



UNC  
CANCER CARE

## Bone Marrow & Stem Cell Transplantation

# Autologous Transplant Patient Guide

February 2012

This guide is dedicated to our  
Patients and their Caregivers

## Preface

This patient guide was written for you and your family to help you become more familiar with what to expect before, during and after your bone marrow transplant. We hope that it helps to ease some of your anxieties and provides you with a place to find information.

You may want to read the entire guide in more than one sitting. Flip through it to learn the contents. You may want to read the “**Glossary of Terms.**” It is full of information and will help you to learn specific definitions of the “lingo” you will begin to hear. Words that appear in *Italics* in the pages that follow are defined in the glossary in Section 9.

This handbook is a general guide for our transplant patients. There may be minor variations with your treatment plan. You may also have questions or concerns after reading parts of the handbook. As an aid to you, there is a page labeled “Notes” at the back of this handbook. There is also a place for you to write notes in the margins of each page. Please use these areas to write down your questions when you think of them to be sure that you discuss them with your transplant Doctor or Nurse Coordinator.

Further information for you and your family is easy to obtain. Additional books, pamphlets, videos and internet access are available in the Cancer Resource Center, located on the ground floor of the North Carolina Cancer Hospital (NCCH). If you still need additional information, please ask your Transplant Coordinator.

Remember that we are here for you, your caregiver and your family. Let us know how we can help.

*The Bone Marrow and Stem Cell Transplant Team*

## Table of Contents

<b>Preface</b> .....	<b>3</b>
<b>Section 1: Getting to know us</b> .....	<b>6</b>
Welcome to the Bone Marrow and Stem Cell Transplantation Program .....	6
Bone Marrow Transplant Team .....	8
<b>Section 2: Overview of stem cell transplantation</b> .....	<b>10</b>
What is a Bone Marrow or Stem Cell Transplant? .....	10
Why do I need a Bone Marrow Transplant?.....	10
Types of Stem Cell Transplantation.....	11
What to expect before your hospital admission for a Bone Marrow Transplant.....	12
A Patient’s Pretransplant Checklist.....	14
<b>Section 3: The Autologous Transplant</b> .....	<b>15</b>
What is Mobilization? .....	15
How do I care for myself as an outpatient during the Mobilization part of the transplant? .....	16
What is Apheresis? .....	16
What is a Bone Marrow Harvest? .....	17
The Transplant .....	18
Day 0.....	18
The Waiting Begins .....	18
When will I be discharged?.....	19
What can I expect when I come to the outpatient Clinic? .....	19
<b>Section 4: Life as an Inpatient</b> .....	<b>21</b>
Bone Marrow Transplant Unit Mission Statement.....	21
Meet the Members of our Inpatient Team.....	21
BMT Unit Routines .....	23
What do I bring to the BMT Unit? .....	25
Personal Hygiene Notes.....	27
Visitor Guidelines .....	28
Infection Control on the BMTU .....	30
<b>Section 5: How do I care for myself when I am an Inpatient?</b> .....	<b>33</b>
Preventing Infections.....	33
Mouth Care .....	33
Skin Care .....	34
Activity.....	34
Distraction .....	34
School .....	35
Take Control.....	35
Exercising Before, During and After Your Transplant .....	36
How will a Recreational Therapist help me? .....	40
<b>Section 6: Therapies</b> .....	<b>41</b>
What to Expect During Chemotherapy .....	41
What to expect during Radiation Treatment.....	42
Late or Long Term Side Effects from Chemotherapy and Radiation Treatments: .....	43
What to Expect During Bone Marrow or Peripheral Blood Stem Cell (PBSC) Reinfusion.....	44
What If I Have Pain? .....	46
Pain Scales .....	46
What is a PCA Pump?.....	47

Common Medications used during and after transplant.....	49
<b>Section 7: Managing at Home .....</b>	<b>52</b>
Infections: Preventing & Recognizing Signs/Symptoms.....	52
Medications.....	54
Oral Care .....	54
Bleeding Precautions .....	55
Skin Care .....	56
Nutrition.....	57
Recreation & Physical Activity .....	58
Sexuality .....	59
Immunizations .....	60
<b>Section 8: Resources.....</b>	<b>61</b>
Your Caregiver: A Very Important Person .....	61
Patient Assistance Options for Bone Marrow Transplant Patients .....	62
Local Cancer Support Groups .....	64
Housing Options.....	64
Ronald McDonald/SECU Family House Shuttle Service.....	68
<b>Section 9: Glossary of Terms.....</b>	<b>70</b>
<b>Directions to Outpatient Tests .....</b>	<b>76</b>
<b>Outpatient Neutropenic Diet.....</b>	<b>78</b>
<b>Frequently Asked Questions.....</b>	<b>80</b>
<b>Notes/Questions: .....</b>	<b>81</b>
<b>Track Your Blood Counts .....</b>	<b>83</b>
<b>Patient Care Conference.....</b>	<b>85</b>
<b>UNC Hospital Patient Rights and Responsibilities .....</b>	<b>87</b>

## Section 1: Getting to Know Us

### **Welcome to the Bone Marrow and Stem Cell Transplant Program at the North Carolina Cancer Hospital**

The Bone Marrow and Stem Cell Transplant Program at the University Of North Carolina (UNC) in Chapel Hill was established in October, 1992. The program has performed over fourteen hundred (1400) transplants since that time. The type of transplant that we initially performed was an *Autologous transplant* (a transplant using the patient's own bone marrow or stem cells). In July of 1994, we performed our first related *Allogeneic* or "donor" bone marrow transplant. In February 1997, the first umbilical cord blood transplant was performed, and in May 1997, we did our first unrelated donor transplant.

The program cares for both adults and children with cancers of the blood, solid tumors and non-malignant blood disorders. We offer a variety of transplants from self, related and unrelated sources. We can use bone marrow, peripheral blood stem cells or umbilical cord blood (mostly for children) as sources for new cells for transplant.

The program moved into the North Carolina Cancer Hospital (NCCH) in August 2009. This state-of-the-art facility is devoted entirely to patients receiving cancer treatment and/or bone marrow transplant. The program is accredited by the Foundation for the Accreditation of Cellular Therapy (FACT) for both adult and pediatric transplants. This is a highly sought-after accreditation awarded only to those programs that meet very high standards in the field of bone marrow transplantation.

The program is a marrow collection, apheresis collection and transplant center for the *National Marrow Donor Program* (NMDP). This affiliation allows us to offer the option of unrelated stem cell transplants.

Our medical facility includes adult and pediatric transplant-specialty physicians, physician extenders (Physician Assistant and Nurse Practitioners), Bone Marrow Transplant Clinical Program Director, Transplant Nurse Coordinators, Pharmacists, adult and pediatric Social Workers, a Data Management office, Administrative Assistants, Recreational Therapists, a Financial Counselor, Chaplains, a Quality Management Coordinator and the Bone Marrow Transplant Unit (BMTU) Nurse manager and staff nurses.

*"Our physicians have diverse backgrounds and include training and prior faculty positions at the Dana Farber Cancer Institute in Boston, Johns Hopkins University, Stanford University, St. Jude Children's Research Hospital, Cincinnati Children's Hospital, MD Anderson and Fred Hutchinson Cancer Center in Seattle. Many of the faculty are members and hold leadership positions in the American Society of Oncology, the American Society of Hematology, the American Society of Blood and Bone Marrow Transplantation, The Cancer and Leukemia Group B, and the Center of International*

*Blood and Marrow Transplant Registries. This spectrum of skills and experience ensure that the care we provide is the finest and most advanced care available anywhere.”*

*Thomas C. Shea, M.D.,  
Program Director*



**Welcome to UNC!**

**BONE MARROW TRANSPLANT PROGRAM PHONE NUMBERS**

**BMT UNIT** 919-966-7792

**BMT OUTPATIENT CLINIC/INFUSION** 919-843-0600

**ADULT BMT PHYSICIANS**

Thomas Shea, MD, Program Director  
Paul Armistead, MD, PhD  
Don Gabriel, MD, PhD  
Jonathan Serody, MD  
Stefanie Sarantopoulos, MD, PhD  
James Coghill, MD  
William Wood, MD MPH

**PEDIATRIC BMT PHYSICIANS**

Kimberly Kasow, DO, Pediatric Medical Director  
Philip Roehrs, MD

**PHYSICIAN EXTENDERS**

Bob Irons, PA (Adult BMT)  
Amber Essenmacher, PA (Adult BMT)  
Cammie Presler, CPNP (Pediatric BMT)  
Jennifer Brady, ARNP  
Kimberly Wehner, DNP

**NURSE COORDINATORS**

Debbie Covington, RN, BSN, OCN, CHTC 919-966-0297  
Dr. Serody & Dr. Coghill  
Betty Hinshaw, RN, BSN, OCN, CHTC 919-966-8968  
Dr. Shea  
Pat Odell, RN, BSN 919-966-6246  
Dr. Gabriel  
Wendy Pino, RN 919-966-0838  
Dr. Armistead & Dr. Sarantopoulos  
Paula Stinson, RN, BSN, CPON 919-966-5277  
Dr. Kasow & Dr. Roehrs  
Marth Tye, RN, BSN 919-445-5594  
Dr. Wood

**CLINICAL PROGRAM DIRECTOR**

S. Elizabeth "Sam" Sharf, RN, BSN, CHTC 919-966-7516

Bone Marrow Transplant Program – Autologous Patient Guide

**PROGRAM COORDINATORS**

Lisa Cooper	919-966-0931
Norma Fullwood	919-445-5306

**BMTU MANAGER**

Gayl Talbert, MS, RN, CPON	919-966-0041
----------------------------	--------------

**FINANCIAL COUNSELOR**

Lisa Sofferin	919-966-9818
---------------	--------------

**QUALITY MANAGEMENT COORDINATOR**

Alicia Friedman, RN	919-966-4337
---------------------	--------------

**SOCIAL WORK**

Kathryn Roundtree, MSW, LCSW (Adult BMT Inpatient)	919-966-7861
Kathryn Kingsbury, MSW, LCSW (Adult BMT Outpatient)	919-843-6721
Chris Sellers, MSW, LCSW (Pediatric BMT)	919-966-2964
Dannette Rutkowski, LCSW	919-445-5263

## Section 2: Overview of Stem Cell Transplantation

### What is a Bone Marrow or Stem Cell Transplant?

A bone marrow transplant, or BMT, is performed to treat many diseases. During a BMT, healthy bone marrow cells, specifically *stem cells*, are transplanted into a person who has a diseased or damaged bone marrow. Bone marrow transplants use cells that are collected from the bone marrow of a patient or donor while stem cell transplants use cells collected from a patient or donors blood stream. Regardless of the type of transplant, the stem cells that grow to be healthy white cells, red cells and platelets all start in the bone marrow. Otherwise, the treatments are the same and the terms “bone marrow transplant” and “stem cell transplant” are often used interchangeably to mean the same thing.

Damaged bone marrow can be caused by:

- Bone Marrow Failure (i.e. Aplastic Anemia)
- Destruction of marrow by disease (i.e. Leukemia)
- Chemotherapy and radiation used to treat underlying disease (i.e. Lymphoma)

BMT candidates may include people with the following diseases or inherited disorders:

- Aplastic Anemia
- Hodgkin’s Disease
- Inherited disorders of bone marrow function (Aplastic anemia)
- Leukemias (chronic and acute)
- MDS (Myelodysplastic Syndrome)
- Multiple Myeloma
- Non-Hodgkin’s Lymphoma
- Pediatric solid tumors (Neuroblastoma)
- Immunological Disorders
- Inherited blood disorders (sickle cell and thalassemia)

### Why do I need a Bone Marrow Transplant?

If you have a blood disease and your bone marrow isn’t working properly, a transplant can help you by replacing your bad bone marrow with healthy bone marrow cells.

If you have a cancerous tumor in your body, a transplant can allow the doctors to give you a very high dose of chemotherapy and/or radiation to kill the cancer cells. Unfortunately, this high dose treatment damages the healthy cells of your bone marrow. To help you rebuild your bone marrow,

the doctors remove some stem cells from you or from a donor to save. When the chemotherapy is over, the saved stem cells are given back to you as a bone marrow “rescue.”

*Where do the stem cells come from?*

Depending upon your disease, you may be able to donate your own stem cells back to yourself. If you can't, someone whose marrow type matches your own will donate your new stem cells. This can be a family member or someone who is not related to you that is on a donor registry, such as the NMDP.

## Types of Stem Cell Transplantation

There are three types of transplants a patient can receive, depending upon where the *stem cells* come from:

1. *Allogeneic transplant*: The donor is someone other than you. It can be a family member (related donor) or someone other than a family member (unrelated donor). An umbilical cord blood transplant is also a type of allogeneic transplant.
2. *Autologous transplant*: The donor is you. You will use your own stem cells which will be collected before the transplant, frozen and stored in a special lab. They are returned to you after the chemotherapy is given for the underlying disease.
3. *Syngeneic transplant*: The donor is an identical twin with a genetically identical bone marrow. This is also considered an ‘allogeneic’ transplant.

## Am I Eligible for a Stem Cell Transplant?

To know if a transplant may help, you will need many tests. These tests may include:

- A history and physical examination
- Blood tests
- Pulmonary Function Test (PFTs)
- MUGA scan or echocardiogram
- CT scan (for certain diseases)
- EKG and Chest X-ray
- 24-hour urine collection
- Bone Marrow Biopsy
- Social Worker Evaluation



Dependent on your disease or clinical situation, you may require additional tests. The purpose of these tests is to find out how well your body functions. We will look at your heart, liver, kidney and lungs to see how well they perform. All of these tests are done to make sure it is safe for you to undergo a transplant.

### **Your Initial Transplant Consult**

#### **Patients are usually not scheduled for tests on their first visit**

During your first visit, a Transplant Physician and a Transplant Nurse Coordinator will see you. This visit may last for several hours. Your medical history will be reviewed, and you will have a physical exam. The Physician and Transplant Nurse Coordinator will explain what is involved in a bone marrow transplant and answer any questions that you may have. During your first visit, you may also meet with our Financial Coordinator who will explain the benefits of your particular insurance coverage and provide you with applications for additional resources if needed.

You may meet our Social Worker during your first visit as well; this will be decided at the first visit by both you and the team.

Your Transplant Nurse Coordinator will spend more time with you and your family further discussing the transplantation process, describing the support services and answering questions. A tour of the Bone Marrow Unit may be possible if there is an empty room available for viewing; however, most beds are filled at all times.

If you are eligible for transplant and wish to proceed, your Transplant Nurse Coordinator will plan your next steps to transplant.

### **What to expect before your hospital admission for a Bone Marrow Transplant**

After you have successfully completed your screening examinations, the next step is to have a *central line catheter* placed in your chest in order to receive treatment. You may have the catheter placed before coming into the hospital or on the same day that you are admitted. If you already have a central line catheter, your Transplant Nurse Coordinator will make sure that it is the right type of catheter for the transplant. There is a chance that your existing line may need to be replaced.

There will be many things to get in order before you can be admitted for this treatment. Your BMT Social Worker will help you with the many social and family arrangements that will need to be organized. Housing arrangements must be made and approved at this time (Please see the “Resource Section”

for further housing information). If you have travel and lodging benefits available through your insurance company, these will be reviewed with you as well.



High dose chemotherapy and radiation treatments may cause *infertility*. Therefore, you may wish to discuss fertility issues so that you may possibly have children in the future. Please talk with your doctor or Transplant Nurse Coordinator about this before you are admitted into the hospital. However, depending on your previous therapy, preserving fertility may not be possible.

Prior to admission for your transplant, you and your family will meet with a BMT physician again. During this conference we will review again the upcoming treatment, the actual transplant, the side effects from this treatment, how we expect the treatment to help you and how the treatment may affect you and your family.

Prior to your transplant, you will be asked to sign a written consent called an *Informed Consent* for the therapy and/or each research study in which you participate. Your signature indicates that procedure has been explained to you, that you understand the risks and benefits, that you have had a chance to ask questions and that you freely agree to participate.

You will be asked to sign a consent form that give the BMT Program permission to send information about your transplant to an international data registry called the CIBMTR (Center for International Blood and Marrow Transplant Research). This registry collects information on transplants from around the world. Information about your transplant will be given to the registry, but your name will not. This information helps the doctors and researchers who are working to make transplants better. While submitting this data may not directly help you, it may help those who have a transplant at a later time.

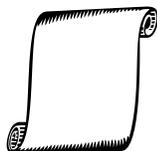
You and your caregiver will be asked to sign our *Family Conference Form*. This reviews all of the information you have received to date and confirms that you have had the opportunity to ask questions.

Since this treatment is very serious and you will need help to take care of yourself immediately afterwards, either a family member or friends must agree to stay with you every day for up to 30 days after your day of transplant.

You will be asked to identify the person who will be your *Health Care Power of Attorney*. This person, usually a family member, will be responsible for making medical decisions about your care if you are unable to do so. It is

important that the staff know who this person is before you are admitted. For our pediatric patients, this person will be the child's parent or guardian.

