Bone Marrow Transplant Program

Patient Education Manual
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Pre-Transplant Planning & Preparation

Bone Marrow Transplant Program Overview

The Virginia Commonwealth University Massey Cancer Center’s Bone Marrow Transplant Program performed its first transplant in 1988. Since that time the program has grown tremendously. The program recently expanded the number of inpatient beds to a total of 21 as well as increasing the size of the outpatient clinic facility. The Bone Marrow Transplant Program offers state-of-the-art transplants for both autologous and allogeneic transplants. Allogeneic donor sources offered include matched and partially matched related and unrelated adult stem cells as well as cord blood stem cells to increase the likelihood of a donor match. Our program includes services to harvest and store bone marrow and stem cells, an inpatient unit where the transplant is performed, and an outpatient clinic that provides your care before and after transplant. The VCU Massey Cancer Center’s Bone Marrow Transplant Program is accredited by the National Marrow Donor Program and the Foundation for the Accreditation of Cellular Therapy (FACT). More recently it became a Blue Distinction Center in recognition of the program’s depth of experience and excellent outcomes with patients.

Our highly trained and comprehensive team is committed to providing the highest level of care possible to you and your family. Our team members include:

- Transplant physicians
- Physician assistants
- Nurse practitioners
- Transplant fellows
- Transplant coordinators
- Clinical research assistants
- Nurse manager
- Registered nurses
- Nursing assistants
- Dieticians and diet aids
- Social workers
- Financial coordinators
- Pharmacologists
- Clerks and secretaries
- Physical and occupational therapists

Your care will be provided by a team of rotating physicians both during your hospital stay and while you are being followed by the BMT Clinic.
When Stem Cell Transplants are Needed

Stem cell transplants are performed when:

- A disease that affects the bone marrow, such as leukemia and myelodysplastic syndrome, causes the bone marrow to not produce healthy blood cells.
- There is a failure of the bone marrow to produce sufficient numbers of blood forming cells or to produce adequately functioning cells for the immune system.
- Some diseases, such as myeloma, lymphoma, testicular cancer, neuroblastoma, and medulloblastoma (to name a few) require more intensive treatments. Stem cell and bone marrow transplantation helps to reduce the risk associated with treatment and also speeds recovery.

Types of Transplant

The Stem Cells can be collected from your own body or can be harvested from another person. This other person would be your donor.

**Autologous transplant:** when a person receives his or her own stem cells.

**Allogeneic transplant:** when a person receives stem cells from another person, either a relative or someone unrelated.

**Syngeneic transplant:** when a person receives stem cells from his or her identical twin sibling.

You will receive more detailed information on the type of transplant that is recommended for you.

Collection Sources for Transplant

Bone marrow is the tissue that is found inside our bones. It has a spongy texture and is rich in stem cells. Stem cells grow and divide into white blood cells, red blood cells, and platelets. Each of these cells has a very important role in our bodies. Stem cells are the cells that are transplanted into your body during a bone marrow transplant. They may be collected from any of the following sources:

**Bone Marrow**- Bone marrow is collected from the iliac crest (hip bone) in the VCUHS operating room. This type of transplant is called a *bone marrow transplant*.

**Blood Stream**- Stem cells in the bone marrow can be stimulated by a special injection (growth factor) where they can then be collected from the circulating blood. Stem cells are collected from the blood stream during a procedure called apheresis. This type of transplant is called a *peripheral blood stem cell transplant*.
**Umbilical Cord**: The umbilical cord of newborn babies is a rich source of stem cells. This type of transplant is called an *umbilical cord blood transplant*.

The stem cells collected from these sources are basically identical, however, the composition of the other cells also collected from each of these sources may differ. Your transplant team selects from these sources based on criteria that tailor the treatment to your unique situation.

**First Consult**

At your first visit the transplant nurse practitioner or physician’s assistant will take a complete history of your current disease and treatments, as well as other medical history. A physical exam will also be done. The transplant physician will then review the information and talk to you about your treatment options, treatment alternatives, and what may be involved in transplant. The doctor will answer any questions you have at this time. The transplant physician will determine what type of treatments and/or transplant you need based on your disease. The transplant physician will then send his consultation note with recommendations and potential plan to your referring physician. You will be introduced to a pre-transplant coordinator who will discuss the phases of transplant and the processes to follow.

*Please refer to the “transplant timeline” in the appendix section of this manual to help you visualize the steps you will need to undergo. Your transplant coordinator will be available to discuss the “timeline” with you.*

**Bone Marrow Transplant Research and Clinical Trials**

Research is extremely important to the advancement of transplant procedures and other cancer treatments. All of the treatment benefits you may enjoy today are due to the participation of others in clinical trials. Through research, we discover better ways to treat cancer and manage side effects of treatment. You may be offered a chance to participate in a research clinical trial. If this is an option for you, the physician will discuss the possible benefits and risks. You will have the opportunity to review this information and discuss it with your family before choosing to participate. The decision to participate in a clinical trial will be up to you and will not affect your ability to receive high quality care at the Massey Cancer Center. If you choose to participate, you will need to sign consent forms. Not all patients will have the opportunity to participate in clinical trial research. The bone marrow transplant team will decide if this is an option for you.
Insurance Approval

At the first visit, you will be asked for information on your insurance company. Please be sure to bring your insurance information and referral if required. Our financial coordinators will work with you and your insurance company to get approval for transplant. All insurance carriers do not have the same process for authorization. Transplant approval can take up to two weeks.

Smoking, Alcohol, and Drugs

Because of the increased risk of severe complications in transplant patients who actively smoke, drink, or use recreational drugs, we highly recommend that you refrain from using these substances. Many of the treatments required for certain kinds of transplant require that you stop smoking and using alcohol and recreational drugs due to the risk of drug interactions and potential for organ injury. In these cases you must stop using these substances to be considered for transplantation. In many instances your insurance company may require that you not use these substances before they approve your transplant and require testing to confirm this.

- Active smoking and exposure to second-hand smoke may cause lung infections, pneumonia, and fungal infections while your immune system is suppressed. It has also been associated with permanent and often fatal lung damage during the transplant.

- Family members who live with you will need to either stop smoking or do so out of your living area.

- Alcohol and drugs increase the risk of damage to the heart, lungs, brain, and kidneys and can also increase the chance of side effects from medications used during the transplant.

- The risks associated with smoking, alcohol, and recreational drugs will remain higher throughout your lifetime because of the high dose chemotherapy and/or radiation therapy used in bone marrow transplant. The transplant team will work with you and your family to help you abstain from alcohol, drugs, and tobacco.
Donor Search and HLA Typing

If it is decided that an allogeneic transplant would be the best option, a donor needs to be found. To increase the chances of a successful transplant it is important that the donor’s genetic code (DNA) matches the patient as closely as possible.

- Each human has a set of proteins on the surface of cells called Human Leukocyte Antigen (HLA) which is what the immune system uses to decide what is “you” from what is “not you” in its decision to fight or reject.
- These are the markers that we look at when trying to find a donor that closely matches your DNA.
- Our DNA is passed down to us from each parent. As a result, our brothers and sisters are more likely to match our HLA type than a parent or grandparent or more distant relations.
- Each brother or sister has a 25% chance of matching. The more siblings the patient has, the greater the chance of finding a “matched related donor”.
- Unrelated donors may also be a match for your HLA. They are primarily located through the National Marrow Donor Program and may come from adult or cord blood sources.
- All efforts are made to obtain the best match for your HLA type.
- The HLA is collected via a swab kit which the donors can perform at home by swabbing the inside of the cheeks in their mouth or by blood test.

Pre-Transplant Evaluation

Once the decision is made to proceed with transplant you will need to undergo a pre-transplant evaluation. The evaluation includes a number of tests to serve as a baseline and to determine if your body will be able to tolerate the transplant. This also allows your transplant team to tailor the process to your overall health status.

Pre-transplant tests are performed at VCUHS as an outpatient. Every attempt is made to have all the testing performed on one day.

Your pre-transplant coordinator will provide you with a schedule of times, locations, and any required preparation for these tests.
Pre-Transplant Testing

Below is a list of tests that may be ordered for you depending on your disease and history. The transplant team physicians will determine which tests are necessary for you.

**Bone Marrow Biopsy and Aspirate:** A sample of bone marrow is collected from the hip bone. This test looks at how well your bone marrow is working and will show if there is any disease present in the marrow.

**Pulmonary Function Tests:** This test determines how well your lungs are working.

**Echocardiogram:** This test is used to look at the function of the heart.

**Additional cardiac or stress tests as appropriate:** To measure overall cardiac or heart function.

**Electrocardiogram (EKG):** This test may be done to look at the function and electrical activity of the heart.

**CAT Scan:** This test is done to look closely at the organs inside the body. It may be done to look for cancer or other problems with the organs. A CAT scan can be done with or without contrast dye and will take anywhere from 15 minutes to an hour.

**PET Scan:** This test can also be used to look for the presence of cancer. The scan itself will last about an hour, and you will have to lie as still as possible during this procedure.

**Bone Survey:** This test is done to see if there is any disease present in the bones.

**Blood and Urine Tests:** These tests are done to see how well your kidney, liver, and bone marrow are working. You may also receive a container to perform a 24 hour urine collection at home. Specific instructions will be provided.

**Infectious Disease Tests:** Blood samples are drawn to test for a number of infectious disease markers to identify infections such as hepatitis.

**Psychosocial Evaluation:** All of our patients being evaluated for transplant are required to meet with our transplant social worker or psychologist. This meeting will take at least an hour.

**Dental Evaluation:** We request that all of our potential transplant patients have a dental visit within one year prior to transplant. Please provide your dentist’s name and office number to your transplant coordinator.

**Gynecological Exam:** We request that all of our female transplant patients have a gynecological exam, including pap smear, within one year prior to transplant. Please provide your gynecological doctor’s name and office number to your transplant
coordinator. All female patients will have a pregnancy test if appropriate during the pre-transplant evaluation and within seven days of starting mobilization and transplant chemotherapy. The menstrual cycle will need to be suppressed. This will be discussed with you during the month prior to transplant. In some instances a mammogram may be required.

**Smoking Screening:** The cotinine level is a blood test to ensure that the patient is not actively smoking and does not have nicotine in the blood stream. Nicotine is also present in patients exposed to second hand smoke. The test is very sensitive and it takes nearly six weeks after your last tobacco exposure to clear from your system. If you smoke, it is important that you stop. Your transplant coordinator can schedule an appointment with our transplant psychiatrist to assist you with a plan to stop smoking.

The transplant attending physician will review all of the performed tests and discuss the results with you at your second consult.

**Donor Evaluation**

Prior to the donation of stem cells, the donor will undergo a thorough evaluation. The evaluation is done to ensure that the donor is healthy enough to undergo the procedures that are required for donation. They will also be tested for infectious diseases that can be passed on through stem cell donation. The evaluation testing includes:

- Blood work
- Pregnancy test on females of childbearing potential
- Chest X-ray
- EKG
- Physical examination and health history

Consents for donation and education of risks and benefits are also reviewed at this time.

**Second Consult and Consent Meeting**

A second consult will be scheduled after the pre-transplant tests have been completed, and consents for the transplant will be presented. Your caregiver should also be present for this meeting. All patients must have a caregiver that will be responsible for transportation, food preparation, and communication with transplant staff. Without a caregiver a patient cannot be accepted for transplant. At the second consult meeting, the transplant process will be reviewed with you and your caregiver. Topics to be discussed include stem cell mobilization and collection, chemotherapy, common side effects, schedule for apheresis and admission for transplant. We want you to be as knowledgeable as possible about the transplant process. Please take this opportunity to ask questions so that we can address your concerns at this time. It is important for you to feel as comfortable as possible before proceeding with transplant. Signed consents are required before you can proceed with apheresis and transplant.
Caregiver Responsibilities

Having a caregiver is a basic requirement to be considered for transplantation. The presence of active and effective caregivers is critical to the success of the transplant process. Below is a list of some of the functions that the caregiver of a transplant patient will be expected to perform. These items will be discussed with you in more detail during the pre-transplant process and throughout your hospitalization. The length of time you will need a caregiver will vary with your unique medical needs and living situation.

A caregiver must be available to the patient 24 hours a day, 7 days a week after transplant. Duties include, but are not limited to:

- Help with basic hygiene as needed.
- Household activities: The patient’s environment should be kept as clean as possible. The patient should avoid contact with dirty items such as laundry, dishes, and pet items (bowls, cages, litter boxes, etc.). The caregiver should wash the patient’s sheets and towels regularly.
- Transportation: The caregiver must drive the patient to all appointments until the patient is informed by the doctor that he or she is able to drive.
- Symptom management: The caregiver will assist the patient with managing symptoms such as pain, nausea, fever, etc. and must alert the healthcare team to any concerns. Signs and symptoms to report will be reviewed throughout hospitalization and at discharge as well as in the BMT clinic.
- Food preparation and nutrition: Transplant patients should not handle uncooked food items due to the risk of infection. Skins, peels, and rinds of fruits and vegetables may have harmful bacteria or fungus and must be washed and removed by the caregiver prior to eating.
- Psychosocial support.
- Emergency issues: The caregiver will alert the healthcare team of any emergencies and provide the team with emergency contact information.

The transplant process is not only challenging for the patient, but also for the caregiver. It is important for you as the caregiver to remember that you also need to take care of yourself. When you take care of yourself you will be more at ease, alert, and capable of caring for your loved one.
Housing for Transplant Patients after Discharge

If you live more than 30 miles or 30 minutes from VCU, you will be required to stay locally. The duration of your stay will vary depending on your unique medical situation, your type of transplant, and any side effects you may experience during your care after transplant. You should contact your insurance company regarding benefits for food and lodging allowance and reimbursement.

Hospitality House
The majority of our patients stay at the Hospital Hospitality House at 612 E. Marshall St., about 7 blocks from the hospital. Their phone number is (804) 828-6901. Shuttle services are available to and from the hospital and the Hospitality House. The Hospitality House is a refurbished Days Inn that provides one room per family with a maximum of 3 to 4 people per room. These facilities are used by various patients and their families. Transplant patients and their caregivers stay (after discharge) on the 5th floor where only transplant patients are located. Some patients may also be from the solid organ transplant services and may have different medical requirements than the bone marrow patients. On the transplant floor there is a small kitchen with a microwave and refrigerator. The kitchen is accessed by going outside on the balcony and walking to the door. There is a large main kitchen downstairs that your caregiver may use to prepare meals. We recommend labeling your food items with your name before storing in the kitchen areas. The Hospitality House has a common area downstairs where patients may go if they wear a face mask. Transplant patients should not use the gym. The rooms on the 5th floor are small and have a double bed and a cot or recliner. Hospitality House is a charitable organization and they ask for a donation of fifteen dollars per person per night to stay there. However, this is not mandatory. There is also a small deposit for linens and keys. Some of the staff are paid and some are volunteers. There are two social workers who work evenings during the week. They do not allow food and drink in the patient rooms. One important thing to remember is that the Hospitality House DOES NOT allow children under the age of 14 to stay there unless the child is a transplant patient.

Extended Stay Hotels
These are an option for those who can afford the cost. Most extended stay hotels offer small to large suites. Average price for a small suite with a bedroom, kitchen and sitting area runs in the 50 plus dollar per night range. Contact the VCU Concierge at (804) 628-1011 for details and help with discounted rates.

Apartments
Some people may prefer furnished apartments. There are some in the area that allow for short term leasing. These will likely be expensive. VCU cannot formally recommend a particular place. Some patients have stayed at Candlewood Suites, Reflections on West Creek in Short Pump, Copper Mill Apartments in Henrico County, Rockett’s Landing near downtown, Tobacco Row apartments downtown, or rented a corporate apartment through the Marriott Corporation. There may be other places as well. An apartment locator guide (usually available in newspaper boxes placed along the sidewalks) or a real
estate agent may help. You may also try a Google search of “Richmond, VA temporary housing”.

**Transplant Apartments**
There are two apartments that are reserved for patients having allogeneic transplants (donor cells) and especially those with children that cannot stay in the Hospitality House. There are only two of these apartments available to all transplant services so availability may be limited. Talk to the social worker if you are interested in this option.

For more information on hotels, contact the VCU Concierge for assistance.

**Catheter Placement and Catheter Care**

Before proceeding with transplant or stem cell collection, you will be required to have a catheter placed. A tube called a catheter will be inserted into a large vein in your chest under the collarbone. The catheter is required for transplant patients and can be used to:

- Draw blood
- Receive fluids
- Receive antibiotics and medications
- Receive blood products
- Stem cell collection
- Receive transplant stem cells

Your pre-transplant coordinator will provide you with the date, time, location, and required preparation or restrictions for catheter placement.

- The procedure is performed as an outpatient procedure.
- The insertion may cause discomfort for a number of days. You may take Tylenol (acetaminophen). DO NOT TAKE ibuprofen (Advil or Motrin) or aspirin as these medications may make you more prone to bleeding.
- Your transplant coordinator will contact VCUHS Critical Care Systems for catheter care supplies and education.
Mobilization for Autologous Transplant and Related Donors

Stem cells need to be collected before the transplant high dose chemotherapy is administered. Stem cells are collected from two sources:

1. Bone marrow
2. Peripheral blood

Stem cells are plentiful in the bone marrow and are also found in our circulating blood in lower numbers. We need to move or mobilize the stem cells out from the bone marrow into the blood stream so the stem cells can be collected. Mobilization is accomplished by using chemotherapy and growth factors or growth factor alone. Growth factors are naturally occurring substances in the body. Some of the chemotherapy mobilization may require hospital admission for a few days. Related donors will only receive growth factor for mobilization.

