

# A Care Partner's Guide to CAR T Cell Therapy and Support

This document does not contain all of the possible side effects of CAR T cell therapy. Be sure to talk to your healthcare provider about any questions that you may have. Refer to the Prescribing Information, Medication Guide, and website for additional safety information for the specific CAR T cell therapy you're receiving.

**IMPORTANT:** The directions in this action plan **do not** replace medical guidance from your healthcare team. Remember to talk to your healthcare provider if you have any questions about your condition, treatment, or symptoms.

Keep your CAR T wallet card with you at all times and tell any healthcare providers you see that you have been treated with CAR T cell therapy.

The care partner is an important part of the CAR T cell patient's treatment team. In your role, you are there to assist the patient along with the healthcare team. As a care partner, you will be an important part of the patient's medical, practical, and emotional support. This may sound challenging, but you may have already been doing this for some time prior to this treatment.

## MEDICAL SUPPORT

The care partner needs to understand and respond appropriately to emergencies and urgent situations if the patient is unable to do so on his/her own.

As the care partner, you will need to be able to recognize if the patient needs help. You will find information in this guide about when to call for help; additional details can be found in the *CAR T Cell Education and Reference Materials* (provided separately).

**The care partner needs to keep and report information as requested if the patient is unable to do so on his/her own. This will include:**

- Checking and recording the patient's temperature at least 3 times a day, and as needed
- Watching for symptoms, side effects, and other changes in the patient's health and behavior
- Calling 911 if the patient is experiencing a medical emergency or calling the patient's healthcare team if side effects develop

To help keep track of this information for the patient, a *Temperature and Symptom Log* is provided. If needed, please assist the patient with taking his/her temperature at least 3 times a day and completing this log. Please remind the patient to bring the log to every appointment.



*The care partner may need to remind the patient to take his/her medications as prescribed. Bring the patient's list of medications to every appointment and keep track of medications in the Temperature and Symptom Log.*

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## PRACTICAL SUPPORT

### As the care partner, you will need to:

- **Assist the patient in getting to appointments.** Remember, the patient will not be allowed to drive for at least 8 weeks after his/her CAR T cell infusion
- **Ensure the patient has someone with him/her at all times for at least the first 30 days.** The risk of serious side effects is greatest during the first 30 days after CAR T cell therapy
- **Be aware of potential side effects and understand what to do about them.** If at any time you are unsure what to do or are concerned that the patient may be experiencing a side effect, call their healthcare team right away
- Prepare healthy meals and snacks for the patient
- Ensure the patient is drinking enough fluids
- Assist with laundry, making sure the patient wears clean clothes and bedding is changed weekly
- Ensure the patient has all required medications. Refill prescriptions as necessary
- **Check with the patient on his/her energy level.** As much as family and friends will want to visit the patient, he/she may not have the energy for it
  - Help manage the number of healthy visitors to minimize the risk of infection to the patient
- Ensure the patient practices good daily hygiene to reduce the risk of infection
- Contact the patient's healthcare team with any questions or concerns
- Avoid physical contact with the patient if you are sick or ill

Patients receiving CAR T cell therapy are at risk for side effects. Some of these can be very serious or threatening and must be treated quickly.



### The most common side effects patients experienced after receiving CAR T cell therapy were:

- Fatigue
- Difficulty breathing
- Fever (100.4°F/38°C or higher)
- Chills/shaking chills
- Confusion
- Difficulty speaking or finding words
- Severe nausea, vomiting, diarrhea
- Headache
- Dizziness/lightheadedness
- Fast or irregular heartbeat
- Swelling
- Low white blood cells (can occur with a fever)
- Low red blood cells
- Severe muscle or joint pain
- Low blood pressure

## 911 EMERGENCIES: SYMPTOMS, SIDE EFFECTS, AND OTHER CHANGES TO WATCH FOR



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

- Severe chest pain
- Difficulty catching your breath or trouble breathing
- Seizure or seizure-like activity
- Dramatic changes in level of consciousness—symptoms like not being able to wake up
- Symptoms of stroke—eg, weakness on one side of your body
- Severe vomiting or diarrhea
- Blurred vision
- Trouble speaking
- Any other situation that would warrant a call for emergency medical help

**AFTER CALLING 911:** Call the healthcare team. When paramedics arrive, show them the patient’s CAR T wallet card that was given to the patient after receiving treatment.

