CAR T-Cell Therapy:

What to Expect Before, During and After





CAR T-Cell Therapy:

What to Expect Before, During and After

Published by BMT InfoNet

Many thanks to our medical advisors for this booklet:

- Nausheen Ahmed, MD, The University of Kansas Cancer Center
- Margaret Franzetti, MSW, LCSW, Hackensack University Medical Center
- Patrick Connor Johnson, MD, Massachusetts General Hospital
- Daniel J. Landsburg, MD, Hospital of the University of Pennsylvania
- Navneet Majhail, MD, MS, Sarah Cannon Transplant and Cellular Therapy Network
- Elizabeth Muenks, PhD, University of Kansas Cancer Center
- Tulio Rodriguez, MD, City of Hope Chicago
- Craig Sauter, MD, Cleveland Clinic
- Gunjan Shah, MD, MS, Memorial Sloan Kettering Cancer Center
- Michael Tees, MD, MPH, HCA HealthOne Presbyterian St. Luke's
- David Vesole, MD, PhD, FACP, Georgetown University Hospital and Hackensack Meridian School of Medicine
- Basem William, MD, MRCP, FACP, OhioHealth

and to Bristol Myers Squibb, Kite, a Gilead Company, and Autolus for their support of this publication.

CAR T-Cell Therapy:

What to Expect Before, During and After

By Susan K. Stewart with Anna Schaal RN, BSN, MS, ARNP Illustrated by Norm Bendell



1548 Old Skokie Road, Highland Park, IL 60035

Visit us online at: bmtinfonet.org email: help@bmtinfonet.org

phone: 847-433-3313 toll-free: 888-597-7674

Follow us: facebook.com/bmtinfonet

Copyright © 2020, 2021, 2022, 2023, 2024

ISBN 979-8-9919717-0-6

Table of Contents

What is CAR T-cell therapy? FDA-approved CAR T-cell therapies	
2. What's involved in undergoing CAR T-cell therapy?	6 7 8
3. What are the side effects of CAR T-cell therapy? Cytokine release syndrome (CRS) Neurotoxicity Infection Low blood cell courts Fatigue New cancers Other rare effects	12 13 15 15 16 16
4. Follow-up care after CAR T-cell therapy Going home Preventing infections Neurological problems	20 21
5. Coping with the stress of CAR T-cell therapy	25
6. The role of the caregiver Watch for neurological problems Take care of your physical well-being Changing relationships Caregiver's emotional well-being	30 31 32
7. Financial considerations	35
8. Medical centers that offer CAR T-cell therapy Clinical trials	
9. Does CAR T-cell therapy cure cancer?	39
Helpful Resources	40



CHAPTER 1

WHAT IS CAR T-CELL THERAPY?

Chimeric antigen receptor T-cell therapy (CAR T-cell therapy) is a treatment that engineers the patient's own immune system to fight cancer.

Certain immune system cells, called T-cells, are normally able to identify abnormal cells like cancer cells, and destroy them before they multiply and cause disease. Sometimes, however, T-cells have trouble detecting cancer cells.

CAR T-cell therapy removes T-cells from the blood and inserts a new gene into them to make it easier for the T-cells to fight cancer. The new cells are called CAR T-cells.

The CAR T-cells are then re-infused into the patient.

Who can receive CAR T-cell therapy?

CAR T-cell therapies are currently approved by the U.S. Food and Drug Administration (FDA) for patients with certain types of acute lymphoblastic leukemia, lymphoma, chronic lymphocytic leukemia, and multiple myeloma.

Research is underway to determine if patients with other types of cancer such as acute myeloid leukemia, Hodgkin lymphoma, some autoimmune diseases, and some solid tumors can also benefit from CAR T-cell therapy.

