



CAR T-Cell Therapy

A Booklet for Patients
and Caregivers

CAR T-cell (Chimeric Antigen Receptor T-cell) therapy is a very complex treatment. You may hear it simply as “CAR T.” It uses a patient’s own immune system and makes it more effective at attacking cancer cells. CAR T-cell therapy is a type of cancer treatment called immunotherapy. Collecting and changing the cells is difficult, and CAR T-cell therapy can cause very severe side effects. Currently, most of the patients treated with CAR T-cell therapy have been people with blood cancers. New CAR T-cell therapy treatments and new ways to use currently approved treatments are being studied in clinical trials.

This booklet provides basic information about CAR T-cell therapy. If you think that this treatment might be right for you or your loved one, you should discuss this with your doctor.



For more information about CAR T-cell therapy, visit www.CancerSupportCommunity.org/CAR-T-Cell-Therapy.

WHAT IS IMMUNOTHERAPY?

Immunotherapy (IO) is a newer way to treat many kinds of cancer. There are different kinds of immunotherapy. They all work by using your body’s own defenses to identify and attack cancer cells. Some immunotherapies can boost your overall immune response. Others can help your immune system recognize cancer cells more clearly so it can fight them. The drugs used in immunotherapy may be made from natural substances produced by your own body, or from substances created in a lab. T-cells are one important component of your immune system that help fight infections or foreign cells. Your immune system works in many ways to identify unhealthy cells and attack them.

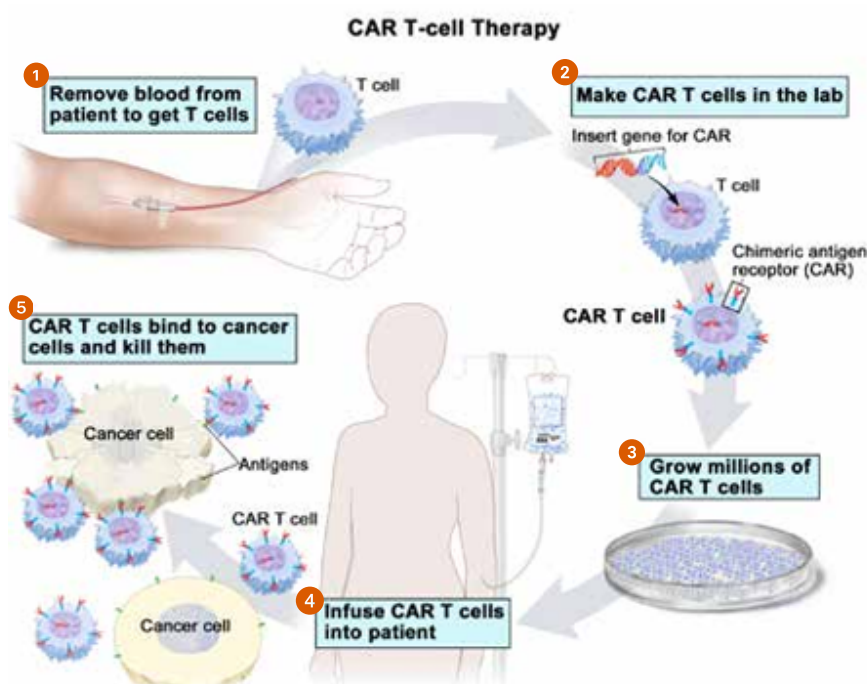


WHAT IS CAR T-CELL THERAPY?

CAR T-cell therapy removes some of the T-cells and changes them to make them better able to fight cancer. These improved T-cells are then returned to your body to find and attack the cancer. Some researchers have called these re-engineered (or improved) cells “a living drug” because they can keep working in the body over time.

