



# The Jewish Hospital — Mercy Health Blood Cancer Center

## CAR-T Patient Handbook

The Jewish Hospital 

 MERCYHEALTH



# Welcome

## **Dear Patient and Family,**

Welcome to The Jewish Hospital — Mercy Health Blood Cancer Center. 30 years ago, we began performing bone marrow transplants and today we are proud to have cared for thousands of patients in Cincinnati and surrounding areas. Our facility is Foundation for the Accreditation of Cellular Therapy (FACT) accredited as well as Joint Commission accredited in Bone Marrow Transplant and Leukemia. Here at the Blood Cancer Center we believe in a multi-disciplinary approach to your care. Our team of trained physicians, nurse practitioners, bone marrow transplant certified nurses and pharmacists are experts in the field of Bone Marrow transplant and Chimeric Antigen Receptor Therapy (CAR-T). We are very excited to partner with you as we embark on your healthcare journey!

This binder will be a resource for you throughout your CAR-T therapy process. You will find helpful tips and information throughout the process in here. We know that this process may cause you to feel overwhelmed so just know that we look forward to the questions you may have! The staff here at the Blood Cancer Center are here to help you in any way that we can.

Thank you for entrusting us with your care. We are truly committed to providing compassionate, comprehensive care for you and your family during this time.

Sincerely,

**Your Blood Cancer Center Team**

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## Contact Information

QUESTIONS/CONCERNS	PHONE NUMBER
<b>Medical Emergency</b> . . . . .	Call 911
<b>Medical Questions/Concerns</b> . . . . .	.513-751-CARE
<b>Jewish Hospital Transplant Office</b> . . . . .	.513-686-5482
<b>Jewish Hospital Outpatient Infusion Center</b> . . . . .	.513-686-5260
<b>Jewish Hospital Inpatient Blood Cancer Center</b> . . . . .	.513-686-5250



# Chimeric Antigen Receptor Therapy (CAR-T)

## What is the process of being treated with CAR-T cell therapy?

1. Your T cells are collected from your bloodstream through a process called apheresis. This process is similar to donating blood and it takes a few hours in the clinic.
2. Then, your T cells are sent to a lab to be treated with gene therapy. Your T cells' genes are reprogrammed so that they make special proteins called CARs. CAR stands for Chimeric Antigen Receptor. The CAR-T cells are grown in a lab for 2-6 weeks until there are millions of them. During this time, you'll be at home or getting other treatments.
3. About 1 week before the CAR-T cells are given to you, you'll go to outpatient infusion to get standard chemotherapy infusions. These drugs are given to remove your regular T cells to make room for the CAR-T cells.
4. You'll be in Outpatient Infusion on the day of your CAR-T cell infusion. The infusion takes about 15 to 30 minutes. You'll be closely monitored for several hours afterwards. You'll go home if the doctors think you are doing well.
5. Treatment isn't over after the infusion. You will be seen daily in the Outpatient setting following the infusion. Once you are doing well enough the visits will change in frequency.

## What are the side effects of CAR-T therapy?

There are potential side effects from receiving CAR-T cells. You will need to call the doctor immediately if you experience any of the below side effects:

- **Cytokine Release Syndrome (CRS)**

CAR-T cell therapy can cause a strong immune reaction, similar to a severe allergy or serious infection. This can happen anytime during the first few weeks after treatment. Most people have some CRS and it ranges from mild to life-threatening. Some signs of CRS include fevers, chills, sore throat, headaches, rash and worsening fatigue.

- **Neurotoxicity**

CAR-T cell therapy can affect your brain. Some people have had seizures, confusion or forgetfulness after CAR-T cell infusions. It's important for your caregivers to report any changes in your speech, memory or coordination to your doctor right away.

# What to Expect on CAR-T infusion day

## Where will the procedure take place?

- Your transplant will take place in your room with you lying in bed. You may have visitors if you like, as long as they are not sick.

## How will I prepare for the procedure?

- You will be placed on the heart monitor during the infusion and the nurse will be in your room through the whole process. The nurse will also be getting your vital signs every 15 minutes through the transplant.
- You will receive Tylenol® and Benadryl® prior to the procedure.

## What will happen during the infusion of stem cells?

- Hoxworth will bring the cells to your room. We double check them to ensure you are receiving the correct cells.
- Your cells will either be in a very small bag that is yellow to clear tinted or in a syringe. They will be infused through your central line.
- The infusion will take about 15-30 minutes.
- We will monitor you closely during the infusion and will take vital signs every 15 minutes.

## What are the common side-effects?

The common side effects for this procedure include:

- Change in vital signs: fever, increase in blood pressure/heart rate. There may also be a decrease in your oxygenation and we may temporarily place you on oxygen.
- Heaviness in your chest or a feeling of pressure in your chest.
- Back pain or flank pain
- Chills, shivers or shakes, also called rigors.
- Itchiness and/or redness to skin

Side effects can be treated by slowing the infusion. We will monitor you closely during infusion of your stem cells with frequent vital signs and adjust the pace as needed.

The medications you received prior to the procedure, will help to prevent serious transfusion reactions, such as:

- Fever
- Shortness of breath
- Swelling of the throat
- Itching/hives

If this happens, we would stop your infusion and manage your symptoms. Once the procedure is completed, it is very unlikely you will have any further reactions.

## What happens after the infusion?

- Your transplant will take place in your room with you lying in bed. You may have visitors if you like, as long as they are not sick.

