

# **Navigating Intracranial CAR T-cell Therapy:**

**A Guide for Pediatric Patients**

**Pediatric Blood and Bone Marrow  
Transplant Program**



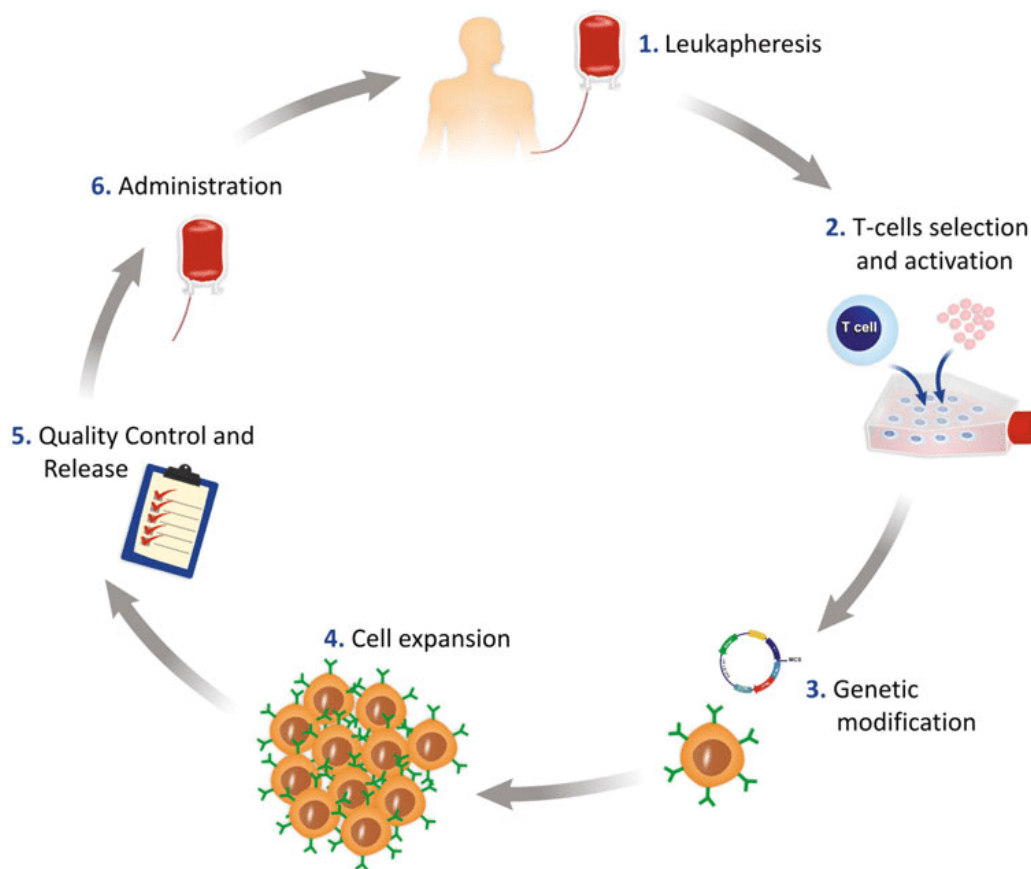
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# An Overview of CAR T-cell Therapy

## What is CAR T-cell therapy?

Chimeric Antigen Receptor cell therapy, or **CAR T-cell therapy**, is a form of immunotherapy that uses your own T-cells — a part of the immune system — and changes them so that they will fight cancer. T-cells' role in the immune system is to hunt down and destroy abnormal cells, including cancer cells. However, for many different reasons, they don't always recognize or attack cancer cells. Turning them into CAR T-cells is a way to fix this issue. Once infused into your body, the CAR T-cells immediately start targeting and destroying cancer cells.



CAR T-cell therapy includes the following parts:

- **Conditioning:** a few days before your first CAR T-cell infusion, you will receive chemotherapy to prepare your body for the treatment
- **CAR T-cell infusion:** the day of your CAR T-cell therapy infusion
- **After infusion:** the days after your CAR T-cell therapy
- **Recovery:** your healing and wellness journey after you are discharged from the hospital

Read through this booklet to learn more about each part of CAR T-cell therapy.

## Part 1: Conditioning

### What should I expect during conditioning?

The preparation time before your CAR T-cell infusion is called **conditioning**. During this time, you may be admitted into the hospital. Conditioning involves chemotherapy, given to you for 2 main reasons:

- Killing cancer cells
- Suppressing (weakening) your immune system

### Your conditioning plan:

Fill this out with your provider.

- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_
- Day ( ): \_\_\_\_\_

### What are the side effects of conditioning?

You can expect certain side effects from each of the medications you receive during conditioning. These will be managed with medications and other supportive care measures. Commonly expected side effects include:

- Nausea or vomiting
- Diarrhea
- Hair loss
- Bleeding

These side effects can last throughout the treatment course, but they are usually not permanent.

### **What is a complete blood count (CBC)?**

The **complete blood count (CBC)** is a test that measures your blood cell levels.

This includes the following counts:

- White blood cells (WBC)
  - Absolute neutrophil count (ANC)
  - Absolute lymphocyte count (ALC)
  - Blast cells
- Red blood cells
  - Hemoglobin
  - Hematocrit
- Platelets

We will look at your counts for changes during conditioning and after your infusion to see how your body is responding to your treatment.

### **What happens to my white blood cell levels during conditioning?**

We monitor your labs (the results of your blood draws) closely and expect that your counts will decrease during and after conditioning.

### **Will I need blood transfusions?**

You may also notice a decline in your hemoglobin and platelet numbers. You may need a transfusion of blood products, including packed red blood cells (pRBC) and platelets, until your body is able to produce them on its own. You may experience some bleeding (nose bleeds, mouth bleeding) at this time.

- You may need a blood transfusion if your platelet count is less than \_\_\_\_\_ or your hemoglobin is less than \_\_\_\_\_.
- If you've had a reaction to blood transfusions in the past, you may get medication such as Tylenol®, Benadryl® to prevent that reaction.

**What do I need to know about central line care?**

You will have a **central line** (a long flexible tube that enters your body through a vein, which helps to give you treatments) placed when you're admitted to the hospital. Most patients will go home with their central line in place, and it may stay in for months. We encourage you to become actively involved in the care of this line, starting from your admission to the hospital, so that you have time to learn and feel comfortable caring for this line at discharge (when you leave the hospital). Care of your central line includes flushing the line, cap changes, and dressing changes. Your nurse will help teach you and oversee your care.

## Part 2: The CAR T-cell Infusion

### What can I expect on the day of my CAR T-cell infusion?

These are the scheduled days that you will receive your CAR T-cell infusions. There may be more infusions after this; however, these are the ones currently scheduled.

Infusion #1: \_\_\_\_\_  
Infusion #2: \_\_\_\_\_  
Infusion #3: \_\_\_\_\_  
Infusion #4: \_\_\_\_\_

### What should I expect during the infusion?

- On the day of your infusion, we will access your Ommaya or intraventricular shunt to draw fluid samples before the infusion.
- We will deliver CAR T-cells to your room in a syringe. They will be thawed at your bedside.
- You may receive medications and IV fluids to reduce your side effects before you get your infusion.
- Your provider will infuse (give you) your cells through your intraventricular catheter.
  - If your stem cells are frozen, you may notice a smell during the infusion. Some people describe the smell as garlic, tomato juice, or creamed corn. This is normal, and it is from the preservative used when the cells are collected and frozen.
- The entire process from start to finish will take a few minutes.
- We will monitor your vital signs (heart rate, etc.) during the infusion.



**What are the side effects of the infusion?**

Many patients have no issues with their infusion. However, some of the most common side effects include:

- Changes in vital signs
- High blood pressure
- Nausea or vomiting
- Fever
- Hives (small itchy bumps on your skin)
- Allergic reaction (rash, difficulty breathing, face swelling)

Many of these side effects typically go away when the infusion is over. However, we may need to do other things to help your side effects, such as giving you medications and longer monitoring and care.

## Part 3: After Your Infusion & Treatment Side Effects

### What can I expect in the days after my infusion?

#### Fluids, electrolyte abnormalities, and nutrition (FEN) monitoring

We will monitor you for the following:

- Fluids
- Electrolyte abnormalities
- Nutrition

#### Fluids:

You will get fluids through an IV as needed during your hospital stay (including if you are not able to drink enough fluid).

Your daily fluid goal is: \_\_\_\_\_ mL/day

- We monitor your weight once or twice a day to check for **fluid overload** (too much fluid in your body).
- We may give you medication such as Lasix® to help your body remove extra fluid.

