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What is CAR T Therapy?

CAR T therapy is a new treatment that uses the patient's own immune system to fight cancer.

Chimeric Antigen Receptor T-cell (CAR T) therapy is a new approach to fighting cancer using the patient's own immune system.

Certain immune system cells, called T-cells or T-lymphocytes, 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 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.

Millions of these CAR T-cells are created and then re-infused into the patient to fight cancer.

Who can receive CAR T therapy?

Two CAR T therapies are currently approved by the U.S. Food and Drug Administration (FDA) for treatment of patients with certain diseases:

- Kymriah® (tisagenlecleucel) for
 - children and young adults (up to 25 years old) with B-cell acute lymphoblastic leukemia (ALL)
 - adults with diffuse large B-cell lymphoma (DLBCL)
 - adults with transformed follicular lymphoma
- Yescarta® (axicabtagene ciloleucel) for adults with
 - diffuse large B-cell lymphoma (DLBCL)
 - primary mediastinal large B-cell lymphoma
 - high grade B-cell lymphoma
 - DLBCL arising from follicular lymphoma

You may be eligible for one of these two CAR T therapies if, after two or more rounds of conventional treatment, your cancer came back or stopped responding to treatment.

Research is underway to determine if patients with other types of cancer, such as multiple myeloma, other types of leukemia or lymphoma, and some solid tumors can also be helped by CAR T therapy.

How long does CAR T therapy take?

There are several steps involved in CAR T therapy:

- **collecting** your T-cells
- **converting** your T-cells into CAR T-cells at a special laboratory
- **growing** hundreds of millions of your CAR T-cells in the laboratory
- **preparing your body** for the CAR T-cells, usually with chemotherapy
- **infusing** the CAR T-cells into your body
- **monitoring** you for complications after treatment

CAR T therapy usually takes four-to-eight weeks from the collection of T-cells through follow-up care after the cells are infused.

How are T-cells collected?

The process used to collect your T-cells is called **leukapheresis**. The collection usually takes place in the outpatient clinic and can take four-to-six hours.

During your T-cell collection:

- you will sit in a comfortable chair or bed
- blood will be withdrawn from you and passed through a machine that separates out your T-cells
- the rest of your blood product will be returned to you

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.

How long does it take for the laboratory to create the CAR T-cells?

It can take three-to-six weeks to create enough CAR T-cells for you. During that time, you will undergo a series of tests to confirm you are healthy enough for an infusion of CAR T-cells. 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 the 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

You may also have a consultation with a social worker to address any emotional concerns you have, as well as issues such as managing expenses, transportation, and lodging. Finding resources to help you pay for transportation and lodging is very important if you do not live close to the treatment center.

The social worker will also discuss the important role of your family member or friend who will serve as your caregiver. You may be invited to attend a class for CAR T recipients and caregivers to help you better understand what to expect during and after treatment.

While your CAR T-cells are being created, your doctor may recommend that you have additional chemotherapy or radiation to prevent your disease from getting worse. Some patients are hospitalized for this treatment, while others can receive it in the outpatient clinic.

What happens when the CAR T-cells are given back to the patient?

A few days before your CAR T-cells are infused into you, you will receive chemotherapy to prepare your body to receive the new cells.

This process is called **lymphodepletion** and may cause:

- fatigue
- low blood counts
- nausea

The infusion of CAR T-cells usually takes place in the hospital where you can be carefully monitored. In some cases, the infusion takes place in the outpatient clinic.

You will be awake during the infusion. Your CAR T-cells will be returned to you much like a blood transfusion. The actual infusion typically takes 15-30 minutes.

Depending on which CAR T therapy you are receiving and whether complications develop after the infusion, you may need to remain in the hospital for several days or weeks.

Follow-up care after CAR T therapy

You will need to remain close to your medical center for at least four weeks after CAR T therapy.

- Complications can develop that may be severe, even life-threatening.
- You will visit the outpatient clinic frequently to be checked for side effects.
- It may be necessary to re-admit you to the hospital to treat complications.

Your dedicated caregiver will be trained to monitor you at home for potential problems.

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

- you will feel very tired
- you may not have much of an appetite
- you will not be permitted to drive a car or operate heavy machinery for at least eight weeks after treatment because CAR T therapy can cause sleepiness, confusion, weakness, and temporary memory and coordination problems

What are the side effects of CAR T therapy?

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

Two major side effects your healthcare team will carefully watch for are cytokine release syndrome (CRS) and neurotoxicity (also known as ICANS)

Cytokine Release Syndrome (CRS)

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

Cytokine release syndrome occurs in most patients after CAR T 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 or very low blood pressure
- low white or red blood cell count
- dizziness/lightheadedness
- fast or irregular heartbeat
- difficulty breathing/shortness of breath
- severe nausea, vomiting, diarrhea
- severe muscle or joint pain
- loss of appetite
- low oxygen levels
- swelling or fluid retention
- 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 your cytokine release syndrome is more severe, you may need to be treated in the intensive care unit and given a drug called tocilizumab (Actemra®), which is quite effective in managing this problem. Steroids or other medications may also be added if tocilizumab, alone, is unable to resolve the problem.

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

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

Neurotoxicity/ICANS

Neurotoxicity (also called immune effector cell-associated neurotoxicity syndrome or ICANS) is damage to the brain or nervous system. It is common after CAR T therapy and is usually temporary.

