

Your CAR T-Cell Therapy

Information for Patients and Caregivers

Read this guide to learn:

- What is CAR T-cell therapy
- What happens before your CAR T-cell therapy
- What to expect during your CAR T-cell therapy
- What to expect during your recovery
- Important phone numbers
- Where you can find more information



IMPORTANT PHONE NUMBERS

BMT Afterhours (Inpatient Unit):

Jim Pattison Pavilion, 15th & 16th Floor,
Vancouver General Hospital
Monday to Friday 7:00 pm – 7:00 am
Weekends & Holidays 6:00pm – 8:00am

P: 604-875-4343



Leukemia/BMT Daycare (Outpatient Unit):

Leon Blackmore Pavilion, 6th Floor,
Vancouver General Hospital
Monday to Friday 7:00am – 7:00pm
Weekends & Holidays 8:00am – 6:00pm

P: 604-875-4073

BMT Navigator Office:

Gordon and Leslie Diamond Health Care
Centre, 10th Floor, 2775 Laurel Street,
Vancouver, BC, V5Z 1M9
Monday to Friday 8:00am – 4:00pm

P: 604-875-4863

Call Us Immediately If You Have:

- Fever: a temperature of 38°C or higher
- New bad bruising and/or bleeding
- Chills or shaking
- Difficulty taking your pills
- Yellow or green mucus when you cough
- New pain
- A bad headache
- Concerns with your IV line
- Diarrhea, nausea or vomiting that doesn't stop
- Unsteadiness when walking or have fallen down
- Flu-like symptoms
- Rash, blisters, allergic reactions
- A seizure

In Case of Emergency – Call 911

If you, or your loved one, has severe chest pain, can't breathe, having a seizure, or requires urgent care – **CALL 911**. An ambulance will take you to the closest hospital. Tell the staff you are a CAR T-cell patient and are part of the Leukemia/BMT program of British Columbia and to contact our doctor on call. These symptoms are rare but if they occur, they cannot be managed over the phone.

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About this Booklet

This booklet has been developed to help you and your family prepare for your CAR T-cell therapy. We hope reading this booklet will help you feel more comfortable with your treatment as you learn about what to expect each step of the way.

We welcome your feedback on how we can improve this book for other patients and families.

Talk to our team or email bmtpatienteducator@vch.ca

The amount of information available on CAR T-cell therapy and in this booklet can be overwhelming. We know you won't be able to remember everything we tell you. This book provides written information to go along with the teaching you'll receive from us, your health care team.

Read each section of these booklets when you are ready. You will not be expected to know or read everything, we will be here to help you along the way. You may think of questions to ask us as you read through it. We encourage you to write down your questions and bring them, and this booklet, with you to your appointments.

At the end of the booklet there is a section on common medical terms.

Introduction to CAR T-cell Therapy

What is CAR-T therapy?

Chimeric Antigen Receptor T cell therapy, often shortened to “CAR-T therapy,” is a treatment made by taking some of your body’s own white blood cells and genetically modifying them so that recognize and attack your cancer cells. CAR-T therapy is a type of immunotherapy.

Immunotherapy (“i-myoo-now-theh-ruh-pee”)

- Uses the body’s own immune system to fight cancer.
- Improves the body’s ability to detect and kill cancer cells.

The immune system

- It is the body’s defense against infection and disease.
- It is made up of billions of cells that are divided into several different types.
- Lymphocytes, a subtype of white blood cells, are a major portion of the immune system.

T lymphocytes (T-cells) have several functions

- They are cells that help control immune response.
- They help your immune system tell which antigens don’t belong in your body.
- They help make antibodies to fight infection.
- They directly kill infected and abnormal cells in the body, like cancer.

Your immune system is able to recognize infections and diseased cells by finding proteins (antigens) on the surface of the cells.

Your T-cells attack abnormal cells and matter throughout your body by attaching (via receptors) to cancer cells (antigens) and destroy them.

How does CAR-T therapy work?

Your blood will be collected and CAR T-cells will be made from your own T-cells. These cells will be genetically edited so that the functions T-cell naturally have in your body become more effective.

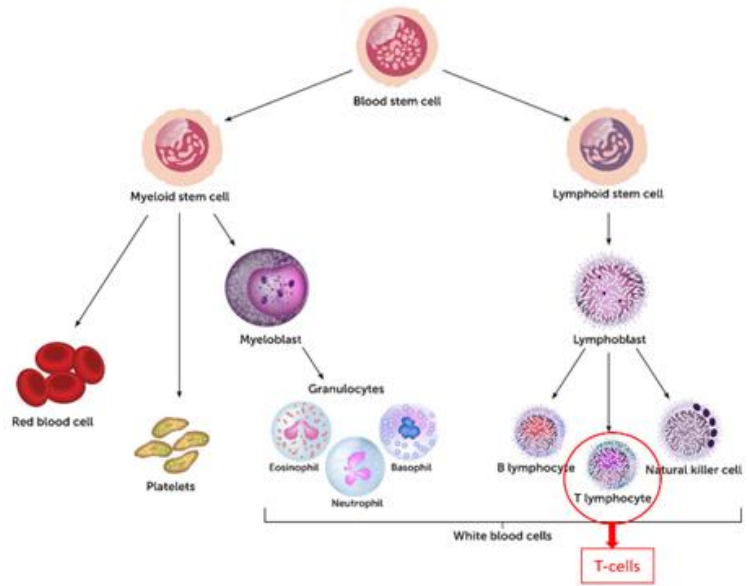


Figure 1. Blood Cells. Adapted from “Figure 2. Blood Cells”, by Healiio, 2023.

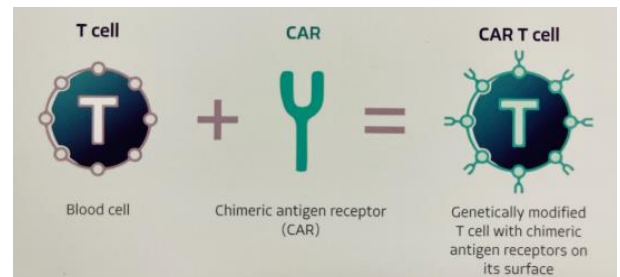


Figure 2. CARs being added to T-cells. From “Getting Ready for Treatment with Tecartus,” by Gilead Sciences Canada Inc., 2022.

Cancer cells have antigens on their surface. T-cells use receptors to recognize these antigens and determine if a cell should or should not be there. In other words, the T-cell receptor reads the antigen and determines if the cell is healthy and can stay OR if the cell is unhealthy (such as a cancerous cell) and must go.

To accomplish this, your normal T-cells will have **chimeric antigen receptors (CARs)** added their surface.

- CARs are a special receptors that binds to a certain antigen on your cancer cells.
- CARs helps your immune system recognize your specific cancer cells.
- CAR T-cell therapy is personalized medicine because it is made using your own cells and will only work for you.

Your CAR-T cells are then given back to you. In your body they increase in number and recognize then attack your cancer cells.

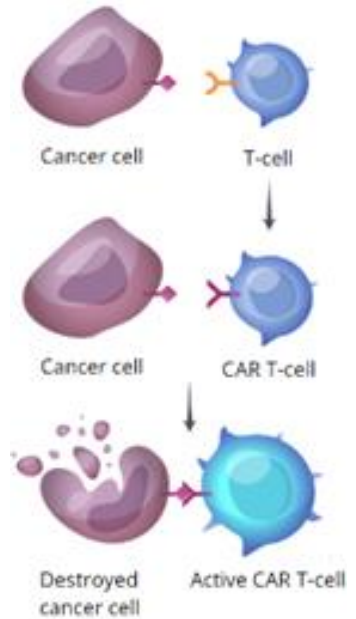


Figure 3. CAR T-cells destroy cancer cells. Adapted from "CAR T-cell Therapy", by The Princess Margaret Cancer Foundation, n.d.

Overview of CAR-T Therapy

1. Your T-cells are collected.
2. Your T-cells are genetically modified to find and kill cancer cells. (CARs are added to your T-cells).
3. These CAR T-cells are then multiplied until there are millions of these attacker cells.
4. CAR-T cells are put back into your body, and these cells will attack your cancer cells.

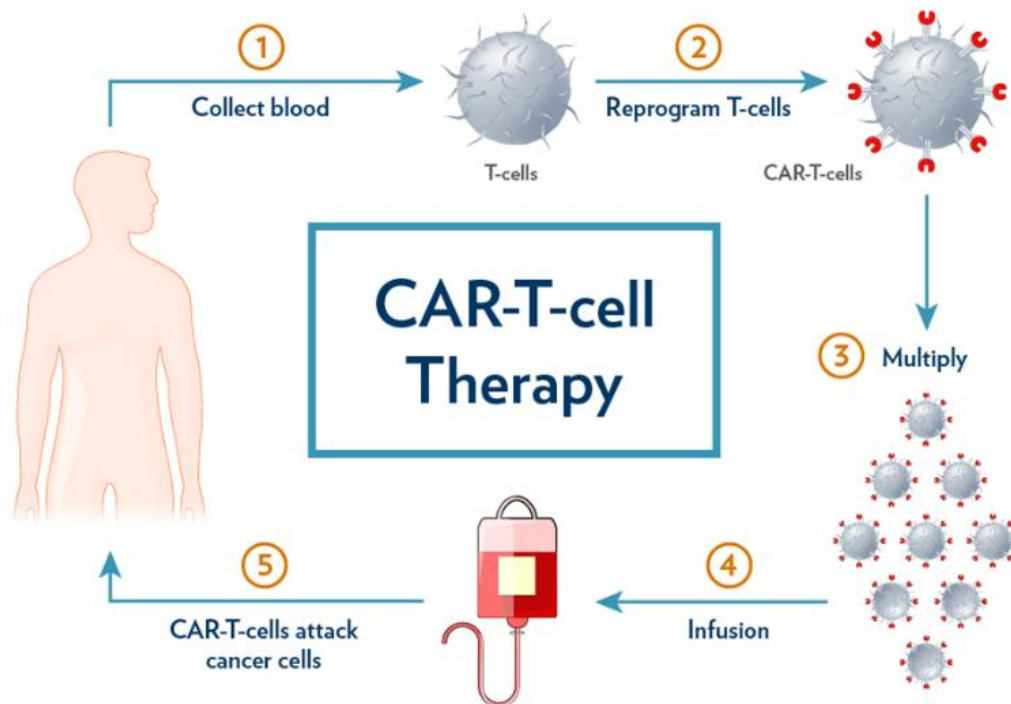


Figure 4. CAR T-cell Therapy. From "CAR-T cell Therapy" by Medical University of South Carolina, 2021.