An *Advanced Directive* is a decision that you make now about your medical care if you are too sick to make those decisions. You can state your wishes about the use of artificial treatments to prolong your life if you are seriously ill. An Advanced Directive is a form with two parts; a living will and a health care power of attorney. For more information you can discuss this with you social worker. This is typically not done for our pediatric patients.



### **A Patient's Pre-transplant Checklist**

I need to complete the following before I am ready to be admitted into the hospital for transplant:

- Physical Exam and blood work
- Pulmonary Function Tests (To test the lungs)
- MUGA or echocardiogram (To test the heart)
- CT scans (May not apply to you)
- Bone Marrow Biopsy (May not apply to you)
- Read the BMT Patient Handbook
- Central Line Catheter Placement
- Complete Housing Arrangements (if applicable)
- Finalize Financial and Insurance Issues
- Attend the *Patient-Family Conference*
  - Review and sign informed consents
  - Review and sign blood transfusion consents
  - Discuss Advanced Directives, code status and ICU transfers

For pediatric-specific testing, the Pediatric BMT team will provide information regarding which tests will need to be done since there may be additional tests not listed above.

## Section 3: The Autologous Transplant

*Autologous transplantation* is a treatment in which you receive your own bone marrow or peripheral blood stem cells.

High doses of chemotherapy and/or radiation therapy are used to treat your disease and kill cancer cells. These therapies also damage your bone marrow's ability to make white blood cells, red blood cells, and platelets. Therefore, stem cells (the cells from which all blood cells develop) are collected from your *bone marrow* or *peripheral blood* prior to the *conditioning* and then given back to you after treatment is completed and on the day of your transplant.

### What is Mobilization?

*Mobilization* is a process that stimulates the bone marrow to produce a large number of stem cells. Most stem cells live in your bone marrow and mature to become red blood cells, white blood cells and platelets. The number of stem cells in the peripheral blood is much lower than in the bone marrow. Because of this, you will take medications to increase the production of stem cells, which in turn increases the number of stem cells in your blood circulation.

Mobilization can be done by giving chemotherapy followed by *growth factor* injections (G-CSF or Neupogen®). This may also be accomplished by using the growth factor injections alone. Your physician will discuss which way is best for you.

For adult patients, before you can be started on the mobilization therapy, a special intravenous catheter will be placed in your chest. This catheter is called an *apheresis* catheter. The catheter placement will be done as an outpatient procedure. You may eat a light meal up to six hours before the procedure. You must have someone with you to drive you home. You and your caregiver will learn how to care for your catheter and be given catheter supplies.

Once the catheter is in place, you are ready to start the mobilization process. You will receive growth factor injections in the outpatient setting. A calendar will be provided with your mobilization schedule. Your transplant nurse coordinator will review your calendar and when you should be given the growth factor injections.

If you receive chemotherapy, your blood counts will be checked frequently. We expect your blood counts to drop to very low levels due to the chemotherapy. This is normal. These low levels will require that you be

treated with a preventative oral antibiotic, and you will need to protect yourself from infections. This will be explained to you in further detail by the clinic nurses and pharmacist.

Approximately 7-10 days after the chemotherapy has been given, your white blood count will increase. When the white blood cell count is sufficient, the stem cell collection can begin.

### **How do I care for myself as an outpatient during the Mobilization part of the transplant?**

Take your temperature three (3) times a day. If your temperature is equal to or greater than 100.5, call the BMT clinic right away at (919) 843-0600 between 8:00am-4:30pm or the BMT Inpatient Unit after hours at (919) 966-7792.

Drink lots of fluids. Try and drink 2-3 liters of fluids each day. This may seem like a lot of liquid, but this can include Jell-O, popsicles and soups. ALWAYS tell the team if you are having nausea and vomiting and unable to keep any liquids down.

Good mouth care is important during this time when your white blood cell count is low. Mouthwashes with baking soda and warm water are good choices; however, do not use any mouthwashes with alcohol as they will dry out and irritate the lining of your mouth.

Extra care should be taken with your *central line catheter* or apheresis catheter. Change the dressing as you were taught (once a week or if visibly wet or soiled) and do a careful inspection of the site. Report any signs of redness, swelling, tenderness or drainage from around the site.

### **What is Apheresis?**

The method that is used to collect stem cells is called *apheresis*. The apheresis unit is on the first floor of Memorial hospital. You will check in at Registration and proceed to the Apheresis department. After a brief physical exam, your catheter will be connected to a machine that circulates your blood. This machine separates the stem cells from the rest of your blood in the apheresis machine so the rest of your blood can be returned to you. When the procedure is completed you will be disconnected from the apheresis machine and the stem cells will be sent to our laboratory for freezing and storage. You may have several collection procedures done over several days. You will be told to discontinue the growth factor injections (Neupogen® shots) after enough stem cells have been collected.

Your Transplant Nurse Coordinator will let you know when adequate stem cells have been collected. If more stem cells are needed, your BMT physician may prescribe a second mobilization with additional medications or a bone marrow harvest. When there are enough stem cells collected, you are ready for your stem cell transplant!

### **What is a Bone Marrow Harvest?**

Your BMT physician may recommend a *bone marrow harvest* to collect the stem cells.

In preparation for the bone marrow harvest, you will complete a health history screening questionnaire and have a physical examination performed by one of the BMT medical faculty such as physician, physician's assistant or nurse practitioner. You will have blood work drawn, a chest X-ray performed and an electrocardiogram (ECG) done on the same day. You will be educated about the bone marrow harvest and sign a consent form. Once this is all completed the bone marrow harvest will be scheduled.

### **The Harvest Day**

On the day of the harvest, you will have to come to the hospital early in the morning. **You may not eat or drink after midnight.** After changing into a patient gown, you will be escorted to an area immediately outside the operating room. If you do not have a central line, an intravenous line (IV) will be placed into a vein in the hand or forearm by a member of the medical team. This is how medications are given for the procedure. After you are asleep, you will be placed onto your stomach and the procedure will begin. (For pediatric donors, their IV may be placed after they are asleep).

### **The Procedure**

Once you are asleep, the bone marrow is collected by inserting a special needle into the hip bone, attaching a syringe to the needle and pulling the liquid marrow into the syringe. This is repeated until the required amount of bone marrow is collected. Approximately one to two quarts of bone marrow is needed for an average size adult.

When the collection is complete, you will have a bandage applied to the area and the anesthesia is stopped. You will wake within a few minutes but may be sleepy for a while. You will be discharged approximately 3-4 hours after the procedure.

The bone marrow is taken to the HPC and processed.

You should plan on resting the next day. After a bone marrow harvest most people feel well enough to resume normal activities within the next several days.

### **The Transplant**

The actual transplant phase requires you to be admitted to the hospital. Your transplant team will keep you informed of potential dates.

Chemotherapy may be given alone or used in combination with radiation therapy. This treatment will last for several days and is called a *preparatory* or *conditioning regimen*. (Please read “What to expect during Chemotherapy” on page 55 and “What to expect during Radiation Therapy” on page 56).

Your transplant (stem cell infusion) will usually take place 1-2 days after your conditioning has completed. This will depend on your particular treatment plan or clinical trial, if you are participating in one.

### **Day 0**

From this point on, your days will be referred to by numbers. The day of your transplant (stem cell infusion) is Day 0.

The transplant is done in your hospital room. The stem cells, which look like blood, are given back to you through your central line catheter. A lab technician will thaw the stem cells, one bag at a time, in a warm bath and then place the stem cells in a syringe. Your stem cells will be infused into your central catheter. This procedure is repeated several times until all the stem cells have been infused. Sometimes this can take less than an hour. This is your transplant!

A nurse will take your vital signs often and be with you throughout the infusion. The stem cells are frozen with a special solution called DMSO. This helps to preserve the cells and make sure they are not harmed during the freezing process. This solution has a garlic-like odor that you may smell or taste during the infusion. Peppermint candy may help you tolerate the taste.

### **The Waiting Begins**

After the stem cells are given to you, they circulate in your blood vessels and then settle back in the bone marrow space where they begin to grow. This is

called *engraftment*. On average, it takes seven (7) to fourteen (14) days for your new bone marrow to engraft or to begin making new stem cells. During this time, you may need red blood cell and platelet transfusions until your new bone marrow produces enough new cells.

While your white blood cell count is below normal, you will be at increased risk for infections. You will be monitored very closely and be treated with medications to help prevent infection. It is very important to tell the nurse or doctor if you notice any changes in your body. If you have a fever or any other sign of an infection, additional antibiotics will be ordered. You will remain on antibiotics until your white blood cell count returns to normal and all signs of infection, if applicable, are gone.

### **When will I be discharged?**

From the time you are admitted to the Bone Marrow Transplant Unit, you will wonder when you will be discharged. The length of stay varies for each patient. The following goals must be met before you will be discharged:

- ✓ Adequate blood count recovery
- ✓ Drinking 2 liters of fluid/water a day and able to eat small amounts of food
- ✓ Can tolerate pills without vomiting
- ✓ No infections
- ✓ Enough strength to do basic daily activities
- ✓ Can take care of your central line catheter
- ✓ Caregiver 24/7
- ✓ Discharge teaching completed

Upon discharge, you will initially be seen in our clinic frequently, usually 2-3 times each week. During your clinic visits, blood will be drawn, and your fluid and nutritional needs will be assessed. You will be taking medications after discharge that you may have never taken before. It is important to maintain the schedule you were given when you were discharged. If you have any questions or concerns, please inform your doctor or call the BMT Clinic.

### **What can I expect when I come to the Outpatient Clinic?**

Patients who had an *autologous* transplant will be evaluated by a physician extender (physician assistant or nurse practitioner) in the outpatient clinic at least twice a week for one to two weeks after their hospital discharge. The follow-up time can vary for each patient and is re-evaluated during each visit.

You will have a nurse appointment prior to your appointment with the doctor or physician extender to allow time for the lab results to be processed and available for review during your appointment.

Please notify the clinic receptionist when you arrive and have a seat in the BMT waiting area.

**Wear your mask at all times while on the hospital property, especially in the elevators, walking outside and in the waiting areas.** The BMT Team will let you know when mask precautions can be discontinued.

If you are feeling too sick to sit in the waiting room, please tell the clinic receptionist right away and the clinic nurses will be notified.

Please bring all of your current medications with you to each clinic visit. Bring the medication bottles and not just a written list.

Be aware of any medications that need to be refilled and tell the physician extender during the clinic visit. Please note that most pain medications cannot be called into the pharmacy under any circumstances - it's the law. Therefore, pay special attention to when these refills are needed.

It's easy to forget your questions during your clinic visit. You can use this notebook or a journal to write down any questions that that you may have

Many clinic visits can turn into long days, especially if you need IV fluids or transfusions. Please be prepared and bring your daily medications, reading materials and snack foods.

Our BMT social worker is available during clinic hours. Please let us know if you need the social worker to stop in and see you.

Once you are discharged from the clinic to your home, your local referring physician will be given a copy of your transplant records. Follow-up visits with the Bone Marrow Transplant Team will be scheduled as needed. After your return home, your local physician who referred you to us will resume responsibility as your primary physician.

## Section 4: Life as an Inpatient

### Bone Marrow Transplant Unit Mission Statement

Our mission is to provide the best quality care to our patients and their families. We provide treatment to both children and adults undergoing bone marrow transplant for solid tumors, hematologic malignancies, genetic disorders and disorders of the bone marrow. We work as a multidisciplinary team to provide holistic care to meet the patient's physical, psychosocial, emotional, spiritual and educational needs.

Our goal is to provide safe, effective patient care. To that end, we have created standards and procedures specific to Bone Marrow Transplant to guide our care. These include chemotherapy and drug administration guidelines, blood product administration policies, infection control practices, bone marrow/stem cell infusion guidelines and teaching plans. Our care follows the policies and mission of UNC Healthcare, the guidelines of the Nurse Practice Act by the NC State Board of Nursing and the laws of the State of North Carolina.

We strive to promote patient/family involvement in their care and increase their independence through comprehensive teaching during all stages of the bone marrow transplant process. We encourage professional development through mentorship, in-services and literature reviews. By participating in and conducting medical/nursing research, we seek to enhance our expertise in the field of bone marrow transplant nursing.

### Meet the members of our Inpatient Team

**Attending Physician:** The attending physician is one of the bone marrow transplant doctors. This is the doctor who will treat you when you are in the hospital and manage the team who will be caring for you during this visit. Adult patients are treated by an adult BMT doctor, and pediatric patients are treated by a pediatric BMT doctor. These doctors work exclusively with the BMT Program. The attending physician cares for the patients at the bedside on a rotating schedule. The doctor you see for your transplant consultation may or may not be the doctor who is the attending physician when you are in the hospital, but all of our transplant physicians are involved in your care. The attending physician may also switch while you are in the hospital. Each attending physician will be aware of you and your particular situation in order to give you the best care possible.

**Oncology Fellow:** Fellows are licensed physicians who have completed training as a specialist in Internal Medicine or Pediatrics and who are now

doing training in oncology. They work closely with the BMT attending physician in managing your care. They are not medical students or residents.

**Physician Assistant:** The physician assistants (or PA's as they are commonly referred to) are certified professionals who help manage your medical care in consultation with your primary BMT physician. They are called physician extenders.

**Nurse Practitioner:** The nurse practitioners are also certified professionals who are physician extenders. He or she works with your physician to help manage your medical care.

**Pharmacist:** The pharmacist accompanies the team and assists with specific medication questions and/or problems. The pharmacist will meet with you at different times during your transplant and before you are discharged to review all your medications.

**Nurses:** Each day while inpatient, you will be assigned a primary nurse who may accompany the team on morning rounds. During the day you may also see several other nurses who will assist with your care. In the outpatient setting, you will also have team of nurses who will take care of you while you are in the clinic. This includes taking vital signs and weights, drawing blood for labs or obtaining other specimens, and administering IV fluids, blood products or other IV medications and chemotherapy.

**Social Worker:** You and your family will meet with a social worker before, during and after your transplant. The social worker will provide support during your in-patient stay as well as your transition to the outpatient setting. The social worker you meet initially may or may not be the social worker who will assist you during your inpatient and outpatient stay after the transplant, but they all work together. A family support group meets weekly to assist family, friends and caregivers with their questions or concerns. A Caregiver Dinner is also available weekly.

**Chaplain:** The BMT service has a dedicated hospital chaplain who provides spiritual and emotional support to patients and families. A hospital chaplain is available for all religions. Visits can be arranged by request. If you prefer to not be visited by a chaplain, that is acceptable as well. A Spirituality Group meets weekly.

**Nursing Assistant:** A nursing assistant will help the inpatient nurses with their duties. They assist with vital signs, daily weights and recording input and output. They will help you with your shower/daily care if you need it. The nursing assistant also changes bed linen daily and performs many other tasks.

**Unit Clerk:** Our unit clerk is key in helping our inpatient unit run smoothly. The unit clerk answers the phones, orders supplies and maintains the daily operations of the unit. The clerk may also answer your call light and let the nurse know what you need.

**Nutrition Services:** The hospital dietician follows your nutritional needs and meets with you as needed. They can also make special dietary arrangements as needed or requested. Individual counseling is available.

**Recreational Therapy:** The recreation therapist will talk to you about the importance of regular and consistent physical activity throughout your hospital stay and help you to set up a daily routine. They will share coping techniques and strategies to use during your treatment process while providing education and resources needed to achieve your goals. A scheduled Wellness group will meet several times during the week. The focus of the group varies and may include stretching, relaxation techniques, games or walking. The group size also varies and offers the perfect opportunity for social interaction with other patients. There are also incentive plans (i.e. Healthy Heels) that encourage activity and allow you to earn points that can be traded for prizes at discharge.

**Volunteers:** Specially trained volunteers are part of our “BMT Buddy Program”. This program offers the opportunity to experience a one to one interaction with a volunteer that will be available during your transplant process. They are available to come to your room and visit. While they cannot replace your primary caregiver, they can provide additional social support. They can assist you with laundry, errands and groceries. A referral can be made to start this process prior to admission and can continue through discharge. Please let your transplant coordinator know if you would like to begin this referral.

If you prefer an occasional volunteer visit, let your nurse know and a visit can be arranged. A hospital volunteer can play games, share conversations or read to you. A massage therapist volunteers as well and appointments can be made by the recreational therapist.

**Interpreter Services:** UNC will provide an interpreter service for non-English or limited English-speaking patients and donors. Your transplant coordinator or social worker will help you arrange for this service.

### **BMT Unit Routines**

**Vital Signs:** Temperature, pulse, respiration, pulse oximeter and blood pressure measurements are done every 4 hours while inpatient, including

during the night. They may be done more frequently at special times, such as during blood product transfusions.



**Weight:** Taken at least once a day for adults and twice a day for pediatrics. Careful and consistent monitoring of your weight will help evaluate your fluid status. For consistency **always** weigh yourself with either with your shoes on, or your shoes off (preference: shoes off).



