

Section 1

CAR T Cell Therapy Basics

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What is CAR T Cell Therapy?

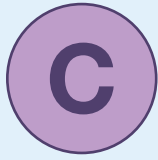
What Does CAR T Stand For?

CAR T cell therapy, or Chimeric Antigen Receptor 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, called a chimeric antigen receptor (CAR), is added to the patient's own T cells, which are a type of white blood cell found in your immune system. The CAR protein helps T cells target cancer cells to be killed and helps train your immune system to attack the cancer.

“We have figured out a way for your T cells to be modified to learn how to recognize cancer cells in the same way that they do a virus and bacteria. We are giving these cells the eyes they need to be able to see the cancer cells.”

—Lizzy Weber, RN, Cellular Therapy Coordinator, Penn Medicine

CAR T STANDS FOR:



CHIMERIC

The CAR protein is called “chimeric” (pronounced ky-MEER-ic) because scientists add this protein to your T cells to get it to better recognize cancer cells. In Greek mythology, a “chimera” was an animal with a lion’s head, a goat’s body, and a serpent’s tail. So “chimeric” means something has parts of different origins. In biology, a chimera is an organism that has a mixture of genetically different cells.



ANTIGEN

Antigens are proteins on the cancer cell that help T cells recognize the cancer cell as something to attack. In general, the immune system works by finding cells with abnormal antigens and attacking them.



RECEPTOR

The CAR protein, which acts like a cancer-cell tracking device, is added to the altered T cell. With the CAR protein added, your T cells become CAR T cells. They can more easily find and destroy cancer cells. The CAR acts as a receptor. These receptors then search for the matching antigen on a cancer cell so the T cell can destroy it.



T CELL

These white blood cells are a normal part of your immune system. They roam throughout the body to seek out and attack viruses, bacteria, and abnormal cells like cancer. In CAR T cell therapy, these T cells are altered to better find and attack cancer cells.

What is CAR T Cell Therapy?

CAR T cell therapy, or CAR T, is a type of cancer treatment that helps your immune system see and kill cancer cells. This type of treatment is called immunotherapy. The U.S. Food and Drug Administration (FDA) approved the first CAR T therapy in 2017. CAR T is an approved treatment option for patients who have multiple myeloma and certain types of leukemia and lymphoma. CAR T is not a first line treatment. Patients who receive CAR T have usually had two or more previously unsuccessful treatments. To learn more about approved CAR T drugs, visit www.CancerSupportCommunity.org/CART.

At first, CAR T treatments were only available at a few cancer centers. Now more than 150 cancer centers in the U.S. offer CAR T cell therapy. Your oncologist may work at a cancer center that has a CAR T program. If not, they may refer you to a

program at another cancer center. This center may be near you or in another city or state. To get CAR T, you may need to be away from home for several months at a time.

You may have read or heard that all people who get CAR T are “cured.” This is not true. For some people, the treatment works very well. Some patients can enter remission with CAR T therapy. Remission means that the signs and symptoms of cancer are gone, and the cancer has disappeared from blood or bone marrow. Some of these patients may ultimately be cured, but unfortunately some do later suffer relapse. Alternatively, some do not respond fully and look for other treatment options. For other patients, it doesn’t work at all. To see if this treatment is right for you, your primary oncologist will refer you to a treatment team that offers CAR T. This guide can help you and your caregivers at each step of the CAR T cell therapy process.



“I think what CAR T gives so many people is hope—the hope that maybe this will work. After exhausting all possible treatment options, maybe using my own immune system to fight the cancer will work.”

—Kristin, CAR T patient

MORE WORDS TO KNOW

APHERESIS

A procedure that allows white blood cells to be removed from the bloodstream, while the rest of the blood (red blood cells, platelets, plasma) is returned to the patient.

BRIDGING THERAPY

Treatment you receive between apheresis and infusion of CAR T cells. Bridging therapy tries to keep the cancer under control so you remain healthy enough to get your CAR T infusion. Most often, the therapy is chemotherapy, but radiation is sometimes used. Bridging therapy is not needed for everyone.

CAR

A protein that can help T cells, a type of white blood cell, target cancer cells to be killed.

CAR T CELLS

After your T cells are altered to add the CAR protein to them, the altered cells are called CAR T cells.

CONDITIONING CHEMOTHERAPY

A low dose of chemo given a few days before CAR T infusion to make room for your new CAR T cells.

CYTOKINE RELEASE SYNDROME (CRS)

A side effect of immunotherapy that can cause a wide range of symptoms, often starting with a fever. If not treated quickly, CRS can become life-threatening.

IMMUNOTHERAPY

A type of therapy that uses your body's natural defenses (the immune system) to identify, attack, and kill cancer cells.

NEUROTOXICITIES (OR NEUROLOGIC TOXICITIES)

Side effects of the brain and central nervous system.

How Does CAR T Work?

Your immune system is your body's natural defense against disease. It is made up of different types of white blood cells. T cells, or T lymphocytes, are one type of white blood cell. They are your immune system's "fighters." Their job is to seek out and attack viruses, bacteria, and abnormal cells like cancer. They are called "T" cells because they grow in the thymus gland, which sits in the space between your lungs. B cells, or B lymphocytes, are another type of white blood cell. They are called B cells because they grow in your bone marrow.