FDA-Approved CAR T-cell Therapies

As of November, 2024 the FDA has approved the following CAR T-cell therapies for patients who relapsed or did not respond to prior therapy:

- Abecma® (idecabtagene vicleucel; ide-cel) for adults with multiple myeloma
- Aucatzyl® (obecabtagene autoleucel; obe-cel) for adults with B-cell acute lymphoblastic leukemia.
- Breyanzi® (lisocabtagene maraleucel; liso-cel) for adults with:
 - large B-cell lymphoma
 - follicular lymphoma
 - o mantle cell lymphoma
 - o chronic lymphocytic leukemia
 - o small lymphocytic lymphoma
- Carvykti[™] (ciltacabtagene autoleucel; cilta-cel) for adults with multiple myeloma
- Kymriah® (tisagenlecleucel) for
 - children and young adults up to 25 years old with B-cell acute lymphoblastic leukemia
 - adults with large B-cell lymphoma and follicular lymphoma
- Tecartus® (brexucabtagene autoleucel; brexu-cel) for adults with:
 - o mantle cell lymphoma
 - o B-cell acute lymphoblastic leukemia
- Yescarta® (axicabtagene ciloleucel; axi-cel) for adults with:
 - large B-cell lymphoma
 - follicular lymphoma

The specific CAR T-therapy available to you will vary depending on the medical center where you are receiving treatment and the characteristics of your diseases. In addition to FDA-approved therapies, your treatment center may offer you an opportunity to participate in a clinical trial testing a new type of CAR T-cell therapy.



CHAPTER 2

WHAT'S INVOLVED IN UNDERGOING CAR T-CELL THERAPY?



There are several steps involved in CAR T-cell therapy:

- collecting your T-cells
- converting your T-cells into CAR T-cells at a special laboratory
- growing your CAR T-cells in the laboratory
- preparing your body to receive the CAR T-cells
- infusing the CAR T-cells into your body
- monitoring you for potential complications after treatment

CAR T-cell therapy usually takes three-to-eight weeks from the collection of T-cells through discharge from the follow-up clinic. Follow-up will continue with your local doctor after you return home.



Are you healthy enough for CAR T-cell therapy?

Prior to collecting your T-cells, you will undergo a series of tests to determine the status of your disease and confirm you are healthy enough for CAR T-cell therapy. These tests may include:

- blood counts
- tests for infection
- pulmonary function tests to determine the health of your lungs
- · echocardiogram to assess your heart's health
- MRI to determine whether your disease has spread to your brain
- blood tests to assess kidney and liver function
- bone marrow tests
- CT or PET/CT imaging to determine where the disease is located in your body
- a biopsy to confirm your diagnosis
- a spinal tap to determine if your disease has spread to your central nervous system

Counseling and Financial Planning

You will likely have a consultation with a mental health professional to discuss your emotional health and any concerns you have. He or she will also explain why it is important to have a family member or friend serve as your caregiver. You may be invited to attend a class for CAR T-cell recipients and caregivers to help you better understand what to expect during and after treatment.

You may also meet with a financial counselor to discuss how to manage expenses, including incidental expenses such as transportation, parking, meals, and lodging, particularly if your treatment center is far from home. Be sure to ask whether the company providing your CAR T-cells has a financial assistance program to help you cover expenses.

How are T-cells collected?

The process used to collect your T-cells is called leukapheresis. The collection usually takes place in the outpatient setting and



lasts four-to-six hours.

During your T-cell collection:

- You will sit in a comfortable chair or bed.
- Blood will be withdrawn from your arm and passed through a machine that separates out your T-cells.
- The rest of your blood product will be returned to you.
- In some cases, patients need a central line inserted into their chest to collect sufficient cells.

The T-cells are then sent to a special laboratory where they are genetically modified and turned into CAR T-cells that can destroy your cancer cells.

Bridging Therapy

It can take several weeks to create enough CAR T-cells for you. While your CAR T-cells are being created, your doctor may recommend that you have some chemotherapy or other therapy to prevent your disease from getting worse. This is called bridging therapy. Some patients are hospitalized for bridging





therapy, while others receive it in the outpatient clinic.