#### Electrolyte abnormalities:

If you have an **electrolyte abnormality**, this means that one or more of the lab values we measure in the blood (such as magnesium, potassium, phosphorus, or sodium) is higher or lower than normal.

- There are many causes of this, including eating less, diarrhea, medications, and IV fluids.
- The most common abnormalities are high or low potassium.

Treatment for any electrolyte abnormality may include:

- Fixing the cause of the abnormality

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- Oral (by mouth) or IV electrolyte replacement
- Adjusting your medications

### **Nutrition:**

You may feel less hungry (you “lose your appetite”) and eat less after your infusion. The main causes are nausea and taste bud changes. Getting good nutrition is important for your healing and overall health!

A dietitian will follow you throughout your treatment. Treatment for your nutritional needs may also include:

- Feeding through the gastrointestinal (GI) tract (stomach and intestines), called **enteral nutrition**
  - You may take supplements by mouth to get more calories and protein. There are many types and flavors of supplements.
  - You may have **tube feeds**, where you’re given medication and liquid nutrition through a small tube placed through the nose into the stomach or small intestine.
- Feeding through an IV, called **parenteral nutrition**
  - You may have **total parenteral nutrition (TPN)**, where all of the protein, calories, vitamins, and minerals you need are given to you through a vein. This type of feeding does not use your digestive system. It can irritate your liver and increases your risk of infection.

Your daily caloric goal is: \_\_\_\_\_kCal/day

You will get these medications to help prevent FEN-related issues:

- Stomach ulcer prevention: Zantac®, Pepcid®, or Prilosec®
- Vitamin D deficiency: cholecalciferol

## **What side effects could I have during my CAR T-cell therapy?**

### **Gastrointestinal (GI) complications**

#### **Nausea and vomiting:**

- This is the most common side effect of chemotherapy.
- To prevent or treat nausea and vomiting, some medications will be given to you on a set schedule while others may be given to you as needed when you're feeling sick.
  - Commonly used medications include Zofran®, Kytril®, Zyprexa®, Ativan®, and Phenergan®.
  - Your medication plan: \_\_\_\_\_

#### **Diarrhea:**

- Diarrhea is usually caused by chemotherapy, although it may also be caused by a virus or bacteria.
- Diarrhea is treated with hydration (IV fluids) and giving time for the GI tract to heal. If you have infectious diarrhea, you may need antibiotics.

#### **Constipation:**

- Constipation (not being able to have bowel movements or having hard bowel movements) is usually caused by not eating or by side effects of pain medication.
- Constipation can be treated by eating and drinking (when possible) to keep things moving in your GI tract. You may also take medications to help with bowel movements like Senna®, Colace®, MiraLAX®, or Lactulose®.

## **Fever**

While receiving this therapy, you may get a fever. This might be caused by an infection, inflammation, or cytokine release syndrome (CRS).

- Inflammation can be caused by cell irritation from chemotherapy.
- The most common sources of infection are from your central line, your GI tract, or your respiratory system (your nose, mouth, throat, windpipe, and lungs).

## **What are the symptoms?**

While you have a fever, some symptoms you might experience include:

- Tiredness
- Faster heart rate
- Blood pressure changes
- Changes in your breathing
- Chills and shaking

If you have an infection, you may also have symptoms specific to the infection site (like stomach pain, pain with urination, diarrhea, runny nose, cough, etc.).

## **What testing will I need?**

If you have a fever, we will need to do these tests to rule out an infection:

- Blood cultures from all of your lines (if you have a fever, we will access your port)
- Cerebrospinal fluid (CSF) cultures from a spinal tap
- Urine (pee) or stool (poop) samples
- Possible viral labs, fungal labs, or respiratory (nose) cultures from a nose swab
- Possible x-rays or CT scans

### **What is the treatment?**

We will need start treating you immediately, just in case the cause of your fever is an infection.

- As a safety measure, we may need to change the antibiotics and antifungals that you were on.
- We will continue to treat you as if you have an infection until we determine that you don't have an infection.

### **Cytokine release syndrome (CRS)**

CAR T-cells can cause a large release of substances called **cytokines** from the cells in your body. This can trigger an inflammatory condition known as **cytokine release syndrome (CRS)**.

