The Jewish Hospital — Mercy Health Cincinnati Cancer and Cellular Therapy Center

Allogeneic Stem Cell Transplant Handbook

The Jewish Hospital

MERCYHEALTH

Welcome

Dear patient and loved ones,

Welcome to The Jewish Hospital — Mercy Health Cincinnati Cancer and Cellular Therapy Center (CCCTC).

In 1992 our center began performing stem cell transplants and today we are proud to have cared for thousands of patients in Cincinnati and surrounding areas. Our facility is accredited by the Foundation for the Accreditation of Cellular Therapy (FACT).

We are very excited to partner with you as we embark on your healthcare journey! This handbook will be a resource for you throughout your entire transplant process. We know that this journey can be overwhelming, but please know that we are here to help you in any way that we can and will answer any questions that you may have.

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

Sincerely,

CCCTC Team

Contents

Your Health Care Team

Doctors

Throughout the stem cell transplant process your care will be provided by a stem cell transplant physician. While you are in the hospital, he/she will see you daily to answer questions you may have and keep you informed of your progress. The physicians take turns covering the inpatient unit in the hospital and the outpatient clinic. 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.

Advanced Practice Providers

While you are admitted to the hospital and in the outpatient clinic for your transplant, nurse practitioners and physician assistants have day to day responsibility for your care. Even if you are not seen by a physician at an outpatient appointment, please know that the advanced practice providers work in very close collaboration with your physicians.

Transplant Coordinators

Your pre-transplant nurse coordinator tracks your treatment prior to your transplant admission and plans the necessary testing you will need to get ready for transplant. They also plan your donor's schedule. The transplant coordinator is your primary point of contact as you work your way to your transplant.

Inpatient Nurses

These nurses are trained and experienced in the care and specific needs of stem cell transplant patients. Each day in the hospital, you will be assigned a nurse for the daytime and the nighttime who will assist in providing your care for the day. This may include giving you your medications, checking your vitals, and notifying the doctor of any changes throughout the day.

Personal Care Assistant (PCA)

PCAs will assist you and your nurses with your daily needs.

Clinical Pharmacists

The pharmacists manage complex medication regimens for your transplant. They ensure safe and effective use of chemotherapy, immunosuppressants, and supportive therapies, while monitoring for drug interactions, side effects, and complications. Pharmacists will also provide education on medication adherence and symptom management.

Discharge Planner

This nurse will specifically help you in your preparation for discharge. 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 appointments in the clinic.

Social Workers

The social worker on our team will assist with financial resources, community resources, and will assist with arranging things that may be needed upon discharge. You will be seen by the social worker throughout your transplant journey.

Psychologist

The psychologist on our team specializes in the psychological impact of cancer and stem cell transplant such as issues of stress, depression, worry, caregiver burnout, memory difficulties, etc. You will be seen by the psychologist prior to and throughout your transplant journey to help you and your loved ones navigate transplant process from an emotional standpoint.

Dietitians

The transplant dietitian will check in with you 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.

Hoxworth Cellular Therapy

This team of individuals are responsible for processing your donors stem cells. A cellular therapy technician brings your cells to the bedside on the day of your transplant.

Physical and Occupational Therapists

Your physical strength and ability to do daily tasks is important before, during, and after transplant. You will meet with physical therapy as part of your transplant workup. Throughout your hospital stay, physical and occupational therapist will check in on you to make sure your physical strength is not declining. You may be referred to rehabilitation services before and/or after transplant to aid in your preparedness and recovery.

Spiritual Care

The spiritual care team consists of a team of chaplains available to see patients during their hospital stay.

Allogeneic Stem Cell Transplant Basics

What is an allogeneic stem cell transplant?

- An allogeneic stem cell transplant uses donor stem cells to replace unhealthy bone marrow.
- A stem cell transplant is not a surgery, but instead it is an infusion of healthy stem cells into a large vein.

