A PATIENT’S GUIDE TO BONE MARROW TRANSPLANTATION

Table of Contents

I. Directions to UAB
II. About Birmingham
III. Maps of Birmingham and UAB Hospital
IV. Introduction
   • Patient Confidentiality
   • Important phone numbers
   • Resources
   • Parking
   • Lodging
V. Medical Terms and the Human Body
VI. The BMT Staff
VII. Pre-Transplant Evaluation
VIII. Final Evaluation
IX. Central Venous Catheters
X. Peripheral Stem Cell Collection
XI. Preparing for admission
XII. Admission Teaching
XIII. Chemotherapy
XIV. Transplant Day
XV. The First 30 Days after Transplant
XVI. Dietary
   • Neutropenic Diet
XVII. Discharge
XVIII. Outpatient Clinic
XIX. Medical Alert Information
XX. Home Environment
XXI. Discharge Test
XXII. Hickman Catheter Care Instructions
XXIII. Long Term Follow-up
Directions to UAB Hospital

If traveling from Birmingham International Airport.
Follow I-20/59 West/South toward downtown Birmingham. Exit at Highway 31/280 (Exit 126A). Proceed on Highway 31/280 and exit at 8th Avenue South (University Boulevard). Turn right onto University Boulevard and proceed to 18th Street. Turn right. Go four blocks to 4th Avenue South and turn right. Halfway down the block, the entrance to the University Hospital parking deck will be on your right. Airport transportation for international patients may be arranged by calling International Patient Services at (205) 934-2096.

If traveling south on I-65.
Exit at 4th Avenue South (Exit 259B). Proceed through the intersection of 4th Avenue South and 18th Street. Halfway down the next block, the entrance to the University Hospital parking deck will be on your right.

If traveling north on I-65.
Exit at University Boulevard (Exit 259). Proceed to 18th Street and turn left. Go four blocks to 4th Avenue South and turn right. Halfway down the block, the entrance to the University Hospital parking deck will be on your right.

If traveling west on Highway 280.
Follow Highway 280 until it merges to the right with Highway 31 North and becomes the Elton B. Stephens Expressway. Proceed north and exit at 8th Avenue South (University Boulevard). Turn right onto University Boulevard and proceed to 18th Street. Turn right. Go four blocks to 4th Avenue South and turn right. Halfway down the block, the entrance to the University Hospital parking deck will be on your right.

If going to Highlands.
However you get to UAB come that way. When you get to the downtown area, you will get on University Boulevard (also called 8th Ave south) and turn onto 13th street south. If you have come from I-65 then you will turn right onto 13th street. If you have come from Highway 280, you will turn left onto 13th street. Go to 11th Ave south. The hospital will be on your right and the parking lot will be on your left. The address is 1201 11th Ave South, Birmingham, Alabama 35205.
The Kirklin Clinic at Acton Road
Map and Directions

Directions:
From Interstate 65, exit onto Interstate 459 toward Atlanta (Exit 250).
Proceed two miles and exit at Acton Road (Exit 17).
Turn left onto Acton Road and proceed 0.4 miles.
Turn right at the second traffic signal (Elmer J. Bissell Road).
Proceed 0.1 miles and turn right onto Bonner Way to enter the clinic.

From U.S. Highway 280, turn onto Interstate 459 toward Tuscaloosa.
Proceed two miles and exit at Acton Road (Exit 17).
Turn right onto Acton Road, then take the first right (Elmer J. Bissell Road).
The clinic is on Bonner Way immediately on your right.
Founded in 1871, the City of Birmingham blossomed into an industrial center and was known for its iron and steel production. Birmingham's early growth was so rapid and dramatic that it was nicknamed "The Magic City."

Because of its rapid growth in the late 19th and early 20th centuries, Birmingham has an international flavor and ethnic diversity that are unusual in the South. This diversity has been enhanced in the last two decades by the phenomenal growth of UAB, which is now the area's largest employer. The population of the metropolitan area is now almost a million people, making Birmingham large enough to be cosmopolitan, yet small enough to navigate easily.

Historically known for steel and iron production, Birmingham's economy now includes both manufacturing and service industries, especially health care.

Although it enjoys a generally mild Southern climate, Birmingham enjoys all four seasons. The weather allows residents and visitors to enjoy the city's wide variety of attractions such as year-round golf on top-notch courses including the Robert Trent Jones Golf trail, terrific restaurants and shopping, jazz clubs, Railroad Park, Ruffner Mountain, Botanical Gardens, Oak Mountain State Park, the Birmingham Civil Rights Institute, the Birmingham Zoo, and McWane Science Center.
Birmingham combines big city sophistication with Southern charm and hospitality. A temperate climate adds to the city's appeal.

Home to nearly a million residents, the greater Birmingham area lies in the gently rolling foothills of the Appalachians. The Gulf's pristine white beaches are a few hours' drive to the south, and the Smoky Mountains are a few hours to the north. Atlanta is but a two hour drive and Nashville is only three hours from Birmingham.
Major Malls

Riverchase Galleria
I-459 at Highway 31 South
205-985-3039
Housed beneath the world’s longest skylight, the Galleria’s 200 specialty shops and stores include Parisian, Rich’s-Macy’s, Godiva Chocolatier, Banana Republic, the Disney store, San Francisco Music Box, Barnie’s Coffee and Tea, and the Discovery Channel store. A huge center food court offers hamburgers, salads, tacos, deli sandwiches and other quick food.

The Summit
I-459 at Highway 280
(205) 967-0111
Among the area’s newest shopping malls. The Summit includes unique stores, such as Williams-Sonoma, the Gourmet Kitchen and home entertainment retailer; Old Navy; SAKS, well known for quality, affordable men’s and women’s fashions; Eddie Bauer, casual lifestyle sportswear and accessories; Talbots, and Bed, Bath & Beyond. Surrounding restaurants: Cheesecake Factory, The California Pizza Kitchen, Macaroni Grill, Johnny Rocket’s, and PF Changs. Entertainment: Carmike Cinema

Brookwood Village
Lakeshore Parkway; (205) 871-0406
Macy’s and Belk’s department stores anchor this well designed, two-level mall. Recently Renovated Brookwood Village also includes Brookstone, Betsy Prince, Victoria Secret, and a number of other specialty and gift shops for a total of more than 70 businesses. A food court and full service restaurants serve a variety of quick and delicious menus for shoppers.

Discount Stores within 10 miles

Walmart – 209 Lakeshore Parkway
Kmart – 7845 Crestwood Blvd
Kmart – 230 Green Springs Highway
CVS/Pharmacy – UAB area – 1431 11th Avenue South
CVS/Pharmacy – 3300 Clairmont Plaza /S
CVS/Pharmacy – Downtown 221 20th Street North
CVS/Pharmacy – Homewood 418 West Valley Avenue
Dollar Tree – Palisades of Birmingham
Dollar Tree – 223 Lakeshore Pkwy Homewood
Fred’s – 234 Green Springs Hwy Homewood
Sally’s Beauty Supply – 210 Green Spring Hwy Homewood 7001 Crestwood Blvd
Dry Cleaners:

Berthon’s Cleaners –
2201 7th Avenue South

Flamingo Dry Cleaners –
3330 Clairmont Avenue

Coin Laundries –
1909 11th Avenue South

Spin Cleaners –
201 Richard Arrington Blvd South

Sani-Clean Laundromat –
3008 12th Avenue North

Grocery Stores

Piggly Wiggly – 3314 Clairmont Avenue

Western Supermarket – 2230 Highland Avenue South

Food World - 216 Green Springs Hwy

Area Restaurants

Arby’s – 7th Ave. & 21st St.

Becky’s South(burgers and sandwiches) – University blvd & 20th St

Burger King – 6th Ave south & 16th St

Captain D’s – 5th Ave south & 16th St

China Master's Express – 4th Ave & 18th St
## Appointment Log

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Questions for my doctor

Questions for my coordinator

Questions for my nurse practitioner
Introduction
The purpose of this booklet is to answer some of the most commonly asked questions about your upcoming stem cell or Bone Marrow Transplant (often called “BMT”).
The doctors and nurses at UAB Hospital will be talking with you about what will happen during your stem cell transplant. Knowing what to expect will make things easier for you. Please feel free to share the information in this booklet with your family and friends. Also, make notes in the booklet about questions you want to ask the staff. **Please bring this book with you to the hospital any time you are admitted.** The nurses will use it to help assist in teaching you about your treatment and what to expect.

Patient Confidentiality
Because we are in the business of providing health care services, University Hospital has a special responsibility to the patients we serve. Patient records, results of tests, diagnoses and other materials in our possession which relate to our patients must be held in the strictest confidence. No patient information shall be revealed to anyone outside of University Hospital without a court order or the expressed written authorization of the patient, his/her guardian, executor, or administrator. Any requests for the release of records must be managed by the UAB Medical Records Department.

Patient information must be held in confidence even inside University Hospital. Employees are required to sign a confidentiality agreement and are required to guard your medical information from others. **For this reason, we must ask that you and your family refrain from sitting/standing behind the desk area or in the hallway where other patients’ confidential information may be kept or overheard.** This also includes computer space/print outs or chart information. Also, the medical staff cannot answer specific questions regarding another patient’s status or care. Please help us maintain a confidential environment for you and our other patients. Thank you.
Important Phone Numbers

PRE-BMT COORDINATORS: 205-934-1911

Diana Tate, RN, BSN
Pat Lyons, RN, MSN
Megan Boullion, RN, BSN, OCN
Amy Flynn, RN, BSN, OCN

PATIENT SERVICES COORDINATOR: 205-934-1911

Jona Duncan, AAS

PATIENT SERVICES ASSISTANT: 205-934-1911

BMT PHYSICIANS: 205-934-1908

Shin Mineishi, M.D.
Donna Salzman, M.D.
Racquel Innis-Shelton, M.D.
Ayman Saad, M.D.

BMT NURSE MANAGER: 205-934-7355

Wendy Madden, RN, BSN, OCN

BMT NURSE PRACTITIONERS: 205-975-2236

Christine Mazumba, DNP, CRNP
Amy Nance, MSN, CRNP
Melissa Sentell, MSN, CRNP
Binita Parekh, MSN, CRNP
Melinda Rogers, MSN, CRNP
Aaron Streufert, MSN, CRNP

POST-BMT NURSE CLINICIANS: 205-975-2236

Lydia Deivanayagam, RN, BSN, OCN
Sharon Jones, RN, BSN

BMT INPATIENT UNIT: 205-934-7102
BMT OUTPATIENT CLINIC: 205-975-2236

For pre-transplant questions please call the coordinator’s office.
For questions after your final evaluation please call your nurse practitioner.
For life-threatening emergencies call 911.
Resources

American Cancer Society http://www.cancer.org

The Bone Marrow Foundation http://www.bonemarrow.org

National Cancer Institute http://www.cancer.gov

Leukemia Society of America http://www.leukemia.org

National Marrow Donor Program (NMDP) http://www.marrow.org

UABH Bone Marrow Program http://www.bonemarrow.uab.edu
Parking

- We have a long-term parking option in the lot behind the Women’s and Infant Center (one block west of the 4th Avenue deck). Guests can park there for $20 per week (as opposed to $42 per week in the 4th Avenue deck). Guests can get info on this option and the parking tag from the Park Rite desk in the 4th Avenue deck of the 2nd floor North Pavilion guest services desk.

- Parking Decks- There are several parking decks for family and/or visitors to use. The closest one is the 4th Ave South deck. It is open 24 hours a day. The maximum cost per day is $6.00. Validated parking is not an option at UAB.

- Family members or visitors can park on the street in a metered parking space. Please be advised there are very diligent meter maids here in the UAB area, and if visitors exceed their allotted time, they will most likely get a parking ticket. If the person is going to be here longer than 2 hours, we do not recommend parking on the street. The exception to this is after 6:00pm on weekdays and all weekends. In the off hours, parking is free. Also, please advise anyone parking on the street that they must be in a metered space. If they park in a non-designated space or in a loading zone, they will most likely get a ticket.

- If you have a room in the Townhouse or Hope Lodge after discharge, there is parking available for each of those facilities.
Lodging

When a person has made the decision to have a transplant and they live outside of the Birmingham area, the Bone Marrow Program tries to find local housing for them to stay in both before they are admitted to the hospital and once they are discharged. We understand the financial hardship that funding a hotel stay can impose on a patient, so we do try very hard to provide free housing. However, there is limited space, and often there are times that there are no rooms available. In some cases the patient’s insurance may have a housing allowance. To know if that is available to you, you can speak with your insurance case manager or your pre-transplant coordinator.

Three places commonly used by BMT patients and caregivers include the Hope Lodge, UAB Townhouse, and the Church of Christ apartments.

**The Hope Lodge** 205-558-7861

1104 Ireland Way
Birmingham, Al 35205

A reservation must be faxed over to hold a room for you, and of course there is no guarantee that a room will be available. Your coordinator or clinician will be glad to send a request for a room for you. Children are not allowed at the Hope Lodge. The Hope Lodge has a community kitchen; absolutely no eating is allowed in your room.

