



CAR T-cell Therapy Discharge Instructions (Pediatric Patients)

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-cell 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-cell 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-cell 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
- 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-cell 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-cell physician as soon as

- Severe or new nausea, vomiting or diarrhea (3 episodes in 8-hr period).

When you call, tell them you are a CAR T-cell patient and need to speak with a C.S. Mott Pediatric BMT/CAR T-cell 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-cell Clinic is open Monday through Friday, from 8am-5pm.
 - During these hours, call (734) 936-9814.
- After 5pm, on weekends and holidays:
 - Call (734) 936-9814 and ask for the BMT/CAR T-cell doctor on-call.

When you call, always identify yourself as a CAR T-cell patient.

- You can also refer to the blue handout in your discharge folder labeled “BMT/CAR T-cell 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-cell 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-cell 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-cell 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-cell doctor. Steroids are only to be used in emergency situations.

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

- Before you get discharged from the hospital, you will receive a date and time for your first CAR T-cell 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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