More information about these symptoms can be found in the *CAR T Cell Therapy Action Plan*.

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*If you are ever unsure about symptoms or physical changes, please call the healthcare team.*

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## URGENT NEEDS



Call the healthcare team or get emergency help at the first sign of:

### Signs or symptoms of cytokine release syndrome (CRS) such as:

- Fever of 100.4°F/38.0°C or higher
- Chills/shaking chills
- Fast or irregular heartbeat
- Drop in blood pressure—lightheadedness or dizziness
- Shortness of breath
- Headache
- Nausea
- Fatigue
- Confusion
- Cough
- Swelling
- Stomach pain

### Neurologic symptoms (neurologic toxicity) such as:

- Confusion, disorientation, not knowing where or who you are
- Difficulty speaking or finding words
- Decreased alertness, drowsiness, or difficulty waking up
- Suddenly becoming weaker or unsteady when walking
- Tremors (fine shaking of hands or feet)
- Headache
- Agitation
- Memory loss
- Personality changes
- Difficulty writing

### Signs or symptoms of an infection such as:

- Fever of 100.4°F/38.0°C or higher
- Chills
- Sore throat
- Cough, or chest or sinus congestion
- Lower back pain, blood in the urine, or a burning sensation while urinating
- Abdominal pain, vomiting, or diarrhea/loose stools
- Sores or white patches in your mouth
- Being unable to eat or drink for 24 hours

## CARE PARTNER SELF-CARE

**The care partner has a significant role and is an important part of the patient's care team.** Much of the day-to-day responsibility falls on the care partner. Taking on this demanding role can often feel like a second job. Nutrition and rest are just as essential for the care partner as they are for the patient.

- **You need sleep, too.** Talk with the healthcare team if the patient's condition does not allow you to get enough sleep each night
- Talk with the healthcare team if you need help with physical or emotional support
- **You need to eat and hydrate.** Don't skip meals. Have snacks available for you and the patient
- **It is OK to alternate caregivers if you need to take a break.** Coordinate with friends and family to ensure the patient has around-the-clock coverage while you get the help and support you need

## IN CONCLUSION

If you have any questions or concerns, don't hesitate to contact the healthcare team. They are there to help you navigate the challenges of CAR T cell therapy.

## ADDITIONAL RESOURCES

Find more support through these organizations.

### **American Cancer Society**

[www.cancer.org](http://www.cancer.org)  
800.227.2345

### **Cancer Support Community**

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)  
1.888.793.9355

### **Caregiver Action Network**

[www.caregiveraction.org](http://www.caregiveraction.org)  
202.454.3970

### **International Myeloma Foundation**

[www.myeloma.org](http://www.myeloma.org)  
800.452.2873

### **Leukemia & Lymphoma Society**

[www.lls.org](http://www.lls.org)  
1.800.955.4572

### **Lymphoma Research Foundation**

[www.lymphoma.org](http://www.lymphoma.org)  
800.500.9976

### **Multiple Myeloma Research Foundation**

[www.themmr.org](http://www.themmr.org)  
1.866.603.6628

### **National Alliance for Caregiving**

[www.caregiving.org](http://www.caregiving.org)  
1.800.445.8106

### **National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)  
1.800.422.6237

### **Well Spouse® Association**

[www.wellspouse.org](http://www.wellspouse.org)  
732.577.8899

This list of independent organizations is provided as an additional resource for obtaining information. This list does not indicate endorsement by Bristol Myers Squibb of an organization or its communications.





More support materials like this and other information  
are available at [ExploreCARTtherapy.com](https://www.exploreCARTtherapy.com).