# ALLOGENEIC TRANSPLANTATION PATIENT AND CAREGIVER GUIDE



# MOFFITT CANCER CENTER

# **ALLOGENEIC TRANSPLANTATION**

# PATIENT AND CAREGIVER GUIDE

Original content written and developed by the Blood and Marrow Transplantation Program



Reviewed by Patient & Family Advisors. 10/2013

H. LEE MOFFITT CANCER CENTER & RESEARCH INSTITUTE, AN NCI COMPREHENSIVE CANCER CENTER – TAMPA, FL. 1-888 MOFFITT H. LEE MOFFITT CANCER CENTER & RESEARCH INSTITUTE, INC. All rights reserved © 2013

# Table of Contents

Chapter 1: Basics of Blood and Marrow Transplantation	5
Chapter 2: Planning for Your Allogeneic Transplant: Non-Medical Considerations	11
Chapter 3: Planning for Your Allogeneic Transplant: Donor Identification	15
Chapter 4: Planning for Your Allogeneic Transplant: Vital Organ Testing and Re-Evaluation	19
Chapter 5: Central Line Catheter Placement	21
Chapter 6: Early Discharge	25
Chapter 7: Inpatient Admission	27
Chapter 8: Conditioning Therapy/Possible Side Effects	35
Chapter 9: Stem Cell Transplant "Day Zero"	41
Chapter 10: Engraftment	43
Chapter 11: Diet Guidelines for Patients with Decreased Immunity	45
Chapter 12: Hospital Discharge/Clinic/Discharge Home	53
Chapter 13: Preventing Infection	57
Chapter 14: When to Call the Transplant Team	61

Chapter 15: Graft versus Host Disease	
Chapter 16: Long-term Follow-up	67
Appendix	
Moffitt Cancer Center Resources	69
Online Resources	71
Acknowledgement of Receipt of Information	75
Glossary	77
Image and Photo Credits	

# Basics of Blood & Marrow Transplantation

# WHAT IS BONE MARROW?

Bone marrow is the soft, spongy tissue found inside the bone. Its goal is to form blood cells and other cells that make up the immune system. All blood cells develop from immature cells called stem cells. Stem cells are found in the bone marrow and in the peripheral blood. *Please see diagram below*.

Stem cells develop into one of the three following types of mature blood cells which enter into the blood stream:

- Red Blood Cells (RBCs): transport oxygen to all parts of the body.
- White Blood Cells (WBCs): fight infection and are part of the immune system.
- Platelets (Plts): aid in the clotting of blood and help stop bleeding.



A peripheral blood or bone marrow transplant is a procedure to replace bone marrow destroyed by treatment with high doses of chemotherapy and radiation. The terms "bone marrow transplant" or "peripheral blood stem cell transplant" refer to how the stem cells are obtained. Whichever term is used, blood stem cells are the cells being transplanted.

Blood or bone marrow transplants are used to treat various cancers such as leukemia, myelodysplasia, lymphoma, and multiple myeloma. Other types of cancers such as testicular cancer, certain blood disorders such as aplastic anemia, and hereditary disorders of the immune system can also be treated with a bone marrow or blood stem cell transplant.

### TYPES OF TRANSPLANTS

There are several types of transplants and each treatment plan is specific for each patient. As you spend time in the clinic during the transplant process, you may hear patients discussing their treatments. Remember that what you hear regarding their procedures may not apply exactly to your experience or to your type of transplant. Below are the types of transplants available within the Moffitt Blood and Marrow Transplant Program. Your transplant doctor will decide which of these transplants is right for you.

•AUTOLOGOUS TRANSPLANT: your own healthy stem cells are removed, frozen, and stored until the time of the transplant. Chemotherapy, and in some cases radiation, is then used to destroy the diseased cells in the body. Autologous stem cells are used to restore blood cell production after radiation and chemotherapy.

•TANDEM AUTOLOGOUS TRANSPLANT: this "double transplant" requires the patient to undergo two planned transplants within two to four months. Stem cells are collected before the first transplant. Half are used for the first transplant and half are used for the second transplant. The second transplant is performed after the patient has recovered from the side effects of the first transplant.

•ALLOGENEIC TRANSPLANT: the stem cells for this type of transplant may come from a related donor (either a brother or sister who is found to be a match) or from an unrelated donor found through the Be The Match registry or other registries. Chemotherapy, with or without radiation, is given to destroy cancer cells and weaken the immune system so that bone marrow can be replaced by the donor's stem cells.

•SYNGENEIC TRANSPLANT: Stem cells are collected from an identical twin and given to the twin undergoing transplant following their conditioning chemotherapy.

•CORD BLOOD TRANSPLANT: The stored cord blood collected from the umbilical cord and placenta after a baby is born is called a "cord blood unit." Cord blood is collected into a sterile bag, given an identification number, and stored temporarily. The cord blood unit is transported to a cord blood bank for testing, freezing, and long-term storage.

# WHAT IS AN ALLOGENEIC TRANSPLANT?

- Allogeneic transplant is when a patient's stem cells and cancer cells are destroyed by chemotherapy and in some cases radiation. Healthy stem cells are collected from a matched donor and infused into the patient to restore blood cell production after radiation and/or chemotherapy.
- You may be confused with the terms *"bone marrow transplant"* and *"stem cell transplant."* The term refers to the same procedure. The main difference is how the cells are collected. The procedure is called a *"stem cell transplant"* when stem cells are collected from the blood using a procedure called apheresis. It is called a *"bone marrow transplant"* when the stem cells are collected from the bone marrow in the operating room.
- In most cases, allogeneic transplants performed at Moffitt are "stem cell transplants."

### WHAT ARE THE STEPS OF AN ALLOGENEIC TRANSPLANT?

These steps will be discussed in detail throughout the guide:

- Consult with the transplant doctor and the development of a treatment plan
- Donor identification
- Pre-transplant testing and education
- Transplant doctor's visit to review testing and sign consents (re-evaluation visit)
- Central line placement

- Admission for conditioning therapy/transplant
- Donor stem cell mobilization and collection
- Stem cell infusion
- Recovery in the hospital
- Discharge from the hospital to local housing
- Clinic follow-up
- Discharge to home

## THE TRANSPLANT TEAM

Moffitt's Blood and Marrow Transplant Program are dedicated to delivering the highest quality of care to our patients by using a team approach. This team includes you, your caregiver, your family, and Moffitt's transplant team. All members of the team must be actively involved to make your transplant successful. The following chart is a guide that lists the most common members of the BMT Team and their roles and responsibilities.

TEAM MEMBER	ROLE/RESPONSIBILITY
Patient (you)	<ul> <li>Communicate with other team members about issues and feelings</li> <li>Ask questions</li> </ul>
	• Follow your treatment plan
Caregiver	<ul> <li>Help you follow your treatment plan</li> <li>Provide physical and emotional support</li> </ul>
	<ul> <li>Maintain a safe environment</li> </ul>
	Will speak up for you when needed
Primary Transplant	• Determine your treatment plan
Doctor	<ul> <li>Obtain your informed consent for treatment</li> </ul>
	• To care for you throughout the transplant process and in follow-up after transplant
Attending Inpatient Doctor	• Assist the transplant team and your primary transplant doctor when you are in the hospital
	• Determine your treatment when you are in the hospital

Advanced Practice Provider (Physician Assistant or Nurse Practitioner)	<ul> <li>Perform a history and physical examination of you and your donors</li> <li>Assist your doctors with your medical care before, during, and after your transplant</li> </ul>
Transplant Nurse Coordinator	<ul> <li>Provide education about your transplant process</li> <li>Organize and manage your care before and after your transplant</li> <li>Provide on-going education and emotional support</li> </ul>
Transplant Scheduling Specialist	• Assist the transplant nurse coordinators in planning your care
Transplant Nurses from the Inpatient Unit and BMT Treatment Center	<ul> <li>Assess and provide needed treatments, tests, medications, and infusions as prescribed by your transplant team</li> <li>Provide information about the transplant process</li> <li>Provide on-going education and emotional support</li> </ul>
BMT Financial Counselor	<ul> <li>Meet with you to discuss Medical benefits &amp; Prescription Co- Pays</li> <li>Collect monies if you are Self-Pay or Under-Insured</li> <li>Will check to see if you can apply for Financial Assistance</li> <li>Discuss Fundraising to help pay for your transplant</li> <li>Answer financial questions about your medical services</li> </ul>
Transition Nurse	<ul> <li>Provide classroom and one-on-one education for you and your caregiver(s)</li> <li>Assist with discharge planning</li> <li>Provide on-going education and emotional support</li> </ul>
Social Worker	<ul> <li>Provide assistance with resources such as local housing</li> <li>Provide family or individual support and counseling</li> </ul>
Case Manager	<ul> <li>Provide information about insurance coverage and out-of-pocket costs</li> <li>Provide assistance with home care planning</li> </ul>
Clinical Pharmacist	<ul> <li>Make recommendations about drug therapy</li> <li>Provide education about medications</li> </ul>
Dietitian and Nutrition Support Team	<ul> <li>Evaluate your nutritional status</li> <li>Teach you and your caregiver(s) about dietary restrictions and help you manage your diet</li> </ul>
Medical Assistant/ Oncology Technician	<ul> <li>Measure your height, weight, temperature, pulse, respirations and blood pressure, and draw your blood if needed in the hospital and outpatient clinic</li> <li>Ask you questions about your health</li> <li>Work closely with nursing to make sure you are cared for in the hospital and outpatient clinic</li> </ul>
Pain and Palliative Care Team	Team of specialists that can help treat pain and other symptoms during your transplant
Physical Therapy	<ul><li>Evaluate your physical strength ability</li><li>Provide exercise programs to maintain strength and energy</li></ul>

Consulting Doctor	<ul> <li>Provide advice to the attending physician (Examples, heart, lung, kidney, infectious disease)</li> </ul>
Pastoral Care/Chaplain	Provide interfaith pastoral care and counseling
	Assist in locating local spiritual resources
Psychologist	Provide psychosocial evaluation before your transplant
	• Refer you to a psychiatrist if medical therapy is necessary

# Planning for Your Allogeneic Transplant

# Non-Medical Considerations

# CAREGIVER SELECTION

- It is a requirement that you have a primary caregiver who is available 24 hours a day to assist in your care throughout the transplant process.
- In addition to a primary caregiver, you will also be required to identify a backup caregiver in the event that your primary caregiver is unable to fulfill their role.
- You will be asked for the name and contact information of your primary caregiver and backup caregiver(s) during the pre-transplant workup.
- Your primary caregiver and your alternate caregiver must be at least 18 years old, dependable, in good health, able to provide hands on care, and available 24 hours a day.
- Your caregiver must attend the pre-transplant class, the caregiver class, and the orientation at Hope Lodge if you will be staying there after discharge.
- Your caregiver must also be available at the time of discharge from the hospital for discharge teaching.
- Your caregiver must be capable of performing the following responsibilities:
  - Communicating with the transplant team when there is a problem
  - Transporting you to and from Moffitt as needed
  - Caring for your central venous catheter as instructed by your nurse
  - o Giving you oral medications and possible intravenous medications (IV) as instructed
  - o Assisting with your nutritional needs including IV nutrition, if required
  - Keeping the home or living area clean

• If at any time before or after your transplant, your caregiver develops symptoms of an active infection, he or she should call the backup caregiver for help. Examples of an active infection are fever, runny nose, sore throat, cough with mucous, nausea, vomiting, or diarrhea. These symptoms should be reported to BMT staff immediately. If your caregiver does have an infection, the caregiver will be asked to leave the Transplant Center and temporary lodging and arrange for backup caregiver support to arrive as soon as possible.

### FERTILITY CONCERNS

If you have questions and concerns about fertility, talk with your transplant doctor about your options <u>before</u> transplant.

### ADVANCE CARE PLANNING

It is very important for us to honor and respect your wishes for health care. It is necessary that these wishes are communicated with all members of your healthcare team, as well as with your loved ones. Advance Care Planning (ACP) is a way to communicate your decisions about health care and is a standard part of your care at Moffitt Cancer Center.

