# Leukemia, Blood, and Bone Marrow Transplant Program Guide

Ochsner
MD Anderson ~~Cancer~~ Center
Making Cancer History®

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# Pre-Transplant Evaluation

Thank you for choosing Ochsner MD Anderson Cancer Center. Our experience, coupled with cutting-edge research, leads to highly specialized, comprehensive, innovative care in a patient-friendly, state-of-the-art facility. We use a multi-disciplinary approach to your care.

At your first visit to the Leukemia, Blood & Marrow Transplant Clinic (BMT), the team will explore all treatment options for your medical condition. Your pre-transplant evaluation may be referred to as a transplant work-up.

- You should come with any medical records from your referring physician.
- Bring your pathology slides and films.

Your transplant team will want to confirm you have the right attitude for a transplant. Our team may become concerned if you show a lack of cooperation or if you are not really committed to this decision. You must be willing to take an active role in your own health care. **A positive mental attitude can go a long way toward helping your physical well-being. It can be a major contributor to your successful recovery.**

## Medical Status Testing

If we determine transplant is in your best interest, and you agree, a series of tests will be scheduled. These tests and consulting physician appointments give our team the necessary information to ensure that transplantation is truly the best option for you. They are typically done in our clinic and labs. No hospital stay is necessary.

**1. A chest x-ray** to look at your actual heart size, lung status and any other areas of concern. This test is done in the radiology department located on the 2nd floor of the clinic.

**2. A 12-lead electrocardiogram (EKG)** will be taken on the 3rd floor of the main hospital Atrium Towers. This test shows the pattern of electrical waves in your heart. Small round sticky pads are placed over different parts of your body. These pads detect the pattern of electrical waves of your heart. The pattern is then converted into lines on a piece of paper. This information will help the cardiologist determine your current heart function.

**3. An echocardiogram** is a method of analyzing how your heart sends echoes back by sound waves. It records the position and motion of the heart walls. It also shows the internal structures of the heart such as the valves.

**4. Pulmonary function tests** measure the ability of your lungs to carry oxygen. These tests are done on the 9th floor of the main hospital.

**5. A series of blood tests** will determine your complete blood count (CBC), blood and tissue type, and the function of your immune system. The blood tests tell us the function of your internal organs and tissues. We will check you for anemia, bleeding problems, and liver function. As the blood tests show us any exposure to viruses such as Hepatitis, HIV, and other previous virus exposure in your blood.

Your doctor may order tissue typing depending on the type of transplant you will need. This test is known as the **HLA test** (human leukocyte antigen). This test will help to determine the best match between a potential donor and you (the recipient) when awaiting an allogeneic stem cell transplant.

**6. A 24-hour urine collection test** to determine the function of your kidneys.

## Additional Evaluations

Your transplant physician may ask that you see **other physicians and medical staff**. These are routine and are personalized to you as needed.

You will also need to visit **your dentist** to look for any potential sources of infection caused by tooth or gum disease. Talk to your transplant coordinator regarding your dental appointment.

If any other conditions become apparent we may send you for further evaluation. Remember, we need to know everything about you before undertaking transplant.

As your work-up concludes, you will have an appointment with the transplant coordinator and the transplant physician. **Please bring family and friends to this meeting.** Transplant involves everyone. All your questions can be fully answered. Remember, every question is a good question.

List any questions you have in the space below.

# The BMT Team

## Our BMT team of physicians and staff work together for you and with you, for the best possible outcome.

Your transplant team includes many people but **you are the most important member of the team.** Only you can share your concerns. Be sure to ask questions until you understand completely.

### Transplant Physician

Your transplant physician is the doctor who will order tests to determine your medical status and who will manage your medical regimen. Your transplant doctor will oversee your care through the transplant process.

- Carter Davis, MD
- Laura Finn, MD
- Ashley Staton, MD
- Clark Alsfeld, MD
- Suki Subbiah, MD

### Oncology Nurse Practitioner & Physician Assistant

Your oncology nurse practitioner or physician assistant works together with the transplant physicians to provide care to patients and families pre- and post-transplant. They often see the patients for follow-up visits. They provide symptom management and psychosocial support, provide education, and work with the team to provide the best care possible.

- Brandi Fincher, APRN
- Holly McNab, APRN
- Amanda Szeltner, APRN, FNP-BC
- Camryn Flannagan, PA
- Clayton E Black, PA
- Katie Hollingsworth, APRN

### Transplant Coordinator

Your transplant coordinator is responsible for managing all of the elements needed to complete your work-up and follow-up care. He or she will keep you well informed and will teach you how to care for yourself.

- Danelle Acker, RN, BMTCN
- Melissa Piglia, RN, BMTCN
- Marsinah Mayfield, RN

### Financial Counselor

Your financial counselor will discuss your insurance coverage to help you plan for future expenses associated with transplantation. She can provide information about Medicare, disability insurance, and other potential sources of financial assistance.