Directions to the Hope Lodge:

Start at the corner of 619 19th St S, Birmingham, going toward 7th Avenue South. Go 0.5 miles. Turn left on 11th Avenue South, go 0.2 miles. Continue on 11th Court South and go 0.2 miles. Turn left on Ireland Way and go 0.1 miles. Arrive at 1190 Ireland Way.

**The UAB Townhouse** 205-975-8820

2008 University Blvd.
Birmingham, Al 35205

The social worker will work with your coordinator or clinician to arrange a room for you. You must be there to pick up your key by 4 pm. If you are checking in after 4 pm, please let the townhouse know. They will gladly take your key to the information desk in the North Pavilion for you to pick up later. If you are checking
out before 4 pm, go through the office. But, if it is after 4 pm put the key in the drop box.

There is transportation available for the Hope Lodge and The UAB Townhouse through UAB Escort services. Their phone # is 934-2028. With other apartments you are responsible for your own transportation.

Rules for the Townhouse:

- While the patient is in the hospital the family must give up the room, unless special arrangements have been made. Those arrangements need to be communicated to the BMT social worker. If a family would like to request a room for a weekend, they can do so by talking with the BMT social worker. However, outpatients get first priority for rooms.
- If you decide not to use the room that is reserved for you, please notify your coordinator or clinician as soon as possible. Remember, rooms are always on short supply and not notifying someone may make another patient have to pay for a hotel room.
- Absolutely no smoking on the Townhouse property. If you are caught smoking, you will be asked to leave the townhouse, and at that point you are responsible for finding your own housing
- Absolutely no pets are allowed.
- You will be given a parking permit when you check-in to the townhouse. The permits are only valid for the designated parking lots. Your parking pass will have an expiration date on it, but it may not correlate to the check out date you have been given by your coordinator or clinician.

The Church of Christ Apartments

1245 29th Street South
Birmingham, Al 35205

Turn onto University Blvd. Going toward St. Vincent’s Hospital, go under the overpass and pass the hospital on the right. McDonald’s is on the right. Turn right onto 28th Street at the light. This will dead-end into Highland Court. Take a left and go 2 blocks. At 29th Street South, turn right. Apartments are on the left next to a two story gray house which has a brick fence. The number 1245 is difficult to see.
Medical Terms and the Human Body

**ABGs (arterial blood gas)**- a specimen of blood drawn from an artery to check the oxygen level of your blood. It is used to see how well you are breathing.

**Anemia**- A decrease in the number of red blood cells.

**Antibiotic**- a medication used to treat a bacterial infection. The term is sometimes used for drugs that treat viral or fungal infections.

**Anti-emetic**- a medication used to control nausea and vomiting.

**BID**- twice a day

**Bilirubin**- is one of the waste products when old red blood cells are broken down by the liver. An increase in the bilirubin can also be caused by an obstruction in the normal flow of bile. This obstruction may be in the liver, hepatic ducts, or the common bile duct. This lab will be monitored as needed during your transplant to assess your liver function.

**Biopsy**- the removal of tissue which is then examined under a microscope.

**Bone Marrow**- Bone marrow, located in the center of your bones, is the place where blood cells are made. Usually just the flat and long bones are responsible for the production of blood cells. These blood cells (called stem cells) are produced in the marrow and mature to become red blood cells, white blood cells and platelets. These cells are then released into the blood where they perform many functions.

**Blood Counts**- There are 3 types of blood cells (all of which originate from the stem cell): red blood cells, white blood cells, and platelets.

- **Red blood cells** - The red blood cells carry oxygen, so if the number of red blood cells is decreased (anemia) you might be short of breath, tired, weak, and pale.

We call the red blood cell count the packed cell volume or hematocrit (hct.) The usual value is 37% to 47%, however a hematocrit of 26% or greater would be
acceptable for someone who has previously had chemotherapy. If your hematocrit falls too low, your doctor will order a transfusion of packed red blood cells for you.

When your red blood cell count is low, there are a few things that you can do to conserve your energy. First, spread out your daily activities so you can arrange frequent rest periods between activities. Secondly, don’t try to move too quickly from one position to another. If you are lying down, slowly sit up, and after sitting a minute, stand up. If you move too quickly you might get dizzy and lose your balance.

- **White blood cells** (WBC) - fight infection and help provide defense against infections. A normal WBC count is 4,000 to 11,000. Granulocytes are one kind of white blood cell. When we are referring to your ability to fight infection, we are concerned with the number granulocytes that you have. “Segs” and “bands” are the names of the granulocytes that are mature and effective in the fight against infection.

We can calculate your absolute neutrophil count (ANC). This tells us the number of mature “fighters” that you have. If you have a WBC of 500, we will order a report from the lab (called “differential”) which will include how many of each type of white blood cell that you have. We will add the percentage of segs and bands and then take the percentage of the total WBC count to calculate your ANC (Segs + Bands x WBC = ANC). This tells us about the recovery of your bone marrow as well as your body’s ability to fight infection.

It is important for you to monitor your body for signs of infection. If you notice any of the following you should alert your nurse right away: fever, pain, redness, tenderness or swelling anywhere on your body, chills, burning when using the bathroom, diarrhea, cough, runny nose, or drainage from any part of your body. We will also monitor you closely, but to be most effective we need your help.

Growth factor drugs such as Neupogen or Leukine are sometimes used in an attempt to speed up your white blood cell recovery. Your NP or Nurse will discuss these medications with you in more detail.

- **Platelets** – are the blood cells that help to form blood clots. If your platelet count gets too low, you may have some bleeding. Your doctor and nurses
will examine you daily in an attempt to locate any signs of bleeding while your blood counts are low. Frequently, the patient is the first to notice any signs or symptoms of bleeding. You should look on your skin for any bruises or small purplish spots called petechiae. Petechiae are caused by small breaks in the capillaries under the skin. Any bleeding from your gums, nose, rectum, bladder, or when coughing, must be reported. Women should report any menstrual bleeding even if you think it is time for your period. The development of a headache or blurred vision should be reported also. If you develop nausea or a cough, you should report this to your nurse so that you can get some medication. The normal platelet count is 150,000 to 350,000. However, your platelet count will have to get very low for there to be any bleeding. If your platelet count gets too low, your doctor may order a platelet transfusion.

**Chemotherapy**- The use of drugs or medications to kill malignant cells. The purpose is to injure the DNA of the cells. When the DNA is injured, the cells cannot grow or survive. The success of chemotherapy depends on the malignant cell being sensitive to the chemicals.

**Conditioning Treatment**- The chemotherapy or radiation therapy given before a transplant is called the conditioning treatment. The treatment is usually given in very high doses and serves to greatly reduce the number of tumor cells.

**Cryopreservation**- The technique used to keep frozen cells intact and functional for many years. The chemical DMSO is one of the more commonly used agents. The freezing temperature is much lower (colder) than that of a household freezer.

**CMV (cytomegalovirus)**- a virus that is usually harmless in healthy people but can cause pneumonia or other infections in the BMT patients.

**GI (gastrointestinal tract)**- refers to the part of your body where food is processed. Begins with the mouth and ends at the rectum.

**Heart**- The heart is a four-chambered, muscular organ that lies in the chest cavity under the ribs, slightly to the left of the sternum (breast bone). Your heart pumps blood throughout the body so that oxygen and nutrients are carried to all parts of your body.
**Hematopoiesis** - The process of blood cell development in the bone marrow. It is a continuous process that is active throughout life.

**Immune System** - Cells and proteins that defend the body against infection. The bone marrow, lymph nodes, lymphocytes and spleen are some of the parts of the immune system.

**IV (intravenous)** - When fluids or medications are put into the vein.

**Kidneys** - The kidney is essential in maintaining water, salt, and electrolyte balance and is an endocrine gland that secretes at least three hormones. The kidney helps to control blood pressure and is susceptible to damage if blood pressure is too high or too low.

**Lymph Nodes** - They are small structures about the size of a bean that contain large numbers of lymphocytes and are connected to each other by small channels. They are distributed throughout the body.

**Liver** - As your body works each day, waste products are made that must be removed. Your liver and kidneys are responsible for monitoring the blood for waste products and removing them. Certain medicines can also build up in your body and must be filtered or removed from the bloodstream.

**LP (lumbar puncture)** - A procedure or test in which a small needle is inserted into the fluid around the spinal cord to give medications or take a sample of fluid for tests.

**Lungs** - The role of the respiratory system is to provide for the exchange of oxygen and carbon dioxide between the air and the blood. For this gas exchange to occur, the heart and lungs must work together. The heart is responsible for the flow of blood through the lungs. The lungs are responsible for respiration.

**Magnesium** - (Mg) is an electrolyte that is found inside the cell. Magnesium is necessary for muscle function. Magnesium is excreted mostly by the kidneys, and the normal range is 1.5-2.0. Some drugs like cyclosporine (CSA) may cause a decrease in magnesium. Signs and symptoms of low magnesium include tremors, muscle cramps, and insomnia. We will replace this electrolyte as needed during the transplant process.
**Mucous Membranes**- This is the inner lining of the mouth, nose and sinuses. These cells are replaced by new ones on a regular basis to keep the lining intact and moist. Chemotherapy and/or radiation therapy can block the cells from replacing themselves as needed. This can cause dry and painful mucous membranes. The loss of their protective barrier can also lead to infection.

**Myeloablation**- The severe or complete depletion of bone marrow cells. Myeloablative therapy completely eliminates an individual’s ability to make blood cells.

**Neutropenia**- A decrease below normal in the number of neutrophils.

**NPO**- nothing to eat or drink by mouth.

**Pancytopenia**- A decrease below normal levels in the concentration of the 3 major blood cell structures: red cells, white cells, and platelets

**Petechiae**- tiny bruises that look like small dark purple spots under the skin.

**Potassium**-(K) is an electrolyte that is found inside the cell and in the blood, and is necessary for muscle and heart function. You may lose a lot of potassium through your GI tract (diarrhea) or kidneys.

Normal levels are 3.5-5.0. We will replace this electrolyte frequently during the transplant process.

**Prophylaxis**- a medicine or treatment given to prevent complications.

**PT**- physical therapy or therapist.

**QD**- every day.

**QID**- four times a day.

**QOD**- every other day.

**Thrombocytopenia**- A decrease below normal in the number of blood platelets.

**TID**- three times a day.

**TPN (total parenteral nutrition)**- an IV solution with high nutritional content given through your catheter instead of food by mouth.
Types of Transplants

Your BMT physician has determined that an Autologous transplant is the best option for your specific disease. Autologous transplant: Auto means “from self”. The bone marrow stem cells are going to be collected from you and frozen until you are ready for your transplant. On transplant day, your stem cells will be taken out of the freezer and thawed at your bedside by your nurse and then infused to you. The process is much like a blood transfusion. We will learn more about this in later sections.

The Donation Process

- The Apheresis Process- The process of removing components of a person’s blood and returning the unneeded parts to the patient. Apheresis uses continuous circulation of blood through a machine and back to the patient. In this process, desired elements are removed from large volumes of blood.
- The process of making your bone marrow grow enough stem cells for collection is called mobilization.
- Neupogen Mobilization of Stem Cells- Patient can have their stem cells mobilized using neupogen. A nurse will instruct you on the neupogen dose you will need to take daily, how to give the injection, and what precautions to take. You will be given an appointment to return to the outpatient clinic for lab work the day before you are “scheduled” to begin stem cell collection. Collection of stem cells is based on the individual patient and will only begin when your lab results indicate you are ready.
- Stem cell collection is performed in the BMT outpatient clinic by technicians and registered nurses. You should eat a good breakfast the day of the procedure and bring a sack lunch, or you may send a family member to get lunch for you. The apheresis process takes about 6 hours to complete; however, additional time may be required for lab work and replacement of electrolytes after the apheresis. The average person is here for 6-7 hours total on a collection day. You may want to bring a book or something to occupy your time because you will be here most of the day while your stem cells are being collected.
- Medications: You may be instructed to bring some previously prescribed medications with you to stem cell collection, so please remember these. You will be instructed to take them by the nurse if you start experiencing side effects.
• A word about Neupogen- There are a few common side effects of Neupogen that you need to be aware of. Sometimes patients say the medicine stings when it is being injected. That is nothing to worry about, and the stinging stops within a few minutes. After several doses, some patients report a few or all of the following: headache, bone pain, or muscle aches like you have the flu. Make sure you take your pain medicine to help with the symptoms.

• There is on occasion that the donor will need to go to the operating room for a traditional bone marrow harvest. If this is the case in your transplant, the BMT team will explain how the process works and give you all the needed information.
The BMT Staff

There are a number of people on the Bone Marrow Transplant Team. You will meet many of them beginning with your first visit to UAB. The information below tells you what different members of the team do. We hope this will help you know which person can best answer your questions. Don’t forget, you can write your questions in this booklet.