#### What is Advance Care Planning or ACP?

ACP is a thoughtful process of planning for future medical care should you become unable to make your own decisions due to injury or a life-limiting illness. It may include:

- Living Will- a legal document that allows you to make health care choices for the future if you can no longer speak for yourself.
  - Completing a living will and discussing it with your loved ones while you are well helps to ensure that your wishes are honored should you become unable to speak for yourself.
- Healthcare Surrogate- An adult chosen to make healthcare decisions for you if you are too sick or injured to make decisions for yourself.
  - Makes decisions and takes actions based on what you would do if you were able to.
  - Honors your wishes.

By developing an Advance Care Plan (ACP), you can help us and your loved ones respect your choices if you cannot speak for yourself after an injury or a life-limiting illness.

- Your BMT physician and nurses will discuss ACP with you at your appointments.
- A BMT social worker will begin the ACP process with you at your psychosocial evaluation prior to transplant (discuss the process, provide educational material for you to take home, and discuss with your loved ones and possible surrogate).
- You will have a follow-up appointment with a social worker before transplant to complete your Living Will and Healthcare Surrogate form, if you desire. If possible, please have your chosen Healthcare Surrogate attend this appointment.
- Your wishes will be addressed throughout the transplant process and can be changed at any time.
- If you already have a Living Will and/or Healthcare Surrogate, please bring the forms with you to your psychosocial evaluation appointment so that your wishes can be communicated with the healthcare team.

# LODGING

- You and your caregiver will be required to stay within 30 minutes driving distance from Moffitt for approximately 90 days after transplant. If there is a question regarding distance, we will use "Google Maps" as a resource.
- Distance is at the discretion of your treating physician who will need to approve your plan for local lodging at the time of discharge.
- Your transplant social worker will meet with you to discuss and arrange lodging options.
- If you have concerns about the cost of lodging, your social worker is available to assess your situation and to recommend resources for which you may be eligible.
- The length of your stay in Tampa will depend on your medical condition.
- Your transplant doctor will determine when you can return home under the care of your local cancer doctor.

## FINANCIAL CONCERNS

- Prior to your transplant, an Insurance Specialist will submit a written request to your insurance company for coverage of transplant-related costs.
- Before your transplant, you will meet with the BMT Financial Counselor to discuss anticipated costs and insurance coverage for your transplant, medications, and other treatment expenses. Other treatment expenses may include home health nursing care, rehabilitation services, lodging, and travel.
- It is also important to be familiar with your insurance benefits, not only for medical treatment, but for treatment related expenses such as medications which can be very costly following transplant.
- Make sure you are aware of deductibles and co-pays that you are required to pay so that you can plan for any expenses that may not be covered through your insurance.

# Planning for Your Allogeneic Transplant

# Donor Identification

# HLA TYPING

Human leukocyte antigen (HLA) typing is used to match patients and donors for transplant. HLA are proteins — or markers — found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not.

You will be tested to determine your human leukocyte antigen (HLA) typing. By testing the leukocytes obtained from a blood sample or cheek swab, transplant physicians can determine the HLA type of the patient and potential donors. This testing is usually performed at your BMT consult, but sometimes is performed before that. At this point in time, Moffitt's BMT Program looks at 8-10 HLA antigens. A fully matched donor would share 8 out of 8 or 10 out of 10 identical HLA antigens with the patient. The degree of difference in HLA typing between donor and recipient determines the intensity of:

- Graft rejection ( patient's cells reject the transplanted donor stem cells), or
- Graft versus host disease (donor immune cells attack the patient's body).

# RELATED DONORS

All eligible siblings may have HLA typing performed to see if they are a match. Siblings can have the typing performed at Moffitt Cancer Center or can have a kit sent to them in the mail to have blood drawn where they live. Please discuss your siblings' health status with your transplant doctor to determine if they are eligible to serve as a donor. If one of your siblings is a match for you, they

may be asked to serve as your donor. On average, a person has one chance in four of matching each of their siblings.

### UNRELATED DONORS

If you do not have any siblings, or your siblings are not a match, a *Be the Match* donor registry search will be performed. The *Be the Match* donor registry is a registry of volunteer donors and cord blood units. Currently, more than ten million donors are listed on the registry. An unrelated donor search is complicated and it may take several months to identify an appropriate donor. If a fully matched donor cannot be identified, a mismatched donor or cord blood transplant may be considered.

### UMBILICAL CORD BLOOD

Umbilical cord blood contains a significant number of blood forming stem cells that can be used for transplant. Cord blood units require less strict matching criteria, so it is often a good stem cell source for patients that cannot find a suitably matched donor.

At the time of delivery, the umbilical cord is cut and discarded along with the attached placenta. Instead of being discarded, the blood from the placenta and cord can be carefully drained into a sterile plastic container. This product, which contains stem cells, can then be frozen and used for transplantation at a later date. When used as a transplant product, it is referred to as "cord blood stem cells."

Donor screening and selection is a process that may take several months to complete. Some patients face a greater challenge in finding a suitable donor or cord blood unit than others. The goal is to identify the best possible donor or cord blood units for your transplant. While your donor search is ongoing, please feel free to contact your transplant nurse coordinator with any questions. Your transplant nurse coordinator will contact you when a donor or cord blood unit has been identified.

## DONOR WORK-UP/EVALUATION

Once a donor has been identified, the donor will undergo comprehensive screening to ensure both recipient and donor safety. This screening involves a health history questionnaire, physical exam, chest x-ray, EKG, and blood tests to test for infectious diseases, such as hepatitis B and C and HIV.

If your donor is your sibling, this testing must be performed at Moffitt Cancer Center. If your donor is from the *Be The Match* registry, they will undergo testing where they live. Cord blood units are also screened for infectious disease. Donors will also need to sign consent, agreeing to the procedure.

### DONATION OF CELLS

There are two methods of stem cell donation: peripheral blood stem cell (PBSC) apheresis and bone marrow harvest.

PBSC collection is the most common form of donation used. For 4 days prior to collection, the donor will receive a daily injection of a medication called filgrastim (Neupogen®, GCSF). This medication will help to increase the number of blood forming cells in the donor's bloodstream. If your donor is your sibling, they will receive the injections at Moffitt. If you have a donor through the *Be The Match* registry, they will receive the injections where they live. PBSC donors may experience a headache, or bone or muscle aches for several days before collection as side effects of the filgrastim injections. These effects disappear shortly after collection.

On the 5<sup>th</sup> day, an IV is placed in each of the donor's arms and they are connected to a machine called an apheresis machine. Their blood will pass through the machine, which will separate their blood stem cells and return the rest of the blood to them. The collection process can take up to 10 hours and may require 1 or 2 days, depending on the number of stem cells needed for the recipient. If your donor is your sibling, they will undergo collection at Moffitt. If you have a donor through the *Be The Match* registry, they will be collected where they live and the cells will be transported to Moffitt. Most donors report a full recovery from this within 2 weeks.

A bone marrow harvest is a surgical procedure and is performed less frequently than PBSC collection. The donor will be taken to the operating room and be given anesthesia. Doctors will use a needle to withdraw marrow from the donor's pelvic bone. If your donor is your sibling, they will undergo the harvest at Moffitt. If you have a donor from the *Be The Match* registry, they will be collected where they live and the marrow will be transported to Moffitt. Marrow donors can expect to feel some soreness in their lower back for a few days or longer following the donation. Most report a full recovery from this procedure within 3 weeks.

# Planning for Your Allogeneic Transplant

# Pre-Transplant Testing and Re-Evaluation

# PRE-TRANSPLANT TESTING

- You will undergo a series of medical tests to determine your overall physical health and the status of your disease before treatment begins.
- Your Transplant Coordinator and Scheduling Specialist will schedule the testing and provide you with a schedule.
- Appointments are scheduled for each test separately and are usually performed on an outpatient basis over 2 to 4 days at the Cancer Center.
- Although it may seem inconvenient, it is important to complete all of these tests and appointments before your transplant.
- Testing may include the following:
  - MUGA scan/EKG -measures heart function.
  - Pulmonary function tests -measures lung function.
  - Chest x-ray/CT scan of chest -checks for abnormalities or infection in the lungs.
  - Blood work/urine tests- measures blood counts, kidney and liver function, and past exposure to diseases.
  - Disease-specific testing such as PET scan, CT scan, bone marrow biopsy, bone survey- performed to check the status of your disease.
  - History and Physical exam with a physician assistant or nurse practitioner.
  - Nurse visit to review important transplant information.
  - Psychosocial evaluation- you will meet with a social worker and a psychologist to discuss concerns, identify informational and resource needs, and review psychological and social factors that could potentially impact your care.

- Pre-Transplant class-you and your caregiver are required to attend this class which teaches you about the transplant process.
- Pharmacy consult-you will meet with a BMT pharmacist to review the chemotherapy and other medications that you will receive during the transplant process.
- Financial consult-you will meet with the financial counselor to review your insurance benefits and to discuss any out-of-pocket costs.
- Other -some insurance companies may require further testing such as Pap smears, mammograms, PSA level, or colonoscopies before providing authorization for transplant.
- Clearance by your dentist is required:
  - Please see your local dentist prior to transplant for a dental exam.
  - You must obtain a letter from your dentist that says that your mouth is "clear" and you do not have any infections in your mouth.
  - A letter of dental clearance is required before you have a transplant.

Please contact your Transplant Coordinator for any questions about Pre-Transplant Testing

### **RE-EVALUATION VISIT**

- This visit is scheduled with your transplant doctor to review your vital organ testing results and finalize the plan for transplant.
- You will sign any consent forms needed for your treatment during the re-evaluation visit. The consent forms will be given to you before this visit so that you may read and review them and be prepared to sign them. If you have any questions about the consents, you can discuss with your doctor.
- Signing the consent forms tell the doctors that you have been given enough information to
  make an informed decision about the transplant and that you understand what the transplant
  involves. Do not sign the consent forms until you are satisfied that you know and
  understand the treatment you will receive, including the risks and benefits.
- You may meet with a social worker at this time to finalize advance care planning.

# Central Line Catheter Placement

# WHAT IS A CENTRAL LINE CATHETER?

- An central line catheter is a thin, flexible plastic tube that is placed into a large vein in your chest.
- It provides access to a major vein so that you can provide blood samples and receive fluids, nutrition, chemotherapy, blood product transfusions, and medications.
- The most common type of central line catheter used for an allogeneic transplant at Moffitt has three lumen accesses and is known as a triple-lumen catheter.
- Your catheter will remain in place in your chest until your treatment is complete. Your transplant doctor will determine when your catheter can be removed. Most patients are discharged from the hospital with their catheter still in place.



## HOW IS THE CATHETER PLACED?

- The insertion of the catheter is done in the Outpatient Surgery Department in a surgical suite. It usually takes 30-45 minutes.
- "Local" anesthesia is used to insert the catheter; however, you may be given intravenous sedation before the procedure as well.
- Two small incisions will be made in your upper chest. One incision will be made in your upper chest near the neck and the second incision will be made a little lower to insert the catheter into the proper place. The catheter will be "tunneled" under your skin and a small Dacron® cuff will hold the catheter in place and help prevent infection. *Please see diagram below.*
- You may have stitches not far from where the catheter exits your chest. These will be removed after 21 days when your skin has healed around the catheter.
- Notify a member of your healthcare team if you are taking any blood thinning medication as it will need to be stopped several days before the procedure.



## POST-INSERTION CARE

- You may have some discomfort in your shoulder and chest area after your catheter is inserted. It usually goes away in a few days.
- You may take oral pain medication as prescribed by your doctor to relieve the discomfort.
- You may apply an ice pack to the catheter site 20 minutes at a time, every hour, as needed, for the first 24-48 hours.
- A small amount of blood and bruising around the exit site is normal.
- Do not shower for 48 hours after the catheter is inserted.
- You will need someone to drive you home after this procedure.

