CAR T-Cell Therapy

Information for Patients and Families

Treatment — Blood and Marrow Transplant

Please bring this book to all of your appointments.

Alberta Health Services

There is a lot of information in this book.

- It's a good idea for you and your caregiver(s) to read this information before your first meeting with the team so you come prepared.
- Write down your questions and bring them with you to your meeting.

You have been referred by your oncologist, or hematologist to talk about **CAR T-cell therapy** and if it is a treatment option for you.

Both Alberta healthcare providers and patient and family advisors helped create this resource to answer your questions. It will help you, and your family and friends:

- talk with your cancer care team about whether this treatment is right for you
- understand key information about living well through CAR T-cell therapy

Information included in this book:

- CAR T-cell therapy — how it works and how it's used to treat your illness
- The steps for how T-cells (one kind of white blood cell) are collected from your blood, how T-cells are changed in a lab to target your cancer, and how your CAR T-cells are given back to you
- Possible side effects or complications you may have during and after CAR T-cell therapy
- How to recognize the side effects and how to manage them and care for yourself with the help of your care team
- Things that may help with your emotional and mental well-being

If there is any information you do not understand, ask your care team to review it with you.

Patients from out of town

An important thing to know before you start treatment is that CAR T-cell therapy is **only offered at the Calgary and Edmonton cancer centres**. If you **live more than 1 hour away** from the cancer centre where you are receiving treatment, you may need accommodations at certain points during your treatment. Your care team will give you more information.

Watch for this yellow symbol in this book. It reminds you when you might need to stay in the city.

For more information:
Other Alberta cancer care resources are available at your cancer centre or online:
ahs.ca/cancertreatment

A. Understanding CAR T-Cell Therapy

CAR T-Cell Therapy

CAR T-cell therapy is a treatment that helps your immune system find and attack cancer cells. This treatment is one kind of immunotherapy. Immunotherapies work with your immune system to help fight cancer. Different immuontherapies work in different ways. CAR T-cell therapy may be a treatment option for you if other options have not worked in the past. You'll need to talk to the doctor to see if CAR T-cell therapy is right for you and how this treatment may help your disease.

The Immune System

What is the immune system?

The immune system is made up of many cells and tissues found all over your body that work together to keep you healthy. It protects your body from harmful things such as bacteria, viruses, fungi (like mold or yeast), and cancer. It usually does a good job of keeping people healthy and preventing infections. Sometimes cancer can hide from the immune system. One of the important cells that helps the immune system protect you is called a T-cell.

What are T-cells?

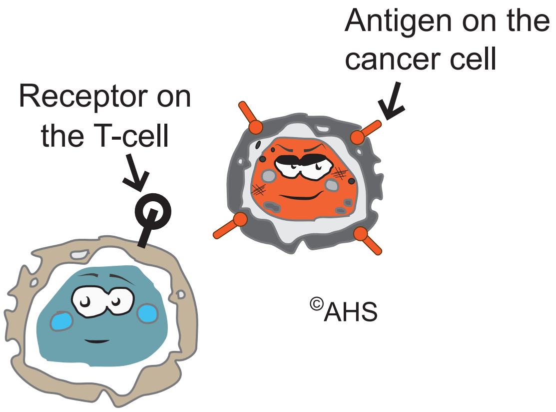
Each person has a special type of white blood cell in their body called a T-cell. The T-cells find, fight and kill cells that are not normal or do not belong, like cancer.

How do T-cells work?

When T-cells recognize harmful substances in the body, they work to get rid of them. They do this by attaching to **antigens** (proteins) on the outside of cancer cells.

T-cells have their own proteins called **receptors.** It is a little like a lock and key system. The T-cell has to have the right "key" (receptor) to attach to the "lock" (antigen) on the cancer cell. When the T-cells attach to an antigen, they send a message out to other cells in your immune system to help find and kill the cancer cells.

Sometimes the cancer cells have an antigen that the T-cells do not recognize (the key does not fit the lock). When this happens, the immune system cannot find the cancer cells and they are able to continue to grow.



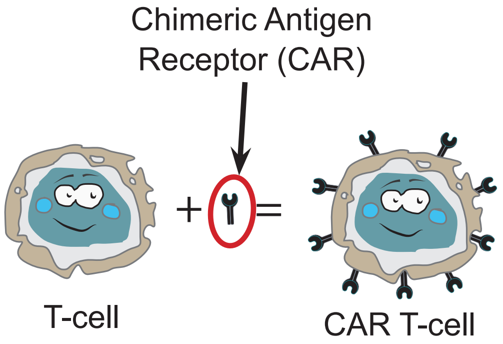
The T-cell has the wrong receptor and cannot find and attach to the cancer cell.

CAR T-Cells

What are CAR T-cells?

CAR T-cells are specially made in a lab using your own T-cells. First, your T-cells are collected from your bloodstream using a special process called apheresis (see **page 11**). After they are collected, your T-cells are sent to a lab.

At the lab, a CAR **(chimeric antigen receptor)** is added to the T-cells, which makes it easier for the T-cells to find and destroy cancer cells.



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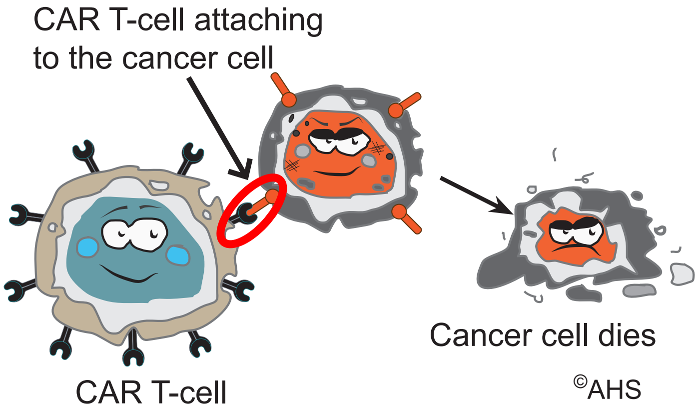
Once the lab has produced enough CAR T-cells, they are then infused back into your bloodstream to find and destroy your cancer cells (**page 16**). They do this by attaching themselves to the antigens on the cancer cells.



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The CAR T-cell can now destroy the cancer cell.

Why are they called CAR T-cells?

Chimeric — (ky-MEER-ik) a word used when things from different origins are joined. In this case, the CAR antigens are joined to T-cells.

Antigens — these are proteins found on the cancer cell.

Receptors — these are found on the surface of the altered T-cell. They act like a key and can open the antigens on the cancer cell. These receptors search for the matching antigen on a cancer cell so the T-cell can "unlock" it and destroy it.

