



**CAR T-cell  
Therapy Guide  
for Patients, Caregivers  
and Families**

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# My Information

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**Medical Record Number:**

**CAR T Physician:**

**Nurse Practitioner:**

**Transplant Coordinator:**

**Clinical Social Worker:**

# Important Contact Numbers

	Phone Number	Hours
<b>UCLA Page Operator</b> Adult & Pediatric	310-825-6301	<b>24 hours a day</b> Ask for the on-call adult or pediatric hematology/oncology doctor

## ADULT

<b>Bowyer Clinic</b>	310-206-6909	Monday – Friday <b>8 am – 6 pm</b>
<b>Bowyer Infusion Center</b>	310-206-6909	Monday – Friday <b>7 am – 8 pm</b> Saturday – Sunday <b>7 am – 7:30 pm</b>
<b>Ronald Reagan UCLA Medical Center</b> <b>6 East Unit (6E)</b>	310-267-7610 310-267-9750	<b>24 hours a day</b> Charge Nurse
<b>UCLA Santa Monica Medical Center</b> <b>Unit 4 North Wing (4NW)</b>	424-259-9420 424-259-9477	<b>24 hours a day</b> Charge Nurse

## PEDIATRIC

<b>Pediatric Infusion Center</b>	310-825-5431	Monday – Friday <b>7:30 am - 5 pm</b>
<b>UCLA Mattel Children’s Hospital</b>	310-825-0867	<b>Appointments &amp; Referrals</b>

# Introduction

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Immunotherapy helps patients fight different forms of cancer by enabling the immune system to both recognize and attack cancer. One form of immunotherapy, chimeric antigen receptor (CAR) T-cell therapy, specifically targets blood cancers so they can be eliminated.

## How do immunotherapies like T-cell therapy work?

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To understand T-cell therapy, you should first understand the immune system. Your immune system is a built-in defense against infection and other diseases. The key parts of your immune system are white cells, for which different types play different roles. Lymphocytes are one type of white cells.

### Lymphocytes are divided into three categories:

- 1 **B lymphocytes (B-cells)** – make antibodies to fight infection
- 2 **T lymphocytes (T-cells)** – are a type of white blood cell that fights infections and plays a big role in destroying abnormal cancer cells
- 3 **Natural killer cells (NK-cells)** – directly target infected cells and viruses

### T lymphocytes (T-cells) are the main ingredient in CAR T-cell therapy. T-cells:

- Fight infected and cancerous cells
- Are engineered in the lab with receptors that can specifically attack your cancer cells
- Are called Chimeric Antigen Receptors (CAR) T-cells
- Signal other immune cells to fight and help remove the cancer cells

As you begin your CAR T-cell therapy, remember that you're in good hands. UCLA Health specialists have delivered more than 100 infusions of FDA-approved CAR T-cell therapy since 2018.

# Patient Checklist

## Before CAR T-cell Infusion

- Activate your myUCLAhealth (MyChart) account
- Download the MyChart app to your smartphone
- Complete tasks assigned to you in myUCLAhealth (MyChart)
- Read education materials
- Meet with a social worker to discuss a plan for your care while receiving CAR T-cell therapy, including local lodging and transport needs
- Complete an Advanced Care Planning appointment with a nurse practitioner (adults only)
- Attend all appointments and screening tests to prepare for CAR T-cell therapy
- Review caregiver expectations on page 8 of this booklet and identify at least one caregiver
- Review and sign consent forms with your health care provider
- Identify alternative transportation for at least eight weeks after your CAR T-cell therapy; you cannot drive or operate heavy machinery for at least eight weeks

## After CAR T-cell Infusion

- Complete daily symptom tracker tasks assigned to you in myUCLAhealth (MyChart)
- Perform daily ICANS self-assessment (on page 17 of this booklet) for four weeks following your CAR T-cell therapy, when not in the hospital
- Do not drive or operate heavy machinery for at least eight weeks
- Keep your wallet card with you at all times; present this to health care professionals
- Keep a list of your medications with you at all times
- Report any symptoms immediately to your health care provider through the UCLA Page Operator by calling 310-825-6301. If you are in the hospital, report symptoms to your care team.