Steps to CAR-T Therapy

CAR-T therapy is a long process and the treatment will take several weeks.

Steps to CAR T-cell therapy	Description	Estimated timeframe
Step 1 Preparing for CAR-T Therapy	You will meet with different member of your healthcare team who will help you prepare for your treatment. You will have tests to ensure it is safe for you to have CAR T-cell therapy.	~2 to 3 weeks prior to CAR T-cell collection. *Most steps in this process will have to occur at Vancouver General Hospital (VGH).
Step 2 Collecting your cells	You will have an appointment for bloodwork prior to the collection. Your T-cells will be collected using an apheresis machine. This machine safely and painlessly collects the cells from your blood and then returns the rest of your blood back to you.	Approximately 1 to 3 weeks after being seen by the program's hematologist. (At VGH)
Step 3 Bridging Treatment (If applicable)	While your CAR T-cells are being manufactured, you may have treatments which will help manage your cancer ("bridging treatment"). This will be determined by your primary oncologist.	May occur over ~3 to 4 weeks *Most appointments can be done in your home community.
Step 4 Tunneled Catheter Insertion (If applicable)	Hickman line will be inserted. This is an intravenous ("IV") line that will be inserted in your chest to help make your treatment more comfortable.	1 day (At VGH)
Step 5 Lymphodepleting (LD) Chemotherapy	You will be given chemotherapy in the Leukemia/BMT Daycare Clinic to prepare the body for the CAR T-cells.	~3 to 4 days
Step 6 Planned Admission to the Hospital	You will be admitted to the inpatient hospital L/BMT unit on the 15th or 16th floor of VGH the day after completing LD chemotherapy. A minimum inpatient stay of 8 days is required.	~7 to 14 days

<p>Step 7 CAR T-Cell Infusion</p>	<p>Your CAR T-cells will be given back to you through your IV catheter. This process is similar to a blood transfusion and will happen on the second day of your admission.</p>	<p>1 day</p>
<p>Step 8 Discharge from hospital & Daycare appointments</p>	<p>After being cleared for discharge, you'll be followed-up as an outpatient in the L/BMT clinic for up to 3 weeks after your infusion.</p>	<p>~7 to 21 days</p>
<p>Step 9 Long-term follow-up & managing at home</p>	<p>Although It will be safe to finish your daycare clinic appointments, it will take time to resume a normal life. You will have follow-up visits with your hematologist or oncologist, who will continue to monitor your blood counts.</p>	<p>>12 months</p>

Getting Ready for your CAR T-cell Therapy

It's helpful to start thinking of the practical, physical, and emotional preparations before CAR T-cell therapy.

What must I do before CAR T-cell therapy?

1. **Choose a 24-hour caregiver** – You will need a 24-hour live-in caregiver for at least 30 days after CAR-T therapy. This could be just one person or a group of family and friends who work together. Your Nurse Navigator can assist caregivers with requesting compassionate time off work and visa application letters. For more information on caregiver roles and support, please see the *Resources and Supports* handout.
2. **Arrange transport** – Patient are not allowed to drive under any circumstances for 8 weeks following infusion of CAR T-cells.
3. **Register for Pharmacare** – If you have not registered for Fair Pharmacare, call 1-800-663-7100 or visit <http://my.gov.bc.ca/fpcare/registration-status/request-status> to clarify your benefit plan and medication coverage.
4. **Plan where you'll stay before and after discharge** – You may not be admitted on your expected admission date, it will depend on bed availability. You will need to stay close to Vancouver General Hospital while undergoing LD chemotherapy, while waiting for admission to the hospital, and again for 30 days after the CAR T-cell infusion when you are discharged from the hospital. Please refer to the boundary map in the “Maps, Parking, and Places to Stay” handout.
5. **Arrange for care of any dependents and/or pets** – Let your Nurse Navigator know if there are any concerns regarding people dependent on you for their care. Pets can stay with you through your treatment but some people to choose to bring them to stay with family or friends.
6. **Purchase a digital Celsius thermometer** – Can be purchased at your local pharmacy (if you do not have one). You will use it regularly to monitor your temperature through your treatment and recovery.
7. **Inform your doctor** – If you have seen a doctor in a separate facility or health care program, ensure your CAR-T doctor is aware. Our doctor are not always informed of all your previous medical records.
8. **Get your Flu Shot & COVID-19 immunization** – Approaching or during the influenza seasons (~October to April), **we strongly recommend** you and your family receive the flu shot and COVID-19 immunizations are recommended year-round. It is offered free at any local clinic and some pharmacies. While not 100% effective, it is the best way to prevent getting an infection, and it will lessen the chances of severe complications if you do contract the flu or COVID-19. Ask your doctor or Nurse Navigator when the best time get your vaccinations.

What are other suggestions to prepare for CAR T-cell therapy?

Connect with a Social Worker and Support Programs

BC Cancer Agency have patient and family counsellors and social workers available at your regional cancer centre and over the phone. We strongly recommend our patients use the excellent support services offered by BC Cancer, the Canadian Cancer Society, and the Leukemia and Lymphoma Society. They can help you cope with your diagnosis and how it may affect you, your family, your living arrangements, your finances, and other practical matters. More information about these services can be found in the “*Resources and Supports*” handout.

Proper nutrition

- Can help heal and repair damaged cells
- Will help minimize complications related to poor nutrition

Your illness, your ongoing treatments, and CAR T-cell therapy can all cause side effects that make people feel unwell. When you do not feel well, your appetite may decrease. For these reasons, before you start therapy start eating foods high in calories and in protein. Ask your family for support, if you are struggling to eat. Try to eat small meals more frequently. Ensure you have enough fluid intake; we recommend you drink 2 litres of water a day. We can refer you to a dietician if you are having difficulties with appetite and weight loss, ask your Nurse Navigator for more details.

Being Active

To building strength and energy, follow your regular exercise routine as best as you can. Or to a start, try light exercises like walking. Consult with your doctor about what is safe for you.

Mental health

Cancer and cancer treatments such as CAR T-cell therapy can be a challenging process. It is important to take care of yourself not only physically but mentally. BC Cancer offers counselling services and support programs to cancer patients and family members.

<http://www.bccancer.bc.ca/our-services/services/supportive-care/patient-family-counselling>

Another resource you can access is InspireHealth: <https://inspirehealth.ca/>. They provide free individual and group support in the areas of stress and mental health counselling, managing treatment side-effects, nutrition support, exercise therapy for better recovery, improving sleep and energy, and managing work, life, and relationships.

Keeping free from infection

While waiting for CAR T-cell therapy take precautions against infections. Make sure to wash your hands often and avoid visiting with friends and family if they are sick. If you do get an infection prior to the collection of your CAR T-cells your collection will need to be delayed. You will need to inform your doctor right away if you start having any signs and symptoms of infection (See page 33 for examples of infections symptoms, and see the “*CAR T-cell Therapy: Side Effects & Management*” handout for further ways to prevent infections).

Quitting smoking and vaping

Quitting smoking can help you on your CAR T-cell therapy journey. Quitting smoking can help make your treatment work, and it can help you get better faster. When you are admitted to the hospital, you will not be able to go outside to smoke/vape. Please ask your doctor about ways you can stop and what they can do to help support you. BC Cancer has a Smoking Cessation

Program and QuitNow is a free program for British Columbians looking to quit or reduce tobacco and e-cigarette use (<https://quitnow.ca/>).

Reproductive health

It is recommended that sexually active females with reproductive potential should use effect contraception and sexually active males should use a condom with females of reproductive potential or pregnant women. There is currently no available clinical data on the effect of CAR T-cell therapy on fertility or regarding breastfeeding. Patients being treated with CAR T-cells should not breastfeed as the lymphodepleting chemotherapy is secreted in breastmilk. If having children after CAR T-cell therapy is important to you, talk to your doctor about your options.

Learn about CAR T-cell therapy

Information from our team and this manual will help you learn about CAR T-cell therapy. It can help you know what to expect and help you feel less anxious through the treatment.

Plan ahead

Putting one's legal affairs in order does not mean expecting the worst and it can give you the peace of mind to focus on getting better. Make sure your family and loved ones know your wishes if you cannot speak for yourself. Connect with a BC Cancer social worker for questions on any of the following:

- **Assign a Power of Attorney (POA).** This person can make your health care decisions for you if you cannot make them yourself. For more information, go to <https://nidus.ca/resource/enduring-power-of-attorney/>
- **Complete your Advance Plan.** For more information, www.advancecareplanning.ca and <https://www.healthlinkbc.ca/more/health-features/planning-advanced-care>
- **Make or update your will.** Type "wills and estate planning" at <https://www2.gov.bc.ca/gov/content/home>

Step 1: Preparing for CAR T-cell therapy

Consultation with Hematologist

Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

1 to 3 months before CAR T-cell therapy. (You may have received this booklet during this appointment)

Your hematologist will review your health history, do a physical assessment, and discuss CAR T-cell therapy with you and your caregiver(s). They may ask for additional tests before deciding that CAR T-cell therapy is safe for you. They will give you instructions and details if this is the case.