Finding a donor

- To find a donor, the treatment team will look at your human leukocyte antigens (HLA) typing and try to match it with someone else's HLA typing. This could be a relative such as a parent, sibling, or child, or it could be someone who is not related to you. We often find unrelated donors through a registry. A well-matched donor is important to the success of your transplant.

Collecting the stem cells

- There are two ways to collect donor stem cells:
  - Bone marrow: When stem cells are collected from the bone marrow, the cells are typically collected from the hip bone via a surgical procedure under anesthesia.
  - Peripheral blood stem cells: Donors are given medications to move the stem cells into the blood stream. Then the cells are collected through leukapheresis, which is not a surgical process.
- The donor's stem cells may be collected before you start chemotherapy, or even the same day of the infusion. Your transplant physician would decide what is the best option for you.

What does a transplant look like?

- You would receive a high dose of chemotherapy and in some cases total body radiation to "empty" your bone marrow and prepare your body to receive the new immune system.
- The new, healthy cells are infused into a large vein through a tunneled central intravenous catheter (see next page for more information on tunneled catheters). This infusion takes place in your hospital room.

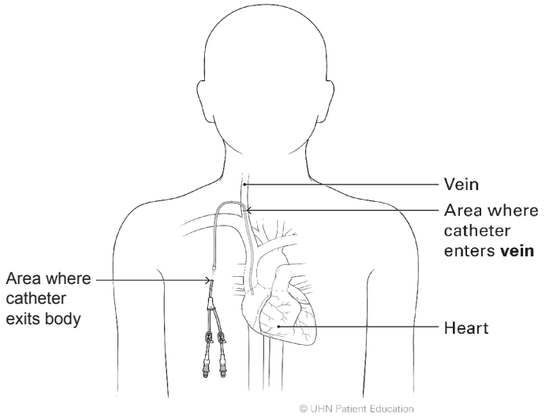
Transplant recovery

- You would be admitted for approximately four weeks because you will be at severe risk for developing infection and side effects related to chemotherapy. Antibiotics are given to prevent and treat infections. Blood and platelet transfusions are administered as needed. Frequent tests and monitoring will also be ordered to try to prevent serious chemotherapy side effects. Medications can be given to help control any symptoms that may be experienced including nausea, diarrhea, and pain.
- When the white blood cell (WBC) count starts to recover, patients are at risk for developing graft-versus-host disease. Graft-versus-host disease is a side effect caused when the donated stem cells (the graft) recognize specific cells and tissue in the patient's body (the host) as being foreign and launch an attack. Patients are monitored very closely for this side effect and medications are given to prevent and treat graft-versus-host disease.
- Following discharge from the hospital, frequent outpatient visits are required for an extended period. Patients will be evaluated for graft-versus-host disease, infection, and any other adverse effects. Depending on the severity of symptoms, some patients may require readmission to the hospital for treatment of complications. Recovery is complex and varies from patient to patient.

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, stem 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 catheter 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.

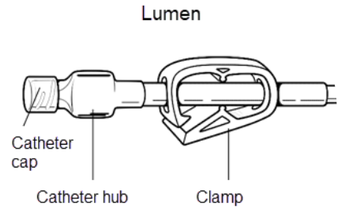
What is a cuff?

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 for 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

