

# Chimeric Antigen Receptor (CAR) T-Cell Therapy Handbook

Saskatchewan Stem Cell  
Transplant and Cellular Therapy  
Program (SCTCTP)



**Sask**  
**cancer**  
AGENCY

# CONTENTS

CONTACT INFORMATION .....	4
OTHER CAR T-CELL THERAPY PROGRAM TEAM MEMBERS .....	5
CAR T-CELL THERAPY BASICS .....	6
WHAT IS CAR T-CELL THERAPY? .....	6
TREATMENT TIMELINE .....	6
1. PLANNING FOR YOUR CAR T-CELL THERAPY .....	11
PERSONAL PREPARATIONS .....	6
2. CELL COLLECTION OR "APHERESIS" .....	6
3. CAR T-CELL MANUFACTURING .....	6
4. BRIDGING THERAPY .....	6
5. CAR T-CELL INFUSION .....	6
6. DISCHARGE FROM HOSPITAL .....	6
OUTPATIENT CARE .....	6
7. LONG TERM FOLLOW UP .....	6
RESOURCES .....	6
GLOSSARY .....	6

# CAR T-CELL THERAPY INFORMATION

## Welcome to the Stem Cell Transplant and Cellular Therapy Program

This binder will serve as a guide to help you better understand the CAR T-cell therapy process.

An important part of your preparation is to ensure that you have all the information you need to feel well informed.

This education binder will provide you with information about:

- Your health care team
- The purpose for CAR T-cell Therapy
- The tests and procedures you will have in preparation for your therapy
- The collection, preparation and infusion of your CAR T-cell product
- Resources for emotional and practical concerns
- Other useful resources

The amount of information in this guide may feel overwhelming. Go through it at your own pace and know that we are here to guide you along the way.

**Please bring this guide with you to all  
appointments**

# CONTACT INFORMATION

## **Saskatoon Cancer Centre**

(306) 655-2662  
20 Campus Drive  
Saskatoon, SK  
S7N 4H4

Regular Business Hours: Monday through Friday 8:00am to 4:30pm (excluding statutory holidays)

**Stem Cell Transplant & Cellular Therapy Program (SCTCTP) CAR T Physician** (Most Responsible Physician or MRP)

**Your CAR T physician is:** \_\_\_\_\_

SCTCTP or CAR T physicians are hematologists with specialized training in CAR T-cell therapy. A hematologist is a doctor who specializes in diagnosing and treating conditions that arise in the blood and blood-forming tissues including bone marrow.

**CAR T Nurse Practitioner (NP)** \_\_\_\_\_

Once you transition to an outpatient, the NP will be following you post CAR T in coordination with your physician.

**Outpatient Primary Care Nurse** \_\_\_\_\_ (306) 655- \_\_\_\_\_

Your Saskatoon Cancer Centre primary care nurse will follow you through your CAR-T journey. The outpatient nurses at the Cancer Clinic work together to provide good care for all patients.

**Cellular Therapy Coordinator** \_\_\_\_\_ (306) 655- \_\_\_\_\_

Responsible for organizing appointments, tests, education, and admission required for your cell infusion, as well as for organizing treatment schedules. The cellular therapy coordinator is your primary contact to help address questions and concerns.

**Social Worker** \_\_\_\_\_ (306) 655- \_\_\_\_\_

Your social worker is an important part of your health care team, and can assist with practical issues such as travel, accommodations and finances as well as emotional support to you and your family/caregivers.

**Clinic Assist** \_\_\_\_\_ (306) 655- \_\_\_\_\_

Call your clinic assist for information about appointment times or to request any appointment changes.

**Saskatoon Cancer Centre Pharmacy** (306) 655-2405

Call your pharmacist if you have questions about your medications or if you concerns about drug coverage.

***AFTER-HOURS & EMERGENCY CONTACTS:*****Hematologist On-Call****(306) 655-1000**

For urgent matters on weekdays after 4:30pm, weekends or statutory holidays call Royal University Hospital Switchboard and ask to page the Hematologist on call and they will call you back.

**Royal University Hospital****(306) 655-1000**

In case of emergency while in Saskatoon, please go to Royal University Hospital Emergency Room

**Out of Town Emergencies****911 or local hospital phone number**

In case of emergencies outside of Saskatoon, please visit your local emergency room.

## Other CAR T-Cell Therapy Program Team Members

**Clinical Associates**

Clinical associates are doctors who work in the field of hematology and cellular therapy. They work in close partnership with your CAR-T physician and manage your daily medical care needs during your hospital stay.

**SCTCTP/RUH Pharmacists**

SCTCTP/RUH pharmacists work directly with patients and their medical team and are responsible for providing patient specific drug information as well as for identifying, preventing and resolving medication related problems.

**Apheresis Nurses**

Apheresis nurses are specially trained registered nurses skilled in the collection ("apheresis") of immune effector cells.

**Transfusion Medicine Technologists**

Transfusion Medicine technologists are responsible for processing and freezing your T-cells following apheresis, and for thawing CAR-T cells at the bedside at time of infusion.

**Inpatient Registered Nurses**

The registered nurses on unit 6100 are skilled in CAR T-cell therapy and will care for you during your hospital stay. An inpatient nurse clinician may also be part of your inpatient care.

**Nurse Practitioners (NPs)**

Nurse practitioners are advanced practice registered nurses. NPs are trained to assess, order and interpret diagnostic and laboratory tests, and prescribe medications.

### **Clinical Trials Nurses**

Clinical trial nurses may contact you if there is a research study for which you may be eligible. Participation is voluntary.

### **Pharmacists**

Both cancer centre pharmacists and inpatient pharmacists will be involved in your care. They will provide you with education on your chemotherapy, help you manage side effects, answer medication-related questions, and assist with any concerns related to the cost of medications.

### **Dietitians**

Dietitians provide you with nutritional support during your hospital stay if you have any difficulty eating or any nutritional concerns. Upon discharge, dietitians in the Saskatoon Cancer Centre are also available for support as an outpatient.

### **Occupational Therapists**

Occupational therapists are part of the inpatient team who will follow you during your hospital stay. They help support you with maintaining basic activities of daily living, assist with energy management, and assist with access to equipment if needed.

### **Physiotherapists**

Physiotherapists are part of the inpatient team who will follow you during your hospital stay. A physiotherapist will see you once you are in hospital, and will design an activity program based on your individual needs.

### **Spiritual Care**

Spiritual care is available upon request to support and encourage you to draw upon your religious and spiritual strengths.

### **Caregivers**

Your caregiver is essential as they help with practical tasks such as helping you get to appointments, keeping track of medications, and helping with daily care. They, may also serve as an important source of communication between you and your health care team.

### **You**

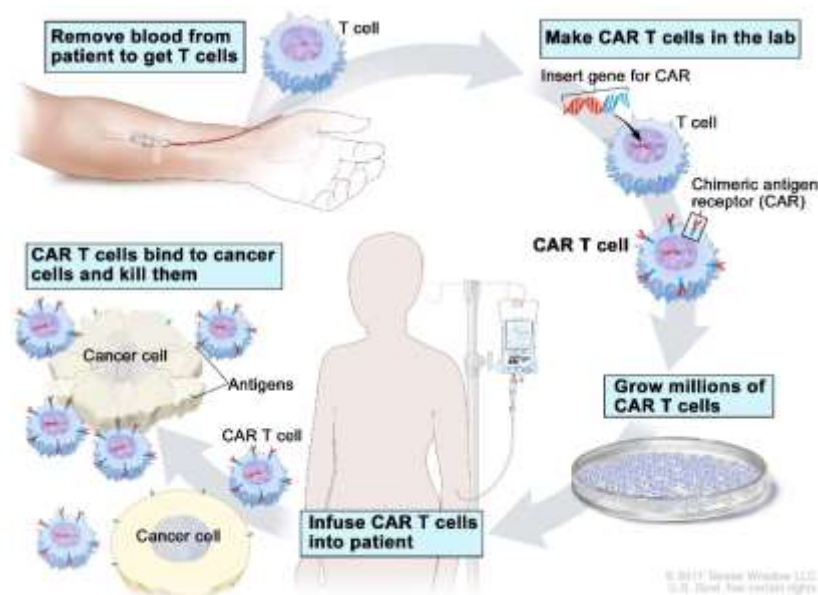
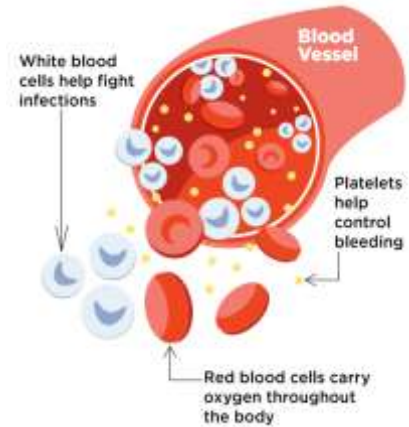
You are an essential part of the team. You will have the most vital role to play in your care and recovery. As you know yourself best, we depend on you to report how you are feeling and how the treatment is affecting you.



# CAR T-Cell Therapy Basics

## What is CAR T-cell Therapy?

The immune system is made up of specific cells and organs that protect your body from infection, disease, and cancer cells. T-cells are a type of white blood cell. Chimeric Antigen Receptor (CAR) T-cell therapy modifies your immune system activity to improve the body's own ability to fight certain cancers. The goal of this procedure is to cure your blood cancer or keep it away as long as possible.



CAR T-cell therapy changes some of your body's T-cells after they have been collected from your bloodstream.

- In a laboratory, your T-cells will be reprogrammed to produce special receptors called chimeric antigen receptors (CARs). The new T-cells are returned to your body through an intravenous catheter.
- The CARs that you are infused with will be designed specifically to fight your type of cancer.

Throughout this process, careful measures are in place to ensure your safety.



# CAR T-Cell Therapy Process

**1**

## Planning For Your Car T Therapy

This includes evaluation of response to previous treatment, testing to ensure major organs are healthy enough to withstand chemotherapy, arranging for a caregiver, organizing legal and financial affairs, and

**2**

## Cell Collection Or “Apheresis”

Collection of T-cells using a special machine.

**3**

## CAR T-Cell Manufacturing

Once the T-cells are collected, they are sent to the manufacturer to reprogram them into CAR T-cells that will fight your cancer. This process can take 3-4 weeks before the CAR T-cells are ready to be infused.

**4**

## Bridging Therapy

While waiting for your CAR T-cells to be manufactured, your doctor may prescribe therapies such as chemotherapy, immunotherapy, radiation, steroids, or other cancer-fighting drugs in an effort to control your disease prior to CAR T-cell therapy.

**5**

## Admission For Infusion

You will receive chemotherapy followed by the infusion of your CAR T-cell product as an inpatient. You will remain in hospital until your immune system recovers from the side effects.

**6**

## Discharge From Hospital

Once your blood counts have recovered, you have no active toxicities from the CAR T-cells, you are able to eat, drink and take pills by mouth, you will be discharged from hospital with detailed instructions.

