

Talking About CAR T-Cell Therapy



A GUIDE FOR DISCUSSING TREATMENT WITH YOUR CANCER CARE TEAM



This guide can help you take control and have better discussions with your healthcare team around CAR T-Cell Therapy. It will provide a quick overview of CAR T as a treatment option for cancer, questions to ask your healthcare team, a worksheet to help you set your own goals, and resources for information and support.



WHAT IS CAR T-CELL THERAPY?

CAR T stands for Chimeric Antigen Receptor T-Cell Therapy. It is a process that helps the T-cells in the body's immune system fight cancer. T-cells are a type of white blood cell that help protect the body from illness. During CAR T-Cell therapy a lab-made protein is added to the patient's own T-Cells. This protein is known as a Chimeric Antigen Receptor (CAR). When CAR T-Cells are infused back into the body, they attack cancer cells.

CAR T is different from other traditional chemotherapy treatments. It is a type of immunotherapy that uses the patient's own immune system to fight cancer. It is customized for each individual patient.

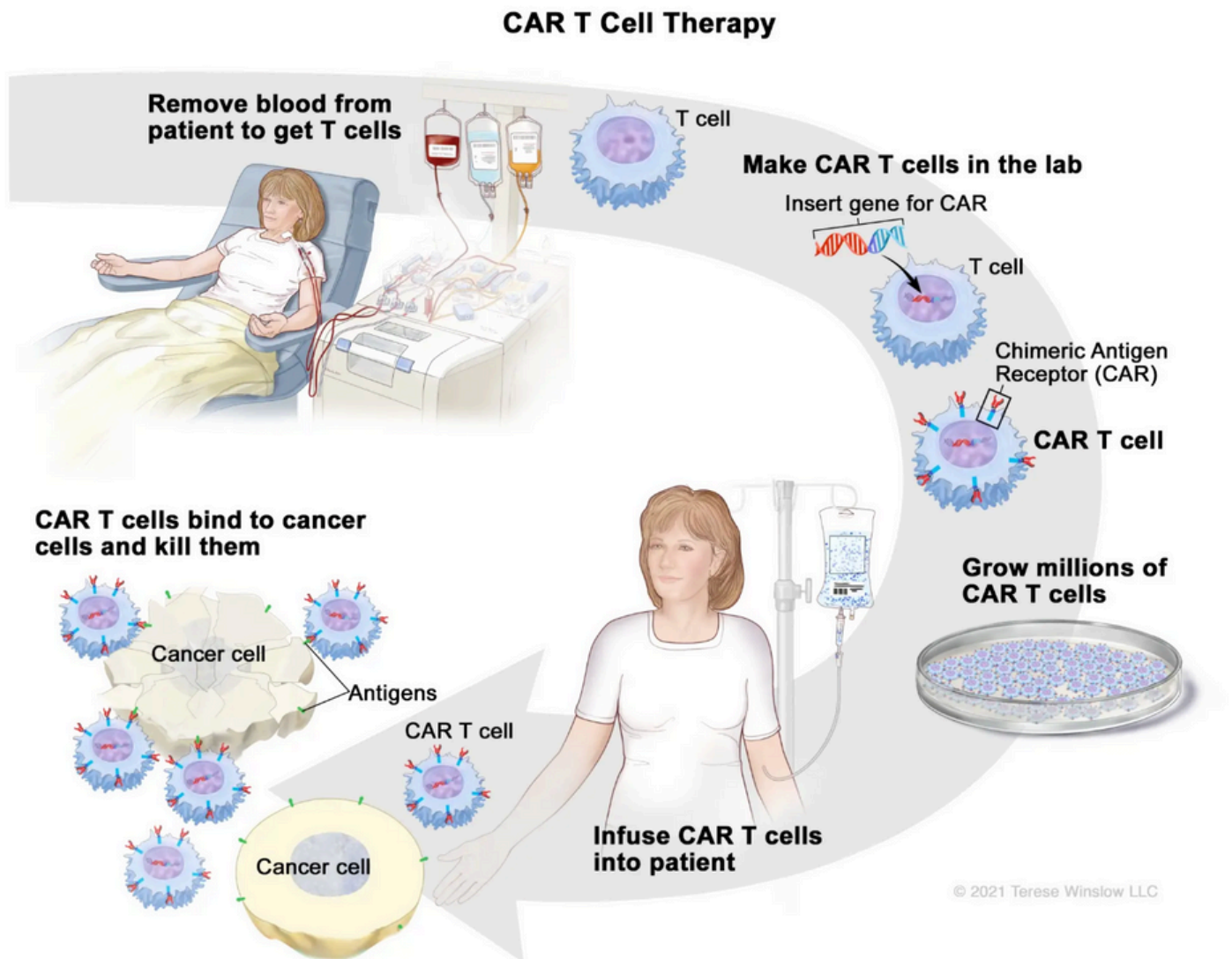
CAR T-CELL THERAPY PROCESS

CAR T is used to treat a variety of blood cancers, like lymphoma, leukemia, and myeloma. Currently, this treatment is not used as a first-line treatment option. This means that other treatments are used first before qualifying for CAR T. The care team may consider CAR T treatment based on your diagnosis, treatment history, and other health information.

If the care team tells you that CAR T is an option, there are steps required before starting treatment. You will meet with the CAR T care team to discuss the process. They will educate you about the steps leading up to treatment, any potential side effects, and let you know about other resources for support. The team will also perform lab tests and other health checks. Your caregiver will also be educated about the process and what they will be required to do. The team will confirm your eligibility and check insurance coverage. Once eligibility and insurance are approved, your team will begin the next steps in the process.

Your care team will:

- Collect T-cells from your bloodstream through a procedure called apheresis.
- Convert your T-cells into CAR T-cells. In this process, CAR proteins are added to your T-cells in a lab. The CAR proteins act like cancer-cell tracking devices to help your T-cells better attack cancer cells. This step in the process may take up to a few weeks.
- Complete a round of lymphodepleting chemotherapy. This lowers the amount of white blood cells in your body to help prepare for the infusion of CAR T-cells.
