



## **Bone Marrow Transplant Program**

Welcome to Massey Cancer Center's Bone Marrow Transplant Program at Virginia Commonwealth University. Because the stem cell transplant is a complex procedure, you will receive a lot of detailed information. This patient education manual has been prepared to help guide you through all the stages of your transplant. We ask that you bring this manual with you to your clinic appointments and when you are admitted to the hospital. The transplant team members will review the information in this manual with you as you proceed through various stages of transplant.

We recognize this may be a stressful time for you and your family. It is normal to feel somewhat anxious as you anticipate the transplant process you are about to undergo. Please do not hesitate to ask questions and voice your concerns to the staff at any time. Most importantly, know that the transplant team will be with you every step of the way.

Sincerely,

The Bone Marrow Transplant Team

## **VCU Health Bone Marrow Transplant Program**

### **Bone Marrow Transplant Clinic Hours of Operation**

Monday through Friday 7:30AM – 5:00PM

Saturday and Sunday 8:30AM – 4:00PM

Main Telephone Number # 804-828-4360

Appointment Scheduling Telephone # 804-628-4463

North 10 Floor –Inpatient Telephone # 804-628-2371

#### Pre-Transplant Nurse Coordinators:

Dana Broadway, RN	Telephone # 804-828-3554	Fax # 804-828-0128
Angela Buskey, RN	Telephone # 804-828-3478	Fax # 804-828-0128
Judy Davis, RN	Telephone # 804-628-2079	Fax # 804-628-3863
Linda Mayhew, RN	Telephone # 804-628-8273	Fax # 804-828-0128

#### Post-Transplant Coordinators

Yvonne Allen, RN	Telephone # 804-628-0264	Fax # 804-628-3863
Carol Cole, RN	Telephone # 804-628-9956	Fax # 804-628-3863

#### Financial Transplant Coordinators:

Becky Williams, RN	Telephone # 804-828-4372	Fax # 804-628-2268
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#### Medication Prior Authorizations:

Denna Chaber, RN	Telephone # 804-628-2359	Fax # 804-628-5955
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#### Scheduling:

Patient Service Rep	Telephone # 804-628-4463	Fax # 804-828-7825
Sharon Goodman	Telephone # 804-628-1168	Fax # 804-628-1566

#### New Patient Coordinator

	Telephone # 804-628-2749	Fax # 804-828-7825
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#### Patient Records Information:

	Telephone # 804-628-1174	Fax # 804-828-7825
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#### VCU/MCV Social Service Department:

Jennifer Blosser	Telephone # 804-828-5451	Fax # 804-828-7825
Karen Mullin	Telephone # 804-628-3861	Fax # 804-828-7825

#### Dietician:

Brett Bowie	Telephone # 804-201-5755	
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#### Discharge Nurse:

Lynn Hoffman	Telephone # 804-628-4694	Fax # 804-628-4752
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#### Prescription and Prior Authorization:

		Fax # 804-628-5955
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#### VCU Hospital Billing:

	Telephone # 800-638-1636	Follow prompts 2, 3, or 4 or telephone #804-828-2841
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#### VCU Physicians Billing:

	Telephone # 800-638-1636	Follow prompts 1 Patient or telephone # 804-342-1391
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#### VCU Patient Portal:

**[vcuhealth.org/myvcuhealth](http://vcuhealth.org/myvcuhealth)**

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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 you 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
- Dietitians 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 Transplants

The Stem Cells can be collected from your own body or can be harvested from another person. This other person would be your donor. You will receive more detailed information on the type of transplant that is recommended for you.

- **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 an identical twin sibling.

## 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. Thus, 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 new born 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 the 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, using alcohol and using recreational drugs due to the risk of drug interactions and potential for organ injury. In these cases you must stop 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 or 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. It could 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 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 matched 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 Test:** This test determines how well your lungs are working.

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

**Additional cardiac/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. 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 patient 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 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.

### **The Doorways**

The majority of our patients stay at the Doorways 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 Doorways. The Doorways 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 5<sup>th</sup> or 8<sup>th</sup> 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 Doorways 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 5<sup>th</sup> floor are small and have 2 twin beds, a double bed, cot, or recliner. The Doorways is a charitable organization and they ask for a donation of \$15 per person per night. However, this is not mandatory. There is a \$30 deposit (may be subject to change) for linens and keys. Some of the staff are paid and some are volunteers. There are two social workers who work weeknights. There are dorm size refrigerators in the rooms. As of 2017, the Doorways is remodeling to offer additional accommodations for families with long term stays.

### **Extended Stay Hotels**

These are an option for those who can afford the cost. Most extended stay hotels offer small to large suites. Prices may vary and some hotels will offer discounts for VCU patients.

### **Apartments**

Some people may prefer furnished apartments. There are some in the area that allow for short term lease. 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. An apartment locator guide (usually available in newspaper boxes placed along the sidewalks) or a real estate agent may help. You may also Google search "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 at the Doorways. 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.

## **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 set you up with a home infusion company for central line care needs.

## **Mobilization for Autologous Transplant and Related Donors**

Stem cells need to be collected before the transplant high dose of 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 4<sup>th</sup> day to see if there are enough stem cells to begin collection. Collection usually begins on the 4<sup>th</sup> or 5<sup>th</sup> day of growth factor injections.

**Mozobil** (Plerixafor) may be added on the 4<sup>th</sup> night if blood tests indicate this is necessary. Mozobil helps to move the stem cells out of the bone marrow into the circulation 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 (Mortin/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 4<sup>th</sup> 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 and Ramopril should not be taken during the apheresis phase.

### **You may bring:**

- A sweater or jacket (with zipper up the front)
- Writing or reading material

- 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, 10<sup>th</sup> Floor  
 P.O. Box 980157  
 Richmond, VA 23298-0157

You are allowed to receive cards, balloons, stuffed animals, silk flowers, books, magazines, puzzles, CD’s, or tapes, DVD’s 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 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 a 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 part-a-cath. **Button down tops are best.**
- Eye glasses (Leave contact lenses at home, due to risk of infection)
- **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 and 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, electric razor

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 every day 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
- Weaknesses 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 yourself if you feel weak, dizzy, or lightheaded. Call your 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**

When 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.

## **BMT Social Work & Resources**

### **Introduction:**

Blood and marrow transplantation (BMT) is a highly complex and resource intensive treatment requiring a specialized multi-disciplinary team. Clinical social workers are core members of the BMT team, providing expertise in psychosocial care for patients, caregivers and families throughout the transplant and recovery process.

### **Educational Background:**

There are two full time social workers dedicated exclusively to the BMT program. Social workers working in BMT have a Master's degree in social work from an accredited program. They are licensed by their state's governing or are under the auspices of the clinical social worker manager. In order to remain licensed, they are required to complete continuing education, and adhere to the National Association of Social Work (NSAW) Code of Ethics. They are guided by the standards of practice under the Association of Oncology Social Workers (AOSW), the Association of Pediatric Oncology Social Workers (APOSW) and NASW.

