

Adult Blood & Marrow Transplant

Autologous Transplant Patient Handbook



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INTRODUCTION

Welcome to the Adult Bone Marrow and Stem Cell Transplant (ABMT) Program at Duke University Health System. This patient handbook will become an important part of your transplant journey. This guide is meant to add to the verbal information you receive from the doctors, nurses, social workers, pharmacist, and other members of the ABMT Program.

The idea of receiving a bone marrow/stem cell transplant causes anxiety and uncertainty for patients and their families. We hope this handbook along with individual instruction can help relieve some of those feelings by explaining what to expect before, during, and after transplantation. Everyone is unique but there is some general information that applies to every patient.

To get the best use from this handbook, please bring it with you to all of your appointments, while you are in the hospital and in the ABMT Clinic. Throughout your care, transplant team members will refer you to sections that are important during various phases of the transplant process. You may also be provided with additional information about your specific disease or treatment plan that you will need to add to your handbook. While the handbook is intended to answer many questions that you may have, you will likely find that you have additional questions as you go through the process. Please write down any questions that you have and your team members will be happy to answer them for you.

The Adult Bone Marrow and Stem Cell Transplant Program at Duke *began in 1983* and has performed *over 2000 transplants*. We currently perform about 200 adult transplants each year for many different diagnoses. But the most important transplant right now is **your** transplant, and our team is ready to assist you through the process.

The Duke Adult Bone Marrow and Stem Cell Transplant Team

The Adult Bone Marrow and Stem Cell Transplant Team is made up of many health care professionals who are dedicated to helping you through all phases of treatment. Initially, they will determine whether you are a candidate for a transplant and then provide you with information to help you decide if it is the right treatment for you. If transplant is not an option, you may be offered treatment on a clinical trial specific for your disease. Your team will be led by an ABMT attending physician.

The following is a list of the team members and their roles. You will meet each member at different times during your treatment.

Attending Physicians

The attending physicians associated with our program are all board certified physicians who specialize in bone marrow and stem cell transplantation. They will oversee your treatment and care. **Even though one specific physician will be your primary physician, you will be cared for by different ABMT physicians during your transplant.** During your treatment, your Duke ABMT physician will communicate with your "local physician" to keep him/her informed of the plan and your progress.

Coordinators-Nurse Practitioners or Physician Assistants

The coordinator will be the primary contact for you, your family, and your "local physician" during the transplant process. The coordinator will communicate with you and arrange any testing that needs to be done. The coordinator will provide you with a calendar to outline your treatment. Your coordinator may be a nurse practitioner or physician assistant.

<u>Acute Care Providers-Nurse Practitioners and Physician</u> Assistants

Another group of nurse practitioners and physician assistants will be responsible for your daily care when you are in the ABMT Inpatient Unit and Outpatient Clinic. They will assess your condition and review your plan of care with the attending physician.

ABMT Inpatient Unit and Outpatient Clinic Nurses

The nurses of the ABMT Program are registered nurses specially trained in the care of transplant patients. There are patient care assistants who will also help with your care.

Clinical Pharmacist

The clinical pharmacist specializes in the care of transplant patients. The pharmacist makes daily rounds with the team on the inpatient unit and will help monitor your medications in the outpatient clinic. If you are in the ABMT inpatient unit and discharged to the outpatient clinic, the clinical pharmacist will review your medications with you and your caregiver, teaching you how to take them properly and inform you of any side effects they may cause.

Clinical Nurse Specialist

The clinical nurse specialist is a registered nurse who works with the ABMT Program. The clinical nurse specialist is a transplant expert and will round with the physicians to be an additional resource to you through the transplant process.

Clinical Social Worker

The clinical social workers are members of the team who help patients and families to manage the stresses that come with the transplant process. The clinical social workers are experienced in the issues of transplant patients. Their services include counseling, support for the patient and family and referrals to other resources as needed.

Financial Counselors

The financial counselors work closely with you and your insurance company to determine your transplant benefits. Each insurance company and their policies are different. The financial counselors are experienced in the insurance issues faced by transplant patients. When your insurance company requires authorization, your financial counselor will assist with that process.

Phone Book for the Duke ABMT Staff

Name	Phone Number
ABMT Coordinators	
Kristi Wiggins, NP (Horwitz)	919-668-1024
Tanya Helms, PA (Long)	919-668-1023
Therese Hennig, PA (Rizzieri)	919-668-1025
Angela Johns, NP (Chao, Chute)	919-668-1050
Amanda Yopp, NP (Gasparetto)	919-668-1021
Kellie Cochran, PA (Sullivan)	919-668-3754
ABMT Acute Care Providers	
Brent Aberant, PA	919-681-4859
Ashley Zanter, ANP, OCN	919-668-3906
Peggy Eren, FNP	919-668-1047
Brianne Buchanan, PA	919-668-4368
Jill Burleson, NP	919-668-6527
Scott Winkel, PA	919-668-1032
Clinical Pharmacist	
Ashley Morris, Pharm D	919-668-1018
ABMT Social Workers	
Karissa Fenwick, MSW	919-668-1036
Judith Mathieu, MSW	919-668-1035
Financial Counselors	
Charles Patterson (last name A-G)	919-668-1005
April Scott (last name H-O)	919-668-1022
Brenda Todd (last name P-Z)	919-668-1003
Nutritionist	
Paige Fisher- Streno	919-681-8604

Clinical Nurse Specialists		
Martha Lassiter, MSN, AOCNS	919-668-6239	
Krista Rowe, MSN, AOCNS	919-684-7115	
Caryl Fulcher, MSN	919-684-4113	
Clinical Operations Director		
Jennifer Loftis, MSN, OCN	919-668-1939	
Nurse Managers		
Jennifer Frith, BSN, OCN (Outpatient)	919-668-4370	
Deborah Russell, BSN, OCN (Inpatient)	919-681-9242	
ABMT Physicians		
Dr. Nelson Chao Dr. John Chute Dr. Cristina Gasparetto Dr. Mitchell Horwitz Dr. Gwynn Long Dr. David Rizzieri Dr. Keith Sullivan	919-668-1002	
Duke Hospital Main Operator	919-684-8111	
ABMT Inpatient Unit	919-681-9241	
ABMT Outpatient Clinic	919-668-6548, 919-668-1052	
To change an existing appointment	919-668-1007, 919-668-1008	

Patient Safety in the ABMT Program

The safety and appropriate care of our patients is our first priority. Our entire medical and nursing staff is committed to creating an environment of patient safety. Our success in providing safe care depends not only on the staff, but also on the understanding and cooperation of our patients. The ABMT program provides very complex treatments and supportive care which often means waiting for several hours before your direct care begins.

The staff must meet safety guidelines every step of the way, as you journey through each day. Wherever you are cared for, your identity will be verified using 2 identifiers. Your name, date of birth or Duke medical record number may be used. In the ABMT clinic, the safety checks begin with the sign-in process and continue through phlebotomy and to the treatment room. For example, patients who require blood transfusions must have their blood type verified every 3 days. This is a precise and time consuming task. You may need to wait 2-4 hours for this process to be completed.

On the ABMT unit, the safety checks begin with admission to 9200. For example, on admission, your weight and height will be verified by two staff nurses.

While on the ABMT unit, a care provider will complete a safety check every 2 hours. The safety check assures that you have free mobility to the restroom, your call bell is in reach and you are as comfortable as possible.

Prior to starting you transplant regimen, you will be asked to provide a stool sample or a member of the health care team will perform a rectal swab (swiping the skin around your bottom with a soft swab). This is to assure that you have not been exposed to or "colonized" with bacteria that can infect patients who have undergone chemotherapy and been in the hospital. If you are "colonized", it does not mean that you are infected, however, you will be placed on "contact isolation" to protect you and other patients from the bacteria. This does not mean you have an active infection, only that you have been exposed to the bacteria.

It is also important for each patient know their own blood type. After your first visit to our clinic, your nurse should be able to provide you with that information. This allows you to be an active participant in your care and is one additional way for us to ensure your safety.

What the staff needs from each patient and family member is the understanding that there may be times when it seems like nothing is happening fast enough, but please be aware that we are often working behind the scenes to assure your safety and satisfaction. Please feel free to forward any patient safety concerns to the nursing staff or nurse manager.

TO DO LIST BEFORE YOUR TRANSPLANT

Read the ABMT Handbook
Identify a caregiver
Arrange transportation
Arrange housing
Review consent form(s)
Have a dental exam-this should be done at least 14 days prior to beginning your transplant care
Change the air filters in your home
Check your prescription coverage and locate a Durham pharmacy you can use
Speak with your physician about fertility options
Make arrangements for child care
Make arrangements for pet care-pets are not allowed to be with you during transplant
Make arrangements for household maintenance while at Duke receiving treatment
Attend New Patient Class
Purchase Medication Organizer
Purchase a digital thermometer
Get a large tote bag or rolling bag to carry supplies to clinic daily

About Your Disease

Transplants are performed for many different diseases, including, but not limited to leukemia, lymphoma (Hodgkin's, Non-Hodgkin's), multiple myeloma, some solid tumors and non-cancerous disorders.

You have been identified as a possible candidate for an autologous bone marrow/stem cell transplant. Autologous means that we will collect your stem cells, freeze and store them and then give the cells back to you after you have received high dose chemotherapy.

About Stem Cells

Stem cells are immature cells that produce the blood cells in the body. These cells are found in the bone marrow and in the circulating blood. You will hear your transplant referred to as a stem cell transplant or bone marrow transplant. Both terms are used interchangeably, but the important thing to remember is that all transplants are technically stem cell transplants because it is immature blood stem cells that are used. They may, however, be taken from either the bone marrow or the circulating blood.

Reasons for Transplant

You may need a transplant for many different reasons. You are in relatively good health and your doctors feel that a stem cell/bone marrow transplant is the best treatment available for your disease. Harvesting your stem cells prior to high dose treatment allows us to administer larger doses of chemotherapy. We will return your stem cells to you to rescue your blood forming cells and your immune system from the side effects of chemotherapy.

Evaluation for Transplant

To prepare for transplant, you will have to make several trips to Duke. At your first visit (New Patient Evaluation), you will meet members of the ABMT team and receive information about transplantation. Before you become a transplant candidate, your overall physical condition and treatment options are thoroughly evaluated. This evaluation may begin at your home physician's office or here at Duke. We often refer to this period of time as the "work up" or "restaging" period. By now, you may have had some of your work up studies completed, you may need to have an entire work up, or we may repeat some studies that you have already had performed elsewhere. During the workup you will need to have some or all of the following studies performed:

- Lab Studies: Blood will be drawn from a vein or central venous catheter to evaluate your past exposure to certain viruses and to check your kidney and liver function as well as your blood counts.
- MuGA Scan/Echocardiogram: These tests evaluate the pumping ability of your heart. If you have a MuGA scan, a technologist will give you two injections: the first injection prepares the red blood cells, and the second is used to "tag" the red blood cells. Then, the technologist will take a number of pictures of your heart with a camera. In an echocardiogram, an instrument that transmits high-frequency sound waves called a transducer is placed on your ribs near the breast bone and directed toward the heart. The transducer picks up the echoes of the sound waves and transmits them as electrical impulses. The echocardiography machine converts these impulses into moving pictures of the heart.
- Pulmonary Function Tests: These tests are performed to evaluate lung function. You will be asked to breathe into a machine that will measure different functional capacity of your lungs.
- © CT scan, PET and MRI: These tests are similar to x-rays but use computers to produce more detailed pictures of the

area being evaluated. Some scans use contrast dye that you drink or have injected into the vein. Please alert your nurse or physician if you have a known allergy to contrast dye, iodine, or seafood. If you have an allergy, you may require pre-medication with a steroid to prevent a reaction.

- Bone Survey: This test is a large series of x-rays and may
 be done to evaluate your bones for signs of disease.
- Bone Marrow Biopsy and Aspirate: A bone marrow aspirate is a small sample of marrow usually taken from the back of the hips. You will be asked to lie on your stomach and the area of your hip will be numbed with lidocaine. A needle will be inserted into the bone marrow and a small amount of bone marrow liquid will be withdrawn. A bone marrow biopsy is performed at the same time, which involves collecting a tiny piece of bone for examination. This procedure is done to evaluate how well your bone marrow is producing cells and to look for any signs of cancer in the marrow.

The work up and review process can take up to four (4) weeks or longer. We understand that at this point you may be eager to get started with your treatment, but please be patient with us. We need to make sure that all of the results are within acceptable limits and it is safe to start your treatment.

After your results have been reviewed, you will be enrolled in a research protocol or treatment plan. If you are enrolling in a research protocol, you will be participating in a clinical trial that we hope represents an improvement from the standard of care. The research protocol or treatment plan includes the overall schedule for your treatment, the chemotherapy or other therapies you are to receive, lab tests to be drawn, tests to monitor your progress and follow up plan of care.

Informed Consent

Prior to being enrolled on a research protocol or treatment plan, you will be given a description of the treatment. This description is called an informed consent form and contains information about the particular protocol or treatment plan. The side effects of treatment as well as benefits and risks are discussed in the consent form.

