CAR T Therapy Expectations:

A Guide for Patients and Care Partners

Before CAR T Therapy

The purpose of this in-office flip-book is to provide a clear, concise, and engaging resource to aid nurses and care coordinators in providing education to patients receiving CAR T therapy and their care partners.

It serves as a visual and informational tool to educate healthcare professionals and patients about this innovative treatment, the adverse events and monitoring associated with it, and what life after treatment with CAR T therapy may look like.

By simplifying complex concepts, the flipbook aims to foster understanding of the journey a patient will embark on by receiving CAR T therapy, facilitate discussions between the patient and healthcare professionals, and support informed shared decision-making.

ENDORSED BY ACADEMY OF ONCOLOGY NURSE & PATIENT NAVIGATORS 2025-2027

AONN Academy of Oncology Nurse & Patient Navigators

The endorsement mark certifies that the information presented in educational seminars, publications, or other resources is reliable and credible.

Consultation

► CAR T therapy education

- How does CAR T therapy work?
- Summary of steps
- Typical duration of CAR T therapy (start through follow-up)

► Determining if CAR T is right for you

- Tests may include:
  - Lab tests, imaging, organ function tests, bone marrow biopsy
- Mental health and fitness assessments
- Availability of a care partner or caregiver team 24/7 for 2-4 weeks

► Support network

- **Care partner support**
  - Required 24 hours a day for 2-4 weeks after CAR T cell infusion
  - Responsibilities:
    - **During CAR T therapy**
      - Identify and report adverse events or symptoms
      - Ensure the patient has and takes all prescribed medications
      - Ask questions and take notes
      - Assist with personal care, hygiene, and daily household tasks
      - Drive and/or coordinate travel (the patient cannot drive for at least 2 weeks)
      - Accompany the patient to appointments or emergency room if needed
      - Coordinate lodging near CAR T medical center
      - Stay with the patient near CAR T medical center for 2-4 weeks
    - **After CAR T therapy**
      - Continue to monitor and report adverse events
      - Drive and/or arrange transportation
      - Manage medications
      - Ask questions and take notes
      - Assist with personal care, hygiene, and daily household tasks
- **CAR T team support can help with:**
  - Care coordination, mental health and well-being, lodging and transportation, insurance, benefits, and financial assistance
  - Clinical management of adverse events
  - Referrals to additional resources as needed

► Additional support

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

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

WHAT IF

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

Creating CAR T Cells

T cell collection (apheresis or leukapheresis)

- **Outpatient setting**
  - Blood is collected from the patient using a special procedure called apheresis that allows the collected blood to flow through a cell separator
  - The T cells are separated out and the rest of the blood is returned back to the patient
  - Central lines need to be inserted in the chest or a peripheral vein to collect enough T cells
- **Time of collection: 4-6 hours**

Converting T cells into CAR T cells

- **T cells are sent to a special laboratory to be genetically modified and transformed into CAR T cells**
- **The CAR T cells can only be used for the patient from whom the T cells were collected**

CAR T cell expansion

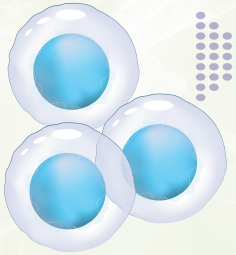
- **CAR T cells are grown for 1-3 weeks in the laboratory**
- **Patients may continue previous therapy, undergo bridging therapy, or receive supportive care while waiting for the engineered CAR T cells to be delivered to the CAR T medical center**

During CAR T Therapy

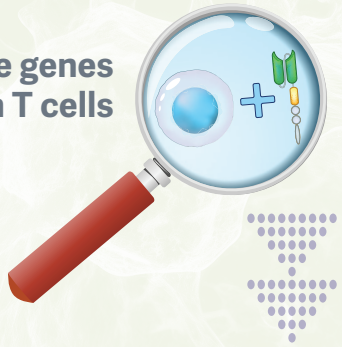
How does CAR T therapy work?