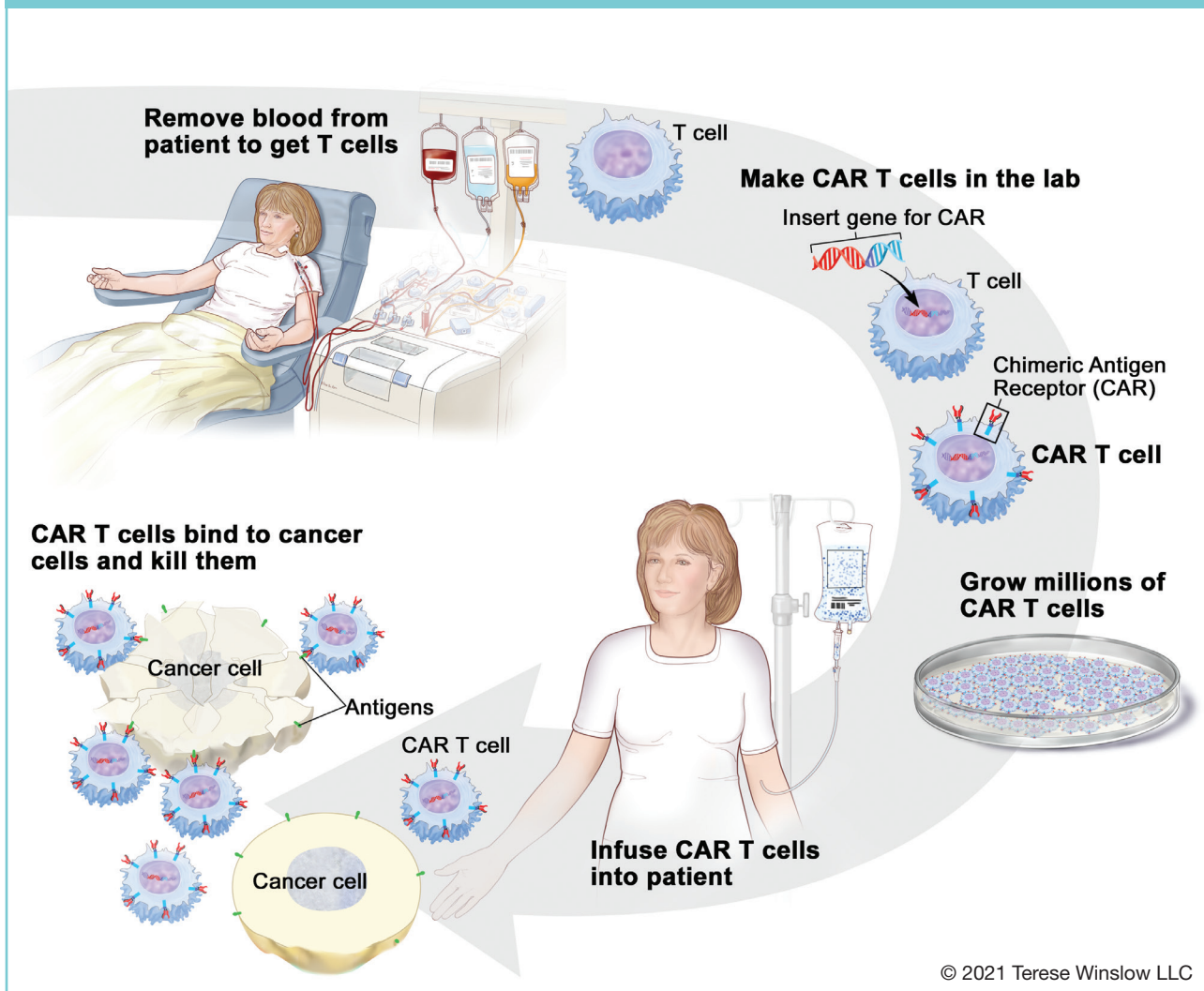
Cancer cells start out as normal cells. But once they become cancerous and start growing out of control, your T cells are not always able to see the cancer cells as a threat and attack them. CAR T helps your T cells find and kill your cancer cells.

CAR T is designed to be a one-time treatment. CAR T cells can remain in the body and continue to be active for a long period of time. After you get the new CAR T cells, you will need a caregiver to be with you 24 hours a day, 7 days a week (24/7), for 4–8 weeks, to support and watch for side effects.

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

- T cells are collected from your bloodstream in a fairly simple procedure called apheresis. The T cells may be frozen and kept at the hospital or CAR T center in a special temperature-controlled storage unit until you are ready to receive treatment.
- The T cells are sent to a lab. Chimeric antigen receptors (CARs), which act like a cancer-cell tracking device, are added to your T cells in a complex lab process. With the CAR added, your T cells become CAR T cells. They can more easily find and destroy cancer cells.
- You may get a treatment between apheresis and the infusion of CAR T cells called "bridging therapy." This is to keep the cancer under control while waiting for the CAR T cells to be made in the lab. It will hopefully keep you healthy enough to get your CAR T infusion. Most often, the therapy is chemotherapy or steroids, but radiation is sometimes used.
- The new CAR T cells are grown in the lab for a couple of weeks to make enough CAR T cells for your treatment. Once enough CAR T cells have been grown, they are sent back to your treatment team.
- You will get a brief course of chemotherapy called "conditioning" or "lymphodepleting" chemotherapy before getting the CAR T cell infusion. This is done to destroy regular T cells and give the new CAR T cells more room to operate.
- The CAR T cells are then infused back into you. If there are no delays, the process from apheresis to infusion can take 3–6 weeks.
- Once the CAR T cells are back in your bloodstream, they find and attack your cancer.