The Duke ABMT Program is committed to improving the outcomes and advancing the science of transplantation. All advances in cancer are evaluated and developed using clinical trials. Our program conducts many clinical trials. These clinical trials have both risks and benefits. Risks may include that the transplant is not as effective against your disease, or you experience side effects. One potential benefit is that the clinical trial may work better than other therapies for your disease. You may also be eligible to participate in a clinical trial that does not directly treat your disease, but may help with supportive care of transplant patients such as a new antibiotic. Read the informed consent forms that you are given and write down any questions or concerns. You are encouraged to ask questions and to discuss the information contained in the consent with your ABMT physician and coordinator. Your signature on the consent means that you understand the information in the consent and you have been given an opportunity to ask any questions. You must sign the consent in the presence of your ABMT physician or coordinator. It gives us permission to begin treatment.

Your Role in a Successful Transplant

A bone marrow/stem cell transplant means new responsibilities. If we determine that a transplant would be the best treatment for your disease, there are many things to consider before making the decision to have a bone marrow/stem cell transplant.

One of the most important areas of concern is that you are living a healthy lifestyle since any harmful habits may damage your immune system. Our program does not consider patients for transplantation who are currently smoking or who are dependent on

alcohol or other mind-altering drugs. We require potential transplant recipients to be substance-free.

There are also many issues to consider regarding follow-up care after your transplant. These include:

- Daily Clinic Visits: When you have an autologous stem cell transplant, you may receive your high dose chemotherapy in the hospital or in the ABMT Clinic. This will depend on your disease, chemotherapy and your overall health. Following the chemotherapy, you will receive your transplant and supportive care in the ABMT outpatient clinic. You will be required to live in local housing for approximately 3-4 weeks and visit the ABMT clinic daily. After you are discharged from the clinic you will still be required to return on a regular basis for several months. The frequency of the visits will depend on your clinical condition.
- Medications: After a bone marrow/stem cell transplant, you may have medications to take for many months. These medications may be expensive and may have some side effects. The social worker and ABMT coordinator will help you with finding financial resources if needed for medications.
- Pollow-up testing: After you complete your treatment with the ABMT program you will be discharged back to the care of your referring/home physician. From time to time you will be required to undergo testing to monitor your response to therapy and major organ functioning. You should consult with your home physician to determine if he or she wants to perform or order these tests, or refer you back to the ABMT program.
- Wealthful habits: After the transplant, you will be expected to maintain a well-balanced diet and exercise regularly to keep yourself in good physical condition.

Preparing for Transplant

We want to help you and your family prepare for your transplant. Making plans to deal with your needs before your transplant can reduce the amount of stress that you will have to cope during the recovery process. If changes do occur, in your home or health situation, please let us know so we can support you through the process.

Financial and Insurance Considerations

Bone marrow/stem cell transplantation is a very expensive procedure. The drugs that are used are costly, as are the blood products used to support you throughout the process. You will also receive many days of care in the ABMT Clinic and possibly the hospital. We want to do everything possible to assist you with your insurance and make sure that your insurance pays for everything that you are entitled to through your policy. The ABMT program has dedicated financial counselors who will work with you and assist in the insurance process. You will meet the financial counselor who is assigned to work with you when you to come to your New Patient Evaluation. As you prepare for transplant, the financial counselor will supply your insurance company with the medical information they request in order to make a decision about whether or not your transplant will be authorized.

If you have commercial insurance or a managed care plan, you should obtain a copy of your insurance policy. Because every insurance policy differs, it is important that you are familiar with your particular policy. You should review your policy in detail so you understand which services are covered by your insurance company, which services are not covered, and what your financial responsibility will be with respect to co-pays, co-insurance or non-covered services. For example, your policy may require a co-pay with each daily visit to the clinic during your transplant care. You can obtain a copy of your policy by calling the Member Services Department of your insurance company, or the Human Resources Department of your employer (or your spouse's employer if you are covered under your spouse's insurance). If you

need assistance in reviewing and understanding your policy you should contact the Member Services Department of your insurance company.

Many insurance companies have special case managers that work with patients who are having a transplant. These case managers often help with many aspects of your insurance as it relates to transplant, so it is a good idea to contact your insurance company and ask if there is a *transplant case manager* who will work with you on insurance issues during the transplant process.

Before proceeding, your transplant and related treatment must be authorized by your insurance company. Unfortunately, there are times when insurance companies deny or limit coverage or benefits. If your insurance company does not pay for your transplant, or if you have a plan that limits the amount they will pay, you will be responsible for making financial arrangements with Duke in order for us to provide services. If this happens, your financial counselor will talk to you about this in more detail and he/she can provide you with information on fundraising options and refer you to other resources. It is important that you notify the financial counselor immediately of any change or any possible change in your insurance because this could significantly impact your approval process. We strongly encourage patients **NOT** to change insurance companies during the transplant process unless you/your spouse's employer provide you with no other alternative but to do so. If this happens, you should consult your financial counselor for assistance.

Central Venous Catheter (CVC)

What is a Tunneled Central Venous Catheter?

A tunneled catheter is a tube that is placed in the upper chest and exits from a tunnel under the skin. The catheter is placed in Vascular Radiology using an x-ray machine to guide the radiologist. You will receive medication to make you sleepy but you will not receive general anesthesia. The procedure takes about one hour and you will rest in a recovery room for several hours after the procedure. You must have a driver with you.

You may hear these called "Hickman catheters". You will have one small suture right after it is inserted. It is also held in place by a Dacron cuff that grows to the tunnel underneath the skin. A part of the catheter is outside of your body with 1 or more lumens or additional tubes to administer more than one medication at a time. You will be able to hide the catheter underneath your clothes when you are away from the hospital. Now that you have a tunneled catheter, it is important to know how to care for it so that you may experience more consistent treatment and less discomfort. Your ABMT nurse will review how to care for your CVC when you are in the clinic.

You are responsible for caring for your central venous catheter when you are away from the clinic or ABMTU for an extended period of time. While you are undergoing your stem cell transplant, the staff will assist you with catheter care.

This section will tell you:

- what symptoms you should report to your doctor
- how to change the dressing on your catheter
- > how to flush your catheter
- how to change the caps on each lumen

Please ask if you need more information or instructions.

When should I call my doctor or healthcare provider?

Infection is the most serious complication to watch for. Remember to look at your site daily. Notify you doctor and switch to gauze dressing if you experience any of the following:

- Redness, swelling, and/or drainage at the exit site
- > Pain or tenderness at the exit site
- > Fever > 100.5°F (38°C)
- > Flu-like symptoms or chills

Other complications may be related to the catheter itself. Notify your doctor for any of the following:

- You are unable to flush the catheter
- You see a hole or break in the catheter
- Swelling in your face, neck or arm on the same side of your body as the catheter
- Pain in your neck or shoulder with flushing during infusion

NOTIFY YOUR ABMT TEAM IF YOU EXPERIENCE ANY OF THE ABOVE!

How should I care for my catheter?

The dressing:

You will wear a transparent dressing over the catheter exit site. It is important that the exit site remains clean and dry. Change to gauze dressing and call your doctor if you experience any of the following:

- · Redness, swelling or pain at the insertion site
- Excessive sweating, bleeding or drainage causing moisture to pool under the dressing
- Allergy to the transparent dressing causing itching and/or redness

Transparent Dressing	Gauze Dressing
Supplies you will need:	Supplies you will need:
• 1 Chlorhexidine Swab	• 1 Chlorhexidine Swab
• 1 pair of clean gloves	• 1 pair of clean gloves
Transparent dressing – OP Site 3000	 2 squares of 2x2 cotton gauze
• 1" tape – silk or paper	• 1" tape – silk or paper

The dressing change:

Transparent Dressing

Change your transparent dressing at least every seven days. Check your dressing in the mirror daily. Change it more often if you see moisture under the dressing orif it becomes wrinkled. Follow these steps for this dressing change:

- 1. Clean your work area with an alcohol square
- 2. Wash your hands with soap and water for 30 seconds
- 3. Open all the packages of your supplies
- 4. Remove the old dressing and check the site for swelling, redness and/or pain
- 5. Wash your hands again
- 6. Put on the clean gloves and wear mask
- 7. Pinch the wings on the applicator to break the ampoule releasing the antiseptic. Do not touch the sponge with your fingers. Wet the sponge by pressing and releasing the sponge against the skin until liquid is visible
- 8. Use repeated back and forth motions with the sponge across the catheter area for 30 seconds
- 9. Allow the area to dry for 1 minute. Do not fan, blow, blot or wipe the site.
- 10. Apply the transparent dressing.
- a. Remove the backing paper. Do not stretch the dressing
- b. Apply the dressing so the center of the exit site is in the center of the dressing
- c. Gently press the dressing down at the exit site. Mold the dressing around the catheter
- d. Smooth the dressing, working outward to the edge of the dressing so that there are not air bubbles under the dressing and that the edges are adequately sealed. Do not stretch the dressing.
- 11. Use the 1" tape to anchor the catheter to the skin at a comfortable point below the dressing. This will keep the catheter and dressing from moving around. Do not put tape on the dressing itself.

Gauze Dressing

Change your gauze dressing every other day. And change it when the dressing becomes dirty or wet. Follow these steps for this dressing change:

- 1. Clean your work area with an alcohol square
- 2. Wash your hands with soap and water for 30 seconds
- 3. Open all the packages of your supplies
- 4. Remove the old dressing and check the site for swelling, redness and/or pain
- 5. Wash your hands again
- 6. Put on the clean gloves and wear mask.
- 7. Pinch the wings on the applicator to break the ampoule. This releases the antiseptic. Do not touch the sponge with your fingers. Wet the sponge by pressing and releasing the sponge against the skin until liquid is visible.

- 8. Use repeated back and forth motions with the sponge across the catheter area for 30 seconds.
- 9. Allow the area to air dry for 1 minute. Do not fan, blow, blot or wipe the site.
- 10. Apply the gauze dressing: Place 1 2x2 gauze square under the catheter.

Place 1 2x2 gauze square over the site. Apply tape to the entire dressing.

11. Use the 1"tape to anchor the catheter to the skin at a comfortable point below the dressing. This will keep the catheter and dressing from moving around. Do not put tape on the dressing itself.

How do I change the cap and flush the catheter?

Change the cap and flush each lumen of the catheter once each week when you do the transparent dressing change. If you are changing your gauze dressing every other day, designate one day of the week when you will do the cap change and catheter flush. Talk with your local pharmacy or home health nurse and request that they stock these supplies or obtain them for you. You will need:

Cap Change	Flush
Supplies you will need for each lumen of your catheter:	Supplies you will need for each lumen of your
• 2 alcohol squares	catheter:
• 1 cap	10 ml of Normal Saline in a 10 ml needle-
	less syringe
	• 5 ml of Heparin flush (100 units/ml) in a 10
	ml needle- less syringe

Follow these steps to change the cap and flush each lumen of the catheter:

- 1. Clean your work area with the first alcohol square
- 2. Wash your hands with soap and warm water for 30 seconds
- 3. Open all the packages of your supplies
- 4. Scrub the area where the end of the lumen and the cap meet with the second alcohol square for 15 seconds
- 5. Make sure the clamp is closed on the lumen
- 6. Unscrew the old cap and discard
- 7. Screw the new cap onto the end of the lumen
- 8. Pick up the 10 ml normal saline syringe and push the air out of the syringe
- 9. Insert the syringe into the cap
- 10. Check to make sure the clamp is open on the lumen
- 11. Begin emptying the contents of the syringe by applying pressure to the end of the syringe with a pulsating motion. If resistance is met, stop. Do not apply pressure to the lumen
- 12. While pushing in the last ml of the flush close the lumen clamp
- 13. Remove the syringe from the cap and discard syringe
- 14. Pick up the 10 ml Heparin flush syringe and repeat steps 9, 10, 11, 12, and 13

When showering or bathing, cover your dressing with a clear plastic wrap like Press N Seal® to keep the dressing dry. If your dressing gets wet, change it.

Autologous Stem Cell Apheresis and Harvest

Apheresis is the process of separating whole blood into its major components (red blood cells, white blood cells, platelets and plasma) and then removing stem cells from the white blood cell component.

Stem cell priming refers to the process of increasing the number of stem cells produced by your bone marrow and released into your blood stream. You may receive Neupogen® only or chemotherapy and Neupogen® to stimulate your stem cell production. It is very important that you continue to take your Neupogen® every day as ordered until you arrive for apheresis.

The day(s) of Apheresis:

- ➤ Plan to arrive at the Adult BMT Clinic at 8:00 am on the day(s) of apheresis. When you arrive, please sign in at the front desk. You should receive your clinic appointment form promptly, and be directed to the apheresis area.
- ➤ If you have not had your Neupogen® injection, it will be given.
- ➤ Labs will be drawn from your central venous catheter to check your blood counts, chemistries, and a stem cell (or CD-34) count. We will need to review your lab results and your stem cell count before starting apheresis.
- You will be scheduled for 1-4 days of apheresis. The exact number of days is determined by how many stem cells are collected each day. Be sure to bring all of your medications and Neupogen® with you.

What happens during Apheresis?