Growth Factor Only
Mobilization usually begins on a Friday at which time you will receive daily subcutaneous injections of a growth factor. Blood tests will be done on the 4th day to see if there are enough stem cells to begin collection. Collection usually begins on the 4th or 5th day of growth factor injections.

Mozobil (Plerixafor) may be added on the 4th night if blood tests indicate this is necessary. Mozobil helps to move the stem cells out of the marrow into the circulating blood. These injections are done nightly until collection is complete.

What to expect: Complications from the growth factor are minimal and include flu-like symptoms, bone pain and injection site irritation.

What to do: You may treat flu like symptoms and bone pain with Tylenol (acetaminophen). DO NOT take aspirin or ibuprofen (Motrin/ Advil).

Chemotherapy and Growth Factor Mobilization
When mobilizing chemotherapy is given, a portion of your chemotherapy will be given as an inpatient. Twenty-four hours after the completion of chemotherapy, growth factor will be administered. Your pre-transplant coordinator will give you a personalized calendar with specific information. You will have labs drawn to monitor your blood counts as they will drop in response to the chemotherapy and then rise in response to the growth factor. Once your blood counts start to recover, the stem cells will increase in number in the blood stream and you will be ready for collection of the stem cells. Mozobil injections are also a potential with chemo mobilization.
What to expect: Possible complications may include potential for infection and bleeding, nausea and vomiting, flu-like symptoms, bone pain and injection site irritation.

What to do:
- You will need to take your temperature daily and call the MD if your temperature is 100.4 or greater.
- You will need to take anti nausea medication as prescribed.
- Perform mouth care as instructed.
- Report any signs or symptoms of infection to BMT staff: chills, temperature of 100.4 or greater, rapid heart rate, pain or redness at catheter site.
- You may treat bone pain with extra strength Tylenol. DO NOT take aspirin or ibuprofen (Motrin/Advil).

Stem Cell Collection: Apheresis

Stem cell collection is done using a procedure called apheresis. For most patients a central venous catheter is used for collection. The catheter will be connected to the apheresis machine. The blood will be removed through the catheter and returned by the apheresis machine. As the blood travels through the apheresis machine, the stem cells are separated from the other blood cells and collected into a separate bag. The rest of the blood is returned to the patient or donor. This is an outpatient procedure performed by a registered nurse (RN) under the direction of a physician. The procedure is performed in the Apheresis Clinic on the 4th floor of Main Hospital. Related donors with adequate veins in their arms may not need a catheter placed. The Apheresis RN will evaluate the veins of all donors.

Common Side Effects
You may experience lightheadedness, chills, numbness around the lips, and cramping in the hands. Most of these side effects are due to a decrease of calcium in your blood as the procedure is performed. The anticoagulant used to prevent your blood from clotting in the machine binds to calcium causing numbness around the lips, tingling in the fingers and cramping in the hands and legs. You will be instructed to take calcium supplements (TUMS) twice a day when you start the growth factor injections. The apheresis RN may also give you supplemental calcium infusions to prevent the side effects of low calcium.

The apheresis procedure lasts about 4-6 hours each day.
- The number of collection days depends on the number of cells collected each day. The number of days required for collection is not the same for every person.
- You must have someone drive you to and from apheresis and you should have a caregiver during this time.

EAT a GOOD Breakfast prior to Apheresis:
- Be sure to increase your calcium intake with dairy products.

Medications:
• ACE inhibitors such as Lisinopril, Captopril, & Ramipril should not be taken during the apheresis phase.

You may bring:
• A sweater or jacket (with zipper up the front)
• Writing or reading materials
• MP3 players with head set
• DVDs to watch
• Cell Phone
• Lap top computer

Drivers and caregivers may wait in the waiting area, but due to limited space will not be able to sit with you. Alternatively, they may leave and come back when you call them as the procedure nears completion.

Preparing for Admission

Now is the time to get ready for your hospital admission. It will be helpful to know what to bring with you and what to expect as you prepare for your hospital stay. Please review the Bone Marrow Transplant Visitor Rules for Patient Safety before you are admitted. The guidelines can be found in the “Inpatient” section of this manual. Make sure your friends and family are familiar with the rules as well.

Your address while you are in the hospital is:
Your name
C/o MCV/VCU Hospital
Bone Marrow Transplant Program
1300 E. Marshall St.
North Hospital, 10th Floor
P.O. Box 980157
Richmond, VA 23298-0157

You are allowed to receive cards, balloons, stuffed animals, silk flowers, books, magazines, puzzles, CDs or tapes, DVDs, etc.

Fresh fruit, real flowers (including dried), or any flower arrangements containing moss are not allowed on the unit as they are a source for infection. Please remind your loved ones not to send these items.

You will get your room number and phone number when you arrive. You will be able to call out at any time. No calls will go through to you after 10 pm. Your family may call the nurse’s station after hours if they need to check on you. All rooms have television connected to cable.
Things you might want to bring
Please keep in mind that space is limited.

- Pajamas and comfortable clothes such as sweat pants. Tops with an opening in the front for easy access to your central line or port-a-cath. **Button down tops are best.**
- Warm socks and underwear
- A hat, scarf, or wig to keep your head warm
- Slippers or comfortable shoes for walking in the halls
- A new, unused foam pillow (no down or feathers) if you desire
- CD/ tape player
- DVDs
- Magazines, books, puzzles, etc.
- Journal or diary, stationary and pens for writing
- Hobby work (*no needles or sharp objects and no glues or solvents with harsh odors*).
- Pictures of family or friends
- Drawings or posters
- Phone card/Calling card/ Cell Phone
- Laptop computer (wireless access available)
- Unopened personal hygiene products: tissues, antibacterial soap, toothpaste, lip balm, hypoallergenic lotion and waterless hand cleanser.

If there are other items you would like to bring, ask your transplant coordinator to be sure that it is approved.

Please be aware, if it becomes necessary for you to be admitted to the Intensive Care Unit, your family/support person will need to be responsible for removing your valuables and belongings from your North 10 room. When you are transferred back to North 10, your family/support person can bring your belongings back.

**Fall Prevention**
Are you at risk?

Falls are a leading cause of injury in the healthcare setting. We are committed to providing you a safe environment during your stay in the hospital. Your nurse will assess you everyday and determine if you are at increased risk of falling. Your risk for falling may fluctuate throughout your stay. There are a number of conditions and situations which put you at risk for falling. Included are:

- Prior history of falling
- Need help with getting out of bed
• Need help going to the bathroom
• Need help moving from chair to bed and bed to chair
• Visual impairment
• Balance problems
• Peripheral neuropathy- numbness or tingling of the feet and legs
• Weakness- especially of the legs
• Weakness on one side of the body
• Taking certain medications that cause drowsiness or dizziness such as sleep and pain medications, sedatives, some antihistamines or anticonvulsants
• Taking diuretic medication that makes you have to urinate frequently
• Urgent need to go to the bathroom such as having diarrhea
• Unfamiliar with the room and environment
• Confusion

If you are experiencing any condition that makes you susceptible to falling your nurse will suggest certain interventions to help protect you.

• Placing a portable bedside toilet near your bed
• Asking you to call for assistance before getting up
• Providing assistive devices if needed such as a walker
• Providing you with a shower chair

You can help yourself further by:

• Getting up slowly from the bed or chair.
• Notifying your nurse immediately if you feel dizzy or lightheaded.
• Do not try and get up by yourself if you feel weak, dizzy, or lightheaded. Call you nurse and wait for assistance.
• Continue to walk in the halls or get daily exercise to maintain your strength.

**The Healing Garden at Massey Cancer Center**

While you are in the hospital your family might like to visit Massey’s beautiful Healing Garden. The Healing Garden is a serene and inviting environment that focuses on nurturing the mind and spirit. You will be delighted to discover blooming and fragrant flowers and trees, water features producing soothing sounds, and complementing garden sculptures to reflect upon. Throughout the garden you will enjoy seating areas for conversation or quiet contemplation. The outdoor garden is located through the lobby of the Goodwin Research Laboratory in the VCU Massey Cancer Center building. The entrance to the building is adjacent to the front entrance of the North Hospital.
Inpatient Care

Admission Day

You have been through a long process of treatments, scans, and lab work to prepare for this day. Most people feel nervous and that is okay. We will do everything we can to make you feel at ease.

Once you arrive on the unit, you will be escorted to your room. A member of the staff will orient you to your room and to the unit. Your nurse will review routine paperwork and guidelines with you. The following are some things you can expect to occur once you are admitted:

- A member of the team will review your medical history including medications and allergies.
- Blood will be drawn from your central line for routine tests.
- You will be asked to provide a urine sample.
- You will be asked to provide a rectal swab sample.
- A chest x-ray will be performed as a baseline for comparison for future x-rays.
- You will have a baseline physical exam.
- A dietary aide will bring daily menus for you to fill out.
- You will be connected to IV lines and IV fluids.
  - Once you are connected, please keep the lines pinned to your gown or clothes with a safety pin to prevent accidentally pulling out your catheter. Your nurse will show you the best way to do this.

BONE MARROW TRANSPLANT PROGRAM
GUIDELINES FOR VISITORS AND PATIENT SAFETY

The BMT unit is designed to be a very special “clean” unit. We have specific rules and regulations to maintain our standard of cleanliness and to help decrease the risk of infections for our patients. Your role in following these guidelines is very important both for your health and for the other patients on the unit. If you have any questions while you are here, please ask.

- Visitors with a cold, sore throat, or the flu should not come onto the unit. All visitors who have been exposed to chickenpox or any live or attenuated (killed) virus vaccinations within the last three weeks should not visit.
- **No fresh flowers or live plants.** This includes dried or artificial flower arrangements that use real moss in the base. Please send cards, gifts, balloons, or a few silk flowers in a vase instead.
- If **outside food** is brought in for a patient, it must be unopened and canned, boxed, bagged, or frozen. Fresh fruit and vegetables are not permitted. Food
prepared at home or in a restaurant is not permitted. No caffeinated drinks or chocolate candy allowed. Food will be labeled with the patient’s name and kept in the unit galley. Space is limited, so please do not bring in too much food at one time. Cooked and prepared food is only good for 48 hours and must be kept in the galley refrigerator. Partially eaten food cannot be returned to the galley, saved or re-heated due to infection control measures. Patients and family members are not allowed in the galley. Please ask a staff member for assistance.

- You may keep individually wrapped candy or single serving snacks at the bedside.
- Staff will remove your food trays from your room. Do not throw away leftover food or food trays in your trashcan.
- Please wash your hands at the sink outside the patient’s room or in the hallway each time you enter the room. Lather your hands with soap and rub them together for fifteen seconds. Rinse and dry them thoroughly with the paper towels provided. You may choose to use the foam cleaner instead. You must also wash your hands after you touch your face, mouth, or anything that is on the floor while you are in the patient’s room.
- Only the patient will use the bathroom, bed, phone and other personal items. Visitors may use the bathroom by the elevators. They should not sit on your bed.
- Visitors may not eat in the patient’s room. Visitors may have a drink in the patient’s room if the drink is covered with a lid.
- Only three visitors are allowed in the room at a time.
- Visitors who leave the patient’s room must remember to wash hands before going back into the patient’s room.
- Visitors should avoid kissing patients. It is okay to hold their hand and sit close by. Hugging is always welcome.
- Only a family member or designated caregiver of a pediatric patient is allowed to spend the night.
- Designated persons of adult patients are only allowed to stay overnight in certain situations and with approval of the medical team.
- Smoking is not allowed on VCU Hospital property.
- Please be aware that patients with reduced immunity will be walking in the halls. Therefore we ask that family not congregate in the halls for the protection of all our patients.
- During the colder months visitors are asked to leave their outerwear on the coat hooks that are located near both of the nurse’s stations.
- Bone Marrow Transplant staff reserve the right, at any time, to request that visitors leave or to inspect bags and belongings brought on the BMT unit. This policy is based on our commitment to maintain and protect the safety of all BMT patients and to avoid any unintentional injury to our patients.

Guidelines for Visiting Children

- Only children in the patient’s immediate family are allowed to visit.
- Siblings may visit with permission of the transplant team. All children must be free from infection for 48 hours before visiting.
• Children must be accompanied by a responsible adult (other than the patient) at all times. Patients can not be responsible for the care of their children while they are visiting in the hospital.
• Recently immunized children must be cleared to visit by the transplant staff. 
  **Vaccines:**  
  Oral Polio- wait one month before visiting.  
  Chicken Pox/ Varicella Live Vaccine- wait six weeks before visiting.  
  MMR – wait 2 weeks before visiting.  
  H1N1 and Influenza Inhalation form: wait 2 weeks before visiting.

• When entering the unit, the child must wash their hands and then proceed directly to the patient’s room.

**A Typical Day on the Unit**

You will be asked to participate in a variety of activities each day. Some activities will be done around the same time each day and some can be at your leisure.

**Vital signs:** Vital signs are typically done every four hours. They may be taken more often if needed. Frequent vital signs are required for blood products and some medications.

**Weight, Bath, and Bed:** You will be weighed at least once daily in the morning. Some patients are weighed more than once. You will be required to shower or bathe daily and your clothes and bed linens must be changed. This is critical, even on days you feel least like doing so, to reduce infections while your immune system is at its lowest. Please let the staff know when you are ready for your shower so we can change your bed for you. Do not get back into a dirty bed after you have bathed. Use this opportunity to sit up in a chair, walk in the halls, or perform other exercise for a while.

**Meals:** A dietary aide will provide you with a menu to fill out each morning. She is available to discuss your choices and special needs. You are allowed to bring frozen, prepackaged and canned foods to the hospital for the dietary aid to prepare for you. Please give these foods to a staff member so your name can be placed on them for storage in the galley. Patients and family members are not allowed in the galley, so please ask for assistance. During transplant your taste and tolerance for foods will vary greatly. Ask your doctors and nurse what would be best for you to try.

**Rounds:** The doctor and other members of the transplant team will come by each morning to examine you and update your treatment plan. This is an excellent time to ask any questions or discuss any concerns that you may have.

**Central Line Care:** Central line dressings are changed every 6 to 7 days unless they become dirty, wet, or loose. Port-a-cath needles are also changed every 6 to 7 days. Your IV line will be changed every 3 days. Please keep your IV lines pinned to your gown or shirt to prevent accidentally pulling them out.
Intake and Output (I’s and O’s): Your nurse may need to measure your intake (fluids that you drink or receive through your IV) and your output (urine, vomit, stool).

Daily Tests: Blood samples will be drawn on admission and then every day. Sometimes blood test values will need to be followed more closely so twice a day blood tests may be ordered. Other tests may be done as needed. You may request a copy of your lab results if you like.

Weekly Tests: Blood cultures are drawn from your central line each week or sooner if you have a fever. A urine sample will be collected and a chest x-ray will be repeated as well.

Other tests: Occasionally, other tests such as bone marrow biopsies, MRIs, CT scans, or ultrasounds are done to monitor your medical condition. Some can be done on the unit and some are only done in other areas of the hospital.

Medications: Medications will be given to you intravenously (IV) or by mouth throughout the day and night. You will frequently hear your IV pump “beep”. Please use your call bell to let your nurse know. For your safety, never touch or manipulate the buttons on your IV pump. Please feel free to ask questions about your medications. Generally, you will be receiving medications that fall into certain broad categories.

- Antibiotics – Used to prevent or treat bacterial infections.
- Antivirals – Used to prevent or treat viral infections.
- Antifungals - Used to prevent or treat fungal and yeast infections.
- Antiemetics – Used to prevent or treat nausea and vomiting.
- Immunosuppression – Used in allogeneic transplants to prevent rejection and graft-versus-host disease.
- Chemotherapy – Used to kill cancer cells.
- Electrolytes – Salts and minerals found in the blood which are necessary for proper cell and organ function.

When you are discharged, you will receive prescriptions for certain medications. The majority of our patients receive prescriptions for acyclovir, Bactrim, fluconazole, and Nexium. In addition, depending on the type of transplant you receive, you may also receive prescriptions for Ursodiol, Flovent, and cyclosporine or tacrolimus for immunosuppression. You may receive other prescriptions based on your personal needs.

Please refer to the medication glossary in the appendix as needed for detailed information. Upon discharge you will receive an updated medication schedule detailing all your medications. The pharmacist or your nurse will review this schedule with you.

IV Fluids: You will be given IV fluids throughout your stay. We will closely monitor your fluid status and adjust your IV rate as needed.
Blood and Platelet Transfusions: After your nightly blood test results come back, your nurse will determine if you need transfusions. These transfusions are generally done on the night shift.

Electrolyte Replacement: After your daily blood test results come back your nurse will determine if you need electrolyte replacement of potassium, magnesium, calcium, or phosphorus. These electrolytes may be low due to a number of reasons such as diarrhea, vomiting, poor nutrition, and certain medications.

Telemetry (Heart) Monitoring: Some patients require occasional or continuous monitoring of their heart function.

Exercise: Your activity will be monitored during your stay. It will be your responsibility to make exercise an important part of your recovery. You are encouraged to walk in the hall at least three times a day. Set goals for yourself such as increasing the number of laps up and down the hall. Family and visitors are welcome to walk in the halls with you as part of your support team. Do not spend all day in the bed. Sitting up in a chair will help you to maintain your strength and decrease complications from inactivity.

Spare Time: In your spare time you may choose to do your hobbies, watch television, talk on the phone, read, or have visitors. You may be tired after a busy day. If this happens, we advise you to take a short nap in the afternoon. Be careful not to sleep for a long period of time because this may make it difficult for you to sleep at night. If a loved one has been with you most of the day, this may be a good time for them to leave the floor for some personal time. It is very important for your loved ones to take time out for themselves so that they may stay well and rested. The better they take care of themselves, the better they can take care of you.