## Your Health Care Team

**Your CAR-T Team includes the following professionals:**

### Doctors

Throughout the CAR-T process your care will be provided by a Bone Marrow Transplant and CAR-T trained physician. He/she will see you daily to answer questions you may have and keep you informed of progress. The physicians rotate to the inpatient unit and the clinic every 4 weeks and weekend coverage will alternate as well. Because of this, you will have the opportunity to receive care from a few doctors during your hospitalization and recovery period. Weekly meetings are held with the doctors and other members of the multi-disciplinary team to keep everyone up to date on the status of every patient.

### Nurse Practitioners

While you are admitted to the hospital or in the Outpatient setting for your transplant the nurse practitioners have day to day responsibility for your care. The Nurse Practitioners work in close collaboration with your physician in both the inpatient and the outpatient setting.

### Transplant Coordinators

Your pre-transplant nurse coordinator tracks your treatment prior to your CAR-T admission and plans the necessary treatment and testing you will need to get ready for the therapy. The transplant coordinator is your primary point of contact as you work your way to your infusion day.

### Inpatient and Outpatient Nurses

These nurses are trained and experienced in the care and specific needs of bone marrow transplant and CAR-T patients. Your inpatient staff nurses organize your care from the time you are admitted until you are discharged from the hospital. Once admitted, your nurse will begin education and what you should expect throughout the process. They will also be available to help you and your family with physical or emotional problems as they may arise. Throughout your

hospitalization, they will provide ongoing education about the transplant process in preparation for your discharge. Majority of the inpatient staff nurses are certified in bone marrow transplant and hold a specific certification that you may see on their badges called the BMTCN.

### Discharge Planner

This nurse will specifically help you in your preparation for discharge if you have to be admitted to the hospital. They partner with the social work team to ensure that everything is prepared for you to be discharged home. This nurse also ensures that you have the medications you need when you are discharged and schedules your follow-up appointment in the clinic.

### Social Workers

Part of your required CAR-T preparation is an initial psychosocial assessment with a social worker that will give you the opportunity to discuss non-medical needs and other concerns you may have. Social work is available to provide as needed mental health support services in partnership with our psychologist. Social workers are available to provide assistance with coping with the stress of hospitalization or post-CAR-T complications. They are available to address practical matters as well, including education regarding social security, disability, caregiver planning, community resources, financial stress and referrals to insurance specialists.

### Psychologist

The Psychologist will also complete an assessment prior to your CAR-T therapy that will give you the opportunity to discuss any social concerns you may have. Caregivers will also have the opportunity to express any concerns they may be feeling during this evaluation as well. The Psychologist will occasionally round with the inpatient team to check in on you and your family.

## Preparing for Your Journey

### Dietitians

The dietitian will check in with you while you are inpatient to explain any diet considerations during your hospital stay and when you go home. They also work with you to set up nutritional goals to prevent weight loss, help with mouth sores, follow your nutritional intake and offer suggestions on how to achieve your nutrition requirements.

### Clinical Pharmacists

A clinical pharmacist participates in the planning of your chemotherapy and other medications you receive as a CAR-T patient. They are available to answer any questions you may have regarding the medications you are receiving.

### Hoxworth Cellular Therapy

This team of individuals are responsible for collecting and processing your T Cells. A cellular therapy technician brings your cells to the bedside on the day of your infusion.

### Physical/Occupational Therapists (PT/OT)

A physical and occupational therapist may see you and assist you if you are admitted to the hospital to help you maintain your strength and endurance during and after your CAR-T infusion.

### Inpatient Spiritual Care

A chaplain is a supportive care resource for coping with the stress of therapy. They are available to provide you with spiritual and religious resources.

### Patient Care Assistants (PCA)

A PCA will assist you with daily activities including hygiene and mouth care, assessing your vital signs, changing your linens and collecting your weight daily if you are admitted to the hospital.



We understand that being in the hospital can be difficult. The Blood Cancer Center team encourages you to bring personal items to make the hospital room feel more like home if you have to be admitted. Items from home can also provide distraction and often help decrease stress and boredom. The items listed below are offered as suggestions. Remember your room size is limited. Check with your nurse or transplant coordinator or social worker if you have questions about items that are not on the list.

### Items to consider bringing:

- Pajamas, sweats, or loose-fitting, comfortable street clothing to change daily
- Clean underwear to change daily
- Slippers with non-skid bottoms or slip on shoes
- Shoes to walk the halls/ride exercise bikes
- Scarves, hats, turbans
- Pillows and blankets may be brought in but must be washed frequently
- Electric Razors ONLY
- Soft toothbrush, toothpaste
- Night light
- Silk plants/silk flowers (Real flowers are not allowed within the unit)
- Favorite photos or decorations (Command strips are allowed for hanging purposes)
- Cell phones and chargers
- Electronic devices (cell phones, laptops, ipads, etc) and chargers
- Leisure activities such as magazines, books, puzzles, games, cards, or crafts
- A journal, stationary, stamps and envelopes
- Pre-packaged snacks for your room and drinks that are bottled or in cans
- 1-2 days of perishable food items that may be brought in and stored in the refrigerator on the unit

### Items **NOT** to bring:

- Dental floss
- Regular razors
- Tampons
- Refrigerators or other small appliances
- Fans
- Live plants/flowers
- Valuables
- Tight restrictive clothing
- Finger nail clippers
- Artificial nails
- Sources of standing water (humidifiers, vases of water with flowers, diffusers, etc)
- Home medications (Actual) – Do bring a list of medications you are taking
- Bar soap or loofah