CAR T-cell Infusion

A few days before your CAR T-cells are infused into you, you will receive chemotherapy to eliminate cells in your body that could prevent the CAR T-cells from multiplying. This process is called lymphodepletion and may cause:

- fatigue
- low blood counts
- nausea
- diarrhea

The infusion of CAR T-cells will take place in the hospital or in the outpatient clinic where you will be carefully monitored. You will be awake during the infusion. Your CAR T-cells will be returned to you much like a blood transfusion.

Depending on which CAR T-cell product you are receiving and whether complications or side effects develop after the infusion, you may need to be in the hospital for several days or weeks.

CHAPTER 3

WHAT ARE THE SIDE EFFECTS OF CAR T-CELL THERAPY?

In the first two weeks following the infusion of CAR T-cells, the CAR T-cells will rapidly multiply in your body, building an army of cells to detect and fight your cancer cells. During this time, you may experience several side effects.



Three major side effects that your healthcare team will carefully watch for are:

- cytokine release syndrome
- neurotoxicity
- infection

Cytokine Release Syndrome (CRS)

Cytokines are proteins normally released by immune system cells to communicate with each other. When an army of CAR T-cells attacks cancer cells, they release a large number of cytokines into the body which can cause serious health problems. This is called cytokine release syndrome.

Cytokine release syndrome occurs in most patients after CAR T-cell therapy. It can begin within a few hours, days, or weeks after treatment.

Symptoms may include:

- fever (100.4°F/38°C or higher)
- chills/shaking
- low blood pressure
- a low white or red blood cell count



- dizziness/lightheadedness
- fast or irregular heartbeat
- difficulty breathing, shortness of breath, and/or low oxygen level
- nausea, vomiting, diarrhea
- muscle or joint pain
- significant fatigue

Your healthcare team will give you IV fluids and/or medications to manage fevers or blood pressure changes, and oxygen if you have shortness of breath.

If the cytokine release syndrome is more severe, you may need to be treated with a medication called tocilizumab or a similar drug to manage this problem. Steroids or other medications may also be needed. If your cytokine release syndrome is very severe, you may need to be monitored in the intensive care unit.

You will be closely monitored until all symptoms of cytokine release syndrome end. This usually takes a few days but may take longer.

If not detected and treated promptly, cytokine release syndrome can be life-threatening.

Neurotoxicity

Neurotoxicity (also called immune effector cell-associated neurotoxicity syndrome or ICANS) is inflammation in the nervous system. It occurs almost exclusively in patients who also had cytokine release syndrome.

Neurotoxicity typically occurs five to ten days after treatment, although it can occur later as well. It is usually a temporary side effect.

Symptoms of neurotoxicity may include:

- headaches, which may be severe
- difficulty speaking, slurred words, stuttering
- confusion, delirium
- difficulty staying awake
- dizziness
- difficulty paying attention
- loss of coordination and/or fine motor skills
- weakness or shakiness (tremors)
- · changes in handwriting
- seizures
- swelling in the brain
- memory loss
- hallucinations
- coma

Depending on the severity of the neurotoxicity, your healthcare team may simply take measures to keep you comfortable until the problem resolves or give you medication to control it. The most common medication is steroids. You may also receive anti-seizure medication to protect you. In severe cases, you will be monitored and treated in the intensive care unit.

Although the symptoms of neurotoxicity can be frightening for you and your loved ones, they usually are fully reversible. However, it can take days, weeks or even months for a patient to return to normal. In rare cases, neurotoxicity is life-threatening.

Some patients have experienced delayed neurological problems with symptoms similar to those seen in patients with Parkinson's disease. This problem is different than the neurotoxicity that occurs early after treatment. It is called delayed neurotoxicity or motor and neurocognitive toxicity (MNT).

Delayed neurotoxicity has been seen most often in patients who have myeloma, but has also been seen in some lymphoma patients as well. Ask your treatment team if you are at risk for this side effect.

Infection

CAR T-cell therapy will reduce your white blood cell count, which weakens your immune system and increases the risk of infection. Until your immune system is functioning normally, you will be given medications to reduce the risk of infection.

If you do develop an infection, you may receive intravenous infusions of immunoglobulins (IVIG) to help fight it.

