

CAR T Therapy Expectations:

A Guide for Patients and Care Partners



Before CAR T Therapy

What will be discussed during your visit about CAR T therapy?



How does CAR T therapy work?

- Summary of the steps involved
- Typical duration of CAR T cell therapy



Is CAR T right for you?

- Blood draws
- Scans
- Bone marrow biopsy



Responsibilities of a care partner:

- Driving or coordinating travel and housing near CAR T center
- Managing medications
- Identifying and reporting side effects
- Assisting with hygiene



Helpful resources

- Advocacy and support groups
- Friends, family, and community members



What can the CAR T team support you with?

- Coordination of care and disease management
- Lodging and transportation
- Finances and coverage
- Mental health and well-being



You do not have a care partner?

Because of the importance of a care partner, a social worker may help to find a care partner for you



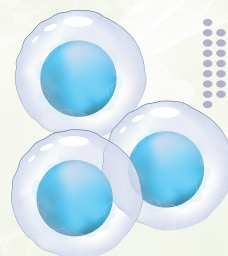
During CAR T Therapy

How does CAR T therapy work?

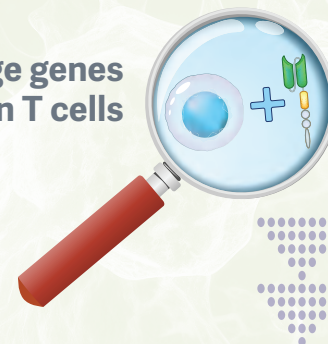
Collect blood
that will
have T cells



Separate
T cells from
other blood
cells



Change genes
in T cells



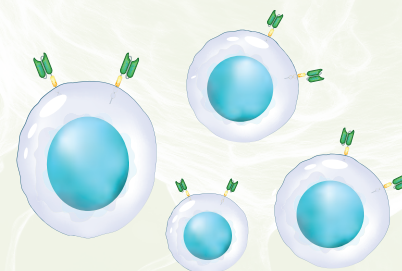
New CAR T cells
are introduced
into the blood
stream



Millions of
CAR T cells are grown



Special proteins called
chimeric antigen receptors
or CAR are added to T cells



Enough T cells are not collected from me?
Your healthcare team may try to collect cells again

I'm not able to make it to the CAR T center to get my cells collected?
Collection at a local hospital may be possible

During CAR T Therapy

Inpatient



Bridging therapy

Chemotherapy may be recommended by your doctor to help control your disease while waiting for the CAR T cells to be made

Outpatient



During CAR T Therapy

Preparing to receive CAR T cells

Low-dose chemotherapy



When: 2-14 days before receiving CAR T cells
Duration: 3 days at clinic

Resting at home



Duration: 1-2 days

Potential side effects



Nausea and vomiting



Feeling very tired



Diarrhea



Fever



I experience side effects from the low-dose chemotherapy?

Your care team may prescribe medication or hold on providing CAR T therapy until the side effects go away

During CAR T Therapy

CAR T cell infusion

Preparing for the infusion

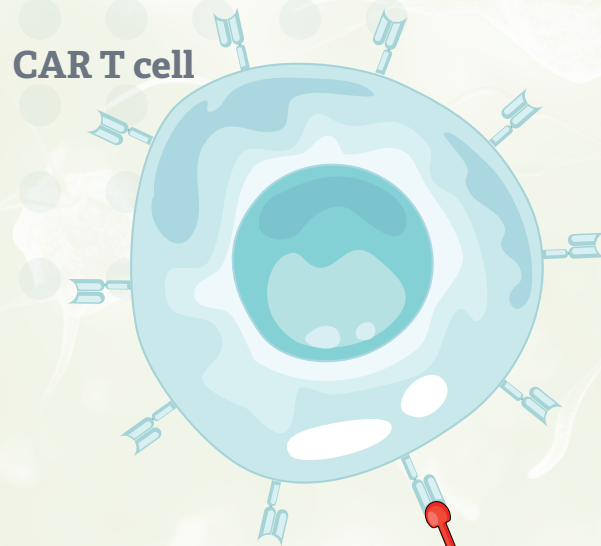
- Arrive to the infusion center approximately 15 minutes before your appointment
- Duration: 15 minutes to 1 hour for the infusion. Be prepared for 1-2 hours of monitoring after infusion
- Premedication is given before the infusion of your T cells. Let your nurse know if you have any allergies to Benadryl and/or Tylenol
- Bring your care partner
- Bring entertainment (eg, books, playing cards, phone)
- Wear comfortable clothing
- Communicate openly with the care team on how you feel during treatment