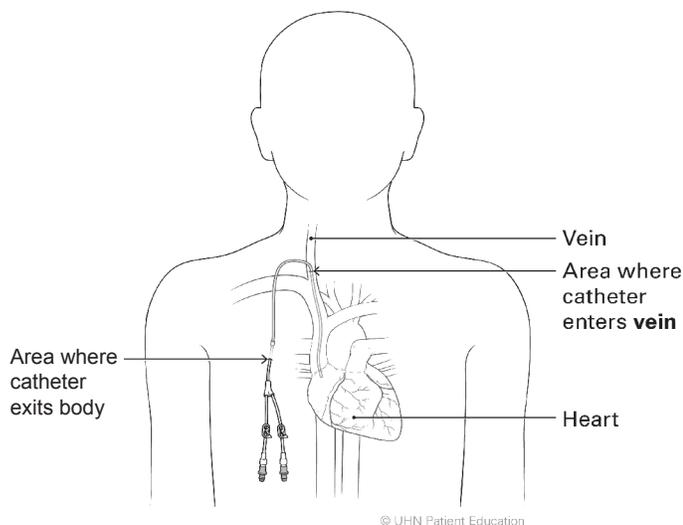
## The Tunneled Catheter

### What is a tunneled catheter?

A tunneled catheter is a small tube made of material called silicone. It is called “tunneled” because it is inserted into a large vein and tunneled under the skin to a place where it exits your body. In this handout, we will simply refer to it as a catheter.

### Why are tunneled catheters used?

A catheter is used to give medications, fluids, blood products, chemotherapy, T cells, or nutrition through a vein. It may also be used for drawing blood or for apheresis.



### How is the catheter inserted?

The catheter is inserted in an operating room or radiology department and should take about 30-60 minutes to insert. The practitioner makes a small opening in the mid chest area. Another opening is made where the catheter enters the vein. A tunnel is formed under the skin between the two openings. The catheter is passed through this tunnel and then gently threaded until the tip is near your heart in the large vein called the superior vena cava. After placement, the catheter will be checked to confirm it is in the right place. Every time you get admitted to the hospital you will receive a chest X-ray to confirm that the line is in the correct place.

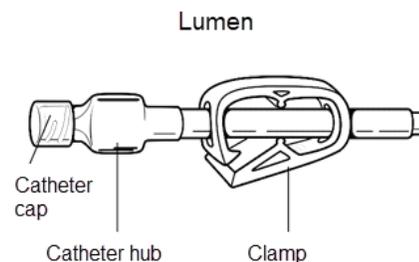
### What is a cuff?

Most catheters have a small cuff that lies beneath the skin about one to four inches from the exit site. The cuff serves two main purposes:

1. The cuff holds the catheter in place by forming scar tissue. Scar tissue will grow around the cuff after 1-2 weeks, making it difficult to pull the catheter out.
2. The cuff helps protect against infection by blocking bacteria from entering the exit site.

### What is a lumen?

The word lumen means the opening or path that is inside the catheter. It is through the opening that you give medications or blood can be drawn. We also use this word to describe the ends of the catheter that are outside your body. You will notice that your catheter has 1, 2, or 3 lumens (see image below).



*Adapted from “Care of Tunneled Catheter” Manual 2016*



## Pre-Infusion Information

### Apheresis Instructions

Apheresis is performed as an outpatient procedure and usually takes 5 hours per procedure. You will have 1 to 4 procedures done to collect the required number of T cells.

Apheresis is done by inserting a needle into one arm and connecting the IV tubing to a machine where the peripheral stem cells are separated and collected. The remaining blood components (white cells, red cells, and platelets) are returned to you through another IV in your other arm or through the other lumen of your tunneled catheter.

You will need to report to Outpatient Infusion early in the morning the day of your apheresis procedure. Someone should accompany you this appointment and drive you home.

#### Before your apheresis:

- Eat a normal breakfast
- Drink a full 8oz glass of milk; you need calcium for the procedure
- Take the prescription medication you usually take, unless you were told otherwise. (Notify the apheresis nurse of all medication taken)
- If you are on blood pressure medication, do NOT take it the day of the procedure
- Do not take over-the-counter medications unless approved by your physician. (You may take Tylenol or Claritin)

**Questions?** If you have questions regarding this procedure, please call your transplant coordinator or the outpatient infusion department at 513-686-5260.

## CAR-T Basics and Individualized Information

# CAR-T Basics and Individualized Information

Kymriah® Resources

<https://www.us.kymriah.com/acute-lymphoblastic-leukemia-children/about-kymriah/understanding-kymriah/>

Yescarta® Resources

<https://www.yescarta.com/about-car-t>

Leukemia and Lymphoma Society Resources

<https://www.lls.org/treatment/types-of-treatment/immunotherapy/chimeric-antigen-receptor-car-t-cell-therapy>

Be the Match Resources

<https://bethematch.org/patients-and-families/about-transplant/clinical-trials/car-t-cell-therapy/>

### **Food Safety for Transplant Recipients:**

A need-to-know guide for bone marrow and solid organ transplant recipients (FDA)

<https://www.fda.gov/media/83755/download>



## Psychosocial Support and Resources

A core member of your Blood Cancer Center team is the clinical social worker and clinical psychologist. You will work with them through your CAR-T journey.

Included in the required CAR-T preparation process is for you and your caregiver(s) to meet with the social worker and psychologist for an initial psychosocial assessment. All patients being considered for CAR-T therapy must be cleared by social work and psychologist to proceed.

The assessment is a comprehensive review to help you and the social worker identify and discuss any concerns you and your caregiver(s) may have, as well as evaluating the following areas:

- Support system
- Caregiver plans
- Lodging plans (patient must be living within 45 minutes of the facility)
- Work, financial, insurance and disability concerns
- Past and current use of drugs and alcohol
- Understanding the need for abstinence from drugs and alcohol

- Coping and mental health support
- Supporters of your family and caregivers and how they are coping
- Understanding and adjustment to the transplant process by you, your family and caregivers
- Ability to follow your treatment plan
- Goals of care

Our social worker and psychologist provide expert assistance with the psychological, social, emotional and practical needs of CAR-T patients and their families. They are available for counseling, education, advocacy and resource identification before, during and after CAR-T as needed.