Collect blood that will have T cells

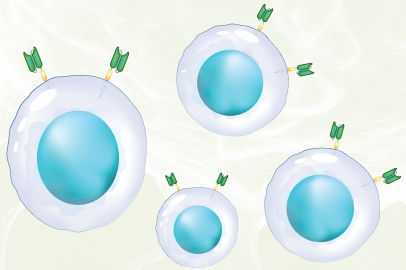
Separate T cells from other blood cells



Change genes in T cells



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



Millions of CAR T cells are grown

New CAR T cells are introduced into the blood stream

WHAT IF

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

Bridging Therapy

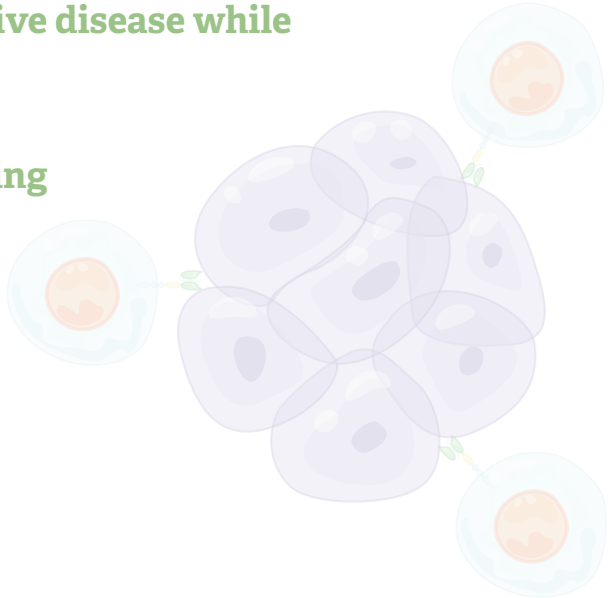
Define bridging therapy

- Bridging therapy is local or systemic treatment that is delivered after leukapheresis for CAR T cells has been completed, and before lymphodepleting chemotherapy and CAR T cell infusion[1]

- The goal of bridging therapy is to stabilize disease while awaiting more definitive treatment with CAR T cells[1]

The doctor may recommend chemotherapy for aggressive disease while CAR T cells are being grown

May be administered in an inpatient or outpatient setting



During CAR T Therapy

Inpatient

Bridging therapy

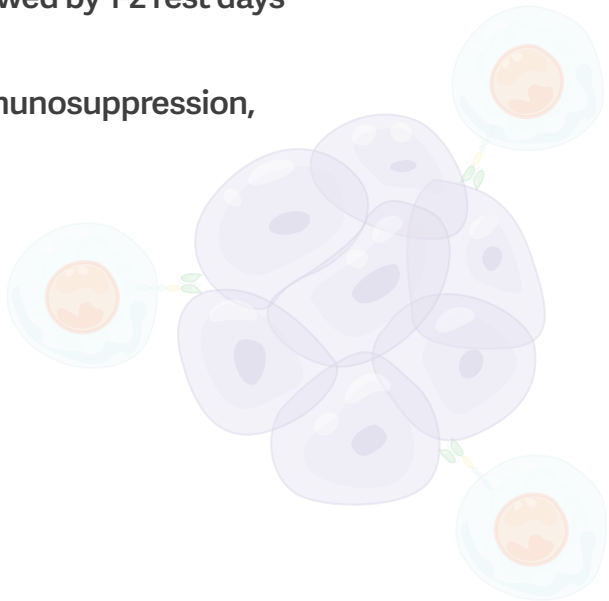
Outpatient

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

Preparation for CAR T Cell Infusion

Low-dose chemo (lymphodepletion)

- **Why:** Lymphodepletion is an essential step in the application of currently used CAR T therapies as it maximizes engraftment, efficacy, and long-term survival of CAR T[2]
  - Engraftment: successful implantation and proliferation of the CAR T cells in the patient's body
- **When:** 2-14 days before infusion of CAR T cells
- **Dosing schedule:** 3 days at clinic or CAR T medical center, followed by 1-2 rest days at home (timing may vary)
- **Adverse events:** Neutropenia, anemia, thrombocytopenia, immunosuppression, and infections



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

WHAT IF

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

CAR T Cell Infusion

CAR T cell infusion

- Define process: delivery of the CAR T product to the patient
- May be given in the inpatient or outpatient setting
- Duration: 15 minutes to 1 hour for the infusion and 1-2 hours of monitoring afterwards
- Potential extended duration of stay if complications should occur

Tips for a successful infusion

- Treatment is generally well tolerated
- Some patients are often underwhelmed or surprised by how small the infusion bag is
- Premedication with Tylenol and/or Benadryl may be given
- Please bring your care partner and some form of entertainment like games or books to help pass time during the infusion
- Communicate regularly with your care team on how you are feeling
- Make sure to review follow-up instructions with your care team after the infusion