- **Physicians**- The BMT physician is a specialist in the diagnosis and treatment of blood and cancer diseases and will be your primary UAB BMT doctor. He or she becomes the manager of your care before and after your bone marrow transplant. He or she will communicate with your personal hematologist/oncologist throughout the entire bone marrow transplant process. This will help your treatment flow as smoothly as possible. Your primary doctor is called the “attending”. In addition to the attending, Hematology/Oncology “fellows”, who are doctors in the final stages of their training as a cancer specialist will play a role in your patient care. The attending and fellow may rotate periodically during your hospitalization.

- **BMT Nurse Coordinators**- The transplant nurse coordinator is a registered nurse who will give educational information to you and your family, as well as arrange certain tests required before transplant. The coordinator will meet with you and will talk with you by phone about the information in this booklet and is available to answer general questions.

- **Nurse Practitioners**- Nurse Practitioners are specially trained advanced practice nurses who assist the BMT physicians with providing care for you during all phases of the BMT process - both inpatient and outpatient.

- **BMT Nurse Manager**- The nurse manager is available to assist the nursing staff with managerial and complex clinical situations. Your satisfaction with the care provided by the unit staff is very important to us, therefore, the nurse manager is available to see you during your hospitalization to ensure that any concerns are addressed. Please feel free to discuss issues that are important to you or your family. The BMT nurse manager is: **Wendy Madden, R.N., B.S.N.**

- **Charge Nurse**- The charge nurse is available to assist with day-to-day management of the unit. Each 12-hour shift has an assigned charge nurse for that shift. The charge nurse is responsible for patient assignments, staffing, and daily duties of the unit. If you have a question or concern, please do not hesitate to ask to speak with the charge nurse.
• **BMT Staff Nurses**- The nursing staff on the Bone Marrow Transplant Unit has been specially trained in caring for patients having stem cell transplants. The nurses will be participating actively with your doctor in planning and providing your care. Please feel free to ask questions and express your concerns to them. You will have an assigned registered nurse to take care of you each 12-hour shift. He/She will assist you with your daily needs by giving you medications and performing physical assessments every 4 hours and as needed.

• **Pharmacist**- You will be taking medicines after your transplant that you need to learn about. The pharmacist can answer questions such as how and when to take your medicine, how much to take, and how to store the medicines. Please do not change anything about your medicines unless specifically instructed to do so by your doctor or nurse practitioner.

• **Social Worker**- The social worker can give you information about insurance, medication assistance or financial help if you need it. The social worker can also assist with arrangements for housing if needed after the transplant. The social worker is also a good person to talk with about the stresses of having a transplant.

  The Social Worker is: Alicia Womack (996-9449) Beeper # 7247

• **Dietitian**- It’s important to eat the right foods before and after your transplant. The dietitian will plan your special diet during your hospitalization and can answer your questions about what to eat after you go home. You will be seen by the dietician prior to discharge. (205-934-4560)

  **Chaplain**- The chaplain is a member of the hospital’s Pastoral Care Department. The chaplain is available to offer support in dealing with the stress of the transplant. There are services scheduled in the hospital chapel if your family and other visitors would like to attend. There is always a chaplain on call if you or your family wants this support. A chaplain may be reached by dialing Guest Services @ *55 from your room.

• **Unit Secretary**- The Unit Secretary will answer your call light and ensure orders regarding your care are communicated to the nurse.

• **Patient Care Technicians**- The PCT will assist you with showering and daily activities, including measuring your urine output, taking vital signs, and performing EKGs.

• **Unit Support Staff**- The USS is responsible for cleaning your room daily, changing your linens, and passing out your meals and snacks.
Once you have made the decision to proceed with transplant you will need to have a pre-transplant evaluation consisting of several tests. These tests are done on an outpatient basis to determine if your body is able to tolerate transplant. Your BMT coordinator will explain these tests and arrange your schedule for you. Various members of the transplant team will interview you as part of the evaluation process. Some of these interviews may include questions you have already answered with other staff members. Please be patient with all these questions. We need all the information you tell each team member so we can assist you to make the best decisions regarding a stem cell transplant. Below is a list of tests that may be ordered for you depending on your disease and history. The transplant team physicians will determine which tests are necessary for you.

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

- **Pulmonary Function Tests (PFT):** This test determines how well your lungs are working.

- **Echocardiogram:** This is an ultrasound of the heart used to look at the function.

- **MUGA Scan or Stress Test:** These tests measure overall cardiac or heart function.

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

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

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

- **Bone Scan:** This test is done to see if there is any disease present in the bones.
• Blood and Urine Tests: These tests are done to see how well your kidney, liver and bone marrow are working. You may also receive a container to perform a 24 hour urine collection at home. Specific instructions will be provided.

• Infectious Disease Markers (IDM’S): Blood samples are drawn to test for a number of infectious disease markers to identify infections such as hepatitis.

• Psychosocial Evaluation: All of our patients being evaluated for transplant are requested to meet with our transplant social worker or psychologist, particularly if you are having an allogeneic transplant. This meeting will take at least an hour.

• Dental Evaluation: We may request that you have a dental visit prior to transplant. If you are instructed to see the dentist, please take the dental letter given to you to your dentist’s office and have it completed before the day you sign the consents.

• Gynecological Exam: We require that all of our female transplant patients have a gynecological exam, including Pap smear, within one year prior to transplant. If you are over the age of 40 you will need to have had a mammogram within the last year. Please provide your gynecological doctor’s name and office number to your transplant coordinator. All female patients will have a pregnancy test if appropriate during the transplant evaluation and within seven days of starting mobilization and transplant chemotherapy. The menstrual cycle will need to be suppressed. This will be discussed with you during the month prior to transplant.

• Lumbar Puncture: In certain diseases it is required to have a lumbar puncture prior to admission for transplant.

• Colonoscopy: For all patients age 50 and over a colonoscopy report is required prior to signing consent for stem cell collection and/or transplant. Your coordinator will talk with you about where the procedure was done and how he/she can get a copy of the report. If it has been more than 10 years since your last colonoscopy, the BMT physicians may require you to have it repeated before you can proceed.
Final Evaluation

After your work up testing is complete you will be given a date to sign the consent forms agreeing to move forward with the stem cell collection and transplant process. The day you sign the consents is called the “Final Evaluation”. The final evaluation day happens on the Bone Marrow Transplant unit. The process usually takes 4-5 hours. During that time, you will meet your nurse practitioner. She will review your history, test results and go through the consent process with you. She will also confirm the schedule that your coordinator has made for you. It is required that at least 1 of your caregivers attend this meeting. You will be given the opportunity to ask any questions you may have.

During the final evaluation process, you will also be given any prescriptions you will need for either the stem cell collection process or for transplant admission. It is important that you know when to get them filled and how to take them.

Central Venous Catheters

Hickmans and Permcaths

Central venous catheters are hollow tubes made of a special material. They are used to draw blood, give you medicines and blood products. In general, patients who are having an autologous transplant will have 1 permcath and 1 double lumen hickman catheter. The exception to this is patients with Myeloma. Myeloma patients generally only have 1 permcath.

Most of our patient’s catheters are placed in the Interventional Radiology Department on the 6th floor of the North Pavilion. You will report to the BMT outpatient clinic and then be taken to Interventional Radiology for the procedure. After the procedure you will return back to the outpatient area. You will have received sedating medications. YOU WILL NEED SOMEONE TO DRIVE YOU HOME. If you need to have a surgeon place your catheter(s), your coordinator and nurse practitioner will talk with you about the procedure.

A prescription for pain medication will be given to you by your nurse practitioner. You should have this prescription filled before your line placement.

Care of the catheter(s) and insertion site is discussed in another section of this book.
Instructions for Interventional Radiology Procedures

Food: Procedure is before Noon - Clear liquids after midnight. You can drink clear liquids up until 2 hours before the procedure. This includes: black coffee, water, sprite, but not fruit juices.
Procedure is after Noon - May eat light breakfast by 6:00 a.m., then may have clear liquids until procedure time. A light breakfast consists of toast, coffee, cereal. NO dairy. NO fried or greasy food.

Regular Medicine: Take your regular morning medicines as normal, including your pain medicine. The only exceptions are listed below.

Insulin: Take only ½ your normal dose on the day of the procedure.

Diabetic Medicine: Do not take morning of procedure.

Glucophage: Do not take morning of procedure and hold for 48 hours after procedure.

Coumadin: 1. If Coumadin is taken due to prosthetic valve, your physician will determine adjustment of this drug.

2. In all other cases, stop your Coumadin 3 days prior to procedure. Example: you are scheduled to have your procedure Wednesday, your last dose of Coumadin would be Saturday.

Lovenox: Do not take morning of procedure.

Conscious Sedation: A responsible adult must accompany you. You will be unable to drive.
Peripheral Stem Cell Collection

The Apheresis Process - The process of removing components of a donor’s blood and returning the unneeded parts to the donor. Apheresis uses continuous circulation of blood through a machine and back to the donor. In this process, desired elements are removed from large volumes of blood.

There are several ways to collect stem cells for an autologous transplant. The process of making your bone marrow grow enough stem cells for collection is called mobilization.

- Neupogen and Chemotherapy Mobilization of Stem Cells

If you are having chemotherapy to help with mobilization for you stem cells, the length of time you are here will be determined by your chemo dose. You may only spend the day in the out-patient clinic or you could be admitted to the Bone Marrow unit for 24 or 48 hours and then discharged home. After your chemotherapy is complete, you will start taking the neupogen injections to help increase the stem cell count. Please look at your calendar and talk with your nurse practitioner to make sure you know when to begin the injections. You should have your neupogen prescription filled before you get the chemotherapy. Your nurse will instruct you on the neupogen dose you will need to take daily, how to give the injection, and what precautions to take after receiving the chemotherapy. You will be given an appointment to return to the outpatient clinic for lab work the day before you are “scheduled” to begin stem cell collection. Collection of stem cells is based on the individual patient and will only begin when your lab results indicate you are ready.

- Neupogen Only Mobilization of Stem Cells

Some patients have their stem cells mobilized using neupogen without chemotherapy. A nurse will instruct you on the neupogen dose you will need to take daily, how to give the injection, and what precautions to take after. You will be given an appointment to return to the outpatient clinic for lab work the day before you are “scheduled” to begin stem cell collection. Collection of stem cells is based on the individual patient and will only begin when your lab results indicate you are ready.
Stem Cell Collection

Stem cell collection is performed in the BMT outpatient clinic by technicians and registered nurses. You should eat a good breakfast the day of the procedure and bring a sack lunch, or you may send a family member to get lunch for you. The apheresis process takes about 6 hours to complete; however, additional time will be required for lab work and replacement of electrolytes after the apheresis. The average person is here for 7-9 hours total on a collection day. It may take up to three days to obtain enough stem cells for the transplant. You may want to bring a book or something to occupy your time because you will be here most of the day while your stem cells are being collected.

Medications: You may be instructed to bring some previously prescribed medications with you to stem cell collection, so please remember these. You will be instructed to take them by the nurse if you start experiencing side effects.

A word about Neupogen:

There are a few common side effects of Neupogen that you need to be aware of. Sometimes patients say the medicine stings when it is being injected. That is nothing to worry about, and the stinging stops within a few minutes. After several doses, some patients report a few or all of the following: headache, bone pain, or muscle aches like you have the flu. Make sure you take your pain medicine to help with the symptoms.

A word about Blood Cultures:

If you have an indwelling catheter (usually a mediport) we will collect blood cultures from it at the time of your work up for collection. If you don’t come to us with a mediport, we will draw blood cultures after your line for collection is put in.

IT IS IMPORTANT TO KNOW: If you get a phone call from anyone in the BMT program about a positive blood culture report, YOU MUST return to the BMT unit immediately if instructed to do so, NO MATTER WHAT TIME OF THE DAY OR NIGHT. The practitioner may also instruct you to go to a local ER department for additional tests. IF YOU HAVE AN INFECTION, NOT FOLLOWING OUR INSTRUCTIONS CAN BE LIFE THREATENING.
Preparing For Admission

What to Pack

You will be admitted to a unit of the hospital called the Bone Marrow Transplant Unit. You will be in a private room that has a specially designed air flow system to decrease your exposure to germs (Hepa Filtration system). Everything you bring to the unit needs to be new or freshly laundered. If you want to sleep on pillows like you have at home they should be new pillows (any type except feather) and still in the original plastic wrap. You may also bring a washable comforter from home if you like. We encourage you to bring comfortable clothes like pajamas, robes, and slippers with hard soles. Nightgowns and shirts that button down the front are more convenient for being connected to the IV medications. Patients should not wear a wig during the first two weeks of hospitalization because certain chemotherapy drugs are excreted through the skin and will be absorbed into your wig. This may result in irritation to your scalp. Turbans and hats may be worn but should be changed or washed daily.

We ask that you limit the clothing you bring to a one-week supply since storage in the patient rooms is very limited. Your family member is responsible for getting the clothing washed after it is used one time. A laundry room is provided on the unit for your convenience. You must supply your own laundry detergent.

You do not need to bring toiletry items like toothpaste, shampoo and so forth. You will need to bring two soft bristle toothbrushes. Because your skin will become very sensitive, you will not be able to use deodorants, make-up or other products that may irritate your skin. We will have products available for skin care.