## Additional Support Resources for You

### Wednesday Caregiver Lunches

There is a lunch held at noon every Wednesday for your caregivers while you are in the hospital. The social worker, psychologist attend these lunches and this is a great time for your caregiver to receive support from other caregivers who are going through a similar situation as you.

### Cincinnati Cancer Support Community

The Cancer Support Communities mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. This group provides many resources to help you through this difficult time. You can find their website by clicking this link

<https://www.cancersupportcommunity.org/>

### BMT Info Net

Blood and Marrow Transplant Information Network (BMT InfoNet) is not-for-profit organization dedicated to providing transplant patients, survivors and their loved ones with emotional support and high quality, easy to understand information about bone marrow, peripheral blood stem cell and cord blood transplants. Their goal is to empower you with credible information and emotional support, so that you can take a more active role in decisions affecting your health and treatment options before, during and after transplant. You can find their website by clicking this link

<https://www.bmtinfonet.org/>

## Pre-Transplant Patient Checklist: CAR-T Therapy

A successful response from CAR-T requires commitment not only from you and your medical team, but from your support system as well. To ensure the best transplant outcomes, it is vital that you, the staff, and your family and friends partner together before, during and after transplant. To ensure this, all areas below must be addressed before moving forward with your CAR-T infusion and will be confirmed by your BMT doctor, transplant coordinator and social worker. Please note that failure to comply with, or providing false information regarding any of the following may result in your CAR-T candidacy being placed on hold temporarily or indefinitely, as determined by the health care team.

- **Caregiver:** One of the most important requirements for every patient is to have **a minimum of one full-time primary caregiver** residing with you within 45 minutes from The Jewish Hospital and attending all of your medical appointments for approximately 3 months after hospital discharge.

**Note:** Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are **not** acceptable caregiver options.
- **Treatment compliance:** A crucial part of successful CAR-T therapy is for you to participate as a partner in achieving your health care goals. You are therefore required to follow the treatment plan recommended by the team before, during and after transplant. This includes but is not limited to: attending all appointments and taking medication as prescribed to you.
- **Alcohol, nicotine and illicit drug use:** All patients are required to stop the use of non-prescription substances before, during and after CAR-T therapy. Alcohol abuse screening, as well as drug and nicotine testing, will be used as necessary to ensure your safety. If you smoke, please ask your team for any resources for smoking cessation.
- **Mental health:** Your mental health status is a key aspect of care when seeking the best transplant outcomes. With or without a previous mental health diagnosis you can still be affected by depression, anxiety or have other coping concerns from your cancer diagnosis or treatment. Your health care team may recommend consultation or ongoing follow-up with a mental health provider as part of your care.
- **Lodging:** If you reside over 45 minutes away from the hospital (mileage will be verified), you will be required to secure and pay for temporary lodging within 45 minutes of the hospital (preferably Blue Ash area) to ensure safe recovery for both yourself and your caregiver **for approximately 3 months after hospital discharge.**
- **Transportation:** While you are in need of caregiver support you are also in need of transportation assistance. You will be unable to drive until cleared by your physician. Caregivers are often also your driver and are required to attend all appointments with you.
- **Dental care:** you are required to undergo a complete dental exam, including a full set of dental X-rays or panorex, and to provide copy of the completed evaluation and treatment plan to your transplant coordinator.
- **Advance Directives/Durable Power of Attorney for Health Care:** As an able, competent adult, you have the right to accept or refuse medical treatment. Should you become too sick to make decisions regarding your medical care, even for only a period of time, "Advance Directives" allow you to identify who you would want to make the decisions on your behalf. To ensure your wishes are met, you are encouraged provide a completed Durable Power of Attorney for Health Care document. Our social worker can assist you in this process.

## Caregiver Responsibilities Agreement: CAR-T Therapy

Successful CAR-T therapy requires commitment not only from the patient and medical team, but from the patient's support system as well. Each patient requires a **minimum** of one full time caregiver.

A caregiver is a responsible adult family member or friend who is able and willing to provide physical care, observation, reliable transportation and emotional support throughout the CAR-T process. Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are **not** acceptable caregiver options. The caregiver or alternate must be available as needed during the entire transplant process, including but not limited to:

- Pre-CAR-T evaluation
- Education classes
- Weekly visits during hospital admission
- Full-time following discharge from the hospital

Being a caregiver for a transplant patient is a vital role. Please consider the following list of responsibilities and requirements from the transplant center before agreeing to this commitment.

- I/we will be available 24 hours a day upon discharge, for about 3 months or for as long as medically required by the physician.
- I will carry a cell phone with me at all times.
- I/we will reside with the patient, within 45 minutes of The Jewish Hospital, for about 3 months or for as long as required by the physician. If the patient's primary residence is not within 45 minutes, I/we will arrange temporary lodging post-CAR-T therapy that is within 45 minutes of the hospital.