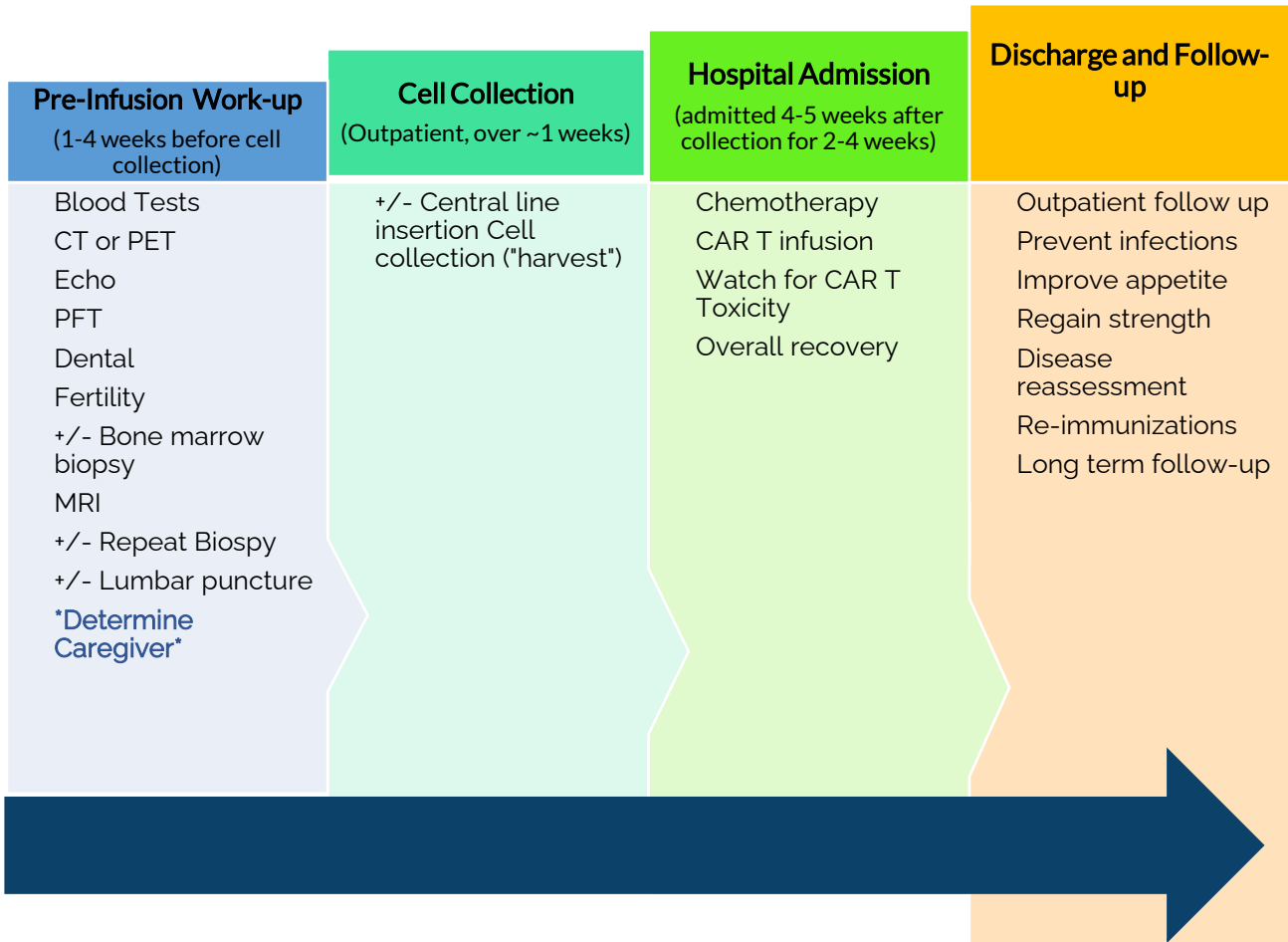
**7**

## Long Term Follow-Up

In order to monitor for unintended long term consequences of CAR T-cell therapy, Stem Cell Transplant and Cellular Therapy programs are required by Health Canada to follow patients, collect, and submit data for 15 years.

# TREATMENT TIMELINE

Here is a general overview of the CAR T-cell therapy timeline. This table is to be used as a guide, as each patient's journey is different.



# 1. Planning for Your CAR T-cell Therapy

Once your physician has discussed with you that CAR T-cell therapy is indicated and you have decided to proceed, your cellular therapy coordinator will plan the required tests. Your schedule will depend on your treatment plan and timing for tests and appointments.

## Pre-Therapy Tests

Many tests are necessary prior to CAR T-cell therapy to assess your cancer as well as to determine that you are fit and eligible to receive this therapy.

Tests may include:

- Blood Tests
  - Blood tests are done to test your kidney and liver functions. Viral testing is also done to test for specific viruses, including Hepatitis B and C, HIV, HTLV, Syphilis, and West Nile Virus
- Bone Marrow Aspirate/Biopsy
  - A bone marrow aspirate and biopsy is a procedure in which a small sample of bone marrow is collected. Bone marrow aspirates and biopsies are done to evaluate your disease status prior to CAR T-cell therapy.
- Dental Assessment and Cleaning
  - It is essential that you make an appointment with your dentist as soon as possible. You will be given a letter informing your dentist that you are going to have CAR T-cell therapy. If it's been more than 6 months since last done, you will require a dental cleaning. As well, your dentist will assess for infection in your mouth and perform any necessary dental work or extractions prior to receiving chemotherapy.
- Echocardiogram
  - An echocardiogram is an ultrasound of the heart that measures heart function. Gel is placed on your chest and a wand-like device, called a transducer is moved over your heart. The transducer will pick up ultrasound waves from your heart. A computer then converts echoes from the sound waves into pictures of your heart.
- Pulmonary Function Test (PFT)
  - A PFT is a breathing test that assesses lung function. It measures how much air your lungs can hold, how well the air moves through the airways, and how well the oxygen penetrates the lung tissue in order to enter your blood

stream. Results of these tests provide your physician with information about how well your lungs work. You may be asked to use an inhaler through which the technician will give you a medication to help “open up” the air passages in the lungs making it easier for air to flow through.

- CT or PET scan (required for some diseases)
  - A CT (Computerized Axial Tomography) scan is a special type of x-ray that takes pictures of different body parts from different angles. Ordinary x-rays, like chest x-rays, give two-dimensional pictures while the CT scan obtains very detailed three-dimensional pictures.
  - A PET (Positron Emission Tomography) scan uses a mildly radioactive drug to show up areas of your body where cells are more active than normal. It is used to help diagnose some conditions including cancer. It can also help to find out where and whether cancer has spread. More activity is seen in cancer cells than normal cells.
- Chest X-ray
  - Chest x-rays are usually done once you are admitted to hospital. A chest x-ray uses a small amount of radiation to take a picture of the chest and lungs. This gives doctors a baseline for comparison of later x-rays and helps in assessing whether the lungs show any signs of infection.
- Lumbar Puncture
  - A lumbar puncture (also known as a “spinal tap”) is used to collect the cerebrospinal fluid (CSF) surrounding the brain and spinal cord to detect disease, infection, or injury.
- Brain and/or spinal MRIs
  - A brain or spinal MRI (medical resonance imaging) can look at the blood flow through different parts of the brain or spinal cord and help diagnose abnormalities in these areas.

## Fertility

Cancer and its treatments can damage the organs or glands in your body's sexual reproductive system. High doses of chemotherapy drugs and radiation therapy can often cause permanent infertility. The possibility of becoming pregnant or fathering a child is unknown after CAR T-cell therapy.

If you would like to be able to have children after your CAR T-cell therapy, please talk to your team about your potential options. Men may want to consider sperm banking prior to starting chemotherapy. Women can be referred to a fertility specialist to pursue options about fertility preservation.

Fertility aid procedures costs are not covered by Saskatchewan Health.

# Personal Preparations

There are many things to consider before your CAR T-cell therapy. You will need to make practical, physical, and emotional plans. These are some of the things you will need to think about:

## Your Caregiver(s)

Your caregiver serves as an invaluable source of support for you throughout your journey.

You are required to have a caregiver in place before your CAR T-cell therapy. Following discharge from hospital, you must have a caregiver for **at least** 60 days after receiving your CAR T-cells (possibly longer depending on your condition).

## Who can be a Caregiver

Caregivers are most often adult family members or friends. Some people have more than one person as a caregiver. It can be challenging for caregivers if they also have small children to care for, or have their own health problems. A caregiver that works outside the home will need to take time off work.

## Responsibilities of a Caregiver

It is recommended that your caregiver attends all appointments with you. While you are in hospital, caregivers are not required to provide care but spending time with you in the hospital can help them to become familiar with your care needs.

Caregivers are expected to attend discharge teaching sessions before you go home. Once discharged from hospital, your caregiver will help with many things including everyday tasks, transportation to clinic appointments, medication management, monitoring your temperature, providing nutritional support or cooking meals, as well as helping to keep track of your tests and appointments.

Your caregiver can help by watching for any changes in your health. There may be times when you may not recognize a problem. Your caregiver can help to identify and report changes in your condition such as fevers, nausea, vomiting, problems eating, rashes, confusion, or any other concerns to your healthcare team.

## Tips for Caregivers

Being a caregiver is a challenging role. Some things for caregivers to remember are:

## CAR T

- Be kind to yourself. Self-care is very important! It is essential to make time for yourself, with the assistance of other friends and family if necessary. As a caregiver for a person with a life-threatening illness, you are going through this journey too. Recognizing this is the first step to good self-care.
- Recognize when you are stressed and identify your stress “triggers.” Learn and practice relaxation techniques. Deep breathing, visualization, meditation, and physical exercise can all be helpful for reducing stress.
- Educate yourself and be informed. Ask questions of the health care team and establish your caregiver role within the team. Learn as much as you can about the patient's medical condition and the available community supports and resources. Knowledge is power.
- Find someone you can talk to. Seek support from other caregivers. Talk to one of the transplant social workers, and seek their counselling support. Consider participating in a support group.
- Consider keeping a journal to keep track of important health information for your loved one on a regular basis. You can also write down your thoughts about caregiving, your hopes and dreams, disappointments and frustrations.
- Write down questions you have or important phone numbers, names and instructions. Remembering all the details can be very challenging.
- Don't underestimate the value of a good sense of humour.
- Remember that you can plan all you like, but you can't control everything.

The role that the caregivers plays is truly invaluable. Your health care team recognizes how just how deeply challenging and rewarding it can be. Equally important is the understanding that all CAR T patients have high-risk disease, and you, as the caregiver, are not responsible for their outcome or complications.

Caregivers may be eligible to apply for Employment Insurance benefits from Service Canada. Speak with your transplant social worker.

### **Physical Preparation**

In preparation for CAR T-cell therapy, you will need to maintain your regular activity program or be as active as possible. In general, the better your physical condition prior to starting treatment, the better you will be able to physically manage each phase of the CAR T-cell therapy process. In addition, exercise is a positive way to channel stress and promote general well-being.

Eating healthy meals and meeting basic nutritional standards pre-treatment is very important.

## Emotional Preparation

The emotional impact of treatment can be significant. Understanding how you and your support network are affected emotionally can help with coping.

Communicating with your health care team as well as your family and support network is essential. It is important to ask for help when you need it. Letting family and friends know how they can support you is helpful to both you and them. Your social worker is also available for emotional and practical support.

A useful strategy may be to choose your priorities and let go of less important obligations. Ask family members and friends to help. Some people also find it helpful to gather information to help them feel more prepared. Ensure you are seeking information from credible sources. Speak to your health care team if you have any questions about where to find reliable information.

## Smoking Cessation

You will be strongly encouraged to quit smoking and avoid second hand smoke, as smoking can increase your risk for infection or other lung complications. Smoking is not permitted in any buildings or on the grounds of the Royal University Hospital.

There are a number of supports available to help you quit smoking:

- SHR Tobacco-free helpline  
Phone 306-655-7777
- Community pharmacist  
<https://www.skpharmacists.ca/patients/quit-smoking>
- Smoker's Helpline - Canadian Cancer Society  
Phone 1-877-513-5333 or [www.smokershelpline.ca](http://www.smokershelpline.ca)
- Clinic pharmacists
- Your family physician

Please speak to a member of the care team if you need support to quit smoking.

## Accommodations

### During Collection:

It will be necessary to stay in Saskatoon at certain times during cell collection, possibly for a few days. You might consider options such as the Saskatoon Cancer Patient Lodge due to their close proximity to the hospital and economical rates. Other options may be more appropriate for extended stays.