## ROUTINE CARE

- The catheter must be covered with a sterile dressing at all times. The nurse will change your dressing 24 hours after it is inserted and then every 7 days, or as needed.
- The dressing needs to be changed if it becomes soiled, loose, or wet. Notify your healthcare team immediately if this occurs.
- A member of your healthcare team will "flush" or clean the inside of the catheter tubing regularly. You will not have to do this.
- Cover your dressing and catheter with a water proof covering, such as, Press and Seal ® made by the Glad company (found at your local grocery store) or a Shower Shield (purchased at Publix pharmacy within Moffitt).
- Every effort will be made to prevent an infection in your catheter.
- Please refer to the patient education handout, "Use and Care of Your Central Venous Catheter."

# Early Discharge

You and your transplant team may decide that a planned early discharge is the best treatment plan for you.

If you are an early discharge patient, you will be admitted to the inpatient unit for your conditioning therapy and stem cell infusion, but you will be discharged before engraftment (recovery of your blood counts).

## **INSTRUCTIONS FOR EARLY DISCHARGE**

- You must have a reliable caregiver that can drive and has a car available at all times. Your caregiver is required to be with you at the following times:
  - All vital organ testing appointments, including pre-BMT class and social work consult.
  - Re-evaluation (consent signing visit).
  - Pharmacy consult.
  - Daily in the BMT Treatment Center until you are seen by the doctor.
  - Daily in the BMT Treatment Center before you leave for the day (to receive instructions).
  - At all times while staying at local housing.
- You will be required to obtain your medications needed for transplant at Moffitt's Publix pharmacy unless your insurance requests they are filled at another pharmacy. Our pharmacists will submit the prescriptions for you before you are discharged from the hospital.

- Please check in at the BMT Treatment Center daily at 7 am. It is very important that you arrive on time so your labs can be drawn and the results are available for your doctor's appointment.
- Please complete your patient diary every day. Document the medications you take every day on your medication list in your diary.
- You will be required to wear a yellow "duckbill" mask any time that you travel outside. You do not need to wear a mask in your own room at local lodging or in the BMT Treatment Center.
- It is very important that you bring the following items with you every day when you are here at Moffitt:
  - o Medication list
  - All medication bottles
  - Completed patient diary

# Inpatient Admission



- You will be admitted for your conditioning therapy (chapter 8) and your stem cell transplant (chapter 9).
- Transplant units are located on 3 West, 4 West, and 3 South.
- Each room is private with a window, bathroom, telephone, television, and access to Moffitt's wireless network.
- You are not permitted to leave the unit or visit another patient room.
- Your feet must be covered at all times when out of bed.

## DAY OF ADMISSION

- On the day of your scheduled admission, please report to the BMT Clinic (4<sup>th</sup> floor, clinic building) at 1 pm. If your bed is ready, you will be directed to the Admitting Office (first floor, main hospital).
- If your room will not be ready when you arrive to the BMT Clinic, you will be seen by the inpatient BMT team and then directed to the Admitting Office for further instructions.

# WHAT TO BRING

- You are welcome to bring some personal items to the hospital, but space is limited. Items should be limited to a quantity that should fit in a carry-on size suitcase. Moffitt is not responsible for any lost, stolen, or damaged items.
- All items must be clean and wiped with disinfectant or washed before entry into your room.
- You may want to bring:
  - Favorite pillow or comforter (new or freshly laundered)
  - Framed pictures (non-glass)
  - Several changes of clothing, plus extra undergarments
  - Clothes hangers
  - Tennis shoes or closed-toe slippers/socks with non-skid bottoms
  - Head covering (hats, scarves, wigs)
  - Plain toothpaste (not containing alcohol)
  - o Skin lotion
  - o Deodorant
  - o Shampoo
  - o Electric razor
  - Small crafts, cards, board games
  - Books, Magazines, laptop computer or tablet, cell phone, game console, or DVD player
  - Personal Medical Equipment such as C-Pap, walkers, and canes (If you use a glucometer and testing supplies, please bring them and store them in your suitcase. DO NOT use them while inpatient).
- Avoid bringing the following items to the inpatient unit:
  - Personal medications
  - o Money
  - Jewelry (remove any body piercings except for earrings)

- 0 Valuables
- Contact lenses (not permitted during transplant, please wear glasses)

# DRUG RESISTANT BACTERIA

It is very important for us to prevent the spread of germs (bacteria). Moffitt staff members care for many patients and extra care is necessary to identify and prevent the spread of bacteria between each patient.

You will be screened for two different kinds of bacteria:

- MRSA (Methicillin-Resistant Staphylococcus Aureus)
  - A common germ that 1 out of every 3 people have on their skin or in their nose.
  - This germ may cause infections in people who are in the hospital or have other health conditions.
  - MRSA can spread to bed linens, bed rails, bathroom fixtures, and other medical equipment. It can spread to the hands of doctors, nurses, and other healthcare professionals.
  - You will have a nasal swab (only once) upon admission to the inpatient unit or upon admission to the BMT Treatment Center if you are having an outpatient transplant. The nasal swab will screen you for MRSA.
- VRE (Vancomycin-Resistant Enterococcus)
  - This germ lives in the intestinal tract and in the female genital tract.
  - This germ may cause infection in people who are hospitalized or have weakened immune systems.
  - VRE can easily spread from person to person. It can spread by touching a person with VRE or it can spread by touching surfaces or equipment contaminated with VRE.
  - A BMT staff member will swab your rectum on admission to the inpatient unit or upon admission to the BMT Treatment Center if you are having an outpatient transplant. This swab will screen you for VRE.
  - You will also have a rectal swab every Wednesday until you are discharged from the hospital.

# CONTACT PRECAUTIONS AND ISOLATION

- Contact precautions are a way for hospitals to decrease the spread of germs.
- If you are placed on contact precautions, a sign will be placed on your door to remind everyone to take extra care to prevent the spread of bacteria. Your door will be kept closed.

- Staff will wear a yellow gown and gloves whenever they have close contact with you.
- If you have a history of MRSA and/or VRE, contact precautions will be started as soon as you are admitted for transplant.
- Contact precautions can also be started any time after you are admitted if you develop MRSA and/or VRE while you are hospitalized.
- Hand Hygiene is important and will be performed by everyone. Before entering your room and after leaving your room, everyone will wash their hands with soap and water or hand gel.
- Visitors do not have to wear gloves and gowns but must perform Hand Hygiene when they enter and exit your room.
- Patients and caregivers must not visit other patients in their rooms. This will help decrease the risk of spreading infection.
- If you develop a respiratory viral infection, infectious diarrhea, or some other infection while you are in the hospital, special isolation precautions will be taken to prevent the spread of infection.

# VISITATION

- Visiting hours are not restricted.
- No more than two visitors per patient are permitted in the room at one time. Other visitors should wait in the family room on the unit.
- Visitors must always check with your nurse before entering your room.
- For the safety of our patients, children under 12 are not permitted on the inpatient unit. Please talk to your nurse or doctor if you have any questions or concerns.
- Visitors must wash hands with soap and water or alcohol-based hand rub and dry hands thoroughly before entry into the BMT unit. As mentioned above, all visitors will follow Hand Hygiene before and after entering your room.
- Visitors with any type of active infection, signs of a cold (runny nose/cough), or signs of a respiratory infection are not permitted on the BMT unit and will be asked to leave.
- Visitors who were exposed to measles or chicken pox within the past 10 days are not permitted to visit until 21 days after their initial exposure.
- Visitors who have been exposed to mumps within the past 2 days are not permitted to visit until 18 days after their initial exposure.

- Visitors who have received any live vaccine within the past 2 weeks are restricted from patient care areas. This includes intranasal flu vaccine and shingles vaccine. Individual situations should be discussed with the patient's doctor.
- Visitors with lice cannot visit you until 24 hours after they have been treated for lice.
- Visitors may be asked to leave during any special procedures or x-rays, or during any emergency.
- No fresh or dried flowers or live plants are allowed on the BMT unit.
- Visitors may not use patient equipment or patient bathrooms. Visitors are permitted to eat and drink in your room. Please throw away any trash when finished.
- Visitors must use the restrooms located outside the patient's room.
- Visitors are permitted to use the shower in the family room only.
- Visitors must not give any medications to you nor bring in medications from outside the hospital.
- Visitors should not touch any pumps or machines in the room. Please call a nurse for assistance.
- Visitors are permitted to hug, kiss, and hold hands with you.
- Visitors may use complimentary valet parking.

# Tell your nurse if you are too tired to entertain visitors

# and visitors will be limited.

# DAILY ROUTINE

- Routine Blood Work
  - Daily labs are drawn every morning between 3am and 5am so that the medical team has the results by 7am.
  - Other lab tests may be drawn at other times as needed.
  - Most labs will be drawn through your central line; however, there may be some labs that need to be drawn from a vein.
- Infusions (Medications, Intravenous fluids, Transfusions)

- You may receive blood products, electrolytes, or intravenous fluids based on your lab results.
- Antibiotics, anti-nausea medication, and pain medication may also be administered.
- Vital Signs
  - Include: temperature, pulse rate, respiratory rate, blood pressure, and occasionally oxygen saturation.
  - Checked every 4 hours (at approximately 8am, 12pm, 4pm, 8pm, 12am, and 4am).
  - May be checked more frequently (during your transplant, during a blood product transfusion, etc.).
  - Your weight will be checked every day at approximately 4am (a bed scale will be used).
- Interdisciplinary Rounds
  - Your BMT team will come to see you every day between 9am and 12pm.
  - They will check on your progress and make changes to your treatment plan as needed.
  - Your family member or caregiver is encouraged to be available during rounds to hear what your team says and to address any issues or concerns.
  - This is a good time to ask questions and discuss your plan of care.
- Physical Therapy and Exercise
  - A physical therapist will evaluate you a day or two after admission.
  - A list of exercises will be given to you to do to help maintain your strength, safety, and energy while you are undergoing transplant.
  - A physical therapy assistant will see you daily Monday through Friday to assess your status, help you do your exercises, and walk in the hall.
  - You are encouraged to spend as much time out of bed as possible and to walk several laps in the hall 3-4 times per day.
    - For your safety, you must remain on the unit when walking, do not enter other patients' rooms.
  - Exercising your lungs is also important and can help prevent lung infections such as pneumonia.
  - A respiratory therapist will give you an incentive spirometer and teach you how to use it once you are admitted.
  - You should use the incentive spirometer at least every 4 hours while you are awake.
- Nutrition
  - o All BMT patients should follow an Immunosuppressed Diet (chapter 12).
  - Each day you will receive a pre-printed menu to select meals for the next day.
  - Usual times meals are served:
    - Breakfast 8:00 am
    - Lunch 12:00-12:30 pm
    - Dinner 5:00-5:30 pm
  - Snacks and drinks are available on the unit; just ask your nurse or oncology tech.
  - A complimentary snack cart will come to your room a few times each week.

- A refrigerator and freezer is available on the unit for you to store your own drinks and snacks if desired (you cannot bring your own refrigerator or freezer).
- A dietician is available to see you Monday-Friday.
- Antibacterial cloths or shower gel
  - Using antibacterial bath cloths or gel has proven to decrease bacteria on your skin and may prevent infection.
  - You should use the bath cloths or gel every day unless you are allergic to them.
  - If you are using gel, it will be used in the shower, just like soap.
  - Cloths should be used opposite of your shower (example: shower in the morning, use bath cloths at night).
  - Talk to your nurse or oncology tech about what time you want to use the cloths.
  - Cloths will be provided to you warm.
  - Wash with the cloths from the neck down and avoid the genital area.
  - Allow your skin to dry completely (do not dry with a towel) before getting dressed.
  - Your skin may feel sticky until it is completely dry.
  - Nurses or oncology techs can help make sure that you have cleaned all areas of your body with the cloths.
- Safety precautions
  - We strive to provide a safe environment for you while you are hospitalized.
  - Please partner with us to ensure your safety.
  - You will be at an increased risk for falls due to the medications you receive, fatigue, treatment side effects, and being in a strange environment.
  - You may be placed on "Fall Precautions" during your inpatient stay, which may include:
    - An alarm on your bed or chair to notify staff when you get up
    - Bedside commode
    - Use of equipment to help you walk safely
  - Please be aware of the intravenous and other tubing (heart monitor, oxygen) that may be attached to you so you do not trip or fall.
  - Please call for staff assistance when needed.
  - Staff will perform hourly rounds to ensure that you and your environment are safe.