CAR T CELL THERAPY



“CAR T cells directly harness the power of a patient’s own immune system against the cancer. We put a new receptor on the T cells so they will target the cancer cells. We make them ‘bionic.’ And then we reinfuse those cells back into their body.”

— Dr. Jeremy Abramson, Director of the Hagler Center for Lymphoma at Massachusetts General Hospital

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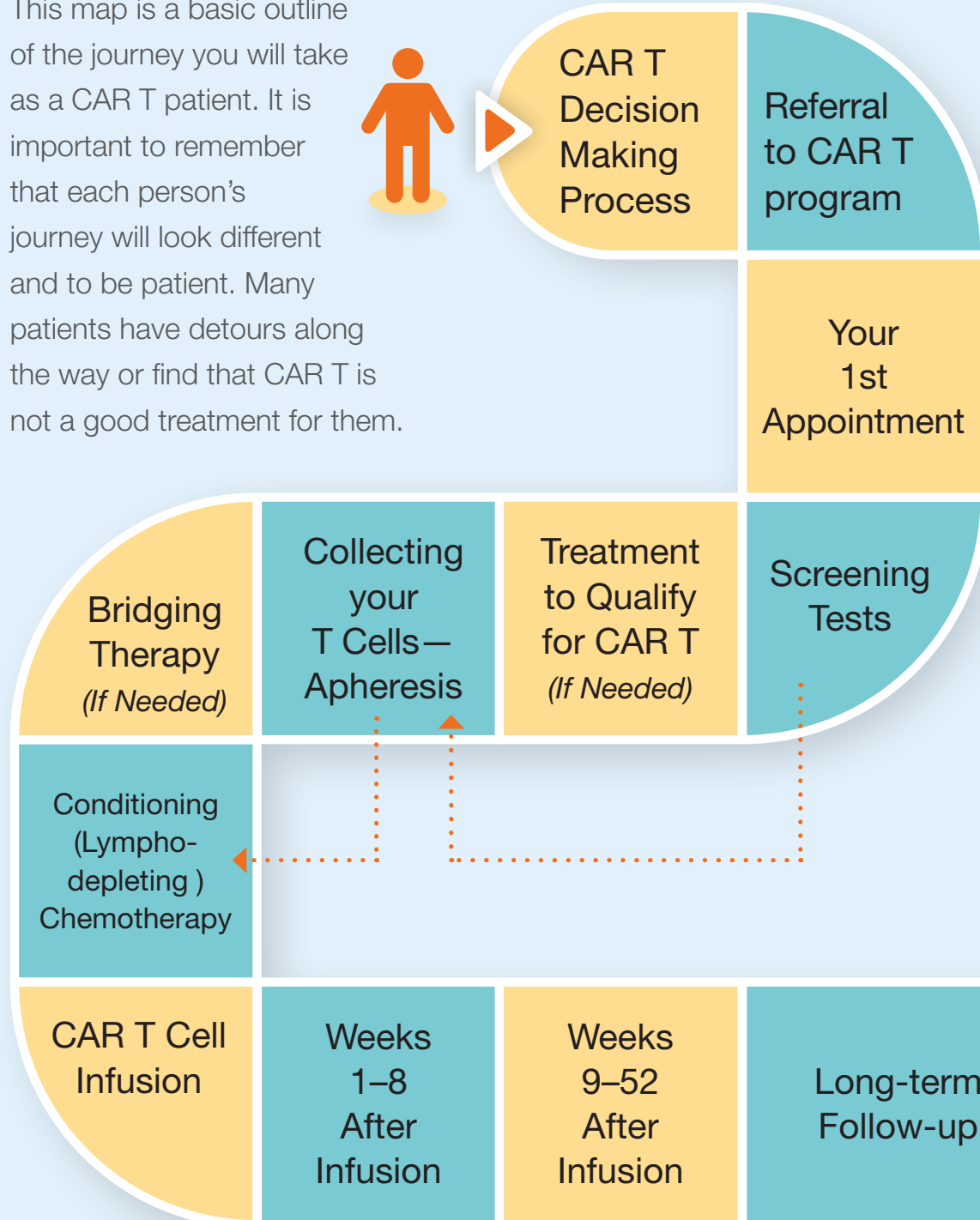
Outline of CAR T Journey

Since CAR T therapy is a process, it is important to follow all steps recommended by your health care team. It is not advised to go to the emergency room or any health care provider's office to request treatment without being referred.

On the next page is a basic outline of a patient's journey, if approved for CAR T therapy. Use the worksheets in Section 3 (pages 142–153) to fill in dates of what you can expect your timeline to look like. You can ask your health care team to help you.

CAR T Patient Journey Map

This map is a basic outline of the journey you will take as a CAR T patient. It is important to remember that each person's journey will look different and to be patient. Many patients have detours along the way or find that CAR T is not a good treatment for them.



The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

CAR T Journey

CAR T DECISION MAKING PROCESS

Choosing to go through CAR T cell therapy is a big decision. There is a lot to consider in deciding if this therapy is right for you. You may be able to explore CAR T therapy at the cancer center where you are currently being treated, or you may be referred to another center that offers CAR T. Choosing to go through CAR T therapy may mean traveling long distances, will require significant caregiver support, and can be costly. Some clinical trials cover all or portions of the costs, such as imaging studies, biopsies, apheresis, CAR T cell production, and hospital stays. Distance, time, and cost are all things to consider in the decision-making process.