Preparing for Transplant

Pre-Transplant Patient Checklist

- **Caregiver:** One of the most important requirements is for every patient to have a minimum of one 24/7 caregiver residing with you and attending all of your medical appointments for approximately 3 months after transplant. (Note: private duty caregivers/home care agencies/nursing homes are generally not adequate caregiver plans).
- **Back-up caregiver:** Due to caregivers being so important, we also identify another individual who could step in full-time as alternative caregiver if for some reason your primary caregiver became unavailable.
- **Lodging:** If you reside over 45 minutes from the Jewish Hospital, you may be required to secure temporary lodging closer to the hospital for approximately 3 months after transplant.
- **Transportation:** You will be unable to drive until medically cleared by a doctor. You will need a reliable vehicle and a caregiver who drives.
- **Alcohol, tobacco, marijuana, and illicit drugs:** All patients are required to stop the use of these substance before transplant and should continue to not use tobacco, marijuana, or illicit drugs for the remainder of your life. Once you are medically cleared, your doctor will let you know when you can consume alcohol.
- **Finding a donor:** Your transplant coordinator will work with your physician to find the best donor for you.
- **Medical clearance:** Your transplant coordinator will schedule testing required prior to transplant.
- **Dietitian visit:** You will meet with our dietitian before transplant for recommendations to help prepare you for transplant from a nutritional standpoint.
- **Finances:** It is important to plan for time off work and your caregiver's time off work. We have social work services available if finances are a concern of yours.
- **Health insurance:** Please make sure your insurance is active throughout the transplant process. If there are any changes to your insurance coverage, please let the care team know immediately.
- **Mental health:** Stable emotional health is an important part of your transplant recovery. You will meet with the transplant psychologist to assess your emotional wellbeing prior to transplant and the psychology team can provide support throughout transplant.
- **Dental care:** You will undergo a dental exam by a dentist of your choosing. Your transplant coordinator will need a completed evaluation and treatment plan.
- **Treatment adherence:** A crucial part of a successful transplant is for you to participate as a partner in your healthcare goals. This includes attending all of your appointments, taking all medications as prescribed, having your full-time caregiver, following nutrition recommendations, maintaining good physical activity, etc.
- **Advanced Directives:** As an able, competent adult, you have the right to make your own medical decisions. If in the future, you become too sick to make your own medical decisions, it is helpful for us to know who you would like to make those decisions for you. By completing Advanced Directives, you identify a primary person and a back-up person to make your medical decisions for you if you are unable. These forms will be provided to you, and we can assist you with completing them if needed.

Caregiver Responsibility Checklist

Below is a list of the main responsibilities of a caregiver. Some patients require individualized caregiving needs that may not be accounted for in this list. Before your primary or back-up caregivers agree to be caregivers, please have them review this list.

- ☐ Attend educational visits and evaluations before transplant.
- ☐ Attend rounds with transplant team at least weekly during your loved one's hospital stay.
- ☐ Meet with discharge planner before your loved one goes home from the hospital after transplant.
- ☐ Be with patient 24 hours a day, 7 days a week for approximately 3 months after transplant or until medically cleared by the transplant doctor.
- ☐ Reside with the patient within 45 minutes of The Jewish Hospital.
- ☐ Drive patient to all appointments and attend all appointments.
- ☐ Learn patient's medications and make sure medications are taken as prescribed. If needed, caregivers may need to learn how to give some medications such as injections.
- ☐ Follow recommendations for infection prevention.
- ☐ Help with food preparation as needed and help patient achieve nutrition goals.
- ☐ Ensure patient is meeting physical activity goals.
- ☐ Monitor for complications of transplant (e.g., infection, GVHD) and notify doctor or bring patient to the hospital in case of an emergency.
- ☐ Pick up medications from the pharmacy.
- ☐ Make sure the home environment is clean.

Your Hospital Stay

We understand that being in the hospital can be difficult. It is helpful to bring personal items to make the hospital room feel more like home and provide distraction to help decrease stress and boredom.

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 blankets and pillowcases 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)
- Electronic devices (cell phones, laptops, iPad, 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 a refrigerator or freezer.
- Microwaveable frozen meals to be stored in the freezer on the unit.
- Glasses and/or hearing aids

Items **NOT** to bring

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

Admission Day

- You will have your central line placed on admission day and admit to the transplant unit directly after line placement.
- We will ask you several questions regarding your medications, screening questions, and other required documentation will be completed on admission day.
- Your home medications can stay home with your family while you are admitted to the hospital because we will dispense all medications through our pharmacy. In the rare event that you take medication that we do not stock, you will need to bring in the medication from home and we will keep it locked in our medication dispenser.
- Our various team members will greet you throughout the day.
- There is a mini refrigerator in your room where you can store items.
- There is also 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 label the item with room number, date, and patient initials. 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 regarding our visitor policy.