# Conditioning Therapy/Possible Side Effects

- The purpose of the conditioning therapy that you receive prior to your transplant is to destroy cancer cells in your body.
- Conditioning therapy can include one or more different types of treatment; such as, chemotherapy, immunotherapy, and/or radiation.
- Your doctor will decide the type of conditioning therapy you receive. Your treatment plan depends on the type of cancer that you have and what treatments you have received in the past.
- You may have been treated with chemotherapy before, but the doses you will receive as part of transplant are much higher doses.

## POSSIBLE SIDE EFFECTS OF CONDITIONING THERAPY/TRANSPLANT

The following side effects may occur as part of your conditioning therapy. Your transplant team will monitor you closely and will make sure that you receive any treatment needed to reduce these side effects. Please be sure to report all side effects to the team!

• Neutropenia (decreased white blood cells): Your immune system is your first line of defense against infection. When your white blood cell count is low, you can easily get a fever or an infection. Please refer to Chapter 13, "Preventing Infection."
- Anemia (decreased red blood cells): Anemia occurs when you have a low red blood cell count. Your red blood cells carry oxygen to your organs and tissues. Symptoms of anemia may include:
  - o Shortness of breath
  - Fatigue or low energy
  - 0 Weakness
  - Pale skin
  - o Headache

If your red blood cell count gets too low, you will receive a blood transfusion.

Thrombocytopenia (decreased platelets): A low number of platelets may cause you to bleed or bruise more easily than usual. You will receive a platelet transfusion if needed. There are a few precautions you can take to help prevent bleeding or bruising.

These include:

- Keeping your skin and lips moisturized. Dryness may lead to cracks and bleeding.
- Sexual intercourse is not advisable if a platelet count is less than 50,000.
- Only use an electric razor.
- o Do not go barefoot. Wear closed toe, non-skid footwear at all times.
- Do not use nail clippers. You may file nails with an emery board.
- Drink plenty of fluids to avoid constipation and avoid straining during bowel movements.
- Do not use rectal thermometers, suppositories, tampons, or enemas.
- Do not use Aspirin, Ibuprofen, or products containing these drugs.
- Use only an extra-soft toothbrush. Do not scrub gums too hard or use floss, toothpicks, or a Waterpik<sup>®</sup>.
- Fever: Fever after transplant may be caused by infection (due to low blood cell counts), medications, or the infusion of cell therapy products such as blood, platelets, or stem cells.
  - A temperature of 100.9 °F or higher one time or a temperature of 100.5 °F to 100.8 °F for more than 1 hour is considered a fever.

- <u>A fever is a medical emergency when your white blood cells are low.</u>
- Samples of your blood, urine, and stool may be collected to check for bacteria.
- A chest x-ray will be done to look for infection.
- Do not take Tylenol or other anti-fever medications unless told to do so by your doctor.
- If you had an outpatient transplant, you will probably be admitted to the hospital.
- You will be started on IV antibiotics.
- Nausea and/or Vomiting: If you experience nausea or vomiting, please notify your nurse or doctor. You can be given medications to help prevent and treat nausea. It is important to control nausea and vomiting because it can result in weight loss and electrolyte imbalances in your blood.
- Diarrhea: If you experience diarrhea, please notify your nurse or doctor. Samples of your stool will be collected to test for infection and medication can be given to treat the diarrhea. It is important to control any diarrhea you may experience because it can result in dehydration and electrolyte imbalances in your blood.
- **Mucositis (mouth sores):** Good oral hygiene is important during your transplant and can help limit the amount of discomfort and prevent mouth infections. Oral hygiene includes brushing your teeth with an extra-soft toothbrush and rinsing your mouth with saline at least 4 times daily. Medications can be given to relieve your mouth or throat pain. Mucositis normally improves when the white blood cells start to engraft (chapter 10).
- Anorexia (loss of appetite): You may lose your appetite after chemotherapy and food may not taste right to you, but it is important to eat. It may be helpful to eat small, frequent meals and snacks throughout the day.

Your weight and your eating habits will be watched by your nurses and doctors. We have dieticians that can meet with you to discuss ways to help you prevent weight loss and help you improve your appetite.

- Dehydration: Dehydration means there is not enough fluid in your body. This is due to loss of fluid from vomiting and/or diarrhea, fevers, and sweating. It is important to drink lots of fluids after chemotherapy and stem cell transplant. You may need to receive IV fluids if your fluid intake is not adequate.
- Electrolyte imbalance: It is common to need potassium and magnesium replacement after chemotherapy and stem cell transplant. You will have labs checked frequently and if your electrolyte levels are low, you will receive pills or IV medication to correct your levels.
- Skin changes or rash: Rashes or skin changes can be related to chemotherapy, medication, or infection. Please examine your skin and notify your transplant team of any changes. It is important to protect your skin from the sun. Please wear sunscreen SPF 30 or higher daily.
- Fatigue: Many patients feel very tired during their conditioning therapy and after stem cell transplant. It can be due to your disease, chemotherapy, radiation, low blood counts, lack of sleep, pain, stress, or poor appetite. The exact cause is not always known. It is very important to exercise daily. Short naps and frequent rest periods may also help with fatigue. Fatigue may put you at an increased risk for falls. Energy levels generally improve with time but sometimes can take up to 3-6 months to fully recover. Please discuss your feelings of fatigue with your transplant team. There are resources on hand that can help you manage fatigue.
- Hair loss (temporary): Most conditioning therapy will cause temporary scalp and body hair loss within one to two weeks. Some patients cut hair short or shave their head before hair loss begins. You may ask your medical team for permission to have Magnolia's (Moffitt's hair salon) come to your room and shave your head. It is free of charge. Hair growth varies from patient to patient, but often grows back within 3-4 months after the transplant.
- **Pain:** Pain is any feeling of hurt or discomfort and it can be mild, moderate or severe. Many people with cancer will experience pain during their illness.

Pain is described as either acute pain or chronic pain. Acute pain can be mild, moderate, or severe, and lasts a short time. Chronic pain can be either mild or moderate and lasts a long time. Chronic pain may require long-term pain management. Pain is a symptom than can occur for many reasons. <u>ALWAYS</u> notify your transplant team about any pain that you may be experiencing, no matter how small. Your transplant team will treat your pain according to type, severity, and location. They may order tests, such as an X-ray, to find out the cause of your pain.

- Numbness and tingling of extremities (hands or feet): This side effect is due to nerve damage caused by certain types of chemotherapy. In some patients, the nerve tissue may slowly re-grow and this will reduce the numbness and tingling. This problem may not go away completely. Medications may be prescribed to help you with this side effect.
- **Changes in memory and concentration:** You may experience changes in your thinking ability; including, memory loss, difficulty concentrating, difficulty performing multiple tasks, and trouble with arithmetic and language skills. The following ideas may help:
  - Make a list of your questions and problems to discuss with the transplant team.
  - Always bring your caregiver to clinic appointments with you.
  - Write down important information and keep it with you at all times; such as, phone numbers, addresses, and people to contact in an emergency.
  - Ask that important information be given to you in writing.
  - Set a watch or clock to remind you when medications are due.

### POSSIBLE LONG-TERM COMPLICATIONS

- Hearing loss: If the chemotherapy that you receive is known to cause hearing loss, you will undergo a hearing test before your transplant and will be monitored for hearing changes after your transplant.
- Infertility: Patients often become sterile after stem cell transplant. If you are interested in fertility preservation, please notify your transplant team early in the process.

- Damage to the heart, liver, or lungs: This may be caused by chemotherapy you have received as part of your conditioning therapy or chemotherapy you have received in the past for cancer treatment.
- Menopause: Women may experience an early onset of menopause with symptoms of hot flashes and vaginal dryness. Hormone replacement and the use of water soluble lubricants with intercourse may be helpful.
- Thyroid problems: May be corrected with medication.
- Cataracts: May be surgically corrected.
- Dry and sensitive skin: Avoid sun exposure and use plenty of sunscreen with SPF 30 or higher.
- Hyperpigmentation of the skin (darkening of the skin exposed to chemotherapy or radiation)
- Dry mouth

# Stem Cell Transplant "Day Zero"

You will receive your stem cells 24-48 hours after finishing your conditioning therapy. The day you receive your stem cells is known as "Day Zero."

- Your stem cells will be infused in your hospital room.
- It is similar to receiving a blood transfusion.
- Your nurse will monitor you frequently during the infusion.

## THE PROCESS

Your nurse will check the physician's order for administration of the stem cell products and coordinate with staff in the Cell Therapy Facility for the start time of your stem cell infusion.

- Your nurse may start intravenous fluids prior to and after the stem cell infusion.
- You may receive pre-medications to help prevent any infusion related reactions.
- Infusion related reactions may include: fever, chills, flushing, rash, hives, heart rate changes, blood pressure changes, chest tightness, shortness of breath, coughing, nausea and vomiting, diarrhea, and/or abdominal cramping.
- A special liquid called dimethyl sulfoxide (DMSO) may be added to your cells if they needed to be frozen before you received them. This liquid is used to prevent damage to your stem cells. DMSO may contribute to some of the above infusion related reactions.
- DMSO has an unusual smell sometimes described as "creamed corn" or "garlic" which will be present in your body and released through your pores and breath for a day or two after stem cell transplant.
- Depending on your past medical history, you may be connected to a cardiac monitor.

- Your nurse will hook you up to a blood pressure machine and a pulse oximeter to monitor your oxygen levels.
- Vital signs will be monitored frequently during the infusion and for 4 hours after the infusion is complete.

## STEM CELL INFUSION

Once everything is prepared for your transplant, a Cell Therapy Technologist will bring your cells to your bedside.

- The Cell Therapy Technologist and your nurse will visually inspect your stem cells and verify that your name and medical record number match your stem cell product.
- Your nurse will infuse your stem cells into your central line catheter much like a blood transfusion.
- The length of time that it takes to receive your stem cells depends on how many bags your cells were stored in and the total volume of your stem cell product collected during Apheresis.
- The nurse will monitor you closely during this process and may slow the infusion or give you additional medications to treat any possible reactions, should they occur.



# Engraftment

- Your red blood cell, white blood cell, and platelet counts will drop after conditioning therapy.
- These counts will rise as new blood cells start to grow from your stem cells following your transplant. The production of new blood cells from your transplanted stem cells is a process called **engraftment**.
- Engraftment usually takes place within two to four weeks after your transplant.
- Usually, the first blood cell count to rise are your white blood cells, followed by your red blood cells, and finally your platelets. Not every patient's cells engraft in this order.
- Engraftment is the beginning of the recovery of your immune system. Complete recovery of the immune system can take months.
- While you are in the hospital, blood will be taken at least once a day to check the recovery of your blood cell counts. This will continue into your outpatient clinic visits.
- You are encouraged to follow your engraftment process by knowing what your blood cell counts are daily. Your transplant team will be happy to discuss these tests with you and help you understand the lab results.

## SUPPORT BEFORE ENGRAFTMENT

- You are most at risk for complications while you wait for engraftment. You must be watched carefully by the transplant team during this critical period.
- The transplant team will observe your vital signs, blood counts, the function of your organs, and your general condition.
- The purpose of close observation is to prevent and treat, as quickly as possible, any lifethreatening complications that may occur; such as, infection. You are at an increased risk for infection before engraftment.
- You may receive antibiotics, antiviral, and antifungal medications to help prevent or treat infections.
- Before engraftment, you may require red blood cell and/or platelet transfusions to keep your blood cell counts at a safe level.