During CAR T Therapy

CAR T cell infusion

Preparing for the infusion

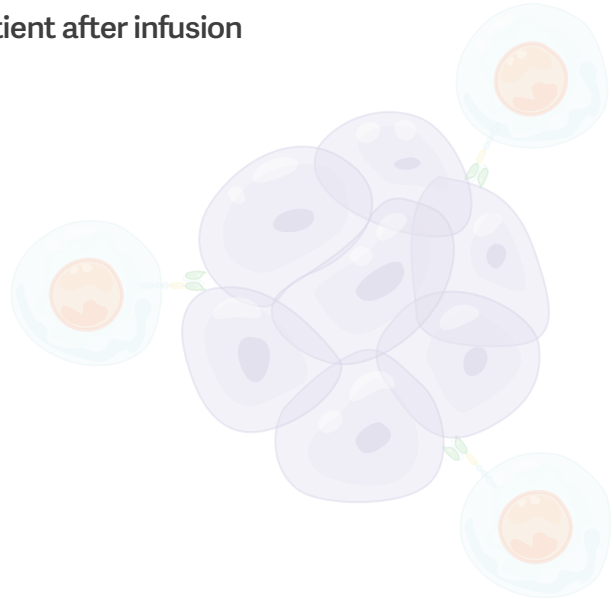
- Arrive to the infusion center approximately 15 minutes before your appointment
- Duration: 15 minutes to 1 hour for the infusion. Be prepared for 1-2 hours of monitoring after infusion
- Premedication is given before the infusion of your T cells. Let your nurse know if you have any allergies to Benadryl 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

What Is CAR T Cell Therapy Doing?

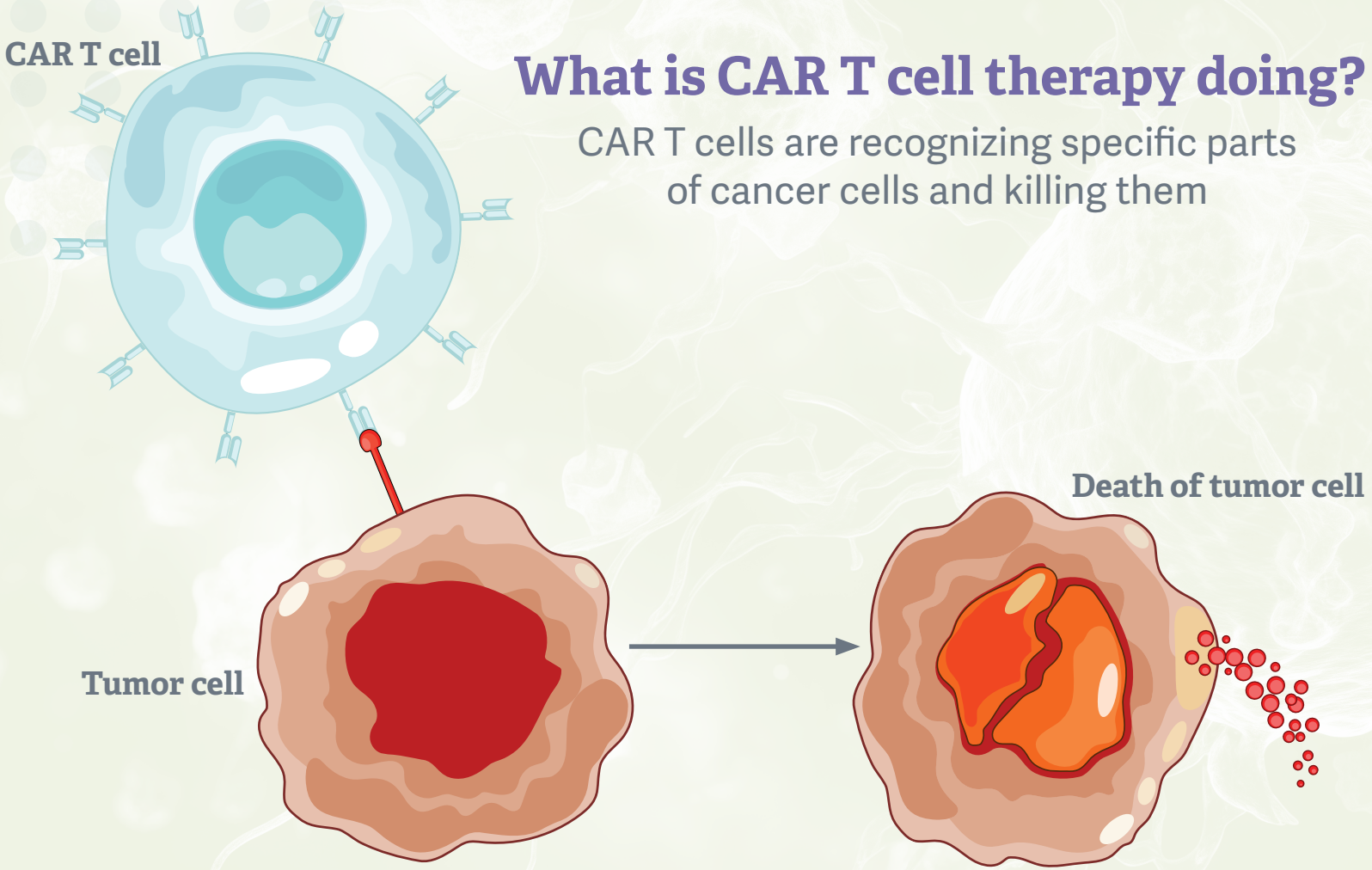
- Patient-friendly explanation: CAR T is giving your T cells goggles that allow them to spot the bad cancer cells
- After manufacturing, the product that is provided is an engineered form of T cells designed to recognize specific surface proteins on cancer cells
- The goal of reinfusing the engineered T cells is to recognize the appropriate protein (CD19, CD20) they were engineered to recognize. Once the target protein is recognized, the CAR T cells bind to the cancer cell and destroy it
- CAR T cells are a living drug as they continue to multiply in the patient after infusion
- The durability of the CAR T cells may vary for each patient



After CAR T Therapy

What is CAR T cell therapy doing?

