

Caregiving for CAR T Cell Therapy

A Worksheet for Caregivers

Receiving a cancer diagnosis can be very stressful. Your loved one may experience challenges that will need to be addressed. This includes managing their physical, functional, and emotional concerns. Some examples are navigating appointments, treatment decision-making, and taking time off from work. These issues may not only affect your loved one, but you as the caregiver. You may also hear the term “care partner.” In this resource, the term caregiver is used to describe anyone who provides or arranges care for a person. The term “loved one” is used to describe the person diagnosed with cancer. This could be someone that you have any type of relationship with that you care about.

A caregiver is someone who volunteers to provide physical and emotional care for a loved one. They may be a spouse, friend, or family member. Caregivers can assist with a variety of tasks. This may include help with transportation, bathing and dressing, managing medications, and watching for side effects. Being a caregiver may feel overwhelming and scary. The purpose



of this guide is to help you understand caregiving for someone receiving CAR T. It will review what to expect if your loved one experiences side effects and how to maintain contact with the care team.

WHAT IS CAR T

Chimeric Antigen Receptor T-Cell Therapy (CAR T) is a process that helps the T-cells of the immune system fight cancer. These new T-cells, or CAR T cells, start killing cancer cells as soon as they are put into the body. CAR T is different from other traditional chemotherapy treatments. It is customized for each individual patient. It is an immunotherapy that uses the patient’s own immune system to fight cancer.

THE CAR T CELL THERAPY PROCESS

CAR T treats a variety of different lymphoma, leukemia, and myeloma diagnoses. 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 should consider CAR T based on diagnosis, treatment history, and other health information.

If the care team tells you that CAR T is an option for your loved one, there are steps required before starting treatment. You and your loved one will meet with the CAR T care team to discuss the process and perform lab tests and other health checks. The team will confirm eligibility and check insurance coverage. If your current care team does not offer CAR T, you may be referred to another provider. This provider may be located at a different center.

Once eligibility and insurance are approved, the care center will begin the next phases of therapy. They will:

- Collect the T cells
- Convert the T cells into CAR T cells
- Complete a round of lymphodepleting chemotherapy (this lowers the amount of white blood cells to prep the body)
- Infuse the CAR T cells back into the patient

Once the infusion is done, the patient is closely monitored for the first 30 days. This may be either in-patient or in an out-

patient setting. The patient may be required to stay in-patient for the initial days following the infusion. This will vary by care center. The patient may stay under this level of care for more than the first 30 days. This will depend on how the patient's body reacts to the infusion. Further monitoring or follow-up may be needed after the 30 days. The location of monitoring will depend on what is available at your care center. In total, the CAR T treatment process can take about three months.

During the first 30 days after the infusion, it is important to monitor for any new symptoms or side effects. Having a caregiver during this time is crucial. They can assist with symptom monitoring and care team communication. It is recommended to have a caregiver after these 30 days, depending on the patient's experience with the infusion.



CAR T CELL THERAPY SIDE EFFECTS

CAR T cell therapy usually requires just one infusion. This typically results in a shorter treatment time overall. CAR T has been shown to provide 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, or CRS, and neurotoxicity.

Cytokine Release Syndrome (CRS)

- This is when the immune system is put into overdrive after the CAR T cell infusion. As a result, cytokines are released. Symptoms can develop if a large amount is released into the body. The common symptoms of CRS are:
 - Fever
 - Chills
 - Tiredness
 - Nausea and Vomiting
 - Diarrhea
 - Body aches
- One important note is that CRS will typically present as a fever first.

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. However, the most common ways that it presents are:

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

There are also some long-term side effects from CAR T that can vary from patient to patient. These symptoms can last up to 6 months or longer after therapy:

- Cytopenia
 - Also known as low blood cell counts
- Infection
- 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
- Hypogammaglobulinaemia
 - This is a disorder when the body has low antibody levels. Antibodies are proteins in the blood that help protect the body from infection.

The CAR T care team can better treat any side effects as soon as they arise. You know your loved one more than the care team. **You are more likely to notice any changes that are new and concerning. If something doesn't seem right, it is always best to contact the care team.**



LOGISTICS OF BEING A CAR T CELL THERAPY CAREGIVER

A caregiver or care partner could be a spouse, friend, neighbor, coworker, family member, adult child, or other supporter. For CAR T, they must be at least 18 years old and be in good health without any restrictions to caregiving. The caregiver must be able to care for their loved one 24/7 for the first 30 days, and possibly up to eight weeks. The caregiver does not need to be the same person for the full length of time. Caregiving can rotate between people or be a team of caregivers; do what it takes to provide the best care.

Monitoring Side Effects

To provide the best care for your loved one receiving CAR T, it is important to know how to watch for side effects. Taking the appropriate steps to contact the care team about these are a vital role of a caregiver. If you are caring for your loved one outside the hospital, it is important to have the appropriate tools at home.