- ➤ The apheresis procedure will take 6 hours each day. You will be able to sit in a recliner or lie in a bed, whichever will be more comfortable for you.
- You will be connected to the apheresis machine by IV tubes attached to your central venous catheter. The machine spins and separates your blood so the stem cells can be collected into a bag that hangs above the machine. Your blood will be warmed to body temperature and returned to you continually.

- You will be able to watch a movie or read a book during the procedure.
- You will be able to stand up and stretch while still connected to the machine.
- ➤ It is easy for the nurse to disconnect you from the apheresis machine at any time to go to the bathroom.
- ➤ You will be able to eat and drink during apheresis. Please bring, or have someone available to provide, some lunch or snacks for you.
- ➤ The stem cell lab will count the number of stem cells collected in the bag after each apheresis procedure. This process takes several hours, so the result will not be available until the evening of collection. You will be notified that evening if you need to return to the clinic in the morning for another apheresis session.

Side Effects of Apheresis:

- ➤ The most common side effect is numbness or tingling in the lips, hands or feet. This is caused by a temporary lowering of the calcium level in your blood during apheresis. We may give you an infusion of calcium during the procedure to prevent this. Please tell your nurse if you experience any of these symptoms.
- ➤ You are given some extra IV fluid during the apheresis procedure. You may notice an increase in weight, or tightness of your rings or shoes. This extra fluid will naturally be eliminated by your body over the next few days.
- ➤ Tiredness is also a side effect of apheresis. Plan to give yourself a day or 2 to recover from this.
- ➤ Your platelet count will be lowered by the apheresis procedure. Platelets are the cells that aid in blood clotting. We will be checking your blood counts each day before we begin apheresis. You may need a platelet transfusion during this time.
- ➤ When you return home after apheresis, if you have any unusual bleeding or bruising, please call your physician or your ABMT coordinator contact at Duke, so your platelet count can be checked.

Checklist before Apheresis:

- ► It is important that you have the Neupogen® injections every day until you arrive for stem cell apheresis. If you are receiving or giving your own injections at home, please let your ABMT coordinator know if you do not have enough of a supply.
- > Be sure to bring all of your medications and Neupogen® with you.
- ➤ Plan to have a healthy breakfast before apheresis including milk products.
- ➤ If you are traveling from out of town, please come prepared to spend at least 2-4 days
- Please do not drink any alcoholic beverages while taking Neupogen® and during apheresis.
- ➤ Dress in warm, comfortable clothes. It is helpful if you wear a button up shirt because this allows us easy access to your central venous catheter.
- ➤ Bring some lunch and snacks with you. There is a refrigerator available for your use if needed.
- ➤ There is a snack bar on the ground floor of the ABMT Clinic building. It is open weekdays from 7:00am-4:00pm, Monday-Thursday and Friday 7:00-2:30pm. We have a portable DVD player, and a selection of DVDs, available for your use. You may want to bring a DVD movie to watch, or a book to read to help pass the time.
- ➤ We also have access to wireless internet if you have a laptop computer.
- ➤ If you have any questions or concerns prior to coming for your apheresis, please call your ABMT coordinator contact at Duke.

For any questions, concerns, or problems during or after apheresis, please call either:

- Duke ABMT Clinic Apheresis area: 919-668-1054
- ➤ Monday-Friday 8am-6pm
- Duke ABMT Clinic Treatment Room: 919-668-6548
 Monday-Friday 8am-6pm
 Saturday-Sunday 8am-4pm
- Duke ABMT Inpatient Unit (9200): 919-681-9241 (please ask for the charge nurse).

Bone Marrow Harvesting

Occasionally, we are unable to collect enough stem cells from the peripheral blood and a patient may need to undergo a bone marrow harvest. A harvest is an outpatient procedure done in the Ambulatory Surgery Center, located here in the North Pavilion. You will receive more specific instructions about bone marrow harvesting, if needed.

Preparative Regimen

Preparative regimen and conditioning regimen are both names for high dose chemotherapy and/or radiation therapy administered prior to the transplant. The specific regimen you receive will depend upon your underlying disease, previous treatments you have received and your specific transplant protocol or treatment plan.

The preparative regimen starts on a "negative numbered" day. For example, if you are receiving one single dose of chemotherapy as your preparative regimen, and your transplant the next day, your preparative regimen would start on DOT -1 (day of transplant minus 1). Your stem cell transplant always takes place on DOT 0. Every day after that is referred to as a "positive numbered" day. An example is below:

DOT -1	DOT 0	DOT +1
Preparative regimen	Stem cell infusion	Start of supportive care

Your ABMT physician or coordinator will discuss the chemotherapy drugs or radiation you will receive and possible side effects in detail. You may receive your preparative regimen on the

inpatient unit (9200) or in the ABMT Outpatient Clinic depending on your individual plan of treatment.

Starting your Preparative Regimen

Your ABMT coordinator will work with you to establish your day of admission. If your admission is scheduled for the ABMT inpatient unit (9200), you should go to Patient Access Services, Duke North lobby office at 8:00am (unless instructed otherwise by your coordinator).

If you are scheduled to receive your preparative regimen in the ABMT Outpatient Clinic, your coordinator will tell you what time to report to the clinic. You will receive all your care in the ABMT Outpatient Clinic on a daily basis. If at any time you need more care than can be provided to you in the clinic, you will be admitted to the ABMT inpatient unit (9200).

In the Hospital

Preparing for Admission to the Hospital

Based on your treatment regimen you may be scheduled for admission to the Adult Bone Marrow and Stem Cell Transplant inpatient unit (9200). The 9200 unit is located on the 9th floor of Duke Hospital on Erwin Road. You should not take any of your own medications from home while you are in the hospital, but please bring them with you so we have an accurate record of medications you've been taking. You should also discuss with your ABMT physicians or the clinical pharmacist whether you should start taking these when you are discharged.

What to Bring to the Hospital

Because cleanliness is a primary concern, everything you bring to the unit must be as clean as possible. Toiletries and personal items should be new and in their unopened packages. The space you will have to store personal items on the unit is very limited so try to bring as little as possible. (For example, there is no room to store a large suitcase.)

Items you may want to bring:

- slippers (either washable or new)
- prescription eyeglasses (you will not be able to wear contact lenses)
- pictures of your family and friends
- > socks
- bathrobe
- a thermometer for when you are discharged
- new soft toothbrush and new tube of toothpaste, new toiletries
- videos or DVD's- there are players in each room
- books, magazines, cards
- > iPod®, small radio or CD player, computer
- front button pajamas or gown (a hospital gown will be provided if you prefer, but many patients like having their own nightwear).
- > Sturdy shoes for walking
- Comfortable lounging clothes

Special Precautions in Your Room

Each room is equipped with a HEPA (High Efficiency Particulate Air) filtration system in the ceiling above the bed. This HEPA filter removes germs and dust particles from the air. Also, each room and the unit itself are under positive pressure so that air is forced outward when a door is opened rather than unfiltered air coming in. No fresh flowers or live plants are permitted in the rooms or on the unit because they can hide fungus, which can cause serious infections.

Visitor Information and Unit Policies

The visitor information on the following pages should be reviewed by your caregiver and any other visitors who are planning to come and see you while you are on the inpatient unit (9200).

- Visiting hours are from 8:00 a.m. to 11:00 p.m. If your visitors are on the unit during physician rounds or nursing change of shift, we ask that they not linger in the halls. This policy is necessary because team members are sharing information about all of the patients on the unit and we need to protect every patient's right to privacy.
- Two visitors may be allowed in the room at a time.
- W Hand washing is required (scrubbing for 15 seconds with soap) before each visitor enters a patient's room. Hand washing or use of alcohol foam must be repeated each time the room is entered. At times, other precautions may be needed. You will know when a sign is on the patient's door.
- Visitors must use the visitor's restroom in the main hospital hallway. No one is allowed to use the patient's bathroom except the patient. This is enforced for the protection of the patient and to minimize bacterial spread in the room.
- No fresh cut flowers or live plants allowed in the patient's room or on the unit. Fresh fruits and vegetables may not be taken into a patient's room.
- Visitors are asked to eat only in the Family Lounge or off the unit, not in the patient rooms. This is enforced for the protection of the patient and to minimize bacterial spread in the room.
- Wisitors/Caregivers do not spend the night on the unit. Allowances are occasionally made, given special circumstances. This is done on an individual basis and must first be approved by the nurse manager or nurse in charge.

Please do not visit if you have any signs of cold, flu, or have been exposed to any contagious illness! If you are a caregiver, it is recommended that you get a flu shot to protect yourself and the patient. If you have any questions about whether or not you should visit, please speak with either a nurse or a physician. Children under six are not permitted on the ABMT inpatient transplant unit (9200).

The goal of the ABMT program is to provide the best quality patient care possible to your family member/friend. Thank you for your cooperation in following the visitor policies.

Preparing for Discharge from the Hospital

After you receive your preparative regimen on the ABMT inpatient unit (9200), you will be discharged to continue your treatment in the ABMT Outpatient Clinic. Special discharge teaching will be provided for both you and your caregiver by the ABMT nursing staff and pharmacist. *Please make sure your caregiver is available between noon and 3:00 p.m. on the day of your discharge to attend this teaching session with you.* During the teaching session the pharmacist will provide both you and your caregiver with important instructions and information about the medications that you will be taking.

Stem Cell Infusion

You will be given your infusion of stem cells (your "transplant") on "DOT 0" of your specific treatment plan, after you have completed your preparative regimen. This may be in the hospital or in the ABMT Clinic. The cells are verified by 2 registered nurses and a laboratory technician before they are given to you.

You will be given medications before the infusion to minimize any possible adverse reactions. Once the frozen cells have been thawed, they are given to you through your central venous catheter and may be dripped in by a short infusion or pushed using a syringe. You will be closely observed and your vital signs will be frequently monitored during and after the infusion. The reactions that occur are caused by the preservative used to protect the stem cells during the freezing process. They may include shortness of breath, low blood pressure, chills, fever, chest pain, rash, hives and cough. You may also experience a "bad" or unpleasant taste in your mouth. You will be offered hard candy to dissolve in your mouth during the infusion. You will be asked to report any side effects, and if you experience any of the above noted symptoms, you will be treated immediately. Your urine may appear "bloody" 24 – 48 hours after your infusion. This is your body's way of getting rid of the byproducts of the stem cells that are not needed. You may also have a strange body odor for several days following your infusion. You may not notice it, but those around you will. This is also due to the preservative that the cells are stored in. It will pass in a few days.

Engraftment

Engraftment is when your body accepts the transplant and your white blood count returns. White blood cell engraftment usually occurs two to three weeks following your infusion, but may vary depending upon your disease and treatment. Platelets and red blood cells usually take a little longer to recover than white blood cells .

The chemotherapy and/or radiation you received affect all of your blood cells. During the time that you are waiting for engraftment you may need to have blood and platelet transfusions. Growth factor shots may be given during this period to speed your white blood cell

recovery. Please remember that you are very vulnerable to infection at this time. You will be closely monitored for any signs of infection every day. **Your best defense against infection is hand washing.** When your cells start to engraft, you may notice a rash on your body. You may also experience bone pain as your bone marrow starts to produce cells. These are all common symptoms during engraftment.

In the ABMT Outpatient Clinic

- Do try to drink healthy drinks including fruit juice, nutrition supplements (Boost®, Ensure®) Gatorade®, sports drinks, and water.
- Do try to eat small, frequent bland meals until your stomach is back to normal. Rice, cereal, plain soups, broth, crackers, pasta, mashed or baked potatoes, well cooked meat and poultry, eggs, well cooked vegetables, canned non-citrus fruits, and frozen ices.
- ② Do exercise: Walk every day, increase your walking as your blood counts begin to recover. You will rest better with exercise.
- Always wear a seatbelt when traveling in any vehicle.
- ② Do not wear make-up, perfume, perfumed skin creams or lotions or harsh deodorants. Apply unscented natural skin creams to dry skin (Lubriderm®, Eucerin®). You may wear newly purchased lipstick or lip balm if you do not have any sores in your mouth or on your lips.
- On not wear open toe shoes or sandals. Wear socks with your shoes.
- On not wear contact lenses until cleared by your ABMT physician.
- Do not smoke or allow others to do so in your room.

Do not drink alcoholic beverages. This is very important as some of the drugs you will be taking can cause liver damage which may be worsened by alcohol.

Cafeteria

There is a small cafe in the atrium of North Pavilion that carries a limited range of sandwiches, soups, and other foods. Beverages are available for patients at the clinic. Vending machines are located near the public restrooms on the first floor.

Family Room

There is a large family recreation room that has a television, computers with internet access, games, puzzles and reading materials. There is another area off the main lobby for your use as well. It has a refrigerator, microwave, coffee maker and educational material in the front room, and a quiet room for prayer or meditation, or just some quiet time in the back.

The clinic has a designated parking area in the garage for bone marrow transplant patients. You should be aware that there is a charge for the parking facilities. Reduced priced parking passes are available from the front desk.

Possible Complications

Infection

What protects us from infection? We have natural barriers our bodies use to prevent infections. The first line of defense is our skin and the mucous membranes of our nose and mouth. They prevent any "foreign invaders" from passing through these openings into our internal body. The white blood cells and antibodies are other defense mechanisms our bodies use to fight infections if the first lines of defense fail. Together, they tag and destroy any infectious organisms. However, after a bone marrow/stem cell transplant, all of these defenses are compromised, allowing for an increased risk of infection.