The space in your room is limited and we need to keep the things that can collect dust to a minimum. You can bring crafts or projects that you enjoy (painting, puzzles, books, model cars or ships, etc.). Please do not bring any sharp items with you that you may cut or stick yourself with. Battery operated radios and tape players are fine. The hospital Biomedical Engineering Department will have to do a safety check on any electronic items like laptop computers or CD players that are not battery operated. You will have a TV/VCR and DVD player in your room. Some movies are available on the unit. If you would like to bring a universal remote control for the TV/VCR, you are welcome to do so. A guitar or keyboard (with headphones) may help pass the time.

You can decorate your room using “Stik Tak” by Devcon Duco to put things on the walls. Pictures from home, posters, and a calendar can brighten things up for you. You can have balloons and mobiles to hang from the ceiling. Some of your friends and family may be very creative and make things that remind you of
home. Just keep in mind that table space for things is limited. There is also a dry erase marker board in each room. Plants and flowers are not allowed because the soil and water can carry germs that would be harmful to you.

**Day of Admission**

Admission day can be very emotional for both the patient and the family. Here are a couple of things that may make your admission a little less stressful. Try to arrive to the outpatient clinic at your assigned time. Don’t feel like you have to bring all of your belongings with you when you check in to the outpatient clinic. You may leave them in the car and use the unit cart to move belongings to your room later in the day. Your room may not be ready for you to move into in the morning. It could be late in the afternoon of your admission day before you have access to your inpatient room. If you get bored with watching TV, you may want to bring something else to occupy you while you are in the outpatient clinic. When you get in your room, you will be given your phone number.

Occasionally patients need to be admitted to the hematology/oncology unit for treatment. This may happen if the BMT unit does not have an available bed. The BMT team strives to have all BMT patients on the BMT unit, but there are times that being admitted to another floor is a must. Please know that the BMT team will still be involved in your care and will be available for any questions or concerns relating to your care.

**Visitors**

All visitors will need to check with the nurse and fill out a visitor illness questionnaire before entering your room.

No more than three visitors can be in your room at any one time. For infection control, we ask that family members of patients do not visit other patients in the inpatient or outpatient areas.

*Only immediate family and close friends should visit.*

We may limit visitation during certain periods of time during your transplant. One person may spend the night, but the sleep chair needs to be folded up by 8am each morning. The rooms become small after all of your things are moved in and having the sleep chair out all day is hazardous to the hospital staff and the patients.
Visitors may not eat anything in the room that you are not also allowed to eat.

Food for patients and family members may be kept in the kitchen refrigerator labeled with a name and date. Food may only be kept in the refrigerator 24 hours (after it is opened). After that time, it will be thrown away. Please label food with name and date opened.

Family members and visitors should not empty your urinal, specimen pans or emesis basins (especially during chemotherapy). The PCT or nurse will do this.

Water and ice for patients are taken from a special filtered machine in the BMT kitchen. You should not drink water from the sink. Bottled water is allowed.

Family members and visitors should not correct the alarms on the IV pumps. Please call your nurse to do this.

Family members and visitors should not give the patient medications unless asked to do so by the nurse.

Your visitors must wash their hands each time they enter the unit and again before they enter your room.

If you need assistance with anything in your room such as temperature control, television, VCR, DVD, etc., please let the staff know.

Visitors are not allowed to use your bathroom. There is a separate shower for visitors to use and several other choices for toilet needs. Upon your arrival for admission you will be oriented to the unit and where these are located.

**Guidelines for Children**

Children under 12 must have an adult with them at all times. No children under the age of 3 at all.

They should be current on all immunizations. Oral polio and other live immunizations should be delayed.

Children who have had oral polio vaccine may not visit until 30 days after the vaccine. It is ok to visit if the vaccine was an injection.

Children who have had an MMR vaccine are not permitted to visit for 30 days.
If a visitor has been exposed to the chicken pox in the last 21 days, talk to the nurse before entering the room.

**Caregivers**

A basic requirement for transplant is having a dedicated caregiver. An active caregiver is critical to the success of the transplant process. Listed below are some of the functions that the caregiver of a transplant patient will be expected to perform. Expect to hear more about these during the pre-transplant process and throughout your hospitalization. The length of time you will need a caregiver will vary with your unique medical needs and living situation.

A caregiver must be available to the patient 24/7 after discharge. The main caregiver will be expected to be present during the very important discharge teaching. Duties include, but are not limited to:

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

*TAKE CARE OF YOURSELF!* Get enough sleep, eat well, and take some time off for yourself. When you take care of yourself you will be more at ease, alert, and capable of caring for your loved one. Communicate to friends that you will need their help during the time your family member is in the hospital. Recruit volunteers ahead of time to stay with your loved one while you take a break.

Your loved one may experience behavior changes. They may not “act like him/her self” and may become angry, depressed or anxious. These changes may be related to the treatment, medications or stress and should go away in time.

Ask questions of the BMT team and report any information that you feel is important. You are one of the best sources of information about your loved one’s health and we need your assistance.

Your love, laughter and support are often the “best medicine” a patient can receive.
Admission Teaching

Infection Precautions

- You are at a higher risk for infection so we will take extra precautions to reduce that risk.
- In order to decrease your risk of infection, please do not visit other patients (inpatient or outpatient) and ask that your family avoid this as well.
- Family members must wash their hands thoroughly after eating, toileting or before helping you with any activities.
- No flowers, plants, silk arrangements or fruit baskets are allowed in your room.
- You may bring items from home such as pictures, books, radios, tape or CD players, games and crafts. These items need to be cleaned before they are taken into the room.
- Family members and friends should not use your bathroom or shower. There are restrooms located on the unit for their use.
- You must take showers daily and not return to your bed until new sheets have been put on the bed. Please call the nurses’ station to let the staff know when you are ready to get your shower so that we can change your sheets.
- Please do not let anyone other than yourself sit on or lie in your bed.
- Wash your hands before mouth care, after toileting and before eating. Do not pick anything up off of the floor. Ask someone to do that if you drop something.
- Two body areas very susceptible to irritation are the mouth and rectum. You will need to take special care of these areas.

Skin Care

- Everyone has germs on their skin that can cause an infection. Good skin care is another essential part of preventing infection.
- You will have to take a shower every day using antibacterial soap which we will provide to you. It is very important to shower daily, even if you do not feel like it.
- You may use a mild lotion on your skin after the shower to keep your skin from drying. This is provided for you.
- You will not need to bring items from home such as deodorant, shampoo, lotions, etc. Please bring bedroom slippers to wear when walking around your room and the unit, so you don’t scrape your feet.
Mouth Care

Bone Marrow Transplant Unit mouth care regimen

<table>
<thead>
<tr>
<th>TIME</th>
<th>AFTER BREAKFAST</th>
<th>AFTER LUNCH</th>
<th>AFTER DINNER</th>
<th>BEFORE BEDTIME</th>
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<tbody>
<tr>
<td></td>
<td>Brush teeth with soft bristle toothbrush ℹ️</td>
<td>Brush teeth with soft bristle toothbrush</td>
<td>Brush teeth with soft bristle toothbrush</td>
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<tr>
<td></td>
<td>Swish and spit ½ cup of baking soda/salt mixture</td>
<td>Swish and spit ½ cup of baking soda/salt mixture</td>
<td>Swish and spit ½ cup of baking soda/salt mixture</td>
<td>Swish and spit ½ cup of baking soda/salt mixture</td>
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<tr>
<td></td>
<td>Nystatin-swish and spit (no drinking or eating for 20 minutes after)</td>
<td>Nystatin-swish and spit (no drinking or eating for 20 minutes after)</td>
<td>Nystatin-swish and spit (no drinking or eating for 20 minutes after)</td>
<td>Nystatin-swish and spit (no drinking or eating for 20 minutes after)</td>
</tr>
</tbody>
</table>

- Replace toothbrush if an infection develops
- You may floss your teeth if it was part of your previous mouth care regimen until your platelet count is less than 50,000.
- We will provide Vaseline for you to use to prevent your lips from drying and cracking.
- If you wear dentures, you may have to remove them during your hospitalization due to mouth sores.
- The nurses will check your mouth daily for signs of infection. Let them know if you have pain or discomfort in your mouth or throat.
**Clothing**

You can wear your own pajamas, gown or clothing if you want. You should put on clean clothes every day after your shower.

Your family members or visitors should wash your clothes for you. Your clothes should be washed in hot water and dried in the dryer. There is a laundry room on the unit for their convenience. If washed elsewhere, the clean clothes should be brought to you in a clean bag. Your bathrobe should be washed every 3 days or right away if it gets soiled. If you bring a blanket or comforter, it should be washed twice weekly or right away if it gets soiled. Please bring your own laundry detergent.

Please do not wear any jewelry, especially piercings, during your hospitalization. Jewelry harbors germs, and can become stuck on your fingers if your hands become swollen. If you bring valuables, we will need to place your valuables in the UAB Police safe until you are discharged.

**Peri-Rectal Care**

You should do peri-rectal care after each bowel movement. This is especially important if you are having diarrhea or frequent bowel movements. Vaseline will be provided to prevent cracking on your rectal area. Also, Shield® barrier wipes are available and are helpful when you are having diarrhea to prevent this area from becoming raw and painful.

**How to do peri-rectal care:**

Take a peri-wash bottle filled with warm water and spray the warm water around your rectum. Women should wipe from front to back and spray the entire vaginal and rectal areas.

Pat the area dry with a clean tissue.

Use a clean tissue or gloved hand to spread Vaseline around your rectal area to serve as a moisture barrier.

It may be necessary to sit in a sitz bath if your rectal area becomes very sore or irritated.

Let your nurse know if you are having any pain or discomfort in your rectal area.
**Bleeding Precautions**

To prevent injuring yourself, you need to take some special precautions because of your low blood count.

- Use electric razors instead of blade razors.
- Do not blow or pick your nose. Call your nurse if you have a nosebleed.
- Always wear slippers or shoes when out of bed.

*Call your nurse if you notice any of the following:*

- Blood in you urine
- Black or bright red bowel movements
- Blood in the material you cough up or vomit
- Headaches and/or blurred vision

**Activity**

You should rest for 15-20 minutes between activities. Move slowly when moving from lying to sitting, to standing so you don’t get dizzy.

You should get out of your room and walk in the halls daily. Allogeneic patients should wear a mask anytime they are outside the room. Autologous patients, please remember to wear a mask when your white blood cell count is low.

*Do not stay in the bed all day.* Get up and eat your meals in the chair and be as active as you can.

There are exercise bikes available for you, just ask your nurse or patient care tech. You could ride this in your room for exercise. (HELPFUL HINT: You can sit in a regular straight chair behind the bike, which reduces the discomfort form the bike seat)

You will also be instructed on use of an incentive spirometer to help expand your lungs and prevent pneumonia while you are in the hospital. Please try and do these exercises at least once every hour while you are awake.
**Intake/Output and Weights**

Your nurse will add up your intake and output at 4 pm and 4 am daily, so you will need to keep up with how much you have had to eat and drink. Keeping a log is often very helpful.

The nurses and patient care techs (PCT) will record your weight in kilograms for the doctor at 4 pm and 4 am daily. The hospital scales will also give the weight in pounds. Just ask the PCT if you want to know.

Medicines will be ordered and adjusted based on this information, so accuracy is very important.

We measure volumes of liquid in cubic centimeters (cc), millimeters (ml) and ounces (oz).

- 5ml = 1 teaspoon
- 15ml = 1 tablespoon
- 1 oz = 30ml
- 1ml = 1cc

**LABS**

Your nurse will collect labs at approximately 4 am every morning and sometimes at 4 pm if needed. Your morning labs should be resulted by 9 am that morning and your nurse can fill out your blue lab card at that time. Just remind your nurse and he/she will be glad to fill out the card. You will receive electrolyte replacement and blood products based on your lab work and physical assessment.

The nurse will give you a blue lab card on admission. It is just a simple tool to help you keep track of you cell counts during your hospitalization.

**Hepa-Filtration System**

The patient rooms on the BMT unit have a special filtration system so germs are kept out of your room. The air is blown out of your room and into the hall. It is important to keep the doors closed at all times and family members should not block the airflow across your bed.
Chemotherapy

Chemotherapy drugs are given to get your body ready for transplant. There are many different types of chemotherapy drugs and different ones are given for different types of cancers. The BMT doctors will decide which plan of treatment is right for you.

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

The chemotherapy drugs used for transplant are given in high doses. You may receive a single drug or be given a combination of two or more drugs.

You will be hydrated with large amounts of IV fluids throughout the chemotherapy. All of the IV fluids will be given through your central venous line. Each day you will be seen and examined by several people including a registered nurse, nurse practitioner or nurse clinician and doctor. All of the staff on the unit is highly skilled and specially trained in bone marrow transplantation.

You will be monitored closely throughout your stay. For example, your vital signs will be taken at least every 4 hours and your weight will be checked twice daily. These things tell us important information about the care that you need. You may have a chest X-ray performed during your hospitalization. This is a routine test that may be performed in your room.