REFERRAL TO CAR T



Your primary oncologist refers you to a CAR T program to discuss an FDA-approved CAR T therapy or a clinical trial. If you seek a second opinion at a cancer center, you may learn of CAR T that way.

FIRST APPOINTMENT



Your first appointment allows you to learn more about the cancer center's CAR T program. This appointment will also help the cancer center decide if CAR T is right for you. The treatment team will do some screening tests to make sure you are eligible and healthy enough to go through the treatment.

SCREENING TESTS



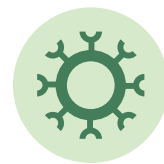
During your first appointment with the CAR T team, you will have screening tests to see if this is a good treatment option for you. Additional screening tests may be broken into multiple appointments during your first visit. Timing of your first appointment and screening tests may vary based on the center's availability and the health care provider's schedule.

TREATMENTS TO QUALIFY FOR CAR T (IF NEEDED)



You may need treatment to become healthy enough to participate in CAR T therapy. These kinds of therapies may cause month-long waits before you start the CAR T therapy process. Even if you are healthy enough at this point in the process to start CAR T, you may need bridging treatment to stay healthy long enough to get to the "Infusion" step of CAR T therapy.

COLLECTING YOUR T CELLS FOR APHERESIS



During apheresis you will be hooked up to a machine where your T cells will be separated from your other blood cells. After apheresis, your T cells will be sent to the lab where the "CAR" antigen will be added. The apheresis procedure will take a few hours.

BRIDGING THERAPY (IF NEEDED)



Bridging therapy is cancer treatment given at any step before CAR T infusion to keep you healthy enough to get to infusion. You may need to get bridging therapy multiple times throughout your journey, or you may not need bridging therapy at all. Each round of bridging therapy can last 1 or more months, but in some cases, it may only span 1–2 weeks.

CONDITIONING CHEMO



Before CAR T infusion, you will have conditioning chemotherapy (also known as lymphodepleting chemotherapy) to make room for your new CAR T cells. Conditioning chemotherapy is most often 3 days of chemo and 2 days of rest. However, the timeframe may vary if you are in a clinical trial.

CAR T CELL INFUSION



At infusion, the new CAR T cells will be infused into your bloodstream. The CAR T cells will begin to find and attack the cancer cells in your body. Depending on your CAR T treatment, you may need to go to the hospital to receive the infusion. If it can be done in an outpatient clinic, the infusion appointment may take 20–30 minutes based on your health care team and facility.

WEEKS 1–8 AFTER INFUSION



CAR T infusion can cause side effects. If you are receiving CAR T as an inpatient, you may have to stay in the hospital for up to 1 week following the infusion. If you are receiving CAR T as an outpatient, you can leave the hospital after the infusion. When you leave the hospital, you will need to be monitored closely by your caregiver and stay near the treatment center for at least 4 weeks after infusion. You may need to return to the hospital if you experience serious side effects.

WEEKS 9–52 AFTER INFUSION



You will need to follow-up with the CAR T treatment team, your primary oncologist, or other specialists that understand your specialized needs after the treatment is complete. Your doctor will likely use PET and CT scans to determine whether the therapy worked. If the therapy worked, most often, you will have monthly lab tests or appointments for the first year after infusion. Then, you may have annual appointments for up to fifteen years after infusion.

What Happens if CAR T is Not Right for Me?

Before you can start CAR T therapy, the CAR T center will need to make sure you are healthy enough to go through the therapy. Throughout the process, your CAR T doctor will pay attention to your health. It is possible that your doctor will decide you are not a good fit for CAR T. If that happens, you may wonder what's next. There are other options you can consider.

Sometimes, it may be that you are not a good fit for CAR T right now and you need to go through bridging therapy. Your CAR T doctor will recommend the best bridging therapy for you. The point of bridging therapy is to help you become healthy enough to go through CAR T.

Another option to explore is whether you are a better fit for another CAR T treatment. There are several CAR T drugs available. Or you may want to think about joining a clinical trial for a CAR T drug that is being developed. There

are also clinical trials studying other new approaches that may be a better fit for you. In some cases, it may be that you were referred to CAR T too late and you don't have the time to wait for your CAR T cells to be made. You will need to talk to your doctor about other treatment options or maybe look into hospice care.

You may also decide that you do not want to get CAR T treatment. CAR T requires a large investment of time, energy, and usually money for both you and your caregiver. There are also some serious and potentially life-threatening side effects from CAR T. You may decide that CAR T does not match your goals for your treatment plan.

These can be hard decisions to make. To help you decide your next steps, you can use our **Making Treatment Decisions** publication and our **Open to Options** program.

Need Help Deciding Between Treatments? Need Help Deciding if You Want to be Considered for CAR T Therapy? Need Help Deciding Between Aggressive Treatment and Palliative Treatment?

Open to Options® is a free telephone or in-person counseling program provided by trained professionals at the Cancer Support Community. It helps you to:

- Talk about your concerns more clearly to your health care team
- Create a list of questions for your health care team that will help you address your specific needs
- Organize your questions for specialists to help you get the most helpful answers from the right people

Call 844-792-6517 to schedule an appointment or visit **www.CancerSupportCommunity.org/OpenToOptions**.



