

The Caregiver Role

Information for Patients and Caregivers

Read this guide to learn:

- What is a Caregiver
- How to Choose a Caregiver
- The Role and Responsibilities of a Caregiver
- Caregiver Resources



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.

Table of Contents

What is a Caregiver?	4
Choosing the Right Caregiver:	4
CAR T-cell Therapy: How to Choose a Caregiver?	6
The Role and Responsibilities of a Caregiver:	7
Caregiver Review and Checklist	9
The Caregiver Role: Know the Side Effects.....	11
The Most Common Side Effects of CAR T-cell Therapy:.....	12
Cytokine-Release Syndrome (CRS).....	12
Neurological Toxicities.....	13
Low Blood Counts.....	14
Serious Infection.....	14
Caregiver Assessments:.....	16
Resources for Caregivers	17
What is Caregiver Burnout?	17
Resources.....	18
Assessment Resources.....	19
References.....	25

What is a Caregiver?

The main responsibility of a caregiver is to make sure the person within their care is safe and healthy. A caregiver needs to be available to help with basic day-to-day medical and practical issues and provide emotional support.

Everyone having CAR T-cell therapy benefits from having support from a caregiver before, during, and after their infusion. When you are an inpatient, during your planned admission to the hospital, your healthcare team will provide care but in the time period beforehand and most importantly after you get discharged from the hospital you will need a caregiver when you are at home. For a patient to undergo CAR T-cell therapy, **a caregiver is required for 24 hours a day, 7 days a week for the first 30 days following the infusion.**

CAR T-cell therapy is a long process, and there are something you will not able to do in the months following your infusion. After receiving CAR T-cell therapy:

- You will not be able to drive for first 8 weeks post-infusion.
- You will not be able to return to work for at least 3 months, but timing may vary, your doctor will discuss this further with you.

Choosing the Right Caregiver:

It's important for your caregiver to stay positive, calm, and flexible while providing you with the support and encouragement you need. It's also important for you to understand that the caregiver role is challenging and that your caregiver might at times feel overwhelmed by the responsibilities.

Take time now to think about who you want to be your caregiver. It should be someone you trust and who can take the time to care for you. Your caregiver should be someone who can give you the practical and emotional support you need.

Caregiver(s) can be:

- Family members
- A close friend
- More than one person
 - If you don't have just 1 person to serve as your caregiver, you can have more than 1 person share the role.
 - But it is recommended to limit the number of caregivers to 1 or 2 people.



Additionally, the primary caregiver is required to be:

- 18 years old or older.
- Someone who can commit to be with you 24 hours a day, 7 days a week for 4 to 8 weeks.
- Able to understand what is required of them.
- Someone who is responsible and who you can count on.
- Physically, mentally, and financially able to commit to the role.
- Has a backup person they can call if something happens to them.

To protect your loved one going through CAR T-cell therapy, we recommend that caregivers are vaccinated against the seasonal flu and COVID-19.

Important to note: If your caregiver gets sick or shows any signs of a cold or flu (such as a cough, fever or sore throat) 1 week before or any time during your CAR T-cell therapy, tell your healthcare team right away.

The Role and Responsibilities of a Caregiver:

Your CAR T-cell therapy team will give your caregiver specific instructions about what they need to do. Some of these responsibilities will include the following tasks:

	Examples of Caregiver Tasks:
Medical support	<ul style="list-style-type: none"> • Helping you prepare for, and recover from the T-cell collection procedure, conditioning chemotherapy, and for at least 30 days after the CAR T-cell infusion. • Gathering information from your CAR T-cell therapy team. • Making sure you take your medications. • Measuring your temperature twice a day (on days you are not coming into the hospital). • Keeping track of your temperatures, and call your healthcare team if it is $\geq 38.0^{\circ}\text{C}$. • Making sure you're drinking enough and getting enough nutrition. • Monitor how frequently you urinate and roughly how much. • Tell your healthcare team if your central venous catheter (CVC) is painful, red, ongoing bleeding or if you have concerns about it. <ul style="list-style-type: none"> ○ Refer to "All about your Central Venous Catheter" handbook • Noticing any changes in your condition <ul style="list-style-type: none"> ○ Changes in neurological assessment results, increased use of "as need" medications, fever, decreased food intake, decreased mobility etc. • Telling your healthcare team about any changes in your condition or new symptoms you have. • Calling for medical help in an emergency.
Practical support	<ul style="list-style-type: none"> • Managing your daily routine while you focus on your recovery. • Helping with a daily activities like toileting, bathing, getting dressed, or brushing hair. • Managing housework and childcare. • Keeping track of appointments and tests. • Assisting you with transportation to and from appointments. <ul style="list-style-type: none"> ○ CAR T-cell therapy patients cannot drive for at least 8 weeks following the infusion. • Dealing with financial and insurance issues. • Helping you arrange lodging prior to therapy. • Cooking or providing meals. • Handling food safely to prevent foodborne illness (food poisoning). <ul style="list-style-type: none"> ○ See the Neutropenic diet handout • Keeping the home or living area clean to minimize risk of infection • Keeping family members and friends up to date about your condition. • Managing the number of visitors you have. • Keeping you away from anyone who's sick.