### **What are the symptoms?**

Symptoms of CRS can range from mild to severe. Common symptoms include:

- A temperature of 100.4° F (38° C) or higher
- Flu-like symptoms, such as muscle aches, headaches, or chills
- Nausea or vomiting
- Diarrhea
- Feeling dizzy or lightheaded

More severe symptoms include:

- Confusion
- Difficulty breathing
- Low blood pressure
- Trouble speaking
- Seizures

### **How can I reduce these symptoms?**

These side effects are usually managed with supportive care and medications. This may require close observation in the Pediatric Intensive Care Unit (PICU). If the symptoms become severe, we will give you a medication called tocilizumab to calm this response.

### **Neurotoxicity (ICANS)**

A neurological effect, called **immune effector cell-associated neurotoxicity syndrome (ICANS)**, can occur with CAR T-cell therapy. **Neurotoxicity** is when your normal brain and nervous system activity is changed or damaged after exposure to a substance.

### **What are the symptoms?**

Neurotoxicity symptoms range from mild to severe. Symptoms include:

- Headache
- Confusion or delirium (having a hard time focusing your attention and awareness, not being able to think or remember clearly)
- Hallucinations (sensing things that are not real)
- Difficulty speaking (aphasia)
- Involuntary muscle twitching
- Unresponsiveness
- Seizures

### **What is the treatment?**

Neurotoxicity has been reversible in most cases, and the symptoms usually go away over several days without intervention or long-term effects. For mild symptoms, we may use acetaminophen (Tylenol®) or other commonly used medications. For more severe symptoms, we may need to use steroid therapy or other treatments.

## **Tumor inflammation-associated neurotoxicity (TIAN)**

**Tumor inflammation-associated neurotoxicity (TIAN)** is a neurological side effect which can occur with CAR T-cell therapy. This is when your brain doesn't function properly due to inflammation from a nearby tumor. This is different than ICANS. Each person may have different TIAN symptoms depending on where the tumor is located. There are 2 types of TIAN:

- Type 1 (mechanical): Neurological issues caused by swelling and pressure inside your skull from the tumor.
- Type 2 (electrical): Neurological issues due to the nerves in the brain not working properly because of inflammation. Type 2 TIAN can worsen your existing neurological symptoms.

## **What are the symptoms?**

Symptoms include:

- Headache
- Fever
- New or worsening neurological issues
- Lack of responsiveness
- Delirium (having a hard time focusing your attention and awareness, not being able to think or remember clearly)
- Signs of increased pressure inside your skull
- Poor muscle control or issues with movement and balance
- Changes in heart rate, blood pressure, or dizziness
- Seizure

## **How is it diagnosed?**

TIAN is diagnosed by doing a physical exam and considering your symptoms. Your doctor will need imaging and consultation with the neurology team.



**What is the treatment?**

Treatment for T1AN is based on the severity of your symptoms. Mild symptoms will be monitored closely, while more advanced symptoms may need to be treated with steroids or other medications. We may need to access your intraventricular catheter system to get cerebrospinal fluid (CSF) for testing or to relieve pressure.

## **Part 4: Discharge and Recovery**

### **What are my goals for discharge?**

Before you are cleared to leave the hospital (called **discharge**), we expect that:

- You have not had a fever for more than 24 hours.
- You do not have any concerning neurologic symptoms.
- You have no active infections.
- You have limited nausea, vomiting, or diarrhea.
- You are able to take medications by mouth.
- You need blood product transfusions 2 days or less per week.
- You're meeting your goals for calories and fluid intake.
- You are able to move around and perform daily care activities (like bathing, taking medications, etc.).
- Your discharge medications have been delivered to your bedside so we can go over them with you.
- Your central line supplies have been delivered to your bedside.
- Your caregiver has shown the hospital staff that they're able to care for your lines and medications.

### **What medications will I take at home?**

- If needed, you will receive your medications from the Taubman Pharmacy before discharge. We will check these at your bedside to make sure you have the right medications, and we will teach you about them.
- You will be responsible for completing central line care and weekly dressing changes at home. You will learn and practice central line care during your hospital stay.

## **What do I need to do to prevent sickness and stay healthy at home?**

You must take the following **precautions** (actions to help you avoid getting sick) until you are cleared by your BMT doctor.

### **Personal hygiene (cleanliness)**

- Shower or bathe every day. All your family members and people staying around you should also shower or bathe daily.
- Avoid direct sunlight. Your skin will be more sensitive after your therapy. Protect your skin with sunscreen that has an SPF of at least 30. Reapply (put more on) often. Cover your skin with cotton clothing and a protective hat.
- Don't get any new tattoos or piercings.