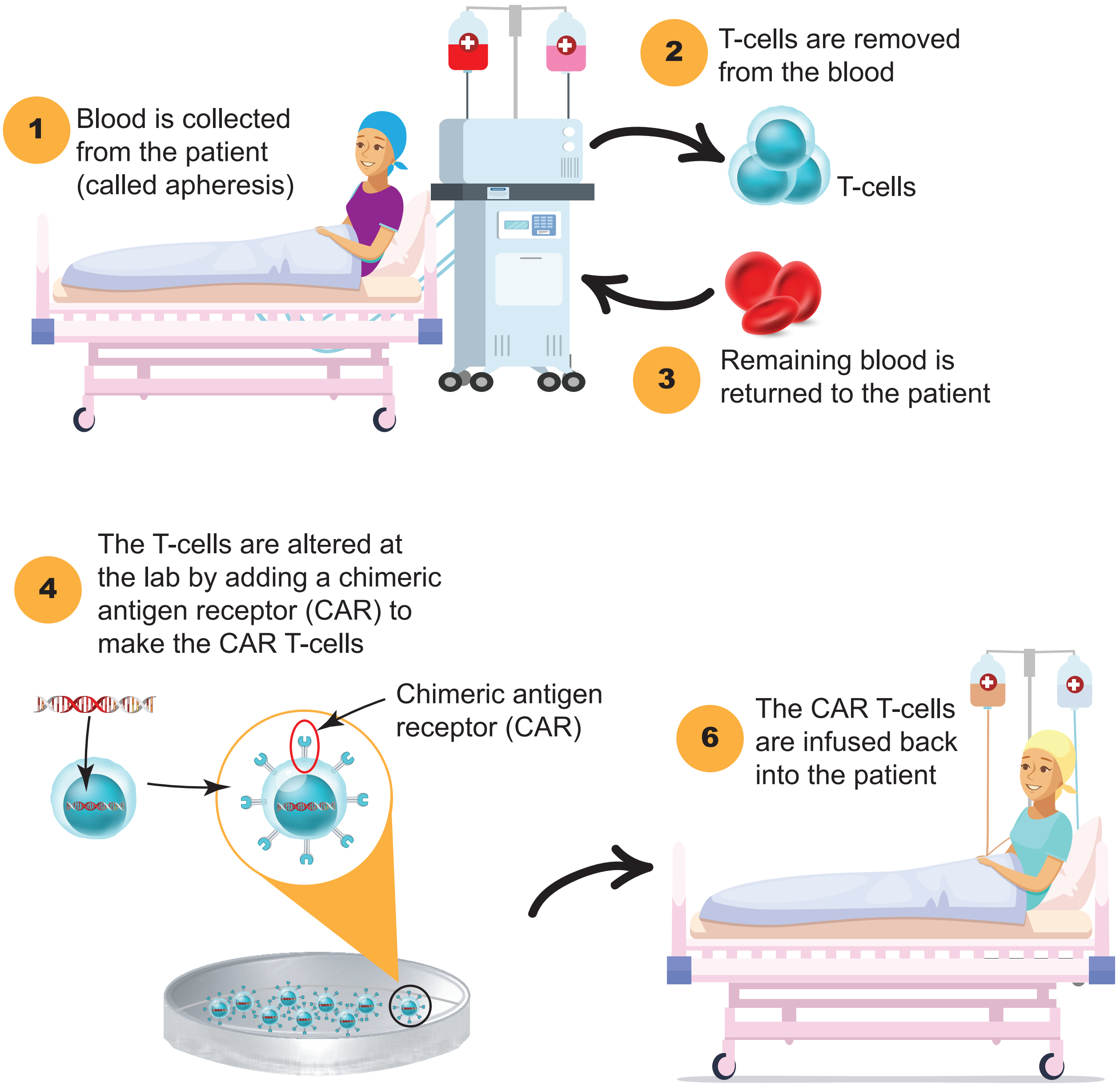
T-cells — once the CAR is added, your T-cells become much better at finding and destroying the cancer cells in the body.

Did You Know?

In Greek mythology, a **chimera** was a monster with a lion's head, a goat's body and a snake for a tail.

Steps of CAR T-Cell Therapy

Below is an image showing some of the basic steps to CAR T-cell therapy. This book will go into more detail and tell you how each step is done.



1 Blood is collected from the patient (called apheresis)

2 T-cells are removed from the blood

3 Remaining blood is returned to the patient

4 The T-cells are altered at the lab by adding a chimeric antigen receptor (CAR) to make the CAR T-cells

5 Millions of the CAR T-cells are grown at the lab

6 The CAR T-cells are infused back into the patient

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CAR T-Cell Journey

If you go ahead with the therapy, the entire process can take a few months. Your path will depend on many things, but your care team will be there to guide and support you.

This map briefly shows some of the main steps of the CAR T-cell therapy process.

Referred to program

Your first consult

Screening tests

Collecting your T-cells (apheresis)

Bridging therapy (if needed)

Lymphodepleting Chemotherapy

CAR T-cell Infusion

Weeks 1-4 after infusion

Long-term follow-up care

Immunizations

Remember that CAR T-cell therapy is **only offered at the Calgary and Edmonton cancer centres**. This means that if you live more than 1 hour away from the cancer centre where you are receiving treatment, you may need accommodations at certain points during your treatment. Watch for this yellow symbol in this book. It reminds you when you might need to stay in the city.

Patients from out of town

Please be aware that you **cannot drive for 2 months (8 weeks)** after your CAR T-cell infusion.

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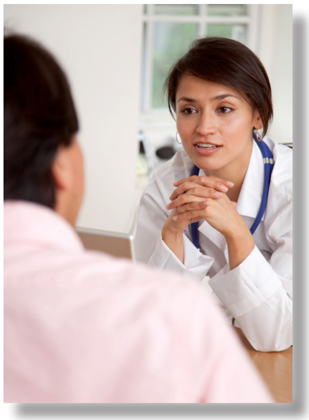
B. Getting Ready for CAR T-Cell Therapy

Your First Meeting — Consultation

You, your support person, and/or your family will meet with your doctor and nurse coordinator to talk about using CAR T-cell therapy to treat your illness.
Here are some of the questions we will answer during the meeting:



What is the reason for the therapy?

- Why the therapy is an important part of your treatment
- How the therapy will benefit you
- Why it is the best choice for you
- The expected risks
- What can happen if you choose not to have it and discuss other options

When will I get CAR T-cell therapy?

The decision about when to do CAR T-cell therapy depends on many things like the response to your current treatment.

The care team will talk to you about your schedule and timelines.

How long will the time commitment be?

It can take around 1-3 months from the time of your consult to the time you are discharged from hospital after the infusion. You will likely stay in hospital for about 2 weeks after you receive your cells, but the length of your stay is decided by your doctor based on how well you are.

You will likely need to stay within 1 hour of the city for about 4 weeks after your infusion. You need a caregiver to stay with you during that time (see page 7). Recovery at home can take weeks to months.

What tests and procedures will I need before my therapy?

Once you consent to the therapy, you will begin a lot of tests and procedures. Tests will be done to examine your heart, lungs, and kidney functions. You will need to have some blood work done before starting apheresis.

You may also get a central line put in place for your chemotherapy and cell infusion. It is a long tube that is inserted through your skin into a large vein. It can be used to collect and infuse T-cells, draw blood and to give chemotherapy, fluids, medication or blood products. If you need more information, ask your nurse.

What about medicine and drug coverage?

Sometimes there may be some medications that you will need to pay for, or your drug plan may need to cover. A social worker may be able to help with this.

Tip!

If you do not have a drug plan, let your care team know **as soon as possible**.

What if I want to start a family?

Some cancer treatments can affect your ability to become pregnant or get someone pregnant. Talk to your care team if you have any questions about this.

What are the financial costs?

- Living expenses if you or your caregiver live an hour or more from your treatment centre.
- Any travelling costs such as fuel.
- Any medicines or medical supplies needed as an outpatient not covered under your drug plan.
- If you have a job or are in school, you will need to take time off during each of the CAR T-cell phases. When you can return back to work or school depends on how well you are after treatment.
- Your caregiver(s) may need to be off work or school to care for you after your infusion.
- Childcare for any children (yours or your caregivers).
- Parking costs at hospital.

If you have financial concerns with any of the above, you can ask to speak to a social worker. A social worker can assess your situation and see if there are any programs or supports available to help you. You may wish to speak to your tax preparation specialist to see if you are eligible to claim some of these expenses on your tax return.

What if I live out of town?

Patients from out of town

If you live more than a drive of 1 hour from the city, you may have to stay in town during the collection phase, the chemotherapy phase and on discharge from the hospital after your CAR T-cell infusion. Your doctor or nurse coordinator will let you know how long you will need to stay. This time away from home can be financially stressful.

Your nurse coordinator or social worker can provide you with information about accommodations and potential financial help if needed.

You can use the free AHS **My Care Conversations** app to prepare for your next appointment and to record conversations with your care team. You can listen to your recordings at home and share with family or trusted friends.

Download it from the App Store or Google Play.

Will I need a caregiver?

Caregivers play an important part in your recovery. Your caregiver(s) may be the same person or a group of people who take turns **but they must commit to the process.** After your CAR T-cell infusion, when you are discharged from the hospital, caregiver(s) need to be with you full-time including staying overnight.

For at least 8 weeks after your CAR T-cell infusion, you must not drive, use machinery, or take part in activities where you need to stay alert.

A caregiver can:

- drive you to and from the hospital
- give you emotional support
- make or remind you of appointments
- help give you your medicine
- care for your central line
- watch for and tell your care team about changes in your health
- care for the people you usually care for like children or parents
- help you with your everyday activities like laundry, shopping, or making meals
- help care for pets

Clinical Trials and Studies:

You may ask what clinical trials or research studies are available. If any are available, we may ask if you would like to join the trial. If you choose not to take part in the studies, your care will not be affected in any way.

Advance Care Planning:

The booklet **Conversations Matter** will tell you more about advance care planning. It helps you think about, talk about and document wishes for healthcare in case you become unable to consent to or refuse treatment or other care. Your care team will discuss this further with you. For more information, go to: **conversationsmatter.ca**

Work-Up Tests Before CAR T-Cell Therapy

Once you decide to proceed, we will begin planning your schedule for tests and important dates. This will be a very busy time for you as you may have many appointments.