Chemotherapy

Chemotherapy drugs are given to get your body ready for transplant. There are many different kinds of chemotherapy drugs and different ones are given for different types of cancers. The BMT physicians will decide which plan of treatment is right for you. Drug specific handouts will be provided and reviewed with you.

Chemotherapy, also known as the conditioning regimen, serves two purposes prior to transplant. The first purpose is to destroy your disease. The second purpose is to suppress your immune system so that the stem cells that you will receive during your transplant can take over in your marrow and produce healthy cells.

The chemotherapy drugs used for transplant are given in high doses. You may receive a single drug or be given a combination of two or more drugs. High dose chemotherapy is toxic to your tissues and organs as well as to the diseased cells. The toxicity causes side effects that will vary in different degrees depending on the type of drug(s) given. Most side effects are temporary and reversible. Discomforts can often be managed or
prevented with medication. Severe side effects and long-term damage can occur, though less frequently. The expected side effects from your specific treatment will have been discussed with you at your final pre-transplant consult. Individual chemotherapy description sheets will have been provided for you to review.

Short-term side effects of chemotherapy include but are not limited to:

- Nausea and vomiting
- Loss of appetite
- Taste changes
- Diarrhea
- Blood in your urine
- Fluid retention
- Mouth sores
- Hair loss
- Muscle spasms
- Confusion (less common)

Long-term side effects may include:

- Possible sterility making you unable to have children
- Possible damage to the liver, heart, kidneys, or lungs
- Numbness and tingling in hands and feet

Your treatment plan will be reviewed with you in detail. Please don’t hesitate to ask questions and voice your concerns with the transplant team.

**Total Body Irradiation**

Some pre-transplant conditioning treatments also include total body irradiation or TBI. TBI is given in one or more sessions and may be started before you are admitted to the hospital. Though you will not actually feel the radiation treatment during the session, you will be given medications to take before each treatment to help prevent delayed side effects such as nausea. You will have met with the radiation oncology doctors prior to transplant to discuss this treatment if it is indicated for your transplant.

**Transplant Day**

You will be receiving your stem cells or bone marrow today. If you are receiving your own cells it is called an autologous or auto transplant. If you have a donor you are having an allogeneic or allo transplant.
The infusion of stem cells takes place after your pre-transplant chemotherapy is completed and enough time passes to make sure all the chemotherapy is out of your body. Your nurse will let you know what time your transplant will take place. The transplant will be done in your room.

Before receiving the stem cells or bone marrow, you will be medicated with Benadryl, Tylenol, and occasionally steroids. The transplant time varies from half an hour to several hours depending upon how many bags of stem cells or bone marrow you will receive. The physician’s assistant (PA), nurse practitioner (NP), or doctor will bring the cells to your room and begin the infusion. The cells are infused into your central IV line similar to a blood transfusion. A nurse will remain in the room throughout the transplant as the PA, NP, or doctor will leave the room to continue thawing and bringing in more bags of cells. In the case of bone marrow, after the PA, NP, or doctor starts the infusion, the nurse will stay with you during at least the first half hour of the infusion and then check on you frequently. The transplant team will take frequent vital signs throughout the transplant process and watch for any side effects.

If preservative was added to your cells, you may taste an oyster-like flavor from the preservative (DMSO) soon after the cells start to infuse. You can have sour or bitter hard candies during the stem cell infusion to help reduce this taste. During the transplant and up to 48 hours afterward, your visitors may detect the distinct odor of the preservative as it is eliminated from your body. Not everyone can taste and smell the DMSO.

You may notice that your urine changes from clear yellow to a pink or red color. Do not be alarmed; you are not bleeding. This color change is caused by the red blood cells in the transplanted cells being eliminated by your body. After the transplant, you will be given large amounts of fluids through your IV line to flush any preservative and broken down cells out of your body.

Patients generally do very well when receiving their transplant. Occasionally, patients may have a reaction to the stem cells or the preservative. The signs and symptoms of a reaction include flushing or redness of the skin, tightness or a heavy feeling in the chest, nausea, vomiting, and difficulty breathing. We monitor you closely so that any reactions can be dealt with immediately.

To help keep track of your transplant progress we refer to the transplant day as “day zero”. The day after that will be called “day plus one” and the next day will be “day plus two” and so on.

**Immunosuppression**

Your white blood cell count will fall in response to your pre-transplant chemotherapy and radiation (if given). Usually by the day of your transplant, you should have very few
white blood cells left or none at all. Sometimes the drop in white cells takes a little longer. If you have received someone else’s stem cells or bone marrow (allogeneic), you will be taking medication to further suppress your immune system to prevent graft-versus-host disease and graft rejection. Your immune system may be suppressed for as long as one to two years because of medications and an immature immune system. If you are receiving your own cells back during your transplant (autologous), you will have a weak immune system for a few months. During this time period, you are at increased risk of infection. Please refer to infection prevention guidelines.

Infection Prevention

Until your white blood cell count returns to a normal level, you will be at increased risk for infection. You will receive medications to help prevent infections up until the 100th day past your transplant and possibly longer for allogeneic transplant patients. These medications may include antibiotics, antifungal, and antiviral medications. You will remain at risk even after your discharge from the inpatient unit since your body’s immune system will not work normally for quite some time. You will need to guard yourself against infection during this time period. Prevention is the most important step in infection control.

Prior to admission to the inpatient unit, please carefully review the “BMT Program Guidelines for Visitors and Patient Safety”. These guidelines are designed to help prevent infection and must be followed while you are on the inpatient unit.

Please use the following to help guide you in preventing infection:

1. Have people wash their hands before coming around you. There are sinks in the hallway for their convenience. They can also use the foam dispensers located in the halls and in each room.
2. Let the transplant team know if you are feeling feverish or are having chills.
3. Wash your hands before eating, taking medications, and after using the bathroom. Hand washing is your best defense against infection.
4. Shower or bathe daily. Your linens will be changed every day after your shower.
5. While on the inpatient unit, do not pick things up off the floor. Have someone else pick up the object and wipe it off with an antibacterial wipe before giving it back to you.
6. Do not let others use your telephone or bathroom. They are also not allowed to sit on your bed or eat in your room. They may have a drink as long as it is covered at all times with a lid.
7. Wear a new, clean mask whenever you leave your room to walk in halls or leave the unit for tests.
8. Wear slippers or shoes when out of bed.
9. Exercise in some way each day. Even a little is important.
10. Try to stay out of your bed and sit up in a chair during the day.
11. Do not throw food trays in the trash can in your room. Allow your nurse or care partner to remove them.
12. Limit visitors, especially in the beginning of the transplant admission. Designate someone to let others know how you are doing.
13. Visitors who have a cold or even suspect they are getting sick should stay away.
14. Remind people not to bring in fresh flowers or fruit.
15. Dried or silk flower arrangements with dried moss are not allowed.
16. Ask people who have been working in the yard or in construction to shower and change before coming to visit you.
17. People exposed to chicken pox or shingles may not visit you for at least three weeks.
18. People who have received a vaccination must check with the transplant team before coming to visit.
19. People who have received a live virus vaccination may not visit for up to three weeks (check with the transplant team for the specific time period).

**What to Expect the 1st 30 Days Following Transplant:**
Side Effects and Management

**Mouth Changes**
During the first couple of days after transplant you may begin to notice that your mouth feels different. This change may be the beginning of mucositis due to the chemotherapy. This process starts to improve with engraftment (recovery of bone marrow function), but taste changes may persist for several weeks.

Symptoms of mucositis may include:
- Swelling or inflammation of the lining of your mouth
- A change in the color of the inside of your mouth
- A coating on the inside of your mouth
- Sores on the inside of your mouth
- Pain with swallowing
- Thick saliva
- Pain when opening your mouth or talking
- Soreness and breakdown of the lining of your esophagus, gastrointestinal tract, and rectal area
- Feeling like pills or food get stuck in your throat when swallowing.

There are activities that we strongly recommend you do to help take care of your mouth and to speed healing.
- You should continue to rinse with saline solution (salt water) at least 4 times a day, after meals, and at bedtime. You may use it more often if you need to.
• Continue to use your Chlorhexidine mouthwash twice a day unless you notice burning. Let your nurse know if this happens.
• If your saliva gets too thick, your nurse can set up suction for you. The suction is similar to the one used when you go to the dentist.

**Pain Management**
To help with any discomfort, the doctor will prescribe a pain medication for you. This medication will be given to you through your IV line by the nurse or through a pump called a PCA which stands for Patient Controlled Analgesia. This pump allows you to control your own pain by pushing a button when you need pain medication. If you are having unacceptable pain please ask for pain medication before your pain gets out of control. Pain is best controlled when treated early.

**Gastrointestinal Problems**
Mucositis can affect the whole GI tract from your mouth to your anus causing a number of symptoms.

You may experience **nausea** and **vomiting**. You will be given anti-nausea medications through your IV or by mouth if needed. If you are having a lot of nausea and vomiting, eating may make it worse and it will be recommended that you stop eating temporarily. After chemotherapy is completed, nausea and vomiting is often due to eating foods that are too difficult for your mucositis affected GI tract to handle. Reducing the amount of foods and eating bland foods may help considerably.

You may develop **gastric reflux**, a sensation of burning in the esophagus and throat. The doctor will order a medication for this.

You may experience **diarrhea**. You may be given medication to help slow or stop the diarrhea. If your stool becomes watery you will be asked to save a sample so your nurse can send it to the lab for testing to identify the cause of the diarrhea. This will help to identify the best treatment plan.

Occasionally, you might get **constipated**. Let your nurse know so they can monitor your bowel activity.

Your doctor and nurse will rely on you to let them know what kind of symptoms you are having. Please be open with them so that you can get the best treatment possible and allow them to direct your food choices.

**Loss of Appetite and Altered Taste Sensation**
It is normal to experience a loss of appetite and food may not taste the same for a while after treatment with chemo. It may be helpful to eat small frequent meals and snacks throughout the day. Liquid nutritional supplements are available as well.
difficulty eating enough to meet your body’s needs for a prolonged period of time, your doctor and dietician may order additional nutritional supplementation.

Alopecia (Hair Loss)
Hair loss will occur during your treatment. Here’s what to expect:

- Your hair will start to thin during your chemotherapy and will gradually fall out within the days and weeks following treatment.
- We recommend shaving your head to help maintain a clean and healthy environment. You may choose to shave your head before admission to the hospital. If you choose to shave your head after your hair starts to fall out, you can have a family member bring in an electric razor to shave your head. The VCUHS does not allow their employees to assist patients in shaving their heads.
- You may choose to wear a wig, hat, or scarf. Massey Cancer Center offers services such as hats and wigs. Ask your nurse for more information.

Skin Changes
You may experience some skin changes or rashes. The causes can vary. Medications, infections, chemotherapy, radiation, and graft-versus-host disease (GVHD) can all cause skin changes. Symptoms may include:

- Redness
- Itching
- Burning or tingling of hands and feet
- Bumps or sores
- Rashes or hives
- Excessive dryness

Treatment depends on the cause of the skin change. Sometimes medicated creams or steroids are used. If the problem is caused by a medication, that medication will be stopped. Let your nurse or doctor know of any skin changes that you notice.

Fatigue
Many patients notice feeling tired and exhausted. However, it is important to maintain your exercise routine. Short naps or rest periods during the day may help with this symptom. Continuing to walk in the halls, use of the stationary bike or treadmill, and sitting up in the chair will actually help maintain your strength and combat fatigue. This symptom will get better as you progress through the transplant period. If you feel weak or
dizzy when standing, please let your nurse or doctor know to prevent a fall. Please refer to the “Fall Precautions” section in the appendix of this manual for further information on fall prevention.

**Neutropenia (low white blood cell count)**
Your immune system is your first line of defense against infection. When your white blood cell count is low, you can easily get an infection. Symptoms of an infection may include:

- Fever or chills
- Redness, pain, or swelling at your IV line, on your skin, or anywhere on your body.
- Infections can develop in your mouth, blood, gastrointestinal tract, lungs, or on your skin.

If you develop a fever of 100.4 or greater, your nurse will draw blood through all of your IV access ports and lines to test for bacteria, viruses, and fungi. You will also have a chest x-ray and will need to give a urine sample. You will be started on IV antibiotics as a precaution until your culture results come back. Many fevers are not associated with infection.

**Thrombocytopenia (low platelets)**
Platelets help your blood to clot. When your platelets are low, you can bleed more easily. Your blood will be checked daily to monitor your platelet counts. You will receive platelet transfusions to keep your counts above a certain level depending on the type of transplant you have received. During the time when your platelets are low, you should not blow your nose or use sharp objects (razors, fingernail clippers, and scissors). You should use swabs to clean your mouth rather than a toothbrush. You will also bruise more easily, so be careful to avoid falls, bumping against or stepping on things. Wear slippers when out of bed. Report any nose bleeds, menstrual bleeding, blood in vomit, urine or stool, new bruises, headaches, or blurred vision. If you feel dizzy or lightheaded, please ask for assistance to get out of bed.

**Anemia (low 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:

- Shortness of breath
- Fatigue or low energy
- Weakness
- Pale skin
If your red blood cells get too low, you will need a blood transfusion.

**Fluid and Electrolyte Imbalance**

Very often patients have difficulty keeping a good balance between fluid and electrolytes in their bodies. Chemotherapy and other medications, diarrhea and vomiting, as well as a low appetite can make it difficult for the body to make its normal adjustments. Your electrolytes will be measured through lab work and you will receive the electrolytes that you need through your IV. These are typically given on the evening shift so that all electrolytes are repleted before the medical team returns in the morning in case additional testing is needed. It may take several months for your body to be able to balance electrolytes on its own.

Swelling and fluid retention is also a sign of imbalance. You may be given medication to help you get rid of extra fluid that can accumulate in your feet, ankles, and legs. Fluid may also accumulate in your abdomen or lungs, which may cause shortness of breath. You will be weighed once or twice a day to help us monitor for extra fluid weight. Let your nurse or doctor know if you feel short of breath or if you feel like you may have swelling.

**Emotions**

You may feel like your emotions are on a roller coaster. Some days you may feel well and happy and other days you may feel under the weather or sad. This is completely normal. If it begins to interfere with your activities of daily living, please notify the BMT team.

**Things to keep in mind...**

- Realize that you are going through a very difficult time.
- You may feel that you are being “difficult” to the people you care the most about. These people are here to support you and understand what you are going through.
- Don’t keep your thoughts and feelings inside. There are many people who are cheering for you and supporting you through this difficult time. Staff members are also available to talk with about any concerns or feelings you may have.
- If you wish to speak with a chaplain or psychologist please let your nurse or doctor know. Staff is here to help guide you.
- Try some relaxation techniques such as guided imagery, breathing exercises, and music.
- If you need assistance or suggestions, please do not hesitate to ask.
- Please see appendix for information on our guided imagery program.
Engraftment

Engraftment starts when the stem cells from your transplant start to grow and produce new blood cells at a level that can be detected in your bloodstream. Almost immediately after the transplant, the stem cells travel into the bone marrow. The stem cells begin making new blood cells and rebuilding your immune system. It usually takes 10-20 days to make enough new cells to be measurable in a blood sample.

Engraftment usually takes place within two to four weeks of your transplant. This is the beginning of the recovery of your immune system. Complete recovery of the immune system can take months in an autologous transplant and up to 1-2 years in an allogeneic transplant. While you are in the hospital, blood will be taken at least once a day to check the recovery of your blood counts. This will continue in your outpatient clinic visits. During the engraftment process, you will be at increased risk for bleeding, infections, and fatigue.

We encourage you to know as much information about your treatment as possible. Many patients like to monitor their blood counts. It can be exciting to watch your white blood cell count come back up as your transplanted cells engraft. If this interests you, please ask your nurse to provide you with a copy of your daily lab tests. Your nurse will be happy to discuss these tests with you and help you understand the lab results. If you would like to keep a record of your blood counts please refer to the “counts tracker” sheets in the appendix section of this manual.

Preparing for Discharge

Following your transplant the medical team will monitor your blood counts and watch for your white blood cell count to rise. This will be an indication that your stem cells are engrafting and your body is accepting the transplant. You will be ready for discharge when the doctor decides your white blood cell count is high enough and stable. You will also need to be eating and having very little nausea and diarrhea before you can be discharged. The transplant team will only discharge you when you meet well defined criteria that minimize risk. It is difficult to say exactly how long the process will take, as everyone will respond differently. It will also depend on the type of chemotherapy you were given and the type of transplant you had. Be prepared to be discharged from the inpatient unit after 3 pm. Once you are discharged from the inpatient unit, you will need to return to the clinic everyday for a while.
Discharge Instructions & Guidelines
The following section will help you prepare for discharge by knowing what to expect, who to call, and how to keep yourself safe and free from infection.

What to Expect on Clinic Days
• Once you are discharged from the inpatient unit you will return to the clinic every day for lab work. Depending on your lab test results you may need blood products, extra fluids, or electrolyte replacement. The length of time you will spend in the clinic cannot be estimated until your test results come back and your needs are assessed. However, be prepared to spend a good part of the day in the clinic. As your blood work gradually improves over the coming weeks, you will have days off between clinic visits.
• Upon arrival to the clinic, you will have blood drawn for testing. You will have a nurse assigned to you each day you are in clinic. Your nurse will let you know when your lab results are back and give you a copy of the lab report if you like.
• Please report directly to the front desk if you or a family member has new upper respiratory symptoms, fever, nausea with vomiting or diarrhea. You may need to be isolated in a private room for these conditions.
• You will meet with a nurse practitioner or physician on a weekly basis. Your progress and plan of care will be reviewed by all members of the treatment team each day that you are in clinic.
• You may want to bring a book, magazine, laptop computer, or other form of entertainment to help pass the time. Some people will pass the time talking or sleeping. Patients often find that other patients are a great support system as they undergo the process of recovery.
• Space is limited in the clinic treatment room. One family member at a time may visit in the treatment room as space allows. There is a large family lounge located outside of the clinic near the elevators and rest rooms outfitted with a television and water & ice machine.
• Pack a lunch, snacks, and something to drink. A small cooler or insulated lunch bag may be useful. Wear comfortable clothes and bring a sweater if you are subject to being cold.
• Bring your day’s oral medications and any IV medications with you along with your most recent medication schedule. Please bring your Patient Education Manual with you.
• Make a list of questions that may come up at home and bring them with you to discuss with the nurses or doctors.