### **Services Provided:**

- Psychosocial assessment for BMT, high risk screening, ongoing psychosocial evaluation
- Continuous screening for adjustment to impact of treatment
- Counseling for adjustment to illness, depression, anxiety, survivorship, grief and loss, and end of life
- Pain and symptom management; i.e.: guided imagery and relaxation techniques
- Discharge and transitional care planning
- Psychoeducation and linkage with resources i.e. support groups and financial assistance
- Advocacy and system navigation
- Evidence-based program development and evaluation

### **BMT clinical social work interventions aim to:**

- Maximize patient and caregiver psychosocial functioning
- Foster patient and family adaption to health crisis
- Promote healthy coping
- Enhance quality of life throughout the transplant treatment trajectory
- Optimize patient outcomes
- Inform patient care strategies for the health care team

### **BMT patients have unique needs that may require clinical social work intervention:**

- Identify a 24/7 caregiver plan
- Complex psychosocial issues involving multiple family members
- Mobilize a support system for an extended period of time
- Relocate and establish temporary housing near the transplant center
- Navigate emotional and practical needs related to complications that can be life-

threatening and require lengthy follow-up care i.e. graft-versus-host disease

## **Financial Resources**

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 804-673-5690

Leukemia and Lymphoma Society- Co-pay Assistance Program covers drug, insurance premiums and MD visit co-pays. Application available (LLS-CO PA) online, but social worker needs to assist. 1-877-557-2672

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. Grant Transplant Assistance available for patients with chronic GVHD.

Peer Connect program - connects patients and caregivers within peer support.

1-888-999-6743

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 Harthorne Foundation – Helps pay non-medical bills up to \$500.00. This is the local group based out of Johnston-Willis Hospital. Patients must go through their MD or social worker to attain this grant. [www.hawthornecancerfoundation.org](http://www.hawthornecancerfoundation.org)

Cancer Care – 1-800-813 HOPE. Helps pay bills associated with treatment such as transportation, child care, chemotherapy, etc. [www.cancercare.org](http://www.cancercare.org)

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

Patient Advocate Foundation – 1-800-532-5274, 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.

BMT Infonet – Information, support, and a small grant is available for financial needs. [www.bmtinfonet.org](http://www.bmtinfonet.org). 1-888-597-7674

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.

## Frequently Asked Questions on Financial Aid

### **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 not have to be determined disabled through Social Security and have low income to get this.

### **Q: Can I have both Medicaid and Medicare?**

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 2020) 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 1-800-633-4227 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 at [www.ssa.gov](http://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 daily activities associated with infection risk (not basic self-care). 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 to you. Local home health agencies can quote you their rates. The exception of the above is for Medicaid recipients who meet the medical and physical dependency criteria for a waiver program, so a reliable care giving situation is necessary.

LINC – Legal Information Network for Cancer – 804-272-5462 or [www.CancerLinc.org](http://www.CancerLinc.org)

They assist with information about many aspects of cancer relate legal issues. The LINC can refer you to free or reduced cost legal services.

Medical Legal Partnership – They are a cooperative effort between VCU, LINC, Legal Justice and Legal Aid. There is a lawyer onsite at VCU Tuesdays and Thursdays from 10-2 on Massey ground floor foyer by the valet parking. You can see them on a first come first serve basis.

Patient Advocate Foundation – 1-800-532-5274, 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.

## Community Resources

Department of Social Services – 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 Eligibility and Service workers to determine your need. They have income support programs such as SNAP for families with children, heating and cooling assistance, 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 sponsored through the Medicaid Waiver programs.

Social Security – 1-800-772-1213; [www.ssa.gov](http://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.org](http://www.needymeds.org) 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. [www.pparx.org](http://www.pparx.org)

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

National Foundation for Transplants – [www.transplant.org](http://www.transplant.org) Helps organize fundraising.

Help Hope Live – <https://helphopelive.org> Helps organize fund raising

nbmt link – [www.nbmtlink.org](http://www.nbmtlink.org) Support for patients and caregivers.

BMT Infonet – [www.bmtinfonet.org](http://www.bmtinfonet.org) Educational information 1888-597-7674

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.

## Hair Replacement

One of the most noticeable side effects of some chemotherapy is hair loss. Many people who have had chemotherapy or radiation therapy that causes hair loss look for ways to cope with this temporary challenge. Hair normally grows back after treatments are complete.

Please note that in order for your insurance company to cover the cost of a wig, make sure that your doctor writes an order for the following: “Full cranial prostheses for alopecia secondary to chemotherapy” or “radiation to the head,” whichever is appropriate. Medicare does not cover the cost of wigs. Your insurance company agent can tell you if a wig is covered.

### **Magical Touch Salons**

VCU Massey Cancer Center’s Magical Touch Salons offer free, private consultation for head-wear and also provide free hats, scarves and wigs. For an appointment at our flagship location on the MCV Campus downtown or at our Stony Point location, please call (804) 827-1043.

### **American Cancer Society**

Provides free wigs and individual styling of wigs for people with cancer.

4240 Park Place Court  
Glen Allen, Virginia 23060  
Toll free: (800) 227-2345

## 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 you 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).

National Coalition for Cancer Survivorship – [www.canceradvocacy.org](http://www.canceradvocacy.org) Information and advocacy on job discrimination.

Cancer and Careers – [www.cancerandcareers.org](http://www.cancerandcareers.org) Information and assistance for woman cancer survivors and work issues.

# **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, which may include an EKG
- A patient care partner will bring you the menu and show you how to order your meals.
- 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.

- 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. During flu season, all visitors and staff may be asked to wear a mask.
- **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.
- No outside food allowed. Patients and family members are not allowed in the galley. Please ask a staff member for assistance.
- Staff will remove your food trays from your room. Do not throw away leftover food or food trays in your trashcan.
- **Visitors will need to wash 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 restroom in the hallway 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 the patients. It is okay to hold their hand and sit close by. Hugging is always welcome.
- **Smoking** is not allowed on VCU Hospital property.
- 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 patient.

## 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 cannot 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.
  - 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 4 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 in 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:** The staff can assist you with ordering your meals through room service phone line.

**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 4 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 and 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, MRI's, 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
- Antiemetic's – Used to prevent or treat nausea or vomiting
- Immunosuppression – Used in allogeneic transplants to prevent rejection of 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 your 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 afternoon 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: A six minute walk test will be done on admission and discharge. You will be given a pedometer and log to record your activity.** 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 hallways 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. The BMT unit has a gym for your use. Check with your nurse on how to access the room during your hospitalization. The gym has a tread mill, bike and weights.

**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 rested. The better they take care of themselves, the better they can take care of you.