**Input and Output:** The amount of food and liquids you take in each day will be strictly recorded. Your urine, stool and emesis (vomit) will also be measured. **Please do not flush these fluids, the nurse will measure it and do it for you.**

**Labs:** We use your catheter for most blood samples. Blood is collected from your catheter daily after midnight. We collect samples at this time so results are available for the BMT team during morning rounds. If you require a blood or platelet transfusion, this may also be started during the night. Often additional blood samples are taken during the day. You may also be asked to give us urine and stool samples.

**Chest X-Ray (CXR)/ Electrocardiogram (EKG):** For adults, these tests are usually done on the day of hospital admission and may be repeated during your stay in the hospital.

**Intercom:** The nurses may often talk with you or answer your call button with the intercom. This reduces traffic in and out of your room. Both the nurse and the patient need to speak slowly and clearly to be understood.

**Nursing Report:** (change of shift report) this occurs from 7am-8am and 7pm-8pm. Please ask questions and make requests of staff before or after this time if possible. This will allow the nursing staff to finish their report efficiently. Also, please ask friends and family to avoid calling the nursing station during this time. There are signs in each patient's room requesting they stay in their rooms during this time for purposes of confidentiality.

**BMT Team Rounds:** The team rounds on patients once or twice daily on weekdays, and once in the morning on the weekends. The doctors and nurses will listen to your heart and lungs, feel your abdomen and look in your mouth each morning. Rounds are your best chance to ask questions (write notes to help you remember questions). Rounds can include anyone involved in your care.

### What do I bring to the BMT Unit?

You will be assigned to your room for 2-6 weeks depending upon the type of transplant you have. Because of special filters, you will be allowed to walk in the hallway wearing a light surgical mask within the BMTU. You must remain on the unit at all times. If you leave the BMTU for a procedure or test, you will need to wear a special mask to protect you from exposure to infections.

You are allowed to have visitors in your room, usually two to three in addition to your caregiver. **Only one caregiver can spend the night with you but they must be 18 years of age or older. They are not allowed to use your toilet.** Visitors must use toilets in the family waiting area in order to protect you. Visiting hours are usually 9am-9pm.

There is a flat screen television and DVD player in each room so that you may watch movies. There is a Wii Game System in your room as well so that you can play virtual games such as bowling, tennis and other sports to help keep you active. There are things you can bring with you to reduce the boredom during isolation. It may be helpful to know that you might have a very short attention span during this time. Some suggestions on how you can keep things interesting are as follows:

Phone/Answering machine	There is a phone in every room, which can be connected to your own answering machine. You may want to change your message with updates on your progress so you can receive messages from your family and friends without answering all your calls. Some patients recommend bringing your own phone/answering machine.
Radio/CD Player	There is a radio/CD player in every room. They also have a “Nature Sounds” option so you can listen to the ocean, rain or other relaxing sounds. Music may help you make

	the time go faster.
DVD's	Each patient room is furnished with a DVD player and TV. You may bring DVDs with you. The unit has a video library as well.
Handwork	Avoid projects that require sharp tools, such as needles or knives. Yarns and threads should be new.
Models & Puzzles	Bring only new ones please!
Art Projects	Bring only new paint, pencils, markers and paper.
Books & Magazines	New and clean. Hospital volunteers can deliver the newspaper every day, just ask.
Cards & Games	Clean and fairly new.
Journal & Stationary	You may bring your own stationary and stamps, although your writing may be shaky during this time.
Computer	There is a free wireless connection available for your laptop computer. If you don't have a laptop computer, we have a limited number that can be shared. There are also computers available in the patient lounge and family lounge(not for patients).
Computer games	You may bring a Nintendo, Playstation, X Box, or Gameboy from home. We have an X Box in our recreation room and several Wii games and accessories that can be signed out through the recreational therapist.

**Clothes:**



The clothes you bring into your room while a patient on the BMTU must be

- Freshly laundered
- Dried in a hot dryer
- Transported from home in clean or gently used suitcases / duffle bags. You can also use clean plastic bags or plastic tubs with lids to keep them clean. You may feel comfortable in your own clothes and do not have to wear a hospital gown. During your hospitalization, clothes may

get soiled or stained, so please bring only clothes that can be cleaned or replaced. Your caregiver is responsible for your laundry while you are in the unit. There is a washer and dryer available for your caregiver to use. Laundry soap is available for everyone’s use unless you’d prefer to bring your own.

We suggest bringing:

Comfortable Pajamas	Preferably ones that open up in the front to accommodate the care of your catheter
Bathrobe, Sweatpants, T-Shirts	The looser and baggier, the better
Scarves/turbans/hats	Hats and turbans are helpful to keep your head warm
Undergarments	Cotton only
Sneakers/tennis shoes	For exercise

**Personal Hygiene Notes:**

- ✓ Shower daily.
- ✓ Lotions and soaps are provided on the BMT unit.
- ✓ Please have toenails and fingernails cut short and straight before admission as only a nail file may be used after you are admitted.
- ✓ Liquid make-up and powders are discouraged, as your skin will be very sensitive and prone to rashes. However, a little lipstick may lift your spirits. If you need to use make-up, it must be new and unopened. We recommend hypoallergenic products. Avoid Carmex™, Blistex™, and products with PABA.
- ✓ We will provide you with special “toothettes” for mouth care. Toothbrushes and dental tape are restricted/allowed based on your platelet count. (Dental floss is never allowed) You will need to check with your nurse prior to using either.
- ✓ If you wear dentures, bring a new denture brush, denture container and denture cleaner (tablet type, not tube).
- ✓ Only electric razors may be used if necessary.
- ✓ Do not wear pierced earrings, acrylic nails, or nail polish.
- ✓ Do not wear contact lenses. Make sure to bring your glasses with you.
- ✓ Please do not wear jewelry, especially rings; your hands may become swollen during this time. These items are much safer if they are left at home!



### Miscellaneous:

- ❖ Bring pictures, posters, photos, etc., to help you feel more at home.
- ❖ A nice non-feather pillow or favorite blanket can help make the room more comfortable. Like the clothes described above, blankets will need to be washed, dried, and placed in a plastic bag during transport. Pillows should be new!
- ❖ If you want to bring things that are not listed, please ask your Transplant Coordinator or the BMTU Nurses if they're allowed.
- ❖ Upon request, special dietary needs will be arranged by the dietician.
- ❖ Fresh or dried flowers/plants are not allowed in the room or on the unit. Silk flowers and balloons are fine.
- ❖ Certain foods can be brought in and kept in your room. We have a microwave available for use. Fresh fruits or vegetables will be allowed while you are in the hospital as long as they are provided by UNC Nutrition Services. **Fresh fruits and vegetables are not allowed to be brought in from home.** You may bring in processed food in single portions. You will have a small refrigerator in your room to store special drinks, individual servings of pudding, Jell-O, popsicles, etc. All items should be single servings. A Patient Nourishment Room is available where you or your caregiver can get a cup of coffee, hot chocolate or use the microwave.
- ❖ Beverages are allowed, including drink boxes, single serving cans or juices. All beverages must be processed or pasteurized. Many people prefer to bring their own individual bottled water to drink. Drinks containing caffeine are discouraged but this can be discussed with the BMT Physician.
- ❖ Do NOT keep money or valuables in your room.

### Decorate your room to make you feel happy!



### Visitor Guidelines

The Bone Marrow Transplant Staff encourages your family and friends to visit. Children under 12 years of age may visit but your nurse or physician must be notified in advance. Children cannot have received any live virus vaccinations (such as the flu mist or chicken pox vaccine) within the previous eight (8) weeks. In addition, military personnel who visit cannot have received a small pox vaccine within the previous eight (8) weeks. Children under the age of 2 are not allowed on the unit.

All visitors, including children, must check in with the nursing staff before each visit. Please report to the nurse **any** recent immunizations received by a visitor, or if they have recently traveled outside of the United States. The nursing staff will screen visitors for any contagious conditions such as a fever, cough, cold, sore throat, runny nose, skin rash or other respiratory symptoms.

We allow two to three (2-3) visitors at a time in addition to your caregiver.

One adult (18 years or older) may stay overnight with you during your hospitalization. Your overnight visitor must sleep in a separate day bed and is not allowed to use your toilet (your nurse can direct your visitor to toilets in the Family Waiting Area). A shower may be taken by an overnight visitor but only after you have showered first.

All visitors must be free of any symptoms of a contagious illness.

To ensure the health of each patient, the medical or nursing staff may revise the above visitor guidelines as needed.

All visitors must request access to the BMTU by picking up the phone outside of the entrance on the fourth (4<sup>th</sup>) floor and saying who you are there to see. All visitors must perform a 15 second hand scrub once inside the Family Waiting Area before entering the BMTU. There are two sinks for the hand scrub in the Family Waiting Area and outside the patient room entrances once inside the unit. The Nursing Staff will be happy to assist you if you have any questions.

We ask that all visitors be aware of and abide by the following visitation rules:

**General visiting hours are between 9:00 AM and 9:00 PM.**

**Family members are encouraged to be in the room during morning rounds.** This will give your family the opportunity to be updated on your progress and to ask questions.

**Family members should leave a correct phone number on file at the nursing station for emergency use.** Also, your family may call the nursing station for updates on your care. It is best if one family member calls to get reports on your care and then shares the information with other family members.

**Identify one family member as your spokesperson.** This helps the staff so that they can refer to your spokesperson with any questions or calls from friends and relatives who ask about your condition. Let the staff know if there are people with whom you do **not** wish to visit.

**Remember: Tell your nurse when you are too tired to handle visitors and visitors will be limited.**



### **Infection Control on the Bone Marrow Transplant Unit**

#### **Hand Hygiene:**

**Hand Hygiene or hand washing is the single most effective way patients (and caregivers/visitors) can stop the spread of germs and infection.**

Healthcare personnel, patients, caregivers and visitors **MUST** wash their hands each time before entering or leaving the patient room. Visitors will be instructed to wash hands before entering the Bone Marrow Unit. The nurses will teach you and your visitors how to properly wash your hands. As a patient you should clean your hands often, especially after using the bathroom and before eating. It is best to use soap and water if possible in these situations.

#### **Vancomycin Resistant Enterococcus (VRE):**

Prior to and/or upon admission to the Bone Marrow Transplant Unit you will be tested to see if you are colonized with a germ called Vancomycin Resistant Enterococcus in your gut. This test is performed by your nurse who will obtain a rectal swab to be sent to lab.

#### **What is VRE?**

Enterococcus is a germ normally found in the intestines. Vancomycin Resistant Enterococcus or VRE means this germ is resistant to the antibiotic vancomycin. VRE may cause infection anywhere in the body. However, some people can be colonized with VRE. Colonization with VRE means it is present in the body without signs of infection. Even if someone is just colonized VRE can still spread to other vulnerable people.

#### **How is VRE spread?**

VRE is spread from person to person by soiled hands and from contact with soiled objects in the environment.

### **What if I am positive for VRE?**

If you are found to have a positive VRE screen you will be placed on **Contact Precautions** for the duration of your hospitalization and subsequent hospitalizations.

- A sign will be placed at the door and all healthcare workers who enter your room are required to wear a disposable gown and gloves. Upon leaving the room they will remove and discard the glove and gowns. It is important to note that gowns and gloves are discarded in the patient's room.
- You will be allowed to walk outside your room for therapy with a healthcare worker but you must wear a clean yellow gown and gloves in order to protect other patients. You should not go into common areas.
- Healthcare workers, caregivers and visitors must wash hands with soap and water or an alcohol based hand rub before entering the room and upon leaving.
- If you don't see your healthcare workers, caregivers or visitors clean their hands speak up and ask them to do so before they touch you or your environment.

### **Clostridium Difficile (C.diff):**

#### **What is Clostridium difficile?**

C. difficile is a germ that may be found in the intestines of healthy people but it can cause infection of the intestinal tract. Sometimes this occurs during or after taking antibiotics because the antibiotics destroy many of the "good" bacteria normally present in the bowel and allow the C. difficile to grow out of control. Symptoms of infection can range from mild diarrhea to severe inflammation of the intestine.

#### **How is Clostridium difficile spread?**

C. difficile can be spread from person to person by hands or from contact with objects in the environment. Alcohol based hand rubs such as Purell are **not** effective against C.diff so hand hygiene must be performed with **soap and water**.

#### **What If I am found to have C.diff?**

If you are found to have C.diff you will be placed on **Enteric Contact Precautions** until you have finished treatment and are free of symptoms. You will be treated for the infection by your Health Care Provider.

- While on Enteric Contact Precautions you will not be allowed outside your room to protect other patients.

- A sign will be placed at the door and all healthcare workers **AND** visitors who enter your room are required to wear a disposable gown and gloves. Upon leaving the room they will remove and discard the glove and gowns and discard before exiting the patient's room.
- Healthcare workers, caregivers and visitors must wash hands with **soap and water** before entering the room and upon leaving.
- If you don't see your healthcare workers, caregivers or visitors clean their hands speak up and ask them to do so before they touch you or your environment.

There are other germs that require patient to be placed on Contact Precautions such as MRSA or other antibiotic resistant germs. If you are found to have one these, your Health Care Provider will explain this to you.



**UNC is a Smoke-Free Facility**

In 2007, UNC joined its neighboring hospitals to convert to a 100% smoke-free environment. **NO SMOKING IS ALLOWED anywhere in or on UNC Hospital grounds.**

**Your BMT nurse is always glad to help!** Please use the “nurse call button” on the side of the bed rail for any assistance you need. Family members should not touch the infusion pumps or try to correct pump alarms. Visitors should not give medications to a patient without permission from the nurse. A strict recording of the patient's intake and output is very important. Therefore, visitors shouldn't empty urinals or emesis basins before the nurse can record the amount of fluid. If you give the patient water to drink, it is important to record how much fluid the patient drank.

## Section 5: How do I care for myself when I am an Inpatient?

The doctors and nurses will take care of you during your hospital stay; but you can also help yourself in your recovery. Please be aware that UNC Health Care employs both male and female nurses and assistants so you may have both helping you with your daily care, linen changes and vital signs. The following information is a self-care guide to follow.

### Preventing Infections

Decreasing the risk of infection is very important during your treatment. The treatment will cause your white blood cells to be very low. This puts you at risk for developing an infection. Therefore, we need your help and that of your visitors to follow these guidelines:

- You must wear a mask every time you leave your room. The Bone Marrow Transplant Unit has a special air handling system that will allow you to walk in the hallways with your mask on. However, you are not allowed to exit the BMTU unless you are going for a test and taken by a member of the transport team.
- Your door must be closed at all times so the special air-filtering system can work.
- If you leave the room for any other reason, you must wash your hands when you return.
- No fresh or dried flowers/plants are allowed on the unit or in your room. (Silk flowers and plants are allowed).
- No fresh fruits and vegetables are allowed unless delivered by the hospital's nutritional services.
- Practice careful daily hygiene (bathing, mouth care, hand washing).
- Stay active. Use the exercise bicycle or treadmill in the patient lounge as much as possible.

Walking in the hallway will give you a change of scenery as well as exercise. Use the incentive spirometer or 'blow bottle' (to help your lungs) at least 3-4 times per day.

### Mouth Care

Chemotherapy and radiation therapy very likely may cause breakdown of the mucous membranes that line your mouth. Frequent and complete mouth care will help to prevent infection, lessen discomfort and promote healing. Mouth care should be done every two hours while you are awake. Details will be given to you in the hospital. Toothettes will be used when you have *mucositis* and low platelet counts. (Toothbrushes and dental tape will not be allowed while your platelet count is low and dental floss is never allowed).

## **Skin Care**

You must shower daily. Wash skin folds, armpits, genital area and rectal area carefully and dry thoroughly. Use lotion on a daily basis to prevent dry skin caused by radiation and chemotherapy. The unit will provide you with the appropriate skin lotions. For those patients receiving radiation, no lotions will be allowed on your skin before treatment. Your nurses can help you decide when it's safe to use lotions for dry skin. Cut your finger nails and toe nails before you come to the hospital. They will not be cut again until your blood counts return to normal. It is common for fingernails and toenails to become cracked. You will notice new nail growth underneath the old ones.

Hair loss is also an expected side effect from the treatment. The treatment affects all body hair; therefore, your hair loss may not just be on your head. Other areas of hair loss may include underarms, pubic area, legs, eyebrows, eyelashes and facial hair. The areas of hair loss will vary with each patient. As your hair starts to fall out, the nurses may offer to shave your head. Some patients choose to take control of their hair loss and may elect to cut their hair shorter or shave their head prior to admission. Hats, wigs, scarves, hair-pieces or turbans may be a short term alternative and are available in the Cancer Resource Center in the lobby of the North Carolina Cancer Hospital.

## **Activity**

Physical activity is very important during your treatment. It helps maintain your muscle strength, flexibility and mass. Inactivity and bed rest will decrease your physical strength and stamina. The Recreational Therapist will develop an exercise program for you and if more intensive therapy is needed, a Physical Therapist will be assigned. It is important to establish an exercise regimen as soon as you are admitted and stick to it on a daily basis. You may be asked to use an exercise bicycle or treadmill and may even be given small weights. Be sure to bring sneakers or tennis shoes with you while using the exercise equipment. It is important to have stable footing during this activity. (Please see the Physical Therapy section for a list of exercises you can do before, during and after transplant.)