Who to Contact When Medical Problems Occur
Please call 828-4360 to contact a nurse or leave a message. Follow the prompts for the department you wish to contact.
To reach the clinic menu directly you may call 628-1169 and follow prompts.
Please refer to the “Quick Reference Guide of Symptoms” on the following page. This will help you decide if you need to call for help immediately or if it can wait until morning. When in doubt, CALL.
# QUICK REFERENCE GUIDE OF SYMPTOMS FOR TRANSPLANT PATIENTS

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<tr>
<th>Concern/Symptom</th>
<th>Emergency--Dial 911</th>
<th>Call BMT Clinic/Unit Immediately</th>
<th>Call BMT Clinic/Unit Within 24 hours</th>
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<td>Change in alertness,</td>
<td>• Unconscious</td>
<td>• New or increased confusion</td>
<td>• Mood swings or behavior changes</td>
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<td>• Seizure</td>
<td>• Change in level of alertness</td>
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<td>• New numbness or tingling</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Unable to move limbs</td>
<td></td>
</tr>
<tr>
<td>Bleeding</td>
<td>Uncontrolled and persistent bleeding</td>
<td>• New or increased bleeding</td>
<td>• Frequent nosebleeds that stop with pressure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Unable to stop nosebleed</td>
<td>• New bruising</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Blood in vomit, stool, urine, or sputum</td>
<td>• Little purple or red spots on the skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Heavy vaginal bleeding (more than 1 pad per hour)</td>
<td></td>
</tr>
<tr>
<td>Breathing</td>
<td>• Not breathing</td>
<td>• Trouble Breathing</td>
<td>• New shortness of breath with daily activities</td>
</tr>
<tr>
<td></td>
<td>• Choking</td>
<td>• Shortness of breath</td>
<td>• New or persistent cough</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Trouble breathing while lying Flat</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Wheezing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uncontrolled cough</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Coughing up bloody, yellow, or green sputum</td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
<td>• Constant or uncontrolled</td>
<td>• New onset diarrhea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• With a fever</td>
<td>• More than 5 diarrhea stools a day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• With abdominal cramping</td>
<td>• Passing whole pills or undigested food in stool</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Bloody, burgundy, or black stool</td>
<td>• Weakness or dizziness with diarrhea</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Unable to wake up</td>
<td>• Dizziness</td>
<td>• Increase in fatigue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Too tired to get up or to go to the bathroom</td>
<td>• Inactive</td>
</tr>
<tr>
<td>Fever</td>
<td></td>
<td>• Fever of 100.4 or over</td>
<td>• New redness, tenderness, swelling, or drainage at IV site</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Shaking chills with or without fever</td>
<td>• Cold or flu symptoms</td>
</tr>
<tr>
<td>Mouth pain or sores</td>
<td>• Not breathing</td>
<td>Having difficulty breathing or swallowing</td>
<td>• Bleeding in mouth</td>
</tr>
<tr>
<td></td>
<td>• Choking</td>
<td></td>
<td>• New mouth sores</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Pain not controlled</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td></td>
<td>• Uncontrolled</td>
<td>• Nausea persists despite medication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Bloody or “coffee ground” appearing vomit</td>
<td>• Weakness or dizziness with nausea/vomiting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Unable to keep down medicine</td>
<td></td>
</tr>
<tr>
<td>Rash</td>
<td>Sudden, new rash</td>
<td></td>
<td>Changes in skin rash</td>
</tr>
<tr>
<td>Swelling</td>
<td>• Not breathing</td>
<td>• Sudden swelling</td>
<td>• New onset of swelling in legs, feet, or hands with or without pain</td>
</tr>
<tr>
<td></td>
<td>• Unable to swallow</td>
<td>• Difficulty breathing or swallowing</td>
<td>• Swelling at IV site</td>
</tr>
<tr>
<td></td>
<td>• Choking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urination</td>
<td>• Unable to void for more 8 hours</td>
<td>• Strong odor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Blood in urine</td>
<td>• Change in color of urine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Painful urination</td>
<td></td>
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</tr>
</tbody>
</table>
Guidelines to Increase Your Safety

ACTIVITY

Overall, you will notice that you probably feel weaker, have less stamina, and fatigue easier than before your transplant. Because each person is different, we recommend that you follow these guidelines for at least 2-3 months after discharge.

- Avoid vigorous activity and heavy lifting...nothing over 10 pounds.
- Light housework only. No dusting or vacuuming.
- Space out your activities, allowing for rest periods in between.
- Walking and using an exercise cycle are good ways to exercise. Start out very slowly, go short distances, and gradually increase speed and distance as your strength and muscle tone increase.
- Check with your doctor before swimming or using a hot tub.
- Discuss any travel plans with your doctor.
- Do not drive until your doctor tells you it is okay.

GUIDELINES TO REDUCE THE RISK OF INFECTION

Each person’s recovery will be different. It can take a year or longer for a patient’s ability to fight infection to return to normal after transplant. If you had an allogeneic transplant follow these guidelines as long as you are on immunosuppressive therapy (Cyclosporine, Tacrolimus, Sirolimus, Prednisone, Mycophenolate), and also if you have graft-versus-host disease. If you had an autologous transplant follow these directions 100 days to give your immune system time to recover. Check with your doctor or nurse before you stop following these guidelines. Even when you take extra care, preventing infection may not be possible while you are recovering from your transplant. Be sure to get medical care at the first sign of infection so treatment can start early.

- Good hand washing is the number one way to decrease your chance of getting infections! Who should wash hands? EVERYBODY—the patient, family members, and visitors. Wash hands well before meals, after going to the bathroom, when preparing meals, after visitors, after handling money, and when returning home from errands.
- Your house should be well cleaned before you are discharged home. (vacuumed, dusted, mopped, bed linens and towels washed, bathrooms disinfected).
- Make sure the home is cleaned at least once a week. Bathrooms and eating areas need to be cleaned more frequently than other areas. Disinfectant cleaners or bleach water solution (10 parts water to 1 part bleach) in spray bottles can make cleanups easier.
- The patient should shower or bathe and change clothes daily. The towel and washcloth should be used by the patient only.
- Towels should be laundered every other day. Use a fresh wash cloth daily. Using paper towels for cleaning or drying hands helps to decrease laundry.
- Bed linens should be laundered twice a week.
- Do not work in the yard or garden. Avoid being around or working with house plants. Place them in a less frequently used room of the house and have someone else care for them.
- Being physically close to those you love is important to your recovery. Hugging and holding hands, for instance, will help you feel happy and normal. Just remember the importance of hand washing, good hygiene, and avoiding people with active infections.
- You may engage in sexual intercourse when your platelet count is over 50,000. Use condoms and water soluble lubricants to increase comfort and prevent infection and bleeding. Oral genital sex is
okay when there are no oral or genital lesions. You should avoid anal sex. Although it may feel awkward, please ask your nurse or doctor questions if you are uncertain or have concerns about sexual activity. Women who experience discomfort during intercourse should let the clinic nurses or physicians know as this may be an easily correctable side effect of treatment.

- Do not share cell phones due to risk of spreading germs. Do clean landline phones in between other household users.
- Clean computer keyboards frequently.
- Plan trips to a mall, restaurant, or theater at non-peak times to avoid crowds.
- Avoid people who are ill, especially those with measles, chicken pox, or mumps. If you are exposed to one of these illnesses, contact the doctor immediately.
- Avoid contact with children vaccinated with live vaccines for 3 weeks and 4 weeks for oral polio.
- No smoking. Avoid second-hand cigarette smoke.
- Avoid construction areas and other dusty, dirty areas.
- Reduce contact with your pets. Wash your hands after touching your pet. Do not let pets on furniture where you sit or sleep.
- Avoid contact with pets recently vaccinated with bordetella or kennel cough.
- Have someone else clean the litter box or clean up after your pet. Avoid being in the room when the litter box is changed.
- Avoid changing diapers if possible. Wear gloves if you have to change diapers.
- If you are discharged in the fall or winter, do not use a fireplace or wood stove.
- **You must have a thermometer available to take your temperature. Please call the clinic right away if you have a temperature of 100.4 or greater.**

**OTHER SAFETY TIPS**

- **Wear 30-block sunscreen and a hat if you plan to be out in the sun.** Some of the medications you may be taking will make you more sensitive to sun-related skin injury resulting in GVHD.
- Avoid knives, scissors, razors, and other sharp objects until your platelets are greater than 50,000. You may use an electric razor.
- You may use a soft toothbrush and floss when your platelets are greater than 50,000.
- Wear slippers or shoes at all times.
- Turn on a light before getting out of bed at night to prevent falls.

**LONG TERM RECOVERY**

You may feel very vulnerable after you are discharged from the hospital. These feelings are understandable. We are here for you every day around the clock to support you and answer your questions.

A bone marrow/stem cell transplant can be very stressful for patients and families who may wrestle physically, emotionally, financially, and spiritually with the therapy and disruption in their lives. We have support services available to help as needed. Talking with others who have been through transplant may help to normalize your feelings.

Remember, your medical care and progress is very individualized. No two people will have exactly the same experience during or after transplant. Don’t compare your progress with other patient’s progress. Don’t be discouraged by long days in the clinic—these will decrease over time. Take pride in your progress and remember that recovery may be slow.

Continue to work on progressive exercise, good nutrition, and getting adequate rest. Take your medications as prescribed. You will feel well again.
DIET GUIDELINES FOR IMMUNOSUPPRESSED PATIENTS

Persons with decreased immune function due to chemotherapy and radiation are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific food choices. Choose foods from the “Approved” column. Do not eat foods in the “Not Allowed” column. You may want to discuss the safety of these or other foods with your dietitian.

This diet should be followed before and after all conditioning (chemotherapy and/or radiation) therapy. Your doctor and dietitian will provide guidelines as to when the diet is no longer required. In general, we are recommending that chemotherapy only patients and autologous transplant patients follow the diet during the first three months after chemotherapy or transplant. Allogeneic transplant patients should follow the diet until off all immunosuppressive therapy (e.g., cyclosporine, tacrolimus, sirolimus, prednisone, cellcept, thalidomide, etc.). Prior to the end of these time periods, patients and their caregivers should discuss with their referring physician whether or not the diet or parts of the diet should be continued.

### Imunosuppressed Patient Diet

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>Allowed</th>
<th>Not Allowed</th>
</tr>
</thead>
</table>
| Dairy       | All pasteurized, grade “A” milk and milk products  
  Commercially packaged cheese and cheese products made with pasteurized milk (e.g., mild and medium cheddar, mozzarella, parmesan, swiss, etc.)  
  Pasteurized yogurt  
  Dry, refrigerated, and frozen pasteurized whipped topping  
  Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes  
  Commercial nutritional supplements and baby formulas, liquid and powder  
  Commercial pasteurized eggnog | Unpasteurized or raw milk, cheese, yogurt, and other milk products  
  Cheeses from delicatessens  
  Cheeses containing chili peppers or other uncooked vegetables  
  Cheeses with molds (e.g., blue, stilton, Roquefort, gorgonzola, etc.)  
  Sharp cheddar, brie, camembert, feta cheese, farmer’s cheese  
  Soft serve ice cream or yogurt |
<table>
<thead>
<tr>
<th>Food Groups</th>
<th>Allowed</th>
<th>Not Allowed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meat and Meat</td>
<td>All well cooked or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)</td>
<td>Raw or undercooked meat, poultry, fish, game, tofu</td>
</tr>
<tr>
<td>Substitutes</td>
<td>Well cooked eggs</td>
<td>Raw or undercooked eggs and egg substitutes</td>
</tr>
<tr>
<td></td>
<td>Well cooked pasteurized egg substitutes (e.g., Egg Beaters®)</td>
<td>Meats and cold cuts from delicatessens</td>
</tr>
<tr>
<td></td>
<td>Commercially packaged salami, bologna, and other luncheon meats need to be heated in the microwave until steaming prior to using</td>
<td>Hard cured salami in natural wrap</td>
</tr>
<tr>
<td></td>
<td>Canned and commercially packaged hard-smoked fish; refrigerated after opening</td>
<td>Cold smoked salmon (fish); lox</td>
</tr>
<tr>
<td></td>
<td>Cooked tofu</td>
<td>Pickled fish</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tempe (Tempeh) products</td>
</tr>
<tr>
<td>Entrees, Soups</td>
<td>All cooked entrees and soups</td>
<td>All miso products (e.g., miso soup)</td>
</tr>
<tr>
<td>Fruits and Nuts</td>
<td>Canned and frozen fruit and fruit juices</td>
<td>Unwashed raw fruits</td>
</tr>
<tr>
<td></td>
<td>Well washed raw fruit; foods containing well washed raw fruits</td>
<td>Unroasted raw nuts</td>
</tr>
<tr>
<td></td>
<td>Dried fruits</td>
<td>Roasted nuts in the shell</td>
</tr>
<tr>
<td></td>
<td>Canned or bottled roasted nuts</td>
<td>Unpasteurized fruit and vegetable juices</td>
</tr>
<tr>
<td></td>
<td>Nuts in baked products</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Commercially packaged peanut butter</td>
<td></td>
</tr>
<tr>
<td>Vegetables</td>
<td>All cooked frozen, canned, or fresh vegetables and potatoes</td>
<td>Unwashed raw vegetables or herbs</td>
</tr>
<tr>
<td></td>
<td>Well washed raw vegetables</td>
<td>All raw vegetable sprouts (alfalfa, radish, cauliflower, broccoli, mung bean, all others)</td>
</tr>
<tr>
<td></td>
<td>Fresh, well washed herbs and dried herbs and spices (added to raw or cooked foods)</td>
<td>Salads from delicatessens</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Commercial salsas stored in refrigerated case</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Raw mushrooms</td>
</tr>
<tr>
<td>Food Groups</td>
<td>Allowed</td>
<td>Not Allowed</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Beveragesii</td>
<td>Tap water and ice made from tap water</td>
<td>Well water (unless tested frequently and found to be free of coliforms)</td>
</tr>
<tr>
<td></td>
<td>Commercial bottled distilled, spring, and natural waters</td>
<td>Cold-brewed tea made with warm or cold water</td>
</tr>
<tr>
<td></td>
<td>All canned, bottled, powdered beverages</td>
<td>Unpasteurized commercial fruit and vegetable juices</td>
</tr>
<tr>
<td></td>
<td>Instant and brewed coffee, tea; cold brewed tea made with boiling water</td>
<td>Mate tea</td>
</tr>
<tr>
<td></td>
<td>Brewed herbal teas using commercially packaged tea bags</td>
<td>Alcohol</td>
</tr>
<tr>
<td></td>
<td>Commercial nutritional supplements, liquid and powdered must be approved</td>
<td></td>
</tr>
<tr>
<td></td>
<td>by a BMT team member prior to use</td>
<td></td>
</tr>
<tr>
<td>Dessertsiii</td>
<td>Refrigerated commercial and homemade cakes, pies, pastries, and pudding</td>
<td>Unrefrigerated, cream filled pastry products (not shelf stable)</td>
</tr>
<tr>
<td></td>
<td>Refrigerated, cream filled pastries</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Homemade and commercial cookies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shelf stable cream filled cupcakes (e.g., Twinkies®, Ding Dongs®, etc.),</td>
<td></td>
</tr>
<tr>
<td></td>
<td>fruit pies (e.g., Pop Tarts®, Hostess Fruit Pies®), and canned pudding</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ices, popsicle-like products</td>
<td></td>
</tr>
<tr>
<td>Bread, Grain, and Cereal Productsiv</td>
<td>All breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast</td>
<td>Raw grain products</td>
</tr>
<tr>
<td></td>
<td>Potato chips, corn chips, tortilla chips, pretzels, popcorn</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cooked pasta, rice, and other grains</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All cereals, cooked and ready-to-eat</td>
<td></td>
</tr>
<tr>
<td>Fats</td>
<td>Oil, shortening</td>
<td>Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw</td>
</tr>
<tr>
<td></td>
<td>Refrigerated lard, margarine, butter</td>
<td>eggs, stored in refrigerated cases</td>
</tr>
<tr>
<td></td>
<td>Cooked gravy and sauces</td>
<td></td>
</tr>
<tr>
<td>Food Groups</td>
<td>Allowed</td>
<td>Not Allowed</td>
</tr>
<tr>
<td>------------</td>
<td>-------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Fats</td>
<td>Commercial, shelf stable mayonnaise and salad dressings (including cheese based salad dressings; refrigerated after opening)</td>
<td>Raw or non-heat treated honey; honey in the comb, Herbal and nutrient supplement preparations</td>
</tr>
<tr>
<td>Other(^v)</td>
<td>Salt, sugar, brown sugar</td>
<td>Brewer’s yeast, if eaten uncooked, Pepper added to food after cooking, Any raw uncooked spices such as cinnamon, ginger, nutmeg, etc.</td>
</tr>
<tr>
<td></td>
<td>Jam, jelly syrups; refrigerated after opening</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Commercial (heat treated and/or pasteurized) honey</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Catsup, mustard, barbeque sauce, soy sauce, other condiments (refrigerated after opening)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pickles, pickle relish, olives (refrigerated after opening)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Candy, gum</td>
<td></td>
</tr>
</tbody>
</table>

\(^i\) Tofu must be cut into 1 inch cubes, or smaller, and boiled a minimum of five minutes in water or broth before eating or using in recipes

\(^ii\) If using water service other than city water service recommend using distilled or bottled water.