## **Pre-Transplant 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 at 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 do not 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 on 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 own 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 on 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 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. Your family may bring individually wrapped candies for you. 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 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 100<sup>th</sup> day past your transplant and possibly longer for allogeneic transplant patients. 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 in the inpatient unit.

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

1. Have people wash their hands. 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 of 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 test.
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 First 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 those 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.
- No dental flossing. Use the soft spongettes to brush your teeth, until your platelet count is 50,000 or greater.

### 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 talk 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. If you have 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 may 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 Prevention” on page 34 of this manual for further information.

## **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 this 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 *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. 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 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 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 social worker 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.
- Guided imagery CD’s related to having a transplant are available from the social worker.

## 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 blood stream. 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 the 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 test. Your nurse will be happy to discuss these tests with you and help you understand the lab results. **If you would like to keep 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 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 responds differently. It will also depend on the type of chemotherapy you were given and the type of transplant you had. Your progress towards discharge will be highlighted on the “BMT Road to Home” white board in your room. A facsimile of the board is on the next page. Be prepared to be discharged from the inpatient unit before 1200 on the day of discharge. Once you are discharged from the inpatient unit, you will need to return to the clinic every day for a while. We have a caregiver class twice a month as well as on line education on our website

(<http://massey.vcu/patient-care/therapies/bone-marrow-transplant/patient-caregiver-education/>).

Prior to discharge a pharmacist and our discharge nurse will see you to prepare for discharge.

# BMT Road to Home

Prep:

Day 0: \_\_\_\_\_

Daily Counts:

WBC: \_\_\_\_\_ HGB: \_\_\_\_\_ PLT: \_\_\_\_\_ ANC: \_\_\_\_\_



## Planning for Discharge

ANC >1500	○ ○ ○	_____
Afebrile for 24 hours	○ ○ ○	_____
Able to tolerate 1,000 calories per day	○ ○ ○	_____
Drinking 1 Liter of fluid per day	○ ○ ○	_____
Tolerating PO medications	○ ○ ○	_____
Out of bed 75% of the time	○ ○ ○	_____

Key:

● ○ ○ On my way

● ● ○ Almost There

● ● ● Goal Reached – Keep it up!

## Navigation of Bone Marrow Transplant Caregiver Education Site

<http://massey.vcu/patient-care/therapies/bone-marrow-transplant/patient-caregiver-education/>

- ❖ You will see the actual Patient Education Manual in the middle of the page
- ❖ You can print out each subject (in the blue print)
- ❖ Scroll further down and you will see a You Tube video. Push “play”
- ❖ Each new speaker will start when the previous has finished.

## **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 addressed. 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.
- Due to our appointment times being based on where patients are in the transplant process and how well they are doing, please be mindful of your appointment times. Unless there is an urgent issue, the patient who will be seen next is based on scheduled appointment times. Please do not arrive earlier than 15-30 minutes prior to your appointment time unless instructed by staff.
- 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.
- When checking in, please report directly to the front desk if you or a family member has new upper respiratory symptoms, fever and 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 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 rooms. In order to help prevent infections and to allow the nurses space to care for patients, we have a family lounge for the caregivers while patients are receiving treatments. It is located outside of the clinic near the elevators and is outfitted with a television, water and ice machine. There are restrooms located next to the family lounge.
- 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 also.
- Make a list of questions that may come up at home and bring them with you to discuss with the nurses or doctors.
- If you need refills on medications, please be sure to make the Practitioner or Physician aware when you are scheduled to see them in the clinic.

## **Who to Contact When Medical Problems Occur**

**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. If it is life threatening emergency, **call 911**. If you are unsure if you need to call the clinic or wait, call our BMT Team. There is always a health care member available to you.

Use the telephone numbers at the front of your BMT Patient Education Manual. If you need help during clinic hours, call the clinic. If it is after clinic hours, call the 10<sup>th</sup> Floor North Hospital Inpatient number.

When scheduling a follow up appointment, please do so prior to leaving clinic. If you are unable to schedule your next follow up visit prior to leaving the clinic, please call the scheduling desk at (804) 628-4463 to make an appointment.

## QUICK REFERENCE GUIDE OF SYMPTOMS FOR TRANSPLANT PATIENTS

Concern/Symptom	Emergency – Dial 911	Call BMT Clinic/Unit Immediately	Call BMT Clinic/Unit Within 24 hours
Change in alertness, consciousness, behavior	<ul style="list-style-type: none"> <li>• Unconscious</li> <li>• Seizure</li> <li>• Difficult to arouse</li> </ul>	<ul style="list-style-type: none"> <li>• New or increased confusion</li> <li>• Change in level of alertness</li> <li>• Vision changes</li> <li>• Falling or change in balance</li> <li>• New numbness or tingling</li> <li>• Unable to move limbs</li> </ul>	<ul style="list-style-type: none"> <li>• Mood swings or behavior changes</li> <li>• Difficulty walking</li> </ul>
Bleeding	Uncontrolled and persistent bleeding	<ul style="list-style-type: none"> <li>• New or increased bleeding</li> <li>• Unable to stop nosebleed</li> <li>• Blood in vomit, stool, urine or sputum</li> <li>• Heavy vaginal bleeding (more than 1 pad per hour)</li> </ul>	<ul style="list-style-type: none"> <li>• Frequent nosebleeds that stop with pressure</li> <li>• New bruising</li> <li>• Little purple or red spots in the skin</li> </ul>
Breathing	<ul style="list-style-type: none"> <li>• Not breathing</li> <li>• Choking</li> </ul>	<ul style="list-style-type: none"> <li>• Trouble breathing</li> <li>• Shortness of breath</li> <li>• Trouble breathing while lying flat</li> <li>• Wheezing</li> <li>• Uncontrolled cough</li> <li>• Coughing up bloody, yellow or green sputum</li> </ul>	<ul style="list-style-type: none"> <li>• New shortness of breath with daily activities</li> <li>• New or persistent cough</li> </ul>
Diarrhea		<ul style="list-style-type: none"> <li>• Consistent or uncontrolled</li> <li>• With a fever</li> <li>• With abdominal cramping</li> <li>• Bloody, burgundy or black stool</li> </ul>	<ul style="list-style-type: none"> <li>• New onset diarrhea</li> <li>• More than 5 diarrhea stools a day</li> <li>• Passing whole pills or indigested food in stool</li> <li>• Weakness or dizziness with diarrhea</li> </ul>
Fatigue	Unable to wake up	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Too tired to get up or go to the bathroom</li> </ul>	<ul style="list-style-type: none"> <li>• Increase in fatigue</li> <li>• Inactive</li> </ul>
Fever		<ul style="list-style-type: none"> <li>• Fever of 100.4 or over</li> <li>• Shaking chills with or without fever</li> </ul>	<ul style="list-style-type: none"> <li>• New redness, tenderness, swelling or drainage at IV site</li> <li>• Cold or flu symptoms</li> </ul>
Mouth pain or sores	<ul style="list-style-type: none"> <li>• Not breathing</li> <li>• Choking</li> </ul>	Having difficulty breathing or swallowing	<ul style="list-style-type: none"> <li>• Bleeding in mouth</li> <li>• New mouth sores</li> <li>• Pain not controlled</li> </ul>
Nausea or vomiting		<ul style="list-style-type: none"> <li>• Uncontrolled</li> <li>• Bloody or “coffee ground” appearing vomit</li> <li>• Unable to keep down medicine</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea persists despite medication</li> <li>• Weakness or dizziness with nausea/vomiting</li> </ul>
Rash		Sudden, new rash	Changes in skin rash
Swelling	<ul style="list-style-type: none"> <li>• Not breathing</li> <li>• Unable to swallow</li> <li>• Choking</li> </ul>	<ul style="list-style-type: none"> <li>• Sudden swelling</li> <li>• Difficulty breathing or swallowing</li> </ul>	<ul style="list-style-type: none"> <li>• New onset of swelling in legs, feet or hands with or without pain</li> <li>• Swelling at IV site</li> </ul>
Urination		<ul style="list-style-type: none"> <li>• Unable to void for more than 8 hours</li> <li>• Blood in urine</li> <li>• Painful urination</li> </ul>	<ul style="list-style-type: none"> <li>• Strong odor</li> <li>• Change in color of urine</li> </ul>