Your schedule depends on:

- your treatment plan
- how quickly you need treatment
- what admission dates are available
- what dates are available for T-cell collection (apheresis)
- what times are available for tests and appointments
- the lab dates for CAR T-cells

Your nurse coordinator will give you a calendar and schedule. T-cell collection, appointments, or infusion dates may change. Someone will let you know if it does change.

Tell your care team if you:

- cannot go to an appointment. All tests are important steps to get you through the therapy. Missing appointments can affect future scheduled appointments.
- take or use any over-the-counter medications, herbal supplements, alcohol, cannabis products, or recreational drugs, as these can all affect cell collection.

Tip!

It is a good idea to have an answering machine, or voice mail so we can leave messages for you.

Remember to identify yourself in your recorded voice message, or we cannot leave a message.

During the work-up phase, you will have some or all of the tests and procedures below:

Blood work:

- Complete blood count (CBC)
- Chemistry
- Blood type
- Virology (including testing for hepatitis, HIV, West Nile virus, chickenpox, syphilis, cytomegalovirus, tuberculosis)
- Blood clotting time
- Pregnancy test

Other tests may include:

- Electrocardiogram (ECG)
- Pulmonary function test (PFT-lung function)
- Urine test
- Lumbar puncture
- Bone marrow aspirate, biopsy or both
- Echocardiogram/MUGA scan (heart function)/ cardiac MRI
- X-rays, CT and PET scans, and an MRI

You may also see a:

- Dietitian
- Psychologist
- Pharmacist
- Social worker
- Cardio-oncologist
- Dentist

Physical examination:

You will have a physical examination to check your overall health and to see if there are other tests you may need.

If you smoke or use tobacco products, your care team will try to support you quitting or reducing your use. This may help you have:

- A better chance of successful treatment
- Fewer serious side effects
- A faster recovery from treatment
- A decreased risk of the cancer coming back, or getting another cancer diagnosis
- A lower risk of infection
- Easier breathing
- More energy
- A better quality of life

For information or support: **www.AlbertaQuits.ca** or call 1-866-710-QUIT(7848)

Consenting to Treatment

Your doctor will explain everything you need to know about your treatment plan, but **you need to decide** if you want to have the treatment. You will get more information and consent forms to read after you meet with the care team.

You, as well as the doctor or the nurse practitioner, or the nurse coordinator, will sign the consent form. You will get a copy to keep. Signing the consent form means you understand and plan to go ahead with the treatment.

Once the care team receives your consent, they will enroll you into the CAR T-cell therapy program and start planning your T- cell collection and CAR T-cell infusion dates.

Consenting to treatment

You need to understand the treatment plan and risks before you sign the consent forms. Only agree to the procedure and sign the consent when you understand:

- how you will prepare for receiving your CAR T-cells
- the CAR T-cell therapy process and recovery, including the side effects and possible complications
- how it will affect you and your family or caregiver
- how your life could change because of side effects or complications you may have
- caregiver support is very important during this treatment process

If you do not understand or have more questions, ask the doctor or nurse coordinator to go over the information with you.

Helpful tips during CAR T-cell therapy:

Tip!

"If you are not sure about what you were told, and you are told a lot, then ask questions. I am a retired nurse, my husband was a veterinarian, and even with the background we had, we often were left wondering about all the information we were given. Ask until you get it!! And don't feel bad!

Mary ~ Caregiver

C. Collecting the T-cells

The process for creating your CAR T-cells starts after you decide to go ahead with this treatment. There are 3 main steps in this phase:

1. Preparing for your T-cell collection
2. Collecting the T-cells (apheresis phase)
3. Making the CAR T-cells in the lab

Preparing for Your T-Cell Collection

To help prepare for your T-cell collection, you will meet with an apheresis team, who has special training on how to collect the T-cells. **If you can, bring someone with you to the meeting.** They can help listen, ask questions and take notes.

What is covered in the apheresis consult:

- The nurse will explain the procedure, review how you can prepare, and answer your questions
- You may need to sign a separate consent for the apheresis procedure
- How your T-cells will be collected, which will be through a central line or through your arm veins

What can I do to prepare for the collection?

- The nurse or doctor will tell you what medications you should or should not take the day of the collection. Let them know if you are taking any blood pressure medication as you may need to withhold this before the procedure.
- Rest well the evening and night before
- Drink lots of fluids the night before
- Eat before coming for your procedure. You can bring food, snacks, and water with you to have during the procedure as well.
- Arrange to have someone drive you to and from the hospital

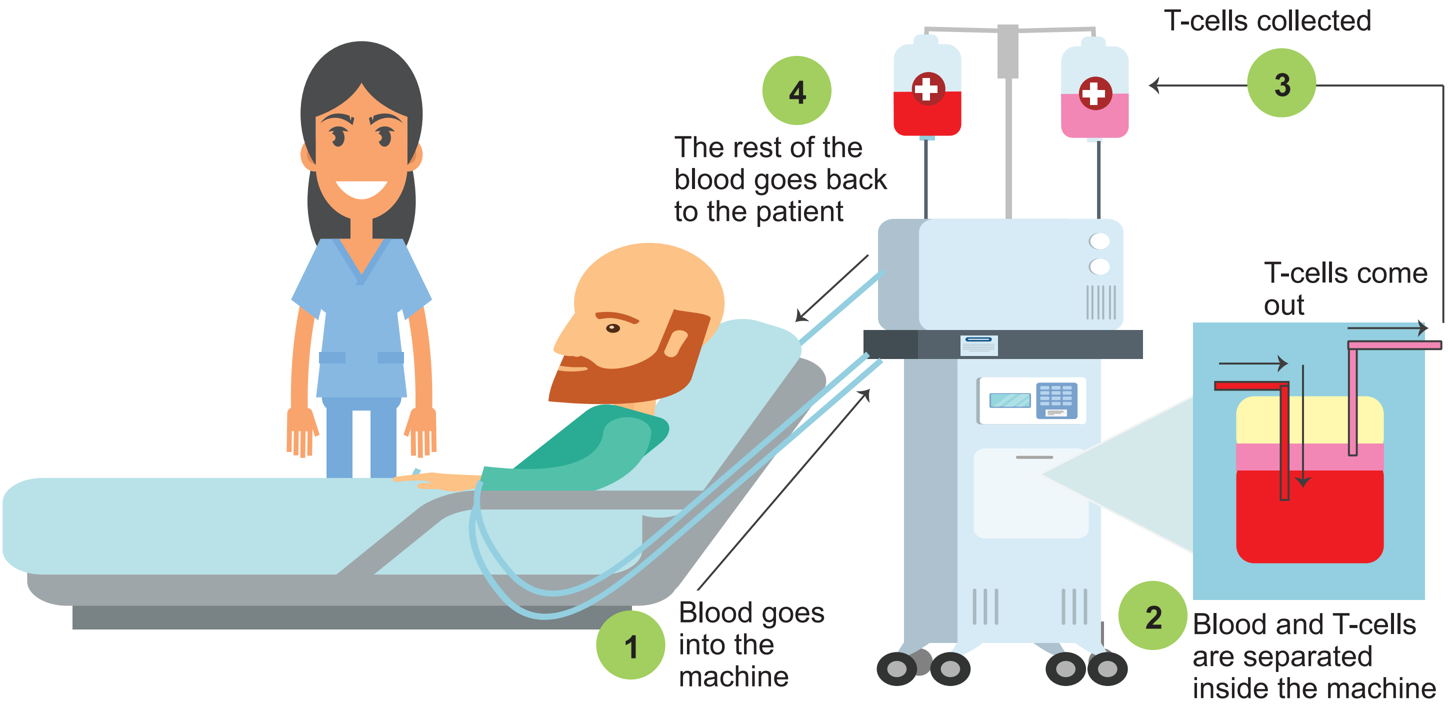
How will I know if I'm ready for my T-cells to be collected?
You will have blood work done either a couple of days before, or the morning of collection. Your care team will let you know if they're ready to be collected.

Collecting the T-Cells

How do you collect the T-cells?

To collect the T-cells, we use a process called **apheresis.** Apheresis means "to take out". Collecting the T-cells is almost like giving blood, except you get your blood back. Here's what will happen:

1. The blood (red blood cells, white blood cells, and platelets) go into a special machine.
2. The machine spins the blood and separates it into layers.
3. The layer containing your white blood cells (including your T-cells) move from the machine and into a collection bag.
4. The remaining blood is returned to you.



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How does the blood get into the machine?

We connect your central line or IVs to the **cell separator machine**. The blood will move to the machine through one IV tube, and the remaining blood will be returned to you through a different IV tube. The procedure is done as an outpatient and can usually be done in one day.

What to Expect During Your Collection

The apheresis nurse will stay with you during the collection, so if you have any questions or concerns, just ask.