# *Diet Guidelines for Patients with Decreased Immunity*

The purpose of this diet is to protect you from certain types of bacteria found in some foods that may be harmful to you when your immune system is decreased.

Food Group	Allowed	Avoid	Comments
Meat/Poultry	<ul> <li>All poultry and ground meat cooked well-done to 165°F</li> </ul>	• Raw or undercooked meats	• Use a meat thermometer.
	<ul> <li>Steaks, and roasts cooked to a minimal internal (center)</li> </ul>	° Refrigerated pâté	<ul> <li>Check expiration dates.</li> </ul>
	<ul><li>temperature of 145°F</li><li>Canned meats</li></ul>		<ul> <li>Cook frozen entrée dinners according to package instructions</li> </ul>
			<ul> <li>Meat from restaurants should be well done</li> </ul>
Hot Dogs and Deli Foods	<ul> <li>Hot dogs and deli meat or cheese may be eaten if heated until steaming hot (microwave, pan fry, grill or boil)</li> <li>Pre-packaged, sealed cold cuts and cheese</li> </ul>	<ul> <li>Hot dogs, deli meat and cheese unless heated until steaming hot</li> <li>Refrigerated, pre- made salads (egg, ham, chicken, tuna or seafood salad, potato salad, pasta salad)</li> </ul>	<ul> <li>Discard non-deli prepackaged cold cuts 4 days after opening.</li> <li>Discard deli cold cuts 4 days after purchase date.</li> <li>Pay attention to expiration dates.</li> </ul>
Fish/ Shellfish	<ul> <li>All well cooked fish and shellfish</li> <li>Canned fish and shellfish</li> </ul>	<ul> <li>Smoked fish is not allowed unless fully cooked or canned.</li> <li>Any raw or undercooked fish and shell fish (sushi, sashimi and ceviché).</li> </ul>	

Food Group	Allowed	Avoid	Comments
Eggs	<ul> <li>All eggs cooked well-done</li> <li>All pasteurized eggs</li> </ul>	<ul> <li>Eggs with runny yolks such as poached or over-easy unless made from pasteurized eggs</li> </ul>	<ul> <li>Pre-packaged foods that use pasteurized eggs are allowed (ex: Caesar dressing, cookie dough, eggnog)</li> </ul>
Milk, Cheese and Other Dairy Products	<ul> <li>All milk, cheese and dairy products made from pasteurized milk</li> <li>Milkshakes, frozen yogurt &amp; ice-cream at home, restaurant (no self-serve)</li> </ul>	<ul> <li>Avoid unpasteurized or raw milk and milk products.</li> <li>Ice cream, milkshakes or frozen yogurt from self- serve machines</li> <li>Smoothies in restaurants using fresh fruits</li> </ul>	<ul> <li>Grade A implies pasteurization in milk, cheese and dairy products</li> <li>Soy milk and other nondairy milk or milk products are allowed if pasteurized</li> </ul>
Fruits and Vegetables	<ul> <li>Thoroughly rinse all whole (un-cut) fresh fruits and vegetables under running water</li> <li>Canned, dried or frozen fruits and vegetables</li> <li>Bagged lettuce and baby carrots if rinsed after purchase</li> <li>Canned or bottled salsa</li> <li>Cooked or canned bean sprouts</li> <li>Cooked mushrooms</li> </ul>	<ul> <li><sup>o</sup> Unwashed fresh fruits and vegetables</li> <li><sup>o</sup> Pre-cut fresh fruits and vegetables unless used in cooking</li> <li><sup>o</sup> Fresh salsa from the grocery store or restaurant (Canned or bottled is OK)</li> <li><sup>o</sup> Raw sprouts of any kind (alfalfa or bean sprouts are examples)</li> <li><sup>o</sup> Raw mushrooms</li> </ul>	<ul> <li>Use a soft scrub brush to clean off soil, etc. from hard skinned fruits and vegetables (potatoes, bananas, melons, etc.)</li> <li>Avoid handling raw mushrooms</li> </ul>
Beverages	<ul> <li>All soft drinks in a can or bottle</li> <li>Pasteurized fruit and vegetable juices</li> <li>Smoothies and vegetable drinks made at home.</li> <li>Coffee from coffee shop (creamer must be provided by personnel from behind the counter)</li> </ul>	<ul> <li>All fountain drinks</li> <li>Smoothies and vegetable drinks made in restaurant or juice bars</li> <li>Self-serve creamer from pitcher</li> <li>Self-serve water from public facility (water fountains).</li> <li>Fresh lemon or lime slices in restaurant drinking water.</li> </ul>	<ul> <li>All commercial liquid nutrition supplements are also allowed (Ensure<sup>®</sup> and Boost<sup>®</sup> are examples)</li> </ul>

Food Group	Allowed	Avoid	Comments
Water	<ul> <li>County or city water is allowed</li> <li>Commercially bottled water</li> </ul>	<ul> <li>Well water unless filtered with approved "Point of Use" filter that removes &lt; 1 micron or a reverse osmosis system.</li> <li>If you have a well, you may also boil water for at least 1 minute before use.</li> </ul>	<ul> <li>Ask your dietitian for more help with choosing a water filter if you have a well for drinking water.</li> </ul>
Ice	<ul> <li>Ice made at home</li> <li>Ice from hospital tray or patient pantry</li> </ul>	<ul> <li>Ice from restaurants</li> <li>Self-serve ice</li> <li>Bagged ice</li> </ul>	
Condiments	<ul> <li>All those purchased for home use</li> <li>Individual sealed packages in restaurants.</li> </ul>	<ul> <li>All from self-serve dispenser in restaurants (ketchup, mustard, etc.) including bottles of condiments on table</li> </ul>	
Restaurants	° All cooked foods	<ul> <li>Salads, fresh fruits, vegetables and garnishes including lemons and limes</li> <li>Buffets and salad bars</li> </ul>	See additional Dining Out guidelines below

#### The following foods are allowed with no restrictions:

• Nuts

- Seeds
- Baked Goods
- Artificial Sweeteners
- Spices

Sugar

• Commercially Produced Honey or Syrup

Cooked Grains (pasta, rice, cereal)

Tea

• Coffee

## DINING OUT

# You may eat in restaurants; however, it is very important that you use extra caution by using the following guidelines:

- Observe and use good judgment regarding the cleanliness of the facility. If sanitation is questionable, choose another restaurant.
- Wash hands before eating.
- Order all eggs, meats, poultry and fish well-done.
- Eat only cooked food that is **served hot**. If the food is lukewarm, ask to have it re-heated or re-order.
- Order all beverages **without ice** and **without garnish** (lemon or lime slices).
- Pay attention to the wait staff to ensure they are practicing safe food handling. Make sure food server is not touching food or tips of silverware with bare hands.
- Place silverware on your plate, clean placemat or napkin not directly on the table.
- If ordering juice, ask if it is pasteurized.
- Eat only cooked vegetables (ask for **no garnish**).
- Avoid salads, fresh vegetables and fruits (including fresh fruit in smoothies).
- Avoid buffets and salad bars.
- Avoid road-side stands or street vendors.
- Avoid self-serve condiments, beverages and desserts (soft serve ice cream, etc.).
- If bringing home leftovers from a restaurant, be sure to refrigerate or freeze within **two hours** from initially being served.

• Carry out food should be picked up and still hot. NO DELIVERY.

## ADDITIONAL SAFE FOOD HANDLING GUIDELINES

- Wash hands with soap and warm water for at least 20 seconds prior to and during food preparation and handling and before eating.
- Wash all food preparation surfaces well before use. Use pre-moistened cleaning/disinfecting wipes or disinfectant spray with paper towel rather than sponges.
- **NO SPONGES: Do not use sponges** for cleaning dishes or other surfaces. Use a clean wash cloth and clean towel each time you clean or do the dishes **or** use disposable cloths.
- **Separate** raw food from cooked food during preparation.
- Wash hands after handling raw food and before touching cooked food.
- Keep cutting surfaces and utensils for preparing raw meats, fish and seafood separate from those used for preparing fruits and vegetables. Clean all equipment and surfaces thoroughly after use. Use plastic or glass cutting boards instead of wooden cutting boards.

## STORE FOODS PROPERLY

- Your refrigerator should be set at 40 °F or below. (Buy a thermometer if you do not have one.
- Cooked foods or those that need refrigeration should **not** be left at room temperature for more than two hours to prevent bacterial growth.
- Within two hours of cooking, food should be refrigerated or frozen in small portions.
- Leftovers in the refrigerator should be thrown away **after two days**.
- Defrost meats in the refrigerator and not on the counter. Meats may also be defrosted in the microwave. Be sure to defrost on a plate or in a sealable plastic bag to avoid seepage of raw meat juices on other surfaces. Cook meat as soon as possible after defrosting. Do not reuse plate that has been used for thawing meats until it has been washed with soap and water.
- Do not reuse raw meat marinades or put on cooked foods unless the marinade is boiled first.
- Anyone handling food should be free of illness. Individuals who have had a stomach or intestinal virus (nausea and vomiting) should not prepare food for others until three days after symptoms are gone.

## WHILE IN THE HOSPITAL

- Food brought from home must be eaten within two hours of cooking or frozen in small portions for reheating later.
- Small containers of food made at home must be labeled and can be stored in the Patient Pantry or Family Respite Room freezer.
- Food from restaurants is allowed if it is picked up by a caregiver and brought directly to the hospital.
- Food from restaurants must be consumed within two hours of preparation and leftovers must be discarded.
- It is important to keep hot food hot and cold food cold during transport.
- Review guidelines for Dining Out (on page 48) and ask to receive *Guidelines for Food Brought in from Outside* for more detailed information.

## ADDITIONAL TIPS

- You may wish to consider taking your own beverage with you to a restaurant.
- Buy a meat thermometer if you do not have one.
- Home grown fruits and vegetables are OK to eat as long as they are not in contact with soil that has been in contact with animals or animal waste.
- When sharing finger foods with others, such as chips or pretzels, put your portion in a separate bowl rather than eating from a large "community "container. (Watch out for "double dippers")
- Baked goods should be thrown away if they show signs of mold growth. Freeze extra bread and baked goods to maintain freshness.
- Watch for expiration dates and storage recommendations on all packaged products.
- Do not buy ready-to-eat foods from bulk food bins. (Includes breads, bagels, nuts, candies, etc.).
- Do not use oral pills, liquid supplements, or powders containing herbs, vitamins, minerals or other nutrition additives unless approved by your doctor or dietitian.
- Do not use Probiotic supplements unless approved by your doctor.

## PATIENT AND CAREGIVER GUIDELINES FOR OUTSIDE FOOD

To help ensure food safety, the preferred source of food for patients is the hospital food service.

In special situations, patients or caregivers may wish to bring outside food into the hospital. When bringing food into the hospital, it is important that you follow the guidelines listed below.

#### GENERAL GUIDELINES

- All outside food must be consistent with the diet your doctor has ordered.
- It is important to keep cold foods cold and hot foods hot while being transported to the hospital. A cooler with ice can be used to keep foods cold. Hot foods can be wrapped in layers of newspaper or other insulating wrap to help keep them hot.
- Once food has been brought into the patient's room it should **not** be stored again in the *Patient Pantry* or *Family Lounge* refrigerators.
- Foods may be heated in the microwave oven located in the *Patient Pantry* or *Family Lounge*.
- Cooked foods or those requiring refrigeration are allowed to remain at room temperature **NO longer than two hours**. After two hours at room temperature, food should be discarded.
- Beverages are considered perishable and should be brought in single serving containers. Any opened can or bottle should be thrown away after four hours outside the refrigerator (exception: bottled water or soda).