- Dwana Bailey, Transplant Financial Coordinator
- Tango Austin, Transplant Financial Coordinator

## Social Worker

Your social worker will help you and your family adjust to the changes that occur with chronic illness. They can help you readjust to school or a job.

- Jonathan Catt, LCSW
- Scott Duncan, LCSW
- Reginald Jackson, LCSW, BACS, PhD

## Dietitian

Your dietitian will help you learn and understand how to maintain and improve good nutrition during your cancer treatment and transplant process. Good nutrition can help lessen side effects and support your immune system. Good nutrition can also help you maintain weight and energy, and prevent muscle loss.

- Michele Gerarve, RD-AP, CSO, LDN
- Ashley Stickman, MS, RD, LDN

## Pharmacist

Your pharmacist will review all of your medications including prescription medicines, over the counter drugs, and any herbal or alternative therapies. They will also walk you through any conflicts between medications and chemotherapy – whether now or for the transplant. The pharmacist can teach you more about your medication during the transplant process.

- Breanne Peyton-Thomas, PharmD, BCOP
- Allison Hamner, PharmD
- Yaredis Emmanuelli Aquino, PharmD

## Blood and Platelet Recruiter

Your blood and platelet recruiter helps to ensure a safe and adequate blood and platelet supply for you and our other patients at Ochsner. This is a great way for friends and family members to help you and other transplant patients. The recruiter will help to coordinate this effort.

- Susan Guidry

## Collection and Processing Facility Physician

Your collection and processing facility physician is the doctor who manages your medical regimen. They will oversee your care through the collection and apheresis process.

- Ed Cooper, MD
- Jennifer O’Brien, MD

## Oncology Clinical Psychologist

Your oncology clinical psychologist helps determine if you have been having problems dealing with your disease and health. They often let us know how you have dealt with health issues and stress in the past. The oncology psychologist will also tell us how your family is coping with your illness.

- Michele Larzelere, PhD
- Tracey N. Murry, PhD
- Joshua Lieberman, PhD

# Patient Guidelines

These guidelines will help you prepare for and begin recovery from your treatment. This information should be shared with family and loved ones. If you have questions, talk with anyone on your BMT team.

## Patient Responsibilities

The activities below are very important to the overall success of your transplant. Please be sure to read them carefully. By following them every day, you will play a big role in the outcome of your transplant.

### How to **Clean Your Hands**

| WET | LATHER & SCRUB | RINSE | DRY |
|---|---|---|---|
| Use warm or cold running water. | Scrub whole hands and under nails 20 seconds. | Use clean water, warm or cold. | Use clean towel or air dry. |

- Wash your hands after using the restroom, before eating, and before brushing or flossing your teeth. It only takes 20 seconds to make sure your hands are truly clean!
- Shower daily to remove the chemotherapy and bacteria from your skin.
- Walk at least three times every day. Walking and moving to a chair several times a day helps to
  - maintain your strength.
  - prevent pneumonia and blood clots
  - prevent infections
- You'll have physical and occupational therapy. Be sure to pay attention to exercises and follow your therapists' treatment plans.
- Save all urine, vomit, and liquid stool so that it can be measured by the nurse. The nurse will also need to record the exact amount you are drinking.
- You will get oral care instructions by your nurse. Frequent mouth care may lessen the severity of mouth sores and will help prevent infections.
- Report pain, soreness, redness, rashes, bleeding, or any type of discharge to your nurse.
- When your white blood cell count is low, you must wear a mask and gloves if leaving your room.
- **Speak up – don't be afraid to ask for help.** Call the nurse if you feel weak or if you need assistance to walk or go to the rest room.

## Patient Rooms

Our patient transplant rooms are located on the 8th floor Oncology and Bone Marrow Transplant Unit in Ochsner Medical Center - New Orleans. You will have a private room that is cleaned daily. Everyone must wash or sanitize their hands before entering or exiting your room. Hand sanitizer is stationed outside every patient room.

- When you are admitted, the nurse will explain how to use and locate the call bells, lights, bed, and shower.
- Each room includes a private bathroom/shower, a phone, a TV, and a small closet.
- Each room also contains a reclining chair and a sofa that can be turned into a bed for one person.

- You may bring in new or freshly washed blankets or quilts and new pillows.
- Down pillows are NOT allowed.
- You must shower and dress in fresh, clean clothes every day. There is no laundry service for personal items.
- A meal menu will be provided for you. You will need to call and order each of your meals daily.

## Nutrition

What you eat and drink is a key factor to your health and recovery after a stem cell transplant.

- The inpatient dietitian will meet with you to discuss nutrition and proper diet.
- **It is important to eat healthily and drink plenty of fluids** throughout your hospital stay.