- I/we will attend the education sessions provided by The Jewish Hospital.
- I/we will review the materials and treatment instructions provided by The Jewish Hospital.
- I/we will ask the Blood Cancer Center team questions and will be available for communication as needed.
- I/we will provide the patient's transportation to all appointments.
- I/we will be with the patient at all appointments (early morning appointments are standard).
- I/we will have an understanding of the patient's medications, assist with administration as needed and keep a log.
- I/we will follow the Blood Cancer Center's instructions and precautions regarding infection prevention
- I/we will coordinate food preparation, maintain a clean home environment and assist with daily living functions.
- I/we will follow the treatment plan and any additional requirements set by the health care team.
- I/we will receive the flu vaccine in the months of October-March unless contraindicated for my health

Caregiver Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## What to Expect in the Outpatient Infusion Department Daily

# What to Expect in the Outpatient Infusion Department Daily

- You will be seen daily in Outpatient Infusion unless the physician team feels that you need to be admitted to the inpatient unit due to side effects from the CAR-T cell therapy.
- You are required to stay within 45 minutes of the hospital for at least the first 30 days after your infusion.
- The unit secretary will give you an appointment time for the following day's appointment. Your appointment time will most likely be at 8 a.m., 8:30 a.m. or 9 a.m. Please arrive at the time you are scheduled.
- Please expect to be there for your appointment for 4-5 hours per day.
- Once you arrive the outpatient nurses will begin by drawing your labs for the day and awaiting the results.
- The outpatient nurses will also begin with a full assessment, listening to your heart and lungs. They will also complete the neurologic assessment to monitor a potential side effect of CAR-T therapy.
- The neurologic assessment includes several tasks that the staff will either ask you to do or repeat. This includes, counting backwards from 100 by 10. Telling the staff the year, month, city and hospital, naming 3 objects the nurses will point to, following a command (i.e. Show me two fingers, stick out your tongue and close your eyes, etc.) and the ability to write a standard sentence. This neurologic exam will take place daily while in outpatient infusion and every 4 hours if admitted to the hospital.
- Once we receive the lab results the nurses and physicians will determine if there are any blood products, fluids or electrolytes that you need at that time.
- We ask that you keep a log (at the back of this handbook) to determine if you are having any episodes of nausea, vomiting, diarrhea while you are at home. We also would like you to keep track of what you are eating and drinking so we can document it as well.
- The dietitian will follow up with you in Outpatient Infusion to determine if there are any areas for improvement with your nutrition.
- The interdisciplinary team of your physician, inpatient nurse practitioner and pharmacist will round on you daily in the outpatient infusion area as if you are in the hospital.

## What to Expect During your Hospital Stay if you are admitted



### Upon Admission

- We will take you on a tour of the unit and show you where the nutrition room, family lounge and laundry room are. We will also show you the walking trail for the hallways at this time.
- We will ask you several questions regarding your medications, screening questions and other required documentation that must be completed on admission day. Your home medications can stay home with your family while you are admitted to the hospital. We will dispense all of your medications through our pharmacy. In the rare event that you take medication that we don't stock, we will send your own home medication to pharmacy to verify it and then we will keep it locked in our medication dispenser.
- A Jewish Hospital ambassador will come to your room to take your meal orders. Breakfast is typically delivered around 7:30 a.m., lunch around 11:30 a.m. and dinner around 4:30 p.m. These times could vary depending on the needs of the kitchen.
- There is a freezer and fridge in the nutrition room that is available for you to use. We ask that this freezer and fridge are only used for patient personal food items. There is a separate fridge and freezer for the families in the family kitchen area outside of the unit. We ask that when you place food in the fridge and freezers that you put a label with room number and patient initials on the food items. We also ask that the patient fridge does not contain any items off food trays, no fast food or restaurant items and no partially consumed foods (all foods need to be individual servings, this includes drinks and condiments). There is limited space available so please limit the amount of food you are bringing in at a time. Food and drinks will be discarded if they do not meet the above requirements.
- There is a small couch that converts to a bed for an overnight visitor. Please see section below regarding our visitor policy.

## What to Expect During your Hospital Stay if you are admitted

### Nursing Care

- The nurses will do your vital signs every 4 hours at a minimum, even overnight.
- Each nurse you have will do a full assessment of you and your symptoms. They will listen to your heart, lungs, look in your mouth and ask you questions about pain, nausea, diarrhea, etc.
- **Every 4 hours we will complete a neurologic assessment to ensure you are not developing neurologic toxicity.**
- Every shift we will get your Orthostatic Blood pressures. This means that we will get your blood pressure lying, sitting, standing and then standing again to see if your blood pressure drops when you change positions. We have found that many of our patient falls were related to a patient standing and their blood pressure dropping quickly. If we find that you are orthostatic, then we will most likely implement a bed alarm until we discuss with the nurse practitioner and most likely treat you with IV fluids.
- Labs are drawn every morning at 4 am.
- Weights are completed every morning before 9 am.
- The Patient Care Assistants will assist you in showering and changing of your bed daily. We require you to shower and change your bed daily to prevent infection.
- The doctor and the rest of the transplant team will come by each day to examine you and update you on your treatment plan.

### Blood Cancer Center Visitor Policy:

**Children under the age of 2 will not be permitted on the Blood Cancer Center due to vaccination schedules. All visitors between the ages of 2 through 18 are permitted to visit with the screening performed by an RN at the front desk.**

1. Children must be able to demonstrate appropriate hand hygiene and isolation precautions.
2. All visitors with potential communicable diseases, including but not limited to: Upper Respiratory illness, influenza like symptoms, recent exposure to communicable disease, active shingles rash, Varicella Zoster Virus like rash within 6 weeks of receiving a live attenuated VZV vaccine or a history of oral polio vaccine within the previous 6 weeks, or FluMist within the previous 3 weeks, or other live attenuated vaccines within the previous 6 weeks of a visit, should not be permitted in the Blood Cancer Center unit or have direct contact with immunocompromised patients.
3. Children between the ages of 2 through 18 must be accompanied by an adult at all times. The responsible adult is not permitted to be the patient.
4. Only two children per patient are permitted at one given time.
5. Visitors between the ages of 2 through 18 must be immediate family to the patient (i.e. children, grandchildren).
6. No child visitors are permitted after 9 p.m.
7. The responsible adult with the children will be required to complete a visitor screening questionnaire and this must be completed on a weekly basis.
8. If the RN deems that the visitor is appropriate to visit, then the visitor will receive a sticker.
9. During the months of October-April children visitors are required to have flu vaccinations if visiting.