Every patient who is undergoing CAR T-cell therapy receives CAR T-cells created in the lab just for them. **It works like this:**

- 1** T-cells are collected from your bloodstream in a procedure called apheresis. Apheresis (AY-fuh-REE-sis) is a procedure where a specific part of your blood, T-cells in this case, are separated and then the rest of the blood is returned. The T-cells may be frozen until you are ready to receive treatment.
- 2** CARs, which act like a cancer-cell tracking device, are added to your T-cells in the lab. After the CAR is added, your T-cells become CAR T-cells. Now, they can easily find and destroy cancer cells.
- 3** The new CAR T-cells are then grown in a lab. This process can take days to weeks.
- 4** The CAR T-cells are then infused, or delivered through an IV, back into you. Many patients receive a brief course of chemotherapy before getting the CAR T-cell infusion. Chemotherapy involves the use of drugs to destroy cancer cells. It is a systemic (whole body) treatment. In CAR T-cell therapy, chemotherapy may be done to destroy other immune cells and give the new cells more room to operate.
- 5** Once they are back in your bloodstream, the CAR T-cells attack your cancer.



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T-cells are the immune system's fighters. They are white blood cells formed in the thymus gland. They circulate throughout the body seeking out and attacking any abnormal cells or substances. Many kinds of immunotherapy activate or boost T-cell activity.

MONITORING FOR SIDE EFFECTS

Once your CAR T-cell infusion is complete, you will be closely monitored for side effects. This may occur in the hospital or as an outpatient. The length and location of this monitoring will depend on how your body responds to the treatment and what is available at your center. You will likely need to stay within a 10–30-minute drive of the treatment site for at least 2 to 4 weeks, which may vary by care center. During this time, you must have a caregiver with you around the clock for the first month. This is because some side effects can be serious and need quick attention.

If staying nearby is challenging due to travel or cost, ask your care team about support services or financial help. They can connect you with a social worker or patient navigator for assistance. Overall, the complete CAR T-cell therapy process can take about three months. Even after the initial follow-up, you may need extra monitoring depending on how you feel and how your body responds. Watch closely for any new symptoms like fever, chills, or headaches, and talk to your care team about everything you notice. Your care team may restrict you from driving for at least two weeks. This is a reason why a caregiver is especially important for travel and support. Once you are ready, you can return home and follow up with your local oncologist as directed by your CAR T care team.



What does CAR T stand for?

CAR T-cell therapy is one way to use the body's natural defenses to fight cancer. It is called CAR T-cell therapy because a lab-made protein, a CAR protein, is added into your own T-cells. The CAR protein helps T-cells target cancer cells and attack them.

CAR stands for:

Chimeric (ky-MEER-ik)

The CAR protein is called “chimeric” because scientists modify it to get the T-cell to do what they want.

Antigen

Antigens are proteins on the cancer cell that the T-cells are engineered to target. In general, the immune system works by recognizing cells with abnormal antigens and attacking them.

Receptor

The CAR protein, which is added to the surface of the modified T-cell, functions as a receptor. A receptor is like a lock on a cell that fits a specific key. These receptors then search for the matching antigen on a cancer cell so the T-cell can destroy it.

T-cells

Modified T-cells are this therapy's primary weapons.



IMPORTANCE OF CAREGIVERS

A caregiver or team of caregivers are very important in CAR T-cell therapy. They can assist with symptom monitoring, travel to appointments, and care team communication. Depending on your experience with the infusion, it may be recommended to have a caregiver during and immediately after your infusion. Make sure you speak with your care team at the CAR T-cell therapy center for their guidelines. It is important to know the details about caregiving, travel, and lodging during the therapy process.

CARING FOR CAR T CAREGIVERS

You play an integral role in providing care for your loved one. For CAR T, care teams rely on caregivers to watch for new or changing symptoms and provide ongoing support. The stress that comes with navigating the CAR T-cell therapy experience can lead to a variety of emotions. At times, you may feel like you have too many responsibilities between caregiving and your everyday life. **You are not alone in feeling the emotional effects of this role.** It is natural to feel frustrated, overwhelmed, and tired at times. Identify who is in your support network and ask the care team for resources and support group options. Also, consider connecting with a therapist, social worker, or psychologist to share your experience.

