

Care Partner Guide for CAR T Cell Therapy

What does caring for someone undergoing CAR T cell therapy look like?

Patients undergoing CAR T cell therapy will be under the care of highly trained medical professionals but will need additional support throughout their treatment journey.

Care partners, also known as caregivers, provide practical and emotional support throughout the treatment journey. They may also help with healthcare support, such as monitoring for any symptoms or side effects. The patient's CAR T cell therapy healthcare team will provide specific instructions for care partner planning, including helping a care partner understand their role and the length of time they will be needed.* The healthcare team will also provide instructions on what symptoms to watch out for and those for which medical care should be sought.

CAR T Cell Therapy Support Network



There is a wide network of people that may be part of a patient's support team.



Healthcare Team

- May include oncologists, nurses and advanced practice providers, social workers, pharmacists, and others
- Provide healthcare and supportive care, coordinate treatment, and manage medications and side effects



Care Partner(s)

- May include family members and close friends; sometimes a primary and support care partner
- Provide practical, emotional, and healthcare support, such as monitoring for symptoms



Support Community

- May include family, friends, neighbors, coworkers, support groups, faith and other community members, additional hired help, and more
- Provide additional support for the patient and care partner(s), such as childcare, eldercare, house or pet sitting, meal prep, transportation, and laundry

Typical Characteristics of Care Partners

- | | |
|--|---|
| <input type="checkbox"/> Family members or close friends | <input type="checkbox"/> Able to make travel arrangements |
| <input type="checkbox"/> ≥18 years of age | <input type="checkbox"/> Responsible |
| <input type="checkbox"/> In good health | <input type="checkbox"/> Understands what is required |
| <input type="checkbox"/> May need to take time off work | <input type="checkbox"/> Positive, calm, and flexible |

Although there may be one primary care partner to closely follow the CAR T process with the patient, some patients may have multiple care partners or have times where care partners alternate support.

*Timings shown here are estimates and may vary by institution and by patient

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Care partners provide many kinds of support such as:



Healthcare



Practical



Emotional

Healthcare



✓ Recognize and respond to emergencies and urgent situations

- Call 911 if the patient is experiencing a medical emergency
- Call the healthcare team if side effects develop



✓ Record and report information as instructed by the healthcare team, such as:

- A list of all medications and when they were taken
- The patient's temperature at least 3 times per day, and as needed
- Symptoms, side effects, and other changes in the patient's health and behavior



✓ Ask questions and take notes at health appointments

✓ Ensure the patient is taking medications as prescribed

Practical



✓ Ensure the patient has a care partner plan in place as instructed by the healthcare team

✓ Assist the patient in getting to and from all appointments



✓ Ensure the patient has all required medications and refill prescriptions as necessary

✓ Prepare healthy meals and snacks, and ensure the patient is drinking enough fluids



✓ Help minimize the risk of infection by assisting with laundry and daily hygiene and managing visitors



✓ Keep family members and friends up to date

✓ Avoid physical contact with the patient if you are sick

Emotional



✓ Pay attention to the patient's mood and feelings, and contact the healthcare team if you are worried about their emotional state

✓ Listen closely and communicate openly



✓ Be understanding of the patient's needs and decisions

✓ Reassure the patient and help keep their spirits high

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An Overview of the CAR T Cell Therapy Process and Considerations for Care Partners

The information below provides an overview of the **CAR T cell therapy process** and highlights where **care partner support may be needed**. Care partner support may be appreciated throughout the process, however, the care partner role is typically minimal until treatment steps begin. For example, the patient may ask that the care partner attend appointments with them. Care partner support may be required by the healthcare team following the patient's CAR T cell infusion.

Care partners may need to arrange some time off work to help monitor the patient following their treatment. If a care partner works remotely, they may still be able to participate in work activities during this time, but it may help to discuss arrangements with their employer. They may also want to coordinate care for their family and household, learn more about CAR T cell therapy, and help organize logistics such as travel and lodging during treatment.

Consult



Talk with the doctor about CAR T cell therapy

- During the first visit, the CAR T cell therapy team will provide information and evaluate if CAR T cell therapy is the appropriate treatment option for the patient. If CAR T cell therapy is selected, the healthcare team may provide specific instructions and help you understand your role as a care partner

Potential care partner support for appointments:

- Help the patient get to appointments by driving or arranging alternate transportation
- Come prepared with questions, take notes, and track future appointments
- Prepare things to help the patient be more comfortable during longer appointments, such as a snack or drink, a tablet with movies downloaded, and a blanket in case it is cold