Nursing Care

Nursing staff will:

- Draw your labs around 4am and as needed.
- Get a standing weight by 9am.
- Do a full assessment of you, your symptoms, and your vital signs every 4 hours.
- Track your intake (i.e., fluids, food).
- Track your output, which includes collecting all of your urine, your stool if needed, as well as tracking episodes and/or volume of vomit.
- Check your orthostatic blood pressure every shift. 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.
  - **If your blood pressure drops when changing positions, you are at risk for falling; therefore, we will implement a bed alarm until we feel that you are safe to walk on your own.**
- Give you all of your medications.
  - There will be medications that will be scheduled to be given at certain times and some medications that you can request as needed (e.g., nausea medication). It is very important that you take these medications when they are given to you.
- Notify your doctor of any concerns throughout the day.

Other important information

- You will have a nurse call light that you can press for any needs that you have throughout the day.
- If your pump starts beeping, press your nurse call light for assistance. We are not automatically alerted when it is beeping.
- You may be placed in "isolation" during your hospital day. This would be due to you having a bacteria or virus that you could give to someone else. If you are in isolation, you would not be able to leave your room and anyone entering your room would wear a gown and gloves. Please ask your nurse about other precautions that may be necessary.

Bed and chair alarms:

Bed and chair alarms are used in the hospital when the treatment team feels that a patient is at risk for falling. A patient can come in to the hospital independent, but become a fall risk due to things like medication side effects, orthostatic hypotension, weakness, confusion, etc. These alarms sound if a patient attempts to get up on their own without calling staff and staff will abruptly enter the room to make sure that the patient is safe. If you are on a bed/chair alarm, hospital staff must be with you at all times when you are not in your chair or bed, even when toileting and showering.

Day To Day Expectations Of You

- Shower every day with chlorhexidine soap that we will provide you. This will help prevent infections.
  - We will show you how to keep your central line dry while showering.
  - Do not use bar soap, liquid soap only.
  - We will provide fresh towels and wash cloths daily.
- Saline mouth rinse at least four times a day to keep your mouth clean and prevent infection.
- Brush your teeth twice daily with a soft toothbrush
- Save all of your urine during your admission for us to record and we will show you how to do that. If you develop diarrhea, we will have you also collect your stool because we will measure how much you are having. We will also test for an infection called Clostridium Difficile or C diff.
- Get out of bed and remain as active and independent as possible during your hospital day. Walk in the hallways at least three times daily and track your laps on the white board in your room.
- Even when you are on a bed alarm, it is important to maintain your physical strength and stamina. With the assistance of your nurse, you should get in the chair every morning and even walk the halls when possible.
- Drink water throughout the day to stay hydrated.
- Focus on your nutrition and meeting the goals the dietitians set for you.
- Log your food and liquid intake in a journal.
- Use an incentive spirometer two to three times a day. This is a breathing machine that will help keep your lungs expanded.
- Keep your mind busy by bringing things to do (puzzles, memory games, Legos)
- **Tell your nurse of any symptoms, changes, or challenges that you are having.**

Blood Cancer Center Visitor Policy

Below are general visitor policies. However, please follow all visitor policies told to you upon your admission.

- Two visitors at a time
- Visitors are asked to wash their hands upon entering the unit and to wear a mask.
- General visiting hours are 8am to 8pm.
- One visitor over the age of 18 can stay the night with you in your room.
- Minors under the age of 15 must be approved by the unit manager.
- Please do not have anyone visit you who is sick or has recently received a live vaccine.

What Is Day Zero?