Please note, a medical consent will be completed during this appointment. If English is not your primary language an interpreter will be needed to ensure informed consent. Family members are not able to provide interpretation for medical consents.

Phone call with BMT Nurse Navigators

Initial phone call: Within 2 weeks after Hematologist Consultation

Our Nurse Navigators arrange all the planning, testing, and appointments needed in preparation for your CAR T-cell therapy. A few weeks after you meet with your Hematologist, you will receive a phone call from one of our Nurse Navigators. They will give you your planned start dates so you can plan accordingly. Please note that these dates can change.

Roughly, 2 to 4 weeks prior to your CAR T-cell collection, they will phone you to ask questions on your health history and discuss the tests and appointments you'll need. After this 20-30 minute phone call, they will send you an email with more information on your scheduled appointments and tests.

Please tell your Navigator if you are from out of town and use any mobility aids, raised toilet seats, bedrails or other assistive devices. They will help you get in touch with our physiotherapy team to arrange for this type of equipment during your treatment.

Pre CAR T-Cell Therapy Tests

Approximately 8 weeks before starting CAR T-cell therapy

Tests must be done to check how well your heart, lungs and kidneys are working before CAR T-cell therapy. Whenever possible, we will try to arrange these tests to be done in your local clinic or hospital. **You may not need all of these tests, and your doctor may order extra testing not listed below. It is normal to require extra testing or consultations; we will arrange these appointments for you.**

These tests include:

Bloodwork: These blood tests can tell us many things, including how healthy your organs are and any past exposures to certain diseases.

- **Infectious disease markers (IDMs):** *~within 30 days of collection*
 - Checks for common infections.

- May indicate you need special treatment before or after your CAR T-cell therapy.
- Infections may be passed in blood and can affect how your T-cells are handled.

Organ function tests:

- **Heart tests:** An electrocardiogram (ECG) and radionuclide ventriculogram (RVG or MUGA) are done to show us how healthy your heart is and how well it pumps blood through your body.
- **Lung tests:** Your doctor may request a Pulmonary Function Test (PFT) and chest x-ray are done to check the health of your lungs and your breathing ability.
- **Kidney tests:** A blood test or kidney or 24-hour urine collection is done to show how well your kidneys are working.
- **CT or PET Scan:** Your doctor may request a computed tomography (CT) scan or position emission tomography (PET) scan to show a more detailed look at tissue and bones in a certain area of your body.
- **MRI:** Your doctor may request magnetic resonance imaging – please alert the physician or navigator if you have any implanted metal devices.

Bone marrow biopsy: This may be done to check how well your bone marrow is making cells and to look for any sign of cancer in the bone marrow.

Lumbar puncture: This test is used to check for abnormal cells in your cerebrospinal fluid (CSF).

Dental screening: Checks your oral health to prevent infections that could delay your treatment. The screening will be done with a BCCA Dentist.

Central Venous Catheter (CVC): If you don't already have one, you will need to have a central venous catheter inserted (also known as a Hickman® line or Trifusion®). This is a flexible plastic intravenous line used to draw blood, give you fluids, nutrition, medications, and your CAR T-cells. For more information please see “*All About Your Tunnelled Catheter*” pamphlet.

- You will be required to have a caregiver with you, to take you home after the CVC insertion and to stay with you overnight.

Further or repeat tests may occur *post CAR T-cell collection*

- If needed, these appointment would occur between collection and the CAR T-cell infusion to assess your health status.
- Your nurse navigator will arrange this for you.
- Most appointments can be done in your home community.

Consultations:

All consultations are on 6th Floor Leon Blackmore Pavilion, Vancouver General Hospital

To help you prepare for CAR T-cell therapy, you will meet with members of your health care team for personalized teaching. CAR T-cell therapy can affect every part of your normal routine. Knowing what to expect and how to plan for it will help make the treatment process easier for you and your family.

1. Hematology Apheresis Unit (HAU):

This appointment must be in Vancouver General Hospital

The nurses in the apheresis unit will meet with you to check your veins and teach you about the CAR T-cell collection process. Checking your veins is important because the apheresis machine needs a certain amount of blood flow in order to work properly. If your arm veins are suitable, we will use them to collect your T-cells.

If your veins are too small or delicate, we will plan for you to have a “central venous catheter” (CVC) inserted. It is an intravenous (IV) line we use not only for collecting your CAR T-cells but also for the rest of your CAR T-cell therapy treatment. It will remain in place until you have recovered 3-4 weeks later. For more information, please see “*Step 4: Central Venous Catheter Insertion*”.

2. Social Worker:

Our social worker will discuss how having CAR T-cell therapy can affect your family, coping, living arrangements, employment, finances and other practical matters. They can talk with you regarding general steps in creating a will, advance care plan, power of attorney, and temporary substitute decision maker.

3. Dietitian:

If you have had problems with appetite or weight loss in the past, you will meet our dietitian. Our dietitian will discuss how you can prepare for CAR T-cell therapy and manage side effects through your diet and food choices.

4. Pharmacist:

If your hematologist requires help with monitoring or adjusting medications you may be referred to one of our pharmacists.

5. Thrombosis Clinic:

This appointment is only needed if you are currently using a blood thinner (i.e. warfarin, heparin, etc.). The thrombosis clinic doctor and nurses will teach you how to manage your blood thinner through your treatment.

What should I bring to my appointments?

- Health card
- A list of all prescription medications you are taking, including the dose and how often you take them.
- A list of all over-the-counter medications you are taking including:
 - natural supplements
 - vitamins
 - minerals
 - alternative medicines
- A list of questions you may have about treatment.
- Your caregiver
 - It may be overwhelming and easy to feel emotional with all the information you will hear from your healthcare team. You can bring a caregiver to help listen, take notes, and can be close to help with those feelings.

Step 2: Collecting Your CAR T-cells

Approximately 2 to 8 weeks after being seen by the program's hematologist

Vancouver General Hospital, Leon Blackmore Pavilion 6th Floor

Your CAR T-cells are collected by a procedure called apheresis (“a-fur-REE-sis”) in the Hematology Apheresis Unit (HAU). You will be connected to the apheresis machine for about 4 to 6 hours. Most patients collect enough T-cells in a single day. Very rarely a second day is needed to collect enough cells.

You will be connected to an apheresis machine which will:

- Collect your blood
 - Through an IV in your arm, a peripheral intravenous line (PIV), or through a central venous line (CVC), your blood is pulled from your body into the machine.
 - There will be only a small amount of your blood circulating in the apheresis machine at any one time.
- Filter your blood
 - Your blood is then separated into its different types.
 - Your white blood cells, including T-cells, are collected.
- Return blood to your body
 - The remaining components of your blood are returned to you via another PIV in your other arm, or through a different tube in your CVC.

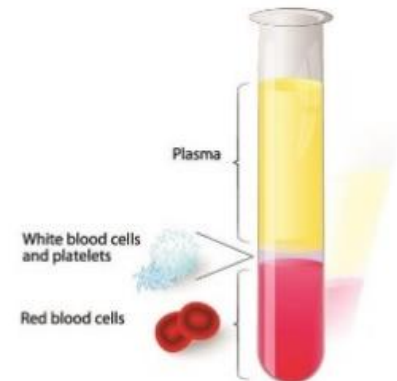


Figure 5. From “Blood Cell Types”, by Knapp, S., 2021.

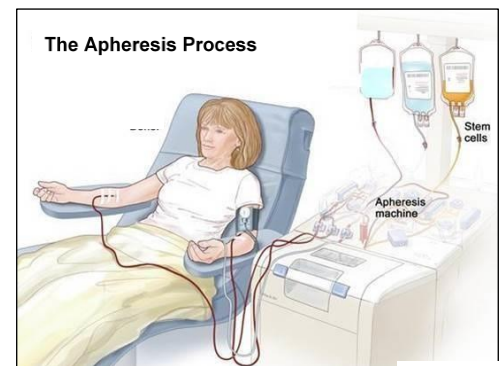


Figure 6. The Apheresis Process, by Winslow, T., 2011.

How can I prepare for CAR T-cell collection?

- Drink plenty of fluids before your collection. Please avoid coffee and tea as they are diuretics (make you go pee), and this can affect the quality of your veins.
- Eat calcium-rich foods for breakfast on your collection day (examples: milk, yogurt, cheese, and calcium fortified foods such as some breakfast cereals).
- You can bring your own lunch and snacks. The unit can also offer water, juice, cookies, and a limited selection of sandwiches.
- You will be able to watch television during the collection. You can also bring in your own music, audiobooks, and podcasts to listen to with headphones. **Please note you will have limited use of your arms (because of the 2 PIV lines).**
- Wear comfortable clothing that allows for easy access of your arms.
- Arrange for someone to drive you home at the end of the day. It may be unsafe to drive afterwards, as the procedure may cause you to feel dizzy or weak.

**You will be given more information on how to prepare for your collection day during your first apheresis unit visit.*

Are there any side effects with CAR T-cell collection?

During the collection, you may feel:

- **Light-headed or dizzy:** This is due to your blood going through the machine.
- **Tingling** in your lips, fingers and toes, **and cramping** in your hands and feet: To prevent your blood from clotting while it circulates in the apheresis machine, a blood thinner is used. Tingling is a side effect of this medication. Calcium given to you during the treatment and can be increased to help the symptoms fade.

Tell the nurse if you feel any of these or any side effects. Your nurse will check on you throughout your procedure and can get you medications that can help the symptoms go away. Most side effects will stop when the collection ends.