Emotional support

- Paying attention to your moods and feelings.
- Communicating with you and listening to you.
- Understanding your needs and your decisions.
- Feeling comfortable contacting your healthcare team if they're worried about your emotional state.
- Helping you keep a list of questions for your healthcare team.

Caregiver Review and Checklist

Being the primary caregiver is an important role and no one expects your caregiver to do it alone. Ask your caregiver to use the checklist below to start preparing for their role. The CAR T-cell therapy team can help provide some of these answers and resources.

	Questions:	Notes
<input type="checkbox"/>	Can I take 4–8 weeks off from work?	
<input type="checkbox"/>	Will I be able to travel with my loved one to their different appointments (1 st appointment, apheresis, additional treatments, infusion, follow-up, etc...)?	
<input type="checkbox"/>	Do I need to apply for family medical leave or family caregiver benefits?	
<input type="checkbox"/>	How will I cover my expenses if I am taking off from work?	
<input type="checkbox"/>	Do I have someone who can care for my/our other family members?	
<input type="checkbox"/>	Do I have someone to house or care for the pets while we are away from home or in the hospital?	
<input type="checkbox"/>	Am I emotionally able to support my loved one for 8 weeks during treatment and recovery?	
<input type="checkbox"/>	Who will I reach out to for support?	
<input type="checkbox"/>	What do I need to learn about CAR T cell therapy to be a good caregiver?	
<input type="checkbox"/>	What concerns and questions do I have, and who can I contact to clear them up?	
<input type="checkbox"/>	Where will I stay while my loved one is being treated?	
<input type="checkbox"/>	What will I do for meals during treatment?	
<input type="checkbox"/>	What do I need to bring to the hospital in the case of an emergency?	
<input type="checkbox"/>	Who can take care of my loved one if I am unavailable?	
<input type="checkbox"/>	Can I commit to all 8 weeks of staying with my loved one?	

<input type="checkbox"/>	Can I commit to only part of the 8 weeks?	
<input type="checkbox"/>	If so, how long and for what part?	
	Other questions:	

The Caregiver Role: Know the Side Effects

The primary reason that those who receive CAR T-cell therapy require a caregiver are due to the potential side effects experienced.

Your healthcare team will also ensure that any side effects from CAR T-cell therapy are managed before you are discharged, and you will only be discharged from hospital when the doctor feels it is safe for you. While before you are discharged, you must show no significant signs of cytokine release syndrome, neurotoxicity, or infection, these symptoms may start to appear afterwards. Therefore, it is important to know the signs and symptoms of CAR T-cell therapy, so you and your caregiver are able to recognize it early and inform the CAR T-cell therapy team.

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**.

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

The Most Common Side Effects of CAR T-cell Therapy:

After the CAR T-cell infusion, you'll be watched closely in L/BMT daycare for side effects. The CAR T-cell therapy team will manage any side effects you may have. It's very important for you, or your caregiver, to tell a member of your healthcare team if you think you're having any of these side effects.

Please Note: This section is a repeat of the side effect section in the CAR T-cell therapy patient education document. If you have already read that section you may skip forward to the next section.

Cytokine-Release Syndrome (CRS)

What is it?

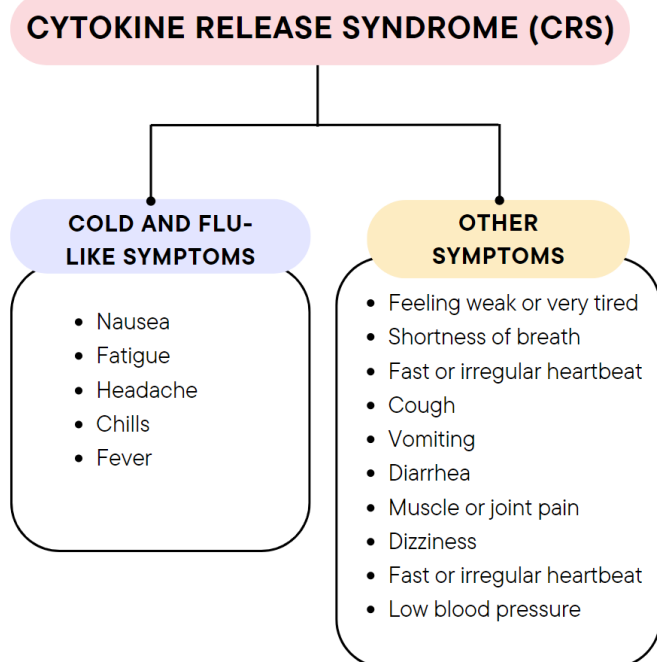
- *Reminder:* CAR T-cell therapy is an immunotherapy, therefore it uses your own immune system to fight your cancer
- This syndrome occurs when your immune system produces large amounts of cytokines very quickly
 - Cytokines are chemical messengers that help the T-cells carry out their functions.
 - Cytokines are produced when the CAR-T cells multiple 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