## Central Line Care

To make it easier for us to draw your blood and give you medications, a surgeon will place a semi-permanent catheter under your skin. This is called a central line. We may also use the central line for transfusions or nutrition should you need them.

**It is important that the site of the central line stays clean and healthy.** A member of your care team will check and clean the central line while you are in the hospital.

- If your care team determines you need to go home with your central line, they will ensure you and your caregiver understand how to care for it at home.
- You will receive IV fluids from the time you are admitted until close to discharge. Your IV fluids are carefully controlled. They will run through an automated infusion pump. **DO NOT attempt to silence the alarm or "fix" the pump. Call your nurse if your pump is beeping.**

## Hospital Routine

During your stay in the hospital, you will notice a very specific routine of tests and visits. Here's what you can expect each day.

- **Every 4 hours vital signs check (including at night)**
  - blood pressure
  - temperature
  - pulse
  - oxygen level
  - respiration (breathing) level

- **Every morning around 4:00 a.m.**
  - blood samples taken from your central line for daily blood tests

- **Every morning 9:00 a.m. – 12:00 p.m.**
  - BMT team visit – This may be your transplant physician or nurse practitioner. If you are not in your room, they will return later.

- **Every morning – time may vary**
  - weight check

**You are NOT allowed to leave the floor during certain times.** This includes

- during chemotherapy
- the day of transplant
- when your white cell count is low (neutropenia)

If you feel you need to leave your room, you must notify your nurse.

## Information for Transplant Unit Visitors

Protecting every patient receiving a stem cell transplant is very important. **Every visitor to the Oncology and Bone Marrow Transplant Unit MUST follow the rules listed below.**

- Only one person may spend the night. Each room has a sofa sleeper to accommodate a guest.
- Children under age 12 are not allowed to visit the transplant unit.
- No one who is sick or who has been ill recently is allowed to visit.
- No one who has received a nasal flu, MMR, or chicken pox vaccine within the last 2 weeks is allowed to visit.
- All visitors must wash their hands before entering and exiting a patient's room.
- No fresh flowers are allowed at any time.
- The IV pumps have alarms that may beep. Notify the nurse when the pump beeps. Do not try to reset or silence the pump yourself.
- The BMT team measures each patient's fluid intake and output. Patients and visitors must not empty any containers. Your stool (bowel movement) may need to be measured as well – do not dump it until the nurse has measured it.

## Infusion Day

The actual stem cell transplant resembles a blood transfusion. (You may hear members of the team refer to your transplant as your infusion.) The infusion of new stem cells usually takes about 30-60 minutes, depending on the amount of stem cells you are receiving. On the day of your transplant, here's what to expect.

### 2 hours before your stem cell transplant

- The nurse will increase your IV fluids.
- You will receive medications to prevent nausea and help you relax.

### During your stem cell infusion

- Two stem cell lab technicians and two nurses will be present for the entire transplant.
- You may have visitors present for the infusion of your stem cells.
- You may feel some side effects. Common ones include nausea, headaches, facial flushing, and coughing.
- The team will take your vital signs frequently during and for two hours after the infusion.
- Most patients' cells will be stored in a preservative called DMSO. This helps protect the cells from the effects of freezing and thawing. The DMSO is excreted from your body over the next 24-48 hours by your lungs as you breathe. DMSO has a peculiar smell (some say like cream corn or garlic). You may not smell it yourself, but your visitors may notice it.

## Complications and Precautions

### Neutropenia

Neutropenia is when your white blood cell count is low, less than 1,000. At this time, you will be at risk for infections. To prevent infections that can threaten your transplant, the following precautions will be in place when your white cell count is low.

- You will need to wear a mask when leaving your room.
- Good hand washing by anyone who enters your room is necessary.

Neutropenia can cause fevers. A fever is considered 100.4° F for over an hour or an initial temperature of 101° F. If you have a fever, your care team will do the following.

- Run tests to determine the cause of the fever including
  - blood tests
  - urine tests
  - chest x-ray
- Give you antibiotics through IV

Once you are without a fever for 24 hours and if your blood cultures remain negative, we will start to decrease the amount of antibiotics.

## Drop in Platelet Counts

The transplant may also cause your red blood cell (hemoglobin) count or platelets to drop. Your team will start blood transfusions if your hemoglobin measures less than 7.

If your platelet count drops below 10,000 or you are actively bleeding, your team will start platelet transfusions.

- Your team will give you Tylenol® and Benadryl® before your transfusion unless you cannot tolerate these medications.
- Your team will take your vital signs
  - at the beginning of the transfusion
  - 15 minutes into the transfusion
  - at the end of the transfusion

Typically, stem cell patients show low platelet counts (also known as thrombocytopenia). When your platelet count drops lower than 50,000, your care team will start bleeding precautions. You also have a part to play to prevent bleeding.