### FOOD STORAGE

- If you intend to store food in the Patient Pantry or Family Lounge refrigerators or freezers, single serving portions are recommended. Please avoid the use of large containers.
- All containers must be clearly labeled with the patient's name and the initial storage date.
- Food that is unlabeled or past the expiration date will be discarded.
- Food prepared at home and brought in for use beyond two days' time should be labeled and stored in the freezer.
- Frozen food should be labeled and placed directly into the freezer upon arrival to the hospital unit.

• Refrigerated foods from home may be stored in the *Patient Pantry* or *Family Lounge* refrigerator for a maximum of two days. After **two days**, refrigerated food items will be discarded.

### CARRY-OUT FOOD FROM RESTAURANTS

- All food brought in from restaurants should be well cooked.
- NO raw fruits or vegetables (including salads, fresh salsa, garnish or sandwich toppings) from restaurants.
- NO buffet food.
- NO delivery of food.
- Restaurant food must be picked up and brought to the hospital by a patient caregiver. Restaurant delivery is not permitted.
- Hot food should be steaming hot when obtained from the restaurant.
- Cooked foods or those requiring refrigeration are allowed to remain at room temperature **NO LONGER than two hours** before eating or proper storage. Leftovers must be discarded.

### DRY FOODS

- Dry foods such as crackers, cookies, cereal, chips, etc. may be stored in the patient's drawer stand or in food storage boxes brought in by the caregiver. Food must not be stored on the windowsill or other areas that would prevent thorough cleaning of the hospital room.
- Foods must be discarded if past the expiration or "use by" date.
- We suggest storing dry foods (crackers, etc.) in re-sealable bags to maintain freshness.

#### APPLIANCES

Due to infection and safety issues, refrigerators and other appliances (microwave ovens, toasters, blenders, coffee makers, hotplates, etc.) are not allowed in patient rooms.

# Hospital Discharge/Clinic/Discharge Home

We start planning for your discharge early so that your transition from hospital to out-patient clinic to home will be a smooth process.

### CRITERIA FOR DISCHARGE FROM THE HOSPITAL

- No fever for a minimum of 24 to 48 hours.
- No signs or symptoms of an active infection.
- No active bleeding. Platelet transfusions are not needed more than once per day.
- Able to eat and drink minimum nutritional requirements (IV fluids can be supported in the BMT Treatment Center if necessary.)
- Able to swallow medications by mouth, including medications for nausea and pain.
- Able to travel back and forth from the hospital in order to maintain daily clinic schedule (getting in and out of the car, walking, or use of wheelchair/walker).
- Caregiver is available 24 hours per day and 7 days per week.
- You may be discharged from the hospital before you completely engraft, if all of the above criteria is met.
- You will be evaluated daily in the BMT Treatment Center.

### PREPARATION FOR DISCHARGE FROM THE HOSPITAL

- Caregivers must attend one Caregiver Class, preferably within the first week after admission and before discharge from the hospital. Class is held every Wednesday and Saturday at 3:30 PM in the 4 West Conference Room. Registration is not required.
- Discharge education is completed with you and your primary caregiver by the Transition Nurses and the Dieticians several days before your anticipated discharge date.
- Your primary caregiver will be expected to arrive at Moffitt no later than one day before your anticipated discharge date, so that discharge education is completed.

- The Case Manager will arrange home care, IV infusion needs, and order medical equipment if necessary.
- Advance Directives may be reviewed and updated with the assistance of the Social Worker.
- The Pharmacist will review medications and provide a detailed medication list to you and your primary caregiver. Medications must be picked up from the pharmacy before your discharge.
- Housing arrangements are completed with the assistance of the Social Worker.
- The schedule for follow-up clinic appointments will be provided by the Transition Nurse.

### CLINIC FOLLOW-UP

- You will be required to remain in local housing until your doctor allows you to return home.
- You may be permitted to return home after discharge if you live within 30 minutes of the center.
- Clinic follow-up is usually 2 months after you are discharged from the hospital. You may be able to return home sooner or you may need to stay in the area longer, depending on your condition.
- You will have frequent follow-up visits in the BMT Clinic and Treatment Center.

### • <u>Children under 12 are not permitted in the BMT Clinic or Treatment Center.</u>

- Visits may include blood draws, administration of blood products, IV medications, and appointments with a Nurse Practitioner, Physician Assistant, and/or your doctor.
- The frequency and length of time of your visits to the clinic and treatment center will depend on your condition.
- Please follow your daily schedule. Showing up early does not mean that you will be seen early.
- Please wear a yellow duckbill mask to the clinic and treatment center until you receive further instruction from your transplant team.
- When arriving at the BMT clinic, please notify BMT staff if you or your caregiver have any of the following:
  - o Fever
  - o Cough
  - o Runny nose
  - 0 Rash

- If you have any of these symptoms, you must put on a mask and wait in the hallway. This is done to protect our patients and staff from contracting any infection that you might have.
- Please bring your medication list to all follow-up visits.
- During the time that you are staying in local housing, it is very important to communicate any issues to the transplant team.
- Your physician may decide that you need to be re-admitted to the inpatient unit for management of symptoms at any time once you are discharged.
- The main phone number for the BMT clinic is <u>813-745-7208</u>.
  - <u>Choose option 1</u> if you have questions about your schedule or need to change your schedule.
  - <u>Choose option 2</u> if you are calling about medical records.
  - <u>Choose option 3</u> if you need to speak with the business office.
  - <u>Choose option 4</u> for medication refills. Please leave a message with the requested information. Please allow 48 hours to process requests.
  - <u>Choose option 5</u> to speak with a member of the transplant team, especially about any symptoms that you may be experiencing. You will be able to speak with someone 24 hours a day.

## DISCHARGE HOME

- Your transplant doctor will tell you when you can return home and resume care with your local oncologist.
- This usually occurs about 90 days after your transplant, but will depend on your condition.
- You should make an appointment with your local oncologist within 1 week of your return home.
- Your local oncologist will manage your care with regular physical exams and blood tests to monitor your blood counts. Please make sure that your local oncologist is sending your lab results to your transplant doctor at Moffitt.
- You will return to Moffitt Cancer Center for follow-up visits as determined by your transplant doctor. These visits may also include restaging of your disease. During the first year after transplant, many patients return to Moffitt for follow-up visits at least every 3 months, but you may need to return more often based on your condition.

# Preventing Infection

- Infection is the most common complication after stem cell transplant.
- This increased risk of infection is caused by the conditioning treatment's effect on the body's immune system (infection-fighting ability).
- It may take several months to years for your immune system to return to normal. You will take medications to prevent infections during this time.
- Your transplant doctor will inform you when you are no longer at high risk for infection. You remain at risk of infection as long as you are on immunosuppressive medications (tacrolimus, sirolimus, cyclosporine, Cellcept).
- People have many kinds of microorganisms on their skin and inside their body. These microorganisms usually do not cause infection for those who are healthy; however, patients with a decreased immune system are more prone to infection. They may get infections from organisms from their own body or transferred from another person.
- Infections are most often transferred by touching. The most important thing to do to prevent infection is practice good hand washing.

## TIPS TO PREVENT INFECTION

- Wash hands frequently!
- Avoid touching your face.
- Use caution when going out in public. Avoid going to public places when they are busy.
- Wear a mask in public places until your doctor tells you it is not needed.
- Handshaking should be avoided.
- Avoid persons who are sick. Be careful around school-age children since they are exposed to lots of germs.
- Do shower daily.
- Cleanse rectal area after each bowel movement.
- Use an incentive spirometer.
- Do not share! Use your own utensils, towels, or toothbrush.

- Follow dietary guidelines as instructed (chapter 11).
- Do not clean litter boxes, bird cages, or fish bowls/tanks and do not handle animal feces.
- Wash your hands after petting a cat or dog.
- Avoid changing diapers. If you must change a diaper, wear gloves.
- Have your caregiver perform household chores. Do not stay in the room they are cleaning.
- Recommendations regarding vaccinations:
  - It is recommended that all members of the household of a transplant recipient receive age-appropriate vaccinations, including the influenza vaccine. We do not recommend that household members receive the FluMist® (nasal spray) vaccine.
  - There are no special precautions needed when household members receive the MMR, Varicella, or Shingles vaccines.
  - All members of the household should wash their hands after contact with feces of an infant who received the rotavirus vaccine for at least 2 weeks after vaccination.

Can I?	30 days or less	1 to 3 months	3 to 6 months	6 months or more
Work in an office	NO	NO	Discuss with MD	Discuss with MD
Work with animals	NO	NO	NO	Discuss with MD
Woodwork	NO	NO	YES, with gloves and mask	YES
Garden	NO	NO	NO	Discuss with MD
Have indoor plants	YES (do not touch)	YES	YES	YES
Mow lawn/rake leaves	NO	NO	NO	Discuss with MD
Clean my house (dust, vacuum)	NO	NO	Discuss with MD	Discuss with MD
Get a new pet	NO	NO	NO	Discuss with MD
Be around/pet my	YES	YES	YES	YES
cat/dog (already lives in house)	(wash hands after)	(wash hands after)	(wash hands after)	(wash hands after)
Have a reptile/bird/exotic pet	NO	NO	NO	Discuss with MD
Clean the litter box	NO	NO	NO	Discuss with MD
Go in a hot tub or community pool	NO	NO	NO	Discuss with MD
Swim in my own private pool	NO	NO	Discuss with MD	Discuss with MD
Golf	NO	YES	YES	YES
		(wear sunscreen)	(wear sunscreen)	(wear sunscreen)
Travel in an airplane	NO	Discuss with MD	YES	YES
Drink alcohol (if 21)	NO	Discuss with MD	Discuss with MD	Discuss with MD
Drive a car	NO	Discuss with MD	Discuss with MD	YES
Engage in sexual activity	YES (if ANC >500 and platelets >50,000)	YES	YES	YES
Attend social events	Discuss with MD	Discuss with MD	YES	YES
Remodel/renovate my home	NO	NO	NO	Discuss with MD
Have dental work done?	NO	Discuss with MD	Discuss with MD	Discuss with MD

# Guidelines to Help You Prevent Infection

# When to Call the Transplant Team

Area of Concern	Dial 911 NOW for these	Dial 813-745-7208 NOW
	emergency symptoms	for these urgent
		symptoms
Alertness	-Unconscious	-New or increased confusion
Consciousness	-Unable to wake up	-Change in level of alertness
Activity	-Seizures	-Mood changes: irritable,
	-Severe headache with vomiting	tearful, agitated
		-Changes in vision
		-Dizziness
		-Inability to get around
Bleeding	-Uncontrollable, constant	-New or increased bleeding
	bleeding	-Bloody urine (pink or red
		colored)
		-Bloody diarrhea (black, bright
		or dark red)
		-Vomiting blood (red or coffee
		grounds)
		-Using 1 or more feminine pads
		per hour
Breathing	-Not breathing	-Trouble breathing upright or
	-Choking	lying flat
	-Feeling like you can't catch	-Shortness of breath on
	your breath	exertion
	-Lips/nail beds look bluish	-Wheezing
	color	-New or recurrent cough
		-Coughing blood or
		green/yellow mucous

Area of Concern	Dial 911 NOW for these	Dial 813-745-7208 NOW
	emergency symptoms	for these urgent
		symptoms
Falls	-Hit head	-Anytime a fall occurs
	out	
	-Broken bone	
	-Severe bleeding	
	-Unable to get up	
Rash		-Sudden onset of rash
		-Rash with severe pain
		-Scaly areas, texture changes
		-Yellowing of skin or whites of
		eyes
Central line	-Air accidentally injected and	-Line broken or leaking
	patient short of breath	-Face, neck, or exit site swollen
	-Line accidentally cut and	-Unable to flush
	unable to clamp	-Line fell out with minor
	-Line fell out with uncontrolled	bleeding
	bleeding	-Redness, swelling, pain at exit
	IMMEDIATELY PLACE	site
	PATIENT ON LEFT SIDE	-Drainage from exit site
	AND CALL 911	-Pain at central line site
		-Pain with flushing of line
Diarrhea		-Constant or uncontrolled
		diarrhea
		-More than 4 stools per day
		-New onset diarrhea
		-Whole pills passed in stool
		-Diarrhea with fever or
		cramping
		-Bloody, dark red, or black
		stool
Fatigue	-Unable to wake up	-Dizziness
		-Too tired to get out of bed
Fever or chills		-Temperature by mouth 1s
		higher than 100.9 once or
		temperature of 100.5-100.8 for
		over 1 hour
		-Shaking or chills without fever
		-Cold or flu symptoms (cough,
		runny nose, body aches)