### Hotels/Motels

## CAR T

- Certain establishments offer discount rates for patients and visitors
- Please go to the Saskatoon Health Region Visitors Accommodations for more information or use following website:  
[https://www.saskatoonhealthregion.ca/visitors/Documents/Hotel\\_lodging-form.pdf](https://www.saskatoonhealthregion.ca/visitors/Documents/Hotel_lodging-form.pdf)

### Saskatoon Cancer Patient Lodge

- The Patient Lodge offers accommodations for a patient and one companion. The daily rate includes three meals per day. Limited parking is available at a reduced rate. The Lodge is closed Friday at 4:00 p.m. until Sunday 4:00 p.m. Please phone ahead for reservations.

Parkville Manor  
625-25<sup>th</sup> Street East  
Phone: (306) 242-4852  
Rate: \$40.00/person/night

### After Infusion of CAR T:

Saskatoon is the only location in Saskatchewan that performs CAR T-cell therapy. **Accommodations within a 30 minute drive of Royal University Hospital are required for minimum of 4 weeks** following CAR T-cell infusion, and possibly longer depending on your condition.

If you are required to relocate during this time period, please speak with your social worker.

### Transportation and Parking

There is pay parking at the Royal University Hospital. The rates for the parkade can be found at:

[https://www.saskatoonhealthregion.ca/locations\\_services/Services/Parking-Services/Pages/Rates.aspx](https://www.saskatoonhealthregion.ca/locations_services/Services/Parking-Services/Pages/Rates.aspx).

There are also limited metered parking spots available nearby on the university campus. All metered parking spaces are available on a first-come first-serve basis.

If you don't mind walking a few blocks, and you have the energy to do so, there are times when free street parking may be available across College Drive. Read the street signs carefully to comply with maximum time limits based on time of day and day of the week.

If you require assistance with transportation within Saskatoon:



### Wheels of Hope (Canadian Cancer Society)

- Phone: 1-888-939-3333
- Website: [www.cancer.ca](http://www.cancer.ca)


### TAXI SERVICE (wheel chair accessible upon request)

- Access Transit 306-975-3555 (for physically disabled)
- Captain Taxi 306-242-0000
- YXE City Cabs 306-500-2339
- Ride 306-652-2222
- Hey Taxi 306-668-8888
- Saskatoon Radio Cabs 306-242-2626
- Uber App

### Legal Affairs

It is a good idea to have your legal affairs in order prior to starting CAR T-cell therapy and to discuss your wishes clearly with your family and caregiver(s). This may include:

- **Power of Attorney.** Refers to a document authorizing someone else to act on your behalf regarding personal and/or financial matters. It can be general or restricted to a specific task, but does not include making health care decisions.
- **Current Will.** A current will is an important financial legal document that helps provide for your loved ones by directing who will care for your minor children, who will get your home and possessions, who will take care of your estate, and any instructions on end of life ceremonies.
- **Advanced Health Care Directive (Living Will).** This is a legal document that specifically states which forms of treatment the individual agrees to accept and which forms of treatment they wish to refuse. Advance care planning begins by thinking about your beliefs, values and wishes regarding future health care treatment. It is important to have conversations with your close family, friends, and health care provider(s) so that they know the health care treatment you would agree to or refuse, if you become incapable of expressing your own decisions.



Please bring a  
copy of your  
health care  
directive with

Many people name a proxy or decision maker in their health care directive. This person will help your health care team make medical decisions if you are unable to do so.

It is important that you discuss your wishes clearly with those responsible for decisions about your care, particularly in the event that critical care decisions need to be made if you are unable to communicate for yourself. Specific concerns regarding these areas can be discussed with your social worker.

## Finances

The costs you incur will depend on your need to relocate, the medications you are prescribed, required travel time, and costs of caring for your home if you do need to relocate.

You may also have costs for necessary dental treatments if you do not have dental coverage. Speak to your social worker.

### ABOUT WORK OR SCHOOL:

If you are currently employed or a student, you will need to take time off from work or school.

Most patients will be off work/school for 3-12 months.

Some patients will need a gradual return to work/school program.

Speak to your social worker for any work-related support.

## EMPLOYMENT-RELATED BENEFITS

Please check with your employer or human resources department for sick leave, short-term and long-term disability benefits.

Some other sources of financial help may be available to you from:

- Service Canada:
  - Employment Insurance Benefit: Employment Insurance Sickness Benefits
    - You may qualify for up to 15 weeks of Employment Insurance
    - Contact Human Resources and Skills Development Canada at 1-800-206-7218
    - Website: <https://www.canada.ca/en/services/benefits/ei/ei-sickness.html>
  - Canada Pension Plan (CPP) Disability Benefits
    - You may also qualify for CPP-D benefits.
    - Contact Social Development Canada at 1-800-277-9914
    - Website: <https://www.canada.ca/en/services/benefits/publicpensions.html>

## CAR T

- Income Tax
  - Keep all your travel, food, and accommodation receipts, if you are traveling more than 40 km for your medical care as you may be able to claim them on your income tax return under medical expenses (Note: expenses where you received funding from an outside source cannot be used for income tax purposes).
- Certain patients may qualify for a Disability Tax Credit, but very strict criteria apply.
  - Website: <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>
  - Phone: 1-800-267-6999
- Income Assistance Plan (Government of Saskatchewan)
  - Financial assistance for living expenses and medically related costs is provided to applicants in need that meet strict eligibility criteria (with no source of income, minimal or no assets, no other available sources).
  - To apply, contact the Ministry of Social Services at 1-866-221-5200 for initial intake and scheduling of an appointment.
- Other Insurance
  - If you have purchased *critical illness/disability insurance* on mortgages, loans or credit card balances, please check with your financial provider.
- Release of Information
  - Any form (i.e. insurance) needing physician completion can be submitted to Release of Information (ROI) at main reception at the Saskatoon Cancer Centre (306-655-6442).

### Medication And Drug Coverage

You will be responsible to pay for certain medications when you are an outpatient. Some of these expenses may be covered if you have private insurance, such as Blue Cross. You can also apply for Special Support through the *Saskatchewan Drug Plan*. You may be eligible for a reduction in your deductible and a decrease in the amount you pay. We recommend that all patients complete a Special Support form. Applications are available through your community pharmacy or you may ask your cancer centre pharmacist for an application form. Alternatively, the application forms for Special Support may be found online:

[Drug Cost Assistance | Extended Benefits and Drug Plan | Government of Saskatchewan](#)

Drug coverage will be discussed with you on the day of your admission to the hospital for CAR T-cell therapy. If you have any concerns about the cost of your medications, please call your cancer centre pharmacist at 306-655-2405.

## Driving

YOU WILL NOT BE ALLOWED TO DRIVE FOR 8 WEEKS  
AFTER YOUR CAR T INFUSION DUE TO THE INCREASED  
RISK OF SEIZURES

***NOTE:** you will not have insurance if you drive during this*

## 2. CELL COLLECTION or “Apheresis”

Once the pre-CAR T-cell therapy assessments and preparations have been completed, you will be scheduled for cell collection.



### How are Cells Collected?

Your white blood cells (leukocytes) will be collected by a process called apheresis, or more specifically for CAR T-cell therapy, **leukapheresis**. The apheresis machine removes some of your blood from an intravenous line in one arm and, after separating out the needed blood cell components, returns the rest of your blood through an intravenous line in your other arm. You may need a temporary central line inserted for collection if your veins are not easy to access. The length of the collection varies, based on the amount of cells recovered. It can last anywhere from 3-8 hours. It is required to have someone drive you to and from your appointment on collection day.

## Apheresis Process

Before your cell collection, you will meet with an apheresis nurse. They will explain the apheresis procedure and will assess your veins to see if a central line is required to collect your cells. If it looks like your veins may not be able to tolerate the procedure, arrangements will be made for a central venous catheter (“CVC”, or “line”) to be inserted prior to apheresis. **Alert your team if you are on a blood thinner as this may be required to be held prior to a CVC insertion.**

If you need a central venous catheter (CVC), it will usually be inserted the morning of cell collection. In this procedure, a small CVC is inserted into a large vein in the neck under local anesthetic. The procedure takes place in Royal University Hospital Medical Imaging Department vascular suite. An interventional radiologist will explain the procedure along with potential complications to obtain your consent prior to the procedure.

On the day of harvest, you will arrive at the Admitting Department of Royal University Hospital, usually at 8:00 am. If a line insertion is required, you will be directed to the Apheresis Unit in the Oncology Day Centre (ODC).

Common side effects during apheresis include:

- Tingling around mouth, tingling of fingertips or vibrations in your chest (can be caused by low calcium levels in your body)
- Body temperature changes (i.e., feeling cold or feeling warmth during the procedure)
- Lightheadedness

Be sure to tell the nurse if you are feeling any of these symptoms.

Your physician will prescribe the number of cells to be collected based on your weight. When the targeted number of cells have been collected, they will be sent to the manufacturer or occasionally stored by means of cryopreservation (freezing).

You must have a driver to pick you up following the cell collection procedure.

As the collection can take a number of hours, you are encouraged to bring diversions such as books, laptop, and so on. There is a TV on the unit as well.

Visitors are welcome, but please limit the number to 1 or 2 as space is limited. Lunch and snacks are provided for yourself, but you can bring your own food as well.

Please bring any medications that you normally take during the day with you but **DO NOT take blood pressure medications the morning of cell collection.** You will be given a calcium infusion to help maintain the calcium level in your body. Bathroom privileges are limited to the use of a commode or urinal while you are connected to the machine.

## CAR T

After the cells have been collected, they are shipped to an external lab for CAR manufacture (typically outside of Canada) are then prepared for infusion back into your body. This process can take a number of weeks. In the meantime, your doctor may prescribe therapies such as chemotherapy, immunotherapy, radiation, steroids, or other cancer-fighting drugs to maintain or improve your current state.

## After Cell Collection

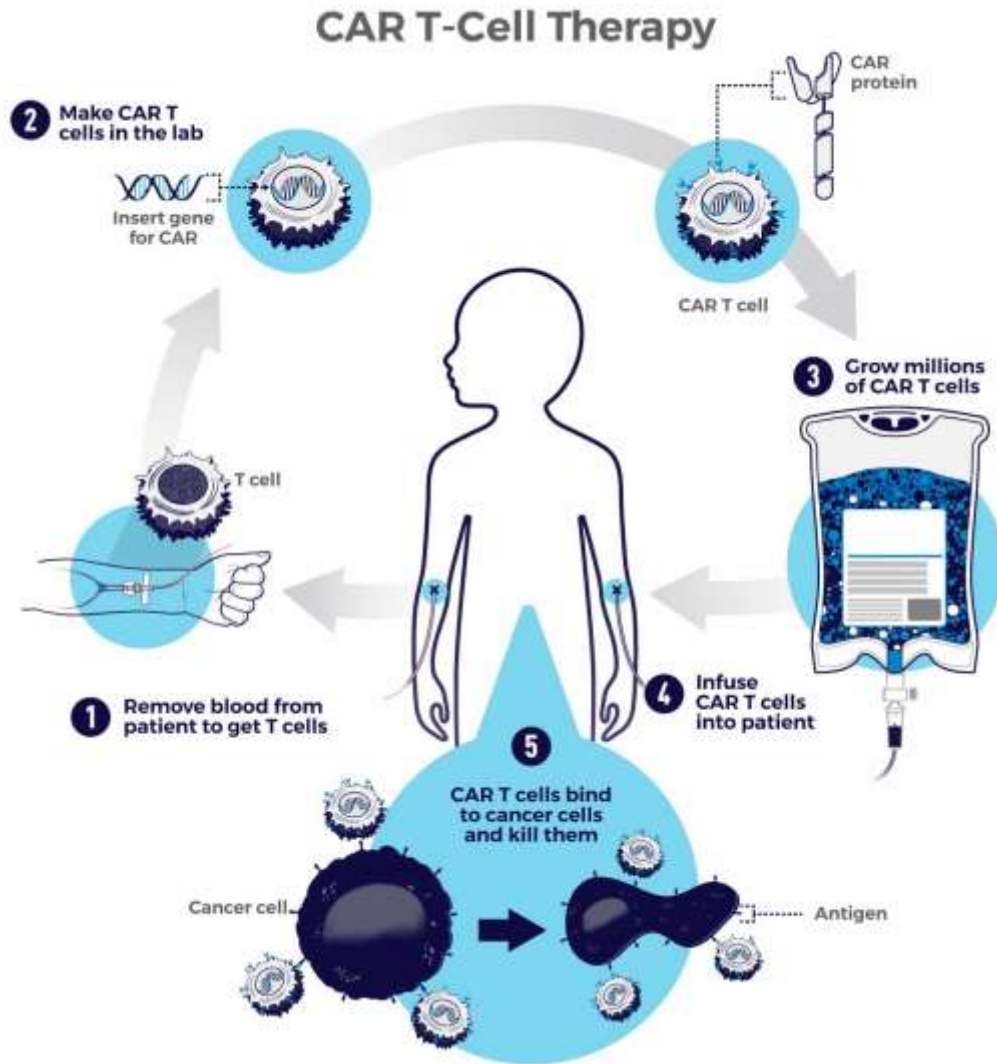
You will be discharged home after the cell collection is completed. If you have a CVC for your cell collection, this may be removed prior to your discharge home.