## **Distraction**

Staying busy can be a challenge. Plan on bringing some projects or activities that help occupy your time, because there will be some days that you may feel bored. Many patients email (Internet access is available in all rooms), read, watch TV or movies, do arts and crafts, write their feeling in a journal, and exercise. Our Recreational Therapist will meet you on admission and

help plan activities with you. Try and think of something you have always wanted to do but never had time for- use this time to do something positive.

### **School**

For our pediatric patients, school will be a part of their day. A hospital school teacher will visit your child's room and continue their studies based upon the information that has been discussed and received from your child's school. It is important to continue studies as much as possible while in the hospital. This helps pass the time and provides structure in your child's day.



### **Take Control**

Work with your nurse to make out a daily schedule that fits your needs. Hang it on the wall for all to see. This will help you achieve your daily goals and give you more control on how you want to spend your day.

### **Example of a Daily Schedule**

8am:	Breakfast, mouth care, incentive spirometry
9am:	Shower, central line dressing change, visiting hours begin
10am:	Walk around BMTU once with mask on
11am:	Ride bicycle, work with Recreational or Physical Therapist
Noon:	Lunch, mouth care, incentive spirometry
1pm:	Arts and Crafts with Recreational Therapist, school time or play the Wii
2pm:	Nap- private time!
4pm:	Walk around the BMTU once with mask on, visit with family/friends
5pm:	Dinner, mouth care, incentive spirometry
7pm:	Read, watch a movie, call friends, play computer games or Wii
9pm:	Walk around the BMTU once last time, mouth care, use incentive spirometry, end of visiting hours, get ready for bed
10pm:	Bed time!

\*Please remember that the BMT Physician and team will round in the morning to examine you and provide your medical plan for the day.

**Research has proven that patients who take an active part in their care and daily routines tolerate the transplant better and recover more quickly**

### **Exercising before, During and After your Transplant**

Regular exercise both before and after your transplant will help keep the important systems of your body working so you can be independent with your lifestyle. Physical therapy (PT) and Occupational Therapy (OT) will evaluate your muscle strength and endurance, cardiopulmonary fitness, balance and walking ability, and your activities of daily living (eating, dressing, energy conservation). In children, PT and OT will evaluate muscle function to establish goals and a plan of treatment to progress a child's normal functional development. It is very important that a child develops his/her walking, playing and self care skills on schedule so he/she will have a good chance at a normal, independent adult lifestyle.

Your Doctor, Physician Extender, Nurse, OT, PT and Recreational Therapist work as a team and will use certain guidelines to determine your activity levels every day. Some of the important guidelines/lab values are your *platelet* and *hemoglobin/hematocrit* levels. Your team will monitor these values to determine the appropriate activity and exercise level for you.

There are different ways for you and your therapist to monitor your exercise tolerance while you exercise. Your therapist may teach you a technique from the list below that will be best for you:

**Monitoring your pulse rate:** Feeling your pulse at your wrist (called your 'radial pulse') before you exercise and immediately after you stop to compare the difference

**The Talk test:** Comparing your ability to talk during exercise to normal talking at rest

**Perceived Exertion Scale:** Rating how you feel during exercise with a number

Your therapists will prescribe specific types of exercise for you based on your evaluation. Some examples of exercises are included in the next few pages. Some general categories of exercises include: passive and active range of motion exercises, muscle strengthening, endurance exercises, balance/coordination and walking exercises, and energy conservation techniques.

You may also need some assistive or adaptive equipment such as a cane, walker, or wheelchair. Your therapist will evaluate, prescribe and help make sure you have any equipment you may need.

Before you are discharged from the hospital, your therapists will discuss any follow-up occupational or physical therapy you may need. The goals that you and your therapists made following your initial evaluation should have been met before you are discharged. Even if your original goals are met, you may need to decide on some new goals and treatment to reach your final goal of functional independence. Then, you will continue therapy as an outpatient. Your therapists will help you to determine the appropriate intensity and frequency of outpatient therapy you need to achieve your goals.

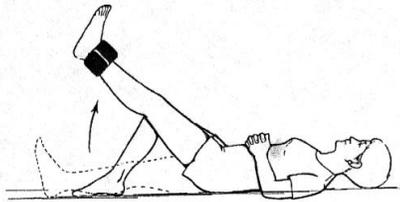
If you have any questions about any part of your occupation or physical therapy treatment, don't hesitate to ask your therapists. We are here to help guide you back to independent function.

On the next page are the exercises promised, and we have included an exercise chart so you can record your progress when you exercise independently...so let's get started!!!

OT/PT  
 UNC Hospitals  
 101 Manning Drive  
 Chapel Hill, North Carolina 27514  
 Phone: (919) 966-2056  
 FAX: (919) 966-0348

OT/PT

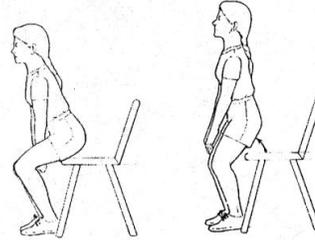
January 12, 2000  
 Exercises for BMT EXERCISE  
 PROGRAM BMT EXERCISE  
 If you have any questions,  
 please contact us.



Exercise 1 of 10

**STRAIGHT LEG RAISE**

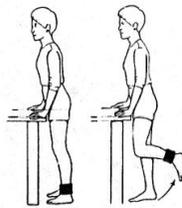
1. Lie on back with \_\_\_\_\_ knee straight and the other knee bent as shown
2. Place a \_\_\_\_\_ lb weight around your ankle
3. Keep the leg completely straight, then raise it \_\_\_\_\_ inches
4. Hold \_\_\_\_\_ seconds and slowly lower
5. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 2 of 10

**QUADRICEPS/EXTENSION**

1. Sit on edge of chair, feet flat on floor
2. Stand upright
3. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 3 of 10

**HAMSTRING/FLEXION**

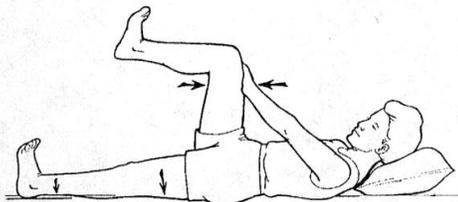
1. Stand holding onto solid object as shown
2. Place \_\_\_\_\_ lb weight on \_\_\_\_\_ ankle
3. Slowly bend knee
4. Hold \_\_\_\_\_ seconds and slowly lower
5. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 4 of 10

**HIP FLEXION**

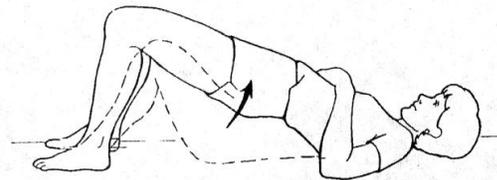
1. Stand with legs straight
2. Bend \_\_\_\_\_ knee and hip upward as shown
3. Hold \_\_\_\_\_ seconds, slowly relax
4. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 5 of 10

**HIP FLEXION/EXTENSION**

1. Lie on back
2. Bend \_\_\_\_\_ hip and knee, lifting leg off floor
3. Place hand on thigh as shown
4. Try to bend hip toward hand, but resist the motion with your hand
5. At the same time, press downward with your opposite leg
6. Hold \_\_\_\_\_ seconds, slowly relax
7. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 6 of 10

**HIP EXTENSION**

1. Lie on back with both legs bent as shown
2. Tighten buttocks and raise them off floor as high as you can
3. Hold \_\_\_\_\_ seconds, slowly relax
4. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day

OT/PT



Exercise 7 of 10

**HIP EXTENSION**

1. Stand with feet slightly apart
2. Lift \_\_\_\_\_ leg backward as shown
3. Hold \_\_\_\_\_ seconds, slowly relax
4. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 8 of 10

**HIP ABDUCTION**

1. Place \_\_\_\_\_ lb cuff weight around \_\_\_\_\_ ankle
2. Lie on side with \_\_\_\_\_ leg on top
3. Bend lower leg slightly
4. Raise top leg straight up, without letting it come forward
5. Hold \_\_\_\_\_ seconds, slowly relax
6. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 9 of 10

**PLANTAR FLEXION - TOE RAISES**

1. Stand with feet 12 inches apart
2. Raise up slowly onto your toes as high as you can
3. Hold \_\_\_\_\_ seconds
4. \_\_\_\_\_ repetitions, \_\_\_\_\_ times per day



Exercise 10 of 10

**DORSIFLEXION**

1. Sit on floor with towel or strap around \_\_\_\_\_ foot as shown
2. Pull top of foot toward your body so that you feel a stretch
3. Hold \_\_\_\_\_ seconds, repeat \_\_\_\_\_ times

## How will a Recreational Therapist Help Me?

After receiving a physician's referral, a Recreational Therapist (RT) will meet with you shortly after your admission and will work with you throughout your hospital stay. He/she will complete an assessment to determine your specific treatment needs. You and your family will collaborate with the Recreational Therapist to develop a plan and goals. The role of the Recreational Therapist is to provide you with the skills and resources needed to increase/maintain your functional abilities and promote your independence, and assist with coping throughout the treatment process.

Some of the interventions offered by RT services include:

- Development of individual exercise plan and coaching to reach desired goals.



- Teaching coping strategies to assist with management of anxiety, isolation, hospitalization, etc.
- Teaching specific relaxation training skills (i.e. diaphragmatic breathing, guided imagery, and progressive muscle relaxation) to help with management of pain, anxiety, etc.



- Wellness groups (these groups typically consist of light stretching exercises, coping skills training, and an opportunity to engage with other BMT patients for social support).

## Section 6: Therapies

### What to Expect During Chemotherapy

Before your transplant, you will receive chemotherapy to wipe out your marrow and allow the newly transplanted cells to be better accepted by your body. You may have been treated with chemotherapy before, but the doses you will receive as part of transplant are much higher doses. Depending on which protocol you are on, you will receive certain chemotherapies over a specified number of days. During these days several things will happen:

Your nurse will be with you frequently to monitor you for any side effects that could occur so that the proper medications can be given to help make you feel better.

You will be given IV fluids to help keep you hydrated and to help protect your body from the effects of the chemotherapy drugs. This may cause you to gain some weight and feel puffy. You may also have to use the bathroom more than normal. The extra fluid in your body will come off over a few days once the chemotherapy is over.



*Captain Chemo defeats Crabby Cancer!*



There will be equipment in your room such as an IV pump and a vital sign machine. Occasionally you will be connected to a monitor during your chemotherapy infusion to measure your heart rate, pulse, and pulse oximeter (the amount of oxygen circulating in your blood). These monitors commonly make a beeping sound so do not be alarmed when you hear these noises.

Each person reacts differently to the chemotherapy; however the most common side effects are nausea and vomiting. There are some medications that can be given to reduce the nausea you experience, but you may still experience some nausea. Also, be aware, that some of these medications will make you drowsy.

Other side effects that you may experience include diarrhea, loss of appetite, a drop in your blood counts, mouth sores, a difference in your taste buds, and hair loss. None of these side effects should be permanent. Although it will take time for your hair to grow back, be assured that hair loss is not permanent; however, it may return a different texture or even a different color.

### **What to expect during Radiation Treatment**

*Radiation Treatment* may be prescribed for you as a part of the conditioning regimen. Your BMT physician will work closely with the *Radiation Oncologist* to determine if you should receive radiation treatment and, if so, how much. There are two main types of radiation that patients receive; total body irradiation, also known as TBI, which delivers a dose of radiation to your whole body, or localized field radiation, which focuses the radiation dose on a specific part of your body. Radiation therapy can damage normal cells as well as cancer cells so treatment must be very carefully planned to minimize side-effects.

The Radiation Oncology Department is located on the Manning level of the North Carolina Cancer Hospital. If radiation is to be part of your treatment plan, you will need to meet with the Radiation Oncologist prior to your admission to the BMTU. Both your BMT Physician and Radiation Oncologist will work together to create your personalized plan of care.

When going for a radiation treatment, it is important to remove all jewelry and remember to wear a mask since you will be leaving the BMTU. Even though you are still going to be within the hospital, it is important to get in the habit of putting on a mask every time you leave the BMTU to protect you from any bacteria that could be floating in the air as people sneeze, cough or blow their noses.

Receiving your radiation treatment is not painful and you will not feel the radiation entering your body. It is just like getting an x-ray. Your family members can accompany you to the Radiation Department, but they will need to wait for you in the waiting room until your treatment is finished. A Radiation Tech will get you set up and positioned correctly. You will be alone in the room while you receive your treatment, but you will be visible over a TV monitor to the Radiation Techs and able to speak to them over an intercom.

It is very important for you to remain still while you receive your treatment, and to help you do this you may need to wear a belt similar to a seat belt that will help to keep you in the proper place. If certain areas of your body need protection from the radiation a shield may be made for you that will be placed over you during your treatment. These shields are not uncomfortable nor do they cause you any pain. They are used for your safety.

The primary side effects of radiation therapy are nausea, loss of appetite, mouth dryness, diarrhea and fatigue. The severity of these side effects will vary with each patient. There are medications that can be given to minimize these effects during and after your treatment. Some side effects that may occur after your treatment are hyperpigmentation (darkening of the skin), increased sensitivity to the sun, infertility, dry mouth and lung changes.

### **Late or Long Term Side Effects from Chemotherapy and radiation Treatments**

- Male or female sterility
- Women may experience an early onset of menopause with symptoms of hot flashes and vaginal dryness (hormone replacement and the use of water soluble lubricants with intercourse may be helpful)
- Thyroid problems may occur and may be corrected with medication
- Development of cataracts that may be surgically corrected
- Dry and sensitive skin (avoid sun exposure and use lots of lotion)
- Hyperpigmentation of the skin (darkening of the skin exposed to radiation)
- Dry mouth
- Lung problems
  - Interstitial Pneumonitis: a lung disease that can be seen up to four months after transplant. It may be a type of allergic reaction to the chemotherapy or radiation treatments or it

may be from an infection that causes inflammation and the lung tissue to fill with fluid.

- Infections
  - Bacterial Infections: can happen in the blood, your IV catheter, lung (pneumonia) or urine. These infections are common problems while your blood counts are low. Most of these infections are successfully treated with IV antibiotics. It is important to try and prevent pneumonia by being active, doing deep breathing exercises and using your *incentive spirometer* (blow bottle).
  - Viral Infections: Herpes Simplex and or Herpes Zoster (shingles) are common in post-transplant patients. Herpes Simplex usually shows up as a “cold sore” on the lips or in the mouth. Herpes Zoster or shingles is related to the Chicken Pox virus and usually shows up as a group of blisters anywhere on the body. There may be burning, itching, pain and a fever. Call the doctor right away if you have any of these symptoms. Starting medications early can prevent serious complications and shorten the symptoms. Many transplant patients are placed on a medicine called Acyclovir or Valtrex to help prevent these viral infections.

### **What to Expect During Bone Marrow or Peripheral Blood Stem Cell (PBSC) Reinfusion**

One or two days after the chemotherapy is completed you will receive your bone marrow or peripheral blood stem cells. You will receive Tylenol™, Benadryl™ and possibly hydrocortisone or an anti-nausea medication before your marrow or PBSC infusion. Eating a very light meal just before the transplant helps to avoid the nausea that can happen during the time of the transplant.

A fresh *bone marrow or peripheral blood stem cell infusion* is similar to a blood transfusion and is performed in the allogeneic setting. It is infused through your IV catheter and is usually tolerated well. The infusion may last a few hours. Occasionally, patients feel flushed or nauseated, but this passes quickly.

Infusion of cryopreserved (frozen/stored) *peripheral blood stem cell* (PBSC) infusion or stored bone marrow is performed differently. You will receive the same pre-medications as those listed above. The PBSCs or BM are brought to your room by one of the technicians from the lab. It is frozen in small bags. The bags will be thawed in a warm water bath one at a time and the stem cells are drawn into syringes. The syringes will

then be attached to your IV catheter and the cells infused into your line. The cells are infused by a BMT nurse over several minutes (5- 10 minutes for each syringe). The time it takes to complete the infusion depends on how many bags and syringes are needed. During this infusion you will have your blood pressure, pulse , respiratory rate, oxygen saturation and temperature monitored often. If the volume of cells is large, the infusion can be divided into two sessions on the same day or completed over two days.

It is normal to have a pink color to your urine for several hours to days after the infusion of stored stem cells. Many people rest after the transplant or re-infusion because of the Benadryl. You will not feel anything new immediately after the procedure even though your cells are going to work!

A chemical called DMSO is used to preserve frozen cells. The DMSO keeps the cells healthy during the preserving, freezing and thawing process. This chemical can cause an unusual taste and sometimes nausea during the infusion. Because the DMSO is excreted from your body through your lungs, you will have an odor from your breath. It may also be noticed in your sweat. This may last up to a few days after the infusion. You may not be aware of the odor, but those around you may notice it. Some folks have described this odor as similar to creamed corn or garlic!