Area of Concern	Dial 911 NOW for these	Dial 813-745-7208 NOW
	emergency symptoms	for these urgent
		symptoms
Mouth pain (Mucositis)	-Choking	-Cannot swallow food, drink,
	-Unable to breathe	or pills
		-Bright red blood in mouth
		-White patches or sores in
		mouth or on lips
		-New mouth sores
		-Mouth or throat pain not
		controlled by medication
Nausea/Vomiting		-Nausea not controlled by
		medication
		-Bloody or coffee ground
		material appearing in vomit
		-Unable to keep medication
		down
		-Stomach pain or cramping
		with vomiting
Swelling		-Sudden swelling anywhere in
		the body with or without pain
		-Swollen hands, arms, or legs
Urination		-Unable to urinate for more
		than 8 hours or only urinating
		in very small amounts
		-Bloody (red or pink) urine
		-Painful urination
		-Difficulty urinating
Pain	-Severe chest or arm pain	-New scrapes, cuts, or
		punctures without severe
		bleeding
		-New or uncontrolled pain
		anywhere in the body
		-New headaches

# Graft versus Host Disease

Graft-versus-Host Disease (GVHD) is a common complication following an allogeneic transplant. GVHD occurs when donor cells (the "graft") recognizes cells in the body of the transplant patient (the "host") as foreign. The graft then mounts an attack on the host cells causing damage to tissues and organs.

- 30-60% of patients develop GVHD
  - Incidence is higher among older patients
  - Incidence is higher for patients transplanted with stem cells from an unrelated or HLA mismatched donor
- GVHD severity can range from mild to life threatening
  - Medications are given to prevent GVHD and may need to be taken for a long period of time
  - o Medications are available to help treat and control GVHD if it occurs
  - Other therapies such as phototherapy may be used as well
- GVHD can be ACUTE when it occurs in the first 100 days after transplant and/or it can be CHRONIC when it occurs after the first 100 days.
  - Acute and chronic GVHD differ in their signs and symptoms and time of onset
  - Patients may develop one type, both types, or neither

## ACUTE GVHD

- Can occur through the first 100 days after transplant
- Affects the skin, liver, and gastrointestinal (GI) tract
- One, two, or all three areas may be affected
  - o SKIN-
    - GVHD may appear as a faint rash on the neck, chest, back, hands or feet
    - Can spread to other parts of the body
    - The faint rash may develop into a general redness, similar to a sunburn, with peeling or blistering skin
    - A skin biopsy may be done to help determine if the rash is GVHD or caused from something else such as an antibiotic
  - o LIVER-
    - Blood tests done to look at liver function may be elevated
    - Right sided, upper abdominal pain may be present
    - Yellowing of the skin or eyes may occur
    - Abdomen may be distended (swollen)
    - A liver biopsy may be done to determine if the liver is affected by GVHD

#### • GASTROINTESTINAL (GI) TRACT-

- Symptoms may include:
  - Diarrhea (can be a large amount, often watery)
  - Intestinal bleeding
  - Abdominal pain
  - Abdominal distension (swelling)
  - Nausea
  - Vomiting
  - Loss of appetite
  - Unable to tolerate food, fluids, oral medications
- An upper and/or lower endoscopy may be done to obtain a biopsy to determine if GVHD of the GI tract is the cause of the symptoms or if symptoms are caused from something else such as a virus

### CHRONIC GVHD

- Most common late complication of allogeneic transplant
- May develop 3 months or more after transplant
- Acts similar to an autoimmune disorder
- Can affect the skin, liver, eyes, oral cavity, lungs, GI tract, neuromuscular system, and other body systems
- Symptoms may include:
  - Dry skin, skin pigment changes, nail or hair loss
  - Skin tightening or dimpling
  - Dry mouth, decreased saliva production, mouth sores
  - Dry eyes, decreased tear production
  - o Shortness of breath, cough, wheezing
  - o Fatigue
  - o Nausea, decreased appetite, diarrhea, weight loss
  - Muscle wasting, muscle cramps, muscle and skin tightening
  - Vaginal dryness, pain with sexual intercourse
- Patients may be referred to other health care professionals such as dentists and eye doctors to help manage and treat chronic GVHD symptoms

#### PLEASE REPORT ANY OF THE ABOVE SYMPTOMS TO YOUR TRANSPLANT TEAM AS SOON AS POSSIBLE. THE EARLIER GVHD IS TREATED, THE BETTER THE OUTCOME

# Long-term Follow-up

Transplant recipients require frequent monitoring of their health. Your transplant team needs to regularly check how you are improving and look for potential issues. When issues are caught early, there may be more options for treatment, and those treatments can be more effective.

Please review the post-transplant guidelines below:

Time post-	Recommended tests/screening
transplant	
6 months	Vision screening
	Dental exam
	Pulmonary function tests
	Evaluation of muscle strength and range of motion
	Post-transplant vaccinations
	Blood test to check for iron overload (ferritin)
	Blood tests to check endocrine function (thyroid, testosterone, estrogen)
12 months	Eye exam
	Dental exam
	Pulmonary function tests
	Evaluation of muscle strength and range of motion
	Dexa scan (screen for osteoporosis)
	Post-transplant vaccinations, including yearly influenza vaccine
	Blood test to check for iron overload (ferritin)
	Blood tests to check endocrine function (thyroid, testosterone, estrogen)
	Screening for other cancers
	General preventative care based on age: gynecological exam/mammogram for women, blood
	pressure/cholesterol screening, colonoscopy
Annually	Eye exam
	Dental exam
	Pulmonary function tests for patients with breathing problems
	Evaluation of muscle strength and range of motion
	Dexa scan (screen for osteoporosis)
	Post-transplant vaccinations, including yearly influenza vaccine
	Blood test to check for iron overload (ferritin)
	Blood tests to check endocrine function (thyroid, testosterone, estrogen)
	Screening for other cancers
	General preventative care based on age: gynecological exam/mammogram for women, blood
	pressure/cholesterol screening, colonoscopy

# Moffitt Cancer Center Resources

#### Arts in Medicine Program

Our program is designed to promote the vital role of the creative arts in influencing well-being and healing for cancer patients, family members, caregivers and hospital staff. Visual artists and musician artists-in-residence offer a broad spectrum of individual and group expressive arts opportunities at patients' bedsides and in clinic waiting areas.

#### **Cancer Screening**

Moffitt Cancer Center Screening and Prevention is an offsite clinic at Moffitt that provides the latest in cancer genetics research, screening technologies for breast, cervical, prostate, ovarian, and skin cancer, as well as preventive counseling. Through these services, Moffitt helps individuals understand and reduce their risk for developing cancer.

#### **Families First**

Families First is a program to help parents and children as they adjust to the changes that occur within the family when a parent has cancer. The program provides guidance on how to convey information about cancer and its treatment to children, TLC backpacks for children and parents, recommended readings, and specialty programs providing peer support and promoting family fun and togetherness.

#### **Financial Assistance Resources**

The following resources can be helpful when financial assistance is needed: Referrals to Community and National Agencies: 813-745-8407 Applications for Medicaid or Social Security Disability: 813-745-4022 Pharmaceutical Patient Assistance Programs to help with drug costs: 813-745-2694 Limited assistance with lodging and transportation: 813-745-8407 Life Insurance Line of Credit to be accessed during treatment: 813-745-8407

#### **Integrative Medicine Program**

Moffitt Cancer Center's Integrative Medicine Program offers many healing and wellness services and integrates safe and effective complementary therapies with conventional treatments to improve the quality of life for our patients during and after cancer treatment. Services include acupuncture, massage, meditation, and yoga.

#### Notary Services

Notary services are available for health-care related documentation weekdays from 8 a.m. to 5 p.m.

### 813-745-8407

### 813-745-4630

813-745-3808

#### 69

### 813-745-6769

813-745-1836

#### Oxygen Services

If you are using oxygen that has been prescribed by your physician, Moffitt will provide a portable oxygen tank for your use during your outpatient visit. We encourage you to pick up one of the Moffitt oxygen tanks at the information desk in the lobby. By using the hospital's tanks you will be able to save your tank for your ride home. We are not able to fill your tank due to fire protection codes so please pick up a tank as you enter the building. We regret we can only supply portable oxygen to Moffitt patients.

#### Patient and Family Orientation

Patients and family members are invited to attend and learn how to use our programs and services, partner with your care team, and find your way around Moffitt. Attendees receive a free microfiber briefcase with Moffitt resources and organizational tools.

#### Patient Library and Welcome Center

We invite you to visit the patient library at any time, where you are free to browse the latest cancer patient information; including, disease and treatment options, ideas for coping and support, and tips on cancer prevention. The Patient Library & Welcome Center is located on the 2nd floor of the Muriel Rothman Building, directly above Common Grounds Coffee Shop and is open Monday through Friday from 8:30 a.m. to 5 p.m.

#### **Patient Relations**

If your care team has not resolved your concerns, please contact Patient Relations.

#### Publix Pharmacy

The pharmacy is located on the first floor of the main hospital.

#### **Smoking Prevention**

Our Smoking Prevention program offers Moffitt patients and their families a personalized plan to help them quit smoking. Services available include education and self-help materials, counseling, nicotine replacement prescription therapy, telephone and online support, classes, and complementary therapies.

#### Survivorship Clinic and Program

For those patients who have ended their acute treatment, the Survivorship Clinic provides coordination with primary care providers and surveillance for recurrences or new cancers, monitoring for long term side-effects from the cancer or its treatment, including physical, emotional and social concerns with a refocus on wellness.

#### 813-745-4710

813-745-2963

#### 813-745-8811

813-745-4630

813-745-3808

813-745-8484

# **Online Resources**

#### Moffitt Cancer Center

This is your one stop on-line source of information regarding Moffitt. The website connects you to:

- Access to Patient Portal
- Important telephone numbers at the cancer center
- Information on Moffitt clinical programs
- Information on active clinical trials
- Disease-specific cancer treatment information
- Online Cancer Answers where you can ask a cancer question
- Access to Moffitt publications
- Links to other cancer information websites

#### American Cancer Society (ACS)

The American Cancer Society (ACS) is a national community-based voluntary health organization whose mission is to eliminate cancer as a major health problem through research, education, advocacy, and service. The Resource Center is an area on the site where patients can learn about the diagnosis and treatment of specific types of the disease.

#### Blood and Marrow Transplant Information Network

BMT InfoNet is a not-for-profit organization that serves families facing a bone marrow, stem cell or cord blood transplant, and survivors. This site includes easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

### Bone Marrow Foundation (BMF)

The mission of The Bone Marrow Foundation is to improve the quality of life for bone marrow and stem cell transplant patients and their families by providing financial aid, education, and emotional support.

#### www.moffitt.org

## www.bmtinfonet.org

www.cancer.org

www.bonemarrow.org
#### Cancer.Net

Use the Search box to search for "Bone Marrow."

Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO), is designed to help patients and families make informed health-care decisions. It includes oncologist approved information on more than 120 types of cancer and cancer-related syndromes.

#### International Myeloma Foundation

The International Myeloma Foundation (IMF) is the world's oldest and largest myeloma organization, reaching more than 195,000 members in 113 countries. Founded in 1990, the IMF is a non-profit organization dedicated to improving the quality of life of myeloma patients and their families.

#### Leukemia & Lymphoma Society

The mission of The Leukemia & Lymphoma Society (LLS) is to cure Leukemia, Lymphoma, Hodgkin's Disease, Multiple Myeloma, and improve the quality of life of patients and their families. LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services.