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



After CAR T Therapy

Major Adverse Events of CAR T Cell Therapy

- **During the first 2 weeks, patients must be monitored closely to detect symptoms indicating adverse events**
  - At or near CAR T medical center for at least 2 weeks (may be longer if complications occur)
  - 3 major adverse events of CAR T cell therapy
    - **CRS:** A condition that may occur after treatment with CAR T cell therapy. Cytokine release syndrome (CRS) is caused by a large, rapid release of inflammatory signaling proteins called cytokines into the blood from immune cells affected by the immunotherapy[3]
    - **ICANS:** Immune effector cell–associated neurotoxicity syndrome (ICANS) is an adverse event that can occur with immunotherapy types. It is theorized that ICANS may be caused by the release of inflammatory cytokines, leading to increased vascular permeability and blood–brain barrier breakdown, leading to neurological symptoms[4]
    - **Infection:** The invasion of tissues by harmful microorganisms which may include bacteria, viruses, and fungi. Because of the natural blunting of the immune system that occurs with CAR T therapy, lymphodepleting therapy, and bridging therapy, patients are at a higher risk of contracting infections

Criteria	CRS	Infections	ICANS
Patient-friendly definition	The immune system uses T cells to fight threats by releasing chemical messengers called cytokines, which signal the body to bring in support. Normally, this process is balanced. With CAR T cell therapy, your T cells are modified to target and destroy cancer cells. However, this can sometimes trigger an overreaction, causing the immune system to go into overdrive. This overactivation, called cytokine release syndrome (CRS), can lead to flu-like symptoms (fever, chills, fatigue) and, in severe cases, affect breathing or blood pressure	To prepare your body for CAR T cells, we give chemotherapy to lower your white blood cell count, which weakens your immune system. After the CAR T infusion, your immune system needs time to recover, and certain immune cells may be depleted, reducing your ability to fight infections	Neurological side effects that can develop quickly at variable points after receiving CAR T therapy (1 day to 4 weeks). Changes may be mild (confusion) or severe (seizures or coma)
Symptoms	High fever and chills, trouble breathing, GI adverse events, feeling dizzy or lightheaded, headaches, tachycardia, fatigue, muscle and/or joint pain	Fever, cough, pain with urination, shaking chills, changes in mental status	Confusion, headache, attention deficits, word-finding difficulties, focal neurological deficits. More serious symptoms include encephalopathy, life-threatening cerebral edema, transient coma, or seizures
Monitoring and reporting parameters	Take patient's temperature regularly or if the patient is feeling warm, flushed. Avoid taking acetaminophen or ibuprofen that may mask a fever. Report temperature >38.3° C, or other changes in patient's symptoms to your CAR T healthcare team	Monitor patient for any new symptoms that are progressive or causing moderate to severe changes in well-being	Monitor patients for changes in mental status. Maintain safety. Report any changes promptly to the CAR T healthcare team
Supportive measures	Grade 1: fluids, steroids and acetaminophen Grade 2+: tocilizumab may be required, hospitalization if outpatient Grade 3+: may require intensive care	Treat the suspected source. Screening for infections prior to infusion Antiviral, anti-infective and in some cases antifungal prophylaxis	Fluids, corticosteroids, anti-epileptic medication (levetiracetam), benzodiazepines
Outcome if not treated	Multiorgan failure or very rarely, death[5]	Progressive and in some cases life-threatening infections	Status epilepticus, fatal cerebral edema, and intracerebral hemorrhage

