

Caregivers and CAR T Cell Therapy Side Effects



Caregivers play a very important role all through the CAR T process, and most especially in the weeks following the CAR T infusion in identifying and responding to their

loved one's side effects. The purpose of this guide is to help caregivers understand their role, what to expect if their loved one gets side effects from CAR T cell therapy, and facilitate communication with the CAR T care team.

CAR T STANDS FOR:



CHIMERIC

The CAR protein is called “chimeric” (pronounced ky-MEER-ic) because scientists add this protein to the patient’s 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, the patient’s 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 the 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.

Caregivers and CAR T Side Effects

As a caregiver you have probably seen your loved one manage side effects from other cancer treatments. But there are some that CAR T can cause that you may have not seen before. CAR T cells can start killing cancer cells as soon as they are put into the body. This may cause serious side effects.

Before the CAR T infusion, the treatment team will meet with you and your loved one to talk about what to expect as well as your roles and responsibilities as a caregiver. For at least 4 weeks after the infusion, you and your loved one will need to be within 30 minutes of the CAR T center. You will also need to monitor your loved one closely 24/7 and provide caregiving support for up to 8 weeks after the CAR T infusion.

After the infusion, you will need to keep track of your loved one's side effects and share any concerns with the CAR T team immediately.

CAR T SIDE EFFECTS

Cytokine Release Syndrome (CRS)

This is by far the most serious side effect of CAR T cell therapy. CAR T cell therapy will start working in your loved one's immune system right away. This can cause the immune system to go into overdrive and release molecules called cytokines. If your loved one's immune system releases a lot of cytokines, they may develop symptoms, such as:

- Abnormal liver function
- Blood clots

- Body chills
- Dizziness
- Fever
- Increased heart rate
- Less urine than normal
- Low blood pressure
- Muscle aches and pains
- Night sweats
- Shortness of breath
- Tiredness

Neurological Toxicities

CAR T therapy can also cause another side effect known as “brain side effects,” “neurological toxicities,” or “neurotoxicities.” Neurological toxicities can be scary for a caregiver. It may be difficult to watch your loved one have extreme side effects. It may help you to know that your loved one will probably not know they've had these side effects. Neurological toxicity can cause symptoms such as:

- Anxiety
- Being unresponsive (coma)
- Confusion
- Difficulty walking
- Facial droop
- Head and body aches
- Infection
- Problems finding the right words
- Seeing things that aren't there (hallucinations)
- Seizures
- Sleepiness

Tumor Lysis Syndrome

Tumor lysis syndrome (TLS) is a condition that happens when cancer cells break down quickly, releasing chemicals into the blood. If the kidneys cannot remove these chemicals fast enough, your loved one can develop this condition that can cause symptoms such as:

- Confusion
- Decreased urination
- Diarrhea
- Fatigue
- Hallucinations
- Irregular heart rate
- Irritability
- Muscle aches or twitches
- Nausea
- Numbness or tingling
- Restlessness
- Seizures
- Vomiting
- Weakness

Cytopenia

Another common side effect is prolonged low blood counts (cytopenias). This is common in the first few weeks because of conditioning chemotherapy. However, your loved one may have this for a longer period, which would become more obvious in the first 4-8 weeks after infusion. Developing cytopenia increases the risk of infections.

B Cell Aplasia

In most cases, the CAR T drug also attacks normal, healthy B cells, which causes B cell

aplasia (low number of B cells). This makes it harder for the body to fight germs and can increase the risk of infection. This is only expected to occur in cancers that form in B cells, like myeloma and certain types of lymphomas.

RESPONDING TO CAR T SIDE EFFECTS

It is important to remember that every patient's experience is unique. Not everyone will have side effects. Side effects will look different from person to person. Side effects may show up sooner for some patients and later for others. You and your loved one receiving CAR T therapy should talk to the care team about what side effects to expect and how you should respond. Ask the care team what is common for your loved one's cancer type and drug type.