To assess CRS or any of its symptoms, it will be helpful to have the following on hand:

- **Digital Thermometer** to take their temperature
- **Automated Blood Pressure Cuff** to take their blood pressure
- **Pulse Oximeter** to measure the oxygen level in their blood

To assess neurotoxicity, pay attention to how they are speaking or answering

questions. Notice if they are not speaking coherently or are slurring their words. You know the personality and normal behaviors of your loved one more than you may think. Pay attention to those changes as well. Keep a log of when you notice any symptoms or side effects. This will be important for the care team to know. Understand that you are not alone. If you are unsure if you should contact the care team, call or message them through the patient portal, if available. It is better to inform the care team so they can best assess how to treat your loved one.



Time off Work or School

If you are working or in school, tell your managers or educators about your new role. After organizing your new tasks as a caregiver, you may find that taking time off work or school is needed. This is a common path that caregivers may take to provide



the best care possible to their loved one. If you are unable to take time away, you may still ask for a plan to adjust your time or commitments. You may wish to explore how other people in your life can help you with caregiving duties. It is better to organize the caregiving before the CAR T cell therapy process begins. Talk to the CAR T care team if you need help finding a team of reliable caregivers. The social workers and other team members can assist you in addressing barriers you may be experiencing.

Childcare

If you or your loved one has young children at home, talk through how they will be cared for during this time. Consider if extra childcare is needed. This could be another family member or friend, nanny/babysitter, or a day care facility. Consult with the CAR T cell therapy care team first. They may be able to recommend some options around the area. If you have employee assistance program (EAP) benefits, they may assist with identifying childcare solutions.

Transportation and Housing

There is a chance that your loved one may have to travel to a different medical center to receive CAR T. If this is the case, you will have to figure out if you will require housing near the treatment center. Your options will depend on the policy of the care center. You may have to stay at the hospital or have the option to stay somewhere else. This could be going back home or staying at nearby lodging (such as a local hotel or hospitality

house). Speak to the care team about your options. There are often rules about how far away you can be from the treatment center. They want to make sure that you can get back to them quickly enough, if needed. The care team may be able to provide resources and financial options to nearby hotels and reliable transportation if your personal home is too far away.

Insurance

The cost of CAR T is known to be very expensive. If you or your loved one have questions about the costs or whether your insurance covers it, speak to the care team first. They should be able to provide cost details and may even assist you with speaking to your health insurance company. CAR T cell therapy may or may not be fully covered by insurance. Associated costs, such as out-of-pocket expenses, can vary. Due to changes made at the federal level, CAR T cell therapy is covered for many Medicare recipients. Many private health insurance plans cover the costs as well. If you or your loved one is unsure of the coverage available, call the insurance company directly.

Living Will or Advance Directives

It may sound unnecessary or scary to speak with your loved one about documenting health care wishes. However, this is a very important discussion to have. Advance directives are legal documents that take effect if the patient cannot make their own medical decisions. These are also known as



a living will. They do not apply to financial matters. The care team may ask about establishing a medical power of attorney. A medical power of attorney is someone who makes medical care decisions if a patient is unable. This person is chosen by the patient. If you don't know what option is best for your loved one, speak to the care team. It is very important to have discussions about advance directives before therapy begins.

Other Concerns

Taking on the role of a caregiver can be difficult and demanding. If you feel that you are overwhelmed at any time, speak to the care team. The care team is available to support you and provide you with resources. It is important that you feel comfortable speaking with the team about your role and concerns. Do not be afraid to ask questions to help relieve concerns that you may have.

YOUR CAR T CARE TEAM

The CAR T cell therapy process will typically take place at one cancer treatment center or clinic. The care team at the center will consist of cancer care professionals specialized in CAR T cell therapy.

Primary Oncologist: this person may be your main physician for your entire oncology care and connect you with the CAR T physicians.

Primary CAR T Physician: this will likely be an Oncologist or Hematologist that specializes in blood cancers. If you are receiving CAR T through a clinical trial,

they may be the Principal Investigator. This person and their CAR T team may or may not be located at your main cancer treatment center.

Clinic staff for CAR T: this may include Nurses, Nurse Practitioners, and Physician Assistants that assist the oncologists with your CAR T care.

Other Physician Specialists: there may be additional specialists on your team to monitor and/or treat side effects. They may be Neurologists, Endocrinologists, and/or Infectious Disease specialists.

Patient Navigator: this person can assist you with coordinating appointments and direct you to other services or resources. They may also be called a Nurse Navigator.

Spiritual Care Provider or Chaplain: this person provides religious or spiritual support.