## Discharge Guidelines for 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 until instructed otherwise by your medical team.
- 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.
- Wear a mask when you are outside or in public to avoid potential respiratory infections.
- 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 wash cloths should be used by the patient only.

- Towels should be laundered every 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 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 are having concerns about sexual activity. Woman 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
- Plant trips to a mall, restaurant or theater at **non-peak** times to avoid crowds.
- 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 woodstove.
- **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 sunblock 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.
- Wear slippers or shoes at all times
- You may use a soft toothbrush and floss when your platelets are greater than 50,000
- 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

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 and their caregivers should discuss with their referring physician whether or not the diet or parts of the diet should be continued.

### Immunosuppressed Patient Diet

<b>Food Groups</b>	<b>Allowed</b>	<b>Not Allowed</b>
<b>Dairy</b>	<ul style="list-style-type: none"> <li>• All pasteurized, grade “A” milk and milk products</li> <li>• Commercially packaged cheese and cheese products made with pasteurized milk (e.g., mild and medium cheddar, mozzarella, parmesan, swiss, etc.)</li> <li>• Pasteurized yogurt</li> <li>• Dry, refrigerated and frozen pasteurized whipped topping</li> <li>• Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes</li> <li>• Commercial nutritional supplements and baby formulas, liquid and powder</li> <li>• Commercial pasteurized eggnog</li> </ul>	<ul style="list-style-type: none"> <li>• Unpasteurized or raw milk, cheese, yogurt and other milk products</li> <li>• Cheeses from delicatessens</li> <li>• Cheeses containing chili peppers or other uncooked vegetables</li> <li>• Cheeses with molds (e.g., blue, stilton, Roquefort, gorgonzola, etc.)</li> <li>• Sharp cheddar, brie, camembert, feta cheese, farmer’s cheese</li> <li>• Soft serve ice cream or yogurt</li> </ul>

<p><b>Meat and Meat Substitutes</b></p>	<ul style="list-style-type: none"> <li>• All <u>well-cooked or canned meats</u> (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)</li> <li>• <u>Well cooked eggs</u></li> <li>• <u>Well-cooked pasteurized egg substitutes</u> (e.g., Egg Beaters®)</li> <li>• <u>Commercially packaged salami, bologna and other luncheon meats</u> need to be heated in the microwave until steaming prior to using</li> <li>• Canned and commercially packaged <u>hard-smoked fish</u>; refrigerated after opening</li> <li>• Cooked tofu</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Raw or undercooked meat, poultry, fish, game, tofu</u></li> <li>• <u>Raw or undercooked eggs and egg substitutes</u></li> <li>• Meats and cold cuts from delicatessens</li> <li>• Hard cured salami in natural wrap</li> <li>• Cold smoked salmon (fish); lox</li> <li>• Tempe (Tempeh) products</li> </ul>
<p><b>Entrees, Soups</b></p>	<p>All cooked entrees and soups</p>	<p>All miso products (e.g., miso soup)</p>
<p><b>Fruits and Nuts</b></p>	<ul style="list-style-type: none"> <li>• Canned and frozen fruit and fruit juices</li> <li>• Well washed raw fruit; foods containing well washed raw fruits</li> <li>• Dried fruits</li> <li>• Canned or bottled roasted nuts</li> <li>• Nuts in baked products</li> <li>• Commercially packaged peanut butter</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unwashed raw fruits</u></li> <li>• Unroasted raw nuts</li> <li>• Roasted nuts in the shell</li> <li>• <u>Unpasteurized fruit and vegetable juices</u></li> </ul>
<p><b>Vegetables</b></p>	<ul style="list-style-type: none"> <li>• All cooked frozen, canned or fresh vegetables and potatoes</li> <li>• <u>Well washed raw vegetables</u></li> <li>• Fresh, <u>well washed herbs and dried herbs and spices</u> (added to raw or cooked foods)</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unwashed raw vegetables or herbs</u></li> <li>• All raw vegetable sprouts (alfalfa, radish, cauliflower, broccoli, mung bean, all others)</li> <li>• Salads from delicatessens</li> <li>• Commercial salsas stored in refrigerated case</li> <li>• Raw mushrooms</li> </ul>

<p><b>Beverages</b></p>	<ul style="list-style-type: none"> <li>• Tap water and ice made from tap water</li> <li>• Commercial bottled distilled, spring and natural waters</li> <li>• All canned, bottled and powdered beverages</li> <li>• Instant and brewed coffee, tea; cold brewed tea made with boiling water</li> <li>• <b>Non-Caffeinated beverages</b></li> <li>• Brewed herbal teas using commercially packaged tea bags</li> <li>• Commercial nutritional supplements, liquid and powdered must be approved by a BMT team member prior to use</li> </ul>	<ul style="list-style-type: none"> <li>• Well water (unless frequently and found to be free of coliforms)</li> <li>• Cold-brewed tea made with warm or cold water</li> <li>• Unpasteurized commercial fruit and vegetable juices</li> <li>• <b>Caffeinated beverages</b></li> <li>• Mate tea</li> <li>• Alcohol</li> </ul>
<p><b>Desserts</b></p>	<ul style="list-style-type: none"> <li>• Refrigerated commercial and homemade cakes, pies, pastries and pudding</li> <li>• Refrigerated cream filled pastries</li> <li>• Homemade and commercial cookies</li> <li>• Shelf stable cream filled cupcakes (e.g., Twinkies®, Ding Dongs®, etc.), fruit pies (e.g., Pop Tarts®, Hostess Fruit pies®), and canned pudding</li> <li>• Ices, popsicle-like products</li> </ul>	<ul style="list-style-type: none"> <li>• Unrefrigerated cream filled pastry products (not shelf table)</li> </ul>