There are three different types of infections, *viral*, *bacterial*, and *fungal*. Viruses are frequent in BMT patients because chemotherapy has compromised the ability of the white blood cells to tag and destroy these viruses. The common time period for susceptibility to viruses is during the first year after transplant. Some of the more commonly seen viruses include herpes simplex or "cold sores", and varicella zoster or "shingles".

If you have experienced cold sores in the past, they are likely to reoccur during your transplant. You will receive antiviral medication to treat symptoms.

Varicella zoster is the virus which causes chicken pox or shingles. Occurrence is typically within the first year following transplant, usually after the third month. The presentation of the virus can be a blistering, itching, painful rash along one of the body's nerve branches called a dermatome. Sometimes shingles causes pain to the area before a rash appears. The pain is usually described as burning or stabbing. The pain associated with the rash may persist for several months after the rash resolves. You will receive antiviral medication and pain medication to treat the virus and the pain.

Bacteria are microscopic organisms that can invade the body and multiply rapidly. We all have bacteria on our skin, in our mouth and in our gastrointestinal system. When your white blood cell count is low and your immune system is impaired, you are more susceptible to having normal bacteria cause infections.

Fungal infections are another type of infection that can occur in the stem cell transplant patient. Fungi reside in our bodies and we are in contact with many different types every day in the environment. The natural bacteria in our body keep fungi from creating an infection. When our normal protective mechanisms are affected with chemotherapy drugs, fungal infections can occur.

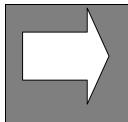
Important ways you can reduce your risk for infection

- 1. WASH YOUR HANDS AND HAVE VISITORS WASH THEIR HANDS. It is the single best prevention of infections.
- Avoid crowds.

- 3. Follow safe food and water guidelines.
- 4. Avoid people with infections.
- 5. Avoid changing baby diapers.
- 6. Limit your exposure to animals and avoid animal waste.

Neutropenia

Following an autologous transplant you can expect to be neutropenic (less than 500 neutrophils) for 2-3 weeks. Neutrophils are a type of white blood cell that fight infection. While you are neutropenic you are at an increased risk for infection.



One of the first signs of infection may be fever and/or chills. If you have a temperature of 100.5°F (38°C) or greater, notify the ABMT clinic or the ABMT inpatient (9200) charge nurse immediately

Some of the most common sites for infection are listed below. If you experience any of these symptoms, you should tell your ABMT team immediately.

<u>Mouth</u> – You may develop mouth sores. Watch for white patches in your mouth or in the back of your throat. This may be a fungus and can be treated. You may also experience "cold sores" in or around your mouth.

<u>Sinusitis</u> – This is an infection of the nasal passageway. You may experience sinus (nose) drainage, which may be accompanied by a sore throat. It is important to note the color of your drainage. If it is yellow or green, it is possible that you may have an infection. You may have headaches with sinusitis.

Skin – The skin must be kept clean. You will shower every day using a mild antibacterial soap and shampoo. Because your skin will be more sensitive after transplant, avoid medicated or heavily

perfumed products and use sensitive skin lotion. If you have a skin reaction, stop using the product and report the reaction to your physician.

If you have dry skin, watch for infection at areas that may have cracked open. Signs of infection include redness, swelling, and drainage. If you have a wound, keep the site clean and apply a dressing if appropriate. Be sure and keep fingernails and toenails well trimmed to avoid scratching and irritating the skin. (Do not cut your toenails or fingernails if your platelets are low because you risk bleeding or bruising).

<u>Catheter</u> –You should report redness, pain or discharge from your catheter site.

<u>Lungs</u> –Report any new cough or increase in prior cough. Other signs and symptoms noted with respiratory infection are shortness of breath, shaking chills, and fever.

<u>Bladder</u> -Signs and symptoms include burning, blood, urgency and frequency of urination. Fevers may also accompany urinary tract infections.

Rectal pain or pressure –Report any burning, bleeding and itching in your rectal area.

The best way to help fight infection is to make sure you and your caregivers practice good hand washing.

Anemia

Anemia is another name for low red blood cells. Anemia can make you feel tired and/or weak and may also cause you to feel dizzy. When your red blood cells are low, our body cannot carry oxygen as well. You may be anemic for a number of reasons before, during, and after your transplant. Your ABMT team will monitor your anemia by blood counts and may treat you with red cell transfusions or medications.

Thrombocytopenia

Thrombocytopenia is a decrease in the number of platelets circulating in the blood stream. Platelets are the cells within the blood stream which help your blood to clot. Therefore, when there is a decrease in the number of platelets, there is the potential for bleeding to occur. You will receive platelets when your platelet count is low or you have signs of bleeding.

Steps to Help Prevent Bleeding

- Protect yourself against bruising or falling
- Avoid strenuous activity
- > Do not lift heavy objects
- > Avoid sexual intercourse if your platelets are less than 50,000
- Lubricate lips
- Cleanse mouth with a soft toothbrush, do not use commercial mouthwashes; alternatives include baking soda and water or salt water
- > Avoid dental floss unless you used it daily prior to transplant
- > Do not strain when moving bowels, report constipation
- Avoid suppositories and laxatives unless prescribed
- Use an electric razor for shaving
- Use an emery board for nail care; avoid cutting nails
- Avoid tight-fitting clothes
- Avoid nose blowing
- Avoid medications that may cause or prolong bleeding (aspirin, naproxen, or ibuprofen). Be sure to check with your physician

before taking any medications not prescribed by them, or over the counter medications.

Pulmonary Complications

For several months after your transplant, you are at risk for lung complications including pneumonia and interstitial pneumonitis. If you develop any shortness of breath, cough or fever, report these symptoms immediately to the ABMT Clinic or ABMT (9200) inpatient unit.

Pain Management

Pain can be a side effect of the treatments needed as part of the bone marrow/stem cell transplant. Since pain is an individual experience, please let the ABMT staff know when you are experiencing pain. Patients are asked to describe their pain in character (dull, sharp, etc.), intensity (on a scale of 0 to 10 with 0 being no pain and 10 being the worst pain imaginable), location, duration, and things that make it worse or better. Describing the pain will better enable us to choose medications and treatments that may be most effective against your pain.

Nausea and Vomiting

Nausea and vomiting are the most common side effects of chemotherapy/radiation. Chemotherapy acts on a specific part of your brain that triggers nausea and vomiting. The amount of nausea and vomiting you have will depend on your past experience and the type of drugs you receive. Sometimes your stomach might feel upset right after your treatment, or the nausea could be delayed for 6-12 hours. Usually the nausea and vomiting will decrease in severity in the days following chemotherapy. Your ABMT team will work with you to find the best methods to help you control your nausea and vomiting. People react differently to different methods, which is why it is important that you let us know what is working best for you. Every effort will be made to prevent and treat nausea and vomiting.

Anorexia

You may experience anorexia (loss of appetite). When your body is stressed (during transplant) it requires more calories to repair

damaged tissue. This is an important time to try to increase your caloric intake even though eating may be a chore. Loss of appetite may be caused by chemotherapy or by the medications you are taking. You may also experience decreased taste sensation or a bitter metallic taste in your mouth, as well as mouth sores that affect your ability to eat. Attempt to eat food that is bland and easily digested. Small frequent meals are better tolerated than large meals.

Diarrhea

Diarrhea is frequent, loose, watery stools. It is important to report diarrhea to your ABMT team if it continues for more than 24 hours. It can occur as a result of the side effects of chemotherapy and/or radiation, other medications, stress, or infection. The problems associated with diarrhea include loss of fluids, electrolytes (minerals), abdominal cramping, pain in the rectal area, and rectal skin breakdown. Medications are available to treat diarrhea.

Constipation

Constipation is the passage of dry, hard stool that occurs when materials move too slowly through the large intestine. There are many causes of constipation, including poor intake of food and fluids, the use of certain types of pain medications, decreased activity or immobility, side effects of some chemotherapy medications, and disease of the colon. Medications are available to treat constipation. Talk with your ABMT team if you are experiencing constipation.

Stomatitis and Mucositis

Chemotherapy agents affect the rapidly dividing cells that line the mouth and digestive tract. This is known as mucositis or stomatitis. Mucositis may cause tenderness, soreness, dryness, and occasional white patches. Sometimes mucositis can make it difficult to eat or swallow.

Brush teeth gently after each meal and at bedtime with a soft bristled toothbrush or spongy soft toothette. Use non-abrasive toothpaste.

- ➤ Remove dentures, bridges, and plates; replace only for meals; cleanse dental work well before returning to mouth, and do not use denture adhesive until mouth soreness improves.
- ➤ Rinse your mouth with a saline (salt water) solution 3-4 times every day and after meals. Avoid commercial mouthwashes because they contain alcohol, which has a drying effect on your mouth. Saline will be provided to you in the hospital.
- ➤ To make salt water: Mix 2 tablespoons of table salt with one quart of water. Bring to a boil in a covered pan for 5 minutes. Store the salt water in the refrigerator in a clean covered container. Throw away unused portion after 3 days.
 - Your physician can prescribe a "numbing" medication to use before meals and as needed to decrease your mouth discomfort; other medications are also available to treat your mouth pain and may be prescribed by your ABMT team.
 - If your mouth is dry, try sucking on hard sour candy several times a day. This may increase your saliva production.

Notify your ABMT team if you experience:

- An increase in redness, tenderness, and burning of the mouth
- > Blisters or white patches in the mouth
- > White coated tongue
- > Bleeding gums
- > Inability to eat or drink
- > Sore throat and/or difficulty swallowing
- Cold sore on lips or mouth
- > Increase in mucous production

Skin Care

Skin changes are common after transplant because of chemotherapy and radiation. Skin changes include increased dryness, flaking, discoloration and darkening. Although skin changes are common, you should report to your ABMT team **the appearance of a new rash or increased redness, pain, itching, or changes in skin texture, such as thickening**. Your skin will be very sensitive to sun exposure and sunburn very easily. Avoid bright sunlight after transplant. When you are outdoors wear sun block (SPF 30), protective clothing such as long-sleeved shirts, long pants, and a hat with a brim.



Exercise



It is well documented that exercise is an important part of the recovery process following stem cell transplantation. Benefits include preventing loss of endurance, muscle strength and bone density. Exercise can also prevent respiratory and circulatory problems and improve your ability to be as independent as possible.

If you are on the inpatient ABMT inpatient unit, you will be assessed by a physical therapist. The physical therapist will design an exercise program based on your strength and abilities. The key to a successful exercise program is consistency. You should try to walk in the ABMT halls at least three times every day. There is a "nu step" recumbent cycling machine, a treadmill and light weights in the exercise room. Please clean off the equipment with the provided wipes when you are finished using it. Your physical therapist will provide you will any additional equipment. Continuing to exercise, even when you don't feel up to it will help with your recovery and hopefully get you discharged out of the hospital sooner!

If your ABMT physician does not recommend that you walk, your physical therapist will assist you with alternative gentle movement and getting out of bed to the chair as tolerated.

In the ABMT Outpatient Clinic you are encouraged to walk the halls several times every day. When you are not in the clinic but staying locally, you are encouraged to walk outside, weather permitting. If it is sunny out, you should wear the appropriate clothing along with sunscreen SPF30 and a hat. You are also encouraged to use the exercise facility at the apartment where you are staying. Be sure to wipe off the equipment prior to using.

After your discharge from the ABMT Program, it is recommended that you continue an exercise program to assist with your recovery.

Nutrition and Safe Food Handling

The following text was adapted from the U.S. Department of Agriculture Food Safety and Inspection. Food safety is important for everyone — but it's especially important for you. This guide is designed to provide practical guidance on how to reduce your risk of foodborne illness. To avoid contracting a foodborne illness, you must be especially vigilant when handling, preparing, and consuming foods.

Although we do not limit your food choices, it is important for you to be aware of how to safely purchase and prepare food.

Handling & Preparing of Food Safely

Food Safety Tools Checklist:

- **Solution** Food thermometer
- **≰** Appliance thermometer
- **★** Multi cutting boards (nonporous surfaces such as plastic, marble, glass, or pyroceramic are easier to clean than wood).
- **Sponges**
- **#** Paper towels
- **≰** Bleach
- Spray bottles

- **#** Hand soaps
- **S** Blender
- **★** Slow cooker/Crock pot

Four Basic Steps to Food Safety

1. Clean: Wash hands and surfaces often Bacteria can spread throughout the kitchen and get onto cutting boards, utensils, counter tops, and food.