Throughout your hospital stay, and sometimes after you are discharged, you may receive blood and platelet transfusions as needed to maintain your blood counts.

It takes approximately 2 weeks for your white blood cell count to start increasing. As this happens, you will feel better and eventually be ready for discharge.

High dose chemotherapy is toxic to your tissues and organs, as well as to the diseased cells. The toxicity causes side effects that will vary in different degrees depending on the drug(s) given. Most side effects are temporary and reversible. Discomforts can often be managed or prevented with medication. Severe side effects and long-term damage can occur, though less frequently. The expected side effects from your specific treatment will have been discussed with you at your final pre-transplant consult.
Short-term side effects of chemotherapy include but are not limited to:

- Nausea and vomiting
- Mouth sores
- Diarrhea
- Hair loss
- Blood in your urine
- Muscle spasms
- Fluid retention
- Confusion (less common)
- Infections
- Anemia
- Thrombocytopenia

Long-term side effects may include:

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

Mouth Changes

During the first few days after transplant you may begin to notice that your mouth feels different. This change may be the beginning of mucositis due to chemotherapy. The symptoms improve when your white cell count begins to increase with engraftment. Suction can be set up in your room to help with thick secretions and difficulty swallowing. Performing your mouth care as directed will help to minimize mucositis and infection to your mouth.

Symptoms of mucositis may include:

- Swelling or inflammation of the lining of your mouth
- A change in the color of the inside of your mouth
- A coating on the inside of your mouth, especially on your tongue
- Sores on the inside of your mouth
- Pain with swallowing
- Thick saliva
- Pain when opening your mouth or talking
- Soreness and breakdown of the lining of your esophagus, gastrointestinal tract and rectal area

Pain

Please notify your nurse if you are experiencing any pain at any time. Medications will be available as needed to help minimize this side effect. The nurse will often ask you to rate your pain on a scale of 0-10, with 0 being no pain and 10 being the worst pain you have ever experienced. We use this scale to determine if the pain medicine is effective by comparing it to your previous pain ratings.
Gastrointestinal Problems

Nausea and vomiting: They are common side effects of chemotherapy. Notify your nurse since medications are available to help decrease these side effects.

Helpful tips include: eat small meals, clear cool beverages, food at room temperature, dry toast and crackers, bland food and taking the top off the tray before bringing it into the room to reduce odors.

Avoid fatty, greasy or fried foods, sweets, spicy or foods with strong odors.

Diarrhea: Notify your nurse if you are having diarrhea. Sometimes stool samples will need to be collected before we can start you on any medications to prevent the diarrhea. But after the samples are collected, we can give you medication to help.

Alopecia (Hair Loss)

Hair loss will occur during your treatment. Here’s what to expect:

- Your hair will start to thin during your chemotherapy and will gradually fall out within the days and weeks following treatment.

- We recommend shaving your head to help maintain a clean and healthy environment. Staff members are available to help you with this task. You may choose to shave your head before admission to the hospital. If you choose to wait until your hair begins to fall out, keep in mind that you need to shave your head before you become neutropenic.

- You may choose to wear a hat, scarf or turban. A wig may be your choice after a few weeks once the chemotherapy is out of your system.

Skin Changes

You may experience some skin changes or rashes. The causes can vary. Medications, infections, and chemotherapy can all cause skin changes. Symptoms may include:

- Redness or itching

- Burning or tingling of hands and feet

- Bumps, sores, rashes or hives

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

**Fatigue**

You will become very tired while your blood counts are dropping. *You still need to shower, be up in the chair and walk daily even if you don’t feel like it.* Take breaks and naps in between activities. Ask the staff for assistance if you feel unsteady walking around the room; **safety is our number one priority.** This will improve, but it will take time.

**Fluid and Electrolyte Imbalance**

Very often patients have difficulty keeping a good balance between fluids and electrolytes in the body. Chemotherapy and other medications, diarrhea and vomiting, as well as a poor appetite can make it difficult for the body to make its normal adjustments. Your electrolytes will be measured through lab work and you will receive the electrolytes that you need through your IV.

Swelling and fluid retention is also a sign of imbalance. You may be given medication to help you get rid of extra fluid that can accumulate in your feet, ankles and legs. Fluid may also accumulate in your abdomen or lungs, which may cause shortness of breath. You will be weighed at 4 am and 4 pm to help us monitor for extra fluid weight. Let your nurse know if you feel short of breath or if you feel like you may have swelling.

**Veno-Occlusive Disease (VOD)**

A few patients have a complication of the liver called veno-occlusive disease. In VOD, some of the small veins in the liver get blocked so blood can’t get through. This is caused by the breakdown of tissue as a result of the chemotherapy used before the transplant. VOD can occur as early as the third week after transplant or may occur many months later as you are tapering your immunosuppressives. It can be so mild that you don’t know you’ve got it or it can be very serious. There are not many treatment options for VOD available except to let the liver rest. It is possible that the liver will completely recover on its own.

**Kidney Problems**

Many of the medicines you take during the entire transplant process cause extra work for your kidneys. This workload and the effect of the transplant process on other body organs that depend on good kidney function can cause kidney problems. The nurses and doctor will keep a close watch on how your kidneys are
Certain blood tests, the amount of urine your kidneys put out and whether or not you gain extra weight will tell us if your kidneys are working well.

**Infection**

Although special measures such as strict hand washing are used on the BMT unit, many patients get an infection.

Everyone has “good” germs that live in and on our bodies. These germs don’t make us sick as long as our immune systems are working normally. The “good” germs can make you sick during this period of immunosuppression.

The germs that other people have can also cause problems with infection. That’s why hand washing is so important. *If you didn’t see your nurse or PCT wash or gel their hands, please ask if they did.* If he/she did not wash their hands, they will be grateful for the reminder.

If you get an infection, the doctors will decide which antibiotic is best for you by finding out which germs are causing your infection. This is done by taking samples of your blood, urine and mucus in your throat, and then identifying the germs growing in the sample. Sometimes germs don’t grow, but you still look like you have an infection. To be on the safe side, the doctor will go ahead and order an antibiotic for you.

Antibiotics are usually given through the central venous line. Some antibiotics have side effects that cause problems for your liver or kidneys. The doctor and nurses will check you very closely to see if these side effects are happening.

**Nutrition**

You will be on a neutropenic diet. It is designed to limit the exposure of immunosuppressed patients to harmful bacteria. Your nurse and dietitian will discuss your special diet with you and you may refer to the Immunosuppressed patient diet section of this handbook.

You will receive a menu of selections from which you may choose, and you or a family member can call and order. Meals are delivered within 45 minutes of the placement of your order.

The water you drink can’t come from the faucet; it must come from the filtered water and ice machine in the BMT kitchen. We will give you a UAB mug to use for your water. Please do not drink out of this mug directly or use the straw that comes with it. This will help to minimize infection. You can pour the water into a cup rather than drinking from the UAB mug, or you can drink bottled water.
It is normal to experience a loss of appetite, and food may not taste the same for a while after treatment with chemotherapy. It may be helpful to eat small frequent meals and snacks throughout the day. Eating bland foods may also help.

Patients who have special nutritional needs will receive extra nutritional support by a method called total parenteral nutrition (TPN). TPN is an intravenous (IV) solution that contains sugar, water, proteins, vitamins, minerals and will be given through your central venous line.

If you are not eating well, the staff can prepare a variety of nutritional supplements that will help you get the necessary amount of calories. All of your food should come from the hospital. If you must have food brought in by your family, please talk with your nurse about specific instructions. The food must be prepared fresh and have a food rating of 90 or above if it comes from a commercial facility outside the hospital.

The staff will keep track of how much you eat and drink; therefore, please do not allow a family member to eat or drink anything from your tray. It is helpful to keep a log of how much you are eating and drinking so that your intake is accurate.
Transplant Day

DAY 0

You will be receiving your stem cells or bone marrow today. You are receiving your own cells, so it is called an autologous or auto transplant.

Your transplant will be done in your room. Your nurse will let you know what time it will take place. The nurse practitioner and doctor will examine you carefully on the morning of the transplant.

It’s natural to feel excited and anxious on transplant day. You may think about all the positive things in your future with a successful transplant. But you may also worry about the negative things that could go wrong. Please share these feelings with those who can help, whether that would be family, friends or hospital staff.

Prior to your stem cell administration you will be given some pre-medications including Benadryl, Demerol and Solu-Medrol. These medications will be given about 30 minutes before your stem cells, and they are given to prevent side effects of the stem cell administration. Some of these medications may make you sleepy.

The stem cell product looks like blood, but it is thinner, brighter and may be pink to red in color. It will be given through your central venous line. The staff will check your blood pressure, pulse and temperature frequently during the transplant. You will be monitored closely during the infusion and for a couple of hours after. The infusion procedure may last up to several hours. If you start having fever, chills, or any other unusual feelings, please tell the nurse right away.

Since you are receiving an auto transplant, a special water bath will be brought to the room to thaw the frozen cells. The first thing you may notice is a strange taste and smell. This is the preservative (DMSO) used in the processing of your stem cells. The smell may last up to 48 hours, as the preservative is eliminated from your body. A few people are allergic to this preservative. Your nurse will have medication to give you in case you have an allergic reaction.

You and your family may feel somewhat “let-down” right after the transplant procedure has been completed. There were no fireworks and you don’t feel any different. During the next several weeks you will wait for the stem cells to grow. The transplanted stem cells enter the marrow cavities of your bones by way of
the lungs and spleen. The cells begin to divide and produce red cells, white cells and platelets. “Engraftment” is the term used when your bone marrow begins to make these normal cells.

Your white blood cell count will still be low because of the chemotherapy so you’re at risk for infection. If you develop a fever, your doctor will order antibiotics.

Your platelet count will also be low during this time. You will receive platelet transfusions as you need them, perhaps every day. You will also need red blood cell transfusions.

This is an anxious time. The isolation may get boring. You may begin to worry about how different things will be for you and your family and friends when you go home. You may worry about what will happen if the transplant doesn’t take. Your doctor can talk about other choices if that becomes necessary. If you need to cry, complain, yell, or whatever; someone on the staff will be willing to listen. You may find that talking with the chaplain or the social worker is helpful.

WHAT TO EXPECT THE FIRST 30 DAYS FOLLOWING TRANSPLANT

SIDE EFFECTS and MANAGEMENT

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- Sores on the inside of your mouth
• Pain with swallowing
• Thick saliva
• Pain when opening your mouth or talking
• Soreness and breakdown of the lining of your esophagus, gastrointestinal tract and rectal area

**Nutrition**

Your appetite may be slow to return to normal. You may need nausea medication even after discharge. Your doctor or nurse practitioner will prescribe this medication for you. Remember that chemotherapy may change the way food tastes. This will resolve. Start with small, frequent meals rather than three large meals. Drink at least 6-8 grasses of water or fluids daily.

- Do not share food or silverware with others.
- Do not handle raw meat or vegetables for 3 months. If you must, wear rubber gloves and then wash your hands. Auto patients may eat raw vegetables including salads after day 90.
- Do not take any over the counter herbs or minerals without consulting your doctor or nurse practitioner.
- The dietician will consult with you regarding your special discharge diet.

**Pain**

Please notify your nurse if you are experiencing any pain at any time. Medications will be available as needed to help minimize this side effect. The nurse will often ask you to rate your pain on a scale of 0-10, with 0 being no pain and 10 being the worst pain you have ever experienced. We use this scale to determine if the pain medicine is effective by comparing it to your previous pain ratings.

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**NEUTROPENIC DIET**

Immunosuppressed patients are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific high-risk foods as potential sources of
infection-causing organisms while allowing maximum healthy food selections. Neutropenic diet also called Low Bacterial or Immunocompromised diet.

In general, AUTOLOGOUS transplant patients should follow this diet regimen during pre-transplant and during the first thirty-nine days after transplant, unless specified otherwise by your doctor. ALLOGENEIC transplant patients should follow this diet regimen during pre-transplant chemotherapy and radiation therapy, and for the first one hundred days after transplant or until off all immunosuppressive therapy (cyclosporine, prednisone, tacrolimus, mycophenolate mofetil, etc.), unless specified otherwise by your doctor.