For most patients who get side effects, CRS happens first. Then, about 24–48 hours after CRS, your loved one may start to have signs of neurotoxicity. CRS and neurotoxicity can start within hours of the infusion and often lasts for 3–4 days. Technically, these side effects can develop at any time after CAR T cell therapy, but it is not common for them to develop more than 3 weeks after the CAR T cell infusion. That is why your loved one needs to remain close to the cancer center for 4 weeks after the CAR T cell infusion. For most cancer centers, “close” means you can get there in 30 minutes or less. It is very important to tell the CAR T care team about any side effects your loved one experiences. Most side effects can be managed if they are treated early.

Don't be afraid to ask questions, try to understand what could you expect, and the timeline of when side effects could happen. Take notes, names, and try to be really organized as a caregiver because the patient will not feel very well at times. In those situations, it's important to be able to reach out to the medical team and explain side effects, because something very small could be very important to them. By making that phone call, they could tell you to come in for treatment right away.

— Benny, CAR T Caregiver



Kristin, CAR T survivor, and her caregiver, Benny.

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 received between apheresis and infusion of CAR T cells. Bridging therapy tries to keep the cancer under control so the patient remains 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 the patient's 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 the 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 the 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.

IS IT AN EMERGENCY?

You should call your CAR T team right away if the person you are caring for has any of the below side effects:

- A temperature above 100.4 degrees
- Chills or shivering
- Confusion
- Dizziness
- A fast or strange heartbeat
- Extreme tiredness or weakness
- Pain, redness, swelling, or warmth in the arm or leg
- Nausea and vomiting
- No appetite for several days
- Sores or white spots in the mouth
- Constipation or diarrhea for more than one day
- Bruises or small red spots under your skin
- Bleeding
- A feeling of pain during urination or the need to go often
- A cough that doesn't go away
- New pain

If this happens, I will call:

Name _____ Phone number _____

Don't be afraid to call your CAR T team if you think your loved one might be having a side effect. They expect your call.

You should call 911 if your loved one has:

- 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 mention that your loved one is a CAR T patient if you call 911 or visit an emergency room for symptoms. Show your loved one's wallet card for CAR T if your loved one needs emergency care or urgent care.

TIP: Take a picture of your loved one's wallet card, so you always have the picture in your phone to show a new health care provider, emergency care, or urgent care.



SIDE EFFECT QUESTIONS FOR CAREGIVERS TO ASK THE CARE TEAM

It is important to communicate with your loved one's CAR T care team. Talk to the nurses and the doctors. Do not be afraid to ask questions. The doctors and nurses are there for you as well as the patient. Below is a list of questions to ask before the CAR T infusion so you know what to expect and what to do if your loved one experiences side effects.

QUESTIONS TO ASK	NOTES
<input type="checkbox"/> 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 take place?	
<input type="checkbox"/> Are there any tests that I should know about (ex: having a temperature above a certain number, the ability to answer specific questions)?	
<input type="checkbox"/> Who should be our 1st contact person if I detect a side effect?	
<input type="checkbox"/> What is their contact information (name and phone number)?	
<input type="checkbox"/> Who should I contact after hours?	
<input type="checkbox"/> What is their contact information (name and phone number)?	
<input type="checkbox"/> What side effects require hospital admission?	
<input type="checkbox"/> For what reasons should I call 911 instead of the CAR T treatment team?	
<input type="checkbox"/> How can I help avoid infections?	
<input type="checkbox"/> Are there any reasons that would require us to extend our stay near or at the CAR T center past 4 weeks?	
<input type="checkbox"/> What support is available for me, as a caregiver, as my loved one is experiencing side effects?	

CHECKLIST FOR CAREGIVERS

Below is a checklist to help you get prepared for when your loved one leaves the hospital after the infusion.