It typically takes several weeks or months for your immune system to recover. However, it can also take longer.

At six months after CAR T-cell therapy, your doctor may recommend repeating many of the immunizations you received earlier in life.

Low Blood Cell Counts

In addition to cytokine release syndrome, neurotoxicity and infection, some patients experience prolonged low platelet, white blood cell, and red blood cell counts.

Until your blood counts recover, you may need frequent transfusions of:

blood and/or platelets



growth factors - medicines to stimulate blood cell production

These problems usually resolve within a few weeks to months following CAR T-cell therapy. However, in some patients, these problems persist for several years.

Fatigue

Fatigue after CAR T-cell therapy is very common and may take weeks or months to resolve. In some cases, it persists even longer.

Some patients need physical therapy to regain their strength, stamina, and stability. Safe exercise, such as daily walks, can also help build stamina and strength.



New Cancers

New cancers have been reported in some patients after CAR T-cell therapy, including rare T-cell lymphomas, myelodysplastic syndrome (MDS), and acute myeloid leukemia (AML). Talk to your doctor about whether you are at risk for developing one of these new cancers.

Other Rare Side Effects

A rare but very serious side effect called immune effector cell associated hemophagocytic syndrome (IEC-HS) has been reported in approximately 1% of CAR T-cell patients, although the incidence may actually be higher due to under-reporting. It is seen most often in patients who have had severe cytokine release syndrome and is caused by a hyperactive immune system.

Symptoms include:

- an enlarged liver
- swollen lymph nodes
- skin rashes
- jaundice (yellow color on skin and in eyes)
- persistent coughing, difficulty breathing
- stomach pain, vomiting, and diarrhea
- nervous system problems such as headache, trouble walking, visual changes, and weakness
- very low blood counts
- fever
- very high ferritin levels
- bleeding

Although these symptoms can be caused by other less serious health problems, you should report them to your doctor immediately because prompt treatment of this condition is important. Steroids and other drugs such as anakinra and rituximab may help manage this complication.

Doctors are still learning about rare side effects after CAR T-cell therapy and how to treat them.

CHAPTER 4

FOLLOW-UP CARE AFTER CAR T-CELL THERAPY

Your CAR-T team may require you to remain close to the medical center for approximately four weeks after the infusion of your CAR T-cells. You will visit the outpatient clinic frequently to be checked for:

- low blood counts
- infection
- electrolyte imbalances
- organ function
- symptoms of cytokine release syndrome or neurotoxicity

You may not be permitted to drive a car for eight weeks because CAR T-cell therapy can cause:

- sleepiness
- confusion
- weakness
- · temporary memory problems
- coordination problems

Your caregiver may need to transport you to and from the clinic for check-ups.

Complications can develop during this time that may be severe or even life-threatening. It may be necessary to admit you to the hospital to treat these problems.



Going Home

Approximately four weeks after CAR T-cell therapy, tests will be done to assess how well the treatment is working. These tests may include:

- a PET/CT scan
- a bone marrow biopsy
- additional lab tests, depending on your disease

If all is well, the frequent clinic visits will end and your care will be transferred to your local oncologist or primary care physician. Your local doctor will be given specific instructions about symptoms to watch for, how they should be managed, and whom to call at the CAR T-cell center if there are questions.

Ask your doctor to explain what your care plan will be after you return home. Some patients need maintenance therapy after CAR T-cell therapy, while others do not.

Recovering from CAR T-cell therapy can take several weeks or months. While your body recovers:

- You will feel very tired and weak.
- You may not have much of an appetite.
- You may have problems with memory, concentration, confusion, word finding, and/or staying organized.

For most patients, these problems resolve over time.

Preventing Infection

Some patients continue to have a low white blood cell count for many months. This can increase your risk of developing an infection. It is common for patients to be on antimicrobial medications for several months after CAR T-cell therapy.