To ensure that your hands and surfaces are clean, be sure to:

- Wash hands in warm soapy water for at least 20 seconds before and after handling food and after using the bathroom, handling garbage, and touching pets
- Wash cutting boards, utensils, and counter tops with hot soapy water after preparing each food item and before going on to the next food. Cutting boards are sanitized weekly using a solution of 1 part household bleach to 10 parts water.
- Use liquid dish soap when washing dishes and pans
- · Replace sponges at least weekly
- Consider using paper towels to clean up kitchen surfaces. If using cloth towels, you should wash then daily in the hot cycle of the washing machine.
- Do not store chemicals and cleaning solutions near food supplies
- Do not store food under the sink.
- Your caregiver will handle, wash, and peel all produce (see list of allowable *raw* fruits and vegetables). Wash fruits and vegetables thoroughly under running tap water for at least 30 seconds. Cut away bruised areas.
- With canned goods: remember to clean lids before opening.
- Wash can opener after each use with warm soapy water.
- Keep appliances free of food particles
- Keep counter and kitchen surfaces free of food particles
- Check microwave oven, toaster, can openers, and blender/mixer blades. Blender blades and bottom should always be removed when washing the jar. Use bleach solution to sanitize these items.

2. Separate: Don't cross contaminate

Cross-contamination occurs when bacteria are spread from one food product to another. This is especially common when handling raw meat, poultry, seafood, and eggs. The key is to keep these foods- and their juices – away from ready –to- eat foods.

To prevent cross-contamination, remember to:

- Separate raw meat, poultry, seafood, and eggs from other foods in your grocery shopping cart, grocery bags, and in your refrigerator.
- Use one cutting board for fresh produce and a separate one for raw meat, poultry, and seafood.
- Never place cooked food on a plate that previously held raw meat, poultry or eggs without first washing the plate with soapy water.

3. Cook: Cook to proper temperatures

Foods are safely cooked when they are heated to USDArecommended safe minimum internal temperatures.

To ensure that your foods are cooked safely, always:

- Use a food thermometer to measure the internal temperature of cooked foods. Check the internal temperature in several places to make sure that the meat, poultry, seafood, or egg product is cooked all the way through. Color of food is not a reliable indicator of safety or doneness.
- Cook whole pieces of Veal, Beef, Pork, Lamb, Rabbit, Goat, and Game to at least 160° F.
- Cook Ground beef, veal, lamb, pork, rabbit, goat, game to at least 160° F and ground poultry to a safe minimum internal temperature of 165° F. Cook Chicken and Turkey: whole bird and dark meat (thigh & wing) to180° F. Breast, Roast to 170° F.
- Cook Fresh (raw) Ham to 160° F.
- Reheat fully cooked hams packaged at a USDA-inspected plant to 140° F. For fully cooked ham that has been repackaged in any other location or leftover fully cooked ham, heat to 165°F.

- Cook Seafood to 145° F. Cook shrimp, lobster, and crab until they turn red and the flesh is pearly opaque. Cook Scallops until they turn milk white or opaque and firm.
- Cook eggs until the yolks and whites are firm. Use only recipes in which eggs are cooked or heated to 160° F.
- Bring sauces, soups, and gravy to a boil when reheating. Heat other leftovers to 165° F.
- Reheat hot dogs, luncheon meats, bologna, and other deli meats until steaming hot or 165° F.
- Stuffing to 165° (always cook in separate container outside the bird)
- During food preparation, do not taste the food with the same utensil used for stirring
- NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!
- When cooking in a microwave oven, cover food with a lid, stir, and rotate for even cooking. If there is no turntable, rotate the dish by hand once or twice during cooking. Always allow standing time, which completes the cooking, before checking the internal temperature with a food thermometer. Food is done when it reaches the USDA recommended safe minimum internal temperature.



4. Chill: Refrigerate promptly

Cold temperatures slow the growth of harmful bacteria. Keeping a constant refrigerator temperature of 40° F or below is one of the

most effective ways to reduce the risk food borne illness. Use an appliance thermometer to be sure the refrigerator temperature is consistently 40° F or below and the freezer temperature is 0° F or below.

To chill foods properly:

- Refrigerate or freeze meat, poultry, seafood, and other perishables within 2 hours of cooking or purchasing. Refrigerate within 1 hour if the temperature outside is above 90° F. Egg dishes and cream-and mayonnaisebased foods should not be left unrefrigerated for more than 1 hour.
- Never thaw food at room temperature, such as on the counter top. It is safe to thaw food in the refrigerator, in cold water, or in the microwave. Use a dish to catch drips when defrosting in refrigerator or microwave. Use defrosted foods immediately; do not refreeze.
- Divide large amounts of leftovers into shallow containers for quicker cooling in the refrigerator.
- Refrigerate only as much as can be eaten in 2 to 3 days; freeze the rest.
- Clean spills in refrigerator or freezer immediately; keep shelves and doors sanitized. The area of the refrigerator most likely to harbor pathogenic bacteria is the produce bin, followed by bottom shelves, and meat drawers, be sure to clean frequently.
- Do not store foods like milk, butter or eggs in the door shelves because the door temperatures are consistently warmer than other areas of the refrigerator.
- · Discard eggs with cracked shells
- Discard entire food packages or containers with <u>ANY</u> Mold present, including yogurt, cheese, cottage cheese, fruit, vegetables, jelly, and bread or pastry products.
- · Discard freezer-burned foods.
- A faulty door seal is among the most common fridge problems, creating condensation, mold and inconsistent temperatures. Check door seal, if dry and cracked have the seal replaced by a repair service.
- Follow the recommendations in the abridged USDA Cold Storage chart.

Cold Storage Chart

These time limit guidelines will help keep refrigerated food safe to eat. Because freezing keeps food safe indefinitely, recommended storage times are for quality only.

Product		Refrigerator (40 °F)	Freezer (0 °F)
Eggs	Fresh, in shell	3 to 5 weeks	Don't freeze
	Hard cooked	1 week	Don't freeze well
Liquid Pasteurized Eggs, Egg Substitutes	Opened	3 days	Don't freeze well
	Unopened	10 days	1 year
Deli or Vacuum- Packed Products	Egg, chicken, ham, tuna, & macaroni salads	3 to 5 days	Don't freeze well
Hot Dogs	Opened package	1 week	1 to 2 months
	Unopened package	2 weeks	1 to 2 months
Luncheon Meat	Opened package	3 to 5 days	1 to 2 months
	Unopened package	2 weeks	1 to 2 months
Bacon & Sausage	Bacon	7 days	1 month
	Sausage, raw — from chicken, turkey, pork, beef	1 to 2 days	1 to 2 months

Hamburger and Other Ground Meats	Hamburger, ground beef, turkey, veal, pork, lamb, & mixtures of them	1 to 2 days	3 to 4 months
Fresh Beef, Veal, Lamb, Pork	Steaks	3 to 5 days	6 to 12 months
	Chops	3 to 5 days	4 to 6 months
	Roasts	3 to 5 days	4 to 12 months
Fresh Poultry	Chicken or turkey, whole	1 to 2 days	1 year
	Chicken or turkey, pieces	1 to 2 days	9 months
Seafood	Lean fish (flounder, haddock, halibut, etc.)	1 to 2 days	6 to 8 months
	Fatty fish (salmon, tuna, etc.)	1 to 2 days	2 to 3 months
Leftovers	Cooked meat or poultry	3 to 4 days	2 to 6 months
	Chicken nuggets, patties	1 to 2 days	1 to 3 months
	Pizza	3 to 4 days	1 to 2 months

Becoming a Better Shopper

Follow these safe food-handling practices while you shop.

- Carefully read food labels while in the store to make sure food is not past its "sell by" date.
- Place all fresh produce in plastic bags; do not place directly in the cart.
- Put raw packaged meat, poultry, or seafood into a plastic bag before placing it in the shopping chart, so that its juices will not drip on – and contaminate – other foods.
- Buy only pasteurized milk, cheese, and other dairy products from the refrigerated section. When buying fruit juice from the refrigerated section of the store, be sure the juice label says it is pasteurized, it may also say flash pasteurized.
- Purchase eggs in the shell from the refrigerated section of the store. (Note: store eggs in their original carton in the main part of your refrigerator once you are at home.)
- Never buy food that is displayed in unsafe or unclean conditions.
- Avoid tasting free food samples, and avoid foods from selfselect bulk containers
- When purchasing canned goods, make sure that they are free of dents, cracks, or bulging lids. (Once you are home, remember to clean each lid before opening the can.)
- Purchase frozen & refrigerated foods last, especially during the summer months.

When shopping for food, reading the label carefully is key

Food Product Dating

Open dating is found primarily on perishable foods such as meat, poultry, eggs, and dairy products. "Closed" or "coded" dating might appear on self-stable products such as cans and boxes of food.

Types of Open Dates

- A "Sell-by" date tells the store how long to display the product for sale. You should buy the product before the date expires.
- A "Best If Used By" (or Before) date is recommended for best flavor or quality. It is not a purchase or safety date.
- A Use-by date is the last date recommended for the use of the product while at peak quality. The date has been determined by the manufacturer of the product.

"Closed or coded dates" are packing number for use by the manufacturer

Transporting Your Groceries

Follow these tips for safe transporting of your groceries:

- Pick up perishable foods last, and plan to go directly home from the grocery store.
- Always refrigerate perishable foods within 2 hours of cooking or purchasing.
- Refrigerate within 1 hour if the temperature outside is above 90° F.
- In hot weather, take a cooler with ice or another cold source to transport foods safely.

Storing Food in Cupboard/Pantry

- Discard without tasting any bulging, leaking, or cracked cans, or those deeply indented in the seam area.
- Rotate food stock so older items are used first. Monitor expiration dates.
- Make sure food storage areas remain reasonably clean; no obvious insect or rodent contamination should be evident.

If home-canned foods are used, review the processing procedure to be sure it was appropriate for pH of the food, size of bottle, and elevation above sea level. Look for mold and seals. If you suspect a home-canned food may not have been processed properly, if the lid bulges, or if the food has any bad odor or unusual characteristics after opening, **DISCARD IT**.

Tips for Transporting Food

- Keep cold foods cold, at 40° F or below. To be safest, place cold food in cooler with ice or frozen gel packs. Use plenty of ice or frozen gel packs. Cold food should be at 40° F or below the entire time you are transporting it.
- Hot food should be kept hot at 140° F or above. Wrap the food well and place in an insulated container.

Being Smart

*Dining out is *not* recommended while neutropenic, always check with your healthcare provider first.

Basic Rules for Ordering

- Check grades at restaurant; look for "A" rating in the 90's.
- Eat early to avoid crowds.
- Ask whether the food contains uncooked ingredients such as eggs, meat, poultry, or fish. If so, choose something else
- Ask how these foods have been cooked. If the server does not know the answer, ask to speak to the chef to be sure your food has been cooked to a safe minimum internal temperature.
- · Request single serving condiment packages
- Avoid buffets, which may contain undercooked foods or foods that have been at room temperature too long. Order from a menu to minimize risk.
- Avoid garnishes, salad bars, delicatessens, smorgasbords, pot lucks, and side walk vendors.
- If you plan to get a "doggy bag" or save leftovers to eat at a later time, refrigerate perishable foods as soon as possible – and always within 2 hours after purchase or delivery. If the leftover food is in air temperature above 90° F, refrigerate within 1 hour.

Personal Hygiene

- Have available liquid or bar soap for hand washing
- · Wash hands with soap and warm, running water before and after every step in food preparation.
- Wash hands before eating, especially when eating hand-held foods.
- Wash hands after using the rest room, handling the garbage, and touching pets.
- Use paper towels for drying hands.

¹ Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; container may require refrigeration after opening ² Aseptically packaged, shelf-stable tofu and pasteurized tofu do not need to be boiled. Unpasteurized tofu must be cut into 1inch cubes or smaller, and boiled a minimum of five minutes in water or broth before eating or using in recipes.

³ Rinse under clean, running water before use, including produce that is to be cooked or peeled (such as bananas, oranges and melon).

⁴Bring tap water to a rolling boil and boil for 15-20minutes. Store boiled water in the refrigerator. Discard water not used within 48 hours (2 days).

⁵ Recommend using boiled or bottled water if using a water service other than city water service. Please see water safety guidelines. ⁶ Water safety guidelines for approved bottled water treatments.

For More Information on Food Safety

You may contact the USDA Food Safety and Inspection Service to obtain additional food safety information in both English and Spanish.

Online:

Information can be accessed on the FSIS web site at www.fsis.usda.gov.

Food Safety Questions? "Ask Karen" - The FSIS Virtual Representative - an automated response system available 24/7 at www.fsis.usda.gov

Send e-mail inquiries to <u>mphotline@usda.gov</u>.

By Phone: Call the USDA Meat and Poultry Hotline at 1-888-MPHotline

(1-888-674-6854) or TTY: 1-800-256-7072

- The year-round, toll free Hotline is available Monday through Friday from 10 a.m. to 4 p.m. Eastern Time
- An extensive selection of timely food safety messages is also available at the same number, 24 hours a day.