What to expect

- Know that the infusion itself is generally well tolerated
- You may be underwhelmed and surprised by how small the infusion bag is
- There will be frequent monitoring of vital signs and other forms of testing
- If your infusion is done in an outpatient setting, you may need to stay in the hospital overnight if symptoms worsen. Plan ahead in case admission is needed
- On the day of your CAR T infusion, review follow-up instructions with your care team, including symptoms to report, whom to contact, and when to seek emergency care



After CAR T Therapy

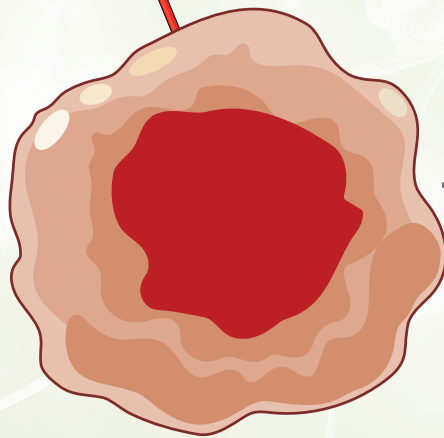


CAR T cell

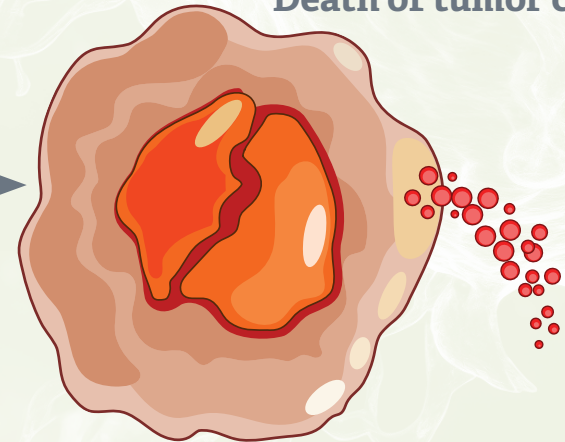
What is CAR T cell therapy doing?

CAR T cells are recognizing specific parts of cancer cells and killing them

Tumor cell



Death of tumor cell



After CAR T Therapy

Major side effects of CAR T cell therapies

Symptoms or side effects that will be monitored at or near your CAR T center for 2 weeks or longer if there are complications

Cytokine Release Syndrome (CRS)



You and your care partner should monitor for these symptoms

- Fast heartbeat
- Chills
- Upset stomach
- Lightheadedness
- Headaches
- Fever

Infections



You and your care partner should monitor for these symptoms

- Fever
- Coughing
- Excessive tiredness

Immune Effector Cell–Associated Neurotoxicity Syndrome (ICANS)



You and your care partner should monitor for these symptoms

- Signs of confusion
- Headaches
- Difficulty finding words
- Lack of attention or presence



I have any of these symptoms?

Call your healthcare team or go to the emergency room immediately

I go to an emergency room that is not my regular CAR T center?