\(^iii\) “Shelf stable” refers to unopened canned, bottled, or packaged food products that can be stored, before opening, at room temperature; container may require refrigeration after opening.

\(^iv\) Recommend patients themselves not make (mix, knead) any bread product containing yeast.

\(^v\) No honey products allowed for children less than one year old and all children with SCIDS until nine months post transplant.
FOOD SAFETY GUIDELINES FOR TRANSPLANT PATIENTS

Food-borne illness is occurring with increasing frequency. Sources of food poisoning may be the handler, the environment (such as a contaminated work surface), or the food itself.

Bacteria and other organisms exist in most common foods. Most of these organisms are of little risk to the average healthy person. However, infection is of major concern to persons undergoing chemotherapy, radiation, or a marrow or stem cell transplant. The food these persons eat must be safe.

These food safety guidelines are intended to supplement immunosuppressed patient diet guidelines, which identify higher risk foods. By following safe food practices, patients and caregivers can reduce the risk of food-borne illness. If you have any other questions regarding food safety and diet guidelines, talk to your dietitian.

All handling, cleaning, and preparing of meats and produce should be performed by someone other than the immunosuppressed patient.

Safe Food Handling

1. Purchase a food thermometer. They are available at most kitchen stores and have either a dial read or a digital read.

2. Caregivers preparing food should wash hands frequently– before, during, and after food preparation. Use plenty of hot water and soap and wash for at least 20 seconds (you can sing the “Happy Birthday” song twice.

3. Hold food at safe temperatures: hot food above 140°F and cold food below 40°F.

4. Cook meat until well done and measure the final temperature with a thermometer. Red meat should reach an internal temperature of 165°F and poultry to 180°F.

5. Thaw meat, fish, or poultry in the refrigerator away from raw fruits and vegetables. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry, you can thaw in the microwave– but you must cook the meat immediately and thoroughly clean the microwave in case of contamination.

6. Never leave perishable food out of the refrigerator for over two hours.

7. Wash fruits and vegetables thoroughly under running cold water before peeling and/or cutting. Ask your dietitian or nutritionist for details on handling and preparation of fruits and vegetables. Do not use well water to wash produce that is going to be eaten raw.
8. Wash the tops of canned foods before opening. Clean the can opener before and after use.

9. During food preparation, do not taste the food with the same utensil used for stirring.

10. Cook eggs until the whites and yolks are completely hard cooked.

11. NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!

**Microwave Cooking**

1. Microwave cooking can leave cold spots in food where bacteria can survive. Rotate the dish a quarter turn once or twice during cooking if there is no turntable in the appliance.

2. When heating leftovers, use a loose-fitting lid or vented plastic wrap to cover. Stir several times during reheating. When heated thoroughly (to at least 165°F), cover and let sit for 2 minutes.

**Outdoor Grilling**

1. When cooking meat on the grill, be sure the meat is cooked well done and measure the final temperature with a thermometer. Red meat should reach an internal temperature of 165°F and poultry to 180°F.

2. Eat your grilled food indoors to avoid outdoor contaminates (e.g., air-borne bacteria, insects).

**Grocery Shopping**

1. Check “sell by” and “use by” dates. Select only the freshest food product.

2. Check packaging date on fresh meats, poultry, and seafood. Do not purchase if they have passed the “sell by” or “use by” date.

3. Reject damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.

4. Select unblemished fruits and vegetables. Fresh fruits and vegetables should look and smell fresh. Wilted salad greens may be an indication that the product is old and not properly handled. Your caregiver should wash all fruits and vegetables (including bagged pre-washed salad greens) before using.

5. Reject foods with any mold present.

6. Avoid foods from delicatessens, including prepared salads and sliced meats and cheeses. In the bakery, avoid unrefrigerated cream and custard containing desserts and pastries.

7. Avoid foods from self-serve bulk containers or bins.
8. Avoid yogurt and ice cream products dispensed from soft serve machines.

9. Avoid tasting free food samples.

10. Avoid cracked and unrefrigerated eggs. Liquid pasteurized egg products may be used instead of eggs in the shell.

11. Purchase frozen and refrigerated foods last, especially during the summer months.


Dining Out...Is It Safe? (Please check with your physicians to see when this is appropriate to start)

1. Eat early to avoid crowds.

2. Due to the uncertainty of the cleanliness of the handler and produce preparation, consumption of raw fruits and vegetables when dining out is not allowed.

3. Request single serving condiment packages to avoid public self serve condiment containers.

4. Avoid high-risk food sources: salad bars, delicatessens, buffets, smorgasbords, potlucks, fast food restaurants, and sidewalk vendors.

5. Check the general condition of the restaurant environment. Are the plates, glasses, and utensils clean? Are the restrooms clean and stocked with soap and paper towels? How the manager and employees maintain the restaurant may be an indication of the amount of pride they take in preparing the food.

**HOME SANITATION GUIDELINES**

**Directions for preparing bleach solution: Mix 1 part household bleach to 10 parts water.**

Personal Hygiene

1. Wash hands with soap and warm, running water for 20 seconds before and after every step in food preparation.

2. Wash hands before eating, after using the rest room, handling garbage, touching pets, etc.
Work Surfaces and Kitchen Equipment

1. Use separate cutting boards (plastic or wooden) for cooked foods and raw foods.

2. Wash cutting boards after each use in hot, soapy water, or in the dishwasher. Sanitize boards weekly using a dilute bleach solution. **Let the boards air dry.

3. Keep appliances free of food particles. Check the microwave oven, toaster, can opener, blender, and mixer blades. Blender blades and bottom ring should always be removed when washing the jar. Wash can openers before and after use. Sanitize these items with a dilute bleach solution. **

4. Keep counter and kitchen surfaces free of food particles. Sanitize using a dilute bleach solution. **

Sink Area

1. Have soap available for hand washing.

2. Use paper towels for drying hands.

3. Replace dishcloths and dishtowels daily.

4. Replace sponges at least weekly.

5. Sanitize sponges daily in a dilute bleach solution** or run through the dishwasher.

6. Do not store food supplies under the sink. Do not store chemicals and cleaning solutions near or over food supplies.

7. Use liquid dish soap when hand washing dishes, pans, and utensils by hand.

Refrigerator and Freezer

1. Keep the refrigerator clean. Clean spills immediately. Sanitize shelves and doors weekly using a dilute bleach solution. **

2. Maintain refrigerator temperature between 35°F to 40°F.

3. Maintain freezer temperature below 5°F.

4. Store all food in covered containers after cooling. First, cool hot foods uncovered in the refrigerator. Then cover storage containers after cooling. Make sure that covers seal tightly. Freeze what will not be used within the next 2 to 3 days. Discard all refrigerated prepared foods after 72 hours.

5. Discard eggs with cracked shells.
6. Discard foods older than their “use by” or expiration dates.

7. Discard entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, and pastry products.

8. Discard freezer burned foods.

Cupboards and Pantry

1. Make sure food storage areas remain clean.

2. Discard without tasting or opening all bulging, leaking, cracked, or deeply dented cans.

3. Rotate food stock so older items are used first. Monitor expiration dates. Do not use foods past the expiration dates.

4. Do not consume any home canned foods with bulging lids, broken seals, or any food that has a bad odor or any unusual characteristics after opening. Home canned foods need to be used within one year of canning.

GUIDELINES FOR FRESH FRUIT AND VEGETABLE CONSUMPTION

Consumption of fresh produce is allowed even during periods of neutropenia. Use the following guidelines for proper handling.

Produce Handling and Storage

Preparation and Washing:

1. A caregiver, not the patient, should do all preparation and washing of produce.

2. Wash hands thoroughly before handling fresh produce. Always use clean cutting surfaces. Use a clean knife.

3. Rinse produce thoroughly under clean, running cold water just before use.

4. Using a clean vegetable scrubber, scrub produce that has thick skins or rinds (such as melons, potatoes) to remove excess soil.

5. Wash the outside of all fruits and vegetables (such as oranges, melons, bananas) even if the produce is to be skinned or peeled. Bacteria on the outer surface can be transferred to the inside of fruits and vegetables when cutting with a knife.
6. Rinse leaves of leafy vegetables (such as lettuce, cabbage) individually under clean, cold running water.

7. Packaged salads and other prepared produce, even when marked pre-washed, should be rinsed under clean, cold running water again. Check for “used by” dates.

8. All raw vegetable sprouts are prohibited due to high risk of Salmonella and E. Coli contamination.

9. Do not wash fruits and vegetables with produce rinses, soaps, detergents, or chlorine bleach solutions. Produce can absorb these cleaning agents.

Storage

1. Refrigeration slows and even suppresses the growth of bacteria. Refrigerate produce promptly. The refrigerator must be clean and cold. (40°F or colder).

2. Discard fruits and vegetables that have been stored too long. Discard fruits and vegetables that are slimy or show mold.

Commercial Products for Cleaning Fruits and Vegetables

Manufacturers of some commercial produce rinses claim that their products are “100% natural,” “300% more effective in removing pesticides,” and “made of natural vegetable-based ingredients taken from foods eaten daily.” However, there have been no recent studies proving that these products are more effective for cleaning bacteria off the produce. The danger with using these products is that they may remain on the produce if not well rinsed with water following use, and may also be absorbed in the produce. There is no information available as to the safety of the chemicals used in these solutions.

Use of Organic Produce

The term “organic” or “natural” refers to growing without the use of chemical fertilizers or pesticides, and has no relationship to the cleanliness of the produce. Bacterial contamination can occur in the fields, either from the use of natural fertilizers (such as animal manure) to human contact during produce harvesting and distribution to the market. As a result, all produce may carry dangerous bacteria, such as E. Coli, Salmonella, and Listeria. These bacteria have been linked to food borne disease outbreaks. Use above recommendations for handling both mainstream and organically grown produce.

WATER SAFETY GUIDELINES

Public water quality and treatment varies throughout the United States. Always check with the local health department and water utility regarding the water source as well as the safety of tap water and ice use by immunosuppressed persons.
**Tap Water**
Water from your home faucet is considered safe if your water is from a city water supply or from a municipal well serving highly populated areas.

**Well Water**
Well water must be tested for coliform bacteria and cryptosporidium a minimum of once yearly and preferably more frequently. The water should be tested immediately prior to your return home after treatment; however, even if the test results are negative the water to be used for consumption by persons considered immunosuppressed and at risk for infection cannot be guaranteed.

No matter how frequently testing is done; there is no guarantee that well water will remain safe over time. More frequent testing should be performed if the well water source is at risk for potential contamination. Examples of risk are when construction is occurring near the well, the well depth is shallow, or the well is located near a dairy or large numbers of livestock. Spring runoff and flooding are further situations which increase the risk of well water contamination.

**Municipal wells:** Drinking well water from municipal wells serving highly populated areas is regarded as safe because the well water is tested more than 2 times each day for bacterial contamination.

**Private wells and small community wells:** The quality of well water from these sources cannot be guaranteed. It is recommended that other approved water sources be used to ensure a safe water supply including boiled water, bottled water, or distilled water (see guidelines below).

**Not considered safe:** Most water filtration devices will not make the water safe if the private well water or smaller community well water supply is not chlorinated.

**Safe Water Sources**
The following sources of water are suggested if your water is not from a city water or municipal well supply.

**Boiled and Distilled Water**
Bringing tap water to a rolling boil for one minute can make safe water at home. Distilled water can be made using a home distiller. After processing, the water should be stored in a clean covered container in the refrigerator and discarded within 72 hours.

**Bottled Water**
Acceptable forms of bottled water have been processed to remove organisms known to cause gastrointestinal infection. Bottled water labels reading, “well water,” “artesian well water,” “spring water,” or “mineral water” does not guarantee that the water is safe to drink. Water labeled as follows are considered safe:
- 1. Reverse osmosis treated
- 2. Distillation
- 3. Filtered through an absolute one micron or smaller filter (NSF Standard #53 for cyst removal)
To confirm that a specific bottled water has undergone one of the above processes, contact the International Bottled Water Association (IBWA) at 1-800-928-3711, or visit their home page at www.bottledwater.org. If the IBWA does not have information on a specific brand, call the bottling company directly.

**Water Filters**

If you use a water filter located on household water taps the following specifications must be met:

1. The filters must be designed to remove coliforms and cryptosporidium. Any of the following are acceptable.
   a. Reverse osmosis filter.
   b. Absolute pore size of one micron or smaller.
   c. Tested and certified by NSF Standard #53 for cyst removal.

2. The water tap filter must be installed immediately before the water tap.
3. Manufacturer directions must be followed for filter maintenance and replacement.

Most filtration devices will not make the water safe if the water supply has not been chlorinated. Portable water filters (such as a Brita® or Pur® system) as well as refrigerator-dispensed water and ice machine systems do not meet filtration standards. Portable water systems filter for chemical impurities, but not for bacteria or spores. If a portable water system is used in combination with a safe water supply (to improve water flavor and remove chlorine and other impurities), it is recommended to change the system’s filters frequently according to manufacturer’s guidelines.

For a list of approved filtration systems, call the America National Standards Institute, NSF International, at 1-800-673-8010, or visit their home page at www.NSF.org.

**INFANT FORMULA SAFETY AND STORAGE GUIDELINES**

**Expiration Dates**

1. All formulas are marked with a “use by” date to ensure a fresh, high quality product. Formula should not be bought or fed beyond the expiration date.
2. Return any formula that is out-of-date at the time of the purchase to the store it was purchased from for exchange or reimbursement.

**Sterilization of Bottles/Nipples**

1. Sterilize all equipment used in preparing infant formula.
2. If available, wash bottles, nipples, lids, and rings in the dishwasher. Otherwise, wash in hot, soapy water. Use a brush to clean the inside of the bottle. Rinse a minimum of 3 times with the hottest tap water (180°F). If unsure of rinse water temperature, dip bottles, nipples, lids, and rings in boiling water for 30 seconds. Use clean tongs or 2 forks to transfer the boiled equipment to a clean towel to drain before filling.
Storage of Opened Formula
1. Opened cans of formula should be tightly covered and immediately refrigerated for up to 48 hours. Prepared formula should be placed in clean, sterilized bottles, refrigerated and used within 24 hours.
2. Infant formula should not be frozen as physical separation of the product may occur.

Heating of Formula
1. Methods of heating infant formula include:
   a. Heating the formula separately in a pan and transferring to a clean sterilized bottle.
   b. Heating the bottle containing the formula by placing in a pan containing simmering water.
   c. Heating the bottle containing the formula in the microwave. Caution, however, must be used when microwaving the bottle, as it may remain cool while the formula inside is heated, which could burn the infant.
2. Factors influencing heating time include:
   a. Initial temperature of the formula.
   b. Size of the bottle.
   c. Variability among microwave heat settings.
3. After heating the formula, shake the bottle to evenly distribute the heat and check the temperature of the formula by testing a few drops on the inside of your wrist before feeding.
GASTROINTESTINAL – DIET 1
For Patients with G.I. Problems

The following diet is for the immunosuppressed patient with Graft vs. Host Disease of the gastrointestinal tract, medication intolerance affecting the gastrointestinal tract, or infection of the gastrointestinal tract. All foods must be selected and prepared according to the Diet Guidelines for the Immunosuppressed Patient.

SUGGESTION TO TRY FIRST:

<table>
<thead>
<tr>
<th>Beverages (1 cup)</th>
<th>CEREALS (1/2 cup)</th>
<th>STARCHES (Allowed with 1 tsp. Margarine)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tea, weak decaffeinated or brewed herb, (except peppermint) Gatorade Rice milk Lactaid® 100milk ½ strength: apple juice, Kool-Aid®, Tang®, Cranberry drinks</td>
<td>Hot (all made with water): Cream of rice Cream of wheat Farina Grits Malt-O-Meal® Cold: Puffed rice Rice Krispies® Cheerios®</td>
<td>White bread, plain bagel, or English muffin, (1 slice) Pasta: macaroni, egg noodles, plain spaghetti (½ cup) Potato (no skin), baked or mashed (½ medium or (½ cup) Rice, white (½ cup) Saltines (2) Pretzels (1 oz.) White dinner roll (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FRUITS (½ cup)</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applesauce, plain Banana (½) Peaches, canned in juice or light syrup Pears, canned in juice or light syrup</td>
<td>Lifesavers Lemon drops Broth, beef or chicken (1 cup) Popsicle</td>
</tr>
</tbody>
</table>

MISCELLANEOUS: Sugar 1 packet or teaspoon; salt, as desired

IF TOLERATED TRY:

<table>
<thead>
<tr>
<th>Protein Sources (Allowed with 1 tsp. margarine or mayonnaise)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well cooked chicken or turkey breast (no skin), Baked, broiled, or boiled (½ breast or 3 oz) Ham, lean (3oz.) Egg, well cooked only (1) Fish, baked or poached (3oz.) Tuna, water packed (¼ cup) Resource® Fruit Beverage (½ cup) Ensure®, Boost High Protein® (½ cup)</td>
<td>Chicken rice or chicken noodle soup (1 cup) Sandwiches made with low-fat mayonnaise on white bread: egg salad, tuna salad, chicken, turkey, or lean ham (½ sandwich) Vanilla wafers, graham crackers (2) Animal crackers (4) Angel food cake Carrots, well cooked (½ cup) Green beans, well cooked (½ cup) Sweet potatoes (no skin), baked or mashed (½ medium or ½ cup)</td>
</tr>
</tbody>
</table>
GASTROINTESTINAL – DIET 2
For Patients without G.I. Problems

This portion of the gastrointestinal diet is for the immunosuppressed patient whose GI symptoms are controlled and that can begin to progress their diet. All foods must be selected and prepared according to the Diet Guidelines For Immunosuppressed Patients.