## Day to day expectations of you

- You will need to shower every day with chlorohexidine soap that we will provide for you. This is to help prevent you from an infection.
  - We will show you how to use a covering over your central line when showering
  - Do not use bar soap, use liquid soap only
  - We will provide you with fresh towels and wash cloths every day.
- We will have you save all of your urine during your admission. We will show you how to do that and we will record it for you in our system.
- We will ask you daily about your bowel movements. If you develop diarrhea, we will need to then begin collecting and measuring your bowel movements to ensure you do not have an infection called *Clostridium Difficile* or *C. diff.*
- We expect that you will get out of bed and remain as independent as possible throughout your stay.
  - You should be walking the hallways at least 3 times a day and then writing your laps on the white board in your room.
- We will encourage you to drink water several times a day to keep you hydrated.
- You will use a saline mouth rinse 4 times a day to keep your mouth clean and help prevent you from getting mouth sores.
- We expect you to brush your teeth with a soft bristled toothbrush at least 2 times a day.
- We will have you use an incentive spirometer several times a day. This is a breathing machine that will help keep your lungs expanded and a respiratory therapist will show you how to use it.
- We will show you how to use Sequential Compression Devices (SCDs) on your legs to help prevent blood clots. We would like you to wear these at night while you are sleeping.
- Be sure to put your call light on when your IV pump is beeping. It does not automatically alert us to when this occurs.
- If at any time the nursing team feels you are unsafe to be walking around without assistance, we will place you on a bed or chair alarm. This just means that if you forget to call us when you need to get up then it will alarm our phones to come help you. This does not mean you will be confined to the bed. We will still walk the halls with you and make sure all your needs are met throughout the day.



## What to Expect During your Hospital Stay if you are admitted



## Infection Prevention

- Wash your hands often, at a minimum: before eating, after using the bathroom, and every time you or your visitors come in and out of your room.
- No sick visitors are allowed on the Blood Cancer Center or in your room. Please see previous section on the visitor policy.
- No real flowers or plants are allowed on The Blood Cancer Center. Fake flowers and balloons are allowed.
- Do not wear contact lenses. Eye glasses only.
- Your IV pole will be connected to you continuously while you are admitted. We do not unhook you for showers. This is for infection control purposes and to keep your risk of infection as low as possible.
- Visitors should not use the bathroom in your room. They should use the bathroom located outside of the unit or in the family kitchen area.

- Please refer to your FDA Food Safety booklet or dietitian for specific food related questions.
- Every Monday you will receive a chest X-ray to confirm line placement as well as to look at your lungs for any infection.
- Every Tuesday we will perform a rectal swab to test for an infection called Vancomycin Resistant Enterococcus (VRE).
  - **VRE** - a type of bacteria called enterococci that has developed resistance to many antibiotics, especially Vancomycin. We do not necessarily treat this bacteria but it is contagious for other patients so you are required to be placed in isolation where your visitors must wear gown and gloves when entering your room. If you choose to leave your room to walk, you must wear gown and gloves in the hallways. We do ask that you do not go into the public areas (i.e. nutrition room, family room).
- If you develop diarrhea we will send a sample for infection testing for an infection called *C. diff*.
  - If you are positive for *C. Diff* we will begin treatment with an oral drug called Vancomycin and place you in contact precautions. *C. Diff* is spread very easily and the spores of the infection can live on many surfaces. Therefore, isolation precautions are very important! Visitors who come to your room and the hospital staff will be required to wear a gown and gloves when entering your room. When visitors leave your room they will throw their gown and gloves away and wash their hands with soap and water.
  - If you test negative for *C. diff* we will begin treatment for your diarrhea with Imodium.
- If you are placed into contact or droplet precautions (where staff wear gowns, gloves and possibly a mask into your room) we will prohibit you from certain areas on the unit to reduce the risk of infection to other patients. We will give you more information on this if you are put into precautions.

## Safety and fall precautions

- We will discuss fall precautions with you and your caregiver upon admission. Your safety is very important to us and there are multiple factors that could increase your risk of a fall.
- If at any time the nursing team feels you are unsafe to be walking around without assistance, we will place you on a bed or chair alarm. This just means that if you forget to call us when you need to get up then it will alarm our phones to come help you. This does not mean you will be confined to the bed. We will still walk the halls with you and make sure all your needs are met throughout the day.
- For your safety, please do not touch the buttons or manipulate your IV tubing on your IV pump.
- Keep us informed of all symptoms you are experiencing. Use your call light as needed to alert us to any symptoms you are having or if you need anything, this is your nurses can help you to be more comfortable.
- Symptoms to alert your nurse about:
  - Feeling hot or chilled
  - Difficulty breathing
  - Chest pain/tightness
  - Nausea
  - Diarrhea
  - Mouth sores
  - Pain, headache
  - Nose bleed
  - Blood in urine or stool
  - Or any other symptoms you may be experiencing