Will the collection hurt?

The procedure is not painful. You may have some side effects but we can help you manage them to make you more comfortable.

Common side effect:	Cause:
Feeling dizzy or light-headed	Caused by the blood leaving your body — extra fluids are given by IV to help with this
Lower calcium levels in your blood that may cause: • a sour taste in your mouth • a tingling feeling around your lips, eyes, hands or feet • nausea • muscle cramps • stomach cramps	We mix a blood thinner with your blood so the blood will not clot when it moves through the machine. This medication affects your levels of calcium, magnesium and potassium. We will give you calcium during the procedure.

Tell your nurse right away if you feel side effects.

How long will it take to collect the T-cells?

T-cell collection is usually a one-day process, taking about 4-6 hours.

What can I do during the collection?

While you are attached to the apheresis machine, you have to stay in your chair or bed. If you have peripheral IVs (T-cells are collected through both arm veins), you will have limited use of your arms. You can bring books or an electronic device, like a tablet, to keep yourself busy, while your cells are being collected. Bring earphones if you plan to listen to something like a movie or music.

Will I be able to go to the bathroom during the procedure?

You must stay in bed while you are connected to the machine. If you need to use the washroom during the procedure, you will need to use something like a portable toilet chair, bedpan or urinal bottle.

What should I wear?

Wear clothing that is comfortable and loose-fitting.

Can I have visitors?

Check with your care team about the visiting policy.

Can I eat during the procedure?
Yes! Bring food and your favourite snacks and eat often throughout the day of your collection.

Can I drive after the collection?
You will need someone to drive you to and from the hospital on collection day(s).

Do I bring my medications?
Bring any medications you need to take in the day with you – this includes medications for pain or diabetes. Follow your usual routine for food and insulin or other diabetes medications and bring your diabetic supplies.

Do not take any blood pressure medications the morning of your cell collection, unless the care team says you can.

Checklist - Day of Collection

- ☐ wear clothing that is comfortable and loose
- ☐ arrange a ride to and from the hospital
- ☐ bring snacks, lunch, something to drink
- ☐ bring things to do — electronic devices, reading, movies (bring earphones if listening to movies or music)
- ☐ bring any medications you need
- ☐ arrange childcare if needed

After the Collection and Follow-up

Make sure to eat enough food and drink lots of fluids after your collection. You may also need to rest a little more than usual for 1-2 days after the procedure.

Are there any side effects I should watch for?
The side effects are usually minimal, but you may feel weaker, light-headed, or discomfort in the arm where the needle was inserted. This should only last 1-2 days.

Tell your care team if you have a fever, sore throat, cough, congestion, diarrhea, or a rash that is new or getting worse.

Contact your care team during regular hours, or call the after-hours number provided to you with any urgent concerns you may have after your collection.

If you have life-threatening concerns, call 911.

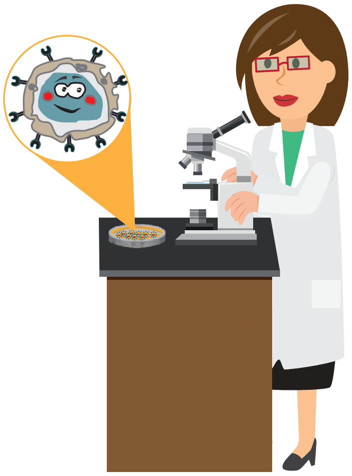
Making the CAR T-Cells in the Lab

What happens to the T-cells after the collection?

Once your cells are collected, they will be carefully packaged and sent to the CAR T-cell lab.

In the lab, the T-cells are altered by adding a receptor (CAR) to them. The new T-cells, now called CAR T-cells, grow and multiply in the lab to make enough to treat you. This can take 2-4 weeks, but your care team will tell you when they expect the cells to be ready.

Once there are enough CAR T-cells, they may need to be frozen and will be shipped back to your infusion centre, where they are stored safely until you are ready for treatment.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What happens while I wait for my treatment?

While you wait for your treatment, it is very important to call your care team if you notice any changes or illnesses, such as cold and flu symptoms.

Bridging/Monitoring While Waiting for Your CAR T-cells

While your CAR T-cells are being made, you will be monitored very closely by your care team. You may need to continue with blood work or other tests during this time as you wait for your cells to arrive. Sometimes patients need something called "bridging" therapy.

Bridging therapy is treatment used to manage your symptoms, shrink your tumour, and helps make sure you are well enough to receive your CAR T-cells. This treatment is offered depending on your disease and your disease status, and may consist of steroid therapy, chemotherapy, immunotherapy, radiation therapy, or a combination of these treatments.

D.

Your CAR T-Cell Infusion

Once your CAR T-cells are sent back to us from the lab, the next phase of therapy starts. This phase includes:

1. Chemotherapy (lymphodepleting chemotherapy)
2. Day 0 - The day of your infusion (your new CAR T-cells are given back to you)
3. Your time in the hospital (for about 2 to 4 weeks)

Chemotherapy (Lymphodepleting Chemotherapy)

Before you get the CAR T-cells, you'll get some chemotherapy called **lymphodepleting (LD) chemotherapy**. This type of chemotherapy will help to get your body ready to accept the new CAR T-cells. It gets your body ready by:

- helping to control the tumour growth or disease
- decreasing the number of T-cells in your body to make room for your CAR T-cells

How long do I need to have the chemotherapy?	This will depend on your diagnosis. Your care team will give you more information about the type of chemotherapy you will be getting, whether you will need to be admitted to the hospital, or if you can receive the chemotherapy as an outpatient.
Are there any side effects for the chemotherapy?	Yes, there are some possible side effects. Chemotherapy destroys cells that divide rapidly. These cells include cancer cells, but also healthy cells in your blood, stomach and intestines. When the healthy cells are destroyed, this causes the side effects. Side effects may include: • low blood counts **p. 27, 28** • fever **p. 29** • fatigue **p. 30** • nausea or vomiting **p. 31** • diarrhea **p. 31** • tumour lysis **p. 21** Other side effects that the chemotherapy can cause are mouth sores, skin changes and hair loss, but these are very rare. If you have mouth sores or skin changes, talk to your care team about how to manage them.

You will be in the hospital for about **2 weeks after your CAR T-cell infusion**. If you have any problems, you may have to stay in the hospital longer.

To see how you are doing, your care team will give you a medical assessment daily.

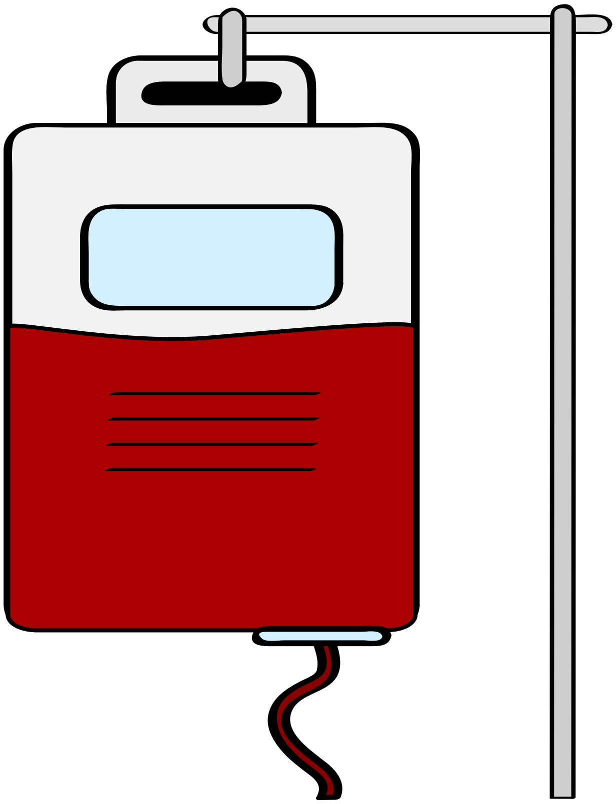
Day 0 - The Day of Your Infusion

What is "Day 0"?
Day 0 is the day you get the CAR T-cells back. The days before Day 0 are negative days (for example, Day -7 or Day -1). The days after Day 0 are positive days (for example, Day +1, or Day +10).