Being a caregiver is an important role. It is rewarding, yet the responsibilities can often be stressful and take up a great deal of time. Throughout caregiving, it is important to take care of your own physical and emotional health. Addressing your ongoing psychosocial health is essential for you to provide long term caregiving.

For more tips on caregiving, visit www.CancerSupportCommunity.org/Caregivers.

ARNOLDO'S TESTIMONIAL

In early 2019, a diagnosis of stage 3 follicular lymphoma sidelined me in a major way that led to my retirement ahead of my planned schedule. While I knew I could conquer this cancer, since I had successfully survived prostate cancer in 2010 with prostatectomy surgery, this proved to be a much more difficult journey riddled with a variety of setbacks and challenges.

Over the course of three years and several courses of different chemotherapies, I experienced two relapses.

In late 2021, with my most recent relapse, my doctor notified me that the hospital had been approved for a new CAR -T-cell therapy clinical trial with patients who had relapsed or refracted. I was told that I was an ideal candidate for the clinical trial and that I would be the first candidate to qualify.

The data seemed very promising, and the hospital provided me as much information on it as I needed to learn about the process. I also spoke to patients at the hospital who had received or were in the process of receiving the therapy. Everyone I spoke to raved about the treatment and their progress. While the possible side effects sounded a bit scary, my wife, who would serve as my caretaker, and I decided this was the best treatment option for me.

There were several adjustments we needed to make for the CAR T-cell therapy process to begin. We reside a five and a half hour drive from the hospital. As such, my wife and I had to make housing arrangements. We were contacted by the hospital social services department who offered their assistance and provided us with a list of possible apartments who offer free or low-cost rentals to hospital patients, some specifically for lymphoma patients. My CAR T-cell infusion required that I stay at the hospital for seven days so that doctors could monitor for side effects and check blood counts and progress daily.

My only side-effect was a headache that I experienced on my last hospital day. Once released from the hospital, I would have to go to the lymphoma clinic several times per week for monitoring of vitals, blood counts, and progress. My final PET scan in January 2022 showed that I was in full remission, which continues to this day almost four years later. I am now a survivor and understand the new normal that follows any cancer diagnosis.



IS CAR T-CELL THERAPY RIGHT FOR ME?

CAR T-cell therapy is an approved treatment option for patients who have certain blood cancers. It has been used when the cancer is refractory (the cancer has not responded to previous treatment) or relapsed (the cancer has returned) after having two or more prior treatments.

Patients eligible for CAR T-cell therapy include:

- Children and adults with B-cell acute lymphoblastic leukemia (B-ALL)
- Adults with large B-cell lymphoma or follicular lymphoma who have had 2 or more unsuccessful treatments where the cancer did not respond or has returned
- Adults with mantle cell lymphoma (MCL) who have not responded to other kinds of treatments or whose cancer has returned after previous treatments
- Adults with multiple myeloma who have had 4 or more unsuccessful treatments where the cancer did not respond or has returned

Please note: this list of patients who are eligible to receive CAR T-cell therapy continues to change as cancer care advances.

Clinical trials will work to include CAR T-cell therapy as a treatment option for other cancer types. **If you are a patient or caregiver interested in learning more about CAR T-cell therapy, talk to your doctor.** CAR T-cell therapy is available at more than 150 cancer centers in the United States. If you do not live near a CAR T-cell therapy center, ask whether there is a patient assistance program available to pay for travel costs.



SIDE EFFECTS OF CAR T-CELL THERAPY

The side effects of CAR T-cell therapy may be very serious. This is a reason why CAR T-cell therapy is done only at experienced medical centers that have a team of physicians, nurses, and support staff with the expertise to manage any side effects. Patients are carefully monitored for side effects after their CAR T-cell infusion. The majority of patients will be in the hospital during the early part of their CAR T-cell therapy.

Everyone receiving CAR T-cell therapy will receive a course of chemotherapy beforehand to prepare their body to receive the CAR T-cells. Talk to your CAR T care team about the chemotherapy side effects you could experience.