- Infuse CAR T-cells back into your body. Once the CAR T-cells are back in your bloodstream, they will bind to any cancer cells and attack them.



Once the infusion is done, you will be closely monitored. This may be either inpatient or in an outpatient setting. Where you are monitored, and the length of time needed, will vary by care center. This will also depend on how your body reacts to the infusion. Further monitoring or follow-up may be needed after 30 days. The location of monitoring will depend on what is available at your care center. Your care team may request that you stay within 10 – 30 minutes of the treatment center during this time. If this is the case, be sure to talk with your care team about any financial or relocation assistance programs. They may refer you to a social worker or patient navigator to help in these areas. In total, the CAR T treatment process can take about three months.

During the first 30 days after the infusion, it is important to look out for any new symptoms or side effects, such as fever, chills, and headaches. Talk with your care team about all possible symptoms you may experience.

Having a caregiver or care partner during this time is a significant part of the process and is often required. They can assist with symptom monitoring, transportation to appointments, and care team communication. Depending on your experience with the infusion, it may be recommended to have a caregiver after these 30 days.



TALKING WITH YOUR HEALTH CARE TEAM ABOUT CAR T

If you do not live near a healthcare center that offers CAR T-cell therapy, talk to your care team. They may be able to refer you to another provider at a different healthcare center.

Cancer treatment can be costly. 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 and/or nurse navigator, as well. These experts can help you find grants or other resources for financial support. Connecting with patient advocacy organizations, like the Cancer Support Community, can help. These organizations may be able to connect you to patient assistance programs to help pay for travel costs and other support resources.

TIPS FOR TAKING CONTROL

Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, take notes and/or record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.

Be proactive. Talk to your healthcare team or financial navigator about ways to manage treatment costs before you start treatment. Connecting with an advocacy organization, like Cancer Support Community, can also help you find resources.