Day -5, -1, etc.
Days leading up to cell infusion

Day 0
CAR T-cell Infusion Day

Day +1, +2, etc.
Days after Infusion

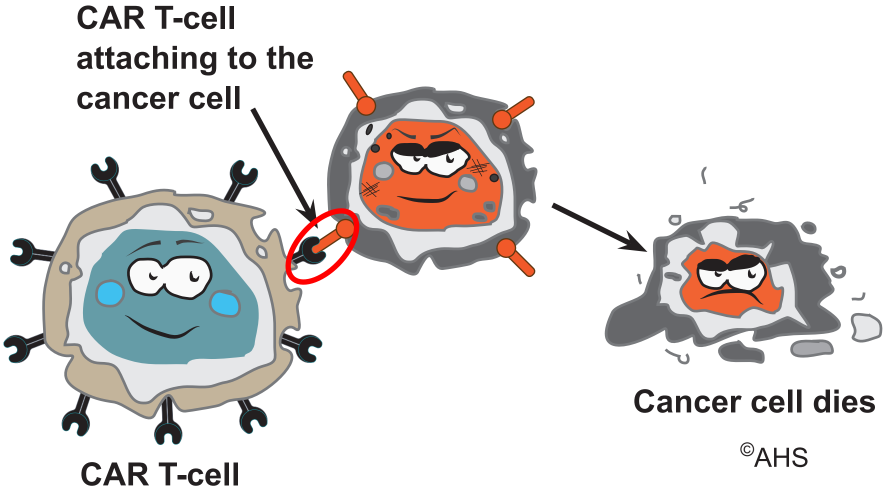


When will I get the CAR T-cells back?
You will get the CAR T-cells infused on Day 0. This is after you have finished getting your chemotherapy and when your body is ready to receive the cells.

How will I get the CAR T-cells?
Getting the CAR T-cells is almost like having a blood transfusion. Your CAR T-cells may arrive fresh or frozen. If the cells arrive frozen, they are thawed in warm water at your bedside right before they are infused.

How do the CAR T-cells help?
Once you get the CAR T-cells, they attach to antigens on cancer cells.

Once a CAR T-cell attaches to the cancer cell, your immune system sends other types of immune cells to kill the cancer cells.



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Are there any side effects during cell infusion?
Most people have very little side effects when getting their CAR T-cells infused. The more common side effects happen if your CAR T-cells are frozen because of a preservative added to them.

The **more common** side effects:

- An unpleasant taste in your mouth during the infusion — to help with the taste, try sucking on sliced oranges, or chew gum.
- A dry cough or a tickle in your throat
- Many patients feel flushed — cold cloths to the forehead help
- A smell for about 24 to 48 hours. The preservative comes out through your sweat and breath. People describe it as smelling like garlic, creamed corn, or oysters.

The **less common** side effects:

- Feeling cold
- Fever or chills
- Feeling sick to your stomach (nausea or vomiting)
- Chest feels heavy or tight
- An allergic reaction to the preservative (DMSO) used to protect the frozen T-cells. We will give you medications before the infusion to try to prevent this and we will monitor you

Tell your doctor or nurse if you have any of these less common side effects.

How long will it take to infuse the CAR T-cells?

The infusion will typically be about 30 minutes. Your infusion nurse will review the infusion details with you.

Days to hours after your CAR T-cell infusion

How will I feel after my infusion?

You should feel well after you get your T-cells back, but you may have side effects from the chemotherapy and CAR T-cells.

During the 4 weeks after infusion, you are at the greatest risk for side effects related to CAR T-cell therapy.

Your care team is prepared to handle these side effects and will monitor you closely for several weeks after getting your treatment. See **page 20** for more information on possible complications.

Will I be in the hospital after my infusion?

Yes, you will need to stay in the hospital after the infusion. How long will depend on how your body reacts. Your care team will talk to you about how long you should expect to be in the hospital.

How will I know if the infusion is working?

You will get some tests that we will monitor. We will check to see if the treatment is working after 30 days. This is called **restaging**. We will also continue to check periodically after this.

Your Time in the Hospital

Many people will care for you during your CAR T-cell therapy. This may include:

- doctors
- nurses
- dietitians
- social workers
- occupational therapists
- healthcare aides
- neurologists
- nurse practitioners
- pharmacists
- psychiatrists
- psychologists
- physiotherapists
- spiritual care providers
- dentists

> You and your family are an important part of the team and we want you to ask questions and share information with us to help in your recovery.

Your room

- You may have a private or shared room. Some rooms have private bathrooms.
- You can have a cell phone but you may need to put your phone away or on vibrate during assessments and procedures.
- There is free wireless Internet in most areas of the hospital.

Checklist - Admission to Hospital

☐ loose, comfortable clothing, pajamas, extra underwear

☐ comfortable footwear for walking and non-slip slippers

☐ personal items such as unscented lotions, toothpaste, toothbrush, electric shaver

☐ activities to do: reading, simple crafts, word search, crossword puzzles, computer games, movies (bring earphones if listening to movies or music)

☐ bring a list of the medications you take

☐ personal pillow or blankets (hospital does not provide personal laundry service)

☐ personal laptop, tablet, phone, and any chargers

☐ consider labelling your personal items in case you forget them

Tip!

Helpful tips during CAR T-cell therapy:

"Bring a laptop and several movies - this will help to pass the time."

~ Rhonda (caregiver)

To help prevent the spread of infections:

- Patient washrooms (including showers) are only for patients to use. This helps to reduce the risk of either you or your visitor getting an infection.
- Patients and visitors should not visit other patient rooms.
- All visitors must wash their hands well with an alcohol hand rub or soap and water. They should do this when they arrive on the unit, often during their visit with you, and after they are finished visiting with you.

Smoking:

- There is no smoking or vaping in or on hospital grounds.

Visitors

- Check with the nursing staff about visitor guidelines, including if a loved one or caregiver would like to stay the night.
- Visitors or caregivers must not use the bathroom in your room. This helps reduce the spread of infection.
- Visitors check in at the nursing station first.
- Visitors who are sick will not be allowed on the unit.
- Check with the unit if children are allowed to visit.
- Familiar foods from home or community can help patients find comfort, connection, and pleasure while in hospital. Speak with the care team if you would like to bring food.

Visitors should **not come** if they have:

- a fever
- a sore throat
- diarrhea (within the last 48 hours)
- a new or unexplained rash or if they feel sick
- a new cough
- a runny nose
- been exposed to an infectious disease, like chickenpox

Lotions, perfumes and other scented products:

- Ask visitors not to wear anything that has a smell like perfume or scented lotions.

Flowers and plants:

- Fresh flowers, plants, and dried flowers are not allowed in your room or on the unit. These can carry germs or moulds that can cause infection.
- Mylar (non-latex) balloons, silk flowers, cards, and pictures are good choices.

Activity

Try to get some activity while you are in the hospital. Some activities will also help if your feet or legs are swollen.

- Change positions often when you are sitting or lying in bed
- Make an effort to do daily activities — get out of bed, take a shower, get dressed, and sit up in a chair when you eat your meals
- Plan activities that last no more than 15 to 20 minutes at a time
- Make sure you get enough rest
- Flex your feet — point toes up toward your nose and then down as far as possible. Do this 10 times a few times daily
- Take short walks 4-6 times a day
- Do heel raises — put your hand on a chair or counter for balance. Slowly raise your heels. Hold for 6 seconds and then lower back down. Do this 10 times a few times a day

Tip!

Helpful tips during CAR T-cell therapy:

"Go for a walk....just to get out of your room... get your body moving...it's very, very important."

~Scott (patient)

Nutrition

Eating well and staying hydrated is important for your health. While in hospital, it can help you fight infection, have more energy, heal and recover quicker, maintain muscle strength, and prevent muscle loss.

Some people have side effects from the CAR-T cell procedure, including poor appetite, nausea, and feeling more tired than usual. A dietitian is available in the hospital to work with you, your food preferences, and side effects to help you get the nutrition you need.
https://bit.ly/eating-well-in-hospital

E. Possible Complications of Treatment

During the first few weeks after the infusion, you may have complications from the treatment. You will be in hospital during this time so that the team of doctors and nurses can monitor you closely. You will get medications to help prevent and control side effects.

Your response will depend on the type of cancer you have, where the cancer is located, the past treatments you have received, and your overall health. Complications can be very serious and can be life-threatening.

Are there any side effects after the cell infusion?
Some side effects (complications) that can happen include:

- Cytokine Release Syndrome (p. 20)
- Neurologic Toxicity (p. 21)
- Tumour Lysis Syndrome (p. 21)
- Infection (p. 22)
- B-cell Aplasia (p. 22)

If you are getting CAR T-cell therapy, it's very important to report any side effects to your care team right away, as there are often medicines that can help treat them.

Cytokine Release Syndrome (CRS)

What it is: As CAR T-cells start working, they can release large amounts of **cytokines** into the blood. Cytokines are chemicals that tell the immune system how to respond and can cause your immune system to become extra active. Sometimes, too many cytokines are released into the body and it can make you feel sick.