Until your immune system recovers you should take precautions to reduce your risk of developing an infection. The most important of these is frequent, thorough handwashing with soap and water before:

- eating or preparing food
- taking medications



Be sure to wash your hands after:

- · touching catheters and wounds
- changing diapers (if you are permitted to do so)
- touching plants or dirt (if you are permitted to do so)
- going to the restroom
- · touching animals
- touching bodily fluids or items that might have come in contact with bodily fluids such as clothing, bedding, or toilets
- going outdoors or to a public place
- · removing gloves
- collecting or depositing garbage

To reduce your risk of developing an infection, your medical team may recommend that you avoid:

- crowds
- people who have an infection or have been exposed to an infection
- gardening or digging in dirt
- smoking or being around people who smoke cigarettes, cigars, e-cigarettes, a pipe, or marijuana
- · walking, wading, swimming, or playing in ponds and lakes
- construction sites and remodeling projects

Cleaning kitchen counters and bathrooms daily with a solution of one part bleach to 10 parts water can help eliminate sources of infection.

Ask your care team about getting the flu, shingles, RSV, and COVID vaccinations to reduce your risk of infection after CAR T-cell therapy.

Neurological Problems

Some patients experience neurological problems for several weeks or months after CAR T-cell therapy, such as:

- difficulty remembering things
- poor concentration
- confusion
- · difficulty finding the right word
- · difficulty planning and staying organized
- · difficulty walking
- poor motor skills

Often it's the caregiver, rather than the patient, who first notices these problems. It helps if the caregiver writes down when the problems start and end, so that accurate information can be shared with the medical team. The problems typically resolve in two to three months.

Report Problems Promptly

If you develop new symptoms or have questions, be sure to reach out to your CAR T-cell therapy team right away for help. Problems are usually easier to treat when they are caught early.



CHAPTER 5

COPING WITH THE STRESS OF CAR T-CELL THERAPY

CAR T-cell therapy can be an emotionally challenging experience for both you and your family.

You may worry about:

- how you will feel while going through treatment
- potential short and long-term side effects
- how long it will take to recover
- whether you will be able to go back to work or school
- whether CAR T-cell therapy will prolong or improve your quality of life
- how you and your family will be able to manage household and financial obligations

It's normal to feel worried, sad, or anxious. You may also feel conflicting emotions such as excitement and fear. If you are constantly worrying or are feeling down more days than not, it may be a sign that you should seek support.

Talk about Your Feelings

It's important not to ignore or downplay your feelings. Finding an outlet to express and process your feelings can decrease stress, facilitate problem-solving, and help you move forward in a healthy manner. Consider talking with a supportive friend, journaling, or blogging.



Talking with a social worker, psychologist, psychiatrist, or pastoral counselor at the hospital often helps. If none is available, search BMT InfoNet's Mental Health Directory at **bmtinfonet.org/mh-directory** to find a mental health provider who can help you.

It can help to talk with others who've been through CAR T-cell therapy. They can share information about what to expect and strategies they found useful while undergoing treatment. BMT InfoNet's Caring Connection Program at **bmtinfonet.org/caring-connection** can connect you with someone who has been through CAR T-cell therapy either as the patient or caregiver.

Many people find that meditation, relaxation programs, and exercise help relieve anxiety. Explore whether your hospital or a local cancer wellness center offers classes that teach these techniques.

BMT InfoNet also hosts support groups for people who have undergone CAR T-cell therapy. Email **help@bmtinfonet.org** for more details.

You can try some apps to help relieve stress. Calm.com and Headspace.com are two worth exploring. The Breathe2relax app can also be helpful.

If you're still feeling stressed, ask your doctor whether medication to reduce your distress is appropriate. Short-term use of these drugs does not lead to long-term dependence for most people.

You can also ask your CAR T-cell team to refer you to a palliative care specialist who can help manage your symptoms and improve your quality of life. Palliative care specialists not only help people near the end of life, but also help patients who are recovering from a serious illness and need help with issues such as pain and managing emotional challenges.





THE ROLE OF THE CAREGIVER

Although highly trained medical professionals will care for your loved one during treatment, most CAR T-cell programs require the patient to identify a family member or friend who can serve as his or her personal caregiver 24/7 for approximately four weeks after the infusion of CAR T-cells.