Additional Food Safety Resources

Food and Drug Administration www.cfsan.fda.gov

Center for Disease Control and Prevention 1-888-232-3228 (24-hour recorded information) www.cdc.gov/foodsafety

- National Center for Infectious Diseases/Traveler's Health www.cdc.gov/travel/index/.htm
- National Center for Infectious Diseases/Water-Related Diseases
 www.cdc.gov/ncidod/diseases/water/index/.htm

U.S. Environmental Protection Agency Office of Water www.epa.gov/OW

Gateway to Government Food Safety Information www.foodsafety.gov

Partnership for Food Safety Education (Fight BAC!) www.fightbac.org

Water Safety Guidelines

Tap water: Water from your home faucet is considered safe if your water is from a city water supply or a municipal well serving highly populated areas.
Well water: Well water must be tested for coliforms and Cryptosporidium yearly. The water should be tested immediately prior to your return home and results must be negative to be used for drinking.
Municipal Wells: Drinking well water from municipal wells serving highly populated areas is considered safe because the water is tested more than two times each day for bacterial contamination.
Private wells and community wells: The quality of well water from these sources cannot be guaranteed. It is recommended that other approved water sources be used to ensure a safe water supply, including: boiled water, bottled water, or distilled water.
Not considered safe: Most water filtration devices will not make water safe if the private well water or smaller community well water is not chlorinated.
 The following sources of water are suggested if your water is not from a city water or municipal well supply Boiled water: At home, safe water can be made by bringing tap water to a rolling boil for 15-20 minutes. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 48 hours (2 days). Distilled water: Water may be distilled using a steam distillation system. After processing, the

water should be stored in a clean, covered

within 72 hours (3 days).

container in the refrigerator; discard water not used

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

Water filters

- If you use a water filter located on household water taps the following specifications must be met:
- A: The filters must be designed to remove coli forms and Cryptosporidium. Any of the following are acceptable:
 - Reverse osmosis filter
 - Absolute pore size of 1 micron or smaller
 - Tested and certified by NSF Standard #53 for cyst removal
- B: The water tap filter must be installed immediately before the water tap
- C: manufacturer directions must be followed for filter maintenance and replacement

Most water filtration devices will not make water safe if the water supply has not been chlorinated. Portable water filters (such as Brita® or Pur® system) as well as refrigerated-dispensed water and ice machines do not meet filtration standards. Portable water systems filter for impurities, but not for bacteria.

Your Medications

Record Keeping

While receiving treatment in the outpatient clinic, you will be responsible for taking your own oral medications. You will be given prescriptions to get filled at a local pharmacy.



The nurse or pharmacist will provide you with sheets to record medication. These recording sheets will be placed in this handbook so please bring it to the clinic each day along with your medications. If you are admitted to the hospital, you will also need to bring your handbook and medications with you.

Reportable Signs and Symptoms

You will be instructed to take your temperature every four hours while awake during your outpatient phase of treatment. Please bring a thermometer with you from home. After your transplant take your temperature every 8 hours while awake. If you develop a chill, take your temperature even if you don't feel like you have a fever. If your temperature is 100.5 degrees Fahrenheit (38°C) or higher, or you have a chill, you should call the ABMT clinic or the ABMT inpatient unit (9200). Even if you are already on antibiotics (by mouth or through your vein) you may need additional antibiotics. Other reasons that you may need to call the clinic or inpatient unit would be:

if you have shortness of breath

- severe nausea or vomiting which keeps you from drinking fluids
- severe diarrhea
- bleeding from any site
- change in mental status
- You should also call if you have any other questions or concerns.

You may be asked to record oral intake (how much you are drinking by mouth). It is also important to document episodes of vomiting and diarrhea, as well as how frequently you are urinating.

Medication Record

The medication record will provide a calendar for you to keep track of the medications that are taking on a daily basis. There is an individual sheet for each day following transplant. The top section of the sheet will list the medications, which need to be taken on a scheduled or regular basis. The time of day at which each medication needs to be taken is indicated by a box. Please use a check mark or an "X" to indicate that a specific medication has been taken. The bottom section of the sheet includes all medications that need to be taken on an "as needed" basis. More information on each of these medications will be provided at the time of discharge from the hospital or when you start your outpatient treatment patient by the clinical pharmacist.

Medications Commonly Prescribed for an Autologous Transplant

Antimicrobials

Your immune system including your white blood cell count will not function normally for several months following the stem cell transplant. You will be susceptible to a variety of infections. We encourage healthy habits to reduce your risk of infection, but you may also need to take medicines that treat or prevent the common infectious complications which may occur after transplant.

Antiemetics

Antiemetics are drugs that are used to prevent nausea and vomiting. You will receive one or more of these medications during your course of treatment.

Ursodiol/Actigall

Depending on the chemotherapy you receive, you may be on Ursoldiol or Actigall. Both of these drugs are used during the stem cell transplant to help prevent damage to the liver (also called Sinusoid Occlusive Syndrome or SOS). This medication will continue until day +30.

Over-the-Counter Medications, Antioxidants and Herbal Preparations

Do not take any over-the-counter medications (including aspirin, ibuprofen (Motrin® or Advil®), naproxen (Aleve®), herbal products and vitamins, antacids or prescription medications without approval by your ABMT physician. We need to ensure that all medications you are taking will be safe during a bone marrow or stem cell transplant and they do not interact with any of your other prescribed medications.

In particular, herbal and botanical preparations include a variety of products made from plants. They may be sold as tablets, capsules, liquid extracts, teas, powders and topical preparations. There are no manufacturing regulations for cleanliness or purity of

these products. Therefore, there is a danger that the products may be contaminated with fungus, bacteria or other chemicals that may be life threatening to a person with an impaired immune system.

A high intake of some antioxidants (vitamin C, vitamin E, and beta carotene) may protect against the development of certain types of cancer. However, taking antioxidant supplements during radiation and chemotherapy may reduce the effectiveness of these treatments in destroying diseased cells. Therefore, you should stop taking antioxidants prior to chemotherapy and radiation.

Antioxidants and herbal medications may be unsafe after your stem cell transplant. The decision to use these medications should be made with your ABMT physician who will consider the effects of the products on your kidneys, liver, and other organs, as well as your risk of infection and any other interactions they may have with your prescribed medications.

The Caregiver

During your transplant experience, you must have a caregiver who stays with you at all times. Your caregiver will receive specific instructions about their responsibilities.

Some of the responsibilities of the caregiver include:

- Providing emotional support
- Providing physical care
- Caring for the central line
- Helping with oral medications
- Recording the medications taken
- Monitoring intravenous fluids and medications using an ambulatory pump
- Identifying changes in the patient's condition
- Obtaining medical care if needed
- Reporting symptoms to the health care team
- Gathering information
- Keeping family members and friends up-to-date about the patient's condition
- Monitoring the number of visitors

- Maintaining a clean home environment
- Preparing food
- Providing transportation to and from the ABMT Clinic

If no one person can be with you during your transplant, you can have different caregivers scheduled during different times. Care giving is a 24 hour job and can be tiring and demanding. During the hours when you are in the clinic, your caregiver should take the time to care for him/herself. Being a caregiver is a full time responsibility and requires someone who is dependable and reliable. This role can be stressful, especially if your condition, schedule or treatment changes. It is important for your caregiver to maintain a positive attitude, calm demeanor and flexible approach to provide you with encouragement and understanding. At the same time, it is important to understand that the caregiver role is challenging and your caregiver may find themselves stressed by the responsibilities.

10 Tips for Family Caregivers Courtesy of www.nfcacares.org

- 1) Care giving is a job and respite is an earned right. **Reward** yourself with respite breaks often.
- **2) Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- **3)** When people offer to help, **accept the offer** and suggest specific things that they can do.
- **4) Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
- **5)** There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.
- **6) Trust your instincts.** Most of the time they'll lead you in the right

direction.

- 7) Caregivers often do a lot of lifting, pushing, and pulling. **Be good** to your back.
- **8)** Grieve for your losses, and then allow yourself to **dream new dreams**.
- **9) Seek support** from other caregivers. There is great strength in knowing you are not alone.
- 10) Stand up for your rights as a caregiver and a citizen

There is a Caregiver Support Group that meets every Thursday at 10 am in the family lounge at the ABMT Clinic

Caregiver's Bill of Rights

I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to **seek help from others** even though my loved one may object. I know the limits of my own endurance and strength.

I have the right to maintain parts of my own life that do not include the person I care for, just as I would if he/she were healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.

I have the right to get angry, be depressed, and express difficult feelings once in a while.

I have the right to **reject any attempt** by my loved one to make me do things out of guilt or anger. (It doesn't matter if he/she knows that he/she is doing it or not.)

I have the right to **get consideration**, **affection**, **forgiveness**, **and acceptance** for what I do for my loved one, as I offer these in return.

I have the right to **take pride in what I'm doing**. And I have the right to applaud the courage it has taken to meet the needs of my loved one.

I have the right to **protect my individuality**. I also have the right to a life that will sustain me in times when my loved one no longer needs my full-time help.

Courtesy of the National Cancer Institute

Some resources for caregivers are listed below:

www.cancercaregiving.com

www.nbmt.link.org comprehensive site specific to BMT

www.caregiving.org

Quality of Life

When you are discharged from the program, you may feel like you'll never return to "normal." The recovery time after autologous transplant can take many months. During this recovery time you may have periods of time when you feel good and some when you feel not so good. It is important to remember that recovery will happen slowly and compare how you feel from week to week, not from day to day. Accept help from family, friends, and neighbors. You will need to gradually increase your activity and set your own daily routines. People who have offered to help in the past are a good resource assist with activities you may not be ready to resume.

The Cycle of Fatigue

There are things you can do to help minimize or prevent fatigue. The sooner you take action to fight fatigue, the better. Fatigue can become difficult to manage if it is prolonged.

One of the major causes of fatigue is inactivity. Both cancer and its treatment can cause you to become inactive. Being inactive

may cause fatigue to occur within two ways. First, muscles become weak and actually shrink a little when they do not get enough exercise. Secondly, when you are inactive your body's engine becomes less efficient, so you get fewer "miles per gallon." When your body's engine becomes inefficient you have difficulty using your muscles even if they are strong.

Not feeling well and being inactive can lead to a cycle of fatigue. This can become like a snowball with fatigue leading to more fatigue if left untreated. When people suffer from long-standing troublesome fatigue it is called "chronic fatigue." Chronic fatigue can interfere with your activities of daily living and may have an effect on your emotional well being if it prevents you from doing things you enjoy. People with chronic fatigue find that sleeping makes their fatigue worse instead of better. They can also have difficulty concentrating and remembering things. The best way to fight fatigue is to manage it early on.

Causes of Fatigue

- Chemotherapy, radiation therapy
- Not eating well: Without food your body cannot produce energy.
- ➤ Eating too much, eating foods high in fat: After large or fatty meals a large portion of your blood and energy is directed toward your digestive tract to digest your food. This can make you feel very sleepy.
- Not sleeping well: Anxiety, stress, pain, nausea, vomiting, and having to get up to go to the bathroom are a few examples of things that can disturb your sleep.
- ➤ Sleeping too much or spending too much time in bed: Inactivity causes fatigue.
- Having too much anxiety or stress: Being anxious or having a lot of stress can drain you of energy (and interrupt sleep).

➤ Anemia: Anemia means that you have too few of the red blood cells needed to carry oxygen. Oxygen is needed to produce energy and make muscles work.

Fatigue may continue to be a prominent side effect for several weeks, and possibly months, following discharge from the ABMT program. Many patients are unprepared for the amount of fatigue they experience once they return home. It is important for you to realize that your discharge from the clinic does not mean that you have fully recovered and can resume your normal activities. In fact, many patients feel that their fatigue level increases when they go home. Factors that can contribute to this feeling of increased fatigue include visiting family and friends providing more stimulation than you were receiving while you were receiving care at Duke, or having to go down the hallway to the bathroom instead of just walking a few feet. The increased activity and stimulation is good, but initially may add to your feelings of fatigue. REMEMBER, your discharge from the clinic actually starts the rehabilitative phase of your treatment!

Your energy level will slowly increase over time. Do not get discouraged – regaining your stamina will take time.

Things you can do to fight your fatigue fall into three categories:

@ EDUCATION

By reading this material you will hopefully come to understand that fatigue is a normal consequence of treatment, and that with time it will improve. You must also understand that too much rest actually increases your feelings of fatigue.

@ EXERCISE

During your rehabilitation following transplant you will need to slowly increase your activities of self-care and responsibilities around your home and gradually add aerobic exercise to your routine. You will need to plan rest periods in between periods of activity, and set goals for yourself. Here are suggestions for decreasing your feelings of fatigue and increasing your "exercise tolerance."

- 1. Get on a schedule! Plan your day and maybe even set an alarm clock, but not too early. What was your routine before BMT and chemotherapy entered your life? Did you have breakfast, take your shower, or read the paper first? Get back into your routine. You may have to sit and rest in between activities, and your concentration, especially for reading, may not have returned yet. The idea is to slowly incorporate new activities into your day.
- 2. Get walking! There are no excuses for not walking! You can do it anywhere and anytime, so find the time! When you first go home, it may mean 1-2 laps around your living room, twice a day; that is OK. Over the next week or so set your sights on longer distances, but remember not too far, because you have to turn around and walk the same distance back! If walking outdoors is not practical, too cold or too hot, try walking in the mall or find a local museum to tour. Make the walk as enjoyable as possible: listen to music, bring a friend, or have a "quiet time" for yourself. You decide what is best for you.
- 3. Ask for help! Remember, you do not have to do everything. Accept offers for assistance. Ask for specific favors such as shopping or cooking. Be sure to save time and energy to do something that you enjoy or that is most important to you.
 - ➤ If you are forgetful: Write things down. Bring a list of questions with you when you see your doctor. Keep a list of things that need to get done and friends who can help out.
 - ➤ <u>If you are feeling stressed</u>: Join a local support group. Meditation and relaxation techniques may be helpful; ask your nurse to show you how.
 - ➤ <u>If you are feeling depressed</u>: Ask your ABMT team or your home physician to recommend a social worker or therapist.
 - ➤ <u>If you need companionship</u>: Ask for it. Friends and family may not know that you would like visitors.