Day Zero is the day that you receive your new stem cells. This handout will describe in detail what you can expect to occur on this day. You may hear the nurses refer to Day Zero as your new birthday! This is a celebration!

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 transplant and the nurse will be in your room throughout the entire process. The nurse will also be getting your vital signs every 15 minutes through the transplant.
- You will receive Tylenol® and Benadryl® and an IV steroid prior to the procedure. You may also receive anti-nausea medicine if needed.

What will happen during the infusion of stem cells?

- Hoxworth will bring the stem cells to your room. We double check each bag to ensure you are receiving the correct stem cells.
- Your cells will be in a bag that looks like blood. They will be connected to your central line and infused through your line.
- How long your transplant will take to infuse will depend on volume and number of stem cells to be infused.
- 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.
- Back pain or flank pain.
- Heaviness in your chest or a feeling of pressure in your chest.
- Chills, shivers, or shakes, also called rigors.
- Itchiness and/or redness to skin.
- Red or pink tinged urine may occur due to break down of remaining red blood cells during infusion. You will be getting IV fluids to help flush out your kidneys, so we expect this side effect to subside within 24-48 hours.
- You may also experience a tickling in your throat while the cells are infusing, and this is due to the preservative. This will subside once the transplant is over.

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 will 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?

After transplant, patients are often tired from pre-medications and lack of sleep in anticipation for the procedure. We find a quick nap sometimes helps to feel better.

When Can I Go Home?

- Once engraftment has occurred and your white blood cell (WBC) count and absolute neutrophil count (ANC) are more than 1.0 or 1,000.
- When your symptoms have resolved or are controlled with medications (for example: nausea)
- Meeting eating and drinking goals.
- Able to take all medications by mouth.
- You have received your home medications and they have been reviewed by the appropriate nurse and caregiver.
- Able to move around independently.

What Is Engraftment?

- Engraftment is when your stem cells that you received on transplant day are growing and now functioning as normal cells.
- Engraftment typically occurs 2-3 weeks after your transplant date, but every patient is different.
- The treatment team can determine if you are engrafting by looking at your white blood cell (WBC) count.
- We will alert you when you are engrafting and when we anticipate you being discharged from the hospital.

Discharge Day

- Your treatment team will start to prepare you for discharge a few days before you go home.
- This is so that you and your caregiver can start preparing for you to be home.
- To prepare for being home
  - Make sure you have a working thermometer.
  - Make sure you have a pill box.
  - Bring in all requested medications.
  - Clean home
  - Having a scale at home can help you with tracking your weight.
- There may be medications that your caregiver needs to pick up from the pharmacy before you go home.
- Your primary caregiver will need to come pick you up from the hospital and meet with the discharge nurse to review important information about you going home.
- Your follow-up appointments will be scheduled for you and provided to you on your discharge paperwork.
- It can take a few hours for the treatment team to prepare your discharge, so expect to be in the hospital until mid-late afternoon that day.

What Happens After Discharge?

Appointments in the clinic

- Plan to be seen in the OHC office frequently and these appointments will become less often over time, depending on your recovery.
- Immediately following transplant, most of your appointments will be in the morning.
- Your caregiver must come to these appointments with you.
- How long you will be at the appointment will depend. Some days you may need transfusions and will be at the office for hours. Therefore, it is helpful to bring snacks and activities.
- Please bring all medications to all of your appointments.
- It is helpful also to keep a log of your activity, nutrition, symptoms, and questions for the visit.

How do I call if I have issues?

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. A provider is also available after hours via phone if an urgent concern arises. If you need to contact 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 to do so.
- When you arrive at the ED, show them your purple transplant card and instruct them that you are a Blood Cancer Center patient. They will place you in a private room and begin taking care of you.

When do I need to call the doctor?