#### Medline Plus

On this website, select "Stem Cell Transplant" and/or "Bone Marrow Transplantation." Medline Plus is a service of the National Library of Medicine (NLM) to help the general public find accurate and current health information on the Internet. Medline Plus brings together authoritative information from NLM, the National Institutes of Health (NIH), and other government agencies and health-related organizations. Pre-formulated MEDLINE searches are included in Medline Plus and give easy access to medical journal articles. Medline Plus also has extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials, and the latest health news.

#### National Bone Marrow Transplant Link (*nbmt*LINK)

The mission of the *nbmt*LINK is to help patients, their caregivers, families, and the health care communities meet the many challenges of bone marrow/stem cell transplantation by providing vital information and support services.

www.myeloma.org

www.lls.org

www.nbmtlink.org

www.nlm.nih.gov/medlineplus/healthtopics

### National Cancer Institute (NCI)

The National Cancer Institute's (NCI) web site provides access to a wide range of accurate, credible cancer information and is based on the latest research. Patients can access information; including, the Physician's Data Query (PDQ), which is a database of summaries on cancer treatment, screening, prevention, and supportive care.

For blood and marrow transplant, the NCI provides a fact sheet at: http://www.nci.nih.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant

#### National Marrow Donor Program

www.bethematch.org

The National Marrow Donor Program (NMDP) helps people who need a life-saving marrow or blood cell transplant. They connect patients, doctors, donors, and researchers to resources they need to help more people live longer, healthier lives.

### ACKNOWLEDGEMENT OF RECEIPT OF INFORMATION

I have received the following information regarding my treatment and have had the opportunity to discuss my treatment with my health care team and ask questions:

- Conditioning regimen: The chemotherapy and/or radiation treatments used in my treatment plan, including potential side effects, have been explained to me. I have reviewed and signed consent to receive this treatment.
  Date reviewed: \_\_\_\_\_\_\_ Reviewed by: \_\_\_\_\_\_\_
- Advance directives: I have been provided information regarding advance directives.
  Date reviewed: \_\_\_\_\_\_ Reviewed by: \_\_\_\_\_\_

- Follow-up instructions: Instructions regarding discharge from local area and return to home have been provided and reviewed.
  Date reviewed: \_\_\_\_\_\_\_ Reviewed by: \_\_\_\_\_\_

## Glossary

Acute: sudden, severe symptoms over a short period of time

Advance directives: legal documents that tell your doctor and your family what kind of care you would like if you become unable to make medical decisions

Allogeneic stem cell transplant: transfer of stem cells from one person to another who is not an identical twin

Alopecia: loss of hair

ANC: absolute neutrophil count

Anemia: decrease in the number of red blood cells which causes a decrease in the cells ability to carry oxygen

Anorexia: loss of appetite

Antibiotic: medicine used to fight bacterial infections

Antiemetic: medicine used to control nausea and vomiting

Antifungal: medicine used to prevent or treat fungal infections

Antiviral: medicine used to prevent or treat viral infections

**Apheresis:** procedure by which blood is drawn from a patient's arm or central line and circulated through a machine that removes certain components; such as, peripheral blood stem cells and returns the remaining components to the patient

Ascites: accumulation of fluid in the abdominal area

Autologous stem cell transplant: receiving one's own stem cells rather than donor stem cells

Baseline test: measures an organ's normal level of functioning

Biopsy: removal of tissue for examination under a microscope

**Blood count**: the number of red blood cells, white blood cells, and platelet in a given sample of blood; also known as CBC

BMT: Bone Marrow Transplant or Blood and Marrow Transplant

Bone marrow: soft tissue in the hollow of flat bones of the body that produces new blood cells

**Bone Marrow Biopsy**: test that evaluates your bone marrow function and health of your white blood cells, red blood cells, and platelets

**Cancer:** group of diseases that causes cells in the body to change and grow out of control. Most types of cancer cells form a lump or mass called a tumor. In blood cancers, the abnormal cells take over the bone marrow.

**Central venous catheter/central line**: small, flexible plastic tube inserted into a large vein through which medication and blood products are given and blood samples withdrawn

**Chemotherapy:** medication designed to kill cancerous cells

Chronic: for a long period of time

Clinical trials: research which compares new medications or treatments to what is currently used

**Conditioning Therapy:** use of chemotherapy, medications, and/or radiation before stem cell transplantation

**Cryopreservation:** freezing at very low temperatures which keeps frozen cells intact and functional for many years

CT scan: a three dimensional x-ray, also called a CAT scan or CT-X-ray

**Cultures:** samples of body fluids; such as, sputum, blood, urine, and swabs of the inside of the nose, throat, and rectum

**Day 0:** marks the day when stem cells are infused into the body

Dermatitis: skin rash

Dysphasia: difficulty swallowing

Edema: abnormal buildup of fluid

Electrocardiogram (ECG): test to determine the pattern of a patient's heartbeat

**Electrolyte:** salts and minerals found in the blood; such as, sodium and potassium that must be maintained within a certain range to prevent organ malfunction

Emesis: vomiting

Endoscopy: inspection of body organs or cavities using a flexible, lighted tube called an endoscope

**Engraftment:** process by which transplanted stem cells migrate to the recipient's marrow and begin to produce blood cells of all types

Esophagitis: inflammation of the throat

Family and Medical Leave Act (FMLA): allows eligible employees the right to an unpaid leave of absence up to 12 weeks within a 12-month period for specific reasons defined by law

Febrile: having a fever

Gastritis: inflammation of the stomach

Growth factors: medication that helps normal cells recover from the side effect of chemotherapy

Hematopoiesis: formation and development of blood cells, usually takes place in the bone marrow

Hematocrit: measures the amount of red blood cells in the blood

Hemoglobin: blood test that measures the amount of oxygen in the blood

Hyperpigmentation: darkening of the skin

Hypertension: high blood pressure

Hypotension: low blood pressure

Immunocompromised: condition in which the immune system is not functioning normally

**Immunosuppression:** condition in which the immune system is functioning at a lower than normal level

**Immune system:** the complex system which helps the body resist infection and rejects transplanted tissues or organs

**Incentive Spirometer: s**mall, plastic device which helps you breathe deeply and keeps your lungs healthy. You will be asked to use this device several times each day while hospitalized.

**Informed Consent:** legal document that explains a course of treatment, the risks, benefits, and possible alternatives; the process by which people agree to treatment

Intravenous: administration of a drug or fluid directly into the vein

Leukemia: cancer of the blood or blood-forming organs

**Living Will:** document under Florida Law which allows you to express in writing your desire to receive or refuse certain kinds of medical care under various circumstances. You must name a person (relative or caregiver) who can make all medical decisions for you in the event you cannot speak for yourself; including, authorizing or refusing any medical treatment.

**Lymph nodes:** small bean-shaped collections of immune system tissue found along lymphatic vessels. They remove cell waste and fluids from lymph and help fight infections.

Lymphoma: cancer of the lymphatic system

Magnetic resonance imaging (MRI): method of taking pictures of the inside of the body using magnetic fields and radio waves

**Mobilization**: process of increasing the number of stem cells in the blood. This can be accomplished by using growth factors, chemotherapy or a combination of both.

**Mucositis**: inflammation and irritation of the fragile membranes throughout the gastrointestinal tract

**MUGA Scan**: test that measures the performance of your heart muscle. A dye is injected into your bloodstream through an IV and then x-rays are taken of your heart.

Neutropenia: decreased number of neutrophils (a type of white blood cell) in the blood

**Neutrophil:** the principal phagocyte (microbe-eating cell) in the blood. This blood cell is the main cell that combats infection.

**Oncologist:** doctor with special training in the diagnosis and treatment of cancer

**Opportunistic infection:** bacterial, viral, fungal, or protozoan infection that usually does not cause disease in a healthy individual but can produce serious infections in persons with immune deficiency, such as those undergoing stem cell transplantation.

PBSC: Peripheral Blood Stem Cells

Petechiae: small red spots on the skin that usually indicate a low platelet count

Platelet: specific blood cell that prevents bleeding in the body after an injury

Prophylactic: to prevent

**Pulmonary Function Tests (PFT's):** measure how well your lungs work. You will be asked to breathe into a tube. You will also have blood drawn from your wrist to measure the amount of oxygen in your blood.

Radiation therapy: treatment with radiation to destroy cancer cells

Recurrence/relapse: cancer that has come back after treatment

**Red blood cell:** contains hemoglobin, which carries oxygen to the tissues of the body

**Remission, complete:** condition in which no cancerous cells can be detected by a microscope or scans and the patient appears to be disease free

**Remission, partial:** at least 50 percent regression of the disease following cancer treatment

**Renal:** pertaining to the kidney

**Sepsis:** presence of infectious organisms in the blood

Side effects: caused by cancer treatment; such as, hair loss or fatigue

**Stem cells:** specialized cells in the bone marrow that mature into red cells, white cells, and platelets. The stem cells are largely found in the bone marrow, but some leave the marrow and circulate in the blood.

Stomatitis: inflammation of the mouth, tongue, or gums

TBI: Total Body Irradiation

**Thrombocytopenia:** decrease in the number of platelets in the blood; it can be a side effect of chemotherapy and carries a risk of bleeding

Ultrasound: technique for taking a picture of internal organs or other structures using sound waves

**URI:** Upper Respiratory Infection

**Vaccine:** injection of a medication into a person to stimulate an immune response and protect the person against disease

**X-rays:** one form of radiation that can be used at low levels to produce an image of the body on film or at high levels to destroy cancer cells

# Image and Photo Credits

Image 1, page 5:	Reproduced by permission of the artist: Hematopoietic Tree© (Terese Winslow, LLC, 2007) National Cancer Institute at the National Institute of Health www.cancer.gov/NCI Visuals OnLine/Hematopoietic Tree - Basic
Image 2, page 21:	Central Line Catheter Patient Education Tools/Moffitt Medical Illustrations BMT/HMP.2.JPG
Image 3, page 22:	Central Line Catheter Patient Education Tools/Moffitt Medical Illustrations BMT/HMP.JPG
Image 4, page 27:	Photo: BMT Inpatient Unit Patient Education Tools/Moffitt Photo archives
Image 5, page 42:	Reproduced by permission of the artist: Patient Receives Stem Cells© (Terese Winslow, LLC, 2011) National Cancer Institute at the National Institute of Health www.cancer.gov/NCI Visuals OnLine/Stem Cell Transplant 3



### **Directions To Moffitt Cancer Center**

Moffitt Cancer Center is located in north Tampa, adjacent to the Health Sciences Center at the University of South Florida.

**From I-275, traveling north or south,** take the Fletcher Avenue exit east to Magnolia Drive (first light after Bruce B. Downs Boulevard). Turn right on Magnolia Drive and proceed south. After passing through a traffic light (West Holly Drive), you will see the Center's main entrance on your right.

**From I-75,** take the Fletcher Avenue exit west to Magnolia Drive and turn left (south), following the same directions.

**From Veterans Expressway,** take the Ehrlich Road exit and drive east. Ehrlich Road becomes Bearss Avenue after crossing Dale Mabry Highway. Continue driving east on Bearss Avenue. Take a right onto Bruce B. Downs Boulevard and proceed south. Turn left onto Fletcher Avenue. Take a right onto Magnolia Drive, following the same directions.



Complimentary valet parking is provided.

- Moffitt Cancer Center Main Building, front entrance, **RED VALET PARKING**
- Muriel Rothman Building GOLD VALET PARKING
- Vincent A. Stabile Research Building GOLD VALET PARKING
- Moffitt Research Center, across the street GREEN VALET PARKING
- Moffitt South Expansion BLUE VALET (Patients Only)

= Points of Interest



12902 Magnolia Drive Tampa, FL 33612-9416 813-745-4673 MOFFITT.org

**BMT Clinic Contact Number** 

813-745-7208