<p><b>Bread, Grain and Cereal Products</b></p>	<ul style="list-style-type: none"> <li>• All breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast</li> <li>• Potato chips, corn chips, tortilla chips, pretzels, popcorn</li> <li>• Cooked pasta, rice and other grains</li> <li>• All cereals cooked and ready- to-eat</li> </ul>	<ul style="list-style-type: none"> <li>• Raw grain products</li> </ul>
<p><b>Fats</b></p>	<ul style="list-style-type: none"> <li>• Oil, shortening</li> <li>• Refrigerated lard, margarine, butter</li> <li>• Cooked gravy and sauces</li> <li>• Commercial, shelf stable mayonnaise and salad dressings (including cheese based salad dressings; refrigerated after opening)</li> </ul>	<ul style="list-style-type: none"> <li>• Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated cases Homemade Caesar dressing (contains raw product)</li> </ul>
<p><b>Other</b></p>	<ul style="list-style-type: none"> <li>• Salt, sugar, brown sugar</li> <li>• Jam, jelly syrups; refrigerated after opening</li> <li>• Commercial (heat treated and/or pasteurized) honey</li> <li>• Catsup, mustard, barbeque sauce, soy sauce, other condiments (refrigerated after opening)</li> <li>• Pickles, pickle relish, olives (refrigerated after opening)</li> <li>• Candy, gum</li> </ul>	<ul style="list-style-type: none"> <li>• Raw or non-heat treated honey; honey in the comb</li> <li>• Herbal and nutrient supplement preparations</li> <li>• Brewer’s yeast, if eaten uncooked</li> <li>• Pepper added to food after cooking Any raw uncooked spices such as cinnamon, ginger, nutmeg, etc.</li> </ul>

- 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 recommended 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. Recommended 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 foods eaten must be safe.

The 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 illnesses. 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, 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, **160°F cooked eggs, 145°F cooked fish** and poultry to 180°F. **Reheat meats to an internal temperature of 165°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 cast 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 165F), cover and let sit for 2 minutes.

## **Outdoor Grilling**

1. When cooking 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 165F
2. Eat your grilled food indoors to avoid outdoor contaminants (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.
12. Store groceries promptly after purchase. Never leave perishable food in the car.

### **Dining Out...Is It Safe? (Please check with your physician to see when 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, water 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 water, running water for about 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 board's air dry.**
  - a. **Tablespoon of unscented liquid chlorine bleach per gallon of water, or as an alternative, you may run the boards through the wash cycle in your dishwasher**
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. You should wash them often in the hot cycle of the washing machine.
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. The 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 and potatoes) to remove excess soil.
5. Wash the outside of all fruits and vegetables (such as oranges, melons and 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 and 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 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 well 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 or 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](http://www.bottledwater.org). If the IBWA does not have information on a specific brand, call the bottling company directly.

### **Water Filters**

If using 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 American National Standards Institute, NSF International, at 1-800-673-8010, or visit their home page at [www.NSF.org](http://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 Bottle/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 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.

#### Suggestions to Try First:

<b>Beverages (1cup)</b>	<b>Cereals (½ cup)</b>	<b>Starches (Allowed with 1 tsp. Margarine)</b>
Tea, weak decaffeinated or brewed herb, (except peppermint) Gatorade Rice Milk Lactaid® 100 milk ½ strength: apple juice, Kool-Aid®, Tang®, Cranberry drinks	Hot (all made with water): Cream of rice Cream of wheat <b>Oatmeal</b> Farina Grits Malt-O-Meal® Cold: Puffed Rice Rice Krispies® Cheerios®	White bread, plain bagel, or English Muffin, (1 slice) Pasta: macaroni, egg noodles, plain spaghetti (1/2 cup) Potato (no skin), baked or mashed (1.2 medium or ½ cup) Rice, white (1/2 cup) Saltines (2) Pretzels (1 oz.) White dinner roll (1)
<b>Fruits (½ cup)</b>		<b>Other</b>
Applesauce, plain Banana (1/2) Peaches, canned in juice or light syrup Pears, canned in juice or light syrup		Lifesavers Lemon Drops Broth, beef or chicken (1cup) Popsicle
<b>Miscellaneous:</b> Sugar 1 packet or teaspoon; salt, as desired		

#### If Tolerated Try:

<b>Protein Sources (Allowed with 1tsp. margarine or mayonnaise)</b>	<b>Other</b>
Well cooked chicken or turkey breast (no skin) Baked, broiled or boiled (1/2 breast or 3oz) Ham, lean (3oz) Egg, well-cooked only (1) Fish, baked or poached (3oz) Tuna, water packed (1/4 cup) Resource® Fruit Beverage (1/2 cup) Ensure®, Boost High Protein® (1/2 cup)	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 (1/2 sandwich) Vanilla wafers, graham crackers (2) Animal crackers (4) Angel food cake Carrots, well cooked (1/2 cup) Green beans, well cooked (1/2 cup) Sweet potatoes (no skin), baked or mashed (1/2 medium or ½ cup)

## 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

Food Recommended	Foods To Avoid
<b>Dairy and Supplements:</b> 3 or more cups per day	
Lactose-free 2%, 1% or skim milk Soy milk Rice milk Ensure®, Ensure Plus® Resource®, Fruit Beverage Resource®, Resource Plus® Boost® Scandishake®, lactose-free, made with lactose free low fat milk  Note: chocolate flavored beverages are allowed .....  Take with lactose enzyme tablet as needed (discuss with dietician) Instant breakfast, made with low-lactose milk Buttermilk Regular 2%, 1%, or skim milk Low fat yogurt (6-8oz) Low fat cottage cheese (non-fat or 1%) Low fat cheeses (cheddar, Monterey Jack, Swiss (1oz) American cheese (1oz) Cheddar cheese (1oz) Jack cheese (1oz) Mozzarella cheese, part skim (1oz) Parmesan cheese: grated or canned (1oz) Ricotta cheese, part skim (1/4 cup) Ricotta cheese, fat free String cheese (part-skim mozzarella) (1oz) Swiss cheese (1oz)	Any milk or milk-based product not pre-treated or not taken with lactase enzyme