Social Worker: this person can provide additional assistance in navigating your CAR T care process. They may help with finding resources and managing the cost and logistics. Examples are housing, transportation, and provide emotional support to you and your loved one throughout the process.

Financial Counselor: they can answer any questions or concerns you have about the cost of care. They may be able to find some grants or other ways to receive financial assistance.



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:

Name and Role

Phone Number

Patient Portal Access?

Weekend or After Hours Contact:

Name and Role

Phone Number

WHEN TO CONTACT CARE TEAM ABOUT CRS OR NEUROTOXICITY

CRS and neurotoxicity typically occur in the first four weeks following infusion, if at all. Severity and onset can vary from patient to patient. A patient may not experience any symptoms at all. That does not mean that the CAR T cell therapy is not working. If your loved one has a fever or other flu-like symptoms after the infusion, contact the care team right away. CRS can be scary, but it is important to seek care at the first sign of symptoms. If you notice any neurotoxicity symptoms, contact the care team right away. It may seem difficult to know when this is happening. But you know your loved one best and are more likely to

notice differences than the care team. Do not be afraid to call your CAR T team if you think your loved one might be having a side effect. They expect your call. Be sure to mention that your loved one is a CAR T patient if you call 911 or visit an emergency room.

You should call 911 if your loved one has:

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

If this happens, I will call:

Name

Phone Number

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





CARE FOR YOURSELF

As a caregiver, it is important for you to also take care of yourself during this time. Addressing your needs first will be important to provide long-term caregiving. This may include coordinating a meal train or setting a schedule for others to take care of your household needs. Your loved one will benefit the most when you are feeling physically, mentally, and emotionally healthy. The care team will support your needs and help find resources that can help balance your responsibilities. You are expected to be with your loved one around the clock for the first month after the infusion. It is important for you to organize

your needs and other duties beforehand. Ensuring that you also have family and/or friend support is very important. This is especially the case if you have a partner and/or children at home. Communicating with them ahead of time is key. Continually check in with your support system. Receiving confirmation that things are going well will provide you with some relief. This will allow you to be more focused and present for your loved one. At any time throughout the CAR T cell therapy process, resources and support are available. Speak to your loved one's care team about any questions you may have about how to best care for both you and your loved one.



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. Below is a list of questions to ask before the CAR T infusion. You should 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 last?	
<input type="checkbox"/> 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)	
<input type="checkbox"/> Who should be our first contact person if I detect a side effect? What is their contact information?	
<input type="checkbox"/> Who should I contact after hours and what is their contact information?	
<input type="checkbox"/> What are the side effects that 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"/> 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 after your loved one receives 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, or do we need an ambulance? How much and where is parking?	
<input type="checkbox"/> Take a picture of my loved one's wallet card 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 consuming and requires your full attention. This is especially true for 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. Due to the vital role you play, you need to make sure you remain physically, mentally, and emotionally healthy. Here are some tips to help you think through your own care plan and needs.

QUESTIONS TO ASK	NOTES
<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"/> How can friends and family support me?	
<input type="checkbox"/> Can I adjust my work schedule and responsibilities? Am I stressed about work?	

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. As much as you may only want to focus on caregiving, it is important to prioritize your own health. Remember, the care team is there for you. Whether you are new to caregiving or have done so for a long time, there are support services available to help you. Taking advantage of these resources will assist you and your loved one throughout the CAR T cell therapy process.

CAR T CELL THERAPY INFORMATION & SUPPORT

Cancer Support Community CAR T Navigation • 844-792-6517 • www.CancerSupportCommunity.org/Car-T-Cell-Therapy

Cancer Support Community Caregivers • www.CancerSupportCommunity.org/Caregivers

Cancer Support Community • 1-888-793-9355 • www.CancerSupportCommunity.org

American Cancer Society • 800-227-2345 • www.Cancer.org

National Alliance for Caregiving • www.Caregiving.org

Leukemia & Lymphoma Society Caregiver Support • 1-800-955-4572 • www.LLS.org/Support-Resources/Caregiver-Support

Leukemia & Lymphoma Society CAR T Cell Therapy • www.LLS.org/Treatment/Types-Treatment/Immunotherapy/Chimeric-Antigen-Receptor-Car-T-Cell-Therapy



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.

Cancer Support Community CAR T Navigation — CSC CAR T Navigators are licensed clinical social workers who are oncology-trained to provide education, resources and emotional support to people with cancer and their caregivers which may include: Practical concerns, adjusting to CAR T-Cell Therapy demands, living with uncertainty, talking to children and family members about diagnosis and treatment, and caregiver stress. Call 844-792-6517 or visit www.CancerSupportCommunity.org/Car-T-Cell-Therapy for more information.

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 190 locations, CSC and Gilda's Club network partners 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/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.

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 health care professionals to answer questions and learn more.

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 publication was made possible through generous support from:

