

It is important to follow these instructions for the first 100 days after CAR-T therapy.



For the first 30 days after CAR-T therapy, you must stay within 60 miles driving distance of Ochsner. Ask the Bone Marrow Transplant (BMT) social worker if you need help finding a place to stay for that time.



Call your provider immediately if you notice any of these signs or symptoms.

- ***Changes in mental status including confusion, headaches, blurred or double vision, difficulty talking or answering questions, memory loss, loss of consciousness, weakness, or seizures***
- Fever of 100.4° F or greater (Take your temperature if you feel sick, or are having aches, shaking or chills.)
- Chest pain or shortness of breath
- Rapid heartbeat or palpitations
- Dizziness or feeling lightheaded
- New or persistent cough
- Bleeding that won't stop easily with pressure
- Blood in the urine or stool
- Persistent nosebleed
- Changes in urine or bowel movements, such as
 - Severe diarrhea for more than 24 hours or more than 6 bowel movements in 24 hours
 - Any new pain or pain with urination or bowel movements
 - Decrease in frequency of urination
- Persistent nausea and vomiting (3 or more episodes of vomiting in an 8-hour period)
- Unable to take medications for ANY reason
- New mouth sores, have difficulty swallowing or a sore throat
- If central line site becomes red, painful, tender, or has discharge
- Skin rash (red, swollen, or painful areas), blistering or yellowing of the skin
- Yellowing of the whites of your eyes

Go to the nearest emergency room if you notice any new chest pain or shortness of breath.



Make sure to keep your wallet card with you at all times. Be sure to show this any time you are in the emergency room. This is especially important during the first 30 days following your CAR-T therapy.

+ **Contact your BMT team at 504-842-3910**, Monday through Friday from 8:00 AM to 5:00 PM. After 5:00 PM, on weekends and holidays, call 504-842-3000 and ask for the BMT/CAR-T physician on call.

Hand Washing, Skin Care, and Mouth Care

- Wash your hands often. Wash your hands before eating, after bathroom use, after handling the trash, and after contact with people and pets. Sanitizer can be used if your hands are not visibly soiled.
- Visitors should wash their hands before and after contact with you.
- Shower daily. Use clean towels each day.
- Your mouth and throat may be sensitive for some time. Avoid foods that may irritate your mouth.
- Talk to your doctor before drinking any alcohol.
- Your skin may be very sensitive to the sun. You may get a sunburn easily. Avoid being outside in the sun for long periods of time for at least 6 months following CAR-T therapy.
- Wear sunscreen with at least SPF 30. Reapply every 2-3 hours when in the sun. Cover your head and wear long sleeves.



Home Environment

- We recommend your house be cleaned before you return home. Don't do this yourself. Patients should not dust, vacuum, or clean bathrooms.
- The person who cleans should
 - Clean, vacuum, or dust floors, carpets, drapes, and furniture
 - Disinfect the bathroom and kitchen
 - Wash your bed linens
- If you have a humidifier or dehumidifier make sure someone cleans and disinfects them. Any filters should be changed if possible.
- Air conditioning filters should be cleaned and changed monthly.
- Avoid contact with bodily secretions from people, animals, birds, and fish. You may touch your pet, but wash your hands afterwards.
- Do not change diapers, clean litter boxes, fish tanks or birdcages. Avoid all contact with reptiles and chickens.
- Your pet's health can affect your health. Be sure your veterinarian confirms they are up to date on vaccinations and have no active infections. Pets should not sleep in bed with you.
- Avoid exposure to secondhand tobacco smoke. Smoking tobacco and exposure to secondhand tobacco smoke can put you at risk of bacterial and fungal lung infections.
- Smoking marijuana can increase risk of fungal infection.

Visitors (Including Children) and Going Outdoors

- Avoid anyone who is sick or ill.
- Avoid crowds when possible. Go to the grocery store, mall, movies, restaurants, etc., when they are not busy. Avoid crowded times such as the weekend and after work hours. Make sure to wash your hands frequently.
- Limit visits with children under age 12 who are not in your immediate family.
- Avoid exposure to someone who has received a live vaccine. Live vaccines might include an inhaled flu vaccine, MMR, or chicken pox vaccine.
- It is okay to go outside. Avoid areas where someone is potting plants, cutting grass and raking leaves.
- Stay away from construction areas because there will be significant dust.
- No yard work, gardening or digging in the soil.
- Masks are generally not necessary. Please continue to follow local and national guidelines (CDC) regarding masks with recent and future pandemics (i.e. COVID-19).
 - When going to clinic appointments, you must wear a mask.