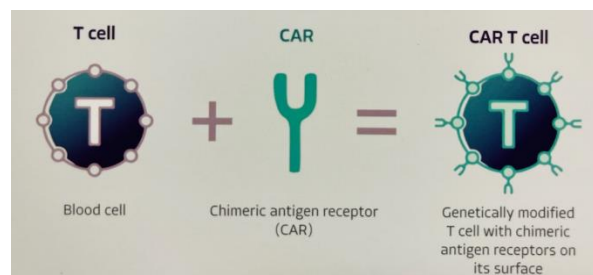
What happens after the CAR T-cells are collected?

At the end of the day, the bag of CAR T-cells that has been collected is sent to the lab where the T-cells are counted. If not enough cells have been collected, you will be asked to come back another day to have the process repeated. **This is normal and there is no need for concern.**

An apheresis nurse will call you 24 to 48 hours later to follow-up. If you have any concerns or further symptoms, please reach out the phone numbers provided on page 2.

Your collected T-cells are then sent to a manufacturing company where:

- Your T-cells will be genetically modified to have a new special receptor, a CAR, on its surface.
- Modified T-cells are multiplied until there are millions of these CAR-T cells.
- Your cells are then frozen after they are made into CAR T-cells, so they can be preserved and sent back to you.
 - A preservative called DMSO is added to protect your cells.
- It typically takes 3 to 4 weeks to make the CAR T-cells. Please note the timing may vary.



Step 3: Bridging Treatment

May occur over ~3 to 4 weeks, while waiting for your CAR T-cells to be made.

It can take several weeks for manufacturing company to make your CAR T-cells. While waiting for the CAR T-cells to be ready you may receive what is referred to as a “bridging treatment”. This treatment can include chemotherapy, radiation, or steroid therapy aimed at keeping your cancer under control. Your doctor will discuss with you which, if any, bridging treatment(s) you will receive.

Step 4: Central Venous Catheter Insertion

Approximately 1 week before CAR T-cell infusion

Vancouver General Hospital, Jim Pattison Pavilion, Radiology Unit Ground Floor

**If you already have a central venous catheter proceed to "Step 5"*

Before CAR T-cell therapy, you will need a central venous catheter (**CVC**) inserted. It is a flexible tube that is put into a large vein in your neck. The other end sits outside of your chest. Having an IV line may sound scary but it will make CAR T-cell therapy experience much more comfortable.

There are 2 CVCs we use in our program. **You will have one of the following:**

- **Trifusion® Line;**
 - Inserted before CAR T-cell collection for people with small, delicate veins.
 - Can be used for CAR T-cell collection, chemotherapy, CAR T-cell infusion, and recovery.
 - In some cases, a "Permcath®" CVC is used only for CAR T-cell collection then removed. A Hickman® line would be inserted later.

- **or a Hickman® Line**
 - Inserted a few days prior to the start of LD chemotherapy given just before CAR T-cell therapy for people who had suitable veins for collection.
 - Only used for chemotherapy, CAR T-cell infusion, and recovery, not CAR T-cell collection.
 - Most people have Hickman lines or a similar line.

What will my CVC line be used for?

- Giving intravenous (IV) high-dose chemotherapy
- Giving IV fluids to help keep you hydrated.
- Drawing blood for tests.
- Giving back your CAR T-cells on the infusion day.
- Giving blood transfusions and medications, as needed.

How will this IV line be inserted?

A doctor will insert your IV line in the VGH Radiology Department, using a local anaesthetic. You may have some minor pain or stiffness in the neck and shoulder area for a day or two after your line is inserted. You will see a bandage dressing covering your IV line.

What happens after it is inserted?

You will be sent to the Daycare unit (or the Apheresis Unit) after the line has been inserted for 1-2 hours of monitoring. Your nurse will make sure the bandage (dressing) covering the line is dry. It is normal for a small amount of blood to be on the dressing after insertion. Contact us if there are ever any concerns with your IV line.

You will feel drowsy from the local anesthetic, so it is not safe to drive yourself home from this appointment. Please arrange for someone to take you back home, or to your lodgings, after your line insertion.

How do I care for my CVC line?

Infection is the biggest risk for any type of IV line. To help avoid infections:

1. Avoid getting the dressing wet and do not shower or bathe for 24 hours after it is inserted. Your nurse will show you how to protect it before showering. Steam can cause the bandage to become wet and fall off, so it is best to take short showers. Aim the shower nozzle away from the line. Baths are not recommended.
2. Look at your tunneled catheter line every day. That chest area should not be tender, red, swollen or have drainage. Contact us if you notice a problem.
3. Do not remove the dressing. If the dressing peels off, wash your hands well and tape it back into place. Call our unit to set up a dressing change.
4. To prevent tugging on the line, we will give you a necklace to attach your CVC to. Some people find it comfortable to place the ends of their CVC line in a clean baby sock. Women can tuck the ends of the catheter in their bra.
5. Please refer to the "All About Your Tunneled Catheter" booklet for more information. **You will not have to flush your line, change caps, or change your own dressings as mentioned in the booklet.**

Pictures of Central Venous Catheters:

Right: A Hickman® line with three lumens. A Trifusion® line is very similar in appearance. A white or clear dressing covers the “exit site” to protect it from infection.

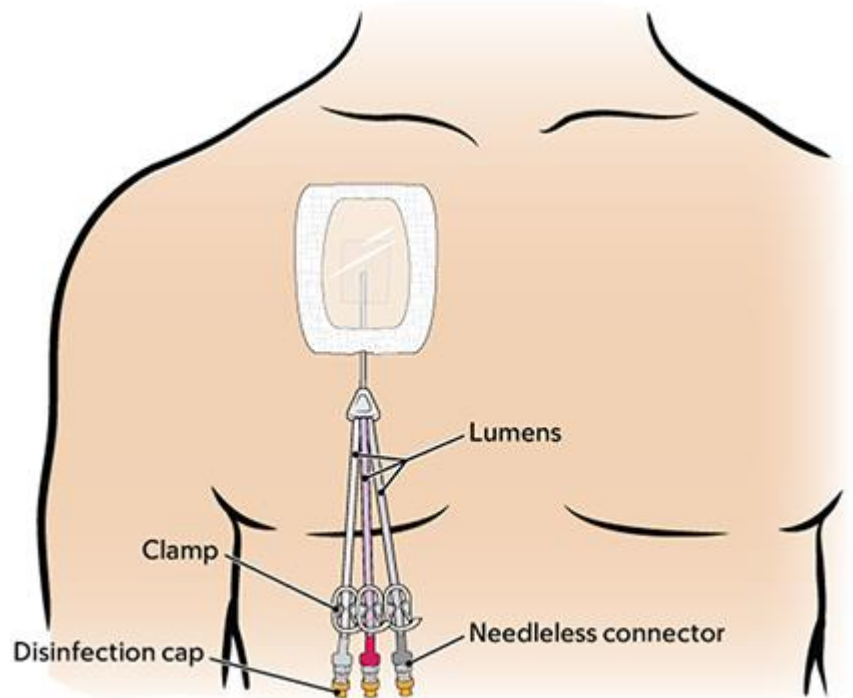
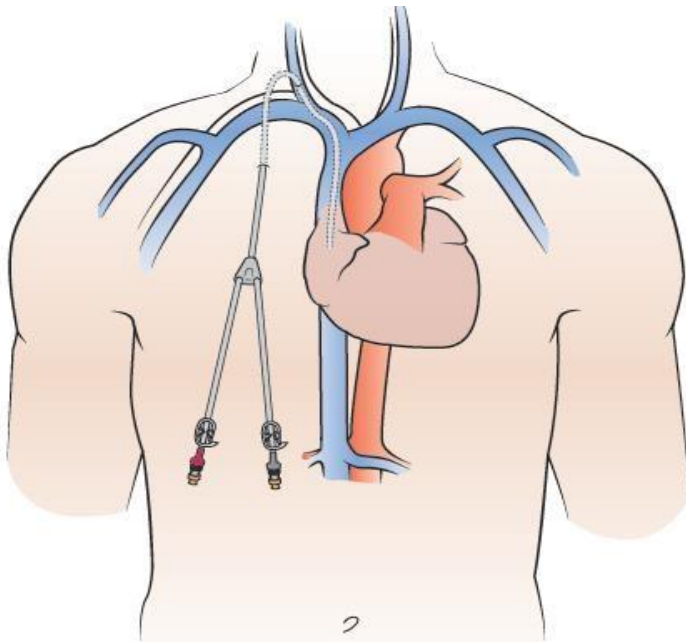


Figure 7. A Hickman line with three lumens. From “Catheter tunneled under your skin, into a vein,” by Memorial Sloan Kettering Cancer Center, 2023.



Left: The white plastic catheter enters your bloodstream through a neck vein. The tip of the catheter sits above the heart (not in it).

This picture show two lumens, most people will have three.

Figure 8. Where the catheter goes in your vein. From “Tunneled Catheter,” by Memorial Sloan Kettering Cancer Center, 2023.

Step 5: Lymphodepletion Chemotherapy

Will take place approximately 1 month after your CAR T-cell collection. Starts ~5 days before your CAR T-cell infusion.

L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, Vancouver General Hospital

***Important to note:** During the apheresis teach appointment, the nurses will have taken your weight and height. If you feel your weight has changed by 10 or more pounds, between the time of the teach appointment and starting LD chemotherapy, please let your healthcare team know. This is important as your weight is used for chemotherapy dosing.

Lymphodepletion (LD) chemotherapy, is a type of chemotherapy that aims to reduce the number of T-cells in your body to make room for your new CAR T-cells to grow. LD chemotherapy is done to prepare your body for CAR T-cell therapy.