Daily Food Allowances

<table>
<thead>
<tr>
<th>FOODS RECOMMENDED</th>
<th>FOODS TO AVOID</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DAIRY AND SUPPLEMENTS:</strong> 3 or more cups per day</td>
<td><strong>Any milk or milk-based product not pre-treated or</strong></td>
</tr>
<tr>
<td>Lactose-free 2%, 1%, or skim milk</td>
<td><strong>Not taken with lactase enzyme</strong></td>
</tr>
<tr>
<td>Soy milk</td>
<td></td>
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<tr>
<td>Rice milk</td>
<td></td>
</tr>
<tr>
<td>Ensure®, Ensure Plus®</td>
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<tr>
<td>Resource® Fruit Beverage</td>
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<tr>
<td>Resource®, Resource Plus®</td>
<td></td>
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<tr>
<td>Boost®</td>
<td></td>
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<tr>
<td>Scandishake®, lactose-free, made with lactose Free low fat milk</td>
<td></td>
</tr>
<tr>
<td>Note: chocolate flavored beverages are allowed</td>
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<td>******************************************</td>
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<tr>
<td>Take with lactose enzyme tablet as needed (discuss with dietitian)</td>
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<tr>
<td>Instant breakfast, made with low-lactose milk</td>
<td></td>
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<tr>
<td>Buttermilk</td>
<td></td>
</tr>
<tr>
<td>Regular 2%, 1%, or skim milk</td>
<td></td>
</tr>
<tr>
<td>Low fat yogurt (6-8 oz)</td>
<td></td>
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<tr>
<td>Low fat cottage cheese (non-fat or 1%)</td>
<td></td>
</tr>
<tr>
<td>Low fat cheeses (cheddar, Monterey jack, swiss) (1 oz.)</td>
<td></td>
</tr>
<tr>
<td>American cheese (1 oz)</td>
<td></td>
</tr>
<tr>
<td>Cheddar cheese (1 oz)</td>
<td></td>
</tr>
<tr>
<td>Jack cheese (1 oz)</td>
<td></td>
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<tr>
<td>Mozzarella cheese, part skim (1 oz)</td>
<td></td>
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<tr>
<td>Parmesan cheese: grated or canned (1 oz)</td>
<td></td>
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<tr>
<td>Ricotta cheese, part skim (¼ cup)</td>
<td></td>
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<tr>
<td>Ricotta cheese, fat free</td>
<td></td>
</tr>
<tr>
<td>String cheese (part-skim mozzarella) (1 oz)</td>
<td></td>
</tr>
<tr>
<td>Swiss cheese (1 oz)</td>
<td></td>
</tr>
<tr>
<td>FOODS RECOMMENDED</td>
<td>FOODS TO AVOID</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td><strong>MEAT OR MEAT SUBSTITUTES:</strong> 3 or more 3 oz. Servings per day (or suggested portion size)</td>
<td></td>
</tr>
<tr>
<td>Well-cooked, lean cut of broiled, baked, or roasted:</td>
<td>High fat luncheon meat (Spam®, potted meat)</td>
</tr>
<tr>
<td>Fish, beef, skinless poultry, ham</td>
<td>Hot dogs</td>
</tr>
<tr>
<td>Crab and imitation crab</td>
<td>Corned beef</td>
</tr>
<tr>
<td>Canned, water-packed tuna and seafood</td>
<td>Pepperoni</td>
</tr>
<tr>
<td>Casseroles prepared with allowed foods</td>
<td>Pickled or cured meats/fish</td>
</tr>
<tr>
<td>Eggs, well cooked</td>
<td>Fried meats or fish</td>
</tr>
<tr>
<td>Cooked tofu</td>
<td>Beans and legumes</td>
</tr>
<tr>
<td>Lean luncheon meat (such as turkey, chicken, ham)</td>
<td></td>
</tr>
<tr>
<td>Low fat hot dogs</td>
<td></td>
</tr>
<tr>
<td>Turkey bacon</td>
<td></td>
</tr>
<tr>
<td><strong>FRUITS AND FRUIT JUICES:</strong> 2 or more ½ cup servings per day</td>
<td>Juices: citrus, prune, V-8®, V-8 Splash®, tomato,</td>
</tr>
<tr>
<td></td>
<td>Pineapple</td>
</tr>
<tr>
<td></td>
<td>All raw fruits except those specifically allowed</td>
</tr>
<tr>
<td></td>
<td>Canned or fresh: berries, figs, oranges, lemons,</td>
</tr>
<tr>
<td></td>
<td>limes, grapes, pineapple, prunes, rhubarb,</td>
</tr>
<tr>
<td></td>
<td>cherries</td>
</tr>
<tr>
<td></td>
<td>Dried fruit: raisins, Craisins®, dates, apricots,</td>
</tr>
<tr>
<td></td>
<td>Apricots, pineapple, prunes, bananas</td>
</tr>
<tr>
<td><strong>VEGETABLES:</strong> 2 or more ½ cup servings per day</td>
<td></td>
</tr>
<tr>
<td>Well cooked, tender vegetables, as tolerated:</td>
<td></td>
</tr>
<tr>
<td>Asparagus tips, beets, carrots, green beans,</td>
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<tr>
<td>Lettuce, mushrooms, pumpkin, sweet potatoes</td>
<td></td>
</tr>
<tr>
<td>And yams (without skin), winter squash</td>
<td></td>
</tr>
<tr>
<td>Skinless potatoes (baked, broiled, boiled, mashed)</td>
<td></td>
</tr>
<tr>
<td>Frozen potatoes: low fat French fries and hash</td>
<td></td>
</tr>
<tr>
<td>Browns (less than 4 gm fat per 3 oz)</td>
<td></td>
</tr>
<tr>
<td><strong>SOUPS:</strong> As desired</td>
<td></td>
</tr>
<tr>
<td>Broth-based soups made with allowed meats and</td>
<td>Highly seasoned soups</td>
</tr>
<tr>
<td>Vegetables (*in moderation): beef broth, beef</td>
<td></td>
</tr>
<tr>
<td>Noodle, chicken broth, chicken noodle, chicken</td>
<td>Tomato-based soups</td>
</tr>
<tr>
<td>With rice, turkey noodle, vegetable, etc</td>
<td>Ready-to-eat cream soups</td>
</tr>
<tr>
<td>Ramen soups, without flavor packet</td>
<td>Soups with more than 2 gm of fiber per serving:</td>
</tr>
<tr>
<td>Homemade milk and cream- based soups and</td>
<td>Bean with bacon, beef noodle with vegetables,</td>
</tr>
<tr>
<td>Chowders (made with low fat, lactose-free milk)</td>
<td>Chili, green pea, manhattan clam chowder,</td>
</tr>
<tr>
<td></td>
<td>Onion, split pea, minestrone</td>
</tr>
<tr>
<td>FOODS RECOMMENDED</td>
<td>FOODS TO AVOID</td>
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<tr>
<td>--------------------</td>
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</tr>
<tr>
<td><strong>BREAD AND CEREAL PRODUCTS:</strong> 4 or more servings per day</td>
<td></td>
</tr>
<tr>
<td>Bagels (plain)</td>
<td>Whole grain bagels, breads, English muffins, or Rolls (cracked wheat, rye, whole wheat, Pumpernickel)</td>
</tr>
<tr>
<td>Breads, enriched and refined (corn, white, pita, Sourdough)</td>
<td>Rolls (cracked wheat, rye, whole wheat, Pumpernickel)</td>
</tr>
<tr>
<td>Cereals with less than 2 gm of fiber per serving: Cheerios®, Corn Chex, corn flakes, cream of Rice, Cream of wheat, Fruit Loops®, Kix®, Rice Chex®, Rice Krispies®, Special K, Sugar Pops®, Sugar Smacks®, Trix®, puffed rice, Captain Crunch®, Cocoa Krispies®, instant Oatmeal, instant grits</td>
<td>Brown or wild rice, bulgur</td>
</tr>
<tr>
<td>Cornmeal</td>
<td>Cereals with more than 2 gm of fiber per serving: Bran, cracked wheat, granola, Grapenuts®, Nutrigrain® (all varieties), puffed wheat, Shredded Wheat®, Wheaties®, regular Oatmeal</td>
</tr>
<tr>
<td>Corn starch</td>
<td>Whole grain macaroni and noodles</td>
</tr>
<tr>
<td>Crackers: animal, graham, saltine, low fat English muffins, white or sourdough</td>
<td>Whole wheat tortillas</td>
</tr>
<tr>
<td>Noodles</td>
<td>Wheat germ</td>
</tr>
<tr>
<td>Polenta</td>
<td>Crackers with more than 2 gm of fiber per serving</td>
</tr>
<tr>
<td>Pretzels</td>
<td><strong>Note:</strong> Avoid products with Olestra®, Olean®</td>
</tr>
<tr>
<td>Rice cakes, plain</td>
<td></td>
</tr>
<tr>
<td>Rolls, white</td>
<td></td>
</tr>
<tr>
<td>Tortillas: corn or flour</td>
<td></td>
</tr>
<tr>
<td>White flour</td>
<td></td>
</tr>
<tr>
<td>White rice, couscous</td>
<td></td>
</tr>
<tr>
<td>Zwieback</td>
<td></td>
</tr>
<tr>
<td>Low fat baked tortilla chips or baked potato chips</td>
<td></td>
</tr>
<tr>
<td>Pancakes, waffles: frozen, mix, or home recipe</td>
<td></td>
</tr>
<tr>
<td>Using allowed ingredients</td>
<td></td>
</tr>
<tr>
<td>DESSERTS:** As desired (read ingredient list)</td>
<td></td>
</tr>
<tr>
<td>Cake (plain, without frosting)</td>
<td>Cake with raisins, nuts, coconut, other omitted Foods and spices</td>
</tr>
<tr>
<td>Custard made with lactose-free milk</td>
<td>Pastries and desserts with dry or candied fruit,</td>
</tr>
<tr>
<td>Jell-O®</td>
<td>Coconut, nuts, raisins, seeds</td>
</tr>
<tr>
<td>Homemade fruit cobbler made with allowed fruits</td>
<td>High fat cream-filled cakes and pastries</td>
</tr>
<tr>
<td>Pastries and pie made with allowed fillings (omit Spices): apple, peach, pear, cherry (use Commercial filling), pumpkin, sweet potato (use evaporated milk treated with lactase)</td>
<td>Premium high fat ice creams</td>
</tr>
<tr>
<td>Popsicles</td>
<td>Sugar cookies, wafer crèmes, and other cookies not Recommended</td>
</tr>
<tr>
<td>Puddings, made with lactose-free milk</td>
<td></td>
</tr>
<tr>
<td>Plain cookies (such as vanilla wafers, graham Crackers, ginger snaps)</td>
<td></td>
</tr>
<tr>
<td>Rice Krispie Treats</td>
<td></td>
</tr>
<tr>
<td>Angel food cake</td>
<td></td>
</tr>
<tr>
<td>Low fat, non dairy ice cream</td>
<td></td>
</tr>
</tbody>
</table>

(continued next page)
<table>
<thead>
<tr>
<th>FOODS RECOMMENDED</th>
<th>FOODS TO AVOID</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Take with lactase enzyme tablet as needed</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Discuss with dietitian:</strong></td>
<td></td>
</tr>
<tr>
<td>Canned puddings</td>
<td>Alcoholic beverages</td>
</tr>
<tr>
<td>Sherbet (check label for milk in package)</td>
<td>Coffee: regular or decaffeinated</td>
</tr>
<tr>
<td>Sorbet (check label for milk in package)</td>
<td>Tea, including regular or strong decaffeinated</td>
</tr>
<tr>
<td>Low fat hard-pack ice cream and frozen yogurt</td>
<td>Carbonated beverages containing caffeine</td>
</tr>
<tr>
<td>(less than 3 gm fat per serving)</td>
<td>Cola type carbonated beverages</td>
</tr>
<tr>
<td>Smoothies made with allowed ingredients</td>
<td>Peppermint tea</td>
</tr>
</tbody>
</table>

**BEVERAGES:** As desired

Non-cola caffeine-free carbonated beverages  
(check labels on carbonated beverages and choose sodas without caffeine)
Chocolate milk or Strawberry Quik® made with Lactose free milk
Fruit-ades: Hawaiian Punch®, Hi-C®, Tang®, Gatorade®, Powerade®
Kood-aid®
Tea, weak decaffeinated and herb teas, in Moderation (except peppermint)
**********************************************************
**Take with lactase enzyme tablet as needed**
**Discuss with dietitian:**
Cocoa

**FATS**

Low fat or Non fat choices—No restriction on Portion size:
Low calorie margarine
Fat free mayonnaise
Fat free non-dairy creamers
Low fat gravies and sauces made with lactose free Milk or broth
Low fat salad dressing

Take with lactase enzyme as needed
Discuss with dietitian:
Fat free or light cream cheese
Fat free sour cream
Low fat whipped topping
Fat free cheeses

(Continued next page)
<table>
<thead>
<tr>
<th>FOODS RECOMMENDED</th>
<th>FOODS TO AVOID</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fats with limited portion size:</strong></td>
<td></td>
</tr>
<tr>
<td>Avocado (1/8 each)</td>
<td></td>
</tr>
<tr>
<td>Bacon, lean crisp (1 slice)</td>
<td></td>
</tr>
<tr>
<td>Butter (1 tsp)</td>
<td></td>
</tr>
<tr>
<td>Cooking oil (1 tsp)</td>
<td></td>
</tr>
<tr>
<td>Cool Whip® (1 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Margarine (1 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Mayonnaise (1 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Peanut butter, creamy (2 tsp)</td>
<td></td>
</tr>
<tr>
<td>Gravies and sauces made with lactose free milk (¼ cup)</td>
<td></td>
</tr>
<tr>
<td>Take with lactase enzyme tablet as needed</td>
<td></td>
</tr>
<tr>
<td>Discuss with dietitian:</td>
<td></td>
</tr>
<tr>
<td>Cream cheese (1 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Sour cream (2 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Whipping cream (2 tbsp)</td>
<td></td>
</tr>
<tr>
<td>Half and half (2 tbsp)</td>
<td></td>
</tr>
<tr>
<td><strong>MISCELLANEOUS</strong></td>
<td></td>
</tr>
<tr>
<td>Gum drops, jelly beans, hard candy, gummi bears</td>
<td></td>
</tr>
<tr>
<td>Herbs and spices for seasoning: basil, bay leaf,</td>
<td></td>
</tr>
<tr>
<td>Oregano, rosemary, thyme, cinnamon</td>
<td></td>
</tr>
<tr>
<td>Honey</td>
<td></td>
</tr>
<tr>
<td>Jelly</td>
<td></td>
</tr>
<tr>
<td>Marshmallows</td>
<td></td>
</tr>
<tr>
<td>Fruit roll-ups</td>
<td></td>
</tr>
<tr>
<td>Ripe olives</td>
<td></td>
</tr>
<tr>
<td>Salt</td>
<td></td>
</tr>
<tr>
<td>Sugar (any type)</td>
<td></td>
</tr>
<tr>
<td>Soy sauce</td>
<td></td>
</tr>
<tr>
<td>Syrups</td>
<td></td>
</tr>
<tr>
<td>Vinegar</td>
<td></td>
</tr>
<tr>
<td>Fried snack foods: corn chips, Doritos®, Cheetos®, Potato chips</td>
<td></td>
</tr>
<tr>
<td>Jams with seeds or skins</td>
<td></td>
</tr>
<tr>
<td>Nuts, seeds, dried fruit, coconut: alone or in any Food product</td>
<td></td>
</tr>
<tr>
<td>Pickles</td>
<td></td>
</tr>
<tr>
<td>Popcorn</td>
<td></td>
</tr>
<tr>
<td>Spices: cayenne, chili powder, garlic (fresh, salt, Powder), mustard, onion (powder, salt), pepper, Paprika</td>
<td></td>
</tr>
<tr>
<td>Condiments: catsup, chili sauce, jalapeno, relish, Horseradish, peppers, prepared mustard, steak Sauce, barbecue sauces</td>
<td></td>
</tr>
<tr>
<td>Salsa</td>
<td></td>
</tr>
<tr>
<td>Tabasco</td>
<td></td>
</tr>
</tbody>
</table>

These dietary restrictions are based on research from the Seattle Cancer Care Alliance and the Fred Hutchinson Cancer Research Center.
TIPS FOR REPLENISHING ELECTROLYTES

After receiving mobilization chemotherapy, and during your stem cell collection, we will closely monitor your blood levels for electrolytes such as potassium, magnesium and calcium. These electrolytes are necessary for your body to function properly. We will replenish fluids and electrolytes through your IV line. The following lists contain foods high in electrolytes. Try to include these foods in your diet if possible, especially during the week of apheresis. Include these foods only if you can tolerate them. These lists are not inclusive of all foods high in these electrolytes.

