <https://www.nshealth.ca/primary-care-and-family-medicine/healthy-ns>

Appendix D

- 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 CTPP social worker or Access Nova Scotia about applying for this permit. Your doctor will need to sign the application. See the map below.
- Please note that most (if not all) of your appointments will take place at the VG Site.



Throughout this resource there are links to other helpful documents that will give you more information about specific topics. Please visit <https://nscancerca.ca> to visit our patient education library.

If you have any questions or concerns regarding the information in this educational pamphlet, please discuss them with your healthcare team at your next appointment.



Access the patient education pamphlet library by going to :

www.nshealth.ca/cancerlibrary



Access our patient education video library by going to:

vimeo.com/showcase/cancereducation

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

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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.

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