WHAT I NEED TO PLAN, DECIDE, AND DO	NOTES
<input type="checkbox"/> Ensure I understand what side effects my loved one may experience and what to look out for.	
<input type="checkbox"/> Confirm I understand who to call at all times of the day if we notice a side effect.	
<input type="checkbox"/> Verify I understand when a side effect requires hospital admission.	
<input type="checkbox"/> Figure out the plan for getting to the CAR T center or hospital if side effects arise. Do we need to take a shuttle, taxi, or rideshare? Can we drive there? How much and where is parking?	
<input type="checkbox"/> Take a picture of my loved one's wallet card for CAR T to show new health care providers if my loved one experiences side effects.	
<input type="checkbox"/> Identify who I can turn to for support after the CAR T infusion.	
<input type="checkbox"/> Re-read information and re-watch videos about CAR T side effects to be reminded that even very severe side effects can be managed.	

Additional notes:

CARING FOR THE CAR T CAREGIVERS

Caring for a loved one undergoing CAR T is wholly consuming and requires your full attention, especially in the weeks following the CAR T infusion. During this time, you may feel overwhelmed, stressed, and exhausted. It is completely normal and valid for you to feel this way. Because of the important role you play as a caregiver, you need to make sure you remain physically, mentally, and emotionally healthy. Here's a worksheet to help you think through your own care plan and needs.

<input type="checkbox"/> What helps me get through bad days?	
<input type="checkbox"/> What helps me relax?	
<input type="checkbox"/> Do I have any health concerns I need to pay attention to?	
<input type="checkbox"/> What am I doing to stay healthy?	
<input type="checkbox"/> Are movies or books an escape?	
<input type="checkbox"/> How can friends and family support me?	
<input type="checkbox"/> Can I adjust my work schedule and responsibilities? Am I stressed about work?	

Additional notes:

PRACTICAL TIPS FOR CAR T CAREGIVERS

- When your loved one is in treatment or at appointments, use that time for yourself. Go on a walk. Read a book. Get some fresh air. Do something for yourself.
- Have a support system. Reach out to your network, communicate with your friends and family when you are having a hard time. Identify those in your network who can help you with everyday tasks like cooking, cleaning, helping with kids, and running errands.
- Find ways to distract yourself. Talking to others, even if they cannot fully understand the CAR T process, can still be distracting and helpful.
- If you are able to, find support groups to help you cope with the process.

Some CAR T patients get severe side effects, while others get mild or no side effects. Whether your loved one has side effects or not does not predict whether CAR T is really working for them. Watch our videos to hear CAR T survivors and their caregivers tell their stories and experiences with CAR T cell therapy:
www.CancerSupportCommunity.org/CART.

For more information, see our CAR T Patient and Caregiver Guidebook for step-by-step support through the CAR T process at **www.CancerSupportCommunity.org/CART**.

If you have questions or need additional support at any point on your CAR T journey, reach out to the CSC's CAR T Support Helpline at 844-792-6517 or **www.CancerSupportCommunity.org/cancer-support-helpline**.

Resources for Caregivers

Cancer Support Community Caregivers Program — www.CancerSupportCommunity.org/caregivers • 844-792-6517

MyLifeLine Community CAR T Discussion Board — www.MyLifeLine.org

Blood & Marrow Transplant (BMT) Infonet Caring Connections Program — www.bmtinfonet.org/get-help • 888-597-7674

CancerCare Caregiving Resources — www.cancercare.org/caregiving

Caregiver Action Network — www.caregiveraction.org • 855-227-3640

Help for Cancer Caregivers — www.helpforcancercaregivers.org

Leukemia and Lymphoma Society Caregiver Support — www.lls.org/caregiver-support • 800-955-4572

Lymphoma Research Foundation Resources for patients and caregivers — www.lymphoma.org • 800-500-9976

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 - Fri 9am - 9pm ET and Sat-Sun 9am - 5pm ET.

Open to Options® — Need help making a cancer treatment decision? 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 170 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 at a location near you. 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 private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up 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.

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