Neurotoxicity typically occurs a week or so after treatment, although it can occur weeks later as well. It almost exclusively develops in patients who have had cytokine release syndrome.

Symptoms of neurotoxicity may include:

- headaches, which may be severe
- difficulty speaking, slurred words, stuttering
- confusion/delirium
- anxiety
- difficulty staying awake
- dizziness
- difficulty paying attention
- loss of coordination
- weakness/shakiness
- changes in handwriting
- seizures
- swelling in the brain
- memory loss
- hallucinations

Depending on the severity of the neurotoxicity, your healthcare team may use supportive care to keep you comfortable until the problem resolves or give you medication to control it. The most common medication is steroids. In severe cases, you will be monitored and treated in the intensive care unit.

Although the symptoms of neurotoxicity can be frightening for you, your family and friends, 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.

Other side effects of CAR T therapy

In addition to cytokine release syndrome and neurotoxicity, some patients experience:

- prolonged low blood cell counts
- severe fatigue
- brain swelling (very rare)

A low white blood cell count weakens your immune system and increases your risk of developing a serious infection. A low platelet count increases your risk of bleeding.

Until your blood counts recover, you may need:

- blood or platelet transfusions
- growth factors - medicines to stimulate blood cell production
- intravenous infusions of immunoglobulins (IVIG) to help your body fight infection
- medicine to prevent infection

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

Severe fatigue can occur after CAR T therapy and may take weeks or months to resolve. You may need physical therapy to regain your strength, stamina and stability. Safe exercise, such as daily walks, can also help build stamina and strength.

Although very rare, brain swelling, which can be fatal, has occurred in some patients after CAR T therapy.

Why is a caregiver important for CAR T patients?

Although highly trained medical professionals will be caring for you during your treatment, a dedicated caregiver – usually a family member or friend - has a very important role to play in your recovery.

Complications after CAR T therapy can start with subtle symptoms that may appear normal to a healthcare professional who does not know you, but will raise alarm bells for someone who knows you well. If you develop 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 you help quickly.

There are also practical considerations after you are discharged from the hospital:

- You will not be able to drive a car for at least eight weeks after your CAR T therapy.
- You may be very fatigued for several weeks or months after CAR T therapy.
- Chores and work you normally perform may need to be handled by a loved one until you regain your strength and stamina.

Does CAR T therapy cure cancer?

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

CAR-T 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

In some cases, CAR T therapy is used as a "bridge" to other treatments, like a stem cell transplant, to reduce the amount of disease in your body.

Talk to your doctor about how likely it is that CAR T therapy will provide you with long-term health. Since your cancer may come back after CAR T therapy, it is important that you are carefully monitored by your oncologist long-term.

Will insurance pay for CAR T therapy?

Because CAR T therapy is so new, most commercial insurers are evaluating reimbursement on a case by case basis. Medicare does cover CAR T therapy, but at a rate below the actual cost to medical centers. Medicaid coverage varies, depending on the state.

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

There will be other expenses that insurance may not cover such as lodging, food, and transportation, even if you are receiving treatment far from home. Talk to your social worker or contact BMT InfoNet at 888-597-7674 or help@bmtinfonet.org (<mailto:help@bmtinfonet.org?subject=Financial%20help%20for%20CAR-T%20patients>) [1] for information about programs that may provide financial assistance for these expenses.

How to find a medical center that offers CAR T therapy

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

*CAR T therapies currently approved by the U.S. Food and Drug Administration (FDA) are offered at more than 100 medical centers throughout the United States. **Click here to find a CAR T therapy program** (<https://www.bmtinfonet.org/transplant-article/medical-centers-offering-car-t-therapy>) [2] near you.*

Several medical centers are investigating different CAR T 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. To find a list of CAR T clinical trials, phone the Jason Carter Clinical Trial Program at 888-814-8610 or [click here](https://www.jasoncarterclinicaltrialsprogram.org/filtered_search/index?disease=&age=&hasTransplant=0&phase1=true&phase2=true&phase3=true&page=1&per_page=8). (https://www.jasoncarterclinicaltrialsprogram.org/filtered_search/index?disease=&age=&hasTransplant=0&phase1=true&phase2=true&phase3=true&page=1&per_page=8) [3]

NEXT: Medical Centers Offering CAR T Therapy

Reviewed January, 2020 by Alix Beaupierre RN, BSN, OCN; Michael Bishop MD; Nelson Chao MD; Kevin J. Curran MD; Matthew Frigault MD; Ajay Gopal MD, FACP; Mark Juckett MD; Navneet Majhail MD, MS; Kenneth Miller MD; Miguel-Angel Perales MD; Steven Pavletic MD, MS; Craig Sauter MD

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Contact Us

Blood & Marrow Transplant Information Network (BMT InfoNet)

1548 Old Skokie Road Highland Park, IL 60035

Phone: 847-433-3313

Toll-free: 888-597-7674

help@bmtinfonet.org (<mailto:help@bmtinfonet.org>)

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[1] <mailto:help@bmtinfonet.org?subject=Financial%20help%20for%20CAR-T%20patients>

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[3] https://www.jasoncarterclinicaltrialsprogram.org/filtered_search/index?disease=&age=&hasTransplant=0&phase1=true&phase2=true&phase3=true&page=1&per_page=8.