LD chemotherapy:

- Will be given through your central line (CVC)
- Occurs over 3 to 4 days depending on the CAR T-cell product.
- Completed at least 48 hours prior to your CAR-T cell infusion.
- Each day of LD chemotherapy is about ~6 hours long
 - It is helpful to bring some items to items for your comfort (see page 26).
 - The timing may vary, it will depend on what other tasks need to be completed that day (for example: CVC dressing change).

What chemotherapies will I be receiving?

The most common LD chemotherapies include:

a. Cyclophosphamide

This chemotherapy will be given for 2 days, and it will take about an hour for it to infuse.

- Please note that this chemotherapy can affect your bladder. Tell you healthcare team of any symptoms such as:
 - Changes in urination
 - Burning or pain when peeing
 - If you see blood in your urine (red or pink coloured pee)
 - Abdominal pain

b. Fludarabine

This chemotherapy will be given for 3 days, and it will take about 30 minutes for it to infuse.

**Please note, different diseases sometimes require different types of LD chemotherapy. Your doctor will speak with you about which chemotherapies you will be receiving.*

When you arrive at the Daycare unit for your LD chemotherapy, the nurses will:

- Connect you to intravenous (IV) fluids. These fluids will run for 2 hours before your chemotherapy to protect your kidneys.
- You will be given medication to prevent you from feeling nauseous. **Ondansetron 8mg.**
- Give you your chemotherapies **Cyclophosphamide** and then **Fludarabine.**
- Run IV fluids for another 2 hours after all your chemotherapies have been completed.
- Begin orientating you to the Daycare unit and routine.

How does Chemotherapy work?

Chemotherapy is a drug treatment that uses strong medications to kill cancer cells. It targets cells that grow and divide quickly, as cancer cells do. Chemotherapy also attacks fast growing healthy cells. The cells that line your stomach, hair, skin and bone marrow are examples of cells that grow quickly. LD chemotherapy primarily destroys lymphocytes. As mentioned, lymphocytes like T-cells recognize antigens that are foreign to the body. Without LD chemotherapy your body would have many lymphocytes which could recognize your new CAR T-cells as foreign and destroy them. LD chemotherapy is therefore crucial to CAR T-cell therapy.

You will start to feel unwell and experience chemotherapy side effects as your healthy cells are damaged. This is why chemotherapy can cause, for example upset stomach, hair loss, and lowers your “blood counts.”

Side effect of chemotherapy:

- Can vary from person to person.
- Typically start within 1 to 2 days of treatment.
- Are usually short term, lasting 2 to 4 weeks.

During and after LD chemotherapy, your healthcare team will check on you and help you manage any side effects.

What are the most common side effects of chemotherapy?

- Nausea and vomiting
- Loss of appetite
 - You may find it hard to eat or do not feel hungry
- Diarrhea
 - loose, watery, unformed poo (3 to 4 times per day)
- Fatigue (feeling very tired)
- Low blood counts
 - Feel tired and weak
 - Bruising more often/easily
 - More likely to get an infection
 - May need a blood transfusion
- Fever
 - high body temperature $\geq 38^{\circ}\text{C}$

*Please see *CART-cell Therapy: Side Effects & Management* Handout for more detail and on how to best manage your symptoms.*

Cytotoxic Safety (“CYTO” = cell “TOXIC” = harmful)

Chemotherapy is a cytotoxic medication, meaning it is harmful to cells. It takes 48 hours for chemotherapy medications to slowly leave your body through your urine and stool. Small amounts of the drug can also be found in blood, vomit, semen, and vaginal fluids.

After receiving chemotherapy, your body fluids are **cytotoxic for 48 hours**. This period is referred to as the “chemotherapy washout period.”

You will receive your CAR T-cell infusion at least 48 hours after your last LD chemotherapy. Your body will need to get rid of the chemotherapy before your CAR T-cells are infused, because if the chemo medications are still in your body they can destroy your new CAR T-cells. While the risk is low, please take precautions to keep you and your family safe while you are cytotoxic.



During the 48 hours that you are cytotoxic:



About the L/BMT Daycare Outpatient Unit:

Your lymphodepleting chemotherapy treatment will be completed at the Leukemia/Bone Marrow Transplant Daycare Unit. This is called the Daycare Unit or LB6 for short and is located on the 6th floor of the Leon Blackmore Pavilion at Vancouver General Hospital.

You will be coming in daily for the 3 to 4 days of LD Chemotherapy and until you are admitted into the inpatient unit for the CAR T-cell infusion.

Amenities

- There are 22 treatment rooms with beds and chairs for patient use. Family members/caregivers are welcome to assist you and keep you company.
- Wi-Fi connection and televisions are available for each patient.
- A kitchen with a water machine is available to fill your own bottles with. A small selection of snacks, sandwiches and juice are available for patients who have an unexpected longer stay.

What should I bring to each visit at the Daycare Unit?



What Can I Expect in the Daycare Unit?

On your first visit, your nurse will give you a tour to show you where to find water, warm blankets, etc. Our unit has a “self-care” routine which includes your nurse teaching you how to check in for each visit, how to take your own vital signs and when to book your next visit. Each visit is typically 4 to 6 hours long, but it can sometimes be longer. This is based on what your chemotherapies you are receiving that day and any symptoms you may have. Each visit, a nurse and doctor will discuss any side affects you may be experiencing and questions you have each visit.

Step 6: Planned Admission to the Hospital

15th or 16th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

You will be admitted to the hospital the day before you receive your CAR T-cell infusion or sometimes the day of your CAR T-cell infusion.

I've been given an ideal admission date. What does this mean?

Your ideal admission date is the date we aim to admit you to hospital. We cannot guarantee that a hospital bed on our unit will be available on this date. We make every effort to admit you as close to your ideal admission date as possible; please see more information on this subject in "The Leukemia/BMT Inpatient Unit" booklet.

What should I have ready while I'm waiting to be admitted?

From your ideal admission date onwards, have your hospital bag packed and be ready to come to the hospital as soon as you are contacted by our unit charge nurse.

***IMPORTANT:** Due to the unpredictability of our unit, we are only able to hold your bed for a limited amount of time. For this reason, it is very important that you come to the hospital right away when you are contacted by our nurse to be admitted.*

What will happen when I am admitted?

When you arrive at the hospital, please check in at the front desk on the 15th floor (T15A) of the Jim Pattison Pavilion. It will take time for our team to help you settle in, do our assessments, and ensure all preparations have been done for you to receive CAR T-cell therapy the next day (or in some cases that same day).

- You may have to wait in the patient lounge while we prepare your room.
- You will be assigned a shared room with one other patient or a private room. Private rooms are not guaranteed as they are required for patients requiring additional isolation precautions or other circumstances.
- Your nurse will orient you to the unit, draw your bloodwork, complete admission forms and perform a physical assessment.
- A doctor will discuss the CAR T-cell therapy process and treatment with you, perform a physical assessment and go over any consent forms needed.
- More information can be found in the "L/BMT Inpatient Unit" booklet.

Step 7: CAR T-Cell Infusion

15th or 16th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

What will happen on my CAR T-cell infusion day?

Your CAR T-cells will be reinfused, put back, into your body.

Prior to the infusion:

- Blood tests and a routine check-up will be completed.
- Pre-medications are medications given to you to help minimize some side effects.
 - Tylenol® and Benadryl®, as needed anti-nausea medications
- Your nurse will stay with you during the infusion.
- Vital signs will be done at the start, middle and end of the infusion.
 - Vital signs are when your temperature, blood pressure, heart rate, breathing rate, and oxygen levels are checked.

Your CAR T-cells:

- Come from the manufacturing company frozen, so a technician will thaw your frozen CAR T-cells in a warm water bath.
- Will appear as a colourless or slightly yellow suspension of cells.
- Will be infused back to you through your central line (CVC).
- Infusion time typically takes less than 15 minutes (maximum of 30 minutes).

While your CAR T-cells are being given to you:

- You will be sitting up comfortably in a hospital bed. Your family and friends can be in the room to celebrate and support you.
- You may feel nervous or excited or both. This is normal; you are safe and we are here to support you and can answer any questions you may have.
- You may have an odd taste in your mouth like canned corn or garlic. This is from the DMSO preservative in the bag of CAR T-cells. We will give you a hard candy to suck on through the CAR T-cell infusion to help get rid of this odd taste.
- You may feel a tickle or tightness in your throat or chest. This is normal and you will feel better if you breathe deeply and cough.
- You may feel nauseated (feeling of having to throw up).
- You may feel some dizziness, or light-headedness.
- You may feel cold. This feeling is caused by the thawed CAR T-cells.
- All these symptoms will go away once the CAR T-cells are finished being infused.
- Occasionally, some people have an allergic reaction to the DMSO preservative. Your nurse and doctor are ready if this happens and will give you medications to quickly stop the allergic reaction.



Figure 9. Thawed CAR T-cells. From "Manufactured CAR T cells ready for infusion into a patient", by Penn Medicine, 2021.



After your CAR T-cells have been given back:

- You can feel sleepy from the IV Benadryl® that was given.
- Monitoring and vital signs will continue every hour for the first 4 hour and then every 2 hours for the 4 hours.
- The canned corn taste from the DMSO may stay on your breath 24 hours after the infusion.

What is happening in your body?

- CAR T cells are put back into your blood stream and they will continue to multiply.
- CAR-T cells identify the cancer cells with the target antigens and kill them.
- CAR-T cells may remain in your body for some time to help prevent the cancer cells from returning.

What are the side effects of CAR T-cell therapy?

Your healthcare team will check you often to watch for the side effects of CAR T-cell therapy. Being knowledgeable and aware of the side effects yourself can help you know what to look out for and when to bring up concerns to your team.

Cytokine-Release Syndrome (CRS)

What is it?