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>May Eat</th>
<th>Must Avoid-High Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dairy</td>
<td>• All pasteurized, grade “A” milk &amp; milk products</td>
<td>• Unpasteurized or raw dairy products (e.g., milk, cheese, cream, butter, yogurt, &amp; other milk products)</td>
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<td></td>
<td>• Commercially–packaged cheese &amp; cheese products made with pasteurized milk (e.g., milk &amp; medium cheddar, mozzarella, parmesan, Swiss, etc.)</td>
<td>• Cheeses from delicatessens</td>
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<td>• Pasteurized yogurt</td>
<td>• Cheeses containing chili peppers or other uncooked vegetables</td>
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<td></td>
<td>• Dry, refrigerated, &amp; frozen pasteurized whipped topping</td>
<td>• Unpasteurized cheeses or cheeses with molds (e.g., blue, Stilton, Roquefort, gorgonzola)</td>
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<td></td>
<td>• Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes</td>
<td>• Sharp cheddar, brie, camembert, feta cheese, farmer’s cheese</td>
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<td></td>
<td>• Commercial medical nutrition supplements, liquid or powdered</td>
<td>• Milkshakes, ice cream &amp; frozen yogurt from soft-serve machines</td>
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<td>• Commercial eggnog</td>
<td>• Probiotic Yogurt</td>
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<tr>
<td>Meat and Meat Substitutes</td>
<td>• All well cooked or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)</td>
<td>• Raw or undercooked meat, poultry, fish, seafood, shellfish*, game, tofu *Allogeneic patients avoid raw shellfish for at least 2-3 years.</td>
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<td></td>
<td>• Well cooked eggs (white and yolk cooked firm)</td>
<td>• Raw or undercooked eggs and egg substitutes, &amp; foods containing them (e.g., french toast with undercooked egg coating, omelets, salad dressings, egg nog, pudding,</td>
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<td></td>
<td>• Well cooked, pasteurized egg substitutes (e.g., Egg Beaters®)</td>
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<td></td>
<td>• Commercially-packaged salami, bologna, &amp; other luncheon meats</td>
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<td></td>
<td>• Canned &amp; commercially-packaged</td>
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<tr>
<td><strong>Hard Smoked Fish</strong>; Refrigerated after Opening</td>
<td><strong>Milkshakes</strong></td>
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<tr>
<td>• Cooked tofu (must cut into 1-inch cube or smaller &amp; boil for minimum of 5 minutes in water or broth before eating or using in recipes)</td>
<td>• Meats &amp; cold cuts from delicatessens</td>
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<tr>
<td></td>
<td>• Hard cured salami in natural wrap</td>
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<td></td>
<td>• Cold smoked salmon (fish); lox</td>
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<td></td>
<td>• Pickled fish</td>
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<tr>
<td></td>
<td>• Tempe (tempeh) products</td>
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<tr>
<td></td>
<td>• Sushi</td>
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<thead>
<tr>
<th><strong>Entrée, Soups</strong></th>
<th><strong>Fruits &amp; Nuts</strong></th>
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</thead>
<tbody>
<tr>
<td>• All cooked entrees &amp; soups</td>
<td>• Canned &amp; frozen fruit &amp; pasteurized fruit juices</td>
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<tr>
<td></td>
<td>• Well washed raw fruits with thick skins (e.g., banana, orange, melons); foods containing well washed raw fruits (all fruits must be washed &amp; peeled by someone else)</td>
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<tr>
<td></td>
<td>• Dried fruits</td>
</tr>
<tr>
<td></td>
<td>• Canned or bottled roasted nuts</td>
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<td></td>
<td>• Nuts in baked products; shelled roasted nuts</td>
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<tr>
<td></td>
<td>• Commercially-packaged peanut butter</td>
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<tr>
<td></td>
<td>• Avoid unwashed raw fruits with a rough texture (e.g., raspberries, blueberries, blackberries) or skins easily bruised (e.g., apples, grapes, pears). <em>Allogeneic patients avoid these for 6 months.</em></td>
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<td>• Precut fresh fruits</td>
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<td></td>
<td>• Rolled &amp; boiled nuts in the shell</td>
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<td></td>
<td>• Unpasteurized, fresh-squeezed fruit &amp; vegetable juices, &amp; ciders</td>
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<td></td>
<td>• Grapefruit/Grapefruit juice (ask you pharmacist about this fruit)</td>
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<thead>
<tr>
<th><strong>Vegetables</strong></th>
<th><strong>Bread, Grain, &amp; Cereal Products</strong></th>
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</thead>
<tbody>
<tr>
<td>• All cooked frozen, canned, or fresh vegetables &amp; potatoes</td>
<td>• Raw vegetables &amp; herbs (e.g., cucumbers, carrots, tomatoes, onion)</td>
</tr>
<tr>
<td>• Fresh, well washed herbs &amp; dried herbs &amp; spices (added to cooked foods only)</td>
<td>• Avoid raw cabbage &amp; lettuce of any type. <em>Allogeneic patients avoid these for 3 months.</em></td>
</tr>
<tr>
<td>• Commercial salsas stored in refrigerated case</td>
<td>• All raw vegetable sprouts (e.g., alfalfa, radish, broccoli, mung bean, all other seed sprouts)</td>
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<tr>
<td></td>
<td>• Garnishes</td>
</tr>
<tr>
<td></td>
<td>• Salads/Meats from delicatessens</td>
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<td></td>
<td>• Home made salsa</td>
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<tr>
<td></td>
<td>• Raw, uncooked grain products</td>
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<tr>
<td></td>
<td>• Grains/cereals/nuts from the bulk bins in stores</td>
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<tr>
<td></td>
<td>• Bakery breads, cakes, donuts &amp; muffins</td>
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<tr>
<td>Beverages</td>
<td>Well water (unless tested yearly &amp; found to be free of coliforms)</td>
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<tr>
<td>Tap water &amp; ice made from tap water</td>
<td>Natural spring water</td>
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<tr>
<td>Commercially-bottled distilled, spring &amp; natural waters</td>
<td>Cold-brewed tea made with warm or cold water</td>
</tr>
<tr>
<td>All canned, bottled, powdered beverages</td>
<td>Fountain drinks</td>
</tr>
<tr>
<td>Instant &amp; brewed coffee, tea; cold brewed tea made with boiling water</td>
<td>Unpasteurized fruit &amp; vegetable juices</td>
</tr>
<tr>
<td>Brewed herbal tea using commercially-packaged tea bags</td>
<td>Egg nog</td>
</tr>
<tr>
<td>Commercial nutrition supplements, liquid &amp; powdered</td>
<td>Fresh apple cider</td>
</tr>
<tr>
<td>Well water (unless tested yearly &amp; found to be free of coliforms)</td>
<td>Homemade lemonade</td>
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<tr>
<td>Natural spring water</td>
<td>Mate’ tea</td>
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<tr>
<td>Cold-brewed tea made with warm or cold water</td>
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<td>Alcohol</td>
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<thead>
<tr>
<th>Desserts</th>
<th>Unrefrigerated, cream-filled pastry products</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refrigerated commercial &amp; homemade cakes, pies, pastries &amp; pudding</td>
<td>Cream or custard filled donuts</td>
</tr>
<tr>
<td>Refrigerated, cream-filled pastries</td>
<td>Homemade ice cream, ice box pies &amp; meringues</td>
</tr>
<tr>
<td>Homemade &amp; commercial cookies</td>
<td></td>
</tr>
<tr>
<td>Shelf-stable cream-filled cupcakes (e.g., Twinkies®, Ding Dongs®), fruit pies (e.g., Poptarts®, Hostess®, fruit pies), &amp; canned pudding</td>
<td></td>
</tr>
<tr>
<td>Ice, popsicle-like products</td>
<td></td>
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<tr>
<td>Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated case</td>
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<tr>
<th>Fats</th>
<th>Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated case</th>
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<tbody>
<tr>
<td>Oil, shortening</td>
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<tr>
<td>Refrigerated lard, margarine, butter</td>
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</tr>
<tr>
<td>Commercial, shelf-stable mayonnaise &amp; salad dressings</td>
<td></td>
</tr>
<tr>
<td>(including cheese-based salad dressings; refrigerated after opening)</td>
<td></td>
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<tr>
<td>Cooked gravy &amp; sauces</td>
<td></td>
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<tr>
<td>Raw or non-heat treated honey, honey in the comb</td>
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<tr>
<td>Herbal &amp; nutrient supplement preparations</td>
<td></td>
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<tr>
<td>Brewers yeast, if uncooked; avoid any contact with raw yeast (*you should NOT make bread products yourself)</td>
<td></td>
</tr>
<tr>
<td>All moldy &amp; outdated food products</td>
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<tbody>
<tr>
<td>Salt, granulated sugar, brown sugar</td>
<td></td>
</tr>
<tr>
<td>Jam, jelly, syrups; refrigerated after opening</td>
<td></td>
</tr>
<tr>
<td>Commercial (heat-treated/ pasteurized) honey</td>
<td></td>
</tr>
<tr>
<td>Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerated after opening)</td>
<td></td>
</tr>
<tr>
<td>Pickles, pickle relish, olives (refrigerated after opening)</td>
<td></td>
</tr>
<tr>
<td>Candy, gum</td>
<td></td>
</tr>
<tr>
<td>Raw or non-heat treated honey, honey in the comb</td>
<td></td>
</tr>
<tr>
<td>Herbal &amp; nutrient supplement preparations</td>
<td></td>
</tr>
<tr>
<td>Brewers yeast, if uncooked; avoid any contact with raw yeast (you should NOT make bread products yourself)</td>
<td></td>
</tr>
<tr>
<td>All moldy &amp; outdated food products</td>
<td></td>
</tr>
</tbody>
</table>
When dining out, choose places that have a health department rating of at least 90 or above.

ALLOGENIC transplant patients should avoid salad bars, buffets and cafeterias for three months.

* These guidelines are adapted from the Clinical Nutrition Department at Fred Hutchinson Cancer Research Center, Seattle Washington, and from the U.S. Department of Health and Human Services: Centers for Disease Control and Prevention (CDC).

* Please call Manisha Vaidya, Clinical Dietitian, with any questions or concerns at (205) 934-4560.

**Food Safety Guidelines**

**When food shopping:**

- To prevent contamination, keep packaged meats away from other foods in the cart.
- Only select fruits and vegetables with intact skins and minimal bruising.
- Avoid foods with any damage to visible packaging, visible mold.
- Avoid self-serve, bulk foods (nuts, candies, bagel bins, and unpackaged donuts/pastries).
- Avoid tasting free food samples.
- Avoid foods from delicatessens, including prepared salads, sliced meats, and cheeses.
- Avoid canned goods that are swollen or dented.
- Get refrigerated and frozen foods last to keep them at a safe temperature before getting home.
- Read expiration dates carefully.

**Storage:**

- Properly refrigerate foods at 35-40 degrees F and freeze foods at 0 degrees F or below.
- Keep foods out of the **DANGER ZONE** between 40-140 degrees F. Remember: Keep hot foods hot and cold foods cold.
- Refrigerate leftovers immediately and throw away if not eaten after 3 to 4 days.
- Place leftovers in a shallow container to allow food to cool as quickly as possible.
- Never leave perishable foods (meats, milk, salads, etc.) at room temperature for more than an hour.
- Keep raw foods stored properly and separately from cooked foods.

**Handling/Preparation/Cooking:**

- Wash hands thoroughly with soap before and after handling raw or cooked foods.
- Someone aside from the patient must thoroughly wash and brush all fruits and vegetables before eating (use a vegetable scrub brush under running water—no soap needed).
- Thaw meats in the refrigerator or microwave, never on the counter or in cool water. Thaw meats on the bottom shelf to decrease the risk of juices dripping onto other foods.
• Use separate plates, cutting boards and knives for raw and cooked foods to avoid cross contamination.
• Cook meat, poultry and fish thoroughly. Red meat is well done at 160 degrees F and brown/gray inside. Poultry is done when no longer pink and juices run clear. Fish should be cooked until it flakes with a fork. You can purchase an inexpensive meat thermometer at your grocery store.
• Thoroughly reheat until steaming all hot dogs and “ready to eat” luncheon meats, cold cuts and “deli-style” meats before eating.
• Cut tofu into 1-inch cubes, or smaller, and boil for a minimum of five minutes in water or broth before eating or using in recipes. This process is not necessary if using aseptically, shelf-stable tofu, such as Mori-Nu® silken tofu.
• Egg yolks should be cooked over-well or scrambled.
• Make sure to heat leftovers through and never mix leftovers with fresh foods.
• Wash countertops and utensils thoroughly in warm, soapy (antibacterial) water. TIP: Put wash cloth/sponge in dishwasher to clean because bacteria love to grow on these; put dish towel in microwave for 30 seconds to kill any bacteria.
• Rule of thumb: When in doubt, throw it out! If a food has a funny odor/color, don’t take the chance. Don’t lose sight of the overall importance of diet for a healthy immune system.