When the infusion (transplant) is complete, the waiting begins. The bone marrow or PBSC find their way to the bone marrow spaces where they begin to grow and multiply. This is called *engraftment*.

Engraftment can take anywhere from seven to fourteen (7-14) days for an autologous transplant and fifteen to twenty-five (15-25) days for an allogeneic transplant. An unrelated transplant or a cord blood transplant may take an even longer period of time to engraft. This is a time when it is very important to stay as healthy and active as possible.

Remember, you may not feel any different, but your new cells are hard at work trying to find their new home in your marrow. Some patients feel that the transplant day is their new birthday!



## What if I Have Pain?

Some medical professionals refer to pain as the 6<sup>th</sup> sense. You may experience some pain during the course of your illness or treatment. Your doctors and nurses, along with your input, will find the best way to control your pain.

Pain has a different meaning to each of us. Your attitude about pain is different from others and we all cope with pain in different ways. Many people have beliefs about pain that may not be true. These are called pain myths. Pain is often under treated because of patient's belief in these myths about pain.

A patient may not report pain because they believe that:

- Pain medications are addictive
- Pain treatment should be a last resort
- Pain means that the disease is back
- It looks better to “tough it out”
- It wouldn't be safe to use such strong pain medications

These myths are wrong and it is our job to educate you about these myths to help you understand your pain and your pain relief options.

As a UNC BMT patient you can expect:

- Useful written and spoken information about pain and pain relief measures
- Staff will respond promptly to your reports of pain
- Appropriate pain management
- Your pain will be taken seriously
- Staff will be concerned and committed to pain prevention and control

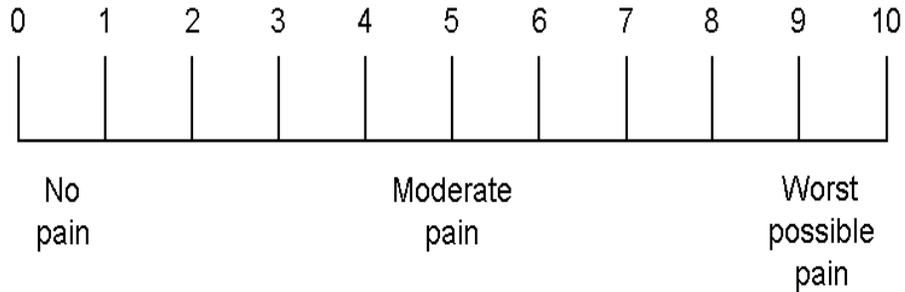
For your part, we expect you to:

- Ask about pain management
- Discuss pain relief choices with your doctor and nurse
- Ask for pain relief when pain first begins
- Describe and rate your pain

## Pain Scales

Everyone feels and perceives pain differently and because of that it makes describing your pain difficult. There are different kinds of scales to help communicate your pain level to the staff. The scale most often used is a number scale. Pain is rated from zero to ten; zero being no pain at all and ten being the worst pain you have ever felt.

Numeric Pain Intensity Scale



Sometimes people feel more comfortable using faces to describe their pain. If you choose to use this kind of scale simply point your finger at the face that describes your pain the best. Children find this scale easy to use.

FACES Pain Rating Scale

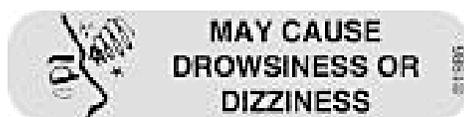


It doesn't matter which scale you choose to use just as long as you tell us how you are feeling. The doctors and nurses will ask you to rate your pain often so that we can adjust the pain medication that you receive.

**What is a PCA Pump?**

A PCA pump is a pump that allows you to have more control getting a dose of your pain medication. PCA stands for patient-controlled analgesia. You will have a button attached to the pump that you can press to deliver your pain medication into your IV line. Your BMT Physician will prescribe the appropriate dose and your nurse will set the pump according to that order. You may receive a continuous infusion of low dose pain medicine to help control your pain. You may also receive slightly more pain medicine for breakthrough pain. You will only be able to receive a dose of pain medication at certain time intervals so that your team can continue to safely treat your pain. The pump will make a beeping noise if you receive a dose of medication, but if you do not hear a beep, it is too soon to get more medication. Wait a few minutes and try again.

One of the benefits of a PCA pump is that you will not have to wait for a nurse to bring you your medication; you will only have to press the button. This is very helpful if you have a difficult time controlling your pain or if you have mouth sores and are unable to take pills or eat and drink easily. If you are using your PCA pump properly and still having pain, please notify your nurse and your team can change the order to give you more medication, or a different medication that may work better for you.



**When you are receiving IV pain medicine, you may be more sleepy than normal. Get help when you want to get out of bed so you don't fall!!!**

**REMEMBER: CALL... DON'T FALL**

The nurses and doctors will need your help to know how well the medicine is working. Each day, they will ask you to rate the level of your pain using one of the pain scales. Your medications will be adjusted appropriately depending on how well your pain is being treated.

FYI: For your information on the UNC Policy of pain management, you can ask your nurse for a copy.

### Common Medications used during and after transplant

Antimicrobial Agents (antibiotics, antifungals, antivirals) – these agents are commonly used to prevent and treat infections that can occur when the immune system and white blood cell counts are suppressed

Name	Type of Drug	How Given / Why used	Side effects
Ceftazidime (Ceftaz)	antibacterial	IV, Used to treat fevers and bacterial infections	Nausea, rash
Doripenem (Doribax)	antibacterial	IV, Used to treat fevers and bacterial infections	Nausea, rash
Vancomycin (Vancocin)	antibacterial	IV, Used to treat fevers and bacterial infections	Reddening of the skin
SMX/TMP (Bactrim, Septra)	antibacterial	Oral, Used to prevent bacterial pneumonias in immunocompromised patients	Rash, electrolyte disturbances, decrease in platelets
Fluconazole (Diflucan)	antifungal	Oral or IV, Used to treat and prevent fungal infections	Abdominal pain, liver abnormalities
Posaconazole (Noxafil)	antifungal	Oral, Used to treat and prevent fungal infections	Liver function abnormalities
Voriconazole (Vfend)	antifungal	Oral or IV, Used to treat and prevent fungal infections	Liver function abnormalities, visual changes
Valacyclovir (Valtrex)	antiviral	Oral, Used to treat and prevent HSV viral infections	Nausea, kidney effects
Acyclovir (Zovirax)	antiviral	IV, Used to treat and prevent HSV viral infections	Nausea, kidney effects
Valganciclovir (Valcyte)	antiviral	Oral, Used to treat CMV and other viral infections	Decrease in white blood count, nausea
Ganciclovir (Cytovene)	antiviral	IV, Used to treat CMV and other viral infections	Nausea, decrease in white blood count

\*Your BMT Team may prescribe other antimicrobial agents depending on your clinical status

Immunosuppressive Agents – these agents are used mainly in allogeneic (donor) transplants, to prevent and treat graft versus host disease. On occasion, some of these are used in autologous transplants to treat drug reactions and other complications

<b>Name</b>	<b>Type of drug</b>	<b>How given/why used</b>	<b>Side effects</b>
Tacrolimus (Prograf)	immunosuppressive	Orally, twice daily. Used to prevent GVHD	Increased blood pressure, tremors, kidney effects
Cyclosporine (Neoral, Gengraf)	immunosuppressive	Orally, twice daily. Used to prevent GVHD	Increased blood pressure, tremors, kidney effects
Sirolimus (Rapamune)	immunosuppressive	Orally, once daily, used to prevent and treat GVHD	Liver effects, increased triglycerides
Mycophenolate mofetil (Cellcept)	immunosuppressive	Orally, twice daily, used to prevent and treat GVHD	Decreased blood counts, nausea
Prednisone (Deltasone)	Anti-inflammatory / immunosuppressive	Orally, once or twice daily. Used to treat GVHD and other inflammatory conditions during transplant	Insomnia, increased blood sugar, bone effects
Infliximab (Remicoid)	immunosuppressive	Used to treat GVHD of the GI tract	Infection risk
Etanercept (Enbrel)	immunosuppressive	Used to treat GVHD of the GI tract and certain lung inflammatory processes	Infection risk
Alemtuzumab (Campath)	immunosuppressive	Used to treat GVHD	Fevers, rigors, allergic reactions, infection risk
ATG (Thymoglobulin)	Immunosuppressive	Used to prevent and treat GVHD	Fever, chills, rigors, allergic reactions

Other Medications – There are numerous medications that may be used during your transplant process to manage side effects or other situations that arise over the course of the transplant. Below is a list of some of the more common medications and the reasons for their use.

<b>Name</b>	<b>Type of Drug</b>	<b>Reason for use</b>	<b>Side effects</b>
Prochlorperazine (Compazine)	Anti-nausea agent	Used to treat and prevent nausea	Drowsiness, involuntary muscle movement (rare)
Promethazine (Phenergan)	Anti-nausea agent	Used to treat and prevent nausea	Drowsiness, involuntary muscle movement (rare)
Ondansetron (Zofran)	Anti-nausea agent	Used to treat and prevent nausea	Constipation, headache
Lorazepam (Ativan)	Anti-nausea agent	Used to treat and prevent nausea	Drowsiness, dizziness
Amlodipine (Norvasc)	Antihypertensive	Used to control high blood pressure	Low blood pressure, lower extremity edema
Furosemide (Lasix)	Antihypertensive and diuretic	Used to control blood pressure and to help get rid of edema and excess water	Low blood pressure, dehydration, kidney effects
Oxycodone (Roxicodone)	Narcotic pain medication	Used to treat pain	Sedation, constipation, itching, nausea
Morphine (numerous brand names)	Narcotic pain medication	Used to treat pain	Sedation, constipation, itching, nausea
Hydromorphone (Dilaudid)	Narcotic pain medication	Used to treat pain	Sedation, constipation, itching, nausea
Levetiracetam (Keppra)	Anti-seizure medication	Used to prevent seizures, especially in patients receiving busulfan as part of their chemotherapy regimen	Dizziness, confusion
Filgrastim (Neupogen, GCSF)	White blood cell growth factor	Used to stimulate white blood cell counts	Bone pain

*Please remember that this is a general guide. Your medications will be chosen just for you.*

## **Section 7: Managing at Home**

When you are medically able to be discharged from the hospital, you will be able to return to your home or temporary residence. The type of transplant as well as your personalized course of treatment will help determine how soon you will be discharged from the BMTU. This is a time of recovery and recuperation; however, during this time you may experience feelings of weakness, fatigue, and decreased appetite. Everyone's recovery time is different and some people may take more time than others. Do not get discouraged if your body takes longer to recover; give it the time and rest it needs. Your post discharge progress will be monitored closely in the BMT Clinic and your team will be able to answer your questions and keep you informed of your plan of care.

There are many things you will need to pay attention to when you get discharged from the hospital. This section will focus on the specific topics related to how you should take care of yourself once you go home, or go to your temporary residence.

### **Infections: Preventing & Recognizing Signs/Symptoms**

Your living space, whether it is your home or temporary housing closer to UNC, should be cleaned in preparation for your arrival. You should not do the cleaning! Your caregiver should be responsible for maintaining a clean living space as you should not be exposed to any dusts, molds or any other bugs. Most infections you get are a result of an overgrowth of the organisms that naturally exist in your body. And although your immune system is slowly building itself back up, you are not yet ready to fight off infections.

The best way to prevent the spread of infection and help keep you from getting sick is good hand washing! You, your family and anyone who comes to visit you should be washing their hands frequently. It is important to wash your hands with soap and warm water (not hot water as it can dry out the skin) and make sure to scrub between the fingers and under the nail beds each time for approximately 15-30 seconds. Alcohol based washes can be used, but if your hands are visibly dirty you must use soap and water.

Other ways to protect you from infections include the following:

- Wear the mask provided to you by the BMT staff when coming to clinic or hospital, or if you are out in public. You do not need to wear a mask while at home around healthy family members

or if you're out in the yard (unless you live around a construction area).

- Avoid large crowds until you have been cleared by your physician. This includes movie theatres, grocery stores, restaurants, places of worship and outdoor functions such as football games, fairs, etc. If you are unsure please ask a member of the BMT team or refer to the "Frequently Asked Questions."
- If other members of your household become sick with a cold or flu, inform your doctor. Avoid close contact; wash your hands frequently and thoroughly. You should wear a mask if you need to be in close contact with the individual or ask the individual to wear a mask around you until he/she has recovered.
- Contact with pets is safe as long as they have remained in the home, are not outdoor dogs, and all their immunizations are up to date. It is very important to avoid litter boxes, feces, birds and reptiles. They carry infections that may be harmful to you.
- You should not work in the yard or garden or dig in the soil. There are organisms that can cause infections to your weakened immune system.
- If you have a central line or are neutropenic, do not go swimming in pools, oceans, lakes or hot tubs.

Maintaining a clean home is extremely important to preventing you from getting any infections. Here are some guidelines to proper cleaning to help you stay healthy:

- Dust, mold and fungus should be kept to as little as possible
- Bathrooms and eating areas should be cleaned daily
- Dirty sponges should be replaced weekly or they can be cleaned in a dishwasher
- Use cleaners with disinfectant properties such as Lysol or Clorox
- When dusting, use a damp cloth rather than a feather duster.
- Make sure air filters are cleaned or new
- Patients should avoid pesticides, solvents and fertilizers
- Avoid outside areas where there is freshly mowed grass, hay, disturbed earth such as construction areas

\*For guidance on activities and allowances, please refer to the "Frequently Asked Question" section.

Although most patients remain healthy as they resume life at home, the risk of infection after leaving the hospital is a common concern. Don't be overly anxious looking for signs and symptoms of illness, but do report any new symptoms to your doctor or nurse. Fever and chills

are the most common signs of infection. If you are neutropenic, a fever may be the only symptom that you have an infection so be sure to monitor your temperature regularly. If you are feeling hot or flushed take your temperature. Report any of the symptoms listed below to your nurse or doctor.

- Temperature of 100.5° F or greater
- Chills or episodes of drenching sweats
- Difficulty breathing
- Hives or welts
- Redness, swelling or drainage from your catheter site or any other wound
- Burning or pain with urination, frequency, urgency, blood with urination
- Toothache or sore gums
- Nausea, vomiting, or diarrhea that lasts more than 24 hours

### Medications

Before you are discharged from the hospital, one of the BMT pharmacists will review your discharge medications with you and provide you with a medication calendar. Also, we will review your medications at your first visit to the BMT clinic following discharge. It is **very important** that you take your medications as prescribed and not miss any doses. Keep track of any medications that need to be refilled and alert the nurse, physician, or pharmacist at your visit. Remember that narcotic pain medication (i.e., oxycodone, Percocet, Vicodin, Dilaudid (hydromorphone)) cannot be called into a pharmacy under any circumstances. If you have questions or problems with any of your medications or need to speak with one of the BMT pharmacists, please call the clinic immediately.

Also, please bring your medications bottles with you to every clinic appointments. Your nurse will review your meds each and every time you have a clinic visit so please be prepared to review this every time. If you have any questions or concerns, the pharmacist can arrange to meet with you.

### Oral Care

Thorough mouth care will continue to be important for many months after your transplant. If you have received total body irradiation the glands in your mouth that make saliva can be damaged. Although rare, it is also possible to have lingering mucositis, or inflammation of

the skin in your mouth, from some of the chemotherapy that you received. Saliva washes the bacteria away from your mouth. The decrease in saliva can cause both dry mouth and an increase in mouth infections because the bacteria are not being moved from the mouth down the digestive tract. This can also cause you to be at greater risk for cavities.

Mouth rinses may help to relieve dryness, but be sure not to use any rinses that have alcohol in them as that will further dry your mouth out. Gargle or swish regularly with normal saline or saltwater rinses, especially after each meal and at bedtime.

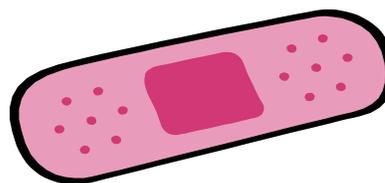
Brush your teeth with a soft toothbrush and mild toothpaste after each meal and at bedtime. If your platelet count is lower than 50,000 you should use toothette sponges instead of a soft toothbrush. If you notice any bleeding at your gums when you are brushing, please notify your nurse or physician.

Lastly, do not have any dental work done, even cleaning, until your physician has cleared you to do so. Extra measures may need to be taken to prevent you from an infection or bleeding.

### **Bleeding Precautions**

You may continue to have a low platelet count for a while after being discharged from the hospital. Platelets are usually the last type of blood cell to start growing in your new bone marrow. Platelets are very important because they help form blood clots that control bleeding. During this time you might require platelet transfusions as an outpatient. Listed below are some of the signs of a low platelet count and symptoms of bleeding.

- Petechiae - tiny pinpoint purplish red spots on the skin
- Nosebleeds
- Easy and excessive bruising
- Black or tarry stools
- Blood in your stools
- Blood in your urine or vomit
- Blood noticed anywhere on your body
- Bleeding from your gums during your mouth care



Please call the clinic if you suddenly develop any of the above symptoms. If you have had these symptoms and your provider is aware, call if there is any worsening.