Physical Activity

- Physical activity is a very important part of recovery. Initially, you may feel weak and get tired easily. It will take time to build your strength.
- Allow rest periods when doing activities. Try to spend the majority of the day out of bed.
- Your ability to return to work will depend on your health, your job, and your personal needs. Ask your CAR-T doctor about the best time for you to return to work.
- Talk with your CAR-T doctor about any upcoming travel plans and the precautions to take.
- **You cannot drive for the first 8 weeks.**
- Do not swim in lakes, rivers, oceans, or pools or use hot tubs for the first year. These activities can put you at risk of infection. If you have a central line, you cannot go swimming or get your line wet.
- Avoid carpentry or woodworking and exposure to sawdust.
- Golf is allowed but avoid areas where grass is being mowed.
- If fishing, do not use live bait or touch the fish with your bare hands. Be careful handling hooks.
- Hunting is not recommended until your platelet count is over 100,000. You may not field dress, gut, skin, or butcher the animal yourself.
- No contact sports such as soccer, basketball, football, or strenuous weightlifting if your platelet count is below 50,000.
- Resuming sexual activity is normal and an important part of your recovery. This will depend on how you feel. Sexual intercourse is not recommended until your platelets are above 50,000 and your white blood count is greater than 2,000. Other activities such as gentle kissing, hugging and touching should cause no problem.
- No oral or anal intercourse. These activities may increase the risk of infection. Use condoms for the first 100 days after your therapy to reduce the risk of infection. Females should use lubricant if experiencing dryness to prevent trauma and bleeding.

Nutrition Guidelines

- You will need a well-balanced diet with enough calories. Try to eat small meals with snacks in between rather than 3 large meals.
- Try to drink at least 6 to 8 8-ounce glasses of water or other fluids daily. Coffee, soda, or any caffeinated beverage are not a substitute for water.

Eating and drinking at home

- If you have well water, use bottled water for drinking and cooking if possible.
- Wash fresh fruits and vegetables thoroughly under warm running water for 2 minutes or more before eating.

Eating out

- Avoid salad bars and buffets. This food sits out in the open and may pose a risk of infection.
- Order meat cooked well-done.
- Avoid salads, fresh fruits, and raw vegetables at restaurants. They may not have been handled properly.

Anywhere – **DO NOT EAT**

- Raw meat
- Raw eggs, runny yolks
- Oysters
- Unpasteurized dairy products, honey, or juices
- Blue cheese, Camembert, or Gorgonzola cheese
- Grapefruit, grapefruit juice, or marmalade from Seville oranges. These can interact with medications.
- Refer to the dietary handout from your hospital dietitian for more information.

Medicines

- You will receive specific instructions before you leave the hospital about your medications.
- Bring all medications you are taking and your list of medications to all of your clinic appointments.
- Avoid Tylenol®, Motrin®, and Aleve® unless instructed by your CAR-T therapy doctor.
- Avoid herbal supplements and over-the-counter medications unless recommended by your CAR-T therapy doctor.
- Check with your doctor before using any new medications.
- Medications can be expensive. If you have trouble affording your medications, talk to your social worker or doctor.

Caregiver Responsibilities

- Having a caregiver is a basic requirement to be considered for CAR-T therapy. An active and effective caregiver is critical to the CAR-T therapy process.
- A caregiver must be available to the patient 24 hours a day, 7 days a week after CAR-T therapy.
- Duties include help with basic hygiene, household activities/cleaning, transportation to appointments, food preparation, symptom management, and emotional or social support.
- For any questions, speak with a member of your BMT care team or call 504-842-3910.

Follow-Up Care

- You will receive the date and time of your first BMT clinic follow-up appointment before you leave the hospital. Your appointment will be listed in your discharge instructions. This appointment will be in the Cancer Center, typically within a few days of being discharged from the hospital.
- You can expect to have your blood drawn (from your central line if you still have it or from your arm) every time you come to the Cancer Center.
- Following your CAR-T therapy, your follow-up visits will be once or twice a week through Day 30. Most therapy-related complications arise during the first 30 days. Your doctor will discuss any plans for future bone marrow biopsies or PET scans.
- You can expect to see a pharmacist at least once every other week. The pharmacist will review your medication list. They will discuss how you are taking your medications and answer any other medication-related questions.
- Your post-therapy vaccinations will usually start after day 100.
- Be sure to follow all instructions during follow-up. Recommendations may frequently change.

These are general guidelines and are always subject to change based on your health and CAR-T therapy status. Your therapy cannot be successful without your participation and cooperation.



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