Lead the conversation. Bring up any side effects or concerns you may have. Talk about any new symptoms you are experiencing no matter how small. Even if your healthcare team doesn't ask about a specific side effect, be proactive and let them know.

Write down your questions before each visit. Keep a journal to take notes or use this worksheet to track your progress over time. This can include information about tests, lab work, and the symptoms and side effects you may be experiencing. Ask your team if you should send any questions before your appointment through your patient portal.

Be your own advocate. If you do not feel your healthcare team is addressing your concerns, consider getting a second opinion. Some treatment centers have offices that specifically advocate for patients. These offices can support you throughout your care. If you feel that your provider is not a good fit or match for your needs, these offices can help you transition to a different provider.

If you do not understand certain words your healthcare team is using to talk about your cancer, **ask them to explain.** They should be able to find other ways to help you better understand your cancer and treatment options.

If you are told that CAR T is not an option, you can consider getting a second opinion. Many people with cancer get a second or even third opinion to confirm their diagnosis and review treatment options. Talking with another doctor may help you better understand your cancer and how to treat it. It may also help you feel more confident that you are making the right choices.

In many cases, you may be working with a “multidisciplinary” care team. This is a team made up of various doctors, nurses, and other professionals all working together for your treatment. Each professional brings specialized knowledge and a different set of skills to support you. They will work with each other to decide how to best treat your cancer and manage any side effects.



QUESTIONS TO ASK YOUR HEALTHCARE TEAM ABOUT CAR T-CELL THERAPY

Is CAR T-cell therapy an option for me?

Can you perform the treatment in this facility?

If you cannot provide the treatment here, can you refer me to another center that offers these services?

Will my insurance pay for this treatment? If not, what financial assistance resources are available?

Does your office have a social worker or financial counselor that can help me determine if my insurance covers CAR T-cell therapy or help me figure out how to cover costs?

I am interested in getting a second opinion about CAR T-cell therapy to make sure I am making the best decision for me. What is the process for making my medical records available to the next provider?



CAR T-CELL THERAPY SIDE EFFECTS

CAR T-cell therapy usually requires just one infusion. This may result in a shorter treatment time overall. CAR T 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) and neurotoxicity.

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

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 of these symptoms may also vary depending on the type of treatment you receive. Some of the most common symptoms, include:

- Headache
- Tremor
- Change in behavior
- Difficulty carrying a coherent conversation
- Change in personality
- Trouble keeping attention or showing confusion

CAR T-cell therapy can lead to some longer-term side effects. These can vary from person to person. Some side effects can last up to 6 months or even years after therapy. They may include:

- **Infection**
- **Cytopenia:** This is also known as low blood cell counts.
- **Loss of B cell function:** B cells are a type of white blood cell in our blood that helps fight off infection to support a healthy immune system.
- **Hypogammaglobulinemia:** This occurs when the body has low antibody levels. Antibodies are proteins in the blood that help protect the body from infection. This side effect can lead to recurrent infections, allergies, and the development of tumors (neoplasia).

It is important to find one person within the CAR T team that you can talk with about your concerns and questions. They can then direct you to other people, if needed.

POINT PERSON FOR ANY QUESTIONS:

WEEKEND OR AFTER-HOURS CONTACT:

Name and Role

Phone Number

Name and Role

Phone Number

QUESTIONS TO ASK ABOUT CAR T SIDE EFFECTS

If something doesn't seem right, it is always best to contact the CAR T care team. The care team can better treat any side effects as soon as they arise. Some treatment centers have a 24-hour call line where you can connect with a professional. During appointments, do not be afraid to ask questions. You should know what to expect and what you or your loved ones can do if you experience side effects. Below is a list of questions to ask before the CAR T infusion:

*What side effects should I look for? Do you have a list of side effects that we can take with us?
How long can these side effects last?*

Are there any side effects that I should know about that should be monitored daily? (ex: having a temperature above a certain number, changes in speech and behavior)

Who should be our first contact person if I detect a side effect? What is their contact information?

