

# CAR-T Cell Therapy Discharge Instructions (Pediatric Patients)

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The following guidelines apply to you/your child for at least 8 weeks after you receive your CAR-T cell infusion. Remember that the following may not apply to each individual patient. Please consult with the Pediatric Bone Marrow Transplant (BMT)/CAR-T team if you have any questions.

You are required to stay within 60 miles driving distance of C.S. Mott Children's Hospital for the first 8 weeks after your CAR-T infusion. If you do not have lodging set up, ask to speak with the social worker before you are discharged. You are also required to have a 24-hour caregiver with you at all times for at least 8 weeks.

## When do I need to *immediately* call for help?

**Call the Pediatric BMT/CAR-T doctor/provider immediately if you have:**

- Difficulty breathing or shortness of breath
  - Fever (100.4° F/38°C) or higher.
  - Chills/shaking chills
  - Low blood pressure, dizziness, or lightheadedness
  - High heart rate/heart pounding
  - Changes in mental status including confusion, headaches, blurred or double vision, difficulty talking or answering questions, memory loss, loss of consciousness, or seizures
  - Sudden weakness or severe muscle/joint pain
  - Severe or new nausea, vomiting or diarrhea (3 episodes in 8-hr period).
- Keep your **patient wallet card** with you at all times.
  - Tell any health care providers that you are seen by that you have received CAR-T therapy.
  - When calling Michigan Medicine for immediate help, tell them you need to speak to a C.S. Mott Children's Hospital Bone Marrow Transplant/CAR-T physician as soon as possible.

**When you call, tell them you are a CAR-T patient and need to speak with a C.S. Mott Pediatric BMT/CAR-T doctor on call as soon as possible.**

### **What other symptoms do I need to notify my doctor about?**

- Problems with eating such as:
  - Unable to keep food, fluids, or medications down
  - Having no interest in eating
  - Difficulty swallowing
- Bleeding problems such as:
  - Nosebleeds
  - Blood in urine or stool
  - Vomiting blood
  - Increased bruising
- Infection problems such as:
  - Pain with urination or bowel movements
  - Reddened, swollen, or painful areas
  - Change in wound (unusual pain, drainage, swelling, or redness)
  - Sore throat or new cough
- Decrease in frequency of urination
- Rash
- Pain that is not controlled with prescribed pain medications
- Changes or difficulty with your central line such as
  - Difficulty flushing
  - Redness, drainage, pain, or site looks different
- Fevers, chills, or hives after getting a blood transfusion
- *Or, you just don't feel right*

### **What is the contact information?**

- The BMT/CAR-T Clinic is open Monday through Friday, from 8am-5pm.
  - During these hours, call (734) 936-9814.

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- After 5pm, on weekends and holidays:
  - Call (734) 936-9814 and ask for the BMT/CAR-T doctor on-call. **When you call, always identify yourself as a CAR-T patient.**
- You can also refer to the blue handout in your discharge folder labeled “BMT/CAR-T Discharge Contact Information.” This gives you several phone numbers that you may find helpful. If you have any questions or concerns about anything, do not hesitate to call.

### **How will I care for myself at home?**

Follow these guidelines for at least 8 weeks after your CAR-T infusion or longer if told by your doctor.

#### **Handwashing and hygiene**

- Wash your hands often! At a minimum, you should wash your hands before eating, after bathroom use, and after contact with people and/or pets.
- Shower every day. Use liquid soap and new washcloth each day, do not use bar soap or loofa.

#### **People, places, and preventing infections**

- Avoid anyone ill.
- Avoid crowds when possible.
- Limit exposure to children outside your immediate family who are younger than 12 years old.
- Avoid wearing contact lenses. Wear eye glasses to prevent infection.
- Notify BMT clinic if you have been exposed to communicable diseases (chickenpox, shingles, flu, etc.).
- Deep cleaning of your house is not necessary before you go home, but please have caregiver wipe down surfaces, dust, and vacuum.
- Avoid construction areas or anywhere dirt and soil are being moved.
- Avoid dirty, dusty, or moldy environments.