You will likely be admitted to hospital for your CAR T-cell infusion 4-5 weeks after the cell collection.



- DO NOT take blood pressure medications the morning of cell collection
- DO remember to bring all your pills with you!
- Eat a breakfast high in calcium
- Wear loose fitting, comfortable clothing
- Be sure to have a driver available to take you home

# 3. Car T-Cell Manufacturing



Once received at the lab, your T-cells are genetically engineered. The T-cells receive genetic instructions to produce chimeric antigen receptors (CARs) on the surface of the cell. The re-engineered CAR T-cells are then expanded by growing the cells in the laboratory to produce enough cells for clinical use. This process can take 3-4 weeks.



## 4. Bridging Therapy

The goal of bridging therapy is to prevent disease progression that could cause complications which might prevent you from proceeding with CAR T-cell therapy.

The aim is to establish adequate disease control prior to the CAR T-cell infusion, rather than to achieve disease remission. After the collection of your cells, your doctor will determine if you need further treatment. Treatment may be omitted if you have stable or a low burden of disease.

Bridging therapy should only be given after cell collection so that the quality of the CAR T-cell product is not affected. Treatment may be given orally or intravenously, and may include chemotherapy, immunotherapy, radiation, steroids, or other cancer-fighting drugs.

## 5. CAR T-Cell Infusion

The next step of your journey is admission to Royal University Hospital (RUH) Unit 6100: Inpatient Oncology, Hematology and Stem Cell Transplant Unit. A nurse, pharmacist, and CAR T physician will see you in the Saskatoon Cancer Center either the day before or the day of admission to hospital. This is to confirm that there have been no new changes to your health, and to finalize details pertinent to your admission. You will also have the opportunity to ask any further questions.

While we ask for an inpatient bed on a specific day, there may not be a bed available on the day requested. If this is the case, you may need to wait until a bed becomes available. Your admission may be delayed by only a day, but can sometimes be longer.

## Welcome to 6100

On admission, once you have been called that your bed is ready, you will go through Patient Registration on the main floor of the Royal University Hospital (RUH). Please (note that if you are being admitted after 4:30 p.m., you may be instructed to come directly to Unit 6100). You will receive an identification wristband as well as admission papers at this time. From this point, take the elevators to the 6<sup>th</sup> floor then follow the signs to Unit 6100. The clerk will direct you to your room once you have reached the unit.

Unit 6100 is comprised of 29 beds, including six beds within the BMT unit - the only one of its type in Saskatchewan. CAR T-cell therapy patients are typically admitted to a private room on the general unit, while patients having an allogeneic stem cell transplant (stem cells from a donor) are admitted to the BMT unit. On occasion, you may be admitted to a shared room at first, but will be moved to a private room as soon as it is available or is medically indicated. You will spend about 2-4 weeks on Unit 6100.

### What to Bring to the Hospital

When planning what to bring to the hospital, please remember that the rooms are not very large. Some suggested items you may wish to bring include:

- Loose, comfortable clothing
- Pajamas or shirts that open in the front
- Slippers and comfortable walking shoes
- Head covering such as scarves, hats, and so on
- Soaps and lotion (fragrance free)
- Soft tooth brush and tooth paste
- Soft tissue and toilet paper
- Books, magazines, games, laptop, and any other comfort items for diversion
- Pictures of family, friends, pets, etc.
- Blankets and/or pillows

Each room has a telephone available for use and there is television available to rent. Payment is due upon activation and can be done directly on the television using VISA credit, VISA debit, MasterCard credit, MasterCard debit, or American Express. You can also visit <https://healthhubsolutions.ca/> and click on 'How to Rent' under the 'Renting' tab, then search for Saskatoon and you will find Royal University Hospital and be able to enter your bed number. There are also frequently asked questions and a contact number for trouble shooting.

Free wireless internet is available. Simply look for <Patients/Visitors> network on your device.

**Do Not Bring** fresh flowers, plants or dried flowers as they can carry spores that cause infection.

## Families and Visitors

Visiting hours on Unit 6100 are not restricted, but your visitors should pay attention to how long they visit to ensure that you get enough rest. All visitors must wash their hands upon entering Unit 6100. To help prevent the spread of infections, visitors are not allowed to come if they have:

- Fevers
- Sore throat
- Have recently been exposed to a communicable disease such as chickenpox, influenza, COVID 19, TB
- Diarrhea
- A new or unexplained rash
- Any other symptoms that make them feel unwell (any active cold or flu symptoms)

Patient washrooms are for patient use only, but there is a public washroom on the 6<sup>th</sup> Floor. There are a few sleep chairs on the unit that may be available if you want to have someone stay overnight with you. There are no shower facilities for visitors to use. If you are on the BMT unit, additional visitor screening measures are in place to protect the health of everyone on the unit.

## Central Venous Access Device (CVAD)

A central venous catheter (CVC) is a long, flexible tube inserted into your arm (peripherally inserted catheter [PICC]) or chest with the help of an ultrasound machine. The type of CVC required will be discussed and decided, and may also be inserted, prior to your admission to Unit 6100. In addition to infusing CAR T-cells, a CVC line may also be used to administer intravenous fluids, medications, blood products, chemotherapy, and nutrition. Nurses must be certified to use CVCs including to draw blood samples.

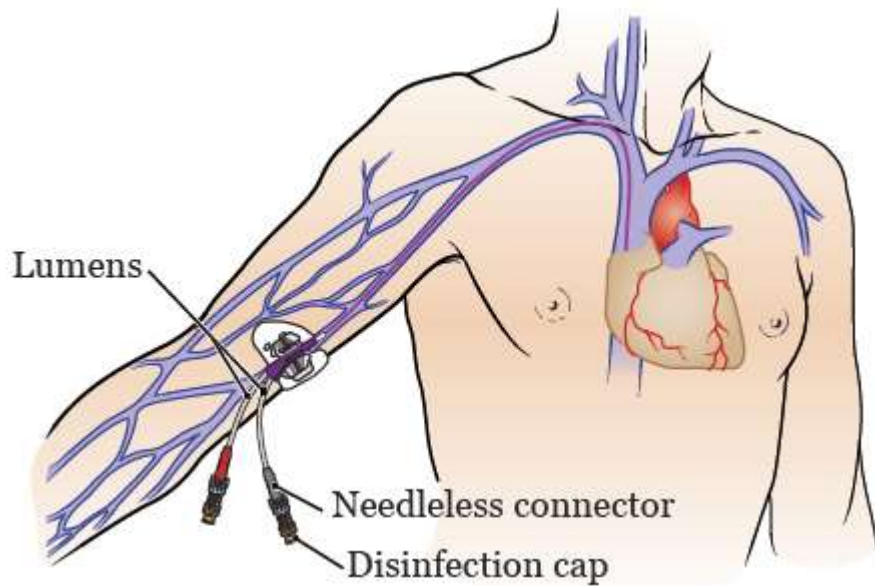


Image Credit: MSK Cancer Center

All CVCs have an end that goes through a vein in your upper arm or chest threading into the large vein near your heart. Outside of your body, the CVC divides into 1, 2, or 3 smaller tubes called lumens (the illustration above has 2 lumens). Each lumen has a needleless connector and a disinfection cap on the end.

The insertion procedure is done by an interventional radiologist. First, the skin around the insertion site is frozen using local anesthetic. Then, the tip of the CVC is threaded through to a large vessel just outside the heart. The hub of the catheter hangs outside your body, often with two or three lumens. Each lumen has a cap and depending on the type of CVC you have, you may notice a plastic clamp on the lumens that keeps blood from leaking and prevents air from getting in.

A sterile dressing covers the insertion site to help keep the area clean and dry to minimize the risk of infection. Dressing should be changed within the first 24-48 hours, then at least once every week. Following the CVC insertion, it is normal to have some redness and discomfort at the site, but this should go away within a few days. Your CVC may have a securement device (like small blunt clips that are beneath the skin) or a stitch (more

common with chest CVCs) to hold the line in place. If a stitch is in place, your Nurse may remove the stitch 7-10 days after the insertion procedure.

### **Living With Your Central Venous Catheter (CVC)**

Proper care of your catheter is important to prevent infection. Your CVC line can stay in place safely for weeks or even months.

**Keep your CVC clean.** You should always keep the exit site covered with a sterile dressing or bandage. The dressing needs to be changed once a week or more often if it becomes dirty, wet, or is no longer sticking to your skin.

**Keep your CVC dry.** Avoid swimming or other activities that may cause your catheter or catheter dressing to become wet. When bathing or showering, the CVC and CVC dressing should be covered by plastic wrap and tape. Do not submerge the area in water.

**Take care not to pull or twist your CVC** when getting dressed or undressed or when changing the dressing. Be careful when lifting objects, children or pets. Avoid any heaving lifting.

**Avoid using scissors or anything sharp on or near the CVC.**

**Use caution when doing any activities with your chest muscles.** Repetitive motion with your arm on the side of the catheter such as vacuuming can cause damage to the area.

### **Possible Complications with a Central Venous Access Device (CVAD)**

Most people with a CVC do not experience any of the following problems. With proper care, most of these problems can be prevented and your CVC should continue to work well for the duration of your treatment.

However, if you do experience issues with your central line, it is important to know what to do. The following chart provides guidance (next page). If you experience issues not listed in the chart, be sure to call your nurse or physician.

## Possible Central Venous Catheter Problems and Actions

Problem	Sign	What To Do
<b>Broken or cut CVC (PICC or chest line)</b>	Blood may leak or drip from the CVC	Clamp the CVC above the cut/broken area and seek medical care as soon as possible.
<b>Infection</b>	Redness, swelling, pain/tenderness, fever or chills	Seek medical care as soon as possible.
<b>Clamp open when the end cap is off (chest CVC)</b>	Blood is dripping/leaking from end of CVC	Clamp the CVC check to make sure the bleeding has stopped. Clean the end with alcohol, replace the cap. Call your Nurse.
<b>CVC is partially pulled out</b>	CVC may appear longer	If not out all the way, secure with tape. Do not push back in. Call your Nurse.
<b>CVC is completely pulled out</b>	CVC is no longer threaded under the skin	Apply pressure to the exit site until bleeding stops. Seek medical attention as soon as possible.
<b>Blood Clot</b>	Redness, swelling, pain to neck or arm	Seek medical care for assessment as soon as possible.
<b>At site of insertion-Stitch falls out or line securement device falls off</b>	Stitch or securement device holding tube to the skin is no longer there	Stitch: If this happens within the first 10 days of insertion, seek medical care immediately – a new stitch may be inserted. Securement device (PICC): tape/secure line Call your nurse.

## Conditioning (Preparative Regimen)

The conditioning (sometimes also called “preparative”) regimen is the chemotherapy used to prevent the immune system from over-reacting to the CAR T-cells. The days that you receive conditioning chemotherapy are referred to as “minus” days (Day -5, -4, -3 and so on), while the day you get your CAR T-cells is called “Day 0”. The days following infusion of your cells are Day +1, +2, and so on.