### **Masking**

- Wear a facemask when you're coming to the clinic or hospital, or when you'll be around large crowds of people.

### **Being around other people**

- Avoid being around anyone who is sick, and make sure they have not had colds, rashes, vomiting, or diarrhea.
- Avoid crowds of people.
- Call your doctor immediately if you, or any other friend or family member around you, have been exposed to chickenpox, shingles, measles, German measles (rubella), or any other contagious (easy to spread) disease.

### **Pets**

- Don't clean up after your pets. This includes changing a litter box or picking up poop.
- Wash your hands after any contact with pets.

- Do not touch any birds or farm animals.
- Do not keep any reptiles (lizards, snakes) or amphibians (frogs, toads) in your home.

### **Home safety and cleanliness**

- Don't play in the dirt or leaves. This includes avoiding gardening and caring for plants. Do not get a living pine tree for the holidays.
- Avoid lung irritants such as smoking, secondhand smoke (being around other people who are smoking), and aerosols (like spray paint).

### **School and work**

- You cannot go back to school or work until your doctor says it's okay.
- You may continue your education at home using printed or computer material through a virtual program.

### **Substance use (including alcohol, nicotine, inhaled marijuana, vaping and other drug use)**

- **To keep you safe, you should not use any of these substances after your therapy unless you've talked with your doctor about it.** There are possible drug interactions (harmful or unsafe drug combinations) and risks of organ dysfunction with many of these substances.
- Smoking and vaping (tobacco or marijuana) can lead to lung injury, fungal infection, and secondary cancer risk.
- Drinking alcohol can harm your liver and interact with your medications.

### **Other activities**

- Ask your doctor when you can travel and drive.
- **Do not swim if your central line is still in place.** Once your central line is removed, you can swim in a private pool that isn't crowded if you aren't neutropenic (you don't have low levels of white blood cells). Make

sure that the pool is chlorinated. You cannot swim in lakes, rivers, or crowded pools until your immune system has recovered.

### **What should I expect for my follow-up visits in clinic after discharge?**

After discharge, if you don't have any complications requiring closer follow-up, you will be seen in the clinic at least weekly for several weeks. Your lab appointments will be scheduled before your clinic appointment.

### **What should I watch for, and when should I call 911 or go to the emergency room (ER)?**

**Call 911 immediately if:**

- You or your child is having **trouble breathing**
- You or your child is **not responsive or experiencing a seizure**
- You or your child has any other **issues that may be life-threatening**

Call the clinic and go to Mott Emergency Department, or go to your local ER (if you live more than 30 minutes away from the University of Michigan), if you notice these symptoms:

- **Fever:** We have given you a thermometer. You do not need to routinely check your temperature unless you are concerned about fever. If you need to check your temperature, do so orally (under the tongue). Rectal temperatures are not recommended for children with cancer. It's a good idea to keep a bag packed at home, just in case, as a fever usually means you will need to check into the hospital. **Call the clinic and go to the ER if your thermometer has these readings:**
  - 2 temperature readings (done 1 hour apart) of 100.4 °F (38 °C) or higher
  - 1 temperature reading of 100.9 °F (38.3 °C) or higher
  - Any temperature reading above 98.6 °F (37 °C) with concerning symptoms such as cough, congestion, behavior changes, etc.

- **Cognitive symptoms:** This may include new weakness, extreme sleepiness or drowsiness, changes in mental status or behavior, vision changes (such as double or blurred vision), or increased pain or headaches.
- **Bleeding:** This includes nosebleeds that last longer than 10 minutes, red or black bowel movements, red or dark brown vomiting, red urine, or an increase in bruising.
- **GI symptoms:** This includes constipation or vomiting that is not helped with prescribed medications, diarrhea or pain with bowel movements, pain with urination, not being able to eat or drink, or not being able to take oral (by mouth) medications.
- **Central line problems:** This may include any pain, redness, drainage (leaking fluid) or swollen areas around central lines or port sites, a break, crack, or tear in the central line, or issues with flushing or leaking from your catheter.

## What is the contact information for my BMT team?

If you have any concerns or any of the symptoms listed above, please contact your BMT team:

- Monday through Friday 8:00 AM – 5:00 PM: Call the BMT clinic and nurse line at (734) 936-9814.
- After clinic hours and on weekends: Call (734) 936-9814 and ask for the BMT provider on-call.

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