COMMERCIAL NUTRITION SUPPLEMENTS  WHERE TO PURCHASE

SCANDISHAKE

- 600 Calories & 12 grams Protein NOT AVAILABLE IN STORES
- Write or call for FREE samples: Write to:
- Available: ScandiPharm
  - Regular: Chocolate, Vanilla & Strawberry 22 Inverness Center Parkway
  - Lactose-Free: Chocolate & Vanilla Birmingham, Al 35242
  - Aspartame: Chocolate & Vanilla Call:
    - (205) 472-2634
    - 1-800-950-8085

ENSURE COMPLETE

- 350 Calories & 13 grams Protein Kmart, CVS, Rite Aid Drug, Winn
- Available: Chocolate, Vanilla & Strawberry Dixie, Walgreens, Super Target & Food World

On line: www.walgreens.com/

www.cvs.com/

ENSURE MUSCLE HEALTH

- 250 Calories & 13 grams Protein same locations as above.
- Available: Chocolate, Vanilla & Strawberry
GLUCERNA DIABETIC SHAKE

- 220 Calories & 9.9 grams Protein
- Exchange: 1 starch, 1 low-fat milk & 1 fat
- Available: Chocolate, Vanilla & Strawberry

ENSURE CLEAR

- 200 Calories & 7 grams Protein
- Available: Mixed Berry & Tropical Fruit

www.abbottnutrition.com

RESOURCE DIABETISHIELD

> 150 Kcals, and 7 gm protein

www.cvs.com/

CARNATION INSTANT BREAKFAST

- 220 Calories & 13 grams Protein
- *Also available in no-sugar-added varieties
- Ready to Drink Available: French Vanilla, Chocolate, & Strawberry

BOOST Very High Calorie (VHC)

- 530 kcals, and 22 grams of protein

www.NestleHealthScience.us

JUVEN: HMB supplement (Abbott) www.JUVEN.com

78 kcals/Pkg 14 gm protein /pkg
GLUTASOLVE (GLUTAMINE): www.NestleHealthScience.us

90 Kcals/pkg, 15 gm. amino acids (protein)

PRO-STAT SUGAR FREE 64 (Medical Nutrition USA) 72 kcals, 15 gm. complete protein, www.pro-stat.info

Reference: ADA Nutrition Care Manual, Copyright 2012 Academy of Nutrition and Dietetics

The Fred Hutchinson Cancer Research Center has an example of a neutropenic nutrition therapy. The FDA Center for Food Safety & Applied Nutrition.

Discharge

Congratulations! Leaving the hospital and going to the Townhouse, Hope Lodge, hotel or home is always exciting. For some patients and family members it can also cause some anxiety. Always be assured that your BMT team is available 24 hours a day to assist you with questions and concerns. Using this booklet, your nurse will teach you how to care for yourself at home. The following items are necessary for you, the PATIENT, to perform as an important part of your recovery. You are asked to sign an agreement as an indication of your understanding of what is necessary and your willingness to participate in your own care.

Outpatient Clinic

Once you are discharged you will return to the outpatient clinic for daily lab work. Depending on your lab results you may need blood products, extra fluids or electrolyte replacement. These will be given in the outpatient area. The length of time you will spend in the clinic cannot be estimated until your test results come back and your needs are assessed. As your blood work gradually improves over the coming weeks, you will have days off between visits.

Please keep your scheduled appointment time. You may be asked to come to the clinic early in the morning for blood draws and return later in the afternoon to see the BMT doctor. The doctor will make rounds with you just like in the inpatient setting.

NOTIFY YOUR TRANSPLANT TEAM IMMEDIATELY IF ANY OF THE FOLLOWING DEVELOP:
• ANY TEMPERATURE OF 100.5 OR HIGHER
• Any signs of infection such as pain on urination or bowel movement, red or draining central venous line sites, cough, sore throat or nasal congestion.
• Any shortness of breath.
• Any new diarrhea or unrelieved constipation.
• Any signs of bleeding such as blood in urine or stool, new bruises or petechiae, headaches or blurred vision.
• Shaking chills, with or without fever.
• Sores on your lips, mouth or genital area.
• Unusual vaginal discharge.

**Medical Alert Information**

You will need to make plans to purchase a medic alert identification tag. It can be a bracelet or a necklace. This identification states that you have had a bone marrow transplant and in the event you needed a blood transfusion, it states the type of blood products you need. This identification tag can be purchased at most jewelry stores, pharmacies, or through medic alert mail order. You will need this ID tag around the time of discharge.

Please ensure your medic alert ID will be available soon after you are discharged. It is very important to wear this ID for at least one year after your bone marrow transplant. After that time ask your doctor if you can stop wearing it. You may want to make a medic alert card for your wallet also, stating the same information and physicians name if desired.

Engraving Information for Autologous Bone Marrow Transplant Patients:

**AUTOLOGOUS BMT. TRANSFUSE ONLY IRRADIATED AND LEUKO-FILTERED BLOOD PRODUCTS**

Your nurse can give you information about places where you can obtain your medic alert bracelet or necklace.

One local jeweler who has assisted many of our patients is:
Here are some links to sites where you can order your tag or do your own search. There are lots of individualized tags available now.

http://www.medicalert.org/home.html

http://www.americanmedical-id.com/

Home Environment

Your home should be thoroughly cleaned and disinfected prior to your arrival home from the hospital. Air filters should be changed before you come home and then changed monthly. If the air is too dry, you may need a humidifier added to your system. Cool mist humidifiers are safe to use. Do not add oils or medicines to the water. These should be changed and cleaned daily by your caregiver.

Keeping Your Home Clean

Personal Hygiene

- Wash hands with soap and warm, running water for 20 seconds before and after every step in food preparation.
- Wash hands before eating, after using the rest room, smoking, handling garbage, touching pets, etc.

Work Surfaces and Kitchen Equipment

- Use separate cutting boards (plastic only) for cooked foods and raw foods.
- Wash cutting boards after each use in hot, soapy water, or in the dishwasher. Sanitize boards weekly using a dilute bleach solution. Let the boards’ air dry.
- Keep appliances free of food particles. Check the microwave oven, toaster, can opener, blender, and mixer blades. Blender blades and
bottom ring should always be removed when washing the jar. Wash can openers before and after use. Sanitize these items with a dilute bleach solution.

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

**Sink Area**

- Have soap available for hand washing.
- Use paper towels for drying hands.
- Replace dishcloths and dishtowels daily.
- Replace sponges weekly.
- Sanitize sponges daily in a dilute bleach solution or run through the dishwasher.
- Do not store food supplies under the sink. Do not store chemicals and cleaning solutions near or over food supplies.
- Use liquid dish soap when washing dishes, pans and utensils by hand.

**Refrigerator and Freezer**

- Keep the refrigerator clean. Clean spills immediately. Sanitize shelves and doors weekly using a dilute bleach solution.
- Maintain refrigerator temperature between 35 to 40 degrees F.
- Maintain freezer temperature below 5 degrees F.
- Store all food in covered containers after cooling. First, cool hot foods uncovered in the refrigerator. Then cover storage containers after cooling. Make sure that covers seal tightly. Freeze what will not be used within the next 2 to 3 days. Discard all refrigerated prepared foods after 72 hours.
- Discard eggs with cracked shells.
- Discard foods older than their “use by” or expiration dates.
- Discard entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, and jelly, bread, and pastry products.
- Discard freezer burned foods.

**Cupboards and Pantry**

- Make sure food storage areas remain clean.
- Discard without tasting or opening all bulging, leaking, cracked, or deeply dented cans.
- Rotate food stock so older items are used first. Monitor expiration dates. Do not use foods past the expiration dates.
- Do not consume any home canned foods with bulging lids, broken seals, or any food that has a bad odor or any unusual characteristics after opening. Home canned foods need to be used within one year of canning.

**Smoking, Alcohol, and Drugs**

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

- Active smoking and exposure to second-hand smoke may cause lung infections, pneumonia, and fungal infections while your immune system is suppressed. It has also been associated with permanent and often fatal lung damage during the transplant.
- Family members who live with you will need to either stop smoking or do so out of your living area.
- Alcohol and drugs increase the risk of damage to the heart, lungs, brain, and kidneys and can also increase the chance of side effects from medications used during transplant.
- The risks associated with smoking, alcohol, and recreational drugs will remain higher throughout your lifetime because of the high dose chemotherapy and/or radiation therapy used in bone marrow transplant.
The transplant team will work with you and your family to help you abstain from alcohol, drugs and tobacco.

- Pets

Autologous BMT patients should avoid facial contact with pets. Also you should not clean up after your pets, especially avoiding litter boxes and all animal waste. If you have a cat, take it to the vet to be checked for toxoplasmosis. If your cat is positive for toxoplasmosis, please consult your doctor for further instructions. Ask your post transplant coordinator for specific information with regards to your individual needs and/or issues.

Food Safety Guidelines

When food shopping

- To prevent contamination, keep packaged meats away from other foods in the cart.
- Only select fruits and vegetables with intact skins and minimal bruising.
- Avoid foods with any damage to visible packaging or visible mold.
- Avoid self-serve, bulk foods (nuts, candies, bagel bins and unpackaged donuts/pastries).
- Avoid tasting of free food samples.
- Avoid foods from delicatessens, including prepared salads, sliced meats and cheeses.
- Avoid canned goods that are swollen or dented.
- Get refrigerated and frozen foods last to keep them at a safe temperature before getting home.
- Read expiration dates carefully.
- Avoid yogurt and ice cream products dispensed from soft serve machines.
- Organic produce: The term “organic” or “natural” refers to growing without the use of chemical fertilizers or pesticides, and has no relationship to the
cleanliness of the produce. Bacterial contamination can occur in the fields, either from the use of natural fertilizers (such as animal manure) to human contact during produce harvesting and distribution to the market. As a result, all produce may carry dangerous bacteria, such as E. Coli, Salmonella and/or Listeria. These bacteria have been linked to food borne disease outbreaks. Use the following recommendations for storage and handling both mainstream and organically grown produce.

Storage

- Properly refrigerate foods at 35-40 degrees F and freeze foods at 0 degrees F or below.
- Keep foods out of the DANGER ZONE between 40-140 degrees F. Remember: Keep hot foods hot and cold foods cold.
- Refrigerate leftovers immediately and throw away if not eaten after 3 to 4 days.
- Place leftovers in a shallow container to allow food to cool as quickly as possible.
- Never leave perishable foods (meats, milk, salads, etc.) at room temperature for more than an hour.
- Keep raw foods stored properly and separately from cooked foods.

Handling/Preparation/Cooking

- Wash hands thoroughly with soap before and after handling raw or cooked foods.
- Someone aside from the patient must thoroughly wash and brush all fruits and vegetables before eating (use a vegetable scrub brush under running water—no soap needed).
- Do not wash fruits or vegetables with produce rinses, soaps, detergents or chlorine bleach solutions. Produce can absorb these cleaning agents.
- Thaw meats in the refrigerator or microwave, never on the counter or in cool water. Thaw meats on the bottom shelf to decrease the risk of juices dripping onto other foods.
• Use separate plates, cutting boards and knives for raw and cooked foods to avoid cross contamination.

• Wash the tops of canned foods before opening. Clean the can opener before and after use.

• Cook meat, poultry and fish thoroughly. Red meat is well done at 160 degrees F and brown/gray inside. Poultry is done when no longer pink and juices run clear. Fish should be cooked until it flakes with a fork. You can purchase an inexpensive meat thermometer at your grocery store.

• Thoroughly reheat until steaming all hot dogs and “ready to eat” luncheon meats, cold cuts and “deli-style” meats before eating.

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

• Cut tofu into 1-inch cubes, or smaller, and boil for a minimum of 5 minutes in water or broth before eating or using in recipes. This process is not necessary if using aseptically, shelf-stable tofu, such as Mori-Nu silken tofu.

• Egg yolks should be cooked over-well or scrambled.

• Make sure to heat leftovers through and never mix leftovers with fresh foods.

• Wash countertops and utensils thoroughly in warm, soapy (antibacterial) water. TIP: Put wash cloth/sponge in dishwasher to clean because bacteria love to grow on these; put dish towel in microwave for 30 seconds to kill any bacteria.

• Rule of thumb: WHEN IN DOUBT, THROW IT OUT!!!! If a food has a funny odor/color, don’t take the chance. Don’t lose sight of the overall importance of diet for a healthy immune system.

**Microwave Cooking**

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

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

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

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

Dining Out

• Do not eat at a restaurant with a health department rating less than 90. The rating sheet is required to be post in plain view, usually near the cash register or in the bar area. If you do not see the rating, you can ask an employee where it is posted.

• Eat early to avoid crowds. Fewer mistakes are made when it’s not busy.

• DUE TO THE UNCERTAINTY OF THE CLEANLINESS OF THE FOOD HANDLER AND PRODUCE PREPARATIONS, CONSUMPTION OF RAW FRUITS AND VEGETABLES WHEN DINING OUT IS NOT ALLOWED.

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

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

Water Safety Guidelines

Tap Water

If your home water is from a city water supply or a municipal well serving highly populated areas, it is considered safe.

Well Water

Many factors can increase risk of well water being contaminated: shallow depth, construction in the area, spring runoff and flooding and locations near a dairy or other large numbers of livestock. The quality of well water cannot be guaranteed. Even water filtration devices will not make the water safe if it is not chlorinated.
Safe Water Sources

If your water is not from a city or large municipal well, plan to use one of the following:

- Boiled and distilled water—bring tap water to a rolling boil for one minute. Distilled water can be made using a home distiller. After processing, store in a clean covered container in the refrigerator and discard after 72 hours.