- Ask your ABMT team or home physician if there could be a medical cause of your fatigue: Anemia is a common problem; low blood sugar, low blood pressure, low thyroid hormone levels, and infection are other causes.
- Ask your ABMT team or home physician about treatment: If fatigue is reducing your quality of life, ask if there is an appropriate treatment available to help you.

Educate yourself about fatigue (what to expect), slowly increase your activity (too much rest is harmful), and plan restorative activities each day to battle the mental fatigue!

REMEMBER...

- 1. Slowly increase your activities each day.
- 2. Alternate periods of activity with rest periods.
- 3. Short naps are OK, no more than 60 minutes, once or twice a day.
- 4. Remember to go to bed, no catnaps on the couch!
- 5. Too much rest and sleep will add to your feelings of fatigue.
- 6. Plan your day; get on a schedule as best you can.
- 7. Compare yourself to a week ago, not yesterday.
- 8. Walking is an excellent form of exercise.
- 9. Plan a satisfying restorative activity into your day for relief of mental and emotional fatigue.
- 10. Most importantly, call your ABMT coordinator if you are concerned about your progress. Sometimes a reassuring phone call is all you need to get you going again.

Driving an Automobile

You will need to talk to your ABMT physician about when she or he feels you are able to resume driving an automobile. After your ABMT physician tells you it is okay to resume driving, we suggest going for a "practice drive" with a companion in a parking lot or other open area prior to driving on the road because some patients experience a temporary alteration in their depth perception.

NOTE: While you are taking sedating medications you should avoid driving your car due to drowsiness. You should also avoid driving if you are still requiring platelet transfusions.

Going Back to Work

It is our goal to make it possible for patients who have been employed to return to work following transplant. Many patients can go back to work about 3-6 months after their transplant. Depending on the type of work you do and your financial situation, you may need or want to return to work as soon as possible. If this is the case, we will help you work out an arrangement with your employer. It may be best to start back to work part-time and eventually move toward full-time work. We will assist you in working with your employer and insurance company by providing them with information they require to help you get back to work again, if you choose to do so.

Sexual Activity

Often times a diagnosis of cancer will be followed by a disinterest and lack of participation in many of the "normal" everyday activities that are performed by patients and or partners. Sex and sexuality are sometimes included in those activities. Many questions or concerns may arise regarding sexual activity and should be discussed openly with your partner as well as your health care provider (physician, coordinator, and counselor). As your blood

counts, diet, and activity level continue to improve, your libido or sex drive will also improve. Give your mind and body time to heal after your transplant.

The American Cancer Society publishes 2 well written books on sexuality following cancer treatment. They are available free of charge from your local American Cancer Society.

Sexuality for the Man with Cancer and His Partner

Sexuality for the Woman with Cancer and Her Partner

Sexual Activity for Women

- ➤ You may resume intercourse with one healthy partner once your platelet count is greater than 50,000.
- Although infertility is likely, birth control should be practiced.
- Practice clean and safe sex.
- Avoid anal or oral sex for 6 months following transplant.
- We advise that your partner wear a condom for 6 months following transplant.
- Avoid sexual intercourse if a genital infection is suspected or present in either you or your partner.
- ➤ You should visit your gynecologist 3 months following transplant. Keep track of your menstrual cycle, and if you've had any menopause symptoms. Menopause symptoms include hot flashes, vaginal dryness, flushing and occasionally difficulty sleeping. Whey you visit your gynecologist, you should discuss the pros and cons of hormone replacement therapy. If you are experiencing menopause symptoms, and you choose

- not to take hormone replacement therapy, an endocrinologist may be able to relieve some menopausal symptoms using non-hormonal therapy.
- Chemotherapy and radiation therapy can cause vaginal dryness and narrowing. To prevent trauma to dry vaginal tissue, use a water soluble lubricant such as Replens®, K.Y. jelly®, or Lubrin®. All of these are available without a prescription at a drug store. Never use petroleum jelly such as Vaseline® because it can cause infection. Report any problems to your ABMT physician or coordinator.

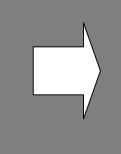
Sexual Activity for Men

- You may resume intercourse with one healthy partner once your platelet count is greater than 50,000.
- ➤ Although infertility is likely, birth control should be practiced. Three months after transplant, you and your partner may need to make decisions regarding birth control; you can have a sperm count done to determine if you are sterile.
- Practice clean and safe sex.
- Avoid anal or oral sex for 6 months following transplant.
- Chemotherapy and radiation therapy can cause your semen to appear brown or burnt orange with the first few ejaculations. The first few times you engage in sexual activity, you may experience pain in the testicles after orgasm. Report any continued brown discharge, pain, inability to obtain or sustain an erection, or any other problems to your ABMT physician or coordinator.
- Six months after transplant, if you find that your interest in sexual activity has not returned to normal, consult your physician. It is possible your testosterone

level is low due to the radiation or chemotherapy. Your testosterone level can be checked by a blood test and if it is low, can be replaced. Testosterone is available in an injection that is given once a month for 3-6 moths. It is also available as a skin patch. This may help your sexual desire return to normal.

Returning to the Care of your Home Physician

When you complete your treatment at the ABMT Clinic, you will be returning to the care of your home physician (usually the physician who referred you to the Duke ABMT Program). Although you may feel some uncertainty about leaving the care of the ABMT program, you will need to be followed locally by your home physician. Patients often worry that their home doctor is not a "transplant specialist" and will not be able to properly care for them. It is important to remember that you will not be discharged to his or her care unless the transplant team feels comfortable that your medical needs will be met. Your course of treatment and possible follow-up needs are discussed with your home physician prior to discharge. Your home physician will probably monitor blood tests once per week the first few weeks you are at home, prior to the first return appointment with the Duke ABMT Team. After the first follow-up appointment at Duke, follow-up tests are at the home physician's discretion unless there are specific requests from the transplant team.



Please call (or have someone call) your ABMT coordinator or the ABMT physician on call if:

- you are admitted to the hospital for any reason
- if you have a temperature greater than or equal to 100.5° F

(38.0° C)

- have severe shortness of breath
- blurry vision, or any other unexpected symptom

Clínic Visits, Follow-up Laboratory Tests, Radiology Studies

Your scheduled follow-up visits to the Duke ABMT clinic will vary depending on your transplant treatment. Your first follow-up visit usually occurs about one month after your discharge from the program. Generally you will return to the ABMT Clinic for a visit every three months for the first year, every six months the second year, and annually after two years. You will also be required to visit your home physician between your visits to the Duke ABMT clinic. We understand that it may be difficult to arrange travel back to Duke frequently and will order your tests through your home physician as much as we can. Tests on follow-up visits may include:

- ➤ Blood tests (usually includes a complete blood count with differential and a chemistry panel that includes liver function studies)
- Radiology studies (CT scans, bone scans, MRI exams, x-rays, PET scans)
- Pulmonary function tests (breathing test)
- Bone marrow biopsies and aspirates

Immunizations 1 cm

Patients who have undergone autologous transplantation should not have a flu vaccine for <u>6</u> months following their transplant. Before that period your immune system will not be able to respond to these vaccines, so they would not be effective prior to that time. We recommend minimal "close contact" with adults or children who have

recently been vaccinated with a live vaccine for a period of one week. Do not change diapers or come into contact with body fluids from these individuals. Examples of live vaccines include oral polio vaccine (OPV) given at two, four, and twelve months of age, and again between four and six years; the varicella vaccine (chicken pox), measles vaccine (part of the MMR vaccine), given at 12 months, and then again at four to six years, and the nasal spray flu vaccine.

Health Maintenance

You should continue to have regular twice-yearly appointments with your dentist for cleaning, and any dental procedures beginning 6 months-1 year after transplant. Be sure your dentist is aware that you have undergone an autologous transplant. **DURING THE FIRST YEAR AFTER TRANSPLANT, YOU SHOULD HAVE YOUR BLOOD COUNTS CHECKED BY YOUR HOME PHYSICIAN PRIOR TO INITIATING ANY DENTAL WORK.** It is important that your blood counts are sufficient prior to initiating any dental work, and your home physician can determine this. You may also be required to take antibiotics prior to any dental work. Other health maintenance includes:

- Breast self-examination for women
- Testicular self-examination for men
- Skin self-examination
- > Annual eye examination
- Pap smears for women
- Mammograms (women over 40 years old)
- Prostate exam for men
- Colonoscopy (patients over 50 years old)

Pet Care

Many people have pets waiting for them at home after transplant. Although most people consider their pets a part of the family, there are a few precautions that need to be taken when first returning home:

- ➤ If you have a cat that spends time outside, do not change its litter box during the first year after transplant. Another family member needs to change the litter box. Although it is fine for you to touch and hold your cat, direct contact with its waste can potentially expose you to certain parasites.
- ➤ If you have a pet bird in your home, do not come into contact with its waste. Have another family member clean the bird's cage. Contact with the bird's waste may expose you to certain infectious agents.
- Don't allow your pets (whether dogs or cats) to sleep with you during the first year you are at home. Don't let your pets lick you in the face. Practice good hand washing if you come into contact with pet waste.

Around the House

Many patients are concerned that when they return home, their house may not be clean enough and worry that they must be in a "sterile" environment. While this is neither necessary nor expected, a <u>clean</u> house is a must. This can easily be accomplished by cleaning once a week. Accept help from others during this time as you reestablish your relationships with extended family members and community. If you clean yourself, space activities throughout the week, and take frequent rest periods.

Additionally:

- Avoid poorly ventilated and/or construction areas.
- Use an antibacterial soap in your home, and practice good hand washing.

- Avoid smoke, as second-hand smoke is dangerous.
- Avoid gardening, mowing the grass, mulching and raking because soil and plants harbor infectious organisms.

Being a Survivor

Although completing treatment and returning home represents a tremendous achievement, it also is a time when emotions previously suppressed may surface. During treatment, the focus is on managing symptoms and just getting through each day. Once home, there may be continuing worries about symptoms and the fear of the cancer recurring. There also may be time to reflect on the transplant treatment experience, and feelings such as anger, anxiety, depression, guilt, and grief may emerge.

- Anger may be for the time "lost" on a treatment path rather than the path of one's choosing. It is difficult to see that friends and colleagues have moved on, and you may feel envious. "Why me?" questions may return, as well as anger about the pain and disability endured.
- Fixiety may revolve around the fears about facing the future, how much to reveal about the cancer history (and to whom), insecurity about living away from the medical team, and of course, fear of recurrence. Some patients and family members describe "flashbacks" to unpleasant aspects of the treatment experience, called post-traumatic stress. Returning for follow-up appointments may produce anxiety.
- ➤ **Depression** is common; a study of survivors by the Lance Armstrong Foundation estimates that up to 70% of survivors face depression at some point during the two years following treatment. Sadly, most of these people did not seek professional help. Depression usually responds well to counseling therapy and medication. Relying on talking to friends and family may not be enough; survivors often report that others cannot understand their experience and suggest they "be grateful they are alive" and "move on." Depression

has been associated with decreased cancer survivorship as well as poorer quality of life, so treatment is vital.

- ➤ Guilt may sound surprising, but it is common to feel guilty about the burden placed on family and also about the fact of survival, when others encountered along the cancer journey died (survivor guilt).
- Fief may emerge suddenly, triggered by events such as the anniversary of the diagnosis or other treatment-related memories. There are many losses associated with cancer and treatment, and as these are encountered the sadness of grief is experienced. Job/income concerns, activity limitations, and body image changes all must be grieved before they can be integrated into the "new normal."

Resources remain important for survivors. Support groups are a way to access others who share the cancer and treatment experiences. The process of sharing and receiving support is beneficial. Organizations focused on disease groups such as the Leukemia & Lymphoma Society provide written material and web casts with valuable information for survivors. They also provide ways for survivors to "give back" by helping others, meeting an important need for many. Family members may also experience some of the same emotions discussed here for patients; they, too, may have put their life "on hold" to be caregivers and witnessed distressing symptoms.

Fortunately, there are also positive emotional outcomes following treatment! Every crisis presents an opportunity for growth, and many stem cell transplant survivors and families endorse this fact. Researchers have found that following transplant survivors report a new philosophy and greater appreciation of life, emotional growth apparent in their families and increased empathy for others.

Resource Directory

HOUSING

Many of the hotels located near Duke offer reduced medical rates for Duke patients and their families. Ask about those rates at the time you make your reservation. Some of these hotels include:

Brookwood Inn

2306 Elba Street, Phone 919-286-3111

Within walking distance to hospital and has a shuttle to hospital or clinics.