- Avoid chips, popcorn, and other sharp food that can cut or scratch your mouth or gums.
- Use a soft bristle toothbrush and avoid flossing your teeth.
- Avoid picking your nose. Limit blowing your nose. These could cause bleeding.
- Do not use razors, clippers, or scissors anywhere on your body.

+ **Contact the BMT Clinic at 504-842-3910**, Monday through Friday from 8:00 AM to 5:00 PM. After 5:00 PM, on weekends and holidays, call 504-842-3000 and ask for the BMT physician on call.

# Caregiver Guidelines

Caregiving can be physically, mentally, and emotionally stressful. It is normal to feel a mixture of positive and negative emotions while you are caring for a loved one. Your loved one may feel a range of emotions and behave differently.

If you feel overwhelmed by your loved one's needs or your own emotions, please let the treatment team know. We are here to help. Remember, if you don't take care of yourself, it will be much harder to take care of your loved one.

## Take Care of Yourself

Taking care of yourself will help you take care of them.

- Sleep, exercise, and eat nutritious foods regularly.
- Take time off from caregiving each week. During this time, don't be afraid to take care of personal needs and enjoy yourself. Do something fun for yourself every week.
- Don't skip your own medications, screenings, or doctor visits.
- Connect with friends or family members.
- Practice a relaxation strategy. This might include meditation, guided imagery, yoga, or prayer, either alone or with your loved one.
- Find time to laugh.
- Make time to communicate with your loved one about things other than their illness. There is more to you and to your loved one than their illness. Help them (and you) remember the other parts of life.

## Tips and Suggestions

Here are some basic guidelines to keep you on the right path.

### 1. Make caregiving plans.

Before your loved one comes in for transplant, make plans for all aspects of caregiving. Refer to the Caregiving Task Checklist on page 12. Even though you will be the primary caregiver, get help where you can.

Support for caregivers is often called respite care. Respite care can renew and refresh both the caregiver and the person receiving care. It can be done informally or by a professional respite service. Informal respite care can come from many sources.

- family members
- friends
- co-workers
- members of church, clubs, and other social organizations
- professional home care providers
- volunteer groups and charities

### 2. Stock up on food.

Prepare, pre-cook, and stock up on food items prior to hospitalization, where possible. This will make things much easier once you are home with your loved one. (This is a great way for friends and family to help.)

### 3. Explore workplace benefits.

Take time to explore options available for workplace benefits. Your employer may offer medical leave or additional benefits for family caregiving.

### 4. Create a record keeping system.

Start a binder, notebook, or digital file with important information about your loved one's care. While your loved one is in the hospital, you can use this to record questions for the medical team and their answers. After discharge, include doctors' names and contact information, a current medication list, and allergies.

### 5. Open lines of group communication.

Decide on a way to communicate with family and friends as a group. This is often easier than trying to update each person individually. Many patient families do this through social media, websites such as CaringBridge.org, group text messaging, and emails.

### 6. Talk about your finances.

Before your loved one is admitted, be sure you know how to access important financial information and pay bills. It may be difficult for them to answer questions after their transplant. You may need access to your loved one's

- durable power of attorney for health care
- durable power of attorney for finances
- loan/mortgage papers and repayment information
- credit card statements and payment information/passwords
- utility bills statements/passwords
- bank accounts (do you need to add co-signers?)
- safe deposit boxes (where are the keys?)
- will and/or living trust (has one been made? if so, where is it stored?)
- life insurance policies (are the beneficiaries up to date?)
- deeds/property
- birth certificate
- military documentation (do you have a copy of discharge papers?)
- social security card
- vehicle registrations

### 7. Offer an emotional support system for children.

If there are children in your life, talking to a counselor may help them to cope with your loved one's illness. Having an outside adult to talk to can sometimes let them address concerns they don't want to share with a family member. Your treatment team can help you find age-appropriate referrals and resource materials to share with them.

# Caregiving Task Checklist

Think through each of these tasks and identify friends, family members, neighbors, community resources, volunteers or paid helpers who might be able to assist you and the patient.

☐ making medical appointments
☐ attending medical appointments
☐ transportation to/from appointments
☐ picking up medications from the pharmacy
☐ filling medication tray or organizing medications
☐ communicating with the medical team
☐ companionship/support when primary caregiver needs a break
☐ bathing/personal hygiene/dressing
☐ deep house cleaning (before your loved one comes home)
☐ light housekeeping (after you are home)
☐ laundry
☐ shopping for food/necessities
☐ meal preparation
☐ doing dishes/kitchen clean-up
☐ home/yard maintenance
☐ pet care
☐ child care
☐ elder care
☐ exercise
☐ bill paying/financial management
☐ handling insurance issues
☐ spiritual needs

# Notes

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