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

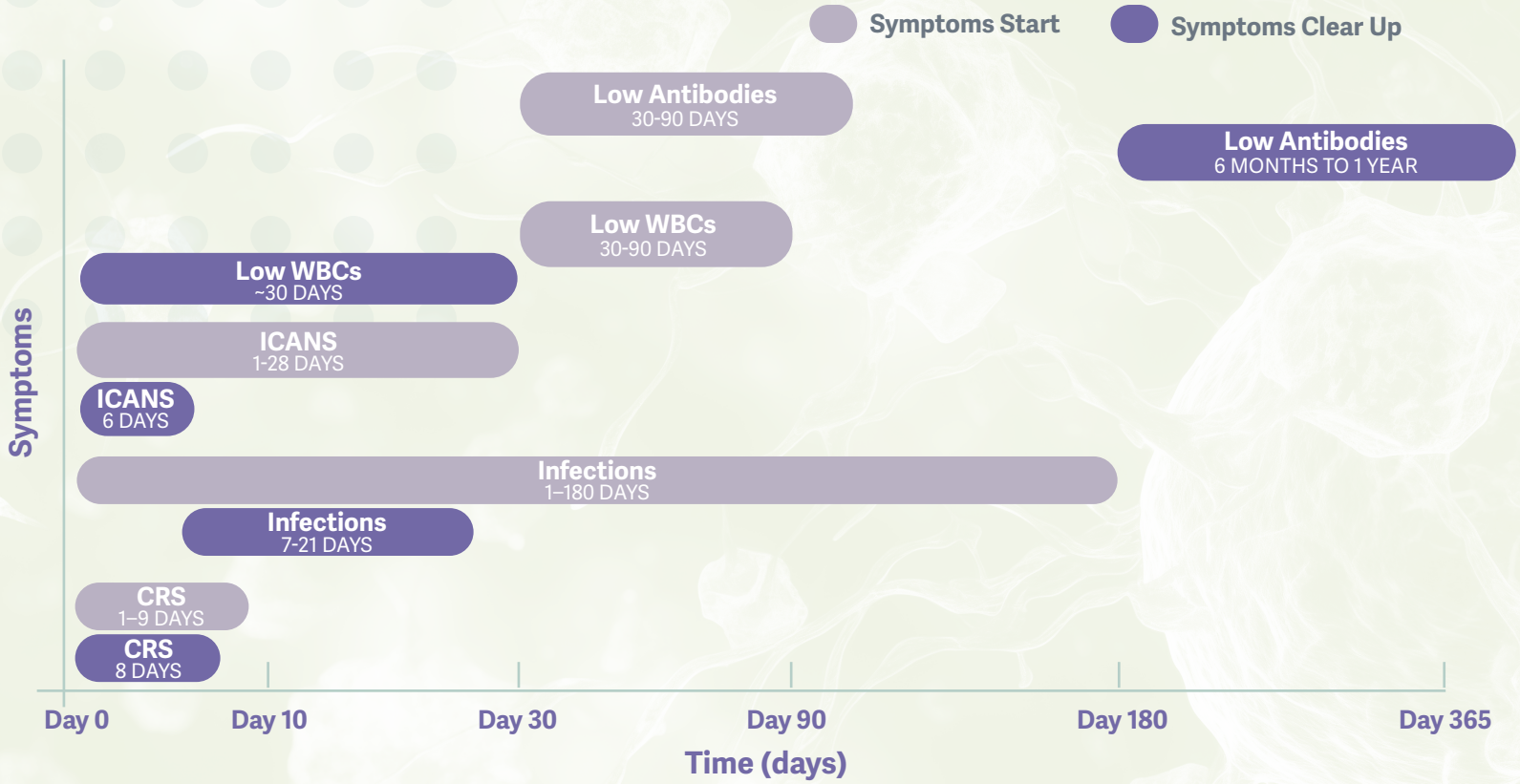
Expected Timing of Major Adverse Events

- The table below provides average estimates. The time to onset and resolution of these adverse events may depend on the drug being utilized and the patient[6]

Time frame	CRS	Infections	ICANS	Neutropenia	Hypogammaglobulinemia
Time to onset	1-9 days	1-180 days	1 day to 3-4 weeks (drug-specific)	Variable: may occur within 30-90 days, or may occur after 90 days	30-90 days
Time to resolution	8 days	Approximately 1-3 weeks	Median time to resolution: 6 days (range: 2-13)[7]	Approximately 30 days	6 months to 1 year

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

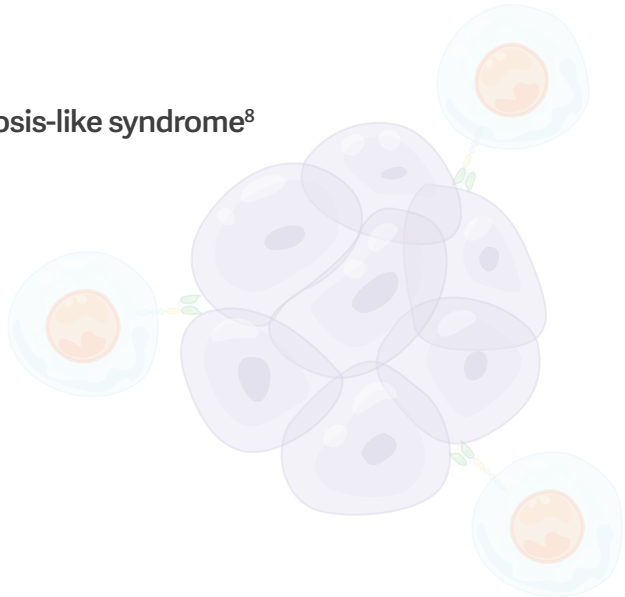
Additional Adverse Events

Other common adverse events

- **Low blood cell counts: leukopenia, anemia, thrombocytopenia, neutropenia**
  - Potential need for frequent transfusions
- **Fatigue**
  - Reduced counts may lead to excessive fatigue, which can have detrimental physical and mental effects
- **New cancers**
  - Reported but rare: T-cell lymphomas, myelodysplastic syndrome, acute myeloid leukemia

