

## Patient Discharge Instructions After CAR-T Cell Therapy

---

### About CAR-T Cell Therapy

There are novel therapies called Immune effector cells (*IEC*) that involve using a specialized cell in the human body. These cells use a patient's own immune system (*T-cells*) to destroy cancer cells. A Chimeric Antigen Receptor (*CAR*) T-cell therapy is a type of immunotherapy that uses genetically modified T-cells to target and destroy cancer cells. The cells are then given back to you through an infusion to treat cancer. You may also receive chemotherapy before the CAR-T cells are infused. After receiving CAR-T cell therapy infusion, it is important to monitor your health closely and to follow specific care instructions to ensure safety and effectiveness.

### What to Expect After CAR-T Cell Treatment

- Have a caregiver, family member, or friend with you for the first 4 weeks after the infusion to support you with monitoring side effects and symptoms.
- Do not drive, operate heavy equipment, or do anything that may be unsafe for at least 8 weeks after your infusion. This treatment can cause temporary memory and coordination problems, sleepiness, confusion, weakness, dizziness, and seizures.
- Call your care team right away if you become ill. Your doctor will check to see if your treatment is working and help you with any side effects that occur. After that, the care team will ask you to come back to the clinic for regular scheduled visits. You will also follow a life-long plan to monitor you for cancer. - Avoid large crowds and sick individuals to reduce the risk of infection.
- Report any new or uncommon symptoms to your care team right away
- Side effects from your treatment may include a severe flu-like syndrome that involves high fevers, chills, nausea and aches. This can also lead to trouble breathing and problems getting enough oxygen, as well as very low blood pressure that can be serious and dangerous.
- Your care team will give you or your caregiver a wallet card to carry with you. It lists all the signs, symptoms and life-threatening events, including cytokine release syndrome (*CRS*) and neuro (brain) toxic condition known as immune effector associated neurotoxicity (*ICANS*) that may occur. Go to the nearest hospital emergency center right away because this condition requires urgent care. You will be evaluated and admitted to the hospital right away if you develop any signs or symptoms of this condition.

## Important Information to Consider

### Infection

*Hand washing* is the most important thing you can do to help prevent the spread of infection. Wash your hands often with soap and water before you eat and after you use the bathroom. Sing “Happy Birthday” 3 times to help you scrub for at least 20 seconds.

Also wash your hands:

- Wash your hands after being outdoors, using the phone and doing housework
- If you encounter body fluids, such as mucus or blood
- Before and after handling food

*Neutropenia* happens when your white blood counts are low (neutropenic). Your white blood counts are a part of the immune system that helps fight infection in the body. You must take extra precautions to reduce your risk of infection.

- Wear a mask when out in public areas
- Good hand hygiene
- Stay away from sick people who may be sick
- Stay away from people who have recently received a live vaccination within the last 8 weeks.

### Precautions

**Bleeding** can occur if your platelet count is below 50,000 when you leave the hospital. This means that your body reduces the ability to form clots and thus can cause your body to bleed and bruise easily.

- Do not use a razor or blade to shave. Electric shavers are okay to use
- Blow your nose gently to prevent nosebleeds
- Avoid using suppository or enemas to avoid any rectal bleeding
- Use a soft bristle toothbrush to prevent gum bleeding
- If bleeding occurs, apply pressure to the injured area for 5-10 minutes or until the site stops bleeding

**Pets and Plants** are safe to be around, if you limit close contact with them due to your immunocompromised status.

- Do not allow your pets to lick your face or sleep in the same bed with you
- Avoid handling bird cages, litter boxes and contact with pet urine and stool while you are recovering from CAR-T cell therapy.