CAR T-cell therapy usually requires just one infusion. This may result in a shorter treatment time overall. CAR T-cell therapy has been shown to lead to prolonged remission and fewer side effects. This makes for a better quality of life for many patients. The most common short-term side effects of CAR T are cytokine release syndrome (CRS), neurotoxicity, and ICANS (immune effector cell-associated neurotoxicity syndrome).



CYTOKINE RELEASE SYNDROME (CRS)

CRS occurs when the immune system is put into overdrive after the CAR T-cell infusion. As a result, cytokines are released. Cytokines are small proteins that control blood cells and other cells in the immune system. Symptoms can develop if a large number of cytokines are released into the body.

Common symptoms of CRS include:

- Fever (CRS usually begins as a fever first)
 - Chills
 - Tiredness
 - Nausea and vomiting
 - Diarrhea
 - Body aches
-

Patients who have more cancer in their body are more likely to have severe CRS than patients with less cancer in their body. It is a sign that the treatment is working and that there is a positive response.

The worst symptoms usually occur in the first days or weeks of treatment. As the number of cancer cells goes down, the symptoms tend to go down as well. Doctors use a variety of medicines to help manage these issues and get patients through the first phase of treatment. These include steroids and medications that can directly block the action of cytokines.

Researchers are working on ways to minimize the chances of CRS occurring.

NEUROTOXICITY

Neurotoxicity is damage to the brain or other parts of the nervous system. Damage can be temporary if caught early. Symptoms of neurotoxicity can vary from patient to patient. The severity and onset of these symptoms may also vary depending on the type of treatment you receive. Symptoms may happen earlier or be delayed long after CAR T-cell therapy.

Some of the most common symptoms include:

- Headache
- Tremor (part of the body shakes or trembles)
- Change in behavior
- Trouble having a clear conversation
- Change in personality
- Trouble keeping attention or showing confusion

ICANS (IMMUNE EFFECTOR CELL-ASSOCIATED NEUROTOXICITY SYNDROME)

Another common side effect is ICANS. This stands for immune effector cell-associated neurotoxicity syndrome. It typically starts within 7 days of CAR T treatment and can range in severity and symptoms. Milder symptoms may include mild confusion and handwriting difficulty. More serious signs may include seizures or coma.

OTHER SIDE EFFECTS

Certain CAR T treatments can cause delayed neurologic side effects, occurring weeks to months after treatment. Your treatment team will talk to you about these delayed side effects if they apply in your case.

In rare cases, CAR T treatment can cause a severe overreaction of the immune system called HLH (hemophagocytic lymphohistiocytosis), which typically occurs after CRS. This can be severe and requires treatment with steroids, cytokine blockers, and sometimes chemotherapy to calm the inflammation.

Your immune system will be weakened by CAR T treatment. This can last for months to years after CAR T treatment. Talk to your treatment team about how to best manage this.

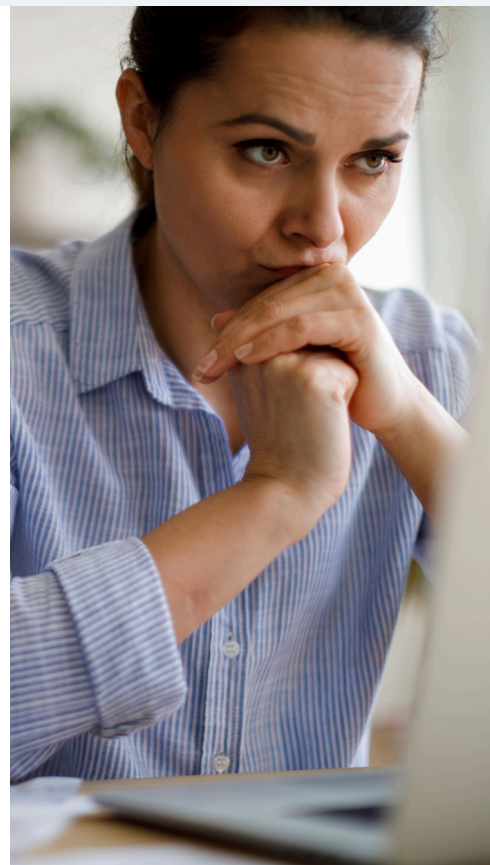
Patients who respond to CAR T-cell therapy and get beyond the initial side effects often have few or no long-lasting side effects. However, some patients may have long-lasting side effects from their other treatments. Some patients respond to CAR T-cell therapy and then relapse with time.