## What to Expect During your Hospital Stay if you are admitted

### Blood Counts

- We will write your labs/blood counts on the whiteboard in your room every day.
- Your chemotherapy will make your white blood cell count and neutrophils decrease. This is when you are most at risk for infections. You will hear the term “Neutropenic” when this happens.
- If your hemoglobin (red blood cells) become too low, we will give you blood.
- If your platelets become too low, we will give you platelets. If you have a nose bleed or are bleeding from anywhere, we may give you platelets to help clot your blood at that point.
- Bleeding precautions when your platelets are less than 50,000:
  - Do not floss your teeth
  - Do not blow your nose harshly
  - Do not rub your eyes
  - Do not scratch your skin hard or pick at any skin
  - Do not strain with bowel movements
  - Do not have sexual intercourse
  - Electric razors only
  - Avoid popcorn and hard to chew items
  - Avoid vomiting - call the nurse for anti-nausea medication
  - Nothing per rectum or vagina (no enemas, tampons, or vaginal dilators)
  - Notify staff of any signs of bleeding (nosebleeds, blood in urine, stool, vomit, sputum)

### When can I go home?

- When your symptoms have resolved (no fevers, nausea/diarrhea controlled with oral meds, neurotoxicity, etc.)
- Eating and drinking well
- Able to take all medications by mouth





## CAR-T Therapy Discharge

The following guidelines apply to at least the first 8 weeks after your CAR-T infusion. Ask your doctor for more specific instructions. Remember that the following may not apply to each individual patient. Please consult with the Blood Cancer Center/OHC team if you have additional questions.

You are also required to stay within 45 minutes from The Jewish Hospital for at least the first 30 days after discharge. If you do not have lodging set up, ask to speak to the social worker before you are discharged.

### What happens after discharge?

- You will be seen in the OHC office daily at first
- Please bring your medication bottles to all of your appointments

### When do I need to call the BMT doctor?

You will call (513) 751-CARE if you experience any of the following:

- **Temperature over 100.4 degrees Fahrenheit**
- **Change in mental status including confusion, headaches, blurred or double vision, difficulty talking or answering questions, memory loss, loss of consciousness, or seizures**
- Shaking or chills
- New cough or difficulty breathing
- Bleeding problems such as:
  - Nose bleeds
  - Blood in urine or stool
  - Vomiting blood
  - Increased bruising
- Pain with urination or bowel movements
- Decrease in frequency of urination
- New or persistent nausea/vomiting and/or if you have more than 3 vomiting episodes in an 24 hour period

- New or persistent diarrhea and/or if you have more than 3 episodes in an 24 hour period
- Problems with eating such as:
  - Unable to keep foods, fluids, or medications down
  - Having no interest in eating
  - Difficulty swallowing
  - Sore throat
  - Development of mouth sores
- Pain that is not controlled with prescribed pain medication
- Changes or difficulty with your central line such as:
  - Redness, drainage, pain or site looks different
- Changes with skin color or new rash
- Reddened, swollen or painful areas
- Increased sleepiness
- Fevers, chills, or hives after getting a blood transfusion

### How do I call if I have issues or concerns?

The OHC office is open 365 days a year, Monday through Friday 8:30 a.m.-5 p.m. and Saturday-Sunday from 8 a.m.-1 p.m.. If you are needing to get in touch with your physician or nurse navigator at OHC call (513) 751-CARE. If you have questions or concerns about anything, do not hesitate to call. Please arrive on time to your appointments.

### What if they want to send me to the hospital after hours?

- Please go to The Jewish Hospital Emergency department if the on call physician instructs you too.
- When you arrive at the ED, show them your CAR-T wallet card and instruct them that you are a CAR-T patient. They will place you in a private room and begin taking care of you.