- While you are neutropenic (low white count), avoid activities that could potentially cause cuts, injury or bleeding that can lead to infection.
- Always wear gloves when handling plants, dirt and soil in the garden

## ***Skin care***

- You should bathe or shower everyday using hypoallergenic soap.
- Use a mild moisturizer to help with dry skin.
- Limit sun exposure to no more than 30min every day. Your skin becomes very sensitive after undergoing chemotherapy and CAR-T cell treatment.
- Prefer to wear long sleeve tops, pants, sunglasses and a hat when spending time outdoors
- Use sunscreen with an SPF 30 or higher on all exposed skin areas any time you are in the sun
- Avoid going out on your barefoot. Always wear shoes or slippers

## ***Oral Care***

- Brush your teeth, gums and tongue after each meal and before bedtime with a soft bristle toothbrush using a slow brushing motion.
- Use regular toothpaste with fluoride without tartar control
- After you brush your teeth, rinse your mouth with the baking soda solution.
- Each day, make your own baking soda solution. Mix 1 teaspoon of baking soda with 12 to 14 ounces of water.
- Swish 1 to 2 ounces of the baking soda solution in your mouth for 30 seconds and then spit it out. You may also gargle with the rinse for several seconds before you spit it out.
- Rinse every 2 or 3 hours while you are awake, especially after meals and at bedtime. Do not rinse with the baking soda more than 6 times a day.
- You may rinse with a non-alcohol mouthwash. Do not use mouthwash products that contain alcohol or phenol because this irritates the mouth.
- Do not use toothpicks or dental floss when your platelet counts are below 50,000 and neutrophil count is below 1,500.
- Take care of dentures, braces or other dental products as normal
- Talk with your doctor if you see white patches on your tongue or mouth or if you have painful mouth sores.

## Nutrition

- Eat a well-balanced diet. If you have a poor appetite, try to eat smaller meals more often. Unless directed otherwise, drink 8 to 12 glasses of fluids (no alcohol or caffeine) to help prevent constipation. Include foods in your diet that help you have a bowel movement, such as prunes, prune juice and warm liquids
- Do not eat or drink anything that may be undercooked or spoiled, such as raw vegetables,
- meat, fish, or anything that you are not sure of is safe.
- Be sure you know how to cook and store food safely. Wash fresh fruits and vegetables well
- Avoid buffet style restaurants and salad bars.
- Do not eat foods and drinks that are high in sugar, especially if you are diabetic or have nausea. To help with nausea, drink clear liquids and eat non-spicy, non-fat meals.
- You may chew sugar-free gum or suck on sugar-free ice pops or hard candy to help with dry mouth.

## Activity and Daily Life

- Avoid driving or operating heavy machinery for at least 8 weeks or until your doctor clears you to do so.
- Take your temperature at least twice a day or as needed. Keep a log to track your temperature trends.
- You must stay within a 2-hour distance drive from Baptist MD Anderson Jacksonville Hospital in case an onset of CRS or Neurotoxicity occurs.
- Make sure to carry and present your CAR-T product wallet card in case of an emergency.
- Get plenty of rest and sleep. Be sure to balance rest and sleep with your normal day-to-day activities. You may resume most of your normal activities, but you may get tired easily. Slowly increase your day-to-day activities and rest between activities.
- Keep a log or journal of all your symptoms and activities to better manage your energy level
- Do not return to work until your doctor clears you to do so
- You may exercise as directed by your doctor, physical therapist or occupational therapist. Walking helps with fatigue, increases blood counts, and lowers the risk of blood clots. It can also help you with your treatment plan.

## Medications

- Take all the medications exactly as prescribed by your doctor. These may include antiviral, antibiotic, anti-fungal, anti-inflammatory and anti-seizure medications.
- Your care team pharmacist will provide and review your medication schedule with you prior to going home.
- Make sure to pick up any new prescriptions and refills from your local pharmacy to prevent delays in the medication schedule.
- Do not take any over-the-counter medications or supplements without consulting your doctor.

## Monitoring for Side Effects

Watch for the following symptoms and notify your healthcare provider if they occur. Make sure to always have your CAR-T product wallet CARD with you. It lists all the possible symptoms of CRS and Neurotoxicity. Notify your provider and proceed to the emergency department if you experience any of the symptoms described below:

*Cytokine Release Syndrome (CRS)* is a serious condition related to CAR-T cell treatment. Cytokines are proteins that are released by the T-cells (a part of your immune system). They communicate with specific immune cells to attack present cancer cells. Cytokines can cause inflammatory symptoms that is similar to someone with a severe infection.