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CAR T Clinical Trials

CAR T Clinical Trials

Clinical trials are research studies with patients. They are a chance for you to play an active role in healthcare and research, while also helping future patients. The goal of cancer clinical trials is to improve treatments and the quality of life for people with cancer. Your doctor may refer you to a CAR T clinical trial, or you may be interested in finding one on your own. Getting into clinical trials can be complicated and complex. Several cancer nonprofits offer free patient navigators to help you search for clinical trials.

Clinical trials for CAR T can test for different things. Some clinical trials are testing if an already-approved CAR T therapy works in other types of cancers. Others are testing a new type of CAR T therapy. Depending on the type of cancer you have, clinical trials may be the only way for you to receive CAR T therapy. There are also clinical trials that study the management of side effects.

Scientists are trying to discover new and different ways to provide CAR T therapies and other cell therapies. Some of these new approaches include “off-the-shelf” CAR T, TIL, T cell banking, and CAR NK cell therapy.

OFF-THE-SHELF CAR T CELL THERAPY

Instead of using the patient’s own T cells, this type of CAR T therapy uses donated healthy T cells from others. These T cells have the CAR protein added to them, which makes them CAR T cells. This type of CAR T therapy is also known as “allogeneic CAR T.”

TUMOR-INFILTRATING LYMPHOCYTE (TIL) THERAPY

This is another type of immunotherapy that uses your own T cells. This therapy removes T cells from the tumor that already find and attack cancer cells. These T cells then have special substances added to them to help them grow more quickly and are then added back into your body. These specific T cells are used because they have shown that they can survive and recognize cancer cells. There just may not be enough of them to make them as effective as they can be.

T CELL BANKING

This is a process that allows people to extract their T cells before they need CAR T. This is usually before they have relapsed (cancer has returned) or refractory (cancer doesn’t respond to treatment) disease and have been exposed to multiple lines of therapy.

CAR NK CELL THERAPY

Much like T cells, natural killer cells (or NK cells) are part of our immune system and help fight and attack foreign cells and

threats. When cancer cells are present, NK cells are not able to work as effectively. This type of therapy adds the CAR protein to the NK cells, to create CAR NK cells. Similar to off-the-shelf CAR T cell therapy, these can potentially be collected from healthy donors.

KEY FACTS ABOUT CLINICAL TRIALS

- People who get their treatment through a clinical trial receive high quality care.
- There are rules about who can join each trial, so they are not available for every patient.
- There are laws to protect the safety of people who join clinical trials.
- No one receives a placebo or “sugar pill” in place of appropriate treatment.
- People who join clinical trials can voluntarily leave at any time and for any reason.
- Some clinical trials may require you to travel away from home, others may be located nearby.
- Not all costs may be covered in a clinical trial, so it’s important to ask what costs the trial will cover and what your insurance will cover.
- Some clinical trials offer a health care team that will schedule and keep track of all of your appointments for you. The health care team will closely monitor your health throughout the clinical trial.

CLINICAL TRIAL PHASES

Clinical trials are designed to answer specific research questions. Researchers submit their clinical trial applications to the FDA, who reviews and approves the study protocols. Clinical trials usually move through several phases to test safety, effectiveness, dosage, and other factors.

- **PHASE 1** clinical trials are the 1st test of the dose and safety of a drug. Doctors work with small groups of patients who may have different kinds of cancer. Many phase 1 trials are for people with cancers that have spread to other parts of their bodies.
- **PHASE 2** clinical trials are done if a phase 1 trial showed that the treatment is safe and has signs of activity against 1 or more types of cancer. A phase 2 trial is typically a larger study, often done with specific cancer types. It looks at how well a treatment can work in that type of cancer.
- **PHASE 3** clinical trials are large studies. They involve hundreds or even thousands of patients. For this phase, you will be assigned to get the new treatment or the “standard of care” (current best treatment). To give everyone an equal chance at the new treatment, a computer randomly decides which treatment you will get. The doctor does not have any role in deciding which patients get which treatments and often does not know who is getting the standard of care.
- **PHASE 4** clinical trials are after a drug or new treatment is approved. Doctors continue to monitor it to learn how it works over the long term. They also look to see if there are any side effects that appear months or even years after treatment.

Informed Consent

If you agree to join a clinical trial, you will go through a process called informed consent. This is a very formal, step-by-step review of everything involved in the trial. You will be asked to sign a consent form that says you understand the clinical trial and agree to be a part of it. This is a very long (and often complicated) document. This is a good time to ask questions and to bring someone with you as an extra set of eyes and ears. Before starting any clinical trial, your doctor will explain the goals and possible benefits of the study. They will also tell you about any potential risks and side effects that you may have while in the study. Use this time to ask any questions you may have about the clinical trial. Informed consent in CAR T clinical trials may happen before or after apheresis.

Close Monitoring

If you get CAR T therapy through a clinical trial, you will likely be followed more closely and for a longer period of time by the CAR T team than if you get a “commercial” CAR T therapy (one that is given as it was approved by the FDA).