# How are T-cells used in CAR T-cell therapy?

1



T-cells are collected from the patient.

2



T-cells are genetically engineered to find and kill cancer cells.

3



The reengineered cells are multiplied until there are millions of these attacker cells.

4



CAR T-cells are infused into the patient and multiply in number. These “attacker” cells will recognize and kill cancerous cells and help guard against reoccurrence.

## Phase 1: T-cell collection

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- 1 The T-cells are collected from your body through a process called apheresis. During apheresis, a machine separates your blood into different parts, with the goal of only removing the T-cells. The remaining blood is returned to your body. Your T-cells may be collected from your arm veins or from a catheter, which is placed before the collection starts.
- 2 The T-cells are sent to a laboratory where they are modified to attack cancer cells.
- 3 The new T-cells are kept in the laboratory to grow and multiply. Once enough have been made, they are frozen until they are ready to be sent to UCLA Health.

## Phase 2: The CAR T-cell infusion:

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- 1 **Lymphodepletion:** You will undergo chemotherapy treatment to prepare your body for the infusion of the T-cells. This treatment usually takes place in our outpatient clinic. You will have a catheter placed before lymphodepletion, which will allow your health care team easy access to give you medications and fluids. The catheter will be kept in place for at least 28 days or longer if needed.
- 2 **Hospital/Clinic Admission:** Once the chemotherapy is complete, you will be admitted to the clinic or hospital. Your care team will determine the location. Your team will review the details for your CAR T-cell infusion. You will be monitored closely by your team for at least seven to 14 days. While in the hospital, you will have a central line and continuous connection to cardiac and/or pulse oximeter monitoring.
- 3 **CAR T-cell Infusion:** Day 0 is the day of the infusion of the CAR T-cells and is used as a starting point for counting how far out you are from receiving them. For example, the day after the infusion would be Day 1, the next Day 2, and so on.
- 4 **After Infusion:** Once infused, the T-cells will continue to multiply to target and attack your cancer cells. Your safety is our number one priority. Once you have received your infusion, your care team will monitor you closely for possible side effects and provide treatment if needed.



# Caregiver Expectations

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Have you chosen a caregiver to help you during your CAR T-cell therapy? Their partnership in caring for you is the key to your health and safety.

The CAR T-cell therapy process includes both outpatient and hospital-based care. Caregivers play a major role in care and are key in communicating with the care team. Your caregiver should be someone who is dependable, calm and understanding, and who can maintain a positive attitude with a flexible approach.

Your caregiver will need to devote a significant amount of time and energy to helping you. **All patients undergoing CAR T-cell therapy require a 24/7 caregiver for the first 28 days after their infusion and discharge from the hospital. The caregiver must stay with the patient at a location within 5 miles of UCLA Health through day 28 at a minimum.** You are not required to have the same caregiver throughout the 28 days, but all caregivers involved must agree to the expectations of the role. To ensure you always have a caregiver, we'll keep track of coverage using a calendar.

If you are an adult patient, it is important that your caregiver visit the hospital regularly and be available once you leave. Your care team will monitor you closely through day 28.

When not in the hospital, you are required to have a caregiver who is available to assist with your care. Your caregiver should also be able to drive you where you need to go for a minimum of eight weeks or longer, if needed.

Your UCLA Health care team will see you (and your caregiver) often at the Bowyer Oncology Clinic or Pediatric Clinic. They will monitor and manage symptoms and side effects. The appointment schedule and follow-up care is based on ongoing conversations between you, your caregiver and your care team.

## Minimum Visit Frequency

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<b>Day 0 - 28</b>	<b>Day 28 - 100</b>	<b>Day 101 - 364</b>
One to three visits per week	One visit every 1-2 weeks	One visit every 4-6 weeks

## Your caregiver is responsible for the following:

### Must Do

- Ensure you (the patient) have 24/7 coverage through day 28
- Identify changes in your status and condition
- Report symptoms to the health care team via the online patient portal (MyChart)
- Attend a discharge education session in the hospital
- Attend all follow-up appointments at the Bowyer Oncology or Pediatric Clinic after your infusion
- Ensure transportation to all outpatient appointments
- If your health changes, report this to the health care team immediately, who will then determine if a different caregiver is needed for your safety