Rare adverse event

- **Immune effector cell–associated hemophagocytic lymphohistiocytosis-like syndrome**[8]
  - Often in patients who had severe CRS
  - Caused by hyperactive immune system
  - Symptoms: hyperferritinemia, coagulopathy, hepatic dysfunction, hepatosplenomegaly, organ failure, and cytopenias
    - Distinctive feature: ferritin >10,000 ng/mL
  - Importance of early reporting and treatment[9]
  - Treatment:
    - First-line: corticosteroids, anakinra
    - Second-line and beyond: ruxolitinib, emapalumab, tocilizumab

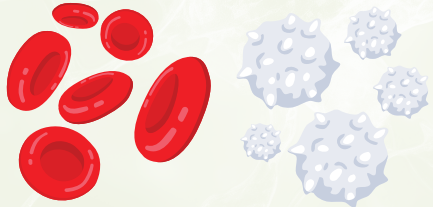


After CAR T Therapy

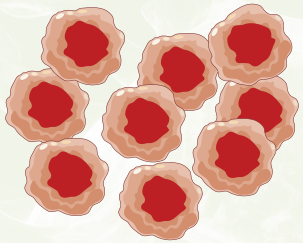
Other common side effects

Fatigue

Low blood counts

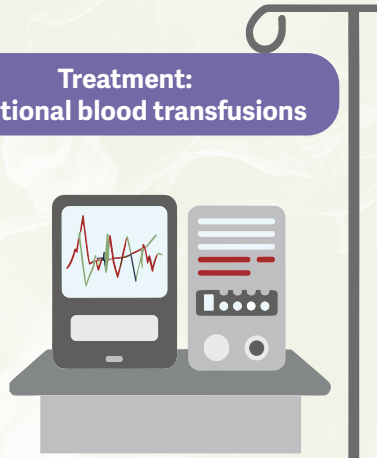


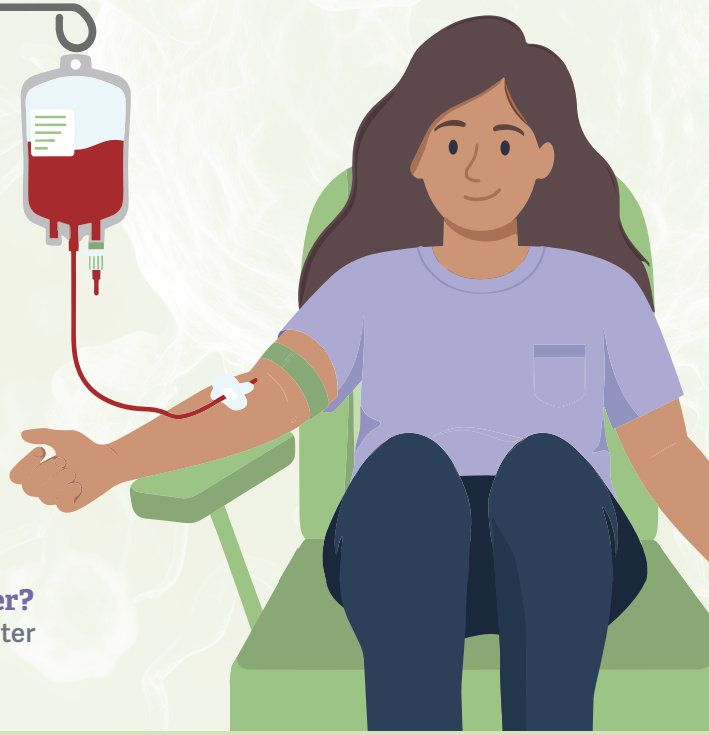
Other cancers



Treatment:
Potentially physical therapy, home care support

Treatment:
Additional blood transfusions





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

Follow-up Care

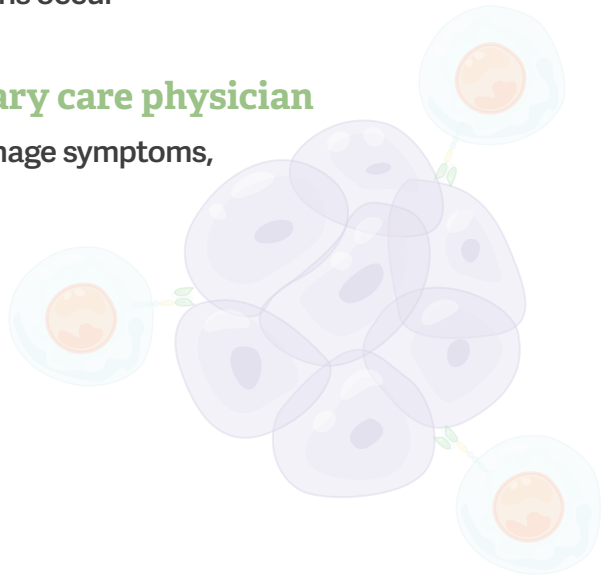
Follow-up care may consist of

- **Continued care partner support for transportation and symptom monitoring**
  - Patient not permitted to drive for at least 2 weeks due to CAR T–related symptoms
  - Sleepiness, confusion, weakness, temporary memory problems, coordination problems
- **Frequent assessments for**
  - Blood counts, opportunistic infection, electrolyte imbalances, organ function
- **Tests will be performed to determine how well treatment is working and potential recurrence may include:**
  - PET/CT scan, biopsy, lab tests
- **Potential hospital admission if severe or life-threatening complications occur**

Patient's care is transferred to local oncologist or primary care physician

- **Specific instructions will be provided on what to look for, how to manage symptoms, and whom to call for questions**

You may want to connect the patient with: nurse navigator, nutritionist, PT, palliative care, financial advisor, mental health professional



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

The Care Team

Medical Hematologist or Oncologist

- Roles and responsibilities: screening and consent for CAR T. Overseeing CAR T infusion. Overseeing clinical management in collaboration with the broader clinical team

Advanced Practice Providers: Nurse Practitioners (NP) or Physician Assistants (PA)