Caring House

Rooms may be available for outpatient cancer patients and a caregiver over the age of 18. A Social Work referral is required if you wish to be placed on the waiting list.

Carolina Duke Motor Inn

On Guess Road, short drive from Duke University, Phone 919-286-0771; Includes small refrigerator and microwave, continental breakfast, and shuttle to Duke.

Extended Stay America

3105 Tower Boulevard, Phone 800-398-7829 or 919-489-8444.

Hampton Inn

1816 Hillandale Road, Phone 919-471-6100. Short drive to Duke University and includes refrigerator, microwave, free continental breakfast, laundry facilities. Typically used for longer stays.

Homestead Village

1920 Ivy Creek Blvd., Phone 919-402-1700. Discounted rates for stays of 7 days or longer. Includes refrigerator, microwave, pots/pans, stove top and van to Duke.

Millennium Hotel

2800 Campus Walk Avenue, Phone 919-383-8575. Shuttle to Duke for small fee.

Oakwood Corporate Housing

Offer reduced medical rates for fully furnished 1, 2, and 3 bedroom apartments. Contact them directly at 1-800-520-5288.

University Inn

502 Elf Street, Phone 919-286-4421. Within walking distance of hospital.

Nearby camping facilities are:

Duke Oversized Parking, Garage II – 919-684-5773; Birchwood Mobile Home Park – 919-493-5573; and Southern Country Inn, Hillsborough – 919-732-8101

PARKING & TRANSPORTATION

Angel Flight, Inc. is a volunteer organization. They may be able to provide flights to and from Duke for medical treatment. Patients must be accompanied by a caregiver. For more information, please contact Angel Flight, Inc. directly at 918-749-8992 or through their website at http://www.angelflight.com.

National Patient Travel Helpline provides information about all forms of charitable, long-distance medical air transportation and gives referrals to appropriate sources of available help. Staff is available Monday through Friday from 9:00 am to 5:00 pm at 1-800-296-1217. After hours help is available within 10 minutes of leaving an afterhours message marked urgent.

FINANCIAL MATTERS

Contact your insurance company if you have questions about your coverage.

You may be entitled to receive Social Security Disability if your medical condition prevents you from working for one year or longer. Discuss this with your doctor, then visit your local Social Security office or call 1-800-772-1213 for more information.

Pharmacy Patient Assistance Programs help with medications for those who have no insurance coverage for their medicines. For more information and to see if you qualify, you may call 919-684-9563, or you may contact national programs that offer information on various patient assistance programs. Two such programs are The Partnership for Prescription Assistance at 1-888-4PPA-NOW (1-888-477-2669) (www.PPARx.org), or search for programs through RxAssist at www.rxassist.org.

The Patient Advocate Foundation is a non-profit group that provides information regarding assistance for problems with insurance, medical bills, employment and financial matters. They can be reached at 1-800-532-5274. www.patientadvocate.org

The Leukemia and Lymphoma Society has a benefit to reimburse for some parking, travel, and co-pay costs related to your medical treatment. Please contact them for more information. They require original receipts. You can contact the Eastern NC Chapter at 1-800-936-9337. www.leukemia-lymphoma.org

Cancer Care provides emotional support, information and financial assistance to cancer patients and their loved ones. Call them to request a financial assistance program application at 1-800-813-HOPE or visit their website at www.cancercare.org.

CANCER SUPPORT & INFORMATION

Duke's Clinical Social Work Department - Clinical Social Workers are available to help patients and families with a variety of issues including: coping with illness, stress, grief, loss, and problems with difficult family or social situations. You will be assigned a social worker who works with ABMT patients.

Duke Cancer Patient Support Program offers counseling, support groups, companionship, educational resources, and a wig and turban program. They work to help patients and families cope with the impact of cancer on their lives. They can be reached at 919-684-4497. Their website address is http://www.cancer.duke.edu/support/

Duke Hematologic Malignancy Program focuses on the care of patients with lymphoma, leukemia, myeloma, myelodysplasias, myeloproliferative disorders, aplasia, or other neoplastic diseases of the marrow or blood system.

http://hememalignancy.mc.duke.edu

American Cancer Society provides information for those whose lives are touched by cancer. They can provide medical information, treatment decision tools, news updates, and support resources. They can be reached at **1**-800-ACS-2345 or to use their online resources. **www.cancer.org**

The National Coalition of Cancer Survivors provides information about symptom management, links to cancer resources, and practical tools to help deal with the challenges of cancer. They may be reached at 1-877-NCCS-YES (1-800-622-7937) www.canceradvocacy.org

Cancer Information Service, National Cancer Institute (NCI)

provides a wealth of information on cancers, treatment options and clinical research projects in your area.

National Cancer Institute
Building 31-room 10A07
9000rockville Pike
Bethesda, MD 20892-2580
800-422-6237
http://cancernet.nci.nih.gov

Lance Armstrong Foundation

www.livestrong.org

National Coalition of Cancer Survivors (NCCS)

www.canceradvocacy.org/resources/posttreatmentguide.aspx

Mayo Clinic provides information on managing late effects of cancer treatment

www.mayoclinic.com/health/cancer-survivor/CA00073

TRANSPLANT RESOURCES

Duke ABMT website http://bmt.mc.duke.edu

National Marrow Donor Program provides a bibliography and literature search service on scientific articles related to bone marrow transplant. A patient advocate is available to answer questions. Information and assistance to families and friends who would like to conduct bone marrow donor drives are also available.

3433 Broadway St. NE Suite 500 Minneapolis, MN 55413 800-627-7692

Office of Patient Advocacy: 888-999-6743

http://www.marrow.org

Blood and Marrow Transplant Newsletter provides publications, attorney referrals for insurance problems, Patient-to-Survivor link, directory of transplant centers. They publish a bi-monthly newsletter for patients, their families, and medical professionals and support organizations that work with ABMT patients. This newsletter provides information and referrals on ABMT-related issues including insurance reimbursement.

2900 Skokie Valley Rd. Highland Park, IL 60035 888-597-7674 http://www.BMTinfo.org

National Foundation for Transplants provides fundraising

assistance information.

1102 Brookfield Suite 22 Memphis, TN 38119 800-489-3863

http://www.transplants.org

National Transplant Assistance Fund (NTFA) provides fundraising assistance.

P.O. Box 258 Bryn Mawr, PA 19010 800-624-8399

http://www.transplantfund.org

National Bone Marrow Transplant Link provides on-line resources for transplant patients as well as a "Peer Support on Call" free service that provides emotional support through one-on-one conversations with trained peer support volunteers who are transplant survivors.

20441 West 12 Mile Road Suite 108 Southfield, Michigan 48076 248-358-1886

http://www.nbmtlink.org

OTHER RESOURCES

CaringBridge provides free, private, personalized websites for easier communication with family and friends during transplant.

1995 Rahn Cliff Court Suite 200 Eagan, MN 55122 651-452-7940 651-789-2300 (customer service)

http://caringbridge.org

House cleaning service available to cancer patients

www.cleaningforareason.org

DIRECTIONS TO AREA SHOPPING

Hillsborough Road shopping area

From the ABMT Clinic, turn right onto Fulton Street. Get into the left lane and at the traffic light take a left onto 147 North. Take the first exit to the right and follow the signs to Hillsborough Road. At the traffic light turn right. Kroger is the first driveway on the right. Eckerd Drugs is on the left. Blockbuster is also on the left.

Ninth Street shopping area

From the ABMT Clinic, turn left on Fulton Street to Erwin Road. Turn left on Erwin Road and this will turn into Ninth Street. Small restaurants and shops on Ninth Street.

Streets at Southpoint Mall

From ABMT Clinic, turn right on Fulton Street. Get into the left lane and at the traffic light take a left onto 147 North. Follow the signs for 15-501 to Chapel Hill. Take 15-501 out of Durham. You will pass exits Morreene Road, 751, Martin Luther King Parkway. Continue on 15-501 to Interstate 40 intersection. Take I 40 East toward Raleigh. Go about 3 exits to Fayetteville Road. Take the Fayetteville Road exit and turn right. The mall is on your right.

South Square shopping area

From ABMT Clinic, turn right on Fulton Street. Get into the left lane and at the traffic light take a left onto 147 North. Follow the signs for 15-501 to Chapel Hill. Take 15-501 South. You will pass the following exits: Morreene Road, 751 and Cornwallis Rd. Take the South Square exit (exit is on the left). SuperTarget is on your right at the bottom of the exit. The road behind Target has grocery and drugstores as well.

Northgate Mall

From ABMT Clinic, turn right on Fulton Street. Take Fulton Street to Club Blvd and turn right. Follow Club for several blocks. You will go through a residential area. Northgate Mall is on the corner of Guess Road and Club Blvd.

Glossary of Terms

TERMS

DEFINITION AND FUNCTION

Allogeneic transplant	The use of a donor's hematopoietic cells to restore bone marrow function and blood cells after receiving the preparative regimen. Hematopoietic cells are obtained from a genetically matched individual. This is usually a family member, but may be an unrelated volunteer donor or umbilical cord blood.
Anemia	A low number of red blood cells. One symptom of anemia is fatigue.
Apheresis	The collection of immature hematopoeitic cells from the blood. This is accomplished using a blood separating machine that sorts the blood cells.
Autologous transplant	The use of one's own hematopoietic cells to rescue you from the low blood counts which occurs after receiving high dose therapy administered to destroy cancer cells.
Bone marrow	A liquid, similar in appearance to blood that is found within the soft sponge like cavities of large bones.
Bone marrow biopsy	A procedure used to obtain a sample of bone marrow from the hip bone for evaluation under a microscope.
Bone marrow harvest	The collection of immature hematopoietic cells from the hip bones. This procedure is done in the operating room.
Central venous catheter	An intravenous catheter will be placed in a large vein under the collarbone.

Differential (Diff)	A lab test that reveals the percentages of different types of white blood cells.
Donor	An individual who will donate hematopoietic cells for another individual. Types of donors include family members, unrelated donors and umbilical cord blood units. The donor and recipient may be fully matched or partially matched.
Graft	A collection of hematopoietic cells that is infused following the preparative regimen. The graft may be autologous (self) or allogeneic (from a donor).
Graft versus Host Disease (GvHD)	Graft versus host disease is a complication of allogeneic transplantation. It is an immune reaction of the donor's cells against your body tissue.
Graft versus malignancy	This is a reaction of the donor cells against the cancer.
Haploidentical donor	This is a donor who is a 50% match to you. This donor may be a parent, child, or sibling (brother or sister).
Hemoglobin (Hgb)	The part of the red cell that contains iron. Iron binds to oxygen to be carried through the body.
Hematocrit (Hct)	The percentage of red blood cells in the blood.
Human Leukocyte Antigen (HLA)	The human leukocyte antigen system is a group of markers on the surface of your immune cells. The human leukocyte antigens are genetically determined (inherited). These markers are used to find a donor within your family, from the donor registry of volunteer donors, or umbilical cord blood banks.

Immune system	Specialized cells in the body that protect us from infections caused by microorganisms.
Immunosuppressants	Medications given to weaken the immune system to prevent graft versus host disease (GvHD).
Microorganisms	This can be a bacteria, virus, protazoa, or fungus. Microorganisms cause infections in individuals with low white blood cell (WBC) counts, or who are taking immunosuppressants.
Mismatched donor	This is a donor who is partially matched to you.
Mobilization	A process to increase the number of immature hematopoietic blood cells. By mobilizing (moving) the immature cells from the bone marrow into the blood, the cells can then be removed by apheresis. Mobilization can occur with chemotherapy and growth factors, or growth factors alone.
Myeloablative	This means that the preparative regimen will completely eliminate your ability to make blood cells.
Neutropenia	A low number of neutrophils. Neutrophils are an important type of white blood cells (WBC) that fight infection.
Non-myeloablative	This term means that the preparative regimen will only weaken or depress your ability to make blood cells.
Platelets	A blood cell that forms a clot to stop bleeding. Low numbers of platelets increases your risk of bleeding.

Preparative regimen	A combination of chemotherapy and/or radiation therapy given prior to the transplant. The purpose of the preparative regimen is to eliminate the malignancy. In an allogeneic transplant, the preparative regimen is also given to weaken the immune system so the donor's cells can grow and function.
Red Blood Cells (RBC)	A blood cell that transports oxygen throughout the body.
Stem cells	These are immature stem cells that can divide and mature into any type of mature blood cell. These cells are in your bone marrow space. They may also be called hematopoietic stem cells.
Syngeneic transplant	A transplant from an identical twin. The care this patient receives is similar to an autologous transplant.
Thrombocytopenia	A low platelet count. A low platelet count increases your risk for bleeding.
T Lymphocytes	A cell of the immune system that works to protect your body from foreign tissue and microorganisms. The T lymphyocyte is responsible for the graft versus host disease (GvHD), and graft versus malignancy effect following allogeneic stem cell transplantation.
Transfusion	Administering red blood cells to minimize the effects of anemia, or platelets to reduce the risk of bleeding.
White Blood Cells (WBC)	Cells that defend the body against infection. Types of white blood cells include neutrophils, eosinophils, basophils, macrophages, T and B lymphocytes. Each of these cells has a unique role in protection against infection.