What can happen: You may feel like you have the flu, with a high fever or chills. Other symptoms may include:

- low blood pressure
- nausea
- dizziness or headache
- difficulty breathing
- vomiting or diarrhea
- confusion
- muscle or joint pain

Everyone will experience the symptoms differently. These symptoms can:

- Be mild or severe
- Happen anytime between 1 day to 14 days after your CAR T-cell infusion
- Last up to about 7 days

What can be done: The doctors and nurses will closely monitor your temperature, breathing function, and heart functions. You may need oxygen, intravenous fluids, or medicines to manage your symptoms. In severe cases, you may need the support of the Intensive Care Unit (ICU). You may receive medications that can reduce the side effects of the cytokines released during CRS. Most of the time these symptoms can be fixed and managed properly. Talk with your care team about the chances of these symptoms.

Neurologic Toxicity

What it is: When the CAR T-cell infusion activates the immune system, it may alter the brain and neurological system. This can happen after your CAR T-cell infusion.

What can happen: It can cause you to become confused, have tremors, have difficulty with talking or with your memory, or in severe cases, lose consciousness. Some people can get very sick and may need to be followed by a neurologist and admitted to the Intensive Care Unit (ICU).

What can be done: Your team will monitor you often. They will ask you questions every day to assess your orientation (your cognitive abilities), your ability to follow commands, and get a sample of your handwriting daily. If you are having neurologic toxicity, we will give you medications to help prevent or control these problems as needed. Most of the time these symptoms are temporary.

Because of these side effects, you cannot drive or operate heavy machinery for at least 8 weeks after the infusion.

Tumour Lysis Syndrome

What it is: CAR T-cells work really well at targeting cancer cells. When the cancer cells die, they release their contents into the bloodstream. When cancer cells die quickly, the kidneys may have trouble removing these contents from the blood. This can lead to Tumour Lysis Syndrome (TLS).

What can happen: This can result in problems with fluids and minerals, or kidney damage.

What can be done: Your team will have a specific treatment plan for you, if needed. This may include chemotherapy before CAR T-cell therapy, IV fluids, or medicines to help the body clear the extra fluids and protect the kidneys.

Infection

What it is: An infection can happen from the germs you already carry on your body, from plants, or other people. Infections can happen anywhere in your body but the most common areas are your lungs, gut, mouth or skin, sinuses, or urinary tract.

What can happen: Your cancer and chemotherapy can affect your immune system and may leave you more at risk for other infections.

What can be done: We will monitor you very closely during this time for any signs of infection. If we think you have an infection, we will do some tests to look for the type and source of infection so we can treat it with the right medications. We will usually give you antibiotics or other medications during and after CAR T-cell therapy to help control or prevent infections. Washing your hands often is also an important thing you can do to prevent infections. (See page 29)

Signs you may have an infection:

- A fever of 38.3°C (100.9°F) or higher at any time OR 38.0°C (100.4°F) to 38.2°C (100.8°F) for at least 1 hour
- Chills, sweating, or shaking
- A cough or a runny nose
- Feel short of breath, have trouble breathing, hurts to breathe, or your chest feels tight
- Pain, redness, or swelling in your throat, mouth, eyes, skin, or joints
- Peeing often, it burns when you pee, or your pee is cloudy
- Pain in your stomach, rectum, vagina, or penis
- Diarrhea
- Tenderness, redness, swelling, or drainage where your central line exits your body
- A new rash

On-Target Off-Tumour Effect

What it is: CAR T-cells are designed to target a specific antigen on a cancer cell. But sometimes the same antigen is also found on some of the healthy cells. The CAR T-cells will attach to the antigen on the cancer cells (on-target), but can also attach to some of the healthy cells (off-tumour) and kill them. This means that the CAR T-cells are hitting their target (cancer cells), but they are also accidentally damaging some healthy cells.

What can happen: If the CAR T-cells kill some healthy cells, this can cause side effects and increase your risk for infection.

What can be done: Your team will monitor you for the most likely side effects caused by the CAR T-cell therapy you will receive.

F. Leaving the Hospital

Long term recovery is different for everyone. It depends on your specific situation and how the cancer reacts to your CAR T-cell therapy. Your care team will tell you what to expect. During this time you will:

1. Be **discharged** and leave the hospital
2. Have **follow-up** care
3. **Be referred back to your primary cancer doctor and recovery**

Discharge from the Hospital

Patients from out of town

When will I be able to leave the hospital?
You will be in hospital for about 2 weeks but this can vary if you are unwell or have complications. **If you are from out of town, you will have to stay within 1 hour of the treatment centre for about 4 weeks after your CAR T-cell infusion.**

How does the care team decide when I am ready to leave the hospital?
How long you stay in the hospital depends on how your body reacts to the cells and any side effecs from treatment. Your care team will decide when it is safe to discharge you.

Usually patients are able to leave the hospital about 2 weeks after their infusion. Some people may need to stay longer if problems develop.

What do I need before I leave the hospital?
Before you leave the hospital, we will give you your follow-up appointments. Appointments may include lab work, clinic appointments or appointments with specialists.

We will also go over any instructions with you and your caregiver about how to care for yourself at home such as:

- when to go to the nearest emergency room. **You will also get a wallet card that you can give to the healthcare providers**
- when to call and important phone numbers
- what you can do to prevent infection
- what to do with your central line (if you have one) if it has not been removed

Checklist - Leaving the Hospital

☐ List of important contact information
☐ Know serious symptoms and side effects to watch for and what to do
☐ Get lab work and follow up appointments with doctor
☐ Any specialist appointments
☐ Your CAR T-cell Therapy patient teaching book (this book)
☐ Your CAR T-cell Patient Alert Card
☐ The drug specific wallet card (if you've been given one)
☐ Your prescriptions and understand how to take them
☐ If you do not already have one, you will need to buy a thermometer to check your temperature at home

Follow-up Care

Once you are discharged from the hospital, your doctor will decide how often your appointments will be. This will depend on how you're feeling. Side effects are still common during this time. It's important to come to all your appointments and monitor yourself closely at home.

Because of these side effects, you cannot drive or operate heavy machinery for at least 8 weeks after the infusion.

Neurotoxicity symptoms are less likely to happen after you leave the hospital but it's important that you and your caregiver recognize any changes in your behaviour and take you to the emergency room right away.

Your doctor will decide when it is safe for you to travel home. If you need help with travel or accommodations, speak with your care team. They can arrange for you to speak to a social worker about financial help resources if needed.

Patients from out of town

Recovery

How long will it take for me to recover?
Recovery time is different for everyone but it can take weeks to months.

Will I still have appointments during this recovery time?
Yes, you will still have routine appointments. Your doctor will decide how often.

What if I am having problems adjusting emotionally?
Tell the nurse or your doctor if you are having a hard time emotionally. They can help connect you with the supports you need.

Are there any side effects I should watch for?
If you have any of the following symptoms, **go to the emergency room**:

- difficulty breathing
- fever of 38.3°C (100.9°F) or higher at any time OR 38.0°C (100.4°F) to 38.2°C (100.8°F) for at least 1 hour
- severe chills or shaking
- confusion
- irregular heartbeat
- severe nausea, vomiting, or diarrhea
- severe muscle or joint pain
- fainting or very low blood pressure
- dizziness or headache
- difficulty speaking or swallowing
- decreased level of consciousness
- seizures

When can I go back to work or school?	Check with your doctor when it is safe to go back to work or school.
When is it safe to travel?	Talk to your doctor before you make any travel plans.
Is it safe for me to be around other people?	Limit the number of people you are around until your blood counts have recovered. You should still avoid people who are sick. Remember to wash your hands well and take care of yourself. **Consider wearing a mask when you are out in public.**

Immunizations

Your care team will talk with you about immunizations. Do not get any immunizations until you have been cleared by your care team.

Caring for Your Central Line

Your care team will decide when to remove your central line. You or your caregiver need to take good care of your central line to help prevent infection. We may show you how to care for your central line, or we may set up home care appointments or appointments at your local cancer centre to help care for your line until it is removed.

Activity

Everyone is different. You may still feel tired for some time after your treatment is done. Some days you may find your energy level is low and you feel like doing nothing. Regular exercise is a goal that can lead to feeling better, being able to do more and reduce the risk of some other cancers. The less active you are, the more risk you have for falls, poor sleep, poor appetite, or feeling worse.

While you should get up and move each day, listen to your body and find balance between activity and rest. Let your family help you with some of your responsibilities for a while. You can expect gradual improvement in your energy as you recover.