If the patient develops symptoms such as fever, confusion, or disorientation, it is critical to have a 24/7 caregiver on hand to alert the medical team and get help quickly.

Caring for a loved one who is recovering from CAR T-cell therapy is a big job. Caregivers must juggle many tasks including:

- assuming some of the medical duties that were previously handled by nurses
- ensuring the patient follows the treatment plan prescribed by the medical team
- acquiring and dispensing the medications the patient needs daily
- scheduling and coordinating transportation to the clinic and specialist visits
- monitoring the patient for new or worsening symptoms

- communicating any change in the patient's condition to the healthcare team
- protecting the patient from sources of infection
- · preparing nutritional meals
- providing the patient with emotional support
- managing usual household chores such as paying bills, childcare, home maintenance, running errands, as well as maintaining a job

Watch for Neurological Problems

While recovering at home, the patient may show signs of neurological problems such as:

- confusion
- memory loss
- disorientation

Observing these changes can be very worrisome for the caregiver. It's important to write down any neurological problems you notice, including when they began, how long they last, and when they end so that you can accurately and promptly report them to the doctor.

If the patient is experiencing neurological problems, try to:

- establish a daily routine for the patient with as few changes as possible each day
- create reminders about when certain tasks need to be done or when events will occur
- use automatic timers to turn appliances and electronic devices on and off
- · keep rooms well lit and free of clutter
- put important items in the same place after each use so that they can be easily found
- keep drapes and shades open during the day and closed at night to keep the patient oriented to the time of day

Take Care of Your Physical Well-Being

To be an effective caregiver, you will need to keep yourself in good physical condition. This includes eating well-balanced meals, getting daily exercise, and getting sufficient sleep each night.

Although it can be hard, pay attention to your own health. If you have any health issues, don't ignore them or put off seeing a doctor about them. Remember, if you become ill you will not be able to care for your loved one.

Try to create a daily routine with time built in to do things that will keep you strong and healthy, both mentally and physically.

Think about ways to 'burn off' stress with physical movement such as walking or yoga. Try to 'turn off' stress with meditation or prayer, journaling, spending time in nature, listening to music, or watching a show that makes you laugh.

Even simple things like a favorite snack midday, five minutes on your favorite website, or two minutes of stretching can help relieve stress.



Gather a Team of Helpers

Don't try to go it alone. It is hard to do all the things you need to do for the patient as well as address your own needs. A good support network is very valuable.

People are often eager to help if they know exactly what you need. Make a list of all the activities that could be done by someone else like shopping, meal preparation, or yardwork, and then reach out to family and friends to see who can help. Build in ongoing support if you can so that you don't have to keep asking for help.

Ask a family member or friend to organize help for you. There are many programs available online that make it easy to organize volunteers to provide meals and other assistance for people with health issues. Some to check out include:

- LotsaHelpingHands.com
- MealTrain.com
- CaringBridge.org

Changing Relationships

Being the caregiver can create a different type of relationship between you and your loved one, at least for a time. If you are



caring for a spouse or partner, you may find yourself in a nurse/ patient role instead of being equal partners. It's common for differences to arise over how much care you should be providing or how much you should be pushing the patient to do various activities, which can lead to frustration, resentment, and anger for both parties.

Communication is key. Bottling up frustration is not healthy.

Try using 'I' statements such as 'I am feeling frustrated' rather than 'You' statements such as 'You make me mad'. Think about caregiving as care-partnering. Work together to name challenges and problem-solve them together.

Encourage the patient to do what he or she can without help so that you both maintain as much independence and self-identity as possible. Don't forget to spend time together doing things you enjoy that are not medical in nature.

Caregiver's Emotional Well-Being

Caring for someone who is recovering from CAR T-cell therapy can be stressful. Fear of the unknown, unexpected complications, frustration over things like getting appropriate medical help, wanting more support from family and friends, and exhaustion can put your emotional health in jeopardy.