- Roles and responsibilities: oversee clinical care, place orders for testing and supportive care, interpret test results, assist with triage and adverse-event management, collaboration with physician team

Clinic Nurses

- Roles and responsibilities: administering therapy, initial adverse-event monitoring in the inpatient setting, providing patient education in some healthcare settings

Nurse Navigator

- Roles and responsibilities: helping the patient to navigate the complexities of CAR T therapy, providing disease state and therapy education to the patient and care partner, connecting the patient with resources to make their treatment journey easier

Pharmacists

- Roles and responsibilities: aid healthcare team in adverse-event management, medication reconciliation, be a resource for drug information to the rest of the multidisciplinary team

Dietitians

- Roles and responsibilities: ensure that the patients are maintaining adequate nutrition and reducing adverse events throughout their treatment

Social Workers

- Roles and responsibilities: provide the patient with psychosocial, emotional, and practical support to the patient

Based on the size of your healthcare center, the individual members of the care team may vary

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

Survivorship

Return to community practice

- Transfer of records, ensuring understanding of what can be done in community vs CAR T medical center

Expectations

- Lab testing frequency
- Cytopenia
  - Supportive care
    - Transfusions, growth factors
    - Duration of cytopenia
- Neurologic problems
  - Care partner to monitor and document changes
    - Monitor for symptoms of ICANS
      - Though neurotoxicity is more common immediately after infusion, there are rare cases of delayed neurotoxicity that the patient and care partner must watch for
- Opportunistic infections
  - Symptoms: fevers, coughs, chills, general malaise. Infection symptoms are general, so it is important for the patient to report any changes
- Metabolic changes
- Return to normal life
  - It may take a while before the patient is able to return to normal life. It may vary from patient to patient

Preventive risk measures

- Infection - wash hands regularly, wear mask, avoid crowds, etc
- Stress - physical activity, meditation
- Metabolic changes - nutritional guidance, physical activity