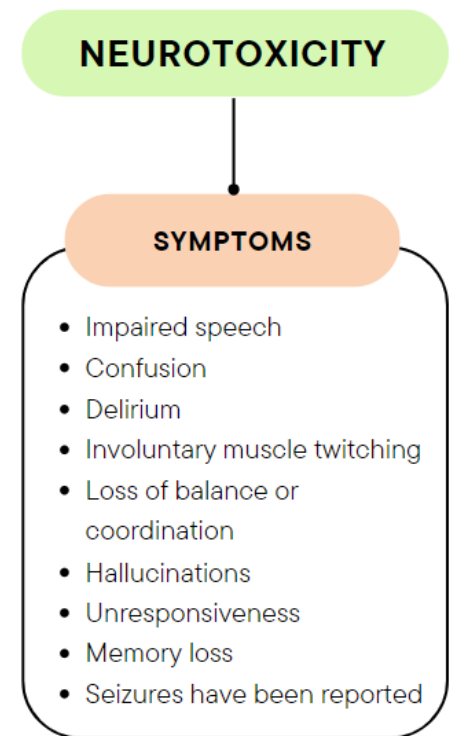
CAR-T therapy can also affect your brain and nervous system.

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

LOW BLOOD COUNTS

SYMPTOMS

- Feeling tired or weak
- Bleed or bruise more easily
- More prone to infection

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.

INFECTION

SYMPTOMS

- Fever (>38°C)
- Chills or shakes
- Cough up yellow or green mucus
- Pain, burning, or blood in your pee or poo

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 “*Supporting You through Treatment*” booklet and see the “*CAR T-cell Therapy: Side Effects & Management*” handout for more information.

Caregiver Assessments:

To help assess for the side effects of CAR T-cell therapy, caregivers are required to complete assessments, on days that you do not go in to be seen in L/BMT daycare.

Neurological Assessment:

Your caregiver will ask you the following questions two times a day. Please calculate the points out of 10. If any one of these are performed incorrectly, if there is a change from before, or if there is a change in the total score, please contact your CAR T-cell therapy team (phone numbers on pg. 2).

Example:

Question/Action	Morning	Bedtime
What year is it? (1 point)	1	1
What month is it? (1 point)	1	1
What city are we in? (1 point)	1	1
What hospital are you going to daily? (1 point)	1	1
Name three objects (example: Point to a clock, pen, button) (Total 3 points/ 1 point per object)	3	3
Follow commands (example: Close your eyes and stick out your tongue) (1 point)	1	1
Count backwards from 100 by 10s (1 point)	1	1
Handwriting sentence (complete on separate form) (1 point)	1	1
Total points out of 10	10 /10	10 /10

Date	Time	Handwrite the following sentence: "The quick brown fox jumped over the lazy dog."	Neuro Score
Example: Nov. 23, 2023	10:00 am	The quick brown fox jumped over the lazy dog.	10/10
			/10
			/10

Resources for Caregivers

Being a caregiver for a loved one can be very rewarding. Most caregivers agree that the experience changes their lives. Some of the rewards that caregivers have reported include:

- feeling a closer bond with the person with cancer
- finding added meaning in life
- finding new strength
- developing a new appreciation for family and friendships



Nonetheless, the responsibility of being a caregiver can be overwhelming and stressful. Caregivers can have physical, emotional, spiritual, and financial distress.

What is Caregiver Burnout?

It's a pervasive state of physical and emotional depletion resulting from prolonged stress and strain. Burnout transcends the predictable stressors that accompany caregiving.

Caregiver burnout is very common. Studies show that more than 60% of caregivers experience symptoms of burnout.

What are the signs and symptoms of caregiver burnout?

Your health and well-being matter just as much as the person you're caring for. It's important to know the signs and symptoms of caregiver burnout so you can get the help you need when you need it most.