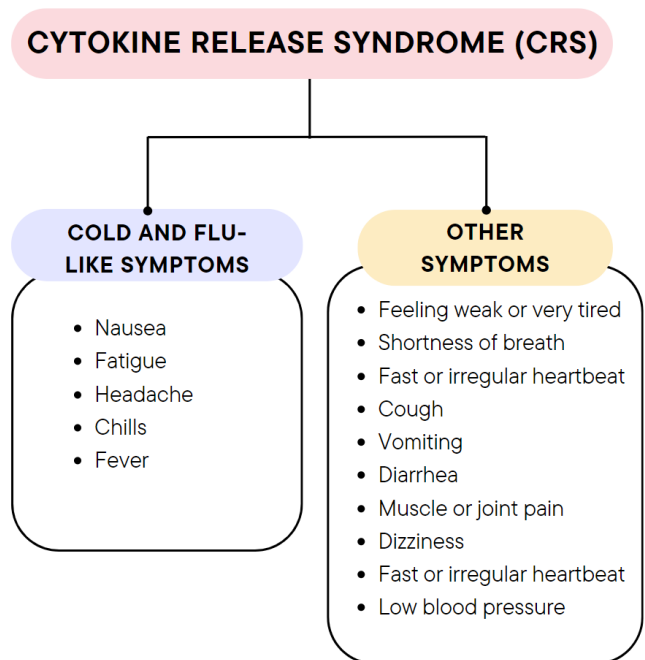
- *Reminder:* CAR T-cell therapy is an immunotherapy, therefore it uses your own immune system to fight your cancer
- This syndrome occurs when your immune system produces large amounts of cytokines very quickly
 - Cytokines are chemical messengers that help the T-cells carry out their functions.
 - Cytokines are produced when the CAR-T cells multiply in the body and kill cancer cells.
- This results in a widespread immune/inflammatory response in the body.
- This can be harmful and interfere with a number of body functions.

Timeframe

- Typically occurs in the first few days after CAR-T infusion but it can occur up to 30 days after treatment.

When should you contact your healthcare team?

- You are advised to *immediately* contact the designated health professional if CRS reactions are suspected.
- Medications can be given to improve symptoms and stop CRS.



Neurological Toxicities

CAR-T therapy can also affect your brain and nervous system.

Timeframe:

- Typically, the symptoms resolve over several days without intervention or apparent long-term effects.
- Most commonly occurs within the first week after CAR-T infusion, but can occur up to 8 weeks after.
- Due to the risk for altered or decreased consciousness or coordination in the 8 weeks following CAR-T infusion, patients are required to refrain from driving or operating heavy or dangerous machinery under any circumstances. This time period may need to be extended should you develop neurologic symptoms.
- Such side effects are some of the reasons you are required to have a caregiver for at least 30 days after CAR-T therapy.
- **Patients treated with certain CAR T-cell products will receive medications to prevent seizures for 30 days after CAR T-cell infusion. It is important you take this medication to prevent seizures. If you experience side effects that you think are from the medication do not stop the medication before discussing them with your doctor.**

When to contact your healthcare team?

- You are advised to *immediately* contact the designated health professional if neurologic adverse reactions are suspected by yourself or your caregiver.
- Medications can be given to improve symptoms and stop neurologic toxicity

Low Blood Counts

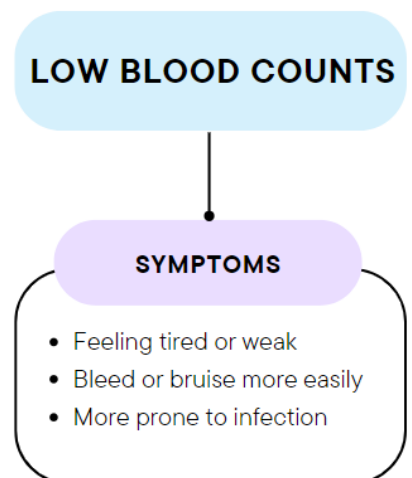
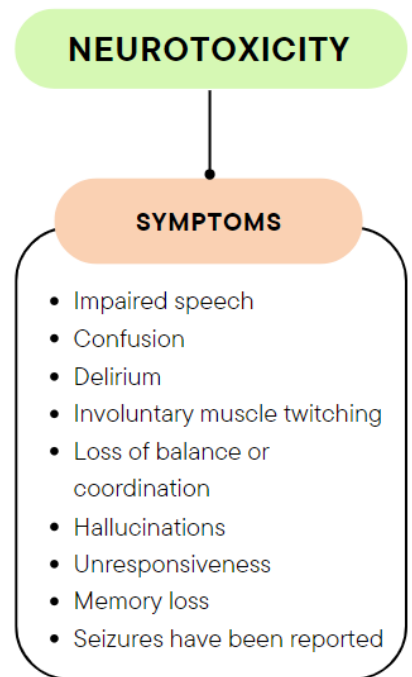
- CAR T-cell therapy can increase the risk of infections, fatigue, and bruising or bleeding
- It can also affect other counts such as B-cells which can result in *B-cell aplasia*, or it can decrease your immunoglobulin or antibody levels in the case of *hypogammaglobinemia*.

Timeframe:

- Typically, your blood cell counts will improve in the 30 days after CAR T-cell infusion, but sometimes low blood counts can persist months afterwards.

When to contact your healthcare team?

- Contact your healthcare team immediately if you have any signs of spontaneous bleeding or bruising or experience any of the following symptoms:
 - Vomit that looks like coffee grounds
 - Black, tarry poo
 - Bright red blood in your urine



Serious Infection

- CAR T-cell therapy, and other concurrent therapy, can cause you to have a weakened immune system, increasing your risk of getting an infection.
- You will be given prescriptions for medications to prevent infections after receiving CAR T-cell therapy.
- This can be due to several factors: immune dysfunction from underlying malignancy, viral reactivation, prior therapies, and LD chemotherapy.
- Infections are illnesses you get from “germs”
 - bacterial, viruses, or fungi
- Symptoms can be similar to *Cytokine Release Syndrome*.

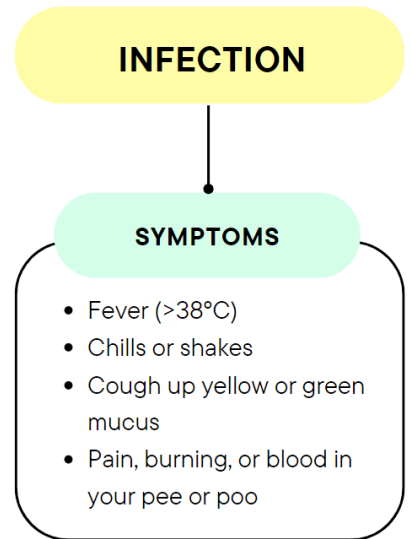
Timeframe:

- As your blood cell counts, in particular your WBCs, increase your immune system function will improve. How quickly these counts improve can be different for different people, as it is related to previous therapies and disease processes.

When to contact your healthcare team?

- You are advised to immediately contact the designated health professional if any signs of infection are suspected by yourself or your caregiver.
- If you have an infection your healthcare team will treat you with:
 - Antibiotic, antiviral, or antifungal medications
- If you are having side effects from medications prescribed to prevent infections:
 - Talk to your doctor first. Do not stop the medication on your own.

Everyone is different – it is normal for some people to have more side effects than others. For more detailed information on potential side effects and how to manage them, see below or refer to the “*CAR T-cell Therapy: Side Effects & Management*” handout for more information.



Step 7 (Continued): Planned Hospitalization

~8 to 14 days

16th or 15th floor, L/BMT Inpatient Unit, Jim Pattison Pavilion, VGH

To ensure your safety and ensure your healthcare team can timely respond to any side effect or adverse effects of CAR-T therapy you will be **required to stay in the hospital for a total of 8 days, this means 7 days after your CAR T-cell infusion**. It is during the first 30 days that you are most likely to see side effects. By being in the hospital, the healthcare team is best able to support you through this period. You will likely be discharged from the hospital after 8 days as an inpatient but this will depend on if you have continuing side effects.

After your CAR T-cells are infused, there will be roughly 1-2 weeks where your blood counts will be low. During this time, you will feel the most unwell from the side effects from chemotherapy and from the side effects of the CAR T-cell therapy itself. As your blood counts return to more normal levels, your side effects will improve.

What will happen while I'm waiting for discharge from the hospital?

While your CAR T-cells begin to work to kill your cancer cells, and while your white blood cells and other blood counts are low, you will be closely monitored and supported by your health care team. Some things to expect include:

- **Tests:** You'll have daily blood tests and other tests as needed (i.e. CT scans, chest x-rays, etc.) to monitor your progress and watch for infection.
- **Managing side effects from chemotherapy and CAR T-cell therapy:** You'll be given medication and teaching to help you manage the side effects and make you more comfortable.
- **Preventative medications:** Your doctor will prescribe medications to prevent infections. You may also receive medication to prevent seizures.
- **Blood and platelet transfusions:** Most people need blood and platelet transfusions when their blood counts drop to lower levels.
- **Stay physically active:** Keep moving after your CAR T-cell therapy! Staying active is a very important way to prevent lung infections and limit the amount of muscle lost. Even when you're feeling unwell, try to stay out of bed as much as possible. Sit up for meals and walk around the unit as much as you can each day. Follow recommendations from your physiotherapist.
- **Teaching:** Learning about your treatment and how to take care of yourself is important as you look ahead to being discharged. Your health care team is here to support you and answer any questions you may have.

Discharge from the Hospital:

As your blood counts recover, you will notice the side effects and symptoms from the chemotherapy will improve. CAR T-cell therapy side effects typically occur during this timeframe, 10 to 14 days post-infusion. Your healthcare team will also ensure that any side effects from CAR T-cell therapy are managed before you are discharged. You will be discharged from hospital when the doctor feels it is safe for you.