Finding a CAR T Clinical Trial

Dozens of CAR T clinical trials are now enrolling patients in the U.S. Even if you are not eligible for an approved CAR T treatment, you may be eligible for a clinical trial. You can find a full list of these trials on www.ClinicalTrials.gov:

- You will need to put your cancer type and the word “CAR T” in the search form.
- Then, click the boxes that will let you see only the trials taking place in the U.S.
- You can also search for trials in a specific city or state or distance from your home.
- Once you find a clinical trial you are interested in, you can contact the study research staff by phone or email.

The screenshot shows the 'Find a study' search form on ClinicalTrials.gov. At the top, it says 'Find a study (all fields optional)'. Below this are several sections: 'Status' with radio buttons for 'Recruiting and not yet recruiting studies' (selected) and 'All studies'; 'Condition or disease' with a text input field and a clear button (X); 'Other terms' with a text input field and a clear button (X); 'Country' with a dropdown menu showing 'United States' and a clear button (X); 'State' with a dropdown menu and a clear button (X); 'City' with a text input field and a clear button (X); and 'Distance' with a dropdown menu. At the bottom, there is a blue 'Search' button and a link to 'Advanced Search'.

For more information and help finding a clinical trial, contact CSC’s Helpline at 844-792-6517 or visit www.CancerSupportCommunity.org/Finding-Clinical-Trial. More resources are also available in Section 3 on page 129.

If You are Considering a Clinical Trial

Read the checklist of questions below in advance of your call/meeting with a clinical trial navigator. During your meeting ask these questions and use the notes section to write down their responses.

QUESTIONS TO ASK THE CLINICAL TRIAL NAVIGATOR	NOTES
<input type="checkbox"/> What phase is this clinical trial in and what are the goals of this trial?	
<input type="checkbox"/> Is the CAR T cell therapy being used in this study approved to treat other cancers?	
<input type="checkbox"/> How is this CAR T cell therapy different from those that have been FDA approved?	
<input type="checkbox"/> What kinds of tests and screenings are involved in the clinical trial?	
<input type="checkbox"/> What are the possible side effects I may have when in the clinical trial?	
<input type="checkbox"/> Will I be hospitalized as part of the clinical trial?	
<input type="checkbox"/> How did patients do in previous clinical trials of this treatment? How successful was the treatment in previous clinical trials?	
<input type="checkbox"/> How long will the clinical trial last?	
<input type="checkbox"/> What does the clinical trial pay for, what will my insurance cover, and what will I need to pay for? <i>(Note: You might need to have a meeting with the CAR T center Financial Counselor to answer this question.)</i>	

- What will be the difference in my total costs between a CAR T clinical trial and an approved CAR T treatment?

(Note: You might need to have a meeting with the CAR T center Financial Counselor to answer this question.)

- How will my care be managed after the clinical trial has ended? What tests might I need after the clinical trial?

Other questions for the Clinical Trial Navigator:

You can learn more about clinical trials on the Cancer Support Community's website: [**www.CancerSupportCommunity.org/ClinicalTrials**](http://www.CancerSupportCommunity.org/ClinicalTrials).

4

CAR T Caregivers & Support Team

All CAR T patients need to have a caregiver, or a trusted team of rotating caregivers, who can be with them 24/7, for at least 4 weeks. This person could be a family member or a friend. For some, this might be more than 1 person. If you don't have 1 caregiver who can stay with you 24/7 for 4 weeks, you may have multiple caregivers who each stay with you for parts of the 4 weeks. If you do not have any caregivers who can stay with you, talk to the social worker at the CAR T center about what other options you have. You may be able to find and hire a healthcare aide to stay with you. After the 4 weeks following the CAR T infusion, you may still need caregiver support, as you will be unable to drive until 8 weeks after your CAR T infusion.

The CAR T treatment team will meet with your caregiver to talk about their role and responsibilities. Most often, centers require that your caregiver is:

- 18 years old or older
- Someone who can commit to be with you 24 hours a day, 7 days a week for 4–8 weeks
- Able to understand what is required of them
- Someone who is responsible and who you can count on
- In good health
- Available for 4–8 weeks

- Has a backup person they can call if something happens to them

The treatment team will want to be sure that your caregiver has certain skills and abilities so they can observe any side effects that you may have and best help you during this process. Your caregiver(s) will also play a significant role in providing you with emotional support throughout the process. As you work to identify a primary caregiver and care support network, use the chart on the next page to outline what support you have in place and any gaps that need to be covered.



Kristin, CAR T survivor, with some of her caregivers on infusion day.

EXPECTATIONS	PRIMARY CAREGIVER	SUPPORT CAREGIVER(S)
<input type="checkbox"/> Talk to the treatment team about problems or concerns.		
<input type="checkbox"/> Contact your CAR T team if you have a fever or other side effects that may mean you need to go to the hospital.		
<input type="checkbox"/> Help get you to and from appointments, either by driving you or by arranging for someone else to drive you.		
<input type="checkbox"/> Help you take and organize your medication.		
<input type="checkbox"/> Manage your day-to-day basic living needs.		
<input type="checkbox"/> Keep your home clean to lower the risk of infection.		
<input type="checkbox"/> Cook, prepare, or arrange for meal delivery.		
<input type="checkbox"/> Help you with paying bills.		
<input type="checkbox"/> Support with child care, elder care, and/or pet care.		

Caregiver Support

To best support you, your caregiver is going to need their own community of support. Your caregiver should seek and identify friends or family members they can turn to. They can also join a caregiver support group or look for support groups online through social media platforms like [MyLifeLine](#). See page 127 in Section 3 to view a list of caregiver support programs.