If you should have an accident and cut yourself, put a clean dry gauze pad, towel or cloth over the area and apply pressure for ten (10) minutes. If the bleeding continues, elevate the area, apply ice and call the clinic or the BMT unit for instructions.

If you are in need of blood transfusions please remember you will need irradiated blood products. You should wear a MEDIC ALERT bracelet. Applications are available from the nursing staff.

If your platelet count falls below 50,000 you will need to take the following precautions:

- Use an electric razor for shaving
- Use toothettes or a very soft toothbrush
- Blow your nose gently, do not pick!
- Avoid aspirin, ibuprofen, Advil™, Motrin™ or any similar medicines such as Alka-Seltzer™, Bayer™, Bufferin™, Doan's Pills™, Anacin™, Excedrin™, Sine-Off™ and Midol™. Check with your doctor before taking any over-the-counter medicines
- Use Tylenol™ for mild pain such as a headache or joint discomforts
- Avoid activities or sports that can cause injury from straining or lifting

### Skin Care

Your skin may be drier and more sensitive after your chemotherapy. Your skin care regimen is very important as healthy skin is a protective barrier against infections.

Your skin care regimen should include a daily shower with warm water (hot water may dry and irritate your skin) and soap that won't dry out your skin. Again, frequent hand washing is the most important thing you and your family members can do to prevent the spread of germs. You may notice that your skin is more dry than normal and this is from the chemotherapy. Apply an alcohol free lotion to your skin each day such as Lubriderm™ or Eucerin™ Cream.

Protect your skin from direct sun exposure. Avoid direct sunlight between 10:00 a.m. and 5:00 p.m. because that is when the sun is at its peak. If you must be outside during this time, be sure to wear a hat, sunglasses and a long sleeve shirt and pants. It is recommended that you wear sunscreen with an SPF of 30 or higher at all times. Use a sunscreen that is PABA free as that may cause irritation to your skin.



## Nutrition

Adequate nutrition is very important after your transplant. It gives your body the necessary energy to heal after your recent treatment. You may find that changes in your appetite can interfere with good nutrition. Eating small frequent meals, snacks or mini-meals six to eight times per day is a good way to combat a lack of appetite and also meet your nutritional needs. It is also important to include foods from all the basic food groups. After you leave the hospital, remain on a special diet. The length of time you will continue this special diet will depend on the type of transplant you have received. Please refer to the Post-BMT Diet guidelines for a list of approved and restricted foods. Typically for autologous patients we request that you follow these diet instructions until you are about 6 months after transplant to allow your immune system to recover.

**Change in taste is one of the most common complaints from transplant patients.** Things that you previously enjoyed no longer taste good. Some medications may leave a metallic taste in your mouth. Frequent mouth rinses can help with this problem. Using gum or hard candy can also help with the lingering unusual tastes. This is a problem that is healed in time. Don't give up on your favorite foods too soon. Your tastes will continue to change, but stimulating the taste buds will help the healing process. **KEEP TRYING!!!**



### Some Tips:

- If you have a sores or a sensitive mouth, try eating foods that are soft, moist and in small pieces. Chilled pudding, Jell-O™ and popsicles can be soothing when your mouth and throat are sore.
- Protein, vitamins and calories are needed to build new cells. High calorie beverages such as milkshakes, Carnation Instant Breakfast™ and other nutritional supplements such as Ensure™, Resource™ and Boost™ can supply valuable vitamins and minerals. Soups, pasta, eggs and dairy products are good sources of protein and are easy to eat.

- Remember that any food too hot or too cold may cause discomfort.
- Spicy foods and foods high in acid content such as citrus juices and tomatoes may also be irritating to the mouth and throat.
- Greasy foods are often difficult to digest and can lead to diarrhea.
- Keep portions small. Divide meals into many smaller ones scattered throughout the day.
- Don't forget to drink **2-3 Liters** of fluids each day. Avoid alcoholic beverages.
- Choose your foods wisely and go slow.



Cigarettes and alcohol are very irritating to the mouth and throat. If you haven't already done so, now is the time to QUIT. If you feel the need to smoke, speak with your provider so we can help you.

As mentioned previously, many patients also notice that their mouth is very dry as a result of radiation or certain chemotherapies. Chewing breads or well-cooked meats may be a problem. Adding sauces to your foods along with having something to drink with your meal can help. When you are not eating, it may be helpful to suck on hard candies or use frequent oral rinses to keep your mouth moist.

If you are experiencing diarrhea after eating, you may want to try a clear liquid diet. If the diarrhea lasts longer than 24 hours contact your BMT provider. When the diarrhea improves, start to add foods that are easily digested such as rice, toast, crackers and fruits. Avoid foods with high fat content such as fried foods and dairy products. If you notice that certain foods cause cramping or diarrhea you should avoid these foods.

### **Recreation and Physical Activity**

You may find that once you are discharged home you are more fatigued than you thought you would be. That is not abnormal. How quickly you recuperate depends on a number of factors, including your blood counts, nutrition and activity level. Regular activity will help you

regain your strength more quickly, even if it's only a short walk to begin with.

Independent functioning is a key factor in regaining endurance. It may be difficult to immediately resume all of your normal activities when you go home. It is important to do what you can for yourself in order to regain your strength and independence. It is also important to realize any limits you may have and ask for assistance as needed. Remember, though, to pace yourself. This simply means planning your daily schedule with the most demanding activities early in the day and allowing for breaks as needed. Space your activities throughout the day and week.



Most patients are not physically strong enough to return to the workplace for several weeks or months, depending on the type of transplant received. This usually means that you may have an increased amount of free time. Enjoy it. Take the opportunity to do something you enjoy. Maybe it is time to get back to a hobby, read a good book, visit with friends or family or do whatever it is you like to do. Getting involved in recreation and leisure activities is an excellent way to increase strength and endurance while doing something you enjoy. These activities are also a great way to reduce stress. Do not hesitate to ask your provider for guidance about your activities.

## Sexuality

Many patients wonder at what point they can resume sexual activity. This decision is based on many factors including your white count and platelet level. You may have sexual intercourse when your platelet count is greater than 50,000 and you have an absolute neutrophil count (ANC) greater than 1,000. It is important to wear condoms to protect yourself against HIV, HSV, HPV or any other viruses or sexually transmitted diseases (such as chlamydia, gonorrhea, syphilis) that could be transmitted through vaginal or seminal fluid. If you are not sure whether you are allowed to begin having intercourse with your partner yet, just ask one of the BMT nurses or doctors. Do not be embarrassed to ask when you can become intimate again with your partner. Intimacy is an important part of a healthy relationship and we are available to answer your questions.

Many women experience decreased vaginal secretions, causing dryness. Many water based lubricants can help relieve vaginal dryness and your doctor can make recommendations if you're interested. Also, many women stop having periods or have irregular cycles. Estrogen



supplements may be recommended after transplant; however this will depend on your specific diagnosis and treatment. Your doctor will talk to you about this after your transplant.

Many men and women experience a decrease in their sexual desire and find they do not have the same interest in sex that they did before their transplant. These are common feelings that can relate to your illness, recovery time, medication side effects and general health. If these problems continue longer than you expect, talk to your doctor.

## Immunizations



After having a bone marrow transplant, you will have some changes, at least temporarily, to your body's immune system.

Adult patients who have had an **autologous** bone marrow transplant will have only a short-term immune system deficiency. You will need to have your immunizations repeated beginning at 1 year after treatment if you have completed their therapy.

Patients who receive an **allogeneic** transplant will have long-term deficiencies with their immune system. This is due to both the chemotherapy and the immune suppressions from the graft vs. host disease medications. These medicines work by suppressing your own immune system so that your new bone marrow can grow. Vaccines may be ineffective as long as you are on drugs to treat or prevent GVHD.

Patients who are one year out from their allogeneic transplant will begin to receive their childhood immunizations again, as long as immunosuppressive medications are not still being taken.



## Section 8: Resources

### Your Caregiver: A Very Important Person (VIP)

A caregiver is the person who will be responsible for taking care of you after you leave the hospital. Your caregiver must make sure that all of your needs are met. Being a caregiver is an awesome responsibility and you will need to choose this person very carefully. This person must be able to help you in many different ways while taking care of him or herself too. Your spouse, child or friend may find that they are now also your caregiver. It can be an adjustment for everyone and requires understanding and patience.

Caregiver's responsibilities include:

- ◆ Providing transportation to and from the Bone Marrow Outpatient Clinic and tracking appointments
- ◆ Observe changes in patient's condition and report to the doctor
- ◆ Calling for medical care if needed
- ◆ Assisting the patient with central line catheter care
- ◆ Monitoring medication schedules
- ◆ Assisting with meal preparation and diet restrictions
- ◆ Assisting the patient with personal hygiene needs
- ◆ Assisting with medical and financial planning
- ◆ Serving as a communication link and advocate
- ◆ Being physically present with the patient
- ◆ Giving encouragement

**“We deceive ourselves when we fancy that only weakness needs support. Strength needs it far more.”**

-Sophie Soymonof

### Taking Care of the Caregiver

Caregivers do so much for you that they will need to take care of themselves too, especially if they are your spouse, parent or child. Caregivers must remember to exercise, eat a proper diet and get adequate sleep in order to help you the most. Your caregiver might experience a mix of emotions about taking on this new role. Supporting your caregiver is essential during this time of adjustment.

The Caregiver should:

- ◆ Take care of their health
- ◆ Take a break when they can
- ◆ Know their limits and ask for help
- ◆ Form a caregiver team to provide backup
- ◆ Join a support group
- ◆ Seek relaxation
- ◆ Have a sense of humor

Helpful hints for the Caregiver:

- ◆ Develop a schedule for the week to include clinic appointments, medications, physical exercise and central line catheter care
- ◆ Maintain a log of what the patient has had to eat or drink
- ◆ Keep a list of questions to bring with you to the next clinic appointment
- ◆ Develop a telephone-calling tree to get information to family and friends
- ◆ Use email or a web site to keep friends and family posted

### **Patient Assistance Options for Bone Marrow Transplant Patients**

Many transplant patients need to do some form of fundraising to cover out-of-pocket expenses not covered under insurance policies. These expenses may include but are not limited to:

- Insurance premiums, co-payments and deductibles
- Medications, both prescription and over the counter
- Transportation to and from the hospital
- Lodging in the Chapel Hill area
- Expenses of a caregiver who has taken time from work

Fundraising is best done prior to transplant. Many patients have found that it is hard to get donations once the transplant has occurred, even though this is when the time of the greatest amount of expenses do arise. There are important guidelines that apply to fundraising and special accounts. It is very important to follow these guidelines to ensure that the funds raised are not subject to taxation. To understand the guidelines, and for suggestions about fundraising, see the personal financial guide cited below, from the NMDP.

For additional information regarding the financial aspects of transplant please see "*Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplant*" put out by the NMDP. This guide may be downloaded from their web site at [www.marrow.org](http://www.marrow.org) or you can obtain a copy by calling (888) 999-6743.

## Transplant Assistance Funds

Many people choose to work with a transplant assistance fund. These organizations offer several benefits. They can:

- Help you to figure how much you will need to raise.
- Teach your fundraising team how to raise money.
- Keep these funds in a tax-exempt account.
- Provide matching funds if you reach certain goals.
- Provide materials to assist with raising awareness of the need for organ donation.

These organizations generally require that you sign a contract saying you will only raise money with them. They also charge an administrative fee, which could be a percentage of the money you raise or interest off of your funds.

The transplant assistance funds can either pay bills directly or reimburse you for bills that have already been paid. The funds can only be used for transplant related expenses. The organizations can be audited by the IRS themselves about how they disburse the money, so they have strict guidelines. Be sure that you and the assistance fund you choose see eye-to-eye about important expenses before you sign on to work with them.

Several of these funds are listed here:

### **[The Children's Organ Transplant Association \(COTA\):](#)**

[Through coordination of patient fundraising campaigns, COTA provides fund-raising assistance for children and young adults in need of funds for transplant and related expenses.](#)  
[1-800-366-2682](tel:1-800-366-2682), [www.cota.org](http://www.cota.org)

### **[National Foundation for Transplants](#)**

[\(Formerly known as Organ Transplant Fund\):](#)

[This foundation helps the families and friends of transplant candidates and recipients to successfully perform community fund raising for expenses related to the patient's transplant care and medication.](#)  
[1-800-489-3863](tel:1-800-489-3863), [www.transplants.org](http://www.transplants.org)

### **[The National Transplant Assistance Fund \(NTAF\):](#)**

[This organization guides patients, families, and friends through the fund-raising process and provides a small matching funds grant for patients actively involved in a fundraising campaign with NTAF.](#)  
[1-800-642-8399](tel:1-800-642-8399), [www.transplantfund.org](http://www.transplantfund.org)

## Local Cancer Support Groups

*For a complete listing of support groups at UNC or in your community, Please ask your BMT Social Worker.*

Meeting	Date/Time	Location	Contact
Bone Marrow Transplant Support Group	Every Wednesday 3:00 – 4:00 pm	Anderson Pavillion 5 <sup>th</sup> Floor UNC Hospital	Kathy Roundtree, 966-7861
Look Good...Feel Better	3 <sup>rd</sup> Monday of Each Month at 10:00 am	Patient Family Resource Center (Ground floor NCCH)	966-3494
Caregivers' (Spouses, Partners, Family Members) Support Group	2 <sup>nd</sup> Monday of each month at 7:00 pm	Cornucopia House Chapel Hill	966-3494
Getting Your Bearings: Living with Cancer	2 <sup>nd</sup> and 4 <sup>th</sup> Wednesdays of each month at 7:00pm	Cornucopia House Chapel Hill	966-3494
End of Treatment Support Group	Call for times and location	Lineberger Cancer Center, Plaza level Conference rm.	966-3494
Metastatic Cancer Support Group	1 <sup>st</sup> and 3 <sup>rd</sup> Wednesdays of each month at 3:30pm	Cornucopia House Chapel Hill	966-3494

Remember: The Bone Marrow Transplant staff is here to support you, your caregiver and your family. Tell us if you need help or call our Social Worker.

For Internet access, log on to the following websites for more UNC information:  
[www.unclineberger.org/bmt](http://www.unclineberger.org/bmt) (or) [www.unchealthcare.org](http://www.unchealthcare.org)

### Housing Options

This list is provided as a service by the BMT team however, the BMT team and UNC Hospitals do not recommend nor endorse these businesses. Rates are subject to change without notice.

## Extended Housing Options

The following corporate housing companies offer furnished apartments in a variety of complexes in the Chapel Hill area. Contact them directly for pricing and availability. An \* by the property name indicates there is a free shuttle to and from UNC Hospitals; please check with the property regarding the shuttle hours and availability.

### Equity Corporate Housing

Jessica Reese or Becky Arguello, 919-851-1511 or 800-533-2370

<http://www.equitycorporatehousing.com/market/propertymarketing.asp?PropID=2135>

### Evergreens at Mt. Moriah

5512 Sunlight Dr.

Durham, NC 27707

919-489-8788

<http://www.evergreensnc.com/>

### 82 Magnolia

100 Saluda Court

Chapel Hill, NC 27516

919-960-8298

### ExecuStay by Marriott

Laray Wiggins, 888-840-7829 x 40333

<http://www.execustay.com/information/about/furnishings.php>

### \*Residence Inn by Marriott

101 Erwin Road

Chapel Hill, North Carolina

(919) 933-4848

<http://marriott.com/hotels/travel/rduhl-residence-inn-chapel-hill/>

### \*Korman Communities

Meagan Matt, 919-484-1321; cell phone: 919-524-8431

Property: The Hamptons

300 Seaforth Dr.s

Durham, NC 27713

<http://www.kormancommunities.com/property.php?id=15&type=furnished>

### Wynne Residential Corporate Housing

919-484-3999

[http://www.networkrichmond.com/cgibin/CityDetail3.cgi?City\\_IN=Greater%20Raleigh%20-%20Durham&State\\_NameIN=North%20Carolina](http://www.networkrichmond.com/cgibin/CityDetail3.cgi?City_IN=Greater%20Raleigh%20-%20Durham&State_NameIN=North%20Carolina)

## Short Stay Options

### **SECU Family House**

123 Old Mason Farm Road  
Chapel Hill NC  
919-932-8000

SECU Family House provides housing, healing, and hope to families with an adult patient being treated for a critical illness or injury at UNC Hospitals or its affiliated clinics. There is a nightly charge of \$35 to stay in one of our 40 private rooms. This includes bus service to and from UNC Hospitals, laundry facilities, a help-yourself pantry with snacks and food staples, and access to a library with Internet resources. If you are interested in staying at the Family House, please make arrangements through your BMT social worker.