Before you are discharged, we consider:

- You show no significant signs of cytokine release syndrome, neurotoxicity, or infection.
- Your blood cell counts have reached a safe level. Your blood counts do not have to be normal for you to be discharged.
- You are well enough to be monitored as an outpatient.
- You are able to eat and drink enough to maintain your weight.
- You have enough strength and mobility to attend regular clinic visits.
- You are able to take your medications in pill form.

**Please note that even after discharge, there is a potential to be readmitted to hospital if the health care team determines the need for it.*

Step 8: Discharge from the Hospital & Daycare Appointments

Short Term Recovery/Follow-ups

Once you've been cleared for discharge from the hospital, you will have appointments again at *L/BMT Daycare Unit, 6th floor Leon Blackmore Pavilion, VGH.*

You will be closely followed and required to come to Daycare appointments twice a week for the first month (30 days) post CAR-T infusion. You are required to stay within an hours drive of Vancouver General Hospital for at least 30 days following your CAR T-cell infusion.

What will happen during each visit to the Daycare unit?

During such appointments the care team will assess you and help you cope with symptoms. Each visit may be a bit different, depending on your blood tests and symptoms. You may have a shorter ~2 hour visit or you may need to stay longer. You can expect the healthcare team to:

- Check you health and vital signs.
 - Tell you nurse if you are experiencing any side effects
- Check you lab work.
 - Look for signs of low blood counts.
- Check for signs of infection and other complications.
 - For example: fever, redness, and swelling around your central line
- Give you medicines
 - Routine medications such as:
 - Antibiotics
 - Antivirals
 - Antifungals
 - Electrolytes
 - Elements such as calcium, potassium etc. that control the balance of fluids in your body.
 - Blood transfusions (if your blood counts are low)
- Arrange for extra tests as needed.

Reminder: First 30 days after your CAR T-cell therapy you CAR-T cells will:

- Divide and multiply in number
- Start attacking you cancer cells
- Destroy some of your normal cells

It is during the first 30 days after your CAR T-cell infusion that most side effects occur. It is the most likely period to have the 3 most common and sometimes severe side effects from CAR T-cell therapy: **infection**, **cytokine release syndrome (CRS)**, and **neurological toxicity**. It is important that the healthcare team can monitor you because most side effects occur during this period. This can cause changes to your immune system and result in both your immune system and blood counts to be low.

Tell your healthcare team if you have:

- Signs of Cytokine Release Syndrome (CRS)
- Signs of Neurotoxicity
- Signs of Infection
- Any bleeding, bruises, or little red spots anywhere on your body

Refer to page 31 for more detail about CAR T-cell side effects signs and symptoms.

Step 9: Long-Term Follow-up & Managing at Home after CAR T-cell therapy

Generally, it will take roughly 3-6 months for you to return to a relatively normal lifestyle. Adjusting to life after CAR T-cell therapy can feel like a slow recovery. You will likely still have good days and bad days. It will take time for you to step back into your roles, such as being a parent, spouse, employee and friend again. Be patient with yourself as you adjust and recover.

What should I do every day?

You are an integral part of the team, and we want you to be an active participant in your care. At home there are several things you can do to ensure your safety and wellbeing:

- Your caregiver and you should know the signs and symptoms of the side effect associated with CAR T-cell therapy (see “*CAR T-cell therapy: Side Effects & Management*” handout for more information).
- Know when to get help! If you are concerned or if you are experiencing any of the associated side effects, please reach out to your healthcare team via the provided important numbers (on page 2).
- Check your temperature twice a day. Check it more often if you are feeling unwell. Call us immediately if you have a temperature of 38°C or higher.
- Take your medications. You will be given a list of medications and when to take them.
- If you feel like it, you can do many of your usual home activities like going for walks, reading, listening to music, and having healthy family and friends visit you.
- Your 24-hour caregiver can help prepare your meals, keep track of how much you are drinking, take your temperature, and anything else you need help with.
- Please follow infection control guidelines

Are there any things I cannot do?

- You will be limited in where you stay. You will need to remain close to the hospital for four weeks (30 days) following CAR T-cell therapy. You must be within one hour's drive of the hospital.
- You will not be able to drive for 8 weeks following your treatment because the treatment can cause sleepiness, confusion, weakness, and temporary memory and coordination problems.
- Due to your immune system being potentially weak, avoid being the one to clean up after your pets because it can potentially cause you to get an infection. Please get your caregiver(s) to, for example clean your cat's litter.
- Avoid coming into close contact with people who are sick and have signs of an infection. For example: New cough, fever, diarrhea, vomiting, sore throat, runny nose, etc.
- Avoid public transportation until your immune system recovers, as it can be very crowded, and you can pick up an infection easily.
- Avoid gardening until your immune system recovers, as plants and soil can contain bacteria, fungi and molds, which can make you sick.
- CAR T-cell therapy may make some vaccines less effective. It may not be safe for you to receive a "live" viral vaccine during or shortly after receiving your CAR T-cell treatment. Your doctor can provide further information on when and which vaccines you should receive.
- Avoid alcohol. Chemotherapy and other aspects of CAR T-cell therapy can cause stress and damage to your liver. It is recommended to avoid alcohol for during, and at least 3 months after. Please check with your doctor, as this may be longer for some patients.
- If you smoke, we suggest that you quit immediately. Smoking can cause serious respiratory infections when your immune system is low. No one should smoke inside your home, and you should try to avoid second hand smoke in public.
- Avoid using marijuana. Marijuana can alter your mental state and mimic some symptoms of neurotoxicity. If you have questions about marijuana use, please talk to your doctor.

What should I do if I have an issue or questions while at home?

Write down any questions you may have and bring them to your next appointment. If you are unsure about a symptom you're having or have an issue that needs attention, contact us. A nurse can help manage your question over the phone or contact the doctor for further instructions.

Call Us Immediately If You Have:

- Fever: a temperature of 38°C or higher
- Flu-like symptoms
- Rash, blisters, allergic reactions
- New bad bruising and/or bleeding
- Chills or shaking
- Difficulty taking your pills
- Yellow or green mucus when you cough
- New pain
- A bad headache
- A seizure
- Concerns with your IV line
- Diarrhea, nausea or vomiting that doesn't stop
- Unsteadiness when walking or have fallen down

IMPORTANT PHONE NUMBERS

The Leukemia/BMT Daycare Unit Hours:

6th Floor Leon Blackmore Pavilion,
Vancouver General Hospital
Monday to Friday 7:00am – 7:00pm
Weekends & Holidays 8:00am – 6:00pm

604 875 4073

Afterhours (T15 Inpatient Unit):

15th & 16th Floor, Jim Pattison Pavilion,
Vancouver General Hospital
Monday to Friday 7:00pm – 7:00am
Weekends & Holidays 6:00pm – 8:00am

604 875 4343

Common Medical Terms

Anemia: A condition in which the blood has too few red blood cells, or not enough hemoglobin in these cells.

Antibiotics: Medications used to fight bacterial infections.

Antigens: Are proteins that are found on the surface of some cells, such as cancer cells. If your body is able to recognize the antigens as a foreign substance, it can cause your immune system to produce antibodies against it.

Apheresis: A painless procedure where blood is run through a machine that removes T-cells and then returns the remaining cells back to the bloodstream.

Biopsy: Removal of small piece of tissue for microscopic examination.

Blood Tests: You will have many blood tests before and throughout your treatment. Blood tests tell us about your blood cells levels (white blood cells, hemoglobin, platelets). They can also tell us about your general health, how well your organs are working (i.e. kidneys, liver, pancreas), electrolyte imbalances (i.e. potassium, magnesium) and if you have any possible infections.

Bone Marrow: Spongy tissue inside the bones where the blood cells are produced.

CAR T-cell therapy: *Chimeric Antigen Receptor T-cell therapy*, is a treatment made by taking some of your body's own white blood cells and genetically modifying them so that recognize and attack your cancer cells.

Chemotherapy: Anticancer drugs or combination of drugs designed to kill cancer cells.

High-dose Chemotherapy is higher than standard doses of anticancer drugs.

Chest X-Ray: This is a picture of the organs, bones and tissue inside your chest. It takes about 30 minutes to complete. Your doctor will decide if you need other x-rays.

Cytokines: Are small proteins that act as chemical messengers that help your body's immune system (such as T-cells) carry out their functions.

Cytokine Release Syndrome: is a collection of symptoms that can develop as a side effect of certain types of immunotherapies, such as CAR T-cell therapy. Having high levels of cytokines may cause increased inflammation throughout the body. This can be harmful and interfere with a number of body functions.

DMSO (dimethyl sulfoxide): A drug used to protect frozen T-cells.

Electrocardiogram (ECG): A heart test to check your heart's electrical activity.

Electrode stickers are placed on your chest to measure your heart's rhythm.

Hematologic: Relating to blood and blood forming tissues. A hematologist is a doctor that treats diseases and disorders related to the blood.

Immune system It is the body's defense against infection and disease.

Immunotherapy: refers to treatments that use a person's own immune system to fight cancer.

Infection Infections are illnesses you get from "germs" (bacteria, viruses, or fungi).

Infusion: The introduction of a liquid into the body through a vein.

Intravenous (IV): A therapy that delivers liquid substance directly into a vein.

Infections: The invasion and spread of harmful organisms (bacteria, viruses, fungi, parasites) that are not normally present in your body.

L/BMT: Leukemia/Bone Marrow Transplant Program of BC, formed in 1981.

Neurotoxicity (or Neurological Toxicities): Can occur when your brain and nervous system are affected after CAR T-cell therapy.