Before Treatment



Apheresis and treatment during CAR T cell manufacturing

- Apheresis is an ~2-5 hour* procedure in which the patient's blood is drawn to collect their T cells, which are then sent to a lab to produce their personalized CAR T cell therapy. While their CAR T cells are being manufactured, the patient may need additional blood work or imaging or receive treatment to help manage their disease while they wait

Care partner role:

- After apheresis, the patient may be advised to take it easy for a day or so, and you should help monitor for any symptoms or side effects
- If the patient requires treatment while their cells are being manufactured, ask the medical team about what support they may need
- While they wait for their CAR T cells to be manufactured, you may encourage the patient to spend time with family and friends or enjoy their hobbies

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Treatment



Required chemotherapy before CAR T infusion

The patient will receive low-dose chemotherapy several days prior to their CAR T infusion to help prepare their body for their CAR T cells to be infused.

CAR T infusion day

The patient will receive an infusion of their CAR T cells. The CAR T cells can now multiply inside the patient and fight off the target cells, including cancer cells and some normal cells. The patient will need to be monitored for side effects.

Care partner role:

- When the patient is in treatment, they are cared for by their treatment team. Since this may take a few hours, this may be a good time for you to do **something for yourself** like take a walk, read, or relax

After Treatment



Close monitoring at or near the CAR T treatment center

Like with any treatment, side effects can occur so the patient will need to be watched closely for some time after treatment. Any side effects they may experience will be managed by their healthcare team. More information will be provided by the treatment team.

Care partner role:

- The treatment team will likely require you to be available and close to the CAR T treatment center during and for some time after the patient's CAR T treatment
- Once the patient is released from the treatment center, you should monitor for symptoms and side effects and know when to get help

Below are some symptoms you may need to look out for. Always reach out to the healthcare team if you have any concerns.



Two common side effects related to CAR T cell therapy are **cytokine release syndrome (CRS)** and **neurologic toxicities**. Common signs and symptoms include:

- | | |
|------------------------|-------------|
| ✓ Fever | ✓ Headaches |
| ✓ Difficulty breathing | ✓ Tremors |
| ✓ Rapid heart rate | ✓ Confusion |

Call the healthcare team or get emergency help at the first sign of these symptoms or any situation requiring urgent medical attention.

Call 911 or get emergency help at the first sign of:



- ✓ Severe chest pain
- ✓ Difficulty breathing
- ✓ Seizure or seizure-like activity
- ✓ Dramatic changes in consciousness
- ✓ Symptoms of stroke
- ✓ Severe vomiting or diarrhea
- ✓ Blurred vision
- ✓ Trouble speaking

After CAR T cell therapy

The patient will continue to visit their treatment team at a frequency determined by their doctor for ongoing monitoring of their disease status and management of any side effects. Over time, the frequency of these visits may decrease depending on their response to treatment.

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Preparing to Take on the Role of a Care Partner

As you consider taking on the role of a care partner, there are several questions you may want to discuss with your family, your employer, or the healthcare team.

Ensuring care partner availability

- ☐ Who can take on my role as care partner if I am unavailable?
- ☐ Am I emotionally able to support the patient through their treatment and recovery?
- ☐ Would asking another family member to share the care partner role be helpful?
- ☐ Who can I reach out to for additional support (family, friends, neighbors, community members, etc)?

Employment and financial considerations

- ☐ Can I take time off from work if needed?
- ☐ Do I need to apply for FMLA or any other type of family medical leave?
- ☐ How will I cover my expenses if I am taking off from work?

Travel considerations

- ☐ Will I be able to help arrange transportation to appointments?
- ☐ Where will I stay while the patient receives treatment?
- ☐ What do I need to bring in the case of an emergency?

Support for you as a care partner

- ☐ Do I have someone who can care for my family, pets, and household in my absence?
- ☐ What will I do for meals during treatment?
- ☐ Who will be my strongest support during this time?

Understanding CAR T cell therapy

- ☐ What do I need to learn about CAR T cell therapy to be a good care partner?
- ☐ What concerns and questions do I have, and who can I contact to clear them up?

Care Partner Self Care

As a care partner, you are a significant part of the healthcare team. It is important to take care of yourself – nutrition and rest are just as essential for the care partner as they are for the patient.

- ✓ You need sleep, too. Make sure you are taking measures for healthy sleep habits
- ✓ You need to eat and hydrate. Don't skip meals. Have snacks available for you and the patient
- ✓ Reach out to your network for help with things like child or pet care, meal preparation, transportation, and household tasks
- ✓ It is okay to alternate care partners if you have another important commitment or need to take a break. Coordinate with friends and family to ensure the patient has coverage while you get the help and support you need
- ✓ If you ever feel like you need more help, talk with the patient's doctor, nurse, social worker, or the treatment center

FMLA, Family and Medical Leave Act

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