### Should Do

- Receive a flu vaccination and all other vaccinations required by the program
- Care for your central line catheter and monitor for signs of infection or drainage at your central line site
- Help with oral and IV medications and record medications taken
- Gather and organize medical information
- Update family and friends about your condition
- Ensure visitors are free of cough, cold or fevers, and minimize visits with children
- Maintain a clean home environment
- Prepare food
- Provide emotional support
- Provide support with bathing, eating or other activities of daily living, if needed

# Caregiver Expectations

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## Care for the caregiver

A caregiver's focus is on you, their friend or family member. But it's just as important for them to take care of their own needs. To be the best version of themselves, caregivers need to be healthy and well, both physically and emotionally.

### Caregivers should follow this checklist to meet their own health and wellness needs:

- Take regular rest periods
- Eat well
- Identify a "stay calm" strategy that works, such as deep breathing, a walk outside or a chat with a friend or family member
- Ask for and accept help
- Delegate tasks
- Feel free to ask questions

For more information on ways that caregivers can keep themselves well, please visit [www.lls.org/support-resources/caregiver-support](http://www.lls.org/support-resources/caregiver-support).

### Agreement to be primary caregiver:

If the caregiving team includes two or more people, one of them must be designated as the primary caregiver.

The primary caregiver is responsible for ensuring that the patient has 24/7 coverage through day 28, communicating the division of caregiving time to the medical team, and updating the team with all changes to the plan.

The primary caregiver must understand what the caregiver role entails and agree that they are able to perform all caregiver responsibilities.

If circumstances change and they are no longer able to make this commitment, they will notify the clinical social worker immediately.

# CAR T-cell Side Effects & Recovery Process

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After receiving your treatment and infusion of cells, your CAR T-cells continue multiplying in your body. This will cause side effects that you may feel for weeks and/or months. It is important to expect both physical and mental effects that could last for some time, although these do vary person to person.

## Possible Side Effects to Expect

Shortly after receiving the T-cells, you may experience common side effects — your body’s normal response to being exposed to these new cells. There are some side effects that can be quite serious if not attended to right away. This is why your health care team will monitor you closely.

**Please note: if you experience any of the below symptoms, you must report them immediately to your care provider through the UCLA Page Operator at 310-825-6301 and ask for the adult or pediatric hematology/oncology physician on call.**

## Cytokine-Release Syndrome (CRS)

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CRS is a potentially serious set of side effects that needs to be managed immediately by your team. Cytokines are normal chemical messengers that are released by T-cells to help your body fight infection. The infusion of CAR T-cells can create a flood of these cytokines, causing an inflammatory response that can be quite harmful if left uncontrolled.

## CRS Symptoms

### Report These Symptoms *Immediately*

- Temperature 100.4F / 38C or greater
- Chills or shaking
- Low or very low blood pressure
- Headache
- Dizziness or lightheadedness
- Fast or irregular heartbeat

- **Trouble breathing or shortness of breath; low oxygen levels**
- **Severe nausea, vomiting or diarrhea**
- **Severe muscle or joint pain**
- **Swelling**
- **Extreme fatigue or weakness**

## **Report at Next Clinic Visit**

- **Change in or loss of appetite**
- **Moderate nausea, vomiting or diarrhea**

Although potentially serious, it is important to note that CRS is the body's natural reaction to the infusion of CAR T-cells and it is usually reversible. The severity of these symptoms cannot be taken lightly, however, as CRS can be life-threatening. Your care team will monitor you closely and teach you what to report. CRS can occur anytime within the first few weeks after CAR T-cell therapy, but most often within the first week. Symptoms can last up to several weeks.

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## Neurologic Toxicities/Immune Effector Cell Associated Neurotoxicity Syndrome (ICANS)

Serious neurologic or brain symptoms can happen. These symptoms vary and may be different in each patient.

### ICANS Symptoms

#### Report These Symptoms *Immediately*

- Headache – can be severe
- Trouble speaking, slurred speech, stuttering or unable to talk
- Anxiety
- Trouble staying awake
- Dizziness
- Trouble focusing or paying attention
- Confusion
- Memory loss
- Loss of coordination; change in handwriting
- Involuntary muscle twitching
- Hallucinations
- Unresponsiveness
- Seizures

These neurologic symptoms can be very scary for you and your family, but most of them are reversible and can be improved over several days with treatment. In certain cases, some of these symptoms can linger and take weeks or months before returning to normal.