Who should I contact after hours and what is their contact information?

What are the side effects that require hospital admission?

When should I call 911 instead of the CAR T treatment team?

What can be done to help avoid infections?

What support is available for my caregiver if I am experiencing side effects?

HAVE YOUR CAREGIVER CALL 911 IF YOU HAVE:

- Chest pain
- Shortness of breath
- Trouble breathing
- Trouble seeing
- A very bad headache that does not go away
- Bleeding that does not stop or slow down after several minutes

Be sure to have your caregiver mention that you are a CAR T patient if you call 911 or visit an emergency room. If you know the specific name of your CAR T treatment and doctor, let them know.



THINK ABOUT TREATMENT AND YOUR PERSONAL GOALS AND EXPECTATIONS

When you talk to your care team about your treatment options, ask about the goals of the treatment and how each treatment might impact any personal goals or what you hope to achieve in your life. You may hope to live as long and as well as possible, contribute to progress by taking part in research, make it to a special event/milestone, or find cutting edge treatments. Let your healthcare team know about your treatment and personal goals. Remember that your goals may change over time.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

Physical Health and Mental Health and Well-being	<i>What is most important for you to be able to do and feel?</i>
Family and Social Relationships	<i>What is going on in the lives of others that is important to you?</i>
Work/School	<i>Do you want or need to continue working? Can you adjust your schedule or responsibilities?</i>
Social Support/Community Involvement	<i>Are you getting the support you need from your loved ones and community? Are you able to stay active/involved in your community?</i>
Other	<i>What else is important to you? What do you hope to achieve?</i>

QUESTIONS TO ASK ABOUT TREATMENT & YOUR GOALS

Will the treatment you recommend help me meet my goals? [see your answers above].

What other treatments are available to me?

What are the benefits and risks of each treatment option that is available for me?

Are there clinical trials that may be right for me?

How will we manage any side effects related to this treatment?

How likely is it that the cancer will return?

Is there a support group or social worker I can talk to about my experience?



FINANCIAL RESOURCES

Even with a healthcare plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

Talk with your healthcare team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for financial help.

Reach out to your healthcare plan to find out what resources they have that could help you. Ask about pharmaceutical assistance programs and what the qualification requirements are. If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

The more you learn, the more you can help to reduce unexpected costs. Visit:
www.CancerSupportCommunity.org/Help-Managing-Cancer-Costs

FINDING SUPPORT

The decision to have CAR T-cell therapy is an important one to make. Know that you do not have to go through this process alone. There are many support resources out there to help you and your care partner through the process. Here are some avenues to find support and navigate your CAR T experience:

- Think about people in your life who can help you during this time. This may be friends, your faith community, a support group, or co-workers.
- Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let others know what you need.
- If you search for information online, make sure that you are using trusted websites.
- Ask your healthcare team for a mentor or to be matched with another person with your specific cancer type or someone who had CAR T-cell therapy.
- Ask your healthcare team about resources for social, emotional, and practical support. Ask if there are any assistance programs that can help cover travel, lodging, and other living expenses during treatment.



FINANCIAL SUPPORT RESOURCES

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Help-Managing-Cancer-Costs

Cancer Financial Assistance Coalition

www.CancerFAC.org

Patient Advocate Foundation

800-532-5274

www.PatientAdvocate.org

CAR T-CELL THERAPY INFORMATION & SUPPORT

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Car-T-Cell-Therapy_

American Cancer Society

800-227-2345

www.Cancer.org

Bone Marrow & Cancer Foundation

800-365-1336

www.BoneMarrow.org

The Leukemia & Lymphoma Society

800-955-4572

www.lls.org

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 11am-8pm ET and Fri 11am-6pm 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 nearly 200 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more:
www.CancerSupportCommunity.org/Find-Location-Near-You

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**

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other healthcare professionals to answer questions and learn more.

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