- Temperature over 100.4 degrees Fahrenheit
- Shaking or chills
- New cough or difficulty breathing
- Persistent headaches
- Blurred or double vision
- 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 three vomiting episodes in a 24-hour period
- New or persistent diarrhea and/or if you have more than three episodes in a 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 on your skin
- Change in mental status or confusion
- Increased sleepiness
- Fevers, chills, or hives after getting a blood transfusion

Life After Transplant

After transplant, you will make many changes to your day-to-day life. These changes are because transplant increases your risk of:

- Infections
- Graft Versus Host Disease (GVHD; see next page for more information)
- Bleeding
- Side effects from chemotherapy
- Or other complications

Blood Counts

Some of these risks such as infection and bleeding are because transplant lowers your blood counts.

- In the hospital, we will write your blood counts on the whiteboard every day. When you are being seen in the clinic, these blood counts are often printed for you and if not, you can request them to be printed.
- 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 you hemoglobin (red blood cell counts) is too low, we will give you blood.
- If your platelets are too low, we will give you platelets. If you have a nosebleed or are bleeding from anywhere, we may need to give you platelets to help stop the bleeding.

What Is Graft Versus Host Disease (GVHD)?

Graft Versus Host Disease or "GVHD" occurs when your new bone marrow (immune system) does not recognize the rest of your body and begins to attack one or more areas of your body. GVHD can occur acutely – usually within the first 100 days after your transplant. GVHD may be considered chronic if specific symptoms are present or if it occurs after 100 days of transplant.

Who is at risk?

- Any person who received an allogeneic stem cell/bone marrow transplant (related or unrelated), although many precautions are taken to lower your risk.

What areas are likely affected?

Acute GVHD is most likely to occur in the:

- **Skin** - may start with a red rash with small, raised areas that may itch or hurt – likely to occur around neck, shoulders, ears, palms of hands, or soles of feet.
- **Liver** - your blood tests will be monitored for early signs, report any yellowing of your skin or eyes and abdominal pain.
- **Gastrointestinal Tract or "GI tract"** – usually diarrhea and cramping of the lower portion of your intestines is involved or nausea/poor appetite if your upper GI tract is involved.

Chronic GVHD is most likely to occur in the:

- **Skin** – may be different for everyone, but often you might notice reddened areas, areas that become lighter than usual, hardened, or tightened areas that are shiny and cannot move easily, may be worsened in sunlight.
- **Liver** - your blood tests will be monitored for signs of injury to your liver, report abdominal pain and yellowing of your skin or eyes.
- **Gastrointestinal (GI) tract** - ulcerations (sore areas where the tissue is breaking down) can occur from your mouth to your intestines resulting in pain, nausea, poor absorption of foods and fluids, and/or diarrhea.
- **Lungs** - often begins with shortness of breath and a cough without sputum and can become progressively worse.
- Other areas of the body such as eyes, mouth, genitalia

How has my doctors tried to prevent me from getting GVHD?

- Choosing the best donor for you
- Giving you immunosuppressant medication(s) and monitoring doses closely

How can I prevent GVHD?

- Take all of your medications exactly as prescribed and get labs drawn.
- Maintain good nutrition. Poor nutrition increases risk for GVHD of the gastrointestinal system.
- Make lifestyle changes such as limiting time in the sun or use of sunscreen which can lead to skin GVHD.

How will I know if I have GVHD?

- Always keep track of your symptoms and how you feel, alerting your nurse or doctor to changes immediately.
- Your providers may suspect you have GVHD and may order a biopsy of the area.

How is GVHD treated?

- Your provider may prescribe steroids or other medications.
- Your provider may adjust your existing immune suppressing medications (change from a pill to IV and/or increase the dose).
- Sometimes a light therapy may be helpful. With this therapy called extracorporeal photopheresis (ECP), blood is removed from the patient and separated into different types of cells. About a pint of blood, mostly white blood cells, is treated with a special drug to make it more sensitive to the light. It is then treated with UV light, and the blood is infused back into the patient.

How Will I Care For Myself At Home?

Do I need to wear a mask?