A chemotherapy certified registered nurse administers this treatment. You will receive more information on the type of chemotherapy medications that you will receive by your health care team. Please refer to “Recovery in Hospital” section on page 31 for more information on chemotherapy side effects.

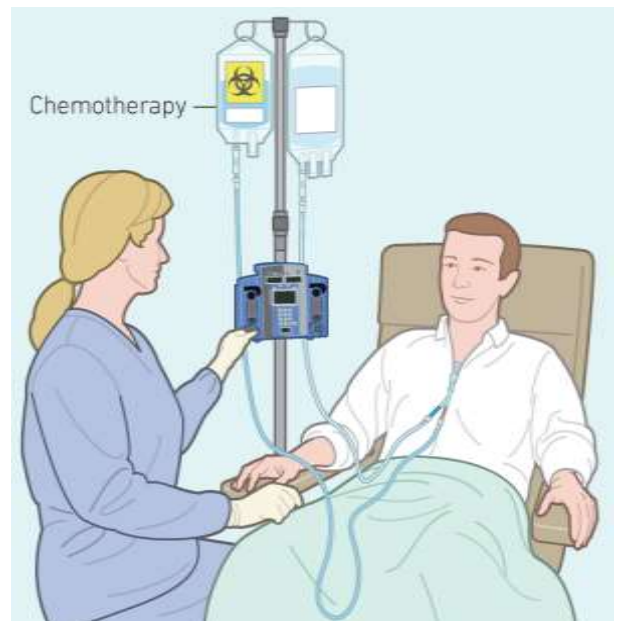
## Cell Infusion – Day 0

The day of your cell infusion is referred to as “Day 0”, with subsequent days referred to as +1, +2, etc. On Day 0, a transfusion medicine technologist will bring your frozen cells to your bedside to thaw right before the infusion. Your nurse will infuse the cells through the CVC line, much like a blood transfusion. This takes approximately 30 minutes. Your nurse will be in the room the entire time to monitor your vital signs and watch for any side effects. The side effects during the infusion of the cells result from a preservative called DMSO (dimethyl sulfoxide), an additive used when your cells were frozen after collection.

Side effects may include:

- A garlic-like taste
- Flushing
- Chills
- Nausea
- Shortness of breath

You will be given medications prior to the cell infusion to help prevent or minimize side effects. You will also receive orange slices on your breakfast tray the day of cell infusion, as holding oranges in your mouth can help with the altered taste during the cell infusion.



## Recovery in Hospital

Your medical team will monitor you closely. You will get medications to help prevent and control side effects. Your response will depend on the cancer type, location, treatment doses, and your overall health. You will need to stay in the hospital for a few days, or even several weeks, depending on your clinical situation and whether the risk for severe side effects is diminished.

CAR T-cell therapy can cause a number of potential side effects. Although cancer cells are sensitive to chemotherapy, so are rapidly dividing normal cells in the body. This means that cells in the bone marrow, mouth, digestive tract, skin, hair, testes, ovaries, and lungs are all affected by chemotherapy. Some patients become quite ill after receiving chemotherapy, while others experience only mild side effects. However, predicting which side effects you will get, and at what severity, is not possible. Admission to the intensive care unit (ICU) is sometimes necessary, although not common.

### **SIDE EFFECTS MAY INCLUDE:**

#### **Infection**

Your white blood cell count begins to drop in the days following chemotherapy, reaching its lowest level within 5 to 7 days of starting chemotherapy. During this time, you are at high risk of developing an infection until your immune system starts to recover. Infections can be bacterial, viral or fungal. Some signs of infection include fevers, chills, a cough, runny nose, shortness of breath, chest tightness, frequent urination, burning when you urinate, pain (in your throat, stomach, or rectal area), diarrhea, and redness or drainage around your CVC site. The inpatient nurses will monitor you closely for infection during your hospital stay by checking your vital signs every four hours when your white blood cell counts are low and more often if there are concerns. Be sure to let your nurse know if you have concerns. Most patients will require IV antibiotics during their hospital stay due to an infection.

#### **Digestive tract changes**

Mouth sores (mucositis), loss of appetite, nausea, vomiting, and diarrhea are all common side effects following chemotherapy. Anti-nausea medications are given prior to chemotherapy to help to minimize nausea and vomiting. Good oral care and mouth rinses are important to prevent mouth sores. Dentures must be meticulously clean. Rinses containing local anesthetic can minimize the discomfort of mouth sores. If sores become too uncomfortable, stronger medications may be used. Occasionally you may be unable to eat or drink during this period and nutrition may be provided intravenously. A dietitian will follow you while in hospital to ensure you are maintaining adequate nutrition.



## Fatigue

Fatigue is the most common side effect from chemotherapy and can last for months or even years after your cell infusion. There are many things that contribute to fatigue including low blood counts, fighting infections and some medications. Some things you can do to help cope with fatigue are try to get enough sleep and rest, save and manage your energy, eat and drink appropriately, and stay active.

Additional resources for fatigue are available on the Saskatchewan Cancer Agency website at <http://www.saskcancer.ca>. Look under the "Patient & Families" tab, then "Managing Side Effects" for "Fatigue".

## Low blood counts

Your red blood cells and platelets will be affected by the conditioning chemotherapy, often resulting in a need for red blood cell and platelet transfusions. When your platelets are low, you will find that you bleed and bruise more easily. A soft bristle toothbrush is recommended when brushing your teeth. Avoid flossing when your platelets are below 20. Only use electric razors for shaving.

## Blood Product Support

Canadian Blood Services (CBS) is the national blood supplier for Canada (excluding Quebec) and looks after the collection, testing, processing and storage of donated blood. Every donation is tested by CBS for known transmissible diseases including HIV, Hepatitis B and Hepatitis C. Blood components are **not** released by CBS for use until all donor transmissible disease testing is completed. Blood components are produced from blood donated voluntarily by people across Canada.

For more information about blood transfusion and associated risks, please see the Saskatoon Health Authority's *Information for Patients about Blood Transfusion and Tissue Transplantation* handout (available on the Saskatoon Health Region website under "Transfusion Essentials" at

[https://www.saskatoonhealthregion.ca/locations\\_services/Services/Pathology-Laboratory-Med/healthpractitioners/Documents/Transfusion%20Essentials/Information%20for%20Patients%20About%20Blood%20Transfusion%20and%20Tissue%20Transplantation.pdf](https://www.saskatoonhealthregion.ca/locations_services/Services/Pathology-Laboratory-Med/healthpractitioners/Documents/Transfusion%20Essentials/Information%20for%20Patients%20About%20Blood%20Transfusion%20and%20Tissue%20Transplantation.pdf). You will be required to sign a consent form before receiving any blood products.

## Organ damage

High dose chemotherapy can have a major effect on your organs, including the liver, lungs, heart, and kidneys. The damage is usually reversible.

## Toxicities caused by the effects of CAR T-cells on your immune system

1. Cytokine Release Syndrome (CRS)

## CAR T

In most patients, the immune system becomes activated as the CAR T-cells travel through the body. Substances called *cytokines* are released into the system. Symptoms can be mild or severe. You may need oxygen, intravenous fluids, and/or medications (including steroids) to keep your fever down. Some patients require time in the ICU. In severe cases, you may receive medications designed to stop the effect of the cytokines. Your medical team will be watching closely for any changes to how you are doing.

This potentially serious side effect is **frequently** associated with CAR T-cell therapy but is reversible. CRS symptoms can range from mild flu like symptoms that include:

- Nausea
- Fatigue
- Headache
- Chills
- Fever

To more serious symptoms such as:

- Low blood pressure
- Tachycardia (abnormally rapid heart rate)
- Capillary leakage syndrome (when fluid and proteins leak out of tiny blood vessels and flow into surrounding tissues resulting in dangerously low blood pressure)
- Cardiac arrest
- Cardiac arrhythmias (irregular heart rhythms)
- Cardiac failure
- Hemophagocytic lymphohistiocytosis (HLH) (life-threatening immune system activation)
- Macrophage activation syndrome (MAH) (life-threatening activation of macrophages)
- Hypoxia (lack of oxygen reaching the tissue)
- Renal insufficiency: poor function of the kidneys
- Poor lung oxygenation
- Multiple organ failure
- Neurological symptoms (see below)

Severe CRS requires intensive care treatment (admission to ICU). Although most symptoms are reversible, the potential life-threatening risk of CAR T-cell therapy must not be underestimated. Deaths have been reported in CAR T-cell therapy trials. Depending on the patient and the CAR T-cell product, CRS may occur within 1 to 21 days of CAR T-cell infusion. The duration of CRS varies and depends on the type of intervention used to manage it.

## 2. Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS)

In some patients, the immune activation after CAR T-cell infusion may alter the brain and neurologic system temporarily. These changes can appear as confusion, difficulty with talking or memory, or loss of consciousness and seizures in severe cases. Some patient may also end up in the ICU. Your team will monitor you frequently and may give you special medications to help prevent or control these problems. In some clinical trials the median onset was 8-13 days after CAR T infusion, but they have been reported past this. Symptoms may include: tremors (shaking), confusion, agitation, seizures, dysphasia (problems speaking), hesitant speech, trouble (deterioration) in handwriting.

- **Cytokine release syndrome (CRS) and Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS) are serious and potentially life-threatening complications that can occur with immunotherapy**
- At-risk patients are monitored closely. Treatments focus on managing symptoms and supporting organ function.
- Patients may end up in ICU to manage these toxicities.

*YOUR DOCTOR CAN HELP YOU UNDERSTAND THESE TOXICITIES. ALWAYS TALK TO YOUR CARE TEAM ABOUT ANY HEALTH CONCERNS, AND REPORT CHANGES IN SYMPTOMS THAT OCCUR DURING OR AFTER TREATMENT.*

### 3. Tumor lysis syndrome

CAR T-cell therapy is designed to target your specific cancer cells. In some cases, this process may destroy a large amount of tumor in a short period of time. When these cancer cells die, the contents of the cells are released into your bloodstream. This can result in shifts of fluid and minerals, and/or kidney damage. Your team will have a specific treatment plan for you, if needed. This may include chemotherapy prior to T-cell therapy, IV fluids, and/or medications to help the body clear these excess fluids and protect the kidneys.

### 4. B-cell aplasia

B-cells are a type of immune system cell. Some cancers also involve B cells, such as lymphoma. When CAR T-cells are engineered to target B-cells, there can be a very large

drop in the number of those cells in the body. Because B-cells are important to your immune system's ability to prevent infections, you may need to receive a product through IV called immune globulin (IVIG) to help support your immune system after receiving CAR T-cells.

## During Your Hospital Stay

### Activity

Staying active before, during, and after infusion is very important to your physical and emotional health and recovery! While you are in hospital, a physiotherapist and occupational therapist will do an assessment and recommend what type of activity you should be doing. You will learn which exercises are safe when your blood counts are very low. Although you will be mostly limited to Unit 6100, we encourage you to go for frequent walks around the unit. Regular exercise will help maintain your strength, and may aid in recovery and lead to an earlier discharge from hospital.

Staying as active as you can be is helpful, even on days that your energy is low. This might mean walking in the hallway several times or marching on the spot. Following your CAR T-cell infusion, spend as much time out of your bed as possible! Use your bed at night for sleeping or for when you are feeling too unwell to be up. It may help to begin slowly and increase your activity level gradually.

### Mouth Care

It is very important to keep your teeth, gums, and mouth clean. Mouth problems are common side effects of chemotherapy and may be worse while your blood counts are low.