<table>
<thead>
<tr>
<th>Foods high in Potassium</th>
<th>Foods high in Magnesium</th>
<th>Foods high in Calcium</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milk</td>
<td>Beans</td>
<td>Milk</td>
</tr>
<tr>
<td>Citrus juice</td>
<td>Tofu</td>
<td>Cheese</td>
</tr>
<tr>
<td>Tomato juice</td>
<td>Avocado</td>
<td>Yogurt</td>
</tr>
<tr>
<td>Lentils</td>
<td>Cereals</td>
<td>Ice cream</td>
</tr>
<tr>
<td>Beans</td>
<td>Greens</td>
<td>Cottage cheese</td>
</tr>
<tr>
<td>Greens</td>
<td>Lentils</td>
<td>Orange juice</td>
</tr>
<tr>
<td>Cereals</td>
<td>Peanuts</td>
<td>Tofu</td>
</tr>
<tr>
<td>Apricots</td>
<td>Banana</td>
<td>Salmon, canned with bones</td>
</tr>
<tr>
<td>Potatoes</td>
<td>Potatoes</td>
<td>Greens</td>
</tr>
<tr>
<td>Figs, dates, raisins</td>
<td>Cocoa, chocolate</td>
<td>Sardines</td>
</tr>
<tr>
<td>Peaches</td>
<td>molasses</td>
<td></td>
</tr>
<tr>
<td>molasses</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Post-Transplant Care

Once the acute phase of your transplant is complete and you are on the road to recovery, your medical team will be doing intermittent testing to check for late transplant side effects and complications. Below is a list of tests. Not everyone will have every test. Testing depends on your physical condition before transplant, your cancer diagnosis, the type of chemotherapy and transplant you received, and your current medical condition. These tests are designed as screening aids to identify potential side effects and complications of transplant at an early stage when they are most responsive to treatment. The long term follow-up phase will occur for 5 - 10 years for autologous transplants, depending on diagnosis, and 10+ years for allogeneic transplants depending on your unique situation.

Post-Transplant Testing

Pulmonary Function Test
This test measures how well your lungs exchange air in and out. It also measures how well your lungs pass oxygen into the blood. You had a baseline pulmonary function test before your transplant. Testing is done on a regular basis after your transplant to help the medical team determine how well your lungs are functioning.

There are many things that can affect your lung function:

- History of smoking
- Pre-existing respiratory conditions
- Chemotherapy
- Radiation Therapy
- Infection (viral/bacterial/fungal)
- Graft-versus-Host Disease

The results of the lung function tests and your physical examination will be discussed with you. A plan for treatment will also be discussed with you should the medical team feel one is needed.

Chest CT Scan
A chest CT scan is a painless test to produce pictures of the structures in your chest such as the lungs, heart, and ribs. It is a type of x-ray but a CT scan shows more detail than a standard x-ray. After transplant, we routinely order a chest CT scan to monitor for any abnormalities or changes that may indicate recurrent disease, an infection, or graft-versus-host disease.

Liver Function Test
This test is used to measure and evaluate how well your liver is functioning. There are several complications of transplant that can affect your liver function, including;
infections, medications, and graft-versus-host disease. A nurse will take a tube of blood from you for this test. The liver helps the body in many different ways:

- Stores iron, vitamins, and sugar which the body converts into energy.
- Acts as the control center for the production and removal of cholesterol.
- Helps the body clear toxic substances such as wastes, medications, and poisons.
- Produces clotting factors (so you don’t bleed after an injury or cut).
- Produces immune factors and helps to combat infection by removing bacteria from the bloodstream.
- Helps with the digestion and absorption of important nutrients by releasing bile.

There are many different blood tests associated with a liver function test, and each test looks at a different part of what the liver does. A member of the transplant team will discuss the results of all of your lab work with you.

**Thyroid Screening**

The thyroid gland is located below the bump midline in the front of your neck (Adam’s apple). It is shaped like a butterfly. The thyroid gland helps the body to regulate body temperature, blood pressure, heart rate, and the rate the body converts food into energy. This is your metabolism regulator. This gland is also responsible for growth and development in children.

- An over active thyroid can lead to a rapid heart rate, elevated blood pressure, and increased appetite.
- An under active thyroid can lead to a slow heart rate, decreased appetite, dry skin, dry and brittle hair and nails, constipation, and feeling tired.

A blood test will be performed to determine how well your thyroid gland is working.

**Bone Density Scan**

As we age, even if we have not had a diagnosis of cancer and a bone marrow transplant, we are all at risk for osteoporosis. Osteoporosis is a condition that decreases the density of bones making them fragile. This can lead to an increased risk for fractures. People who have a history of decreased physical activity, low body weight or thin body shape, advanced age, poor health, rheumatoid arthritis, having received chemotherapy/radiation, chronic steroid use, and the use of birth control pills have a higher chance of having osteoporosis. Your medical team will order a bone density scan to assess your bone health on an annual basis after transplant.

**Cardiovascular Risk Assessment**

Your heart is a very important muscle in the body. Unfortunately, it can sometimes be affected by your past chemotherapy and radiation therapy. It can also be affected by some infections. Your health care team will do intermittent assessments of your heart to look for any transplant related problems. Again, there are many different ways to assess your heart. Your doctor will order the test that is right for you.
These are a few of the tests that you will be given after your transplant to help the transplant team detect any complications that you may develop. Early detection allows the team to change your treatment plan quickly to decrease the side effects from complications.

**Complications of Transplant**

**Kidney problems** may occur because many of the medications you receive during your transplant are broken down in your kidneys. Some of these medications can also cause damage to the kidneys. Usually, the body can repair these damages. When the kidneys do not function properly, waste products build up in the body. Fluid may shift out of the bloodstream into your tissues causing swelling and fluid retention.

We will watch your kidney function through your lab work and through physical examinations. Should we detect a developing problem with your kidneys, your medication doses may be adjusted and changes may need to be made in your daily fluid intake. Fortunately, most kidney problems respond to these changes. Please let the transplant team know if you notice any swelling or fluid retention.

**Veno-occlusive disease (VOD)** is a complication involving the liver. Sometimes the pre-transplant chemotherapy causes the lining of the liver’s blood vessels to become swollen. This swelling decreases the amount of blood that can flow through the liver which impairs the liver’s ability to function properly.

Signs and symptoms of VOD include tenderness of the abdomen, weight gain, fluid retention, increased liver size, and abnormal liver function labs. The transplant team will monitor your liver function tests and your weight to detect any indication of VOD early so changes can be made in your treatment plan.

**Secondary Cancer Screening**

A rare potential side effect of a bone marrow transplant is a secondary cancer. Many factors come into play that affect your risk: the disease for which you were transplanted, whether or not you received radiation therapy, your sex, age, family history, and the amount of time that has passed since your transplant. Your medical team will review your individual risks and a screening plan for secondary cancers will be recommended for you. Your medical team will assess your complete blood counts. Everyone should have an annual visit to the dermatologist for a full body exam. Women should have annual mammograms and pap testing done. Men should undergo prostate exams as indicated. Regular exams by your dentist every six months are recommended with particular attention to assessing your mouth for cancer. A colonoscopy to assess for colon cancer should be performed based on the recommendations by the American Cancer Society.
Complications of Transplant - continued

Sexual Function
Many patients have concerns about resuming sexual activity following transplant. Your body has been through a great deal of stress and it may take some time to regain your energy level or interest in having sexual relations. This has also been an emotionally stressful time, which may affect your desire to have sex. Please recognize that these are normal responses. Each individual will cope differently with this aspect of life. It may be helpful to discuss your concerns with your partner, and realize your partner may also have concerns about resuming sexual relations. Sexual problems following transplant may be related to a number of issues. Some of these include:

- Fatigue
- Decrease in hormone levels
- Medications
- Vaginal dryness
- Erectile dysfunction
- Pain during intercourse
- Psychosocial concerns
- Interpersonal relationship issues
- Changes in body image

Please share your concerns with your health care provider. There are interventions that may be helpful depending on the problem you are having.

Complications of Allogeneic Transplant

Graft-versus-Host Disease (GVHD) is a common complication for patients who receive an allogeneic bone marrow transplant. It occurs in approximately 40-50% of all allogeneic bone marrow transplant patients, more often in those people who have received unrelated transplants. The job of a normal immune system is to try to protect the body from harm. The immune system will try to destroy anything that it does not recognize as “self” such as a bacteria or virus. With an allogeneic transplant, the new bone marrow/stem cells see your body as a stranger and may attack different organs in your body. Therefore, to make the transplant successful, we must suppress the action of your new immune system while still allowing it to fight infection. We do this by giving you immunosuppressant medications while you are in the hospital and after you go home.

There is an advantage to having some GVHD. Your new immune system will also hunt down and kill any remaining cancer cells not killed by your chemotherapy. This is called
the Graft-Versus-Leukemia/Tumor Effect. It lowers the chance for relapse following your transplant. The team may actually allow some GVHD to occur in order to get the benefit of the leukemia/tumor effect. They will try to tightly control how much GVHD you get.

GVHD may affect any of your body systems, including: skin, liver, lungs, muscles, joints, vagina, and the gastrointestinal (GI) tract. GVHD can be classified as mild, moderate, or severe, and can be either acute or chronic. Acute GVHD generally occurs within the first 100 days following the transplant. Chronic GVHD can happen anytime after the first three months following your transplant. The transplant team will make the diagnosis based on the symptoms you are experiencing, laboratory information, and biopsy results.

The signs and symptoms of GVHD vary according to the body system that is affected.

**Signs and Symptoms of GVHD**

**Skin GVHD** in the acute stage usually begins with a fine rash on the palms of the hands and the soles of the feet. It may then spread over the forehead, face, arms, legs and torso of the body. The skin may become swollen, tender, and may itch. The skin may become reddened. You may have dry, peeling skin and may even develop blisters. Chronic skin changes include color changes, texture changes, tightness, and thinning hair. You may experience discoloration and brittleness of your fingernails, grittiness and irritation of your eyes, and pain and dryness in your mouth.

**Gastrointestinal tract GVHD** in the acute stage generally begins with frequent, green watery diarrhea. The diarrhea may become a burgundy color if the tissue in the bowel becomes irritated and bleeding occurs. Frequently this GVHD is accompanied by nausea, vomiting, and abdominal cramping. Chronic gastrointestinal GVHD may begin with loss of appetite, unexplained weight loss, persistent nausea, vomiting, and frequent loose bowel movements.

**Liver GVHD** can cause fatigue and weakness. Your abdomen may become tender and swollen. The bilirubin level in your blood will climb even before you begin to develop other symptoms. Daily labs will show any increase in this level. Other liver function lab tests may also be elevated. Some patients develop jaundice (yellow coloring of the skin and of the whites of the eyes). Your liver function tests will be closely monitored while you are in the hospital and after your discharge.
Lung GVHD can be detected early even before you have symptoms. Due to routine testing with chest CT scans and pulmonary function tests, we are able to detect early changes in your lung function. GVHD of the lungs can present with shortness of breath at rest or with activity and may be accompanied by a non-productive cough.

Prevention and early treatment are most important. Make sure you take your medications exactly as prescribed and notify the doctor if you have any problems with the medication or develop any symptoms of GVHD. When you received your transplant, you were prescribed an immunosuppressive therapy such as cyclosporine, tacrolimus, mycophenolate, prednisone, or sirolimus. We will monitor the level of some of these drugs in your body through lab work to make sure you are receiving the correct dose.

Several post-transplant tests, such as pulmonary function tests and liver function tests help the transplant team decide if you are developing GVHD. Should you develop GVHD, the medical team will decide upon a treatment plan specifically for you. The treatment for GVHD varies depending on which system is affected, how severe it is, and whether or not another system is involved. The overall goal of treatment is to find the one that works best for your situation with the least disruption to your day to day life.

Re-immunization for Post Transplant Patients

Allogeneic and autologous transplant patients need to be re-immunized or re-vaccinated after transplant for the same diseases you received vaccinations for as a child. The chemotherapy and radiation you received for your transplant destroyed your bone marrow as well as the antibodies you made in response to vaccinations you received throughout your life. For autologous transplant patients, this re-immunization process will begin at one year post transplant. For allogeneic transplant patients, there are several criteria that a patient must meet in order to begin the re-immunization process. The transplant patient must be at least six months post transplant and have been off immunosuppressant medications for at least one month without any signs or symptoms of graft-versus-host disease. The medical team will test your immune system’s ability to make antibodies. We do this by checking the levels of certain antigens (CD4 and IgG) in your blood and by checking a skin test on your forearm to assess if you react to it. If there is a positive response to 2 of the 3 tests, we can draw some blood and do further testing to determine if you have retained any of the antibodies that you developed with previous immunizations. We will only re-immunize you for the diseases that you no longer have protection against.

There are several immunizations that you may potentially receive. These immunizations require intermittent injections over a specific period of time in order to fully protect you.

- Hepatitis B
- Diptheria/Tetanus/Pertussis (DTaP)
• Heamophilus influenza type B (HiB)
• Pneumococcal
• Influenza
• Measles/mumps/rubella (MMR)
• Polio

Each vaccination has its own potential side effects that you should be aware of before you receive the injection. Please discuss any concerns you have with your doctor or nurse before the vaccination. Your nurse will give you a copy of the VCU Medical Center’s Care Note for each vaccination that highlights important information including side effects.
Appendix

Financial Resources for Transplant Patients

Grants are available primarily based on income and sometimes on assets and diagnosis. You can apply for these through the transplant social worker.

**Leukemia and Lymphoma Society** – helps with mileage reimbursement, some drug costs not covered by insurance. Local office in Richmond is 804-627-0400.

**Leukemia and Lymphoma Society** – Co-pay Assistance Program covers drug and MD visit co-pays. Application available online, but social worker needs to assist. 1-877-LLS-COPAY.

**National Marrow Donor Program Foundation** – [www.marrow.org](http://www.marrow.org). Post transplant grant covers those whose UNRELATED donors have been obtained through the NMDP.

**The Lymphoma Research Foundation** 1-800-500-9976.

**The Bone Marrow Foundation** – Helps pay non-medical bills up to $500 and $1,000, depending on monies available. [www.bonemarrow.org](http://www.bonemarrow.org).

**The John’s Foundation** – Helps pay non-medical bills up to $500.00. This is a local group based out of Johnston-Willis Hospital. [www.johnsfoundation.org](http://www.johnsfoundation.org).

**Cancer Care Foundation** – 1-800-813-HOPE. Helps pay bills associated with treatment such as transportation, child care, chemotherapy, etc.

**Health Well Foundation** – Helps with treatment related bills. Apply on their site online. [www.healthwellfoundation.org](http://www.healthwellfoundation.org). 1-800-675-8416.


**Patient Advocate Foundation** – 1-866-512-3861, a case management organization in the Tidewater area (Hampton) that can help connect you with resources.

**Patient Services, Inc.**, 1-800-366-7741. Co-pay assistance for some diagnoses.

Most of the grant programs offer help once a year only. There may be other resources available. Most of the above can be located online.
Community Resources

Department of Social Services – These are administered by each county or city. You must go to the one in your area of residence. If you have temporarily relocated to Richmond due to a transplant, the local office may be able to serve you. You can apply for a specific program or meet with both Eligibility and Service workers to determine your need. They have income support programs such as SNAP for families with children, general relief (temporary income for non-disabled adults – not all localities have this), State and Local Hospitalization Funds (for acute care hospital stays for those with no insurance), and Medicaid. They also provide access to day care – occasionally subsidized – and health care service sponsored through the Medicaid Waiver programs.

Social Security – 1-800-772-1213; www.ssa.gov. Apply here for disability benefits you may have based on your work history and current medical condition. You may also be eligible for Supplemental Security Income. Application for Disability will also potentially lead to getting Medicare.

Your local Area Agency on Aging Ombudsman can help you with understanding some of these programs as they work with the elderly (who often need these services). Check your phone directory for this office.

www.needymeds.com is a site that directs you to your drug company’s indigent programs to help pay for medicines. You must meet income and asset requirements and particular insurance requirements of each program.

The Partnership for Prescription Assistance – 1-888-4PP-ANOW. Offers information to link you to manufacturer’s assistance programs.

American Cancer Society has an information and referral line that may help you with other community programs. 1-800-ACS-2345.


Check with your insurance company to explore what benefits or programs they may have. If you have a case manager, this is a good person to call. Some companies pay for or reimburse travel, lodging and meal expenses related to transplant.

Frequently Asked Questions

Q: What is the difference between Medicare and Medicaid?
A: Medicare is insurance provided at retirement age when one has had a job paying Medicare tax, or when one has received Social Security Disability payments for 24 months. It includes parts A, B, and D. A is hospitalization, B is outpatient benefits and D is the drug program. There is extra help available for low income beneficiaries for drug co-pays through Social Security. Call them and ask about the Extra Help or Low Income
Beneficiary Program. There are now Medicare Advantage plans run by private HMOs available.

Medicaid is for people with very low income and is obtained through the local Department of Social Services. Children under 18 and those over 65 do not have to be determined disabled to receive this. People aged 18 through 65 do have to be determined disabled through Social Security and have low income to get this.

Q: Can I have both Medicare and Medicaid?
A: Yes, if you meet the requirements for both.

Q: What is the doughnut hole?
A: That is the period during which a Medicare covered person needs to pay up to 100% (changed to 50% with the Affordable Care Act and set to be eliminated in 2014) of the costs of their medicine before Medicare kicks back in to cover them. There are some options with co-pay assistance programs and prescription assistance programs through drug companies.

Q: What is “dual eligible?”
A: This is a person who has both Medicare D and Medicaid. They should not have a doughnut hole problem and Medicaid should pay the premiums for their Medicare. Contact 1-800-Medicare and your local Department of Social Services to help you.