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

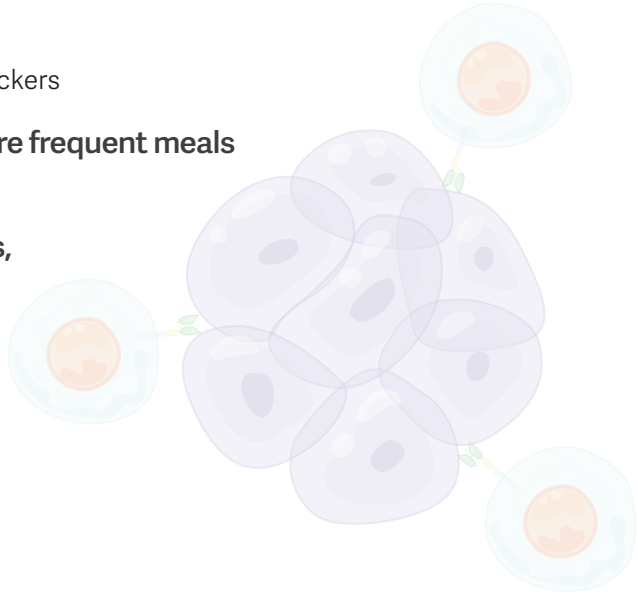
Make healthier diet choices

Increase physical activity

PATIENTS AND CARE PARTNERS

Nutritional Guidance

- After CAR T cell therapy, patients may experience adverse events such as nausea and vomiting, diarrhea, constipation, changes in taste, and weight loss
- These adverse events can be minimized through dietary changes, and it is important to link the patient up with a dietitian in order to aid that process
- Overall, the goal should be to eat anything that can help maintain energy levels, ensure adequate caloric intake, prevent malnutrition, and minimize the adverse events of CAR T cell therapy
- Guidance for patients on CAR T therapy trying to minimize adverse events may include:
  - Diarrhea: BRAT diet, clear broths, clear juices, soups
  - Constipation: high-fiber foods like oatmeal, fruits, and vegetables
  - Nausea and vomiting: BRAT diet, soups, clear juices, clear broths, plain crackers
- Refined foods, sugars, and red meats should be limited. Smaller, more frequent meals may aid patients with GI issues
- Make sure the food you are eating is safe: avoid undercooked meats, unpasteurized products, and wash fruits and vegetables well



Nutritional guidance

Dietary modifications that may reduce symptoms of CAR T cell therapy

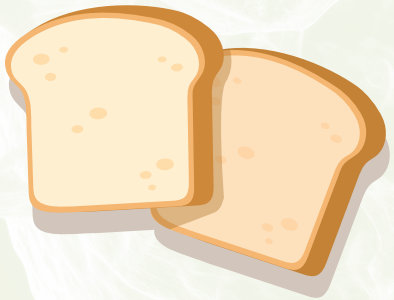
BRAT Diet

Bananas

Rice

Applesauce

Toast



Clear broths, soups, juices

Oatmeal

References

1. Bhaskar ST, Dholaria B, Savani BN, Oluwole O. The evolving role of bridging therapy during CAR T therapy. *Clin Hematol Int*. 2024;3:9-16.
2. Lickefett B, Chu L, Ortiz-Maldonado V, et al. Lymphodepletion - an essential but undervalued part of the chimeric antigen receptor T cell therapy cycle. *Front Immunol*. 2023;14:1303935.
3. National Cancer Institute. Cytokine Release Syndrome. Accessed September 3, 2025. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/cytokine-release-syndrome
4. Rees JH. Management of immune effector cell-associated neurotoxicity syndrome (ICANS). 2022. In: Kröger N, Gribben J, Chabannon C, et al, eds. *The EBMT/EHA CAR T Cell Handbook* [Internet]. Cham (CH): Springer; 2022. https://www.ncbi.nlm.nih.gov/books/NBK584157/
5. Rubin DB, Vaitkevicius H. Neurological complications of cancer immunotherapy (CAR T cells). *J Neurol Sci*. 2021;424:117405.
6. Shahid Z, Jain T, Dioverti V. et al, Best practice considerations by The American Society of Transplant and Cellular Therapy: infection prevention and management after chimeric antigen receptor T cell therapy for hematological malignancies. *Transplant Cell Ther*. 2024;30:955-969.
7. Wesson W, Dima D, Suleman N, et al. Timing of toxicities and non-relapse mortality following CAR T therapy in myeloma. *Transplant Cell Ther*. 2024;30:876-884.
8. Hughes AD, Teachey DT, Diorio C. Riding the storm: managing cytokine-related toxicities in CAR T cell therapy. *Semin Immunopathol*. 2024;46:5.
9. Hines MR, Knight TE, McNerney KO, et al. Immune effector cell-associated hemophagocytic lymphohistiocytosis-like syndrome. *Transplant Cell Ther*. 2023;29:438.e1-438.e16.

Thank you to the nurses and nurse navigators who dedicated their knowledge, time, and efforts to enhance the care of patients through the development of this CAR T resource.

- Allison Appenfeller, RN, BSN, OCN
- Christy Donovan, DNP, RN
- Misha Hawkins, MSN, RN, OCN
- Sandra E. Kurtin, PhD, ANP-BC, AOCN, FAPO
- Carrie Peterson, DNP, AGNP-C, AOCNP
- Melissa Reinhold, RN, BSN, OCN
- Carsen Schmid, BSN, RN, BMTCN
- Laura J. Zitella, MS, RN, ACNP-BC, AOCN

Download full PDF of this guide

Download patient-facing PDF of this guide

Feedback survey

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/

Download patient-facing PDF of this guide

amplity

© 2025 Amplity, Inc. All Rights Reserved.

This resource was supported by Kite, a Gilead Company