Tips for good mouth care:

- Continue with routine mouth care each day
- Brush teeth and gums with a soft toothbrush or toothette to prevent sore gums and bleeding
- Continue flossing as you normally would, unless platelets are under 20
- Rinse your mouth at least 4 times daily (after meals and at bedtime)
  - Use: 1 teaspoon baking soda and 1 teaspoon of salt in 4 cups of water
  - Swish, gargle then spit out
  - Keep in a covered container at room temperature
  - Make fresh batch each day
- Brush and rinse dentures after eating and before bed
  - Keep them out as much as possible
  - Soak in a cleansing solution for at least 8 hours
- Remove dentures for sleeping

- Use a moisturizer on your lips that does not contain glycerin or petroleum jelly (these can dry your lips)
- Avoid mouthwash that contains alcohol (can cause more pain and irritation)

## Diet

During your hospitalization, you will be on a diet that is safe for immunocompromised patients. This includes avoiding certain foods such as deli meat, as they may contain high amounts of harmful organisms. Your dietitian will provide education on foods to avoid during this time. They will also follow you throughout your stay to optimize nutrition and prevent weight loss while providing helpful tips on managing potential symptoms.

Helpful tips include:

- High protein/high calorie snack and meal options to manage weight loss
- Nutritional supplement options (e.g. Boost, Ensure, Resource 2.0, high protein/high calorie drink) to increase calories and protein
- Softer, moist foods for sore mouth and difficulty swallowing
- Small frequent meals for nausea and lack of appetite
- Educating families about foods and fluids that are nutrient dense to make every bite and sip pack a powerful nutritional punch
- Foods with little or no smell to reduce nausea
- Experiment with different flavors/textures for changes in taste
- Add lemon wedges or flavors (Mio, Crystal Lite, etc.) to help flavour water
- Maintain optimal oral hygiene so mouth bacteria will not cause further changes to taste
- In addition to maintaining excellent mouth care choose, tart or sour foods to stimulate saliva for dry mouth (decreased saliva production can also change the way taste is perceived).

## Constipation

Regular bowel movements can be a challenge because of nausea, lower food intake, lower activity level, and side effects of medications. If you are having difficulty having a daily bowel movement, medications can help. Be sure to speak to your nurse if you are experiencing constipation.

## Diarrhea

Diarrhea can occur as a side effect of chemotherapy or infectious causes. Once infectious causes of diarrhea have been ruled out, medications can be used to manage it.

## Personal Hygiene

Daily showers, excellent hand-washing, clean clothing and bedding changes are important for your health as well as a sense of well-being, even though it is difficult when your energy is low and you are not feeling well.

## 6. Discharge From Hospital

You may feel excited about being discharged but this time can also come with mixed feelings, including feeling overwhelmed. Because every patient and family is unique, please be sure to discuss any questions or concerns with your health care team.

### When Will I Be Discharged?

Deciding when you are ready to go home is based on feedback from your physicians, nurses, social worker, dietitian, and physical therapists. In order for you to be safely discharged from hospital after your CAR T-cell infusion, you must:

- Be free of fevers or active medical problems
- Have satisfactory blood counts
- Be off all intravenous medications
- Be able to swallow medications
- Be able to eat and drink adequately
- Be able to walk
- Be strong enough to perform activities of daily living

It is important to remember that discharge from hospital is a transitional process, because you are still recovering. You, as well as your family or friends, may expect that you should feel and act as you did prior to your illness and treatment, but the reality is that most patients feel weak and tired. It is common to feel impatient or frustrated while waiting for your energy to recover and get back to feeling "normal". Give yourself permission to take the time needed for recovery and know that as you get stronger you will be able to do more. Your medical team will continue to support you during your recovery at home.

### Problems to Report and When to Call

It is critical for you and your caregiver to know when to contact your health care team after going home. Many symptoms cannot wait until your next scheduled appointment – if you are not sure, please call and speak to someone from your health care team. Occasionally it is necessary to return to hospital after discharge to deal with a complication.

## Problems to Report

### **URGENT Symptoms to report include:**

- Temperature of 38.0° C or higher
- Chills, sweats or shakes
- Redness, swelling pain or discharge around central line site
- Bleeding
- Coughing, shortness of breath or chest pain
- Persistent nausea or vomiting
- Frequent or painful urination
- Constant urge to urinate
- Cloudy or foul smelling urine
- New skin rash or painful blisters on skin
- Diarrhea or abdominal cramping
- Yellowing of skin or white of eyes
- Inability to keep medications or fluids down due to nausea

### **Examples of Emergencies may include:**

- Uncontrolled bleeding
- Choking
- Loss of consciousness
- Difficulty/unable to wake up
- Sudden chest pain
- Severe shortness of breath
- Rapid change in overall condition
- Seizures
- Unable to swallow
- Confusion, or mental changes

## When to Call

If...	When...	Where	Contact
Urgent	<b>Weekdays:</b> Call Saskatoon Cancer Centre <ul style="list-style-type: none"> <li>▪ Monday through Friday 8:00 am to 4:30 pm</li> <li>▪ Closed statutory holidays</li> </ul>		Call your primary nurse
Urgent	<b>Evenings, weekends and statutory holidays:</b> Call Royal University Hospital <ul style="list-style-type: none"> <li>▪ <b>Weekends:</b> All day Saturday and Sunday</li> <li>▪ <b>All Evenings:</b> Monday to Friday 4:30 pm until 8:00 am</li> <li>▪ <b>Statutory holidays</b></li> </ul>		Call <b>306-655-1000</b> and ask to page the Hematologist on call
Emergency* (See what to bring below)	<ul style="list-style-type: none"> <li>• For an emergency <b>AT ANY TIME</b> (Day or night, weekdays or weekends)</li> </ul>	In Saskatoon: Royal University Hospital (RUH) Emergency Department  Or Nearest local ER	Come to RUH Emergency (by caregiver or ambulance)  Or Call 9-1-1

\* In the event of an **EMERGENCY**, you must come to Royal University Hospital for immediate assessment. Please bring a current medication list with you.

- **Car T-Cell Therapy Alert Card.** You will be given a wallet card indicating that you are an immunocompromised patient who had just received CAR T-cell Therapy. Present this card immediately to staff at any emergency department. This indicates that you should be triaged as urgent and placed in isolation.

***Carry this card with you at all times.***



# Outpatient Care

## Follow Up Appointments

Following discharge, you will have frequent follow up appointments at the Saskatoon Cancer Center. You will be seen two to three times a week initially based on how you are feeling and your blood counts. Expect to see the nurse practitioner and/or physician minimum of once a week and then your outpatient nurse on subsequent visits. As you recover, your follow up appointments will become less frequent.

Appointments will be early in the morning to allow for blood tests. You will have blood work drawn, and a nurse will assess you. Once blood work results are back (usually takes about an hour), you can expect to receive intravenous (IV) blood and/or platelet transfusions that same day. Fluid and electrolyte infusions might be needed following CAR T-cell therapy, as some of the medications you will be on can cause your body to lose electrolytes.

## Immune-Mediated Toxicities Associated with CAR-T Cell Therapy

Your health care team will continue to evaluate you for evidence of Cytokine Release Syndrome (CRS) and Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS) when you are an outpatient.

Some patients may experience *late* CRS as a result of the activated immune system from the infused CAR T-cells. You may need intravenous fluid support, and/or medicines (including steroids) to stop the effect of the cytokines and evaluated for re admission to hospital if needed. This will rarely occur after Day +28 from your cell infusion.

Some patients may experience a late immune activation after CAR T-cell infusion that **temporarily** alters the brain and neurologic system. These changes can present as confusion, difficulty with talking or memory, or even loss of consciousness in severe cases. Although the occurrence of late ICANS is rare after Day +28, your health care team will monitor you frequently.

**Remember, it is mandatory that you cannot drive for a minimum of 8 weeks after your CAR T infusion.** Your Nurse Practitioner or Physician will advise you when you are cleared to drive. Note that your insurance is invalid during this timeframe.

## Medications

Following the infusion of your CAR T-cells, there are many medications prescribed to help prevent infections and other common post-CAR T-cell therapy complications. Prior to discharge, a pharmacist will explain the purpose of each medication, how and when to

## CAR T

take each medication, and for how long. A personalized education calendar will be provided to help follow your new medication regimen. It is vital to have a current list of your medications with you at all times! This list will be reviewed at each visit. If you require an updated medication calendar, please ask your primary nurse or SCTCTP pharmacist. It is important for you and your caregiver to be familiar with your medications.

Please do not stop any medication without specific direction to do so from your doctor, nurse, or pharmacist. Also, do not take any medication without consulting your pharmacist, physician or nurse, as certain medications may not be recommended (for example, any nonsteroidal anti-inflammatory drugs such as ibuprofen).

Please bring ALL of your medication bottles to your first outpatient appointment so that the pharmacist or primary nurse may review everything once again in detail.

### Preventing Infections

Following CAR T-cell therapy, your risk of infection remains higher than normal for up to 1 year, even if your blood counts are normal. Even though your body has started to produce white blood cells again, your new immune system needs time to mature, just like when you were a child. This includes repeating childhood vaccinations once directed.

One of the most important ways to prevent infection is frequent **hand washing** every time you return home, after using the bathroom, and before eating. If you feel unwell or have a fever, you will need to check your temperature and either call the Cancer Clinic or seek medical attention on a more urgent basis if you have a fever.

Some other hygienic recommendations include:

- Shower daily
- Perform regular mouth care
- For dry skin, use a mild moisturizer or baby oil after showering
- Avoid lotions with alcohol and fragrances
- Use your own clean towel and face cloth every day
- Avoid close contact with people who are ill or coughing
- Avoid crowded areas where close contact with persons with respiratory illnesses is likely; instead try visiting public places at times when they are less busy
- Do not use tampons for the first 12 months after CAR T-cell therapy

Be sure to notify your health care team if you will be or have been in contact with children that have been immunized with live virus vaccines who has developed a rash or fever, or a child who has chicken pox, measles or other viruses.

Special blood work can detect specific viral levels. These common viruses do not cause illness in a healthy person, but can reactivate in your body after CAR T-cell therapy because of your weakened immune system. Here is additional information on specific viruses that are closely monitored:

### Cytomegalovirus (CMV)

- Many adults have been exposed to CMV in their lifetime, usually without knowing it
- Following exposure the virus remains asleep in your body without causing symptoms
- Blood work is checked regularly to monitor for increased CMV levels, as required
- Medications are started if there is a rise in CMV levels, even without symptoms
- If there is progression to CMV disease, symptoms can be present in the lungs (CMV pneumonitis), colon (CMV colitis), liver (CMV hepatitis) and eyes (CMV retinitis)
- Admission to hospital may be required to treat CMV reactivation
- Early intervention is important

### Epstein Barr Virus (EBV) and Post-Transplant Lymphoproliferative Disorder (PTLD)

- Many adults have been exposed to EBV in their lifetime without symptoms; only a minority will have been diagnosed with mononucleosis, usually as an adolescent
- Following exposure, the virus remains “asleep” in your body without causing symptoms
- EBV-infected white blood cells can result in post-transplant lymphoproliferative disease (PTLD)
- Blood work is regularly monitored following transplant for detection of EBV reactivation
- Symptoms of PTLD can be vague (such as fever, weight loss, fatigue) and varies depending on the type and location of PTLD
- Intravenous medications are started with a rise in EBV levels, even without symptoms

### **Home & Environment**

Before returning home from hospital, it may be helpful to have your home thoroughly cleaned including cleaning and replacing all filters (air conditioning, heaters, and humidifiers). Exposure to molds and dusts can be risky while your immune system is weakened.

In order to protect yourself:

- Avoid yard work, gardening, and farming until your doctor says it's okay
- Avoid construction areas
- Avoid activities that expose you to dust or dirt; when near a construction site, wear a mask

You can do things such as:

#### CART

- Clear dishes from the table
- Wash dishes
- Make beds

Someone else should:

- Dust and vacuum
- Clean bathrooms with a disinfectant regularly, especially the tub and toilet

## Pets

It is okay to return home to your pets with some limitations. Dogs, cats, and fish do not pose a great risk of infection to you if you follow the guidelines below. If you have any other animals at home, please discuss it with your physician. It may be best to let someone else care for them for a while. If you do not have a pet, now is not the time to get a new pet.