- Bottled water---water labeled as follows is safe:
  - Reverse osmosis treated
  - Distillation
  - Filtered through an absolute one micron or smaller filter (NSF Standard #53 for cyst removal)

Just because bottled water says “well water,” “artesian well water,” “spring water,” or “mineral water” does not guarantee that it is safe. The International Bottled Water Association (IBWA) will help you check on a specific brand of bottled water. 1-800-928-3711 or www.bottledwater.org

Water Filters

Acceptable filters for household water taps must be designed to remove coliform and cryptosporidium bacteria. The filter must be installed immediately before the tap and manufacturer directions must be followed for maintenance and replacement. Any of the following are acceptable:

- Reverse osmosis filter
- Absolute pore size of one micron or smaller
- Tested and certified by NSF Standard #53 for cyst removal

BRITA® and PUR® do not meet filtration standards. A list of approved systems can be found at the America National Standards Institute, NSF International, 1-800-673-8010 or www.NSF.org
Gardening

Avoid gardening for at least 100 days post transplant. This includes cutting the grass. Please check with your doctor prior to resuming gardening. You may keep low maintenance houseplants and flowers. Let your caregiver tend to them.

Skin Care

- Continue to bathe or shower daily using antibacterial soap.
- Wash hands after using the bathroom and before eating or preparing food.
- Check skin daily for any new rashes, petechiae (small red/purple dots on skin) or bruises.
- Continue rectal care at home, especially if you have diarrhea. Women should wipe from front to back to avoid spread of infection. Do not use rectal creams or suppositories without talking to your doctor or nurse practitioner. You may try sitting in a hot bath to ease any discomfort.
- Introduce make-up and lotions one at a time, and observe for signs of allergic reactions. You must buy all new hygiene products. Don’t use make-up, lotion, shampoo, etc. that was previously opened before your transplant. You may use previously unopened make-up that is the same type/brand that you used prior to BMT.
- Use electric razors until your platelet count reaches 50,000 or greater.
- Use pH balanced shampoos and conditioners on your scalp and new hair.
- Limit exposure to the sun since chemotherapy makes your skin very sensitive. This sensitivity can last for years. Sit in the shade when possible during outdoor activities. Use sunscreen of at least SPF 25 to protect your skin (don’t forget to protect your ears and the back of your hands).
- Remember to wear a hat, wig or head cover until your hair grows back.

Oral Care

- Continue your oral hygiene at home to ensure healthy teeth and gums and prevent infection.
- You may or may not be asked to continue the salt and soda rinses.
• Remember to use a new, soft toothbrush and change it each time you have an infection.
• Let your doctor or nurse practitioner know before you schedule any dental work. Tell your dentist you have had a transplant.

Physical Activity

Having a bone marrow transplant is physically stressful. Your energy and endurance will take some time to return to its previous level. There are some things you can do to help recover your strength.

• Limit activity the first month of discharge. Try not to over exert yourself.
• Space out your activities, allowing for rest periods in between them.
• Walking is a good form of exercise. Start slowly and limit your distance at first. Increase distance and pace once you begin to feel better.
• Driving is allowed when your platelet count gets to 50,000. Check with your doctor prior to making travel plans in the immediate post transplant period.
• Limit home visitors to close friends and relatives. Do not allow sick people to visit you at home.

Sexuality

• You may resume sexual activity once your platelet count is 50,000.
• You may need to use KY Jelly® or Replens® (water soluble) for lubrication.
• Patients may receive but not perform oral sex.
• Condoms are not necessary if you have a monogamous partner. They are necessary if the partner has a history of genital herpes. Condoms should be lubricated.
• Although BMT chemotherapy significantly reduces fertility in men and women, it is still possible for conception to occur. Talk with your doctor or nurse practitioner regarding birth control options.
• Remember you may be fatigued or have a decreased sexual desire while in the post transplant period. Please discuss any concerns you have with your nurse practitioner or doctor.
Bleeding Precautions

- Do not use suppositories or enemas. You may need to change your diet or increase your exercise to resolve constipation.
- Avoid over the counter medications such as aspirin, ibuprofen, Advil®, Goody's®, or Alka-Seltzer®. These medications may cause bleeding.
- Blow your nose gently.
- Use an electric razor until your platelet count is >50,000.

Infection Precautions

- Take your temperature daily at the same time each day. Take it more often if you are not feeling well.
- You should wear disposable rubber gloves if you must change a diaper.
- You may go to public places, but do so during down hours and slow times. Allogeneic transplant patients need to wear a mask when in public for at least 100 days post transplant.
- Wash your hands after using the bathroom, petting animals and before eating.
- Remember to avoid children who have received a live virus vaccine for 3 weeks after they have been vaccinated. Please ask your doctor if you are unsure if the vaccination is a live virus.
- NO swimming in public pools, lakes, rivers and hot tubs while you still have your central venous lines.
- After you catheter(s) are removed talk with your nurse practitioner or clinician before swimming.
- Clean insect bites and minor cuts with soap and water and apply antibacterial cream to the site.

Medications

- You may take Maalox® or Mylanta® for indigestion or heartburn. If stomach gas is a problem, try an antacid with simethicone.
- You may use ocean spray nasal spray for dry nasal passages. Do not use Afrin®, or any over the counter medicated nasal sprays. For the first 30 days after transplant you must open a new bottle every 24 hours. After 30 days you must use a new bottle every week.
• You may use natural tears for dry eyes. For the first 30 days after transplant you must open a new bottle every 24 hours. After 30 days you must use a new bottle every week.
• Do not take Tylenol® unless specifically authorized by your physician or clinician and each situation should be Okayed by them.
Discharge Test

1. You should report a temperature of ____________.

2. What do you do if you experience any signs of infection or bleeding at midnight?

3. Your hickman catheter should be flushed and the caps changed:
   A. daily
   B. once weekly
   C. twice weekly

4. Which of the following can you not eat?
   A. banana
   B. watermelon
   C. strawberries
   D. cantaloupe

5. When can you go to a buffet or hot bar?

6. Can you change your cat’s litter box?

7. Can you go shopping or to the movies?

8. When can you drive your car?

9. Under what conditions can you go out to eat?

10. What is the BMT outpatient unit phone number?

11. Can you eat Feta cheese?

12. When should you get your Medical Alert bracelet?

13. Is smoking allowed in your home?

14. What kind of soap should you use?

15. How often should you take your temperature?
Hickman and Permcath Care

**ALWAYS WASH YOUR HANDS BEFORE DOING ANY CATHETER CARE.**

Hickman and Permcath catheters are long silicone tubes inserted under local anesthesia and can be used immediately.

The catheter is placed in a large blood vessel leading to the heart. It is tunneled under the skin before it exits on the chest.

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**When to Call the BMT Unit**

It is very important that you monitor your catheter closely and notify the BMT unit of any questions or concerns. The phone numbers are 934-7102 and 975-2236. Be sure to call the unit if:
You have drainage, swelling, or tenderness at the site.
The catheter is leaking, torn or otherwise damaged.
The catheter has come partially out.
Your temperature is above 100.5.
You cannot flush the catheter easily.

Always secure your catheter. Do not let it dangle or pull at the exit site. You may use a piece of tape or women may tuck it under their bra strap. It is ok to shower, but if the dressing becomes damp, it should be changed immediately after showering.

If your catheter leaks, first check all connections. If there is a hole or opening in your catheter, clamp it between the hole and the exit site and notify the BMT unit. In most cases this can be repaired. Protect your catheter from damage. Never use scissors around your catheter and do not use force when flushing.

**Entrance and Exit Site Care**

The exit site is the area on your chest where the catheter comes out of your body. It takes about 10-14 days for this area to heal. During this time, the exit site dressing should be changed as directed by your nurse or when it becomes loosened, soiled or damp. If you have two catheters, completely finish changing the first exit site before you start on the second one. If one of the sites is reddened or infected, change that site last. Once the catheter exit site has healed, the catheter site can be left open to air.

You will notice above the exit site an entrance site where an incision was made. It is usually above or near the collar bone. It is very important to keep this area dry and covered when in the shower. Patients are asked to cover this site with a transparent dressing prior to showering.

**Changing the Dressing**

1. Clean the surface of your work area with soap and water or 70% alcohol before gathering your supplies. Use a clean cloth to clean the area, NO SPONGES.

2. Collect your supplies: the dressing kit contains:
a. Chlorhexidine applicator sponge
b. Alcohol wipes
c. Dressing (microdon or transparent)
d. Tape

3. WASH YOUR HANDS.

4. Remove the old dressing and discard. Be careful not to pull on the catheter.

5. Look for tenderness, heat, redness, swelling and drainage. If these signs are present, notify the BMT unit after completing the dressing change.

6. Look to see if the catheter has slipped out or if the cuff is exposed. If this occurs, notify the BMT unit after completing the dressing change.

7. Open the dressing change kit and remove the chlorhexidine sponge. Do not touch the sponge end of the stick.

8. Gently squeeze the side arms on the stick to mix the contents.

9. Firmly place the sponge end on your skin where the catheter comes out on the chest.

10. Move the sponge around the catheter in a circular motion and clean out from the catheter about 3 inches. Apply friction as you clean. Don’t go back over any area you have already cleaned. Be sure to remove any crust or drainage.

11. Let the chlorhexidine dry for at least 30 seconds.

12. Open the alcohol pad. Hold the end of the catheter and clean from the exit site and move away from the body.

13. Apply the dressing. You may loop the catheter under the dressing to prevent the catheter from pulling. You may also secure it to the skin with a small amount of tape.

14. After the exit site is healed, you will be asked to leave it open to air. It will be cleaned daily with soap and water.

**Flushing Your Catheter**

Your nurse will teach you how and when to flush your catheter. Some types of catheters will not need to be flushed, while others will need to be flushed according to the guidelines below. If you are hospitalized soon after your
catheters are placed, the nursing staff will take care of flushing the lines while you are in the hospital. Please do not flush your catheters until directed to do so.

You may need to flush your catheter twice a week to keep it open (patent). If this is the case, it may be helpful to pick two days of the week and flush your catheter on those two days, for example, every Tuesday and Friday. The catheter will also need to be flushed any time blood is withdrawn or after medication is infused. If the catheter does not flush easily, do not force the fluid. Check to see if the catheter is clamped or kinked. If this is not the problem, please notify the BMT unit.

1. Clean the surface of your work area with soap and water or 70% alcohol before gathering your supplies. Use a clean cloth, NO SPONGES.

2. Collect your supplies:
   a. 2 10cc pre-filled saline syringes
   b. alcohol swabs

3. WASH YOUR HANDS.

4. Open a new alcohol wipe and clean the end of the catheter.

5. Screw the tip of the syringe into the catheter valve, turning clockwise.

6. Unclamp the catheter.

7. Inject 9cc flush solution into the catheter.

8. Clamp the catheter before removing the syringe.

9. Remove the syringe. Dispose of the syringe in the sharps container.

10. Repeat this process for the other lumen of the catheter.
Changing Your Catheter Caps

Change each injection cap twice a week. It is good to do this at the same time you flush your catheters.

1. Clean the surface of your work area with soap and water or 70% alcohol before gathering your supplies. Use a clean cloth, NO SPONGES.

2. Gather your supplies:
   - 1 injection cap for each lumen
   - Alcohol swabs

3. WASH YOUR HANDS.

4. Clamp the catheter.

5. Open the package with the new cap(s) and put it near you.

6. Clean the area where the cap and the catheter meet with an alcohol swab.

7. Unscrew the old cap. Do not let the open end of the catheter touch anything.

8. Take the cover off the new cap. Screw the new cap onto the end of the catheter. Make sure the cap is on tight.

9. Unclamp the catheter if the nurse has told you to do this.

Central Line Care Contract

I, _____________________________, have received instruction, demonstration and reference material concerning care of my central venous line or lines.

I acknowledge understanding of how to properly care for my line and the importance of taking good care of it as I have been instructed.

I understand that if a staff member attempts to access my line without cleaning the port, I should stop them and report this to the charge nurse.

I understand that I can call the Bone Marrow Transplant unit at any time with questions or concerns I may have.

Patient or family member _________________________________

Nurse _________________________________

Date_______________________
When to Call the BMT Unit

It is very important that you monitor your catheter closely and notify the BMT unit of any questions or concerns. The phone numbers are 934-7102 and 975-2236. Be sure to call the unit if:

- You have drainage, swelling, or tenderness at the site.
- The catheter is leaking, torn or otherwise damaged.
- The catheter has come partially out.
- Your temperature is above 100.5.
- Shaking chills with or without fever.
- You cannot flush the catheter easily.

Important Phone Numbers

BMT INPATIENT UNIT: 205-934-7102 or 4-7102 from the townhouse

BMT OUTPATIENT CLINIC: 205-975-2236 or 5-2236 from the townhouse

Long Term Follow-Up

When the BMT team thinks you are ready, you will be referred back to your primary oncologist. At that point he/she will manage your care. However, you will need to return to BMT for your long term follow up appointments. Typically those are done around day 100, day 200, and then yearly. A long term follow up usually takes 2 separate visits. The first visit is to complete tests and the second visit to review the results with your clinician and BMT doctor. The actual appointment for the tests and visit is made about 1 month in advance.

At 200 days you will begin your revaccination process. You will receive your first round at your 200 visit and your second round at your 1 year visit. It is very important that you get these vaccinations after you have had a transplant.