

# Symptom Monitoring Guide for Care Partners

## Symptoms and side effects after CAR T cell therapy

As with any treatment, CAR T cell therapy can cause side effects, so it is important that patients are watched closely after treatment. The care partner may help monitor the patient for symptoms and notify the care team who are trained to assess and manage any side effects.

Patients may experience early side effects, which could feel like a bad case of the flu. Some patients may experience more serious side effects including cytokine release syndrome (CRS), neurologic toxicity, or infections.

## What does monitoring by the care partner look like?

The treatment team will likely require you to stay with the patient close to the CAR T cell treatment center after treatment. Talk to the healthcare team for more information regarding the monitoring period. Once the patient is released from the treatment center, the treatment team may ask you to monitor the patient for symptoms and side effects. The treatment team will provide you with instructions on how to monitor and when to call the patient's doctor or emergency services.

**The treatment team may ask you to record and report information if the patient is unable to do so on their own. This may include:**



Checking and recording the patient's temperature at least 3 times a day and as needed and blood pressure as directed by the treatment team



Asking the patient to print their name daily to monitor changes in handwriting to help identify potential neurologic side effects



Watching for and recording 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 occur

## Most Common Symptoms/Side Effects

Fever is one of the most common symptoms of cytokine release syndrome (CRS) and can also indicate an infection.

- Fever (100.4°F/38°C or higher)
- Fatigue
- Difficulty breathing
- Chills/shaking chills
- Confusion
- Difficulty speaking or slurred speech
- 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

This document does not contain all of the possible side effects of CAR T cell therapy and is not intended to replace medical guidance. Refer to the Prescribing Information, Medication Guide, and website for additional safety information for the specific CAR T cell therapy received. You may report side effects to the Food and Drug Administration at 1-800-FDA-1088, or contact the manufacturer of the product received. For more information and resources about CAR T cell therapy, visit [explorecelltherapy.com](https://explorecelltherapy.com)

# Symptom Monitoring Guide for Care Partners

## Urgent Symptoms of Serious Side Effects

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

### Cytokine release syndrome (CRS)

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

### Neurologic symptoms (neurologic toxicity)

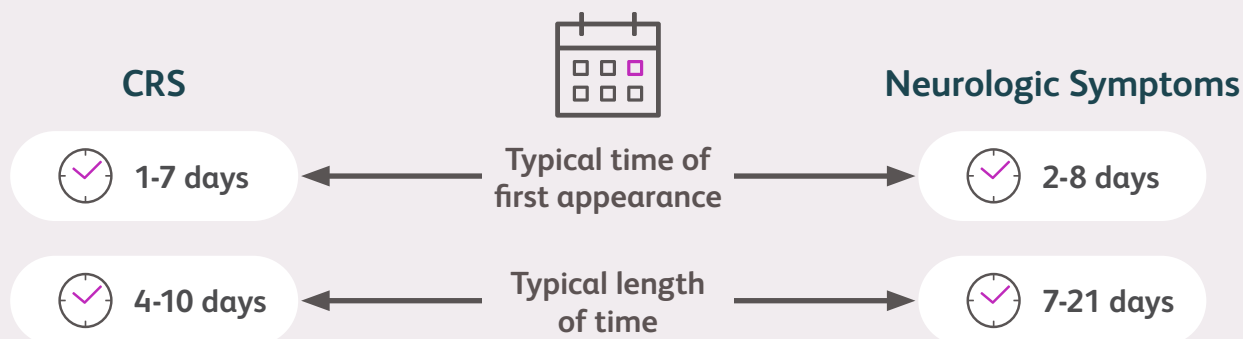
- Confusion, disorientation, patient does not know where or who they are
- Difficulty speaking or finding words
- Decreased alertness, drowsiness, or difficulty waking up
- Suddenly becoming weaker or unsteady when walking
- Tremors (fine shaking of hands or feet)
- Headache
- Agitation
- Memory loss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

### Infection

- 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 the patient's mouth
- Being unable to eat or drink for 24 hours

## Timing of CRS and Neurologic Symptoms

Timing may vary based on the patient and the CAR T cell therapy received. These side effects typically occur within the first week after CAR T cell therapy and peak within the first few weeks after infusion but can occur later in some cases.



# The CAR T Cell Therapy Symptom Guide

## Emergency Symptoms

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

- Severe chest pain
- Difficulty catching breath or trouble breathing
- Seizure or seizure-like activity
- Dramatic changes in level of consciousness—symptoms like not being able to wake up
- Stroke-like symptoms such as weakness on one side of the patient's body or a new onset of slurred speech
- Severe vomiting or diarrhea
- Blurred vision
- Trouble speaking
- Any other situation that would warrant a call for emergency medical help



Serious side effects can occur immediately, or very soon after treatment. Patients will need to be closely monitored after treatment, and it is important to be aware of driving restrictions during this period.