- Have someone else clean your pet's cage, litter box, pen, or fish tank for the first 3 months
- Have your pet sleep in another room
- Be sure to wash your hands after petting and handling your pet
- Avoid being scratched by your cat
- Do not have your pet's litter box or cage in kitchen where food is prepared and eaten
- Do not let your pets lick you – keep them away from your face
- Only feed your pet with food that has been bought from a store
- Ensure your pet's vaccinations are up to date
- Take your pet to veterinarian at the first sign of illness

## Diet & Food Preparation

While food safety is important to everyone, CAR T-cell therapy patients are at an increased risk of developing a serious illness from eating foods with bacteria, viruses, or parasites. Refer to the *SHA Food Safety for Patient's with Weakened Immune System* booklet for more information on what foods to avoid for the first 3 months after CAR T-cell therapy.

It is common for your appetite to remain lower than normal when you leave hospital. Good nutrition is important to help prevent infections, maintain and rebuild your muscles, and restore energy. Your dietitian can help you with strategies to get the calories you need and provide teaching on safe food preparation and storage.

Some suggestions for safe foods and foods to avoid include the following:

Type of Food	Foods to Avoid	Safer Food Choices
<b>Deli Meat and Hot Dogs</b>	Non-dried deli meats, such as bologna, roast beef and turkey breast. Cold hot dogs straight from the package.	Dried and salted deli meats such as salami and pepperoni. Non-dried deli meats heated until steaming hot. Hot dogs cooked to safe internal temperatures (74 F).
<b>Meat, Poultry, and Pâtés</b>	Raw or undercooked meat or poultry, such as rare steak or steak tartare. Fresh pâtés and meat spreads.	Meat and poultry cooked to a safe internal temperature. Pâtés and meat spreads sold in cans.

**Seafood**

Raw or undercooked seafood such as sushi, poke bowls. Raw oysters, clams, and mussels. Refrigerated, smoked seafood.

Seafood cooked to a safe internal temperature of 74 C (165 F). Cook until the shell has opened. Canned seafood (smoked salmon, canned tuna, etc)

*Food suggestions cont.*

**Other**

Any foods/fluids with probiotics added (ex Activia and Danactive yogurt, Kefir, Yakult and Good Belly drinks). Home canned goods (jam, preserves pickled foods). Fresh fermented foods

Canned goods commercially made and processed.

Commercially fermented foods that have been pasteurized after fermentation

**Eggs and Egg Products**

Raw or lightly cooked eggs or egg products including salad dressings, cookie dough, or cake batter, homemade mayonnaise, aioli and homemade eggnog.

Egg dishes thoroughly cooked to a safe internal temperature.

Eggs should be cooked until the yolk is firm.

Homemade eggnog must be heated to 71°C (160°F).

Pasteurized egg products in a carton.

Commercially made mayonnaise and salad dressings

**Dairy Products**

Raw or unpasteurized dairy products including unpasteurized milk, soft and semi-soft cheese such as Brie, Camembert and blue-veined cheese.

Pasteurized dairy products, and hard cheeses, such as Colby, Cheddar, Swiss and Parmesan.

**Sprouts**

Raw sprouts such as alfalfa and bean sprouts.

Thoroughly cooked sprouts.

**Beverages**

Unpasteurized fruit/vegetable juice, cider, beer or other unpasteurized alcohol, kombucha tea.

Pasteurized fruit/vegetable juice, cider or beer.

Check with a doctor before consuming any alcohol.

CAR T

<b>Water</b>	Well water that has not passed safety tests (major ion test and bacterial test) by the local health department	Municipal tap water, bottled water, well water that has passed a safety test, boiled well water
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Source: Health Canada and the Canadian Food Inspection Agency

Even though you may not feel like eating, good nutrition during and after CAR T-cell therapy is important to maintain your strength and help your body recover.

Here are some more helpful tips when it comes to eating after your treatment:

<b>Make every bite count</b>	Eat high calorie, high protein foods, such as ice cream/non-dairy frozen dessert, yogurt, sour cream, nut butters, smoothies, milkshakes, dried fruit, nuts, eggs, fish, meat, cheese, dried beans, peas and lentils Drink homogenized milk instead of 2%, and try cream-based soups instead of clear soups
<b>Make every sip count</b>	Drink a high protein high calorie supplement drink throughout the day such as Ensure or Boost, or make your own high protein high calorie drink by mixing 1 tablespoon of skim milk powder, 1 cup of cow or soy milk, 1 banana (or ½ cup of your favourite fruit) and ½ cup of ice-cream. Blend all of these ingredients and serve chilled.
<b>Eat often</b>	Aim to eat 6–8 small meals daily instead of 2–3 large meals. Ideas include granola bars and milk, cheese and crackers, toast and peanut butter, bagel and cream cheese, pita bread and hummus or tzatziki, chips and dip, dried fruit, trail mix, pudding (rice, tapioca), cookies, fruit custard.
<b>AND...</b>	Eat in a pleasant atmosphere with family or friends to raise your spirits

Temporary changes to your sense of taste may last several weeks. Food may taste bitter or metallic. Some ways you can try to cope with these taste changes are:

- Eat when you are hungry rather than just at meal times
- Rinse your mouth before and after eating to help clear taste buds
- Keep trying different foods - keep a list of foods that taste good to you
- Citrus fruits, such as oranges or lemons, can help stimulate the taste buds, but avoid citrus fruits if they irritate your mouth or if you have mouth sores
- Use seasonings to make foods taste better, but be cautious with spices and seasonings as they can irritate a sore mouth and bother an upset stomach.
- Try marinating meats; if red meats don't taste good, try other sources of protein such as chicken, eggs, fish, peanut butter, beans or dairy products
- If food tastes metallic, use plastic utensils instead of metal
- Suck on sugar-free lemon candies or mints, or chew gum, to help get rid of unpleasant after-tastes

The Saskatoon Cancer Centre and Allan Blair Cancer Centre have outpatient dietitians available for ongoing support. If you have further questions or concerns after you leave hospital, please discuss these with your primary nurse who can initiate an outpatient dietitian referral.



Chemotherapy and some medications can affect the liver. Do not drink alcoholic beverages during treatment and for 3 months after CAR T-cell therapy, and in some cases longer. Check with your physician before consuming alcoholic beverages.

### Activity/Exercise

It is important to continue activity and exercise as tolerated after leaving hospital. Some benefits of exercise after CAR T-cell therapy include:

- Decreased incidence of chest infections and blood clots
- Improved mental and emotional well-being
- Improved sleep
- Decreased need for pain medication
- Improved heart function
- Increased appetite

After being discharged from hospital, it is important to get out and do things you enjoy. However, try to stay away from crowded areas for the first 3 months after your CAR T-cell infusion, such as malls, buses, and movie theatres. It is better to visit these areas during less busy times to minimize the risk of coming into contact with someone sick. Continue with strict hand washing after such activities.

Fatigue tends to last for some time after CAR T-cell therapy. Increase activity over time and take frequent rest breaks. Before starting any strenuous activity, check with your health care team. If your hemoglobin is quite low you may experience fatigue, shortness of breath, lightheadedness and a rapid heart rate. When your platelets are low, you may bruise and bleed easier so should avoid high impact activities such as running to prevent injury to muscles and joints.

Avoid swimming in lakes, rivers, swimming pools and hot tubs for 3 months after CAR T-cell therapy.

### Smoking

We strongly encourage you to quit smoking if you are a smoker, and avoid second-hand smoke as it can lead to infections and lung complications. Smoking includes cigarettes, cigars, pipes, marijuana, inhaling cocaine and chewing tobacco. If you need assistance with quitting smoking, please talk to your health care team.

### Plants & Flowers

Soil contains bacteria, fungi and molds that can cause infections. It is not necessary for you to remove all houseplants, but we recommend that you do not re-pot plants or flowers. Avoid gardening, raking leaves, and mowing the lawn until your doctor says that it is safe to do so. When you get the okay to go back to gardening, be sure to wear gloves for at least 3 months.

## Sun

Chemotherapy can make your skin more sensitive to the sun so avoid direct sun exposure on the skin especially for the first 3 months after CAR T-cell therapy. Use a sunscreen with an SPF of 30 or higher, and wear a wig, scarf or cap when outside. Sunscreen should be used along with shade, clothing and hats, not instead of them. Try to avoid direct and prolonged exposure to sunlight especially between the hours of 1:00 pm and 3:00 pm. Be especially careful of areas that can reflect sun/UV rays such as the beach, water and swimming pools.

## Sexual Intimacy

The extent to which CAR T-cell therapy affects one's sexual life varies, but it is normal to feel a decrease in sexual desire after treatment. Contributing factors include hormone changes, fatigue, pain, and changes in self-image. Please discuss questions and concerns with your health care providers at any time.

Resuming intimate relationships will take patience and time. While it is safe to have sex once your blood counts have recovered (platelets >50,000 and neutrophils > 1500), it can take several months or more for your libido to return, therefore open communication with your partner is key. Feel free to kiss, hug, and sleep in the same bed as your partner unless they are ill. Touching and caressing usually involves less energy than sexual intercourse and can provide an ongoing sense of intimacy.

It is unlikely that you will be able to become pregnant or father a child after CAR T-cell therapy. Men and women should continue with birth control measures for at least 3 months following CAR T-cell therapy, then consult their physician.

Women who were pre-menopausal may experience some symptoms of menopause such as:

- Hot flashes
- Loss of bone mass
- Vaginal dryness
- Mood swings
- Decreased interest

These symptoms can occur because of the lack of ovarian hormone production. Using lubricants, gels, or other vaginal creams (such as K-Y® jelly) may help to relieve some of the vaginal discomfort. Consult your physician with concerns as they can refer you to a specialist to help with some of these issues. Please feel open to discuss any questions and concerns with your health care providers at any time.

## Fatigue

Fatigue is one of the most common concerns following CAR T-cell therapy, and can significantly affect your quality of life. One of the most common causes of fatigue are the side effects of chemotherapy. Other factors that can contribute to fatigue are disruption of

eating and sleeping habits that are often due to nausea, pain, and/or changes in routines. It may be helpful to know that everyone feels and deals with fatigue differently.

Here are some helpful tips to assist you in dealing with fatigue:

- Be active: Research shows that exercise is the best way to improve your energy
- Improve your sleep: Try waking up at the same time each morning; at night, relax before going to bed by doing activities such as reading, listening to music, or taking a warm bath
- Manage stress and emotions: Talking to someone about your feelings or doing activities to relieve stress and anxiety can help with fatigue
- Pace yourself: Use your energy wisely in order to be able to do the things that are most important to you; rest between activities; try easier or shorter versions of the activities you enjoy
- Eat as well as you can, and drink plenty of fluids
- Ask your family or friends to help you with tasks you find difficult or taxing
- Keep a diary of how you feel each day to help you with planning your daily activities
- Cultivate an interest in less strenuous activities such as listening to music or reading

## Returning to Work or School

In general, expect to be off work or school for at least 3 to 12 months following CAR T-cell therapy in order to allow adequate time for recovery of blood counts, immunity, and overall well-being. This timeline may vary based on your tolerance of treatment, in addition to your work/school environment and other factors. It is important to begin this discussion with your health care team following your discharge from hospital to ensure that expectations are realistic.

## Travel

For at least the first 3 months following CAR T-cell therapy, you should talk to your physician or nurse practitioner before planning travel. Activities that increase potentially dangerous environmental exposures such as gardening, camping, hunting, and fishing are discouraged during this early recovery period.

If your travel plans involve travel by air, you should discuss the potential concerns and complications with health care team before booking your trip. Certain destinations require vaccinations before travelling there; however, because your immune system is still new, it may not be strong enough to react well enough to the vaccinations to protect you. In general, short trips in which you have control over the environment are safe, particularly to locations where a full-service health care center is located in case complications arise.