**When Family House is full, we need to refer guests to one of the area hotels with whom we have discounts.**

**Aloft Chapel Hill- - 919-932-7772 (dial O to get front desk) 1001 S. Hamilton Rd., CH, 27517**

**Comfort Inn - - 919-490-4949 3600 Mt. Moriah Rd. Durham. (near intersection of I-40 and 15/501, behind Outback and Bob Evans.) Breakfast included. Across from Home Depot. NO PETS. **Outdoor pool****

**Hampton Inn -- 919-968-3000:** located at 1740 N. Fordham Blvd (on service road near Rams Plaza). This hotel is the closest to the hospital, and there is **a shuttle** and breakfast is included. **Near McDonalds. Outdoor pool NO PETS**

**Holiday Inn – Chapel Hill -- 919-929-2171:** located at 1301 N. Fordham Blvd. **Shuttle service is available 7:00am-8:00pm**, individual breakfast items \$2 and up, Buffet \$9. **Across from Eastgate. Outdoor pool. Pet friendly \$40 onetime fee with designated room.**

**Homestead Studio Suites – 919-402-1700:** located at 1920 Ivy Creek Blvd., Durham. This hotel has **a shuttle** to the hospital and all rooms include a kitchenette. They are also “pet friendly.” in case someone needs to bring a pet with them. Cannot check in until 3:00pm. **Close to South Square No pool Allow pets \$25 per night, 6 night maximum charge.**

**Homewood Suites -- 919-401-0610:** located at 3600 Mt. Moriah Road (near intersection of I-40 and 15/501). Breakfast and dinner are included, and there is **a shuttle to the hospital**. Cannot check in until 3:00pm. **Across from Home Depot. Outdoor pool NO PETS**

**Red Roof Inn– 919-489-9421:** located at 5623 Durham-Chapel Hill Blvd., Durham - (intersection of I-40 and 15/501). Any problems can be addressed with Gerald Mandosia, the manager, at 904-566-5171. No breakfast. Pets no charge. **Adjacent to I-40 and 15-501 No pool**

**Sheraton Chapel Hill Hotel- 919-968-4900** One Europa Drive/Chapel Hill, NC 27517. **Complimentary Shuttle Service** seven days per week Mon-Fri. 7:00am-10:00pm and Sat.-Sun 8:00am – 10:00pm Breakfast Buffet \$5 per person. **Outdoor Pool NO PETS**

**Springhill Suites -- 919-403-1111** - located at Patterson Place (in front of Home Depot – on corner of 15-501 and Mt. Moriah). 5310 McFarland Drive, Durham. - Hot breakfast buffet. **No Shuttle** Other nice amenities. **Indoor pool**

**Hotels to which we refer ONLY upon request. Must check availability first:**

**Courtyard by Marriott -- 919-883-0700:** located just off of Friday Center Drive off of NC 54. All non-smoking hotel, **no shuttle**, but CH Transit bus stop is nearby. **Near Meadowmont. NO PETS Indoor pool. Require new referral AFTER 3 DAY stay.**

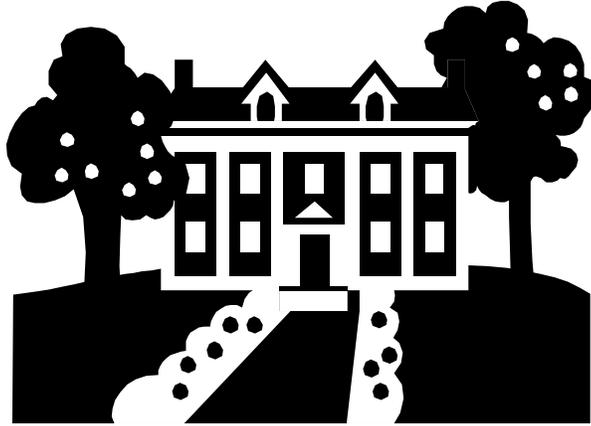
**Residence Inn- 919-933-4848 :** 101 Erwin Rd. **Shuttle available** 7am to 7pm M-F and Breakfast included. **Outdoor pool.** Across from Europa. PET FRIENDLY ONE TIME CHARGE OF \$100

***The Ronald McDonald House of Chapel Hill***  
101 Mason Farm Road  
Chapel Hill, NC 27514  
(919) 966-6752

The Ronald McDonald House provides temporary housing for the families of children being seen at UNC Hospitals. Close to UNC Hospitals, the house serves as a convenient and comfortable home-away-from-home.

Admissions are limited to pediatric patients and their families.

If you are interested in staying at the Ronald McDonald House, please make arrangements through your BMT social worker .



### **Ronald McDonald Shuttle Service**

UNC Hospital provides a shuttle service for the guests of the Ronald McDonald House. The Ronald McDonald House and Family House are located on the HU Chapel Hill bus line which is free. Check with the front desk for a bus schedule or call Chapel Hill Transit at 919-485-RIDE or go to [www.nextbus.com](http://www.nextbus.com). Since this is an employee shuttle service, it is very important that house guests use this service appropriately. Please wait for your shuttle at least ten minutes ahead of its scheduled arrival time and remember that the van drivers are on a schedule and cannot wait for stragglers. Your fellow Ronald McDonald House guests may be able to coordinate schedules with you; there are always guests willing to help out! If you have transportation on the weekends, please see the Front Desk and page the House to see if you can give a fellow guest a ride.

#### **Important phone numbers:**

SECU Family House:	919-932-8000
Ronald McDonald House:	919-913-2040
RMH Admissions:	919-913-2043
PICU:	919-966-5491
BMT:	919-966-7792
Social Work:	919-966-2031

#### **Parking**

Valet parking...is one available option at a cost of \$10 per day.

Free parking is not available. If you do not have the funds to cover parking expenses, please talk with our BMT Social Worker.





If you are in need of handicap parking, please ask our social worker for the Department of Motor Vehicles Handicap Form. Our physicians or physician extenders will fill it out and you will then need to return it to the DMV to get your parking sticker.

## Section 9: Glossary of Terms

***Allogeneic transplant-*** using the stem cells from another person's blood, bone marrow or umbilical cord. Allogeneic transplants can be from a related family member, such as a sibling, or from an unrelated donor.

***Absolute Neutrophil Count (ANC)-*** the number of neutrophils in your blood. Neutrophils are the most active white blood cell against infection. We use the ANC to tell us how well you can fight infection.

***Advance Directives-*** "Advance means you tell your doctor ahead of time and "Directives" means that you direct your medical care. An advance directive is a form that you sign now to direct your future medical care in the event that you cannot speak for yourself in the future. You decide if you want to use artificial treatments to keep you alive for a long time. This legal document must be signed by you and witnessed by two people. Our social worker has this form and will help you fill it out.

***Anemia-*** is a decrease number of red blood cells.

***Antiemetic-*** A medicine to prevent or relieve nausea and vomiting. Examples of this type of medication are Zofran™, Compazine™ and Ativan™.

***Antibiotic-*** a medication used to prevent or treat bacterial infections. Examples of this type of medicine are Cipro™, Levaquin™, Bactrim™, and Vancomycin™.

***Antifungal-*** a medicine used to prevent or treat fungal infections. Examples of this type of medication are Fluconazole™ and Micafungin.

***Antiviral-***a medicine used to prevent or treat viral infections. Examples of this type of medication are Acyclovir™, Valtrex™ and Ganciclovir.

***Apheresis-*** the process of collecting stem cells from your blood. From your central line catheter, your blood will circulate through the apheresis machine. The machine will filter out your stem cells and collect them. This is a painless procedure.

***Autologous transplant-*** a transplant using your own stem cells.

***Blood Counts-*** see Complete Blood Count

***Blood Draws-*** a sample of blood from your catheter to check you blood cell counts.

***Bone Marrow-*** a spongy tissue inside the bones. The "factory" where blood cells are made.

***Bone Marrow Biopsy-*** A bone marrow biopsy evaluates your bone marrow function and health of your white blood cells, red blood cells and platelets. This test is also used to detect any tumor cells in your bone marrow. This test is routinely done prior to transplant. The BMT physician or the nurse practitioner does the biopsy in the outpatient clinic. You will lie on your

stomach and your back hipbone will be cleaned and numbed with a local anesthetic. A needle will be inserted into your bone and the liquid bone marrow will be collected. The needle is inserted again to collect a very small piece of the bone. In some cases, both hipbones will need to be examined. A large pressure bandage is applied to prevent any bleeding. The entire procedure will take 15-20 minutes.

**Bone Marrow Harvest-** process of collecting stem cells from the inside of the back hip bones. (see “What is a Bone Marrow Harvest?” section in text)

**CAT Scan-** (Computerized Axial Tomography) This process takes pictures inside your body. To better visualize certain areas, you may receive an injection of dye into an IV line. You will lie still on an examination table while a machine circles around you to take the pictures. The test can take up to one hour depending on how many areas need to be imaged.

**CBC-** see Complete Blood Count

**Central Line Catheter-** A catheter is a tube that is inserted through your skin and into a large blood vessel. Part of the tube will lie outside your chest. This catheter is necessary to have for the transplant because of the many medications and blood products that you will be receiving at the same time. It is used to draw your blood samples without poking you with needles several times a day.

**Chest X-ray (CXR)** - A picture of your chest, which shows the condition of your lungs and may identify infection or fluid. During your transplant, chest x-rays may be done frequently if you have fevers.

**Chimerism-** A test after stem cell transplant which involves identifying the genetic profiles of the recipient and the donor and evaluating the extent of mixture in the recipients blood, marrow or tissue; this test is performed in the allogeneic setting

**Clinical Trial** - An organized investigation of the effects of a treatment on a specific group of people with a particular disease. In cancer research, clinical trials are conducted with cancer patients, usually to evaluate a new treatment.

**Complete Blood Count** - (CBC) a blood test that measures the white blood cell count level, platelet count and red blood cell level.

**Conditioning-** Treatment with high dose chemotherapy with or without radiation therapy, to destroy cancer cells throughout the body. Conditioning in allogeneic transplantation serves an additional purpose by destroying the cells of the immune system, reducing the risk that the recipient will reject the graft. Conditioning regimens vary according to the disease being treated and the medical center protocols being investigated.

**Cytomegalovirus (CMV)** - a type of virus that can cause infection in a transplant patient. Allogeneic patients are screened for CMV weekly with a blood test.

**Cytogenetics** - a test on your bone marrow to evaluate the health of your chromosomes.

**Day 0** - the day of your transplant (infusion of the stem cells).

**Do Not Resuscitate (DNR)** - DNR stands for Do Not Resuscitate. This order tells the medical staff not to perform CPR, (Cardiopulmonary Resuscitation). CPR is used when you stop breathing or your heart stops. It is helpful to decide about CPR before you need it. In order to get a DNR order you must talk with your physician. A doctor will not write a DNR order without talking to your family. It is important to note that you will still receive all the medical care that you need even if you have a DNR order.

**Echocardiogram (Echo)** - This test uses sound waves to make a picture of your heart. A jelly-like substance is spread on your chest. A pen-like object is moved across your chest to make the picture.

**Electrocardiogram (ECG)** - An ECG will make a picture of the electrical currents of your heart. Stickers are placed on your chest, arms and legs and attached to lead wires which read your heart rate. The test will take approximately 10 minutes to complete.

**Engraftment** - The process in which the transplanted bone marrow or the peripheral blood stem cells begin to grow in the bone marrow of the recipient and to manufacture new white blood cells, red blood cells and platelets.

**GCSF** - see growth factors

**Graft-versus-host-disease (GVHD)** - The new marrow (graft) recognizes the patient as foreign and sends out lymphocytes (white blood cells) to attack. The most common areas of involvement are the skin, stomach, intestines and liver. This is a common complication in allogeneic transplants. (See “Complications of Allogeneic Transplant” section)

**Growth Factors** - Growth factors are proteins normally produced by the body that stimulate the development of blood cells from stem cells. These substances can also be produced in the laboratory. Growth factors are commonly called GCSF and GMCSF. They are used in mobilizations and after transplant to increase the white blood cell count. They are given as an injection under the skin. Most common side effects include bone pain and low-grade fevers.

**Haploidentical Transplant** – a type of allogeneic transplant (from someone other than yourself) when the HLA match is not 100% identical but is 50% identical. This type of transplant is used for patients in whom a full (100%) match cannot be found and the donor is a parent or sibling who is not a 100% match.

**Hematocrit** - a blood test that measures the amount of red blood cells. You may receive a blood transfusion when your hematocrit drops below 25.

**Hemoglobin** - a blood test that measures the amount of oxygen in your blood. You may receive blood transfusions when your hemoglobin drops below 8g/dL (this parameter is generally used for pediatric patients).

**HLA (Human Leukocyte Antigen)** - This is a series of proteins that are found on the surface of your cells, which are important in allogeneic transplantation. When an allogeneic stem cell transplant is being considered, the HLA's on the white blood cell of the patient and the potential donor are compared. The HLA's are inherited from each parent. Therefore, the best matches are found between brothers and sisters.

**Immunosuppression** - A weakened immune system can be caused by drugs or certain conditions. If you are immunosuppressed, you are at risk of developing an infection that your body cannot fight on its own. During this time, you will take medicines to help prevent infections. If you have an allogeneic transplant, you will be given medicines to suppress your own immune system, which can decrease the chance of developing Graft-versus-host disease after the transplant.

**Informed Consent** - Informed Consent is the process in which you are educated about a clinical trial or treatment plan, including the risks and benefits of the treatment. If you sign an informed consent form and enter the trial, you are still free to leave the trial or the treatment at any time and will continue to receive medical care.

**Incentive Spirometer** - Small, plastic device which will help you breathe deeply and keep your lungs healthy. You will be asked to use this device several times each day during the transplant.

**Infertility** - Radiation and/or chemotherapy may make you sterile. The extent of this problem depends on your sex and age. It also depends on the dosage and duration of treatment. If you are planning to have children in the future, you need to discuss this prior to transplant.

**Intravenous** - the administration of a drug or fluid directly into the vein.

**IV**- see Intravenous

**Mini transplant** - See Reduced Intensity Regimen

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

**Mucositis** - Inflammation and irritation of the fragile membranes throughout the gastrointestinal tract. The mouth is most often affected. Mouth sores, bleeding and pain is common.

**MUGA Scan** – MUGA Scan measures the performance of your heart muscle. A dye is injected into your bloodstream through an IV, and then x-rays are taken of your heart while you lie still on a table and/or while you ride a bike. The test lasts about an hour. You will have this test before and after your transplant.

**Neutropenia** - when your white blood cell level is below normal and your body does not have its normal infection-fighting abilities. You are considered to be neutropenic when your neutrophil count is less than 1000.

**NMDP**- the National Marrow Donor Program (NMDP) was established in 1987 to coordinate bone marrow transplants. The NMDP is a network of donor centers, transplant centers, collection centers and recruitment groups. Volunteer donors join the NMDP through a local Red Cross. The NMDP helps facilitated unrelated marrow or PBSC transplants in the US and worldwide.

**Non-ablative transplant**- See Reduced Intensity Regimen

**Pancytopenia** - all of the three major blood cell types; red cells, white cells and platelets are below normal values.

**Patient -Caregiver Contract** - a document signed by the patient and caregiver and approved by the BMT Team, confirming the commitment of an individual to be a caregiver for the patient.

**Patient-Family Conference** - a pre-transplant meeting to answer questions and sign the research protocol consent forms. The patient and all family members are requested to be present. The Caregiver must be present to sign the Patient-Caregiver Contract.

**PCA (Patient-controlled analgesia)** - This means you have control of your pain medicine. The doctor will program your PCA pump to deliver an amount of pain medicine that is safe for you. When you need pain medicine, instead of calling the nurse, you can push your PCA button. The pump will give you pain medicine through your IV. You cannot get too much and you cannot get addicted.

**Peripheral blood stem cells (PBSC)** - stem cells that circulate in the peripheral blood.

**Petechiae** - pin-head size sites of bleeding in the skin resulting from a low platelet count, frequently seen on the legs, feet, trunk and arms. They disappear gradually when the platelet count increases.

**Physical Therapist (PT)** - helps you to exercise and stay fit while you're in the hospital.

**Platelets** - help to form clots to stop bleeding. You will receive a platelet transfusion when your count drops below 10,000.

**Power of Attorney** - In North Carolina, you can name a person to make medical care decisions for you if there comes a time when you are unable to make decisions yourself. In this legal document, you name a person as your "health care agent". You can state what treatments you would want and not want to have. This form must be witnessed by two people and signed by you. Our social worker has this form and will help you fill it out.

**Protocol** - the outline or plan of a course of treatment.

**Protocol Nurse** - A registered nurse that specializes in the administration of protocols. The protocol nurse reviews your medical information to determine your eligibility for a clinical trial. May also provide informed consent and manages the data collection.

**Pulmonary Function Tests (PFT's)** - PFT's measure how well your lungs work. You will be asked to breathe into a tube. You will also have blood drawn from your wrist to see you well oxygen is getting into your blood. You will have this test before and after your transplant.

**Radiation Oncologist**- A doctor who specializes in using radiation to treat disease.

**Radiation Therapy**- Treatment with high-energy rays to kill cancer cells, also called radiotherapy. Used in combination with chemotherapy as a preparative regimen in transplant patients.