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## CRS/ICANS Treatment

Your health care team will support you with some of these common treatments to address your symptoms:

Supportive Care	Medications
<input type="checkbox"/> IV Fluids	<input type="checkbox"/> Tocilizumab
<input type="checkbox"/> Frequent monitoring	<input type="checkbox"/> Steroids and other immunosuppressants
<input type="checkbox"/> Oxygen support	<input type="checkbox"/> Blood pressure controlling medications
<input type="checkbox"/> Transfer to the ICU	<input type="checkbox"/> Anti-seizure medications

## Medication Management

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- Take your medications exactly as instructed by your health care provider
- Understand why and how to take each medication
- Know the possible side effects of your medications
- Notify your health care team of any new or additional medications, including over-the-counter vitamins or supplements you are taking

## Medication Tips

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- Refer to MyChart or your After Visit Summary (AVS) to access the list of medications that are ordered for you and instructions on how and when to take them
- Bring your medications to every follow-up visit
- Keep a medication log to remain on schedule with your treatment; you may bring this log with you to your visits to share with your health care team

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## Other Side Effects

### Low Blood Counts

Your blood cells are continuing to recover.

- Your white cell counts may be low; supportive medications may be given to protect you against infection after you recover from the immediate side effects.
- You may need occasional transfusions due to low red cells and platelets.
- Your red cells will slowly recover over time.
- Your platelets will also recover, allowing your blood to clot, prevent bleeding and bruising.

## Infection Prevention Tips

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- Clean your hands frequently, including before meals and after using the restroom.
- Bathe or shower daily.
- No gardening until first discussing it with your doctor.
- Do not clean up after pets.
- Avoid large crowds.
- Wear a mask in public and at your follow-up appointments.
- Practice good oral hygiene, such as brushing your teeth.
- Take all medications as prescribed.

## Fatigue

It is normal to feel very tired after receiving CAR T-cell therapy. Your body is hard at work fighting off cancer. You may find it hard to concentrate or remember things when you return to work or school. It is important to rest to support this recovery period.

## Fatigue Tips

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- Balance rest and daily activity to manage fatigue.
- Reserve time in bed for sleep only.
- Take regular walks or do gentle activity, which can boost energy and mood.
- Do not drive or operate heavy machinery until at least eight weeks after receiving CAR T-cells.



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## Change in Appetite

You may not feel like eating or may not enjoy the foods you used to for a short time after your CAR T-cell infusion. This could be caused by chemotherapy or CRS.

## Appetite Tips

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- Attempt small and frequent meals or snacks.
- Stay hydrated.
- Protein or nutritional drinks may be helpful.

## Things to Remember

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- The risks of CAR T-cell therapy decreases over time.
- Side effects vary from person to person; they can last a few days to weeks.
- You will be closely monitored and receive treatment for your symptoms as needed.
- You will have frequent visits with your health care team; expect to have appointments at least one to two times a week.
- You will have the opportunity to ask any questions and learn how your disease has responded to the therapy.
- Remember to remain within 30 minutes of the hospital and clinic for the 28 days following CAR T-cell therapy.
- Do not drive or operate heavy and/or dangerous machinery for at least eight weeks or longer.
- Always carry your wallet card and share it with any health care provider involved in your care. Keep a picture of your wallet card on your smartphone.
- Discuss with your health care team how and when to safely resume sexual activity.

# ICANS Self-Evaluation Tool

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Your caregiver and your health care team will perform daily neurologic assessments to check for signs of serious neurological side effects (ICANS). You or your caregiver can use the self-evaluation tool below to keep track of any new or worsening neurological issues. Also, comparing handwriting samples every day is a good way to check your fine motor coordination.