What can help?

- Walking is one of the best ways to improve the strength in your legs. Increase your exercise as you can but remember to also get enough rest.
- Eat a well-balanced diet and drink plenty of fluids to help your energy level.

Caring for Your Skin

To protect your skin and help prevent infection:

- **Stay out of the sun as much as possible.** Wear a hat, protective clothing, and always use sunscreen with SPF 50 or greater
- Do not share your toothbrush, towels, shavers, or other personal hygiene products
- Wash your bed sheets and bath or hand towels regularly using hot, soapy water
- If you notice any new rashes or wounds, let your care team know.

Nutrition

Getting enough nutrition is important after you have treatment. If you have low energy or feel tried, have a poor appetite, or are feeling sick to your stomach, it can make it harder to eat or drink. Even a small amount of calories and protein can help you feel stronger and help your body recover from treatment.

Tip!

Here are some tips to help you eat well:

Fluids:

- Drink enough fluids to keep your pee pale yellow. Most people need about 9.25–12 cups (2-3 litres) of fluids a day.
- Fluids include water, milk, fortified soy beverage, soups, and nutrition supplement drinks.

Food:

- Eat small meals and snacks often. Try to eat every 2-3 hours, even when you don't feel hungry.
- Eat higher calorie and protein foods at each meal and snack. Make every bite count. Check out: **https://bit.ly/adding-calories-protein**
- Sometimes, fluids are an easier way to get nutrition when you aren't feeling well. Try smoothies (**https://bit.ly/making-smoothies**) or nutrition supplement drinks such as Ensure®, Boost®, or store-brand versions. Look for "high protein" and "high calorie" on the label.
- Carry shelf stable snacks with you or keep them around your home. Try granola bars, protein bars, peanut butter or cheese-filled crackers, trail mix, jerky, or energy bites.
- For recipes or meal ideas, check out ahs.ca/MoreProteinRecipes

An outpatient dietitian can help you get enough nutrition for recovery after CAR T-cell therapy.

If you have been told your white blood cells are low, see page 28 and check out:

For more tips, check out Canada's **Safe Food Handling for Immunocompromised Individuals**:

https://bit.ly/cafoodguideimmunocompromised

G. Managing Your Side Effects

You will have side effects throughout the CAR T-cell therapy process. This section talks about possible side effects you may have and gives you tips on how to manage them. If a side effect is really bothering you and none of the tips help, talk to your care team about other things that can help.

Low Blood Counts

When the chemotherapy attacks the cancer cells in your body, it also attacks your blood cells. This is what causes you to have a **low blood cell count**. Having a low blood cell count is the most common side effect of chemotherapy.

Low Platelets

Your platelets drop after chemotherapy. Until your body recovers from the chemotherapy, you will be at risk for bleeding.

Normal Platelet Count:
150 to 440/L

What are the symptoms?

- Bruising
- Red or brown urine
- Nosebleeds
- Bleeding gums
- Blood in your stool
- Small red or purple spots on the skin caused by bleeding under the skin (petechiae)
- Headaches
- Bleeding from your vagina not from your menstrual cycle (period) or heavier menstrual cycle than usual

What can help?

- We may give you a transfusion of platelets to lower your risk of bleeding until your bone marrow begins to make platelets.
- **If you are constipated, you may need a bowel softener**. Bowel movements should be regular and soft.

To help prevent bleeding:

- **Do not shave with a razor**, instead use an electric shaver
- Do not pick your nose or blow it hard
- Sit at the edge of the bed for a minute to make sure you are not dizzy before standing up
- Wear non-slip slippers that fit when walking around
- Do mouth care more often
- Use a soft toothbrush to prevent your gums from bleeding
- Remove things that you can trip on
- Do not participate in high-contact activities
- Do not use suppositories or insert anything in your rectum (avoid constipation by using stool softeners as needed)

Low Red Blood Cells (RBCs)

When your RBC count drops after chemotherapy, your hemoglobin (Hgb) also drops and stays low until blood counts or bone marrow recovers.

Normal Hgb Count:

Women: 120 to 160 g/L
Men: 137 to 180 g/L

What are the symptoms?

- Feeling cold
- Headache or dizziness
- Feeling short of breath
- Feeling tired (fatigue) and having low or no energy
- Pale appearance (skin, nails, lips)
- Fast heart rate

What can help?

- Try to keep a good balance between activity and rest
- We may give you a blood transfusion of RBCs to increase your Hgb

Low White Blood Cells (WBCs)

Your WBCs will stay low until blood counts or bone marrow recovers. When your WBCs are low, your body's immune system becomes weak, which puts you at risk for infection.

WBC Normal Count:
4.0 to 11.0/L

Neutrophil Normal Count:
1.8/L or more

Neutrophils are the type of WBC that we monitor.

You are at high risk for infection if your neutrophils are 0.5/L or less This is called **neutropenia**.

What are the symptoms?

- Infections (viral, bacterial, or fungal) (**pg. 22**)

What can help?

- Wash your hands well and often
- Stay away from sick people
- Avoid gardening or working with soil
- Do not clean the cat litter or pick up after your pet. Have someone else do this for you
- We may give you a growth factor (GCSF) to help your WBC count go up
- We may give you medications and antibiotics to prevent or help if you get an infection

Sexuality and Fertility

Changes in your desire and sexuality may happen as a side effect of cancer treatment. These changes in sexuality, sexual function, and sexual desire may also affect your partner and your relationship with your partner.

What can I do to help?

- Use water-based lubricants during sexual activity.
- When sexual intercourse is not possible, keep your loving and caring feelings alive with good communication, cuddling, and other activities that create emotional and physical intimacy.

Pregnancy and Fertility

Do not try to get pregnant or get someone pregnant until your care team says it's okay.

You may not be able to become pregnant or get someone pregnant after CAR T-cell therapy.

To get more information, talk with your care team.

Fever

A fever may be the first or only sign of Cytokine Release Syndrome (p. 20) or an infection. Infections can be life-threatening and need to be taken seriously. You should have a thermometer at home to monitor your temperature. **We recommend a digital thermometer**, which come in many styles. They give you an accurate temperature reading quickly.

A fever is a temperature of:

- 38.3°C (100.9°F) or higher at any time

OR

- 38.0°C (100.4°F) to 38.2°C (100.8°F) for at least 1 hour

Why does it happen?

Cytokine Release Syndrome or lower blood counts (p. 27) can cause fever.

⚠ If you have a fever, go to your nearest emergency room.

Remember to take your wallet card with you to give to the care team.

Washing your hands

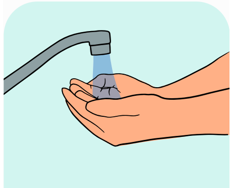
Washing your hands well and often is the most important thing you can do to reduce your risk of infection. It's important for visitors and caregivers to also wash their hands. You can use hand sanitizer or soap:

Hand sanitizer is best to use when:

- your hands don't look or feel dirty
- water and soap aren't available

The sanitizer should have 60% to 95% alcohol in it to work best.
Follow these steps:

1. Put an amount the size of a coin (like a quarter) on your hands.
2. Rub the sanitizer all over your hands, wrists, fingers, fingertips, and thumbs.
3. Rub until your hands are completely dry.



Soap and water is best to use:

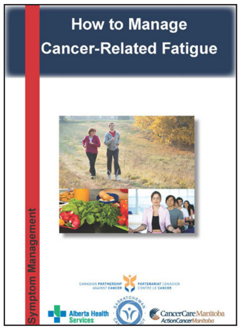
- when your hands look or feel dirty
- before you eat or prepare food
- after you use the bathroom

Follow these steps to clean your hands with soap and water:

1. Wet your hands with warm water.
2. Put enough soap on your hands to cover them.
3. Rub the soap all over your hands, wrists, fingers, fingertips, and thumbs.
4. Wash and scrub your hands for 30 seconds.
5. Rinse your hands under warm running water.
6. Pat your hands dry with a paper towel.
7. Turn the tap off with the paper towel.

Fatigue

Fatigue (or tiredness) is a very common side effect related to treatment. It is best treated with regular exercise and good nutrition. Fatigue can happen within days after a chemotherapy treatment and can last long after treatment ends, but it usually gets better over time.



How to Manage Cancer-Related Fatigue

Symptom Management

Alberta Health Services

CancerCare Manitoba

Get more tips from the booklet "How to Manage Cancer-Related Fatigue" at your cancer centre or online.