# Symptom Tracker



The treatment team may ask you to routinely monitor and record any symptoms the patient experiences after receiving CAR T cell therapy because symptoms can help you and the team identify and manage side effects of treatment.


Consider assisting the patient with recording their daily temperatures and symptoms in a notebook and bringing it with you to every doctor visit for the healthcare team to review. You may follow the example and template below.


## LOG EXAMPLE:

<b>Date:</b> <i>5/23</i>	<b>Time:</b> <i>8:30 am</i>	<b>Time:</b> <i>2:30 pm</i>	<b>Time:</b> <i>8:30 pm</i>
 <b>Temperature</b> <i>(Take at least 3 times per day, or as instructed by your healthcare provider)</i>	<b>Temperature:</b> <i>98.3°F</i>	<b>Temperature:</b> <i>100.5°F</i>	<b>Temperature:</b> <i>99.7°F</i>
	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms
<b>Blood pressure:</b> <i>126</i> mmHg / <i>80</i> mmHg <i>(Guidance on how often to check blood pressure will be provided by the healthcare provider. They may adjust frequency over time as needed)</i>			
<b>Symptoms, medications, and calls:</b> <i>Mild fever - started in the afternoon, Muscle pain- 10 am, Called nurse at 2:30 pm and was told to come in for monitoring.</i> <input checked="" type="checkbox"/> Healthcare team called			
<b>Have the patient print their name daily and review with the healthcare team.</b> Monitoring for changes in handwriting can help identify potential neurologic side effects (neurologic toxicity). Call the healthcare team right away if there are significant changes in the patient's handwriting. <b>Name:</b> <i>Jane Smith</i>			

**Call your healthcare team or get emergency help right away if the patient has a temperature of 100.4°F/38.0°C or higher.**

# Symptom Tracker

<b>Date:</b>	<b>Time:</b>	<b>Time:</b>	<b>Time:</b>
 <b>Temperature</b> <i>(Take at least 3 times per day, or as instructed by your healthcare provider)</i>	<b>Temperature:</b>	<b>Temperature:</b>	<b>Temperature:</b>
	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms
<b>Blood pressure:</b> _____ mmHg / _____ mmHg <i>(Guidance on how often to check blood pressure will be provided by the healthcare provider. They may adjust frequency over time as needed)</i>			
<b>Symptoms, medications, and calls:</b>  <div style="text-align: right;"><input type="checkbox"/> Healthcare team called</div>			
<p><b>Have the patient print their name daily and review with the healthcare team.</b> Monitoring for changes in handwriting can help identify potential neurologic side effects (neurologic toxicity). Call the healthcare team right away if there are significant changes in the patient's handwriting.</p> <p><b>Name:</b></p>			

<b>Date:</b>	<b>Time:</b>	<b>Time:</b>	<b>Time:</b>
 <b>Temperature</b> <i>(Take at least 3 times per day, or as instructed by your healthcare provider)</i>	<b>Temperature:</b>	<b>Temperature:</b>	<b>Temperature:</b>
	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms	<input type="checkbox"/> No symptoms
<b>Blood pressure:</b> _____ mmHg / _____ mmHg <i>(Guidance on how often to check blood pressure will be provided by the healthcare provider. They may adjust frequency over time as needed)</i>			
<b>Symptoms, medications, and calls:</b>  <div style="text-align: right;"><input type="checkbox"/> Healthcare team called</div>			
<p><b>Have the patient print their name daily and review with the healthcare team.</b> Monitoring for changes in handwriting can help identify potential neurologic side effects (neurologic toxicity). Call the healthcare team right away if there are significant changes in the patient's handwriting.</p> <p><b>Name:</b></p>			

**Call your healthcare team or get emergency help right away if the patient has a temperature of 100.4°F/38.0°C or higher.**

# Contact Sheet



Be sure to record the contact information for who you should call if the patient develops side effects or if you have questions about a possible side effect.

Consider collecting information for a contact at the CAR T cell treatment center, and once the CAR T cell treatment team decides that the patient is well enough to transition back to their local doctor, note down information for your contact at the local doctor's office. You may add these contacts to your phone or use the space below:

## CAR T cell treatment center

<b>Address:</b>	<b>Doctor's name:</b>
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<b>During regular working hours (9:00 AM – 5:00 PM)</b>		
<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>
<b>During after hours (after 5:00 PM) and weekends:</b>		
<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>

## Pharmacy

<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>
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## Other important contacts

<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>
<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>

## Local doctor's office

<b>Address:</b>	<b>Doctor's name:</b>
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<b>During regular working hours (9:00 AM – 5:00 PM)</b>		
<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>
<b>During after hours (after 5:00 PM) and weekends:</b>		
<b>Contact name:</b>	<b>Contact role:</b>	<b>Phone number:</b>