## Immune Effector Cell-Associated Encephalopathy (ICE) Score

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<b>Orientation</b> 4 points	Ability to name year, month, city, hospital: <b>1 point for each</b>
<b>Naming</b> 3 points	Ability to name three objects; for example: point to a clock, chair, pen: <b>1 point for each</b>
<b>Following Commands</b> 1 point	Ability to follow simple commands; for example: close your eyes and stick out your tongue, march in place, or raise your left arm above your head: <b>1 point</b>
<b>Handwriting</b> 1 point	Ability to write a standard sentence; for example: write “Our national bird is the bald eagle” using the handwriting example tracker on page 19: <b>1 point</b>
<b>Attention</b> 1 points	Ability to count backwards from 100 by 10: <b>1 point</b>
<b>TOTAL</b> <b>10 points</b>	<b>Total:</b>

If your score is lower than 10, you must report the score immediately to your care provider through the UCLA Page Operator at 310-825-6301 and ask for the adult or pediatric hematology/oncology physician on call.





# Follow-up Expectations: CAR T-cell Patients

## Discharge to Day 28

### Visit Frequency and Requirements

- Minimum visit of **once a week** or more often if clinically indicated, up to day 28.
- You will need to stay within 5 miles of Ronald Reagan UCLA Medical Center to at least day 28.
- You will need a **24-hour caregiver for 28 days** after infusion and discharge from the hospital.

### Bring to Every Visit

- All of your medications
- Caregiver
- Wallet card

### What to Expect

- Prior to your discharge, your inpatient nurse will give you a handout with your appointment time for lab draw and follow-up appointment with your health care team.
- You will have a nurse practitioner assigned to you in the outpatient clinic; the initial appointment will most likely be with your nurse practitioner. **Visits will alternate between your doctor and nurse practitioner thereafter (adults).**
- On your first visit, the nurse practitioner will decide when your next follow-up visit is. **You should not leave the clinic without confirming your next appointment.**
- Your blood is drawn before each clinic visit and your medication list is reviewed. If you have any side effects or symptoms making you feel unwell, please discuss them with your health care team and additional testing may be ordered.

## Day 28 - 100

### Visit Frequency

- Visits will be **once a week** or more frequently if needed.

### Bring to Every Visit

- All your medications
- Wallet card

### What to Expect

Imaging or other disease assessment tests; these will be reviewed with you by your doctor.

Your blood is drawn before each clinic visit and your medication list is reviewed. If **you have any side effects or symptoms** making you feel unwell, please discuss them with your health care team and additional testing may be ordered.

## Day 101 - 364

### Visit Frequency

- Visits will be **every six weeks** or more frequently if needed.

### Bring to Every Visit

- All your medications
- Wallet card

### What to Expect

Your blood is drawn before each clinic visit and your medication list is reviewed; if **you have any side effects or symptoms** making you feel unwell, please discuss them with your health care provider, and additional testing may be ordered.

# Notes

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# Questions for my health care team

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# Goal setting

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Setting goals helps you focus on what you find important. Achieving goals is powerful and uplifting. Goals are what you want them to be. What are your goals?

## Goal 1

My goal is:

---

My target date is:

To reach my goal, I will do these three things:

1

2

3

---

I will know I have reached my goal because:

---

Two things that will help me stick to my goal are:

1

2

---

## Goal 2

My goal is:

---

My target date is:

To reach my goal, I will do these three things:

1

2

3

---

I will know I have reached my goal because:

---

Two things that will help me stick to my goal are:

1

2

# References

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**Anthony Nolan:**

<https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-car-t-cell-therapy>

**BMT InfoNet:**

[BMT infonet.org/transplant-article/car-t-cell-recovery](https://www.bmtinfonet.org/transplant-article/car-t-cell-recovery)

[www.cancer.org](https://www.cancer.org)

**Leukemia and Lymphoma Society:**

<https://www.lls.org/treatment/types-treatment/immunotherapy/chimeric-antigen-receptor-car-t-cell-therapy>

**Peter MacCallum Cancer Centre:**

[https://www.petermac.org/sites/default/files/page/downloads/PM0065\\_PatientEducationBooklet\\_CAR\\_TCell\\_Therapy\\_FINAL%20WEB.pdf](https://www.petermac.org/sites/default/files/page/downloads/PM0065_PatientEducationBooklet_CAR_TCell_Therapy_FINAL%20WEB.pdf)

**NCI website for definitions**

**T-cell:** <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/t-cell>

**B cell:** <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/b-cell>



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