When you are coming to and from the hospital for your appointments, we suggest you wear a mask due to the amount of people. 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 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 toothbrush.
- 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:** Do not let dogs lick you. Wash your hands after any contact with a dog. Have someone else pick up your dog's feces.
- **Cats:** Do not let cats go outside. Have someone else clean the litter box. Do not 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 should not have birds or reptiles in your home. Plan to temporarily remove them from your home until off of immune suppression or cleared by provider.
- Avoid barns, fields and contact with farm or ranch animals. If you live in an area where farmers are working in nearby fields, ask your doctor if you can be outside.

Returning to work

- In most case, at or around 1 year after your transplant date, you can return to work. Your return should be approved by your physician because individuals vary greatly in their time to recover. Individuals also vary in terms of when they can go back to work due to the type of work that they do (for example working from home versus working as a teacher at a school).

Skin and the Sun

- Take steps to make sure that you are protected from the sun beginning on transplant day.
- Too much sun exposure can trigger graft-vs-host disease of the skin.
- Also, your skin will burn more easily because of chemotherapy.
- You will need to be careful in the sun for the remainder

of your life to help prevent graft-vs-host disease.

Physical Activity

- Physical activity is very important for your recovery. Stay active!
- Walking outside 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, or heavy weightlifting if your platelets are less than 50,000.
- No swimming in lakes, ponds, hot tubs, or public pools.
- Physical therapy will give you exercises before and during transplant that you can continue to do once you go home.

Food

- **Eating enough food and drinking enough fluids after transplant if very important.** You will regularly meet with our transplant dietitian to make sure you are meeting all of your needs.
- **Poor nutrition after transplant can increase your risk of graft**-vs-host disease of the GI tract.
- Use the Food Safety Booklet you received from the transplant coordinator until you are off of all immunosuppressant medications or until cleared by your doctor.
- While on immunosuppressant drugs, do not consume grapefruit or pomegranate fruit or juice (for example Sunny D).
- Avoid well or cistern water.
- Avoid restaurant and carry-out foods for the first 90 days following your transplant or until cleared by your doctor.

Immunizations

- You will need to be reimmunized beginning at approximately 6 months after your transplant. You will be given an immunization schedule with recommendations.

Sexual Activity

- Sexual activity should be discussed with your doctor when you feel that you are ready to engage in sexual activity.
- You can have sex if your platelets are above 50,000.
- Use a condom for the first 100 days to prevent infection.
- No anal sex
- No kissing or oral sex if your partner has any sores on their mouth or genitals.
- Use water-based lubrication for vaginal dryness.

Household work

- Do not mow your yard or rake leaves.
- Do not do rigorous outdoor work such as chopping wood.
- Do not work on cars or other machinery.
- Avoid vacuuming, dusting, cleaning bathrooms.

Medications

- Take all medications exactly as prescribed and only take what is prescribed to you.
- You and your caregivers should be aware of what medications you are taking and why you are taking them.
- We recommend using a weekly pill box to help you organize your medications.
- Do NOT take immunosuppression medication (example tacrolimus, cyclosporine) on the morning of your clinic appointment until after getting your labs drawn. If you take the medication before your labs are drawn, it will give a falsely high result. Please bring this medication with you to your appointment to take after your labs are drawn.
- Avoid acetaminophen (Tylenol), ibuprofen (Advil, Motrin), aspirin (Bayer, Excedrin), and naproxen (Aleve)

Emotional Support For Myself And Caregivers

Core members of your team include the clinical psychologist, clinical social worker, and spiritual care team. There are support groups and prayer groups available to patients and caregivers. Please request additional information regarding current groups from any of these team members or your transplant coordinator.