<b>***Foods Recommended</b>	<b>Foods to Avoid</b>
<b>Meat or Meat Substitutes: 3 or more 3oz. Servings per day (or suggested portion size)</b>	
Well-cooked, lean cut of broiled, baked or roasted fish, beef, skinless poultry, ham Crab and imitation crab Canned, water-packed tuna and seafood Casseroles prepared with allowed foods Eggs, well cooked Cooked tofu Lean luncheon meat (such as turkey, chicken, ham) Low fat hot dogs Turkey bacon	High fat luncheon meat (Spam®, potted meat) Hot doge Corned beef Pepperoni Pickled or cured meats/fish Fried meats or fish Beans and legumes
<b>Fruit and Fruit Juices: 2 or more ½ cup servings per day</b>	
Juices: cranberry, cran-raspberry, nectars ½ strength juices: apple, grape (mix equal parts of water and juice) Fresh Fruit (peeled): apricots, bananas, melons, pears, papaya, mango, nectarine Apples, baked and peeled Canned Fruit: peaches, pears, plums, apricots Other: applesauce (plain) and canned cranberry Jelly or sauce	Juices: citrus, prune, V-8®, V-8 Spalsh®, tomato, Pineapple All raw fruits except those specifically allowed Canned or Fresh: berries, figs, oranges, lemons, limes, grapes, pineapple, prunes, rhubarb, cherries Dried Fruit: raisins, Craisins®, dates, apricots, pineapple, prunes, bananas
<b>Vegetables: 2 or more ½ cup servings per day</b>	
Well cooked, tender vegetables, as tolerated: Asparagus tips, beets, carrots, green beans, lettuce, mushrooms, pumpkin, sweet potatoes, yams (without skin), winter squash, skinless potatoes (baked, broiled, boiled, mashed) Frozen potatoes: Low fat French fries and hash browns (less than 4 gm fat per 3oz)	Raw or undercooked vegetables; also the following cooked vegetables: artichokes, baked beans, bamboo shoots, bean dishes, bean sprouts, beets, greens, broccoli, celery, Brussel sprouts, chives, cabbage, corn, cucumbers, peas, eggplant, bell peppers, leeks, legumes, lentils, lima beans, mustard greens, parsley, rutabagas, tomatoes, sauerkraut, summer squash, turnips, spinach, collard greens, swiss chard and all other similar foods
<b>Soups: As desired</b>	
Broth-based soups made with allowed meats and vegetables (*in moderation): beef broth, beef noodle, chicken broth, chicken noodle, chicken with rice, turkey noodle, vegetable, etc. ramen soups, without flavor packet, Homemade milk and cream – based soups and chowders (made with low fat, lactose-free milk	Highly seasoned soups Tomato based soups Ready-to-eat cream soups Soups with more than 2 gm of fiber per serving: Bean with bacon, beef noodle with vegetables, chili, green pea, manhattan clam chowder, onion, split pea, minestrone

**\*\*\*Recommended if having GI issues such as diarrhea**

*** Foods Recommended	Foods to Avoid
<p><b>Bread and cereal products:</b> 4 or more servings per day</p> <p>Bagels (plain)  Breads, enriched and refined (corn, white, pita, sourdough)  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  Cornmeal, corn starch  Crackers: animal, graham, saltines, low fat  English muffins: white or sourdough  Noodles, Polenta, pretzels  Rice cakes: plain  Rolls: white  Tortillas: corn or flour  White flour  White rice, couscous  Zwieback  Low fat baked tortilla chips or baked potato chips  pancakes, waffles: frozen, mix or home recipe using allowed ingredients</p>	<p>Whole grain bagels, breads, English muffins, or rolls (cracked wheat, rye, whole wheat, pumpernickel)  Breads and cereals with raisins, nuts or seeds, brown or wild rice, bulger 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  Whole grain macaroni and noodles  Whole wheat tortillas  Wheat germ  Crackers with more than 2 gm of fiber per serving</p> <p><b>Note: Avoid products with Olestra®, Olean®</b></p>
<p><b>Desserts:</b> As desired (read ingredients list)</p>	
<p>Cake (plain, without frosting)  Custard made with lactose-free milk  Jell-O  Homemade fruit cobbler made with allowed fruits  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)  Popsicles  Puddings, made with lactose-free milk  Plain cookies (such as vanilla wafers, graham crackers, ginger snaps)  Rice Krispie Treats  Angel food cake  Low fat, non-dairy ice cream</p>	<p>Cake with raisins, nuts, coconut, other omitted foods and spices  Pastries and desserts with dried or candied fruit, coconut, nuts, raisins, seeds  High fat cream-filled cakes and pastries  Premium high fat ice creams  Sugar cookies, wafer crèmes and other cookies not recommended</p>

***Foods Recommended	Foods to Avoid
<p><b>Take with lactase enzyme tablet as needed</b>  <b>Discuss with dietitian:</b>  Canned puddings  Sherbert (check label for milk in package)  Sorbert (check label for milk in package)  Low fat hard-pack ice cream and frozen yogurt  (less than 3 gm fat per serving)  Smoothies made with allowed ingredients</p>	
<p align="center"><b>Beverages: As desired</b></p>	
<p>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®, Kool-aid®  Tea, weak decaffeinated and herb teas, in  moderation (except peppermint)  *****  <b>Take with lactase enzyme tablet as needed</b>  <b>Discuss with dietitian:</b>  Cocoa</p>	<p>Alcoholic beverages  Coffee: regular or decaffeinated  Tea, including regular or strong decaffeinated  carbonated beverages containing caffeine cola  type carbonated beverages  Peppermint tea</p>
<p align="center"><b>Fats</b></p>	
<p>Low fat or nonfat choices – No restrictions 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</p>	
<p><b>Fats with limited portion size:</b>  Avocado (1/8 each)  Bacon, lean crisp (1 slice)  Butter (1 tsp)  Cooking oil (1 tsp)  Cool Whip® (1 tbsp)  Margarine (1 tbsp)  Mayonnaise (1 tbsp)  Peanut butter, creamy (2 tsp)  Gravies and sauces made with lactose free milk  (1/4 cup)  .....  Take with lactase enzyme tablet as needed  Discuss with dietitian  Cream cheese (1 tbsp)  Sour Cream (2 tbsp)  Whipping cream (2 tbsp)  Half and half (2 tbsp)</p>	

Gum drops, jelly beans, hard candy, gummi bears Herbs and spices for seasoning: basil, bay leaf. Oregano, rosemary, thyme, cinnamon Honey Jelly Marshmallows Fruit roll-ups Ripe olives Salt Sugar (any type) Soy sauce Syrups Vinegar	Friend snack foods: corn chips, Doritos®, Cheetos®, Potato chips Jams with seeds or skin Nuts, seeds, dried fruit, coconut: alone or in any food product Pickles Popcorn Spices: cayenne, chili powder, garlic (fresh, salt powder), mustard, onion (powder, salt), pepper, paprika Condiments: catsup, chili sauce, jalapeno, relish, horseradish, peppers, prepared mustard, steak sauce, barbecue sauces Salsa Tabasco
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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

<b>Foods High in Potassium</b>	<b>Foods High in Magnesium</b>	<b>Foods High in Calcium</b>
Milk	Beans	Milk
Citrus Juice	Tofu	Cheese
Tomato Juice	Avocado	Yogurt
Lentils	Cereals	Ice Cream
Beans	Greens	Cottage Cheese
Greens	Lentils	Orange Juice
Cereals	Peanuts	Tofu
Apricots	Banana	Salmon, canned with bones
Potatoes	Potatoes	Greens
Figs, dates, raisins	Cocoa, chocolate	Sardines
Peaches	Molasses	
Molasses		

## REFRIGERATOR & FREEZER STORAGE CHART

These short but safe time limits will help keep refrigerated food 40° F (4° C) from spoiling or becoming dangerous. Since product dates aren't a guide for safe use of a product, consult this chart and follow these tips.