Don't ignore your feelings. If you don't deal with them, they will deal with you. Find a person with whom you can honestly express your feelings and discuss your worries. This could be:

- a trusted family member, friend, or religious counselor
- another caregiver for a CAR T-cell recipient (find one through BMT InfoNet's Caring Connections Peer Support Program at bmtinfonet.org/caring-connection)
- a mental health professional (find one at bmtinfonet.org/ mh-directory)
- a Facebook group

Give Yourself the Credit You're Due

You are a vital member of the healthcare team working to help your loved one recover. Acknowledge the hard work you are doing and take pride in mastering many tasks that you once may have thought you could not do.

Sometimes, despite your best efforts, problems like an infection may occur or things don't go as planned. It can be easy to question yourself and wonder if something you did caused the problem.

Resist the urge to blame yourself. Like everyone involved in patient care, you are doing your best and not everything is within your power to control. Try to show yourself the same compassion as you would show to a friend.

FINANCIAL CONSIDERATIONS

CAR T-cell therapy is expensive. Many commercial health insurance plans pay for CAR T-cell therapy but some may limit coverage. Others may not cover it at all.

Medicare covers CAR T-cell therapy. Medicaid coverage varies depending on the state in which you live.



Before beginning CAR T-cell therapy, your medical team will contact your insurance provider to determine if it will pay for the treatment.

Be sure to tell the financial coordinator at the medical center about all insurance policies you have so that he or she can maximize your benefits.

Out-of-Pocket Expenses

Although your insurance provider may pre-approve payment for CAR T-cell therapy, some procedures may not be covered. You may also have deductibles and co-pays that add to your out-of-pocket expenses.

Prescription drugs and medical devices may or may not be covered by your plan. You may also need help with expenses such as food, lodging, travel, and parking.

Ask the financial coordinator at your medical center to help you estimate your out-of-pocket expenses. If you have been assigned a case manager by your insurance company, he or she may be able to help you estimate out-of-pocket expenses as well.

Ask your medical team if the pharmaceutical company providing your CAR T-cells has a financial assistance program to help defray the cost of the therapy and/or other expenses such as food and lodging.

You may be eligible for financial help from BMT InfoNet's Patient Assistance Fund. To learn more go to **bmtinfonet.org/patient-assistance-fund** or phone 888-597-7674.

For a list of other organizations that offer financial support go to page 40.

MEDICAL CENTERS THAT OFFER CAR T-CELL THERAPY

Your oncologist may recommend a medical center that provides CAR T-cell therapy or you can search for a center online.

BMT InfoNet's online Directory of CAR T-cell Centers lists medical centers that offer one or more CAR T-cell therapies approved by the U.S. Food and Drug Administration (FDA). To access the directory, go to **bmtinfonet.org/car-t-cell-directory** or phone 888-597-7674.



Clinical Trials

Researchers at some CAR T-cell centers are investigating CAR T-cell therapies that have not yet been approved by the FDA. These therapies may be available to you if you agree to participate in a clinical trial testing their safety and effectiveness.

For example, some centers are researching whether using CAR T-cells that are made from T-cells provided by a donor, rather than the patient, is safe and effective.

To find a list of CAR T-cell therapy clinical trials, contact the NMDP* Jason Carter Clinical Trial Program online at **ctsearchsupport.org** or call 888-814-8610.

The Leukemia & Lymphoma Society also has navigators who can help you find a clinical trial that's right for you. Go to **lls.org** or phone 800-955-4572,

Clinicaltrials.gov, a website hosted by the National Institutes of Health, provides details about clinical trials worldwide.



DOES CAR T-CELL THERAPY CURE CANCER?

Although no one can predict with certainty whether CAR T-cell therapy will cure you, it has helped many patients.

CAR T-cell therapy may:

- put you into complete remission (no evidence of disease) for many months or years
- put you into remission for a short period of time before your disease comes back
- put you into a partial remission (there is still evidence of disease, but the amount is less)
- not put you into remission at all

Talk to your doctor about how likely it is that CAR T-cell therapy will cure you or improve your health. It is important that you are carefully monitored by your oncology team long-term to ensure that relapse and other issues that can arise are caught early and treated promptly.