The signs and symptoms of caregiver burnout are similar to those of stress and depression. They can include:

- Emotional and physical exhaustion.
- Withdrawal from friends, family and other loved ones.
- Loss of interest in activities previously enjoyed.
- Feeling hopeless and helpless.
- Changes in appetite and/or weight.
- Changes in sleep patterns.
- Unable to concentrate.
- Getting sick more often.
- Irritability, frustration or anger toward others.

Caregiver Support

To best support you, your caregiver is going to need their own community of support. Your caregiver should seek and identify friends or family members they can turn to. Resources and support are available to help manage the many responsibilities that come with caring for a person having CAR T-cell therapy. They can also join a caregiver support group or look for

support groups online. The L/BMT program's social works can help connect you with further support resources and information.

Tips for Self-Care

1. **Set aside a regular time to do something you enjoy.** Take a bath or visit a friend. Watch a TV show from start to finish. Read a book. Get your hair done. Listen to music. Catch up on your sleep. Remember this is your time to rest and recharge your batteries.
2. **A good way to reduce stress is to get some exercise:** walk, swim, jog, play golf. Work in the garden. Do some stretching. Try Tai Chi or Yoga.
3. **Eat a well-balanced diet.** Good nutrition is important to your health.
4. **Have regular check-ups.** Talk to your doctor about any health problems. Use medications with care.
5. **Try to get enough sleep.** It may be difficult, but sleep is important for staying healthy. If you have trouble getting to sleep, try breathing or relaxation exercises (there are books or tapes to help). You may want to use your time off to catch up on sleep.
6. **Take part in activities you have enjoyed in the past.** Or try something new.
7. **Keep in touch with friends.** You need a life apart from your caring role. If you cut yourself off, you are also cutting off the support that friends will give you. And you will find it hard to pick up the pieces of your life when you are no longer spending so much time caregiving. You might like to join a support group. It is a good way to meet new people who have the same concerns you do.
8. **Don't try to be superman or superwoman.** Be realistic. Think about what really matters most to you. Let the less important things wait. Learn to say "no".
9. **Reward yourself.** Remember to congratulate yourself for all of your successes. Think about the supports you have and use them.



Resources

- **BC Cancer** – has supports available for patients and caregivers. Through this agency you can access various support programs and counselling services. <http://www.bccancer.bc.ca/health-info/coping-with-cancer/emotional-support#Counselling--&--support>
- **Leukemia and Lymphoma Society** – Provides caregiver support resources and access to support groups. <https://www.lls.org/support-resources/caregiver-support>
- **Family Caregivers of BC** – a not-for-profit organization that supports caregivers by providing access to information, education and supports so that caregivers feel more confident and successful in their important role. <https://www.familycaregiversbc.ca/>
- **L/BMT Social Workers** – Can help you find and access various support programs, such as financial supports and access to housing.

Assessment Resources

Neurological Assessment:

Question/Action	Morning	Bedtime
What year is it? (1 point)		
What month is it? (1 point)		
What city are we in? (1 point)		
What hospital are you going to daily? (1 point)		
Name three objects (example: Point to a clock, pen, button) (Total 3 points/ 1 point per object)		
Follow commands (example: Close your eyes and stick out your tongue) (1 point)		
Count backwards from 100 by 10s (1 point)		
Handwriting sentence (complete on separate form) (1 point)		
Total points out of 10	/10	/10

Date	Time	Handwrite the following sentence: "The quick brown fox jumped over the lazy dog."	Neuro Score
			/10
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PATIENT TREATMENT CALENDAR

Note upcoming appointments in this calendar. If your loved one misses an appointment, reschedule as soon as possible.

JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
SU	M	TU	W	TH	F	SA					
SU	M	TU	W	TH	F	SA					
SU	M	TU	W	TH	F	SA					
SU	M	TU	W	TH	F	SA					
SU	M	TU	W	TH	F	SA					

Key dates you may want to write down:



Leukapheresis appointment: this should be the first day of the treatment process

Low-dose chemotherapy: takes place 3 days before the

CAR T-Cell Infusion

Infusion: the day your loved one receives their

CAR T-Cell Infusion

Follow-up appointments: monitoring after treatment with

CAR T-Cell Therapy


CAREGIVER APPOINTMENT CALENDAR

Maintaining your own health during your loved one's treatment is vital. You can use this section to keep track of your own healthcare appointments.

JAN FEB MAR APR MAY JUN JUL AUG SEP OCT NOV DEC

SU	M	TU	W	TH	F	SA

Important appointments to remember may include annual physicals, dental and eye exams, therapy, or support groups.



References

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