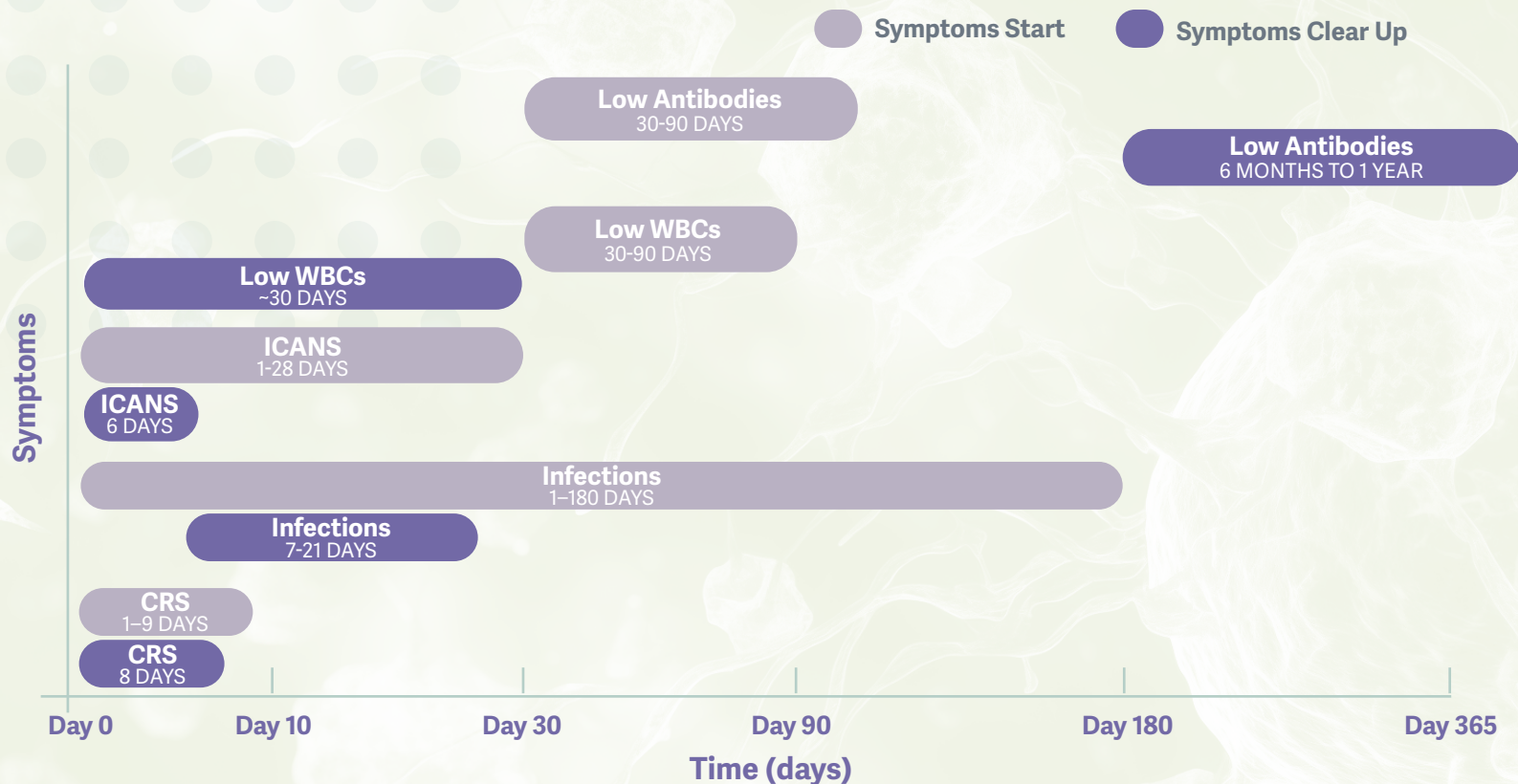
Give the local emergency room staff the information of the CAR T center so they can be contacted



PATIENTS AND CARE PARTNERS

After CAR T Therapy

Timing of major side effects



CRS, cytokine release syndrome; ICANS, immune effector cell–associated neurotoxicity syndrome; WBCs, white blood cells.



I have any of these symptoms?

Call your healthcare team or go to the emergency room immediately

I go to an emergency room that is not my regular CAR T center?

Give the local emergency room staff the information of the CAR T center so they can be contacted