Watch videos about CAR T-cell therapy at bmtinfonet.org/video/car-t-cell-therapy

MORE RESOURCES

CAR T-cell Therapy Information Online

- BMT InfoNet (BMTInfoNet.org/car-t-cell)
- International Myeloma Foundation (**myeloma.org**) (search CAR T)
- Leukemia & Lymphoma Society (lls.org) (search CAR T)
- Lymphoma Research Foundation (lymphoma.org) (search CAR T)
- Multiple Myeloma Research Foundation (**themmrf.org**) (search CAR T)
- NMDP[®] (**NMDP.org**, search CAR T)

Directory of CAR T-cell Therapy Centers

bmtinfonet.org/car-t-cell-therapy-center-directory

Financial Assistance

- BMT InfoNet
 - o bmtinfonet.org/financial-aid
 - o Email: help@bmtinfonet.org
 - o 888-597-7674
- Bone Marrow & Cancer Foundation
 - o Bonemarrow.org
 - o Email: BMCF@Bone Marrow.org
 - o 800-365-1336
- Leukemia & Lymphoma Society
 - o lls.org/support-resources/financial-support
 - o 877-557-2672

Financial Assistance from the Company Providing Your CAR T-cells

- Abecma®
 - o celltherapy360.com/patients
 - o 888-805-4555
- Autolus®
 - o AutolusAssist.com
 - o 855-288-5227
- Breyanzi®
 - o celltherapy360.com/patients
 - o 888-805-4555
- Carvykti™
 - o carvykti.com/resources-and-support
 - o 800-559-7875
- Kymriah®
 - o Talk with your CAR-T team about accessing assistance.
- Tecartus®
 - o tecartus.com/resources-and-support
 - o 844-454-5483
- Yescarta®
 - o yescarta.com/support-and-resources
 - o 844-454-5483

Professional Mental Health Support

• BMT InfoNet' Mental Health Directory bmtinfonet.org/mh-directory

More Resources 41

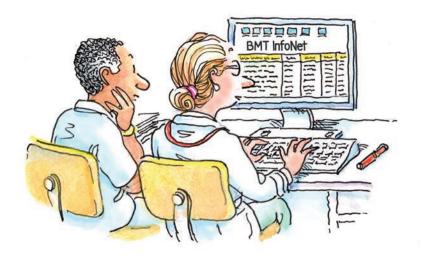
Peer Support

- BMT InfoNet's Caring Connections Program o bmtinfonet.org/caring-connection
- BMT InfoNet's CAR T-cell Support Group o Email: help@bmtinfonet.org for details

Videos

- CAR T-cell Therapy for Acute Lymphoblastic Leukemia bmtinfonet.org/video/CAR-T-2023/ALL
- CAR T-cell Therapy for Lymphoma bmtinfonet.org/video/CAR-T-2024/lymphoma
- CAR T-cell Therapy for Myeloma bmtinfonet.org/video/CAR-T-2024/myeloma
- Quality of Life after CAR T-cell Therapy bmtinfonet.org/video/QOL-CAR-T
- Being a CAR T-cell Caregiver bmtinfonet.org/video/being-caregiver-car-t-cell-therapy
- Transplant and CAR T-cell Therapy in Older Adults bmtinfonet.org/video/CAR-T-2024/older-adults





Visit bmtinfonet.org

Your gateway to up-to-date information about CAR T-cell therapy including:

- a list of medical centers that offer CAR T-cell therapy
- emotional support for CAR T-cell patients and their loved ones
- videos by leading experts about CAR T-cell therapy
- financial support

Let us know how we can help you!



BMT InfoNet

1548 Old Skokie Rd. Highland Park, IL 60035 USA phone 847.433.3313 toll-free 888.597.7674 fax 847.433.4599

help@bmtinfonet.org bmtinfonet.org
Follow us: facebook.com/bmtinfonet