Most side effects can be managed if they are treated early. **Anytime you notice new symptoms or side effects during or after treatment, let your care team know right away.** There are no “silly” questions, and speaking up early helps keep you safe and healthy. Always feel empowered to ask your doctor or nurse about what to watch for. **Remember, they are there to answer your questions and support you throughout the entire process.**

CAR T-CELL THERAPY COST

CAR T-cell therapy is complex and can be an expensive cancer treatment. **If you are concerned about the cost of treatment, let your care team know.** They may be able to connect you with a financial counselor or patient navigator. Ask if your insurance will cover the drug and hospital costs. Ask if you qualify for this therapy as part of a clinical trial where the drug cost is covered. You may have to travel long distances to get this therapy. Ask if you can get assistance to cover travel, lodging, and food costs for you and a caregiver. Connecting with patient advocacy organizations, like the Cancer Support Community, can help. These organizations can connect you to patient assistance programs to help pay for travel costs and other support resources.

Visit www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment for more help on coping with cancer costs.



CANCER SUPPORT COMMUNITY CAR T-CELL THERAPY CONCIERGE PROGRAM

Our CAR T navigators are licensed clinical social workers who are oncology-trained to provide education, resources, and emotional support. They provide these services to people with cancer who are considering or are actively being treated with CAR T-cell therapy. The CAR T navigator can act as a liaison between your local treatment center and the CAR T treatment center, guiding you and your caregiver through the process. The CAR T navigator is available to follow your therapy process for up to one year after the infusion. This program provides free personalized navigation for both patients and caregivers. **If you have any questions or need additional support during the CAR T-cell therapy process, call Cancer Support Community's CAR T Helpline at 844-792-6517.**

GETTING SUPPORT

Patients who get CAR T-cell therapy and their caregivers receive a high level of support from their cancer centers during the process.

If you are considering CAR T-cell therapy, you should:

- Have an open and honest discussion with your care team about your cancer and its treatment
- Be willing to change doctors or travel to a different cancer center, if your current cancer center does not offer CAR T-cell therapies or CAR T-cell clinical trials
- Have a caregiver who can provide physical and emotional support before, during, and after the treatment

You can find support and additional materials about immunotherapy from the Cancer Support Community's Helpline as well as your local CSC or Gilda's Club.

RESOURCES

CAR T-CELL THERAPY RESOURCES

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Car-T-Cell-Therapy

Cancer Support Community CAR T Navigation

844-792-6517

American Cancer Society- CAR T-Cell Therapy

800-227-2345 | www.Cancer.org

BMT InfoNet

BMTInfoNet.org/Directory-Car-T-Cell-Therapy-Centers

Bone Marrow & Cancer Foundation

800-365-1336 | www.BoneMarrow.org

Blood Cancer United

800-955-4572 | BloodCancerUnited.org



Search for CAR T-cell Therapy Clinical Trials

Ask your doctor about clinical trials that might be available. If a trial is “open to accrual,” it means the trial is accepting new patients. Each trial will have inclusion criteria. These are certain factors that you need to enter the trial. Exclusion criteria are certain factors that you cannot have. Please review these with your care team. www.ClinicalTrials.gov.

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC’s toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11 am–8 pm ET and Fri 11 am–6 pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda’s Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda’s Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda’s Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more

www.CancerSupportCommunity.org/FindLocation

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org

MyLifeLine® — CSC’s secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our network at www.CancerSupportCommunity.org/Become-Advocate

This publication is available to download and print yourself at www.CancerSupportCommunity.org/CAR-T-Cell-Therapy.

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

This current publication was made possible through generous support from: **Kite**

(Previous support was received from Novartis & Bristol Myers Squibb)

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