- Avoid lung irritants such as smoking, second hand smoke, aerosols, and spray paint.

### **Do I need to wear a mask?**

- You do not need a mask unless you have a low white blood cell count (neutropenic) or you are around construction.

### **Bleeding precautions**

You are at highest risk of bleeding when your platelet count is 50,000 or less.

Take these precautions if this applies to you:

- Do not floss, use a soft toothbrush
- Do not blow your nose harshly
- Do not rub your eyes
- Do not scratch your skin hard
- Do not strain with bowel movements
- Do not have sexual intercourse (vaginal or anal)
- Do not shave with a razor. Only use electric clippers for hair cutting.
- Do not play contact sports
- Avoid popcorn and hard to chew items
- Avoid vomiting if possible, use anti-nausea meds preventatively
- Nothing in your rectum or vagina (no enemas, tampons, etc)

### **Pets**

- Current pets are ok. No contact with new pets, birds, reptiles, or farm animals.
- No sleeping with pets.
- Wash hands after direct contact with pets.
- No contact with cat litter or any animal excretions.
- Avoid pets on raw food diets.
- No reptiles or amphibians should be kept in the house or handled by you.

- It is a good idea to keep your pet clean and their shots up to date.

### **Plants and flowers**

- Plants may stay in the home but do not handle or care for them.
- Avoid direct contact with plants, trees, flowers and mulch.
- No yardwork, gardening or digging in soil.
- Go inside during lawn mowing.
- No live Christmas trees.
- Wood burning stoves & fireplaces may be used if vented properly. No wood should be stored in the house or handled by you.

### **Travel and driving**

Ask your doctor when you can travel and drive. You cannot drive for at least 8 weeks.

### **Return to work or school**

Your return should be approved by your doctor, as individuals vary greatly in their time to recovery.

### **Skin and sun**

You will need to take steps to make sure you are protected from the sun after your CAR-T infusion.

- Avoid exposure to sunlight when possible.
- If exposure to sunlight is unavoidable, use as much protection as possible such as long sleeve shirts, long pants, hat, and sunscreen SPF 30 or higher.

### **Physical activity**

- Gradually increase activity as tolerated. Activities outdoors such as walking are good for you.
- Trail hiking is ok but no camping, hunting, fishing, or deep woods hiking.

- No contact sports such as soccer, hockey, basketball, football or strenuous weightlifting if platelet count is less than 50,000.
- No swimming in lakes, ponds, hot tubs, or public pools.

### **Sexual activity**

- You can resume intercourse when your platelet count is greater than 50,000.
- Use standard safe sex precautions.
- Use a condom to prevent risk of infection.
- No anal intercourse.
- No kissing or oral sex if your partner has any mouth sores.
- Use water-based lube for vaginal dryness.

### **Diet and food safety**

Use the FDA Food Safety booklet you received from the dietary team for at least 8 weeks after CAR-T infusion or as long as your doctor instructs you to use it.

### **Medications**

You will receive specific instructions before you leave the hospital about the medications you are taking.

- Bring all medications you are taking and your list of medications to your clinic appointments.
- Only take what is prescribed to you.
- Avoid Acetaminophen (Tylenol®), Ibuprofen (Motrin®, Advil®), Aspirin (Bayer®, Excedrin®), and Naproxen, (Aleve®) unless instructed by your doctor.
- Avoid herbal supplements and over the counter medications unless prescribed by a doctor.
- Do **not** take steroids or allow any other doctor to prescribe you steroids unless approved by your BMT/CAR-T doctor. Steroids are only to be used in emergency situations.

## What is my CAR-T follow-up care?

- Before you get discharged from the hospital, you will receive a date and time for your first CAR-T clinic appointment. This appointment will typically be within a few days of you being discharged from the hospital.
- Be sure to get labs drawn one hour before this appointment at the blood drawing station on level 2 of Mott Children and Women's Hospital. This allows time for results to be available when you see your doctor.
- You will then proceed to the 7th floor of Mott Children and Women's Hospital and check into the Pediatric Hematology/Oncology/Transplant clinic.
- Additional follow-up clinic visits will be scheduled at this time.

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