Psychological Services

- You and your caregiver will meet with the psychologist for a pre-transplant visit during your transplant work-up. During this appointment, you and your caregiver will be given the opportunity to discuss any emotional or logistical (e.g., caregiver, transportation) needs that you may have. The psychologist will also ask questions to identify any potential barriers to a smooth and successful transplant journey. Recommendations would be made to address any of these barriers.
- During your hospital admission, the psychologist regularly meets with patients and caregivers to monitor and treat any emotional concerns or symptoms.
- The psychologist is a free resource available to patients and caregivers until approximately 1 year after transplant.

Social Work Services

- You may be called by the social worker during your transplant work-up if another member of your team consults the social worker or if you or your family request to be contacted by the social worker.
- During your hospital admission, the social worker will meet with you and your caregivers frequently to check in and offer any assistance.

Spiritual Care Services

- We have a team of dedicated chaplains who see patients while they are admitted to the hospital to provide support from a religious or spiritual standpoint. Spiritual care is also available to assist with completion of advance directives (i.e., designating healthcare power of attorney) as needed.

Additional Support Resources For You

BMT Info Net

Blood and Marrow Transplant Information Network (BMT InfoNet) is a 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

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

Survivorship Clinic

After your transplant, you will have regularly scheduled appointments in our survivorship clinic. Life after transplant can be hard for patients and for loved ones. Your outpatient appointments will meet many of your needs. However, in this clinic, you will have the unique opportunity to meet with specialists in the following areas:

Dietitian
To help you use nutrition to support your recovery.

Physical Rehabilitation
To help you get your strength back after transplant.

Social Work
To help you with financial problems or find resources after transplant.

Psychology
To help you and your caregiver cope with life after transplant.

Medical
A medical provider is available and a nurse to teach you important medical information after transplant.

Pharmacy
To review your current medication list, make sure you are taking medications correctly, and to teach you about medications.

Nutrition And My Recovery

Nutrition plays a critical role in the recovery process after a bone marrow or stem cell transplant. The registered dietitians will help guide you through your transplant process to improve your calorie and protein intake, which can **significantly** impact the success of a bone marrow or stem cell transplant and your overall quality of life.

How often will I see the dietitian?

You will work closely with a registered dietitian throughout your transplant process- before, during, and after- to meet your unique nutritional needs. Before transplant, they will make suggestions to prepare you for transplant. You will see a dietitian multiple times a week during your hospital stay for transplant. After you go home, you will see a dietitian in the survivorship clinic and/or have separate scheduled appointments if needed.

What issues can I expect that will affect my nutrition?

The intense chemotherapy and/or radiation treatments used to prepare you for the transplant often lead to side effects such as nausea, loss of appetite, taste changes, and difficulty swallowing, all of which can contribute to significant weight and muscle loss. If you were to have graft-vs-host disease of the gastrointestinal tract, you would likely have symptoms that would significantly affect your nutrition.

Are there certain foods I should focus on eating?

As the body works to rebuild the immune system and repair damaged tissues, it requires additional calories and nutrients. Protein is especially important during this time because it supports immune function, protects muscle mass, and helps heal the body. Without enough protein, you are at increased risk for infections, delayed healing, and longer hospital stays. Calorie-dense foods help prevent weight loss and provide the energy needed to support daily activities and recovery. Your transplant dietitian will help you choose the right foods to meet your specific nutritional needs.

Physical Activity And My Recovery

Your physical strength and abilities before, during, and after transplant are very important. You will meet with a physical therapist before transplant to determine how "fit" you are before transplant. The physical therapist may make recommendations to improve your strength and endurance before transplant. They may even recommend "prehab."

Prehabilitation "Prehab"

Prehab is rehabilitation to get you physically fit and reduce the impact of side effects of treatment. Prehab can:

Rehabilitation

During your hospital stay for transplant, physical and occupational therapists will see you regularly to make sure that you are maintaining your strength. If they notice that you are getting weaker, they will see you more often and give you exercises to do on your own.

After transplant, some people benefit from rehabilitation services such as acute rehabilitation or therapy services from home or outpatient.

If this is recommended for you, the treatment team will let you know and help you set up these services.

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