### Signs and Symptoms of CRS:

- Fever of 100.4 Fahrenheit (38 Celsius) or higher with increased fatigue
- Shortness of breath, rapid or difficulty breathing
- Abnormal heart rhythm, rapid heart rate, low blood pressure and symptoms of heart failure
- Nausea, vomiting and diarrhea
- Liver damage, inflammation or injury
- Kidney damage, inflammation or injury
- Bleeding problems

Treatment of CRS symptoms is based on a grading scale. Grade 2 or higher requires immediate treatment with a *steroid* and *Tocilizumab* to reduce symptoms.

***Immune Effector Cell Neurotoxicity syndrome (ICANS)*** is a serious brain toxic condition that is associated with CAR-T cell treatment and may be related to CRS.

Possible side effects include:

- Subtle or sudden confusion, delirium, agitation, hallucinations
- Headaches, vision changes and increase pressure in the head

- Problems with speech or unable to comprehend or use language
- Tremors or seizures
- Problems with walking and maintaining gait balance
- Muscle weakness and inability to control bowel and bladder function

***Tumor Lysis Syndrome (TLS)*** is a metabolic condition that occurs when cells or cancer cells are rapidly breaking down, dies and releases its contents in the blood stream. It typically starts in the beginning of CAR-T cell therapy. This can be serious and life threatening if not managed in a timely manner. Standard supportive therapy including IV fluids, Electrolytes replacement (calcium, potassium, magnesium, sodium, phosphate and chloride) and organ function lab test are routinely performed during this event.

***B-cell Aplasia*** occurs when B cells (part of the immune system) are low or absent. This occurs after CAR-T cell therapy because it targets antigens on both the cancerous B cells, as well as the normal functioning B cells. When B cells are reduced or absent, your body lacks the ability to make sufficient amounts of antibodies that can help protect you against infection. Treatment for this B cell condition is typically done through Immunoglobulins (blood plasma) IV infusion.

## When to call with urgent medical concerns after hours (Weekends and Holidays)

- Fever of 100.4 Fahrenheit (38 Celsius)
- Nausea and vomiting longer than 24hrs that is unresolved
- Diarrhea longer than 48hrs
- Burning or painful urination
- Constipation is longer than 72hrs
- Worsening or new onset of pain
- Difficulty with eating and drinking
- Dizziness
- Bleeding
- New Rash
- Swelling, pain, or numbness in the arms and legs

## When to Seek Emergency Help

***Go to the emergency room or call 911 if you experience:***

- Difficulty or irregular breathing
- Stroke like symptoms (facial droop, slurred speech, sudden weakness or confusion)
- Uncontrolled bleeding

- Chest pain
- Severe abdominal pain
- Irregular or abnormal heartbeat
- Uncontrolled Nausea, Vomiting, and Diarrhea
- New Seizure
- Unresponsiveness or sudden changes in consciousness

## Follow-Up Care

Your doctor will order a PET scan and lab test to evaluate your overall response to CAR-T cell therapy. You can expect to see your doctor frequently for the first few weeks after CAR-T cell therapy. You may discuss your short and long-term follow-up plans at your next clinic visit. It is important to note and report any possible side effects of CRS or ICANS right away and proceed to the nearest hospital emergency center. Remember to always present your CAR-T product wallet card to help expedite your care and treatment once you arrive. It is essential to attend all follow-up visits and tests to monitor your progress and detect any complications early.

Things to keep in mind before your follow-up visit:

- Be sure to get your lab work completed on time before your next provider visit
- Write down any questions or concerns ahead of time to make sure it is discussed during your appointment
- Be prepared and flexible with your appointment schedule as you may need same day supportive treatments (ex. IV infusion, blood transfusion, additional labs and tests etc.)
- Always Have a caregiver with you to help with transportation and understanding important medical information updates from your provider while you are recovering.

BMDA Reviewed 4/18/2025.