- Purchase the product before "sell-by" or expiration dates.
- Follow handling recommendations on product.
- Keep meat and poultry in its package until just before using.
- If freezing meat and poultry in its original package longer than 2 months, overwrap these packages with airtight heavy-duty foil, plastic wrap, or freezer paper; or place the package inside a plastic bag.

Because freezing 0° F (-18° C) keeps food safe indefinitely, the following recommended storage times are for quality only.

Product	Refrigerator	Freezer
<b>Eggs</b>		
Fresh, in shell	3 - 5 weeks	Don't freeze
Raw yolks, whites	2 - 4 days	1 year
Hard cooked	1 week	Don't freeze
Liquid pasteurized eggs or egg substitutes, opened	3 days	Don't freeze
unopened	10 days	1 year
<b>TV Dinners, Frozen Casseroles</b>		
Keep frozen until ready to heat		3 - 4 months
<b>Deli &amp; Vacuum-Packed Products</b>		
Store-prepared (or homemade) egg, chicken, tuna, ham, macaroni salads	3 - 5 days	Don't freeze
Pre-stuffed pork & lamb chops, chicken breasts stuffed w/dressing	1 day	Don't freeze
Store-cooked convenience meals	3 - 4 days	Don't freeze
Commercial brand vacuum-packed dinners with USDA seal, unopened	2 weeks	Don't freeze
<b>Raw Hamburger, Ground &amp; Stew Meat</b>		
Hamburger & stew meats	1 - 2 days	3 - 4 months
Ground turkey, veal, pork, lamb	1 - 2 days	3 - 4 months
<b>Ham, Corned Beef</b>		
Corned beef in pouch with pickling juices	5 - 7 days	Drained, 1 month
Ham, canned, labeled "Keep Refrigerated," unopened	6 - 9 months	Don't freeze
opened	3 - 5 days	1 - 2 months
Ham, fully cooked, whole	7 days	1 - 2 months
Ham, fully cooked, half	3 - 5 days	1 - 2 months
Ham, fully cooked, slices	3 - 4 days	1 - 2 months
<b>Hot Dogs &amp; Lunch Meats (in freezer wrap)</b>		
Hot dogs, opened package	1 week	1 - 2 months
unopened package	2 weeks	1 - 2 months
Lunch meats, opened package	3 - 5 days	1 - 2 months
unopened package	2 weeks	1 - 2 months

Product	Refrigerator	Freezer
<b>Soups &amp; Stews</b>		
Vegetable or meat-added & mixtures of them	3 - 4 days	2 - 3 months
<b>Bacon &amp; Sausage</b>		
Bacon	7 days	1 month
Sausage, raw from pork, beef, chicken or turkey	1 - 2 days	1 - 2 months
Smoked breakfast links, patties	7 days	1 - 2 months
<b>Fresh Meat (Beef, Veal, Lamb, &amp; Pork)</b>		
Steaks	3 - 5 days	6 - 12 months
Chops	3 - 5 days	4 - 6 months
Roasts	3 - 5 days	4 - 12 months
Variety meats (tongue, kidneys, liver, heart, chitterlings)	1 - 2 days	3 - 4 months
<b>Meat Leftovers</b>		
Cooked meat & meat dishes	3 - 4 days	2 - 3 months
Gravy & meat broth	1 - 2 days	2 - 3 months
<b>Fresh Poultry</b>		
Chicken or turkey, whole	1 - 2 days	1 year
Chicken or turkey, parts	1 - 2 days	9 months
Giblets	1 - 2 days	3 - 4 months
<b>Cooked Poultry, Leftover</b>		
Fried chicken	3 - 4 days	4 months
Cooked poultry dishes	3 - 4 days	4 - 6 months
Pieces, plain	3 - 4 days	4 months
Pieces covered with broth, gravy	3 - 4 days	6 months
Chicken nuggets, patties	3 - 4 days	1 - 3 months
<b>Fish &amp; Shellfish</b>		
Lean fish	1 - 2 days	6 - 8 months
Fatty fish	1 - 2 days	2 - 3 months
Cooked fish	3 - 4 days	4 - 6 months
Smoked fish	14 days	2 months
Fresh shrimp, scallops, crawfish, squid	1 - 2 days	3 - 6 months
Canned seafood (Pantry, 5 years)	after opening 3 - 4 days	out of can 2 months



**U.S. FOOD & DRUG  
ADMINISTRATION**

## **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 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 blood stream.
- 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 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 tissue 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 transplant team.

### 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.

### 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.

## **Graft-Versus-Host Disease**

**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 normal immune systems 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 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. 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. It is very important that you report any new signs and symptoms with the transplant team to be evaluated.

## Sign 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, 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 receive 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 twostep re-immunization process. The transplant patient must be at least six months post-transplant to begin the first group or mandatory immunizations. Beginning the second group or titer-based immunizations, require then to 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. If there is a positive response to these two 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
- Diphtheria/Tetanus/Pertussis (DTaP)
- Hemophilus 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.

## Medication Glossary

<b>Common Name</b>	<b>Alternative Name(s)</b>	<b>Reason for Use</b>
Abelcet	Lipid complex amphotericin	Antifungal
Acyclovir		Antiviral
Allopurinol		Prevent kidney toxicity
Ambien	Zolpidem	Sleep aid
AmBisome	Liposomal amphotericin	Antifungal
Amphotericin		Antifungal
Ara-C	Cytarabine	Chemotherapy
ATG	Atgam, Thymoglobulin	Prevent GVHD
Ativan	Lorazepam	Anti-nausea, anti-anxiety
Bactrim	Sulfamethoxazole/trimethoprim	Antibiotic
Benadryl	Diphenhydramine	Premedication for blood, meds
Busulfan	Busulfex	Chemotherapy
Calcium	Ca	Electrolyte
Carboplatin		Chemotherapy
Carmustine	BCNU	Chemotherapy
Cefepime		Antibiotic
Ceftriaxone	Rocephin	Antibiotic
Celexa	Citalopram	Depression
Cellcept	Mycophenolate	Prevent or treat GVHD
Ciprofloxacin	Cipro	Antibiotic
Cisplatin		Chemotherapy
Clonidine		High blood pressure
Clotrimazole troche		Treats thrush in mouth
Codeine		Cough, pain
Compazine	Prochlorperazine	Anti-nausea
Cyclosporine	Cya, Neoral, Gengraf	Prevent or treat GVHD
Cytosin	Cyclophosphamide	Chemotherapy
Dapsone		Antibiotic
Dexamethasone	Decadron	Steroid; antiemetic
Dilaudid	Hydromorphone	Pain
Etoposide	VP-16	Chemotherapy
Fentanyl	Duragesic	Pain
Flagyl	Metronidazole	Antibiotic
Flovent	Fluticasone	Inhaler to protect lungs
Fluconazole	Diflucan	Antifungal
Fludarabine	Fludara	Chemotherapy
Foscarnet		Antiviral
Ganciclovir		Antiviral
G-CSF	Filgrastim, Neupogen	Stimulate white blood cells
Gleevec	Imatinab	Chemotherapy
Hydrocortisone		Steroid
Imodium	Loperamide	Diarrhea
Itraconazole	Sporanox	Antifungal
IVIg		Boost immune system
Kytril	Granisetron	Anti-nausea