After CAR T Therapy

Other common side effects

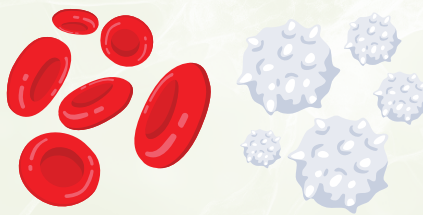
Fatigue



Treatment:
Potentially physical therapy,
home care support



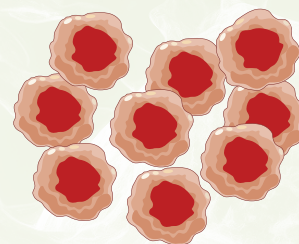
Low blood counts



Treatment:
Additional blood transfusions



Other cancers

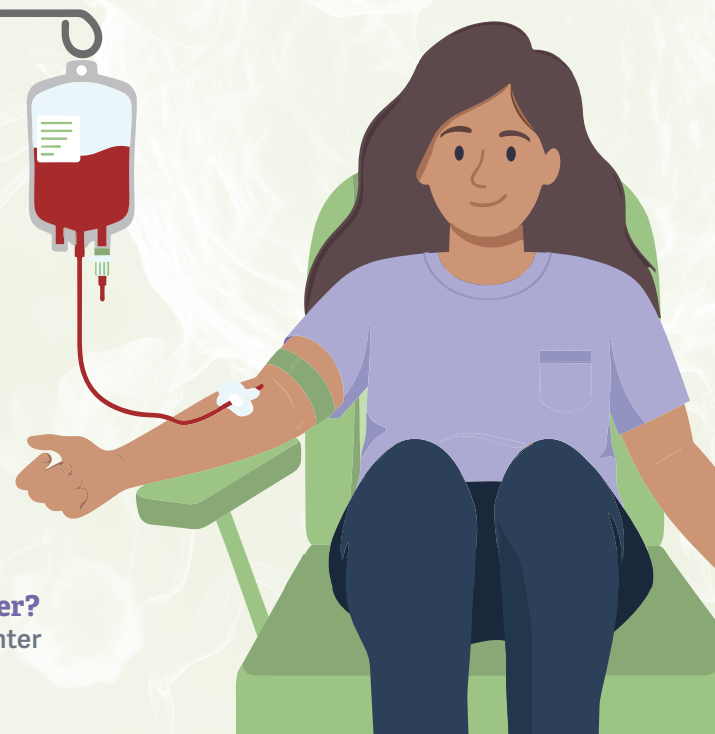


I have any of these symptoms?

Call your healthcare team or go to the emergency room immediately

I go to an emergency room that is not my regular CAR T center?

Give the local emergency room staff the information of the CAR T center so they can be contacted



After CAR T Therapy



Parts of follow-up care

- Continued care partner support
- Lab tests and scans

Your healthcare team may include

These members may be at the center where you received your therapy, or if you are progressing well, out in the community with a local primary care physician and oncologist

Follow-up care



After CAR T Therapy

Your care team may include a:

Medical Hematologist or Oncologist

Makes the diagnosis and leads your treatment

Clinic Nurse

Administers CAR T therapies and may provide education in some settings

Nurse Navigator

Guides you through your treatment journey and provides resources to resolve logistical or clinical barriers

Pharmacist

Provides drug-related information to you and the rest of the care team

Dietitian

Ensures you are eating healthy and in a way that minimizes side effects

Social Worker

Provides emotional and social support to help you along your treatment journey

Nurse Practitioner or Physician Assistant

Oversees day-to-day clinical care including side effect management, ordering supportive care, and ordering or interpreting tests that minimize side effects



PATIENTS AND CARE PARTNERS

After CAR T Therapy

What to expect long after receiving CAR T therapy

Tips for long-term home care

Your blood counts and antibodies may take a long time to fully recover. You may need extra medication at home to support you during this recovery. Don't skip appointments with your community oncologist and continue to have regular bloodwork and check-ups.

Side effects from CAR T cell therapy are always possible, even after you're discharged home. Report any unusual signs or symptoms, especially fever, confusion, headaches, signs of illness or infection, severe fatigue, weakness, or anything that doesn't feel right.

Have your doctor reach out to the CAR T team if you are being prescribed a new medication or being referred for a procedure. It may be recommended that you wait until your immune system is more fully recovered.

How You May Prevent Side effects

Wash hands often



Monitor for symptoms of side effects



Wear a mask



Avoid crowds



Reduce stress



Make healthier diet choices



Increase physical activity



After CAR T Therapy

Nutritional guidance

Dietary modifications that may reduce symptoms of CAR T cell therapy

BRAT Diet

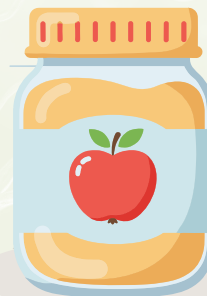
Bananas



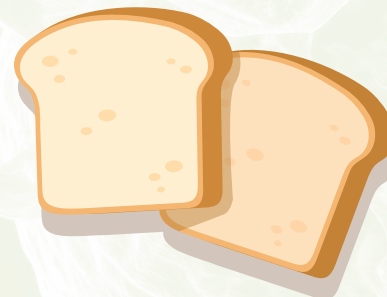
Rice



Applesauce



Toast



Clear broths, soups, juices



Oatmeal



Resources

Cancer Support Community CAR T Cell Therapy Concierge Navigation Program

<https://www.cancersupportcommunity.org/car-t-navigation-referral>

BMT Infonet Online Peer Support Group

<https://bmtinfonet.org/event/car-t-support-group>

Blood Cancer United Online Community

<https://bloodcancerunited.org/resources/patients/community>

Lymphoma Research Foundation: Lymphoma Support Network

<https://lymphoma.org/resources/supportservices/lsn/>



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