Q: I am confused by the Social Security Disability and Social Security Income application processes. What are the steps?
A: Generally, you must have stopped working. You can call 1-800-772-1213 to schedule a phone interview to start your application, you can apply on line for Disability (not SSI) at www.ssa.gov or you can visit your local office. They will give you many papers to fill out (or online pages) asking you questions about your illness and treatment, your job duties, your work history, your everyday function and what keeps you from working. It helps if you have your doctor and hospital information with you (names, addresses, phone, and medical record number). Important things to note are if pain or other physical problems hinder your ability to work. For BMT patients, immune suppression is one of the major reasons why work is not possible. You will sign consent forms so they can ask your doctor for information. The application goes from your local office to the area Disability Determination Office where they make the medical decision. Then it goes back to your local office where they determine if you have enough work history to qualify. They notify you in the mail of the decision. You can appeal a denial decision. If an appeal is denied, you can then ask for a reconsideration that is done by one of their administrative law judges (this can take a long time). Getting them medical information at any part of this process is very important.

Q: Why didn’t I get money right away, but some people do?
A: Congress decided when they made this program that there would be a mandatory 6 month waiting period (you are “eligible” in 5 months) from the date you are seen as disabled until you get your first check. There are a couple of diagnoses that don’t have this waiting period, but most do. Some people, depending on income, can get SSI checks in that 6 month period. Some people get a date of disability that is retroactive (in the
past) enough months that they get their checks sooner. Remember, the checks come 6 months after the date they say you were disabled, not from when you hear about their decision.

**Q: Are there resources for caregivers in the community? Is there anything that pays for caregivers?**

A: In most cases, the answer is no. Transplant requires patients have a caregiver due to the medical risks with the patient and because patients are restricted from doing many of the necessary daily activities. Most private insurance has no benefit for this. Caregivers, such as an aide or sitter, can be hired privately, but this is an out of pocket cost to you. Local home health agencies can quote you their rates. The exception to the above is for Medicaid recipients who meet the medical and physical dependency criteria for a waiver program that provides mostly aides. Sometimes the commitment to treatment can span years, so a reliable care giving situation is necessary.


Medical Legal Partnership – They are a cooperative effort between VCU, LINC and Legal Aid. There is a lawyer onsite at VCU Tuesdays and Fridays from 10-2 in the office next to the wig shop on Massey ground floor. You can see them on a first come first serve basis.

Patient Advocate Foundation – 1-866-512-3861, a case management organization in the Tidewater area (Hampton) that can help connect you with resources.


**Employment Resources**

FMLA – Family Medical Leave Act. [www.dol.gov](http://www.dol.gov). Check with your HR department or the Department of Labor website.

COBRA – Consolidated Omnibus Budget Reconciliation Act – This act created the privacy rules that contained the regulations allowing you to take your employer’s health insurance with you after separating from a job. This involves your payment of the whole premium (without employer subsidy) to a third party administrating agency. There are specific steps to take to get the benefit extended after the standard 18-month allowance. Speak with your HR office or go to the Department of Labor website at [www.dol.gov](http://www.dol.gov).


# Medication Glossary

<table>
<thead>
<tr>
<th>Common Name</th>
<th>Alternative Name(s)</th>
<th>Reason for Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abelcet</td>
<td>Lipid complex amphotericin</td>
<td>Antifungal</td>
</tr>
<tr>
<td>Acyclovir</td>
<td></td>
<td>Antiviral</td>
</tr>
<tr>
<td>Allopurinol</td>
<td></td>
<td>Prevent kidney toxicity</td>
</tr>
<tr>
<td>Ambien</td>
<td>Zolpidem</td>
<td>Sleep aid</td>
</tr>
<tr>
<td>AmBisome</td>
<td>Liposomal amphotericin</td>
<td>Antifungal</td>
</tr>
<tr>
<td>Amphotericin</td>
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</tr>
<tr>
<td>Ara-C</td>
<td>Cytarabine</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>ATG</td>
<td>Apgam, Thymoglobulin</td>
<td>Prevent GVHD</td>
</tr>
<tr>
<td>Ativan</td>
<td>Lorazepam</td>
<td>Anti-nausea, anti-anxiety</td>
</tr>
<tr>
<td>Bactrim</td>
<td>Sulfamethoxazole/trimethoprim</td>
<td>Antibiotic</td>
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<td>Benadryl</td>
<td>Diphenhydramine</td>
<td>Premedication for blood, meds</td>
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<tr>
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<td>Busulfex</td>
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<td>Electrolyte</td>
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<tr>
<td>Cefepime</td>
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</tr>
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<td>Ceftriaxone</td>
<td>Rocephin</td>
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<tr>
<td>Celexa</td>
<td>Citalopram</td>
<td>Depression</td>
</tr>
<tr>
<td>CellCept</td>
<td>Mycophenolate</td>
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<td>Ciprofloxacin</td>
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<td>Cisplatin</td>
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<td>Clonidine</td>
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<td>Clotrimazole troche</td>
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<td>Codeine</td>
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<td>Cyclosporine</td>
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<td>Cytoxan</td>
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<td>Dexamethasone</td>
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<td>Dilaudid</td>
<td>Hydromorphone</td>
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<td>Flovent</td>
<td>Fluticasone</td>
<td>Inhaler to protect lungs</td>
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<td>Fludarabine</td>
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<td>Ganciclovir</td>
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<td>G-CSF</td>
<td>Filgrastim, Neupogen</td>
<td>Stimulate white blood cells</td>
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<td>Imatinab</td>
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<td>IVIG</td>
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<td>Boost immune system</td>
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<td>Common Name</td>
<td>Alternative Name(s)</td>
<td>Reason for Use</td>
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<td>Lasix</td>
<td>Furosemide</td>
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<td>Leucovorin</td>
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<td>Help clear methotrexate</td>
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<td>Levofoxacin</td>
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<td>Antibiotic</td>
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<td>Lomotil</td>
<td>Diphenoxylate and atropine</td>
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<td>Magnesium</td>
<td>Mg</td>
<td>Electrolyte</td>
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<td>Mesna</td>
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<td>Protect bladder from chemo</td>
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<td>Melphalan</td>
<td>Alkeran</td>
<td>Chemotherapy</td>
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<td>Meropenem</td>
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<td>Antibiotic</td>
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<td>Methotrexate</td>
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<td>Morphine</td>
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<td>Nexium</td>
<td>Esomeprazole</td>
<td>Reduces stomach acid</td>
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<td>Nystatin</td>
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<td>Pentamidine</td>
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<td>Antibiotic breathing treatment</td>
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<td>Pepcid</td>
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<td>Percocet</td>
<td>Oxycodone and Acetaminophen</td>
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<td>Phenergan</td>
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<td>KCl</td>
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<td>Prilosec</td>
<td>Omeprazole</td>
<td>Reduces stomach acid</td>
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<td>Rituxan</td>
<td>Rituximab</td>
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<tr>
<td>Sprycel</td>
<td>Dasatinib</td>
<td>Chemotherapy</td>
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<tr>
<td>Tacrolimus</td>
<td>Prograf, Tac</td>
<td>Prevent or treat GVHD</td>
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<td>Taisigna</td>
<td>Nilotinib</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>TBI</td>
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<td>Total body irradiation</td>
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<tr>
<td>Thalidomide</td>
<td>Thalomid</td>
<td>Treatment for Myeloma</td>
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<td>Tobramycin</td>
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<tr>
<td>Triamcinolone Cream</td>
<td>Steroid cream for rash</td>
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<td>Tylenol</td>
<td>Acetaminophen</td>
<td>Fever, pre-medication</td>
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<td>Sirolimus</td>
<td>Rapamune</td>
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<td>Ursodiol</td>
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<td>Liver protection</td>
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<td>Valcyte</td>
<td>Valganciclovir</td>
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<td>Valacyclovir</td>
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<td>Zofran</td>
<td>Ondansetron</td>
<td>Anti-nausea</td>
</tr>
<tr>
<td>Zosyn</td>
<td>Piperacillin/tazobactam</td>
<td>Antibiotic</td>
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## Overview of Transplant Pathway for Allogeneic Transplant Donor and Patient

<table>
<thead>
<tr>
<th>Dates/Time frame</th>
<th>Donor’s Process</th>
<th>Dates/Time frame</th>
<th>Patient’s Process</th>
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<tr>
<td></td>
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<td>First Visit: New Patient Consult</td>
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<td>Pre-transplant Phase</td>
<td>Insurance Authorization</td>
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<tr>
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<td>Sibling Donor Identification</td>
<td></td>
<td>HLA Typing</td>
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<td>Related Donor HLA Typing (siblings)</td>
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<td>Pre-transplant Evaluation for Transplant Eligibility</td>
</tr>
<tr>
<td></td>
<td>First Visit &amp; Evaluation, Education, Donor Consent</td>
<td></td>
<td>Insurance Approval for Transplant</td>
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<tr>
<td>Mobilization/ Collection Process</td>
<td>Transplant Phase</td>
<td></td>
<td>Second Consult for Transplant Consents and Education Confirmation</td>
</tr>
<tr>
<td>*catheter placement</td>
<td></td>
<td></td>
<td><strong>ADMISSION</strong></td>
</tr>
<tr>
<td>*Stem cell collection</td>
<td></td>
<td></td>
<td>Start of Conditioning Therapy</td>
</tr>
<tr>
<td>*Catheter removal</td>
<td></td>
<td></td>
<td>(chemotherapy/ Total body irradiation)</td>
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<tr>
<td>After donation follow-up</td>
<td></td>
<td></td>
<td>Donor cells infused</td>
</tr>
<tr>
<td>DAY 0</td>
<td></td>
<td></td>
<td>Discharge from hospital</td>
</tr>
<tr>
<td>Post-Transplant Phase</td>
<td></td>
<td></td>
<td>Transplant Clinic daily visits</td>
</tr>
<tr>
<td>DAY 100</td>
<td></td>
<td></td>
<td>Day 100 evaluation</td>
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<tr>
<td>6 MONTH</td>
<td></td>
<td></td>
<td><strong>Long Term follow up care</strong></td>
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<tr>
<td>1 YR</td>
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<td><strong>6 MONTH EVALUATION</strong></td>
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<td>6 MONTH</td>
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<td><strong>ONE YEAR EVALUATION</strong></td>
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<td></td>
<td><strong>Long Term Follow up Care</strong></td>
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# Overview of Transplant Pathway for Autologous Transplant

<table>
<thead>
<tr>
<th>Dates/Time Frame</th>
<th>Pre-Transplant Phase</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>► First Visit / Consult</td>
</tr>
<tr>
<td></td>
<td>► Insurance Authorization for Transplant Eligibility testing</td>
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<tr>
<td></td>
<td>► Evaluation for Transplant Eligibility</td>
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<tr>
<td></td>
<td>► Insurance Approval for Transplant</td>
</tr>
<tr>
<td></td>
<td>► Second Consult, Sign Consents, Education Affirmation</td>
</tr>
<tr>
<td></td>
<td>► Mobilization of stem cells</td>
</tr>
<tr>
<td></td>
<td>► Apheresis Catheter Placed</td>
</tr>
<tr>
<td></td>
<td>► Stem Cell Collection</td>
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<thead>
<tr>
<th>Transplant Phase</th>
<th>Admission</th>
</tr>
</thead>
<tbody>
<tr>
<td>DAY 0</td>
<td>Start of Conditioning/ Preparative Regimen</td>
</tr>
</tbody>
</table>

| DAY 0            | Infusion of Stem Cells |
| DAY 0            | ► Recovery |

<table>
<thead>
<tr>
<th>Post Transplant Phase</th>
<th>Discharge from hospital</th>
</tr>
</thead>
</table>

| DAY 60 or DAY 100 | ► Day 60 or day 100 evaluation – depending on the type of Disease. |
| 6 Month evaluation | ► 6 Month Evaluation |
| 1 Year evaluation | ► One Year Evaluation |
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<thead>
<tr>
<th>DATE</th>
<th>WBC</th>
<th>HGB</th>
<th>PLT</th>
<th>CREAT</th>
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Getting around VCU Medical Center

Understanding Floor Numbers

You are in the North Hospital, which is at the bottom of the hill on Marshall Street.

The hospital’s other buildings are higher on the hill.

For this reason, North Hospital’s fifth (5th) floor connects to the first (1st) floor of all other hospital buildings.

Parking

Valet parking is available Monday through Friday, 7 a.m. to 5 p.m. (cars can be retrieved until 7 p.m.), at the main entrances of the Gateway Building, Ambulatory Care Center, Children’s Pavilion and North Hospital. The cost is $5.00 for the service.

The VCU Medical Center’s Patient and Visitor Parking Deck, located at 12th and Leigh streets, is open 24 hours a day, 7 days a week. Reduced parking rates for self-parked cars in the Patient and Visitor Parking Deck ($2.00 per visit) are available for patients and visitors who obtain a parking validation at the Information Desks located in the Gateway Building, Ambulatory Care Center, Nelson Clinic and North Hospital. (This reduced rate does not apply to valet parking.) There is a $10.00 charge for lost parking tickets.
Food Services

Main Hospital, 1st floor
- Hospital cafeteria
- Au Bon Pain (French Bakery)
- Chick-fil-A
- Subway

Gateway Building, ground floor
- Wendy’s
- Einstein Bros Bagels

Ask the Reception Desk for directions

Banks

Wachovia Bank ATM machines are available on Main Hospital, 2nd floor and Gateway Building ground floor. A branch is also located at Eleventh & Marshall: 401 N 11th Street, Richmond, VA 23219 (804) 698-5466.

Suntrust branch is located at 10th & Main: 919 East Main Street Richmond, VA 23219 (804) 782-5689 or 1-(800) 786-8787

Bank of America ATM machine is located outside of the cafeteria on Main 1 of the hospital.

Shopping

Kroger: Supermarket
901 N Lombardy Street
Richmond, VA 23220
(804) 213-3620

Martin’s Grocery Store
3522 W Cary Street
Richmond, VA 23221
(804) 353-0676
(804) 353-9791
(804) 353-6995
Target
5401 W Broad Street
Richmond, VA 23230
(804) 285-3492

Walmart
1504 N Parham Road
Richmond, VA 23229
(804) 270-7050

**Pharmacies**

CVS Pharmacy
1007 East Main Street
Richmond, VA 23219

Rite Aid
520 West Broad Street
Richmond VA 23220
804 255 1340

Walgreens
5802 W Broad Street
Richmond, VA 23230
(804) 288-3191
(804) 288-3090

Westbury Pharmacy (delivers downtown and to the Hospitality House)
8903 Three Chopt Road
Richmond, VA 23229
(804) 285-3428

**Theatres**

Ethyl IMAX Dome & Planetarium
2500 West Broad Street, Richmond, VA, USA - (804) 864-1400

Regal Westhampton Theatre
5706 Grove Avenue, Richmond, VA, USA - (800) 326-3264 -ext 391

Regal Virginia Center 20
10091 Jeb Stuart Pkwy, Glen Allen, VA, USA - (800) 326-3264 -ext 384
**UA West Tower**  
8998 West Broad Street, Richmond, VA, USA - (800) 326-3264 -ext 671

**Regal Short Pump 14**  
11650 West Broad Street, Richmond, VA, USA - (800) 326-3264 -ext 390

**Hotels in the area**  
*Marriott Downtown* 500 East Broad Street 804 643 3400  
*Omni Richmond* 100 South 12th Street 804 344 7000  
*Crowne Plaza* 555 East Canal Street 804 788 0900

**Houses of Worship** - The chaplain’s office has a list of local houses of worship and can be reached at 828-0928

**Cancer Resources**

**Careers**  
[www.cancerandcareers.org](http://www.cancerandcareers.org)

**Cancer information**

Legal Information Network for Cancer (LINC)  
[http://www.cancerlinc.org](http://www.cancerlinc.org)

National Cancer Institute  

University of Pennsylvania Cancer Reference  
[http://www.oncolink.com](http://www.oncolink.com)

American Cancer Society  
[http://www.cancer.org/docroot/CRI/CRI_0.asp](http://www.cancer.org/docroot/CRI/CRI_0.asp)

National Cancer Institute Clinical Trials Listing  

The National Marrow Donor Program  
[http://www.nmdp.org](http://www.nmdp.org)

**Diseases**  
Multiple Myeloma  

Leukemia & Lymphoma  
[http://www.leukemia.org/hm_lls](http://www.leukemia.org/hm_lls)
Linen-Powell Patient Resource Library

The VCU Massey Cancer Center has a resource library for patients, family and friends to visit.

We have:
- Books about cancer, coping with cancer, cancer treatment and more – all can be checked out for as long as you need them;
- Brochures & tear sheets about cancer treatment side effects;
- Two computers in the library for patients, family or friends use to check your email, keep in touch with family and friends and to do research;
- A staff person or volunteer at the desk who can help you find information about any cancer, treatment option or side effect information.
- Information about legal and financial assistance;
- Support group & counseling information and referrals.

Location: The library is located on the Ground Floor of North Hospital.

From the Bone Marrow Transplant units (both 7th & 10th floors) take the elevator down to G and follow the sign for Massey Cancer Center. We are located right off the main Massey lobby near the exit doors.

Hours: 9am–12pm & 1pm–5pm
Monday through Friday

Contact: (804) 828-8709 or email mcclibrary@vcu.edu
PRESCRIPTION REFILLS

or

PRIOR AUTHORIZATIONS

Prescription Refill Information Line: 804-628-1169 Option *3
*This line does not except voice messages

REFILLS
When you only have enough medication to last 5 days, please call your pharmacy and ask them to fax a refill request to 804-628-2268. Usually, this process is completed with in 24-48 hours.

PRIOR AUTHORIZATIONS
If your prescription needs a prior-authorization, please follow the same process for refills but allow 48-72 hours for the insurance company to complete their review of your medication and medical information.

You may contact our Financial Coordinators at 804-828-4372 if you need to follow up on a refill request or prior authorization that has already been initiated.