Fatigue may make you feel:

- worn out, tired/sleepy, no energy
- can't concentrate/think
- lack of interest in doing anything with friends or family
- no interest in sex or being intimate with your partner
- depressed, disconnected or not interested in anything
- like you have no energy to do normal daily activities, even self-care like showering
- short of breath

For more information visit:
http://bit.ly/fatigue-videos

What can cause fatigue?

- weight loss
- stress
- cancer treatment
- depression
- low red blood cell count – red blood cells carry the oxygen in your body
- poor nutrition or not getting enough calories and protein
- changes in your daily schedule or interrupted sleep schedule
- low iron in your blood

What can help?

- Rest — plan your day so you have time to rest in between activities
- Try to get some activity — simple exercises like walks can help boost your energy
- Save your energy when you feel too fatigued
- Get others to help out when you need it
- Try to eat a balanced diet
- Drink lots of fluids - aim for at least 2 litres a day
- Lower stress, ease your mind and know this is part of the recovery process

Nausea and Vomiting

Nausea and vomiting can sometimes happen with this treatment. Severe nausea and vomiting can cause a loss of fluids and nutrients, so it's important to control nausea and vomiting effectively.

What are the symptoms?

- feeling queasy
- upset stomach
- increased saliva production
- inability to eat or drink without feeling like you need to vomit
- dizziness
- restlessness
- irritability
- lack of appetite

What can help?
The best way to control nausea and vomiting is to prevent them before they happen. Your care team can prescribe anti-nausea medications to prevent or reduce nausea and vomiting.

Let your care team know if the medications are not working. We may need to give you extra fluids, medications, or both using an IV, or supplemental nutrition to manage the effects of nausea and vomiting.

Tip!

Other tips that can help with nausea and vomiting:

- *Drink and eat slowly while sitting up*
- *Avoid lying down 2 hours after you eat*
- *Try to eat small meals or snacks more often*
- *Eat foods that are more dry or bland*
- *Avoid strong-smelling, spicy or greasy foods*
- *Practice good mouth care*
- *Take nutritional supplements*
- *Take slow and deep breaths when you feel nauseated*

Diarrhea

Diarrhea is when you have loose stools often. You may also have cramps, pain, or feel bloated.

What causes it?
It is usually caused by the medications you get or sometimes an infection. Finding out the cause is important so we can treat the diarrhea with the best treatment.

Why is it important?
It is a common side effect and can cause dehydration, which can lead to fatigue and changes in your blood work. Diarrhea needs to be managed quickly and effectively for comfort, and to prevent dehydration and damage to the skin around the rectum.

What are the symptoms?

- loose or watery stools 3 or more times a day
- stomach cramps
- pain, or feeling bloated
- gas, cramping
- dehydration
- weight loss
- rectal pain
- bleeding or discharge

What can help?

- We may need to give you extra fluids and nutrients, usually through an IV
- Changes in diet
- Medications for pain or discomfort
- We may give you medications to help or prevent diarrhea
- Good handwashing (see **p. 29**)
- Comfort measures such as a warm bath for a sore rectum

H. Emotional and Mental Well-being

Emotional Adjustment and Support

You may have many emotions and feelings during and after CAR T-cell therapy. These can include hope, fear, anger, confusion, frustration, guilt, and anxiety. Some days you may feel powerful, strong, and in control. Other days you may feel powerless and out of control.

You may feel a bit lost once you are discharged from hospital. Some people feel down or anxious as they go through the change from staying in the hospital to leaving the hospital. These feelings are normal when going through intense treatment for a life-threatening illness.

You may need to be re-admitted to the hospital if any problems come up. This can be disappointing, but it is not uncommon after cancer treatment.

Everyone deals with stress in their own way. You and your family must find what works best for you. Family members can also struggle to deal with their own stress.

Family and friends may be the first to notice that you are struggling to cope and may need help. They can be very supportive and they may be able to remind you of the ways you dealt with stress successfully in the past.

Social workers, spiritual care providers, and psychologists are available to support you and your family through every phase of the CAR T-cell therapy.

Ask your doctor or nurse for contact information.

Tip!

Below are some tips that may reduce stress. These may help you cope and feel more calm and relaxed:

- listen to recorded relaxation meditations or music
- talk to someone who will listen without “fixing” or giving advice
- attend to your spirituality as you explore your emerging sense of meaning, purpose and hope
- pray, speak to your religious leader, or meditate
- watch a funny movie or tv show
- practice deep breathing exercises or yoga
- seek out local support groups

Your care team can help you learn other ways to reduce your stress.

Your body will need weeks to many months to rebuild and recover from the intense CAR T-cell therapy process.

You will still need help from your family after the CAR T-cell treatment. Family members who support you during your treatment may not understand how long it takes to recover and that you still need help. This can cause relationship struggles. Talk to your care team if you need to find some support.

Children

Parents often want to protect their children from the impact of cancer or other diseases. One way to do this is to give children clear and honest information using words they understand rather than keep your illness a secret. You can explain your illness, how you are being treated, and any changes they can expect because of the illness or treatment.

Listen to your children, answer their questions, and share your feelings as well as the facts. Let them know you will tell them if anything changes and that it is okay to talk about their thoughts, feelings, and questions.

Tell them you and the care team are doing what you can to get better, that they will continue to be loved and cared for, and that you will try to keep things as normal and routine as possible for them.

Feeling Depressed

It is common to feel down or depressed during and after your treatment. Depression is when feelings of sadness, hopelessness, despair, and lack of purpose are strong and will not go away for weeks or months. A person who is feeling depressed cannot just “snap out of it” or “cheer up”.

Depression can cause physical and emotional symptoms and may make it harder to cope and enjoy other areas of your life. Speak with your partner or family members if you find your mood is low and does not get better.

If you feel depressed, let your care team know. With professional counselling, you can learn about different ways to help you cope.

If your depression does not get better or gets worse, you may need medications to feel better.

Sometimes depression can affect your sleep. You may find you wake up more often, have trouble staying asleep, sleep longer, or stay in bed for many more hours than you usually need. Speak with your care team if you are having difficulty with sleep.

The care team is available to help you get through all parts of your treatment program.

Adjusting to a new normal after treatment

Cancer survivors and their loved ones have been through a lot. Going through CAR T-cell therapy involved many important steps and was a huge time commitment for both you and your support system (family or friends).

As you move through the recovery process, you may find yourself feeling different than your former self. While you may experience physical side effects for months after treatment, you may also discover a new appreciation for life, interests, or priorities.

Figuring out how to incorporate the physical, emotional, mental and spiritual changes into your life after CAR T-cell therapy is complex and will take time. You may need to adjust your goals and expectations. Over time, most people are able to adapt to the changes from treatment, and a new normal emerges.

We hope the information in this book has helped you understand the steps and the importance of CAR T-cell therapy as a part of your treatment program.

Please contact us if you have any questions or concerns or if there are any changes to your condition during or after this treatment. We have a team of people to help you with any concerns. To help you have the best outcomes, it is important to try to stay as active, engaged, and as positive as you can through this treatment while following the directions and steps your care team gives you.

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The information is to be updated every 3 years, or as new clinical evidence emerges. If there are any concerns or updates with this information, please email cancerpatienteducation@ahs.ca.

Cancer Care Alberta

Leading care through compassion, courage, learning and discovery

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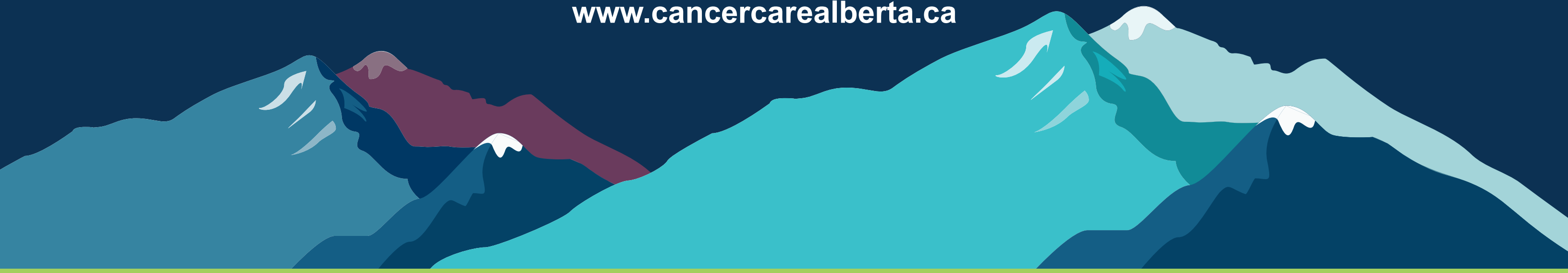

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