# How will I care for myself at home?

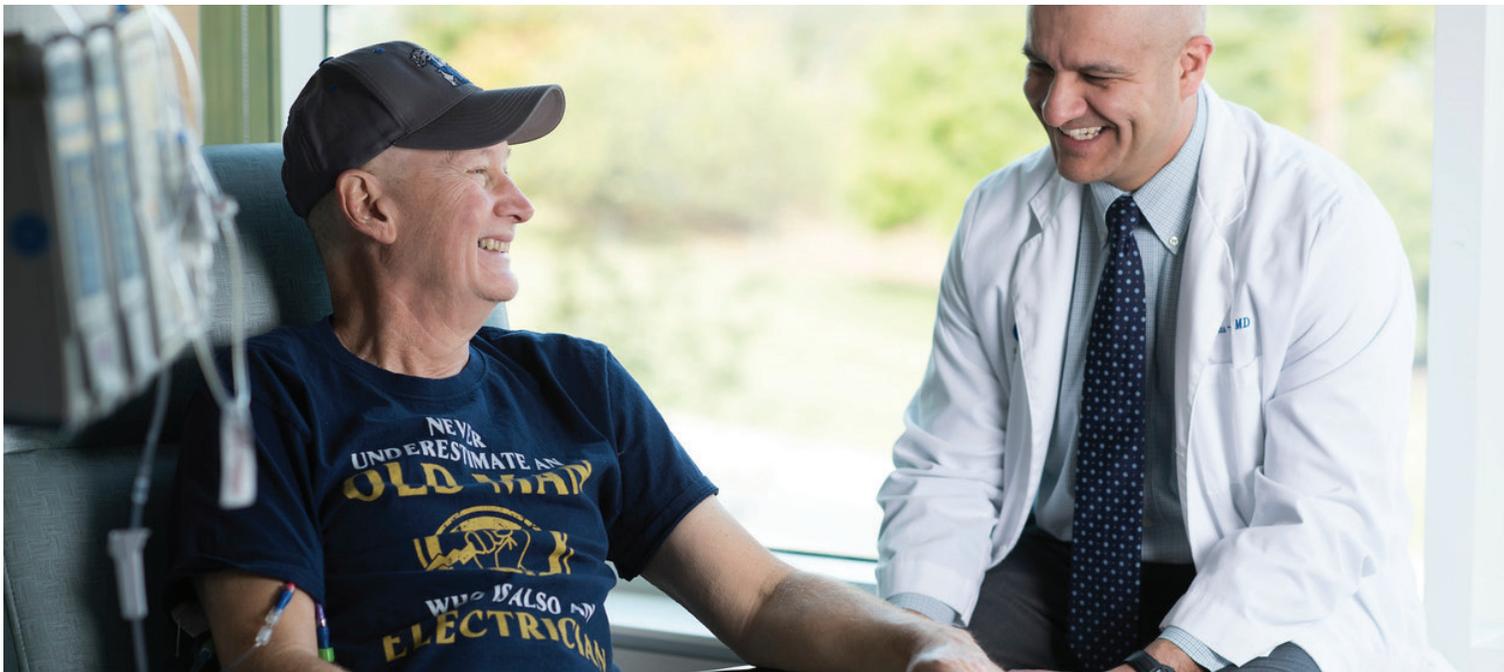
## Handwashing and Hygiene

- 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 share towels or washcloths.
- Continue to maintain good peri-care after each bathroom use.
- Change your sheets once a week.
- Nothing per rectum or vagina

## People, Places and Preventing Infections

- Avoid anyone ill.
- Avoid crowds when possible.
- Limit exposure to children outside your immediate family who could potentially be sick.
- Avoid anyone who has had a live vaccine (immunization) in the past 2-4 weeks, as recommended by your doctors.

- Deep cleaning of your home is not necessary before you go home, just have your caregiver wipe down surfaces, dust, and vacuum.
- Avoid construction areas or anywhere dirt and soil are being moved.
- Stay away from areas being vacuumed. Ask a family member or friend to help clean your house clean and to reduce dust by mopping instead of sweeping.
- Don't bring any new live plants or flowers into your home.
- No live Christmas trees.
- Don't smoke anything and avoid second-hand smoke. Both tobacco and marijuana smoke can increase your chances of getting a serious lung infection.
- Avoid swimming in public or private pools, lakes or the ocean. Avoid using hot tubs.
- Avoid dusty, dirty, or moldy environments.
- Discuss with your physician before traveling.



## CAR-T Therapy Discharge

### Do I need to wear a mask?

When you are coming to and from the hospital for your appointments, we suggest you wearing a mask due to the amount of people and construction being done around the facility. It is a good idea to keep a mask with you at all times while out in public in case you run into a crowd, construction, or someone mowing grass. Your doctor will then discuss with you when it is no longer necessary to wear a mask.

### 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 tooth brush.
- Do not blow your nose harshly - use saline nasal spray to keep your nose moist and prevent nose bleeds.
- Do not rub your eyes - use artificial tears.
- Do not scratch - Use lotions after showering.
- Do not strain with bowel movements.
- Do not have sexual intercourse (vaginal, anal).
- Do not shave with a razor blade - only use an electric razor for shaving and electric clippers for hair cutting.
- Do not play contact sports.
- Avoid popcorn or hard to chew items.
- Avoid vomiting - take nausea medications as needed.
- Do not put anything in your rectum or vagina (no enemas, tampons, vaginal dilators).
- Do not use Aspirin/Excedrin/Ibuprofen or medications that affect your platelets.

### Pets

- Current pets are okay. No new pets should be brought into your home during your recovery.
- Do not allow pets in bed with you.
- It is a good idea to keep your pets clean and their shots up to date.
- **Dogs:** Don't let dogs lick you. Wash your hands after any contact with a dog. Have someone else pick up after your dog.

- **Cats:** Don't let cats go outside. Have someone else clean the litter box. Don't let cats into areas where you eat, sleep, or spend long periods of time. Tell your doctor right away if your cat scratches you and causes you to bleed.
- **Fish:** It is okay to have a home aquarium as long as someone else cleans it regularly.
- **Birds and Reptiles:** You shouldn't have birds or reptiles in your home.
- **Patients in rural areas:** you should avoid barns, fields and contact with farm or ranch animals. If you live in a rural area and farmers are working in nearby fields, ask your doctor if you can be outside.

### Returning to work

In most cases, at or around 1 year after your CAR-T infusion date you can return to work. Your return should be approved by your physician, 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, beginning on your transplant day. Your skin will be much more sensitive to the sun and will burn easily because of the high doses of chemotherapy used in transplant.

- Avoid exposure to sunlight, especially before your transplant and within the first 100 days after transplant.
- If exposure to sunlight is unavoidable, use as much protection as possible such as long sleeve shirts, long pants, hat, sunscreen SPF 30 or higher.

### Physical activity

- Gradually increase activity as tolerated. Activity outdoors, such as walking is good for you.
- Trail hiking is okay 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

- Resuming sexual activity should be discussed with your physician when you feel you are ready.
- You can resume intercourse when your platelet count is greater than 50,000.
- Use standard safe sex precautions.
- Use a condom for the first 100 days to prevent infection.
- No anal intercourse.
- No kissing or oral sex if your partner has any mouth sores.
- Use water-based lubrication for vaginal dryness.

## Diet, food and water safety

- Use the FDA Food Safety Booklet you received from the dietary team until you are off all immunosuppressive medications, or as long as your doctor instructs you to use it.
- Avoid well or cistern water.
- Avoid buffets.

## Medications

- You will receive specific instructions before you leave the hospital about medications you are taking.
- Do NOT take steroids (such as Prednisone, Decadron®, etc.) or allow any other doctor to prescribe you steroids unless approved by your CAR-T trained physician. Steroids are only to be used in emergency situations.
- 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 your doctor.





The Jewish Hospital 

 **MERCYHEALTH**

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A Catholic health care ministry  
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