**Recreational Therapist**- A member of the BMT team who helps you stay active during your inpatient stay.

**Red blood cell**- A blood cell that carries oxygen (fuel) from your lungs to all parts of the body.

**Reduced Intensity Regimen**- also called a “non-ablative transplant” or a “mini transplant”. This type of transplant is an allogeneic transplant where you get your stem cells from a related or an unrelated matched donor. The goal is to give a moderate dose of chemotherapy to set up a mixed immune system. The new immune system will attack the cancer.

**Remission**- complete or partial disappearance of the signs and symptoms of your cancer.

**Staging**- a process to find out where the cancer may be present. The tests are different for each disease but may include blood work, a bone marrow evaluation or a variety of scans.

**Stem cells**- the "mother" cells. Their job is to produce baby cells that will grow up to become mature red blood cells, white blood cells and platelets. They can be collected from the bone marrow by a bone marrow harvest or from the blood by apheresis.

**Total Body Irradiation (TBI)** - used as a treatment to condition the patient and to promote immunosuppression. Used with chemotherapy and may be given over the course of several days and in most cases, twice daily (fractionated radiation) Fractionated schedules may decrease the risk of side effects.

**T cells**- white blood cells that mature in the thymus and perform important immune system functions, also known as T lymphocytes.

**Thrombocytopenia**- a platelet count that is below normal. A platelet transfusion will generally be given when the platelet count is less than 10,000

if you're an inpatient and less than 20,000 when you are an out-patient or having bleeding.

**TPN (Total Parenteral Nutrition)** - a solution with high nutritional content given through the central line catheter.

**Ultrasound**- a pain-free way to study the organs of the body by using sound waves. The technologist will apply a warm gel to your skin over the area to be examined then move an instrument across your body and images will be photographed.

**Umbilical Cord Transplant**- a transplant using the stem cells collected from an umbilical cord.

**White blood cells**- White blood cells are the infection fighting blood cells. They are the body's defense against infection and disease.

### **Directions to Outpatient Tests (Scans, PFT, EKG, CXR, Cafeteria, Apheresis, Precare)**

#### **MUGA SCANS, X-RAYS AND CT SCANS:**

- ❑ Located on the basement floor of the Women and Children's Hospital.
- ❑ Enter through the Women's Hospital entrance. Take the Women's Hospital elevators down to the basement (for Children, take the Children's Elevators to the basement)
- ❑ Check in at the large desk in the waiting room area.

#### **PFTs (Pulmonary Function tests):**

- ❑ Located on the 6<sup>th</sup> floor of the main hospital.
- ❑ Enter through the NC Memorial Hospital entrance
- ❑ Take the main hospital elevators up to the sixth floor.
- ❑ Turn right and go down hallway.
- ❑ Half way down the hallway on your right you will see a sign that says, "Pulmonary Diagnostics".
- ❑ Check in at the front desk.

#### **EKG:**

- ❑ Located on the first floor of the main (NC Memorial) hospital.
- ❑ Go in through the main lobby of the NC Memorial Hospital.
- ❑ Take the escalator up one flight. Make an immediate left.
- ❑ You will see a sign that says, "Blood drawing/EKG lab".
- ❑ Check in at the desk.

#### **Apheresis (stem cell collection):**

- ❑ Located on the first floor of the east wing of the NC Memorial Hospital.
- ❑ Go in through the main lobby of the NC Memorial Hospital.

- ❑ Take the escalator to the first floor (or elevator which is around the corner from the escalator).
- ❑ Go down a long hallway, past Pastoral Care towards the Blood Bank.
- ❑ At the end of the hallway, take a right, follow the signs for “Blood Bank.”
- ❑ Take the first left towards “Blood Bank Waiting” and walk down the hallway.
- ❑ The Blood bank waiting area is located at the end of that hallway on the left.

**Women and Children’s Hospital Café**

- ❑ Located in the lobby of Children’s Hospital.

**Precare:**

- ❑ Located on the first floor of the main hospital.
- ❑ Go in through the main lobby of the hospital.
- ❑ Take the escalators up one flight.
- ❑ Precare is immediately on your left.

**Autologous Recipients Should Follow Restricted Diet Until Day +30 After HCT**

<b>Food Group</b>	<b>APPROVED</b>	<b>RESTRICTED</b>
<b>Meat and Meat Substitutes</b>	<ul style="list-style-type: none"> <li>* All <b>well cooked or canned meats</b> (beef, pork, lamb, poultry, ham, bacon, sausage)</li> <li>* <b>Well cooked</b> eggs (white cooked firm with thickened yolk)</li> <li>* <b>Pasteurized</b> egg substitutes</li> <li>* <b>Cooked</b> tofu – must be cut into 1 inch or smaller and boiled in water or broth before eating or using in recipes</li> </ul>	<ul style="list-style-type: none"> <li>* Raw or undercooked meat, poultry, fish, game or tofu</li> <li>* Cooked fish and seafood</li> <li>* Meats and cold cuts (non-packaged, fresh deli meats)</li> <li>* Hard cured salami in natural wrap</li> <li>* Cold smoked salmon, lox or pickled fish</li> </ul>
<b>Fruits and Nuts</b>	<ul style="list-style-type: none"> <li>* Canned and frozen fruit and fruit juices</li> <li>* <b>Well washed</b>, thin or thick skin, peeled raw fruit (NO SKINS); food containing well-washed raw fruits</li> <li>* Dried fruits</li> <li>* Canned or bottled roasted nuts; cooked nuts</li> <li>* Nuts in baked products</li> <li>* Commercially-packaged peanut butter</li> </ul>	<ul style="list-style-type: none"> <li>* Unwashed raw fruits</li> <li>* Raw nuts</li> <li>* Roasted nuts in shell</li> <li>* Unpasteurized fruit and vegetable juice</li> <li>* Raw raisins (in cereals and snack boxes)</li> <li>* Berries- strawberries, raspberries, blueberries</li> <li>* Grapes and cherries</li> </ul>
<b>Vegetables</b>	<ul style="list-style-type: none"> <li>* All <b>well-cooked and washed</b> frozen, canned, or fresh vegetables and potatoes (if you can peel it or scrub it, you can eat it)</li> <li>* Dried herbs and spices <b>added prior to cooking</b> (including pepper)</li> </ul>	<ul style="list-style-type: none"> <li>* Unwashed raw vegetables or herbs</li> <li>* Salads from delicatessens or buffets</li> <li>* Commercial salsa stored in refrigerated case</li> <li>* Sprouts</li> </ul>
<b>Bread, Grain, and Cereal Products</b>	<ul style="list-style-type: none"> <li>* All <b>cooked</b> 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, uncooked grain products</li> </ul>
<b>Dairy</b>	<ul style="list-style-type: none"> <li>* All <b>pasteurized</b>, grade “A” milk and milk products</li> <li>* Commercially packed cheese and cheese products made with <b>pasteurized</b> milk</li> <li>* <b>Pasteurized</b> yogurt (no live bacteria)</li> <li>* Dry, refrigerated and frozen pasteurized whipped topping</li> <li>Ice cream, frozen yogurt, sherbet, milkshakes</li> </ul>	<ul style="list-style-type: none"> <li>* Unpasteurized or raw milk, cheese, yogurt, and other milk products</li> <li>* Cheese from delicatessens</li> <li>* Cheese containing chili peppers or other uncooked vegetables</li> <li>* Cheese with molds (blue cheese, stilton, Roquefort, gorgonzola)</li> <li>* Brie, feta, camembert and farmer’s cheese</li> </ul>

Bone Marrow Transplant Program – Autologous Patient Guide

	* Commercial nutrition supplements and baby formulas (liquid or powder)	
<b>FOOD GROUP</b>	<b>APPROVED</b>	<b>RESTRICTED</b>
<b>Fats</b>	* Oil, shortening * Refrigerated butter or margarine * Commercial, shelf-stable mayonnaise and salad dressing * Cooked gravy and sauces	* Fresh salad dressing containing aged cheese, or raw eggs * Salad dressing from buffets
<b>Entrees, Soups</b>	* All cooked entrees and soups	* All miso products
<b>Beverages</b>	* Filtered tap water and ice * Commercial bottled distilled, spring natural water * All canned, bottled, powdered beverages * Instant and brewed coffee and tea * Brewed herbal teas using commercially packaged tea bags * Commercial nutrition supplements, liquids and powders * CHECK WITH MD: Pasteurized beers (retail beers)	* Well water or natural spring water * Cold-brewed tea made with cold or warm water * Unpasteurized fruit and vegetable juices * Mate tea * CHECK WITH MD: Unpasteurized beers (home brewed and some microbrews)
<b>Desserts</b>	* Refrigerated commercial and homemade cakes, pies, pastries and pudding * Refrigerated, cream-filled pastries * Homemade and commercial cookies * Shelf-stable cream filled cupcakes, fruit pies, and canned pudding * Ices, popsicle-like products	* Unrefrigerated, cream-filled pastry products (not shelf-stable)
<b>Other</b>	* Salt, granulated sugar, brown sugar * Jam, jelly, syrups; refrigerated after opening * Commercially-packaged honey ( <b>pasteurized</b> , may not say so on label) * Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerate after opening) * Candy, gum	* Raw or unpasteurized honey * Unpasteurized real maple syrup * Herbal and nutrient supplement preparations- must be approved by pharmacist due to medication reactions * Brewer's yeast, if eaten uncooked * raw, uncooked pepper

Version 1 Sept 2011

### Autograft Frequently Asked Questions

**Wear a mask if in a crowded area until Day +30**

What Can I Do and When Can I Do It?	30 days or less post BMT	Between 30 days and 3 months post BMT	Between 3 and 6 months post BMT	More than 6 months post BMT
<b>Work</b>				
Work at an office	No	No	Yes	Yes
Work with animals (Veterinarian, farmers, slaughter house, etc.)	Avoid	Avoid	Avoid	Review with MD
Carpentry work/ Woodworking	No	No	Yes-gloves and mask	Yes
<b>Household</b>				
Gardening**	Avoid	Avoid	Avoid	Review with MD
Indoor Plants (in place prior to transplant)	Yes	Yes	Yes	Yes
Mowing the lawn/Raking the leaves**	Avoid	Avoid	Avoid	Review with MD
Household cleaning (vacuuming, dusting)**	No	Yes	Yes	Yes
<b>Animals</b>				
New pets/Stray Animals	No	No	No	Yes
cats/dogs (already in the house)	Yes	Yes	Yes	Yes
Cat litter box- cleaning	Avoid	Avoid	Avoid	Review with MD
Reptiles/Birds/ Exotic pets	Avoid	Avoid	Avoid	Review with MD
<b>Recreational</b>				
Hot Tub/Swimming (no IV line)	No	No	No	Yes
Golfing (Wearing Sunscreen)	Yes	Yes	Yes	Yes
Spectator events (church, movies, games; no hand shaking)	No	No	Yes	Yes
Airline travel	No	No	Review with MD	Yes
Sexual activity (ANC>1.0, Platelets>50,000)	Yes	Yes	Yes	Yes
Drink alcohol (if of legal age)	No	No	Yes	Yes
Operate car or other motorized vehicle	No	Review with MD	Yes	Yes
Travel out of the Chapel Hill area by car	No	Yes	Yes	Yes
Having 24/7 caregiver	Yes	No	No	No
Exposure to adults or children with viral infections (cold, flu, etc.)	During first six months following transplant, recommend that patients stay away from infected people until viral infection has completely resolved and person has received clearance from their PCP			

**\*\*\* If receiving more than 1 Auto HCT, review with MD for any time period between the transplants**

\*\* Recommend wearing gloves and N95 mask

Version 1 Sept 2011









### Patient Care Conference

Patient Name: \_\_\_\_\_ MR # \_\_\_\_\_

Caregiver Name:  
\_\_\_\_\_

Family Members Present:  
\_\_\_\_\_

- ❑ **Conditioning Regimen:** The chemotherapy and/or radiation treatments used in the protocol or treatment plan are discussed. Potential side effects, therapy related toxicities, risks and benefits will be included. Alternatives to transplant therapy are discussed. A protocol or treatment consent form is reviewed and signed. A blood product transfusion consent form is signed.
- ❑ **Advance Directives:** The patient's living will is discussed. The potential for intubation and ventilator support is addressed. The patient's Health Care Power of Attorney is identified.
- ❑ **Pain Management:** The expectations for pain control during the hospitalization are solicited from the patient. The Nurse Manager discusses how the medical and nursing team will manage pain issues during the transplant.
- ❑ **Isolation Procedures:** Visitors must perform hand hygiene before entering patient's rooms. Visitors must not have fever, runny nose, sore throat, flu, vomiting, diarrhea, or rash. Visitors will not be allowed into the unit if they have had any live vaccines within the previous 6-8 weeks.
- ❑ **Visitor Guidelines:** Two- three guests in addition to the patient's caregiver are welcome at any one time during visiting hours. General visitation is from 9:00am to 9:00pm. There is no overnight visitation. Children 2 years and older are allowed to visit if they are accompanied by a supervising adult. The children will be screened by a BMT nurse to assure that they do not have any evidence of an active infection. Children under the age of 2 years are not allowed on the BMTU.
- ❑ **BMTU Room Assignments:** All transplant patients assigned a room on the BMTU will have a heap filtered room.
- ❑ **BMT Unit Policies:** Nursing assignments, medical rounds, unit routines, catheter care, infection control and dietary restrictions will be discussed. Bathrooms (toilets and showers) are for the patients only.
- ❑ **Role of the Caregiver:** The role and responsibilities of the caregiver are discussed. The patient designates a caregiver and a Patient-Caregiver Contract is signed.

- ❑ **Housing Arrangements:** The Social Worker will discuss housing options for the family during transplant and for both the patient and family following the transplant. Allogeneic patients will be required to stay in the area for 100 days after the transplant and autologous transplant patients will be required to stay in the area for 2-4 weeks after the transplant.
- ❑ **Financial Issues:** The Transplant Coordinator ensures that all financial issues to date have been addressed by the Financial Coordinator and the Social Worker.
- ❑ **Support Services:** An overview of the role of the support services staff is given which includes Social Work, Recreation Therapy, Physical Therapy, Nutritional Services and the Chaplain.

**For Pediatric Patients only:**

- ❑ **Visitation:** One parent may stay with the patient at all times. Both the Nurse Manager and the BMT Attending Physician must approve requests for other overnight guests.
  - ❑ **Bathroom Privileges:** Parents may use the private bathroom facilities if the child is too young to use the bathroom (i.e. infant).
- ❑ Changes to the above rules as a result of this meeting are as follows:

---

---

**I, the undersigned, agree that the above issues have been discussed. I have had the opportunity to ask questions and they were answered to my satisfaction. I understand that future changes in any of the above rules will require approval by the BMT Nurse Manager and the BMT Attending Physician.**

_____	_____
<i><b>Patient</b></i>	<i><b>Date</b></i>
_____	_____
<i><b>Caregiver</b></i>	<i><b>Date</b></i>
_____	_____
<i><b>Transplant Coordinator</b></i>	<i><b>Date</b></i>
_____	_____
<i><b>BMT Attending Physician</b></i>	<i><b>Date</b></i>

## UNC Hospital Patient Rights and Responsibilities

To help in assuring that you receive the best care possible, we have listed the rights and responsibilities that you have as a patient.

These are:

- **Respect and Dignity.** You have the right to considerate and respectful care, which will be provided to you at all times and under all circumstances, with recognition of your personal dignity.
- **Privacy and Confidentiality.** You have the right to privacy of your personal medical care. All communications and records pertaining to your care will be treated as confidential.
- **Caregiver Identification.** You have the right to know the identity and professional qualifications of individuals caring for you, and to know who is primarily responsible for your care. Information. You have the right to complete and accurate information about your diagnosis, treatment, and prognosis from your doctor. It will be communicated to you in a way that you can understand. You are responsible for providing your doctor with accurate and complete information about present complaints, past illnesses, hospitalizations, medications, demographics, and other matters relating to your health. You are encouraged to ask questions and to ask your doctor if you don't understand your care or treatment.
- **Medical Records.** You have the right to view the information contained in your hospital medical record.
- **Consent.** You have the right to participate in decisions involved in your health care. If alternatives for treatment exist, you will be informed of these alternatives. Advance directives will be recognized. You are responsible for making your doctor aware of your wishes as expressed by these documents.
- **Clinical Research.** You have the right to be advised if the hospital proposes to engage in or perform clinical investigation affecting your care or treatment. You have the right to refuse to participate in such research projects.
- **Refusal of Treatment.** You have the right to refuse treatment as permitted by law and to be informed of the medical consequences of such refusal.
- **Continuity of Care.** You have the right to expect reasonable continuity of care and advance notice of appointment times and physician availability. You are responsible for the treatment plans recommended by your doctor. If an appointment must be missed, you are responsible for notifying the doctor's office as soon as possible.
- **Hospital Charges.** You have the right to request and receive itemized and detailed explanations of the total charges for your hospital care. You are responsible for assuring that the financial obligations for your health care are fulfilled in a reasonable amount of time.