## Immunizations

Following CAR T-cell therapy, your immune system is less capable of fighting off common infections for months. All childhood vaccinations will need to be repeated. Approximately 6 months after CAR T-cell therapy, you will receive a letter from the SCTCTP coordinator with instructions to begin immunizations. Approximately one year after CAR T-cell therapy, you will receive another letter outlining the process for further re-immunization, which you can then arrange through your public health office. "Killed" vaccines can only be given one year after CAR T-cell therapy, and "live" vaccines after two years.

In addition, all CAR T-cell therapy patients should receive a flu shot each year starting 4 months after CAR T-cell infusion; discuss with your physician or NP prior to arranging this. Household members and close contacts are also encouraged to receive the flu vaccine. Please discuss any questions or concerns with your health care team.

## Shingles

Shingles is a painful blister-like rash that is often on one side of the chest or back, but it can also affect other areas including the face. You may feel burning, itching, or tingling up to two days before the rash appears. It is very important to seek medical attention as soon as possible once the rash appears to start on treatment if you think you have shingles.

Shingles are caused by the same virus that causes chickenpox (called Varicella Zoster). Once you have had chickenpox, the virus remains asleep in the body but can be reactivated when your immune system is weakened. You will be on an antiviral medication to prevent shingles for some time after receiving CAR T-cell therapy.

These viruses can be easily passed on to others who have never had chickenpox or vaccinations. It is important to avoid contact with anyone who has been exposed or has an active infection. Report any exposure to chickenpox or shingles to your health care team immediately.

**Be sure to report blister-like rashes, or exposure to chickenpox or shingles to your health care team as soon as possible**

Shingles vaccinations are recommended post-treatment and should be first discussed with your CAR T physician.

## Coping and Support

Although having a serious illness is an experience that permanently changes you and your relationships, that change does not necessarily have to be negative. It is common to

be anxious for things to “get back to normal”, and it can be frustrating if this does not happen as expected. Understanding that you can create a new normal can help with the frustration. In fact, some people find the experience quite positive. Many patients and family members come through treatment with a new appreciation for life, sometimes taking on different roles within their family and community, and seeing their lives and futures in a different light. This transition period is a process and is something that your social worker can help with and support you through, if you choose.

A resilient attitude is essential. Your emotions may go up and down - try not to be too hard on yourself, and try to accept what you are feeling. Try to take one day at a time, knowing that you will have good days and bad days. The after-effects of chemotherapy and CAR T-cell therapy can be hard, and recovery can be a very slow and difficult process. Be patient with yourself. For both you and your family, recognizing and acknowledging feelings and concerns is the starting point to developing physical, mental, emotional, and spiritual strengths in the face of your diagnosis and treatment.

## 7. Long Term Follow Up

Approximately 3 months following CAR T-cell therapy, tests such as PET scans, bone marrow biopsy along with blood tests will be done to evaluate the response to the treatment. Typically, at this time, you will also be referred back to your primary physician at the Allan Blair Cancer Center (ABCC) or the Saskatoon Cancer Center (SCC), if your CAR T-cell therapy physician was not your primary physician. This will be discussed with you to address any questions you may have. Your doctor will decide how often follow up needs to be done. Because there can be long-term effects following CAR T-cell therapy, regular follow-up with your doctor continues to be important.

Patients usually return to a relatively normal lifestyle about 6-12 months after CAR T-cell therapy.

### **Mixed emotions**

You may feel many different emotions after your CAR T-cell therapy. These feelings are a natural response to stress and usually lessen over time. If these feelings interfere with your daily life, you should talk to your doctor, nurse practitioner, or social worker. Persistent sad feelings and lack of interest in things you normally enjoy could be signs of depression.

### **Secondary malignancies**

Chemotherapy can increase the risk of developing a new cancer or what is called a "secondary cancer," particularly as a late complication of high-dose chemotherapy. It is important to be aware of the risk of a secondary cancer and discuss with your CAR T physician.

### **Disease relapse**

It is important to understand the goal of receiving CAR T-cell therapy in your situation. Sometimes the goal is to get your disease into remission for as long as possible. Other times the goal is to achieve lifelong remission or cure of the disease. In this situation, even after going through CAR T therapy there is a chance the disease could return. Talk to your physician about the likelihood of this happening.

### **Regular health screening**

It is very important to remain in contact with your family doctor or nurse practitioner. Your health care team will be very involved for the first 3 months; however, your family doctor or nurse practitioner will ensure that you have age-recommended health screening

CAR T

including mammograms, pap smears, FIT tests, colonoscopy, prostate checks and so on, as appropriate.



It is important to keep in touch with your family physician or nurse practitioner for non-CAR T related concerns and health screening.

# RESOURCES

## Further Information

If you wish to access further information regarding your particular disease and the CART process, some reliable sources of information include:

- **Cancer Information Services** (Canadian Cancer Society), 1-888-939-3333
- **Saskatoon Cancer Centre and Allan Blair Cancer Centre Patient and Family Resource Centres**
  - [www.saskcancer.ca](http://www.saskcancer.ca) <<Patient and Families>> Managing Side Effects
  - Patient Library
- **Internet Sites** (Note: these sites are provided as reference only - the BMT Program does not endorse specific information provided by these sites)
  - Lymphoma Foundation Canada, [www.lymphoma.ca](http://www.lymphoma.ca)
  - Leukemia and Lymphoma Society (LLS), [www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)
  - LLS- Young Adults (18-39), [www.LLS.org/YAconnect](http://www.LLS.org/YAconnect)
  - Lymphoma Information Network, [www.lymphomainfo.net](http://www.lymphomainfo.net)
  - Myeloma Canada, (514) 570-9769, [www.myelomacanada.ca](http://www.myelomacanada.ca)
  - The Canadian Cancer Society, [www.cancer.ca](http://www.cancer.ca)
  - People Living With Cancer, <http://www.plwc.org>
  - Medline, [www.nlm.nih.gov](http://www.nlm.nih.gov)
  - Young Adult Cancer Canada, [www.youngadultcancer.ca](http://www.youngadultcancer.ca)
  - Caringbridge, [www.caringbridge.org](http://www.caringbridge.org)
  - Lotsa Helping Hands: A site to coordinate care, [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)
  - Cancerchat Canada, [www.cancerchatcanada.ca](http://www.cancerchatcanada.ca)

Please remember not everything you read about cancer will apply to you, and not all information on the internet is reliable. The best source of information for your individual case is your hematologist and the health care team. While it is important to be informed, some patients find too much information overwhelming - you are the best judge of how much is right for you.

## Support Groups

- **Look Good Feel Better**  
This popular workshop is held the 2<sup>nd</sup> Thursday of the month for *women only*, providing tips on looking your best while going through your treatments. The sessions are led by a professional cosmetologist. Please note that space is limited and sessions tend to fill quickly.



- **Saskatchewan Multiple Myeloma Support Groups**

The Saskatchewan Myeloma Support Groups welcome all multiple myeloma patients, caregivers and family to join in a sharing, caring and positive environment, centered around mutual support and keeping up with the latest developments in treatment and care.

- Regina [reginasupport@myeloma.ca](mailto:reginasupport@myeloma.ca)
- Saskatoon [saskatoonsupport@myeloma.ca](mailto:saskatoonsupport@myeloma.ca)
- Facebook Saskatoon Myeloma Support Group

- **First Connection Program (Leukemia & Lymphoma Society of Canada)**

Connects patients, families, and caregivers with individuals who have personally experienced the challenges of dealing with a diagnosis of leukemia, lymphoma, myeloma or myelodysplastic syndrome.

- Phone: 1-866-547-5433, press 2, extension 8

- **CancerConnection**

*CancerConnection* is a one-to-one telephone-based support service that matches people who are living through an experience with cancer with trained volunteers who recently have had cancer.

Every effort is made to match you with a cancer survivor with a similar diagnosis and treatment. Caregiver support and connecting caregivers is also offered.

- To access *CancerConnection*, call the *Canadian Cancer Society* toll free at 1-800-263-6750.

- **Emotional Support and Counselling**

The emotional impact of treatment and transplant can be very significant. Understanding how you and your caregivers/family are affected emotionally can help with coping. Counselling is available to you and your family – please ask for help when you need it. Social workers are available to meet with you to discuss any concerns, and provide counselling to you and your support person.

- **Young Adult Support Group**

Our Young Adult Program (YAP) provides emotional and practical support to anyone aged 18-39 who has had a cancer diagnosis.

YAP aims to help those facing the challenges surrounding a cancer diagnosis by providing a safe place where young adults can find peer and professional supports to help them as they go through diagnosis, treatment and recovery.

More information is available at [www.saskcancer.ca](http://www.saskcancer.ca) <Patients and Families> <Support Services> <Young Adult Program>.

CART

- **Young Adult Cancer Canada (YACC)**

Young Adult Cancer Canada (YACC) supports young adults living with, through, and beyond cancer in Canada.

More information is available at [YACC'S GOT YOUR BACK \(youngadultcancer.ca\)](http://youngadultcancer.ca)

# Glossary

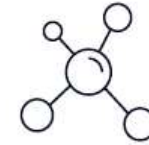
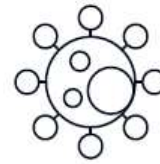
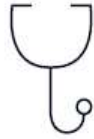


TERM	DESCRIPTION
Absolute Neutrophil Count (ANC)	The total number of neutrophils (infection-fighting cells) in your blood; a very low ANC means the risk of infection is very high
Activities of Daily Living (ADLs)	Activities of everyday living such as bathing, dressing, eating, and using the toilet
Apheresis	A procedure in which peripheral blood cells are collected from the blood stream
Bone Marrow	This is the tissue found in the soft center of bones. It creates blood cells (red blood cells, white blood cells and platelets)
Bridging therapy	Treatment used to prevent disease progression from the time of cell collection until CAR T-cell infusion. Not all patients will require bridging therapy.
Capillary leak syndrome	Can occur when fluid and proteins leak out of tiny blood vessels and flow into surrounding tissues, resulting in dangerously low blood pressure
Central Venous Catheter (CVC)	A small tube inserted into a large vein leading to the heart that can be used to collect cells as well as to draw blood and infuse intravenous fluids, medications and cells
Collection	The process of collecting cells through peripheral blood cell apheresis; also referred to as "harvest"
Conditioning Chemotherapy	High dose chemotherapy drug(s) given to destroy cancer cells before receiving the cells as a rescue
Cytomegalovirus (CMV)	A relatively common herpes virus that can cause complications in immunocompromised patients
Day 0	Day of CAR T cell infusion
Hemophagocytic lymphohistiocytosis (HLH)	Life-threatening immune system activation
ICU	Intensive care unit

TERM	DESCRIPTION
Infectious Disease Markers (IDMs)	Blood tests that indicate whether a person has been exposed to specific viruses such as cytomegalovirus (CMV), hepatitis, HIV, HTLV, syphilis, varicella, etc.)
Macrophages	Infection-fighting cells that protect against foreign cells in the body
Macrophage activation syndrome (MAS)	Life-threatening activation of macrophages







### Patient referral and entry

Patient qualifies and is referred to a CAR T physician

### Patient eligibility

Patient undergoes pretreatment eligibility assessment

### Leuka- pheresis

Peripheral blood mononuclear cells undergo apheresis and are shipped to a manufacturing facility

### Conditioning therapy

Patient undergoes conditioning chemotherapy during cell processing

### CAR T creation and expansion

CAR T-encoding genetic material is transferred via viral vector— CAR T cells are then expanded

### CAR T infusion

CAR T cells are administered to patient following lympho-depletion

### Monitoring

Patient is closely monitored with a long-term follow-up plan

Image Credit: Sarah Nam, et al, Mackinsey and Company



Your caregiver will need to be with you for a minimum of 4 weeks after CAR T-cell infusion.



After receiving your CAR T-cell infusion you cannot drive for 8 weeks.



You must stay within 30 minutes of Saskatoon for at least 4 weeks after your CAR T-cell infusion.



There is a high chance of requiring the intensive care unit.