Neutrophils: A type of white blood cell that protects you from infections. They are the first cells to arrive on the scene when you have a bacterial infection.

Platelets: Cells that are needed for blood to clot.

Pulmonary Function Test (PFT): A lung test to check your breathing ability. A clip will be placed on your nose, and you'll be asked to breathe in and out of a mouthpiece.

Red Blood Cells: Cells that carry oxygen from the lungs to the rest of your body.

Radionucleotide Ventriculogram Scan (RVG or MUGA): A type of x-ray used to look at how well your heart is pumping. A series of images of the heart are taken after 2 injections of radioactive solution are given in your arm. The scan takes about 90 minutes.

Receptors: Are proteins that are found on your body's T-cells. These receptors are able to attach to foreign antigens, which can then trigger your immune system to destroy the foreign substance.

T-cell: T lymphocytes are a type of white blood cell. They help control the immune system, make antibodies to fight infections, and can destroy infected or defective cells.

White Blood Cells: A group of blood cells in your body that are a major part of your immune system. WBCs protect your body from illness and disease.

Where Can I Get More Information?

Ask a member of your health care team for any of the materials listed below. You can read or order them online. They can also be found on the inpatient unit near the public washrooms or on the Daycare Unit patient library (room 631).

- Supporting you through Treatment (Leukemia/BMT Program of BC)
- Resources and Support (Leukemia/BMT Program of BC)
- Chemotherapy and Other Drug Therapies (Canadian Cancer Society)
- Coping When You Have Cancer (Canadian Cancer Society)
- Eating Well When You Have Cancer (Canadian Cancer Society)
- Sex, Intimacy and Cancer (Canadian Cancer Society)

Find these booklets, video, and more information at:

The Leukemia Bone Marrow Transplant Program of BC
“Resources”

<https://www.leukemiabmtprogram.org/>

BC Cancer

“Patient Handout Search”

<http://www.bccancer.bc.ca/>

The Leukemia & Lymphoma Society of Canada
“Resource Library”

<https://www.bloodcancers.ca/>

The Canadian Cancer Society
“Cancer information” → “Resources”

www.cancer.ca/en/

Princess Margaret Cancer Foundation
Princess Margaret Cancer Classes “CAR T-cell Therapy”

<https://pmcancerclasses.ca/>

*This document was created with the intent to help patients enrolled in the Leukemia/
Bone Marrow Transplant Program of BC undergoing CAR T-cell Therapy.*

*Please note that the information contained in this manual is not intended to replace
the advice of your health care team. Use this as a reference and education guide.
Consult with your doctor if you have any questions or concerns.*



References

- American Cancer Society. (2023). *CAR T-cell Therapy and Its Side Effects*. <https://www.cancer.org/cancer/managing-cancer/treatment-types/immunotherapy/car-t-cell1.html>
- American Cancer Society. (2023). *Cytokines and Their Side Effects*. <https://www.cancer.org/cancer/managing-cancer/treatment-types/immunotherapy/cytokines.html>
- BC Cancer Agency. (2007, March). *Fludarabine Patient Handout IV*. BC Cancer Agency Cancer Drug Manual. http://www.bccancer.bc.ca/drug-database-site/Drug%20Index/Fludarabineiv_handout_5Mar07.pdf
- BC Cancer Agency. (2007, February 20). *Cyclophosphamide Patient Handout IV*. BC Cancer Agency Cancer Drug Manual. http://www.bccancer.bc.ca/drug-database-site/Drug%20Index/CyclophosphamideIV_handout_20Feb08.pdf
- Canadian Cancer Society. (2023). *Antigen*. <https://cancer.ca/en/cancer-information/resources/glossary/a/antigen>
- Canadian Cancer Society. (2023). *Bladder Problems*. <https://cancer.ca/en/treatments/side-effects/bladder-problems>
- Canadian Cancer Society. (2023). *Chemotherapy*. <https://cancer.ca/en/treatments/treatment-types/chemotherapy>
- Canadian Cancer Society. (2023). *Immunotherapy for non-Hodgkin Lymphoma*. <https://cancer.ca/en/cancer-information/cancer-types/non-hodgkin-lymphoma/treatment/immunotherapy>
- Canadian Cancer Society. (2023). *The Immune System*. <https://cancer.ca/en/cancer-information/what-is-cancer/immune-system>
- Canadian Cancer Society. (2023). *White Blood Cell (WBC)*. <https://cancer.ca/en/cancer-information/resources/glossary/w/white-blood-cell-wbc>
- Gilead Sciences Canada Inc. (2022). *Getting Ready for Treatment with Tecartus* [Brochure].
- Gilead Sciences Canada Inc. (2021). *Getting Ready for Treatment with Yescarta* [Brochure].
- Gilead Sciences Canada Inc. (2022). *How does Tecartus work* [Image]. *Getting Ready for Treatment with Tecartus* [Brochure].
- Gilead Sciences Canada Inc. (2021). *Identifying and Preparing Patients for Yescarta Therapy* [Brochure].
- Gilead Sciences Canada Inc. (2023, March 23). *TECARTUS™ Brexucabtagene autoleucl* [Monograph].

- Gilead Sciences Canada Inc. (2022, December 6). *YESCARTA® Axicabtagene ciloleucel* [Monograph].
- Healio. (2023). *Figure 2. Blood Cells* [Online image]. Healio Learn Immuno-Oncology <https://www.healio.com/hematology-oncology/learn-immuno-oncology/the-immune-system/components-of-the-immune-system>
- Knapp, S. (2021). Blood Cell Types [Online image]. <https://biologydictionary.net/blood-cell/>
- Leukemia and Lymphoma Society of Canada. (n.d.). *CAR T-cell Therapy: What You Need to Know [Brochure]*.
- Leukemia and Lymphoma Society of Canada. (n.d.). *Chimeric Antigen Receptor (CAR) T-cell Therapy*. <https://www.lls.org/treatment/types-treatment/immunotherapy/chimeric-antigen-receptor-car-t-cell-therapy>
- Lymphoma Canada. (n.d.). *CAR-T: Protocol Overview*. https://www.lymphoma.ca/resources/patient-resource-manuals/?_ga=2.227023519.301248186.1695145126-1767718532.1695145126
- Lymphoma Canada. (2017, December 19). *CAR-T: Science Overview*. https://www.lymphoma.ca/resources/patient-resource-manuals/?_ga=2.227023519.301248186.1695145126-1767718532.1695145126
- Medical University of South Carolina. (2021, June 21). *CAR T-cell Therapy* [Online image]. <https://medicine.musc.edu/departments/surgery/news-and-announcements/2021/june/car-t-cell-therapy-research>
- Memorial Sloan Kettering Cancer Center. (2023). *Catheter tunneled under your skin, into a vein* [Online image]. <https://www.mskcc.org/cancer-care/patient-education/about-your-tunneled-catheter>
- Memorial Sloan Kettering Cancer Center. (2023). *Tunneled Catheter* [Online image]. <https://www.mskcc.org/cancer-care/patient-education/about-your-tunneled-catheter>
- Memorial Sloan Kettering Cancer Centre. (2021, March 30). *CAR T Cell Therapy: A Guide for Adult Patients & Caregivers*. <https://www.mskcc.org/cancer-care/patient-education/car-cell-therapy-guide-adult-patients-caregivers>
- National Comprehensive Cancer Network. (n.d.). *Your Guide to Understanding CAR T Therapy: A Personalized Approach to Treating Large B-cell Lymphoma* [Brochure].
- Novartis Pharmaceuticals Canada Inc. (2018, September 5). *KYMRIAH® Tisagenlecleucel* [Monograph].
- Novartis Pharmaceuticals Canada Inc. (2023). *KYMRIAH® (tisagenlecleucel): Important Information for You (the Patient), Guardians, and Caregivers* [Leaflet].
- Penn Medicine. (2021). *Manufactured CAR T cells ready for infusion into a patient* [Online image]. National Cancer Institute. <https://www.cancer.gov/news-events/cancer-currents-blog/2021/fda-ide-cel-car-t-multiple-myeloma>

- St. Jude Children's Hospital. (2023). *Cytokine Release Syndrome (CRS) After Immunotherapy*. <https://together.stjude.org/en-us/diagnosis-treatment/side-effects/cytokine-release-syndrome-crs.html#:~:text=In%20severe%20cases%2C%20CRS%20can,supportive%20care%20to%20control%20symptoms>.
- The Leukemia/Bone Marrow Transplant Program of BC. (2019). *Your Inpatient Autologous Stem Cell Transplant* [Booklet]. <https://www.leukemiabmtprogram.org/wp-content/uploads/2020/12/Auto-Inpatient-SCT-July2019.pdf>
- The Leukemia/Bone Marrow Transplant Program of BC. (2020). *Your Inpatient Autologous Stem Cell Transplant* [Booklet].
- The Leukemia/Bone Marrow Transplant Program of BC. (2019). *Your Outpatient Autologous Stem Cell Transplant* [Booklet]. <https://www.leukemiabmtprogram.org/wp-content/uploads/2020/12/Auto-Outpatient-SCT-July2019.pdf>
- The Leukemia/Bone Marrow Transplant Program of BC. (2020). *Your Outpatient Autologous Stem Cell Transplant* [Booklet].
- The Princess Margaret Cancer Foundation. (n.d.). *CAR T-cell Therapy*. Princess Margaret Cancer Classes. <https://pmcancerclasses.ca>
- The Princess Margaret Cancer Foundation. (n.d.). *CAR T-cell Therapy* [Online image]. Princess Margaret Cancer Classes. <https://pmcancerclasses.ca>
- Winslow, T. (2011). The Apheresis Process [Online Image]. Fox Chase Cancer Center. <https://www.foxchase.org/blog/2014-02-09-too-old-stem-cell>