Caregiver Review and Checklist

Being the primary caregiver is an important role and no one expects your caregiver to do it alone. Ask your caregiver to use the checklist below to start preparing for their role. The CAR T team can help provide some of these answers and resources.

I NEED TO KNOW	NOTES
<input type="checkbox"/> Can I take 4–8 weeks off from work?	
<input type="checkbox"/> Will I be able to travel with my loved one to their different appointments (1st appointment, apheresis, additional treatments, infusion, follow-up, etc...)?	
<input type="checkbox"/> Do I need to apply for FMLA or any other type of family medical leave?	
<input type="checkbox"/> How will I cover my expenses if I am taking off from work?	
<input type="checkbox"/> Do I have someone who can care for my/our other family members?	
<input type="checkbox"/> Do I have someone to house or care for the pets while we are away from home or in the hospital?	
<input type="checkbox"/> Am I emotionally able to support my loved one for 8 weeks during treatment and recovery?	
<input type="checkbox"/> Who will I reach out to for support?	
<input type="checkbox"/> What do I need to learn about CAR T cell therapy to be a good caregiver?	
<input type="checkbox"/> What concerns and questions do I have, and who can I contact to clear them up?	

<input type="checkbox"/>	Where will I stay while my loved one is being treated?
<input type="checkbox"/>	What will I do for meals during treatment?
<input type="checkbox"/>	What do I need to bring to the hospital in the case of an emergency?
<input type="checkbox"/>	Who can take care of my loved one if I am unavailable?
<input type="checkbox"/>	Can I commit to all 8 weeks of staying with my loved one?
<input type="checkbox"/>	Can I commit to only part of the 8 weeks? If so, how long and for what part?

Other questions:



Robyn, CAR T survivor, on vacation with her husband and caregiver, Scott, 4 years after her CAR T therapy.

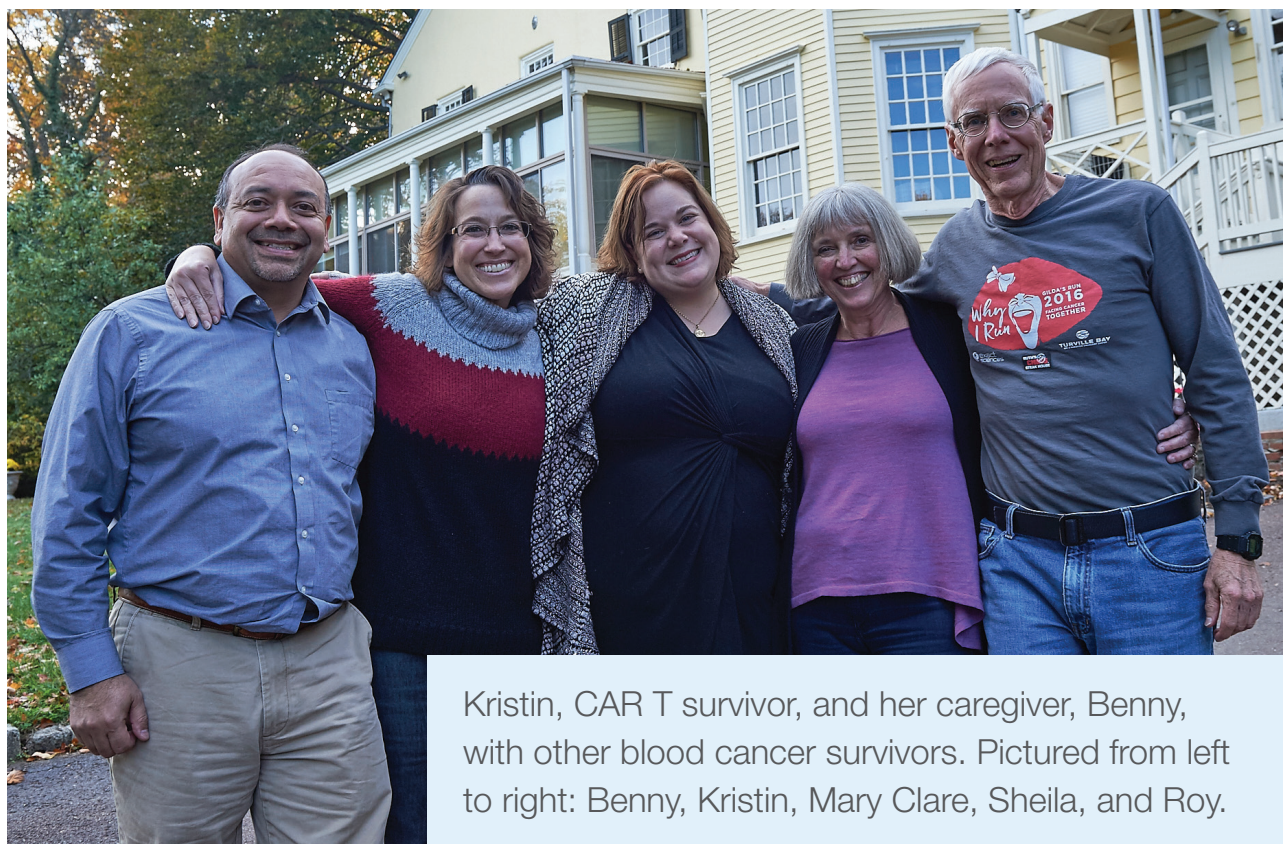
Gathering Your Support Team

At this point in your journey, you have likely experienced relapses and have side effects from other forms of treatment. You may not be doing well on your current treatment. As you prepare for CAR T, there are many logistics to consider. For example, you and your caregiver may need to make travel arrangements. Your caregiver may be worried about being away from home or family or the need to take time off work. This is a time when you and your caregiver(s) can ask for support from family members and friends.