<b>Common Name</b>	<b>Alternative Name(s)</b>	<b>Reason for Use</b>
Labetalol		High blood pressure
Lasix	Furosemide	Fluid retention
Leucovorin		Help clear methotrexate
Levofloxacin	Levaquin	Antibiotic
Lomotil	Diphenoxylate and atropine	Diarrhea
Magnesium	Mg	Electrolyte
Mesna		Protect bladder from chemo
Melphalan	Alkeran	Chemotherapy
Meropenem		Antibiotic
Methotrexate		Prevent GVHD
Methylprednisolone	Solu-Medrol	Steroid
Micafungin	Mycamine	Antifungal
Morphine		Pain
Nexium	Esomeprazole	Reduces stomach acid
Nystatin		Antifungal
Pentamidine		Antibiotic breathing treatment
Pepcid	Famotidine	Reduces stomach acid
Percocet	Oxycodone and Acetaminophen	Pain
Phenergan	Promethazine	Anti-nausea
Phosphorus	Ph	Electrolyte
Posaconazole	Noxafil	Antifungal
Potassium	KCI	Electrolyte
Prednisone		Steroid
Prevacid	Lansoprazole	Reduces stomach acid
Prilosec	Omeprazole	Reduces stomach acid
Rituxan	Rituximab	Chemotherapy
Sprycel	Dasatinib	Chemotherapy
Tacrolimus	Prograf, Tac	Prevent or treat GVHD
Tasigna	Nilotinib	Chemotherapy
TBI		Total body irradiation
Thalidomide	Thalomid	Treatment of Myeloma
Thiotepa		Chemotherapy
Tobramycin		Antibiotic
Triamcinolone Cream		Steroid cream for rash
Tylenol	Acetaminophen	Fever, pre-medication
Sirolimus	Rapamune	Prevent of treat GVHD
Ursodiol		Liver protection
Valcyte	Valganciclovir	Antiviral
Valtrex	Valacyclovir	Antiviral
Vancomycin		Antibiotic
Vidaza	Azacitidine	Chemotherapy
Voriconazole	Vfend	Antifungal
Zofran	Ondansetron	Anti-nausea
Zosyn	Piperacillin/tazobactam	Antibiotic

**Overview of Transplant Pathway  
For Allogeneic Transplant Donor and Patient**

<b>Dates/Time Frame</b>	<b>Donor's Process</b>	<b>Dates/Time Frame</b>	<b>Patient's Process</b>
		Pre-Transplant Phase	<b>First Visit:</b> New Patient Coordinator
	Sibling Donor Identification		Insurance Authorization
	Related Donor HLA Typing (siblings)		HLA Typing
			Pre-transplant Evaluation for Transplant Eligibility
			Insurance Approval
	First Visit & Evaluation, Education, Donor Consent		
			Second Consult for Transplant Consents and Education Confirmation
	Mobilization/Collection process *catheter placement *Stem cell collection *Catheter removal	Transplant Phase	<b>Admission</b> Start of Conditioning Therapy (chemotherapy/Total body irradiation)
	After donation follow up		
		Day 0	Donor cells infused
		Post-Transplant Phase	Discharge from hospital
			Transplant Clinic daily visits
		Day 100	Day 100 Evaluation
			<i>Long Term Follow up care</i>
		6 month	<b>6 Month Evaluation</b>
		1 YR	<b>One Year Evaluation</b>
			<i>Long Term Follow up Care</i>

## Overview of Transplant Pathway For Autologous Transplant

<b>Dates/Time Frame</b>	<b>Pre-Transplant Phase</b>
	First Visit / Consult
	Insurance Authorization for Transplant Eligibility testing
	Evaluation for Transplant Eligibility
	Insurance Approval for Transplant
	Second Consult, Sign Consents, Education Affirmation
	Mobilization of stem cells
	Apheresis Catheter Placed
	Stem Cell Collection
<b>Transplant Phase</b>	<b>Admission</b> Start of conditioning/Preparative Regimen
<b>Day 0</b>	<b>Infusion of Stem Cells</b> <b>Day 0</b>
	Recovery
<b>Post-Transplant Phase</b>	Discharge from hospital
	Transplant Clinic Visits
	Discharge to Primary Hematologist/Oncologist
<b>Day 60 or Day 100</b>	Day 60 or day 100 evaluation – depending on the type of disease
<b>6 Month Evaluation</b>	<b>6 Month Evaluation</b>
<b>1 Year Evaluation</b>	<b>One Year Evaluation</b>





## Getting around VCU Health

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 (5<sup>th</sup>) floor connects to the first (1<sup>st</sup>) floor of all other hospital buildings.

### Parking

Valet parking is available Monday through Friday. We offer **free valet parking** curbside for our patients coming to BMT Clinic. Bring your valet slip to our receptionist, she will validate it for your free parking at our North Hospital entrance at East Marshall and College Streets.

The VCU Health Patient and Visitor Deck, located at 12<sup>th</sup> 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 are \$2.00 per visit, and are free on weekends and some holidays.

## **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 e-mail, 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
- Support group & counseling information and referrals
- Information about legal and financial assistance

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

*From the Bone Marrow Transplant units (both 7<sup>th</sup> & 10 floors) take the elevator down to G follow the sign for Massey Cancer Center. We are located 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](mailto:mcclibrary@vcu.edu)

## **Prescription Refills or Prior Authorization**

For medication refill needs, your pharmacy has to fax the clinic a refill request form for each medication that is needed. When you call your refill into your pharmacy, please verify they have the correct fax number.

The medication refill fax number is 1 (804) 628-5955

For current pain medication refill needs, please call the BMT Clinic during clinic hours. You will need to come to clinic and pick up these prescriptions because they cannot be called in or electronically sent to the pharmacy.

For all new medication or new pain medication needs, please call the BMT Clinic during clinic hours and schedule a Nurse Practitioner or Doctor Visit to discuss those needs.

**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.

If you need to follow up on a prior authorization that has already been initiated. You may contact our Prior Authorization RN at 1 (804) 628-2359.