Think about people in your life (both near your home and near the CAR T center) who can help. It might be family, friends, faith community, support group, or co-workers.

Make a list of the specific ways each of them can help (childcare, eldercare, house or pet sitting, meal prep, transportation, laundry, help with planning, etc.). After your CAR T infusion, you likely won't be able to drive for at least 4–8 weeks and will need caregiver support with transportation.

Consider using CSC's [MyLifeLine.org](https://www.mylifeline.org) to help you organize your requests for help to friends, family, and your community while keeping them up to date on your progress. You may also want to use other resources, such as in-person, telephone, or online support groups, helplines, and more to help you out. See page 124 in Section 3 to learn more about these resources.



Kristin, CAR T survivor, and her caregiver, Benny, with other blood cancer survivors. Pictured from left to right: Benny, Kristin, Mary Clare, Sheila, and Roy.

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Costs and Logistics of CAR T

The CAR T treatment process takes many months. It can affect your finances by making you and your caregiver unable to work for a long period of time. It can affect your family if you have children or parents you take care of. It can also require you to travel to another city or state if CAR T is not offered at a cancer center near you. You may need to secure transportation and lodging frequently throughout this process. Be sure to review the planning steps before each appointment and the resources in Section 3, starting on page 124, to ensure you have secured your logistics. You may also qualify for certain programs that can help with the cost. Working with your social worker can also help. You can learn more about these below or call **CSC's Cancer Support Helpline** at 844-792-6517 for more information and resources.

Cost of Care

CAR T cell therapy is an expensive treatment. On top of the medical costs, it can require a lot of travel and time off from work.

FMLA/TIME OFF WORK

If you or your caregiver are working, you will need to make plans for taking time off work. The Family and Medical Leave Act (FMLA) is a law in the United States that requires employers to give employees job protection and unpaid leave for qualified medical and family reasons. You and your caregiver should talk to your employers to know what options you have. Each job is different, but usually you should reach out to your human resources department and direct manager or supervisor. For planning purposes, the sooner you look into this the better.

You will need to budget for the 4–8 weeks that you will not be working. You will also need to plan for expenses like housing, meals, and transportation.

HOW MUCH WILL THIS COST ME AND MY FAMILY?

Ask to meet with your CAR T center's financial counselor to talk through how much CAR T therapy and any bridging therapy will cost you and what will be covered by your health insurance plan or a clinical trial. Talk to the financial advisor about any and all types of expenses from smaller costs like hospital parking to larger costs like labs and scans.

INSURANCE

The CAR T center will want to know the status of your health insurance before you start treatment. If you have insurance, start the claims process early, as it may take time to evaluate the medical records and approve the payment.

If you don't have a health plan, contact CSC's Helpline at 844-792-6517 or go to www.CancerSupportCommunity.org/Cost and see pages 4-5 in our *Frankly Speaking About Cancer: Coping with the Cost of Care* book. If you have Medicare or private health insurance, it is important to learn about the specifics of your policy. Call the phone number on your insurance card and ask them to explain what they would cover. Ask your insurer if travel and lodging support is provided.

TRAVEL COSTS

Health insurance doesn't typically cover CAR T costs for travel, lodging, transportation, and meals, but there are programs you may qualify for. The CAR T center may provide free or low-cost lodging or transportation. Talk to the social worker at your CAR T treatment center. Some nonprofits have programs that reimburse patients for some of their costs. Additionally, drug company assistance programs may help with drug co-pays or reimbursement of some lodging and transportation costs. See page 124 in Section 3 for lodging and transportation resources that you may be able to use.



“People need to know the financial cost ahead of time and take any financial help that they can get. Save all receipts for food, which can be a big expense. It may seem like a small thing, but sometimes there are programs that will refund your expenses that your social worker may be able to help you find.”

—Dave, Caregiver to CAR T Patient

Asking the right questions is key. This is an important part of your process and something that needs to be considered at every step. You and your care team should work together to ensure there is always a plan in place for where you will stay during every step of your treatment and how you will get to and from treatment sites. Use this chart to ask questions and map out your lodging and transportation plan in the notes column.

QUESTIONS TO ASK YOUR INSURER AND CAR T TEAM ABOUT LODGING AND TRANSPORTATION:	NOTES
<div> <input type="checkbox"/> Do you offer lodging assistance? <ul style="list-style-type: none"> ■ If so, is it available to use for all appointments? Or only at certain steps in the process? ■ How can I access it? ■ Is there any assistance available from the drug company or other resources? ■ Is assistance only available as a reimbursement after I have already paid for it? </div>	
<div> <input type="checkbox"/> Do you offer transportation assistance? <ul style="list-style-type: none"> ■ If so, is it available to use for all appointments? Or only at certain steps in the process? ■ How can I access it? ■ Does the assistance cover both ground and air transportation? ■ Is there any assistance available from the drug company or other resources? ■ Is assistance only available as a reimbursement after I have already paid for it? </div>	
Other questions:	