

# Allogeneic Transplant

UNC Bone Marrow Transplant and Cellular Therapy Program



## Welcome to the UNC BMT and Cellular Therapy Program

The Bone Marrow and Stem Cell Transplant Program at the University of North Carolina (UNC) in Chapel Hill was established in October 1992. Since then, our program has done over 2000 transplants. We offer a variety of transplants including self, umbilical cord blood, related and unrelated donors. We started with **autologous** transplants, which is a transplant using your own bone marrow or stem cells. In July 1994, we performed our first related **allogeneic** or donor bone marrow transplant. In February 1997, the first **umbilical cord blood** transplant was performed. And in May 1997, we did our first Allogeneic unrelated donor transplant. Patients and families travel from all over North Carolina and beyond to receive care from our experienced team.

We care for adults, teens and children with cancers of the blood, solid tumors and non-cancerous blood disorders. This includes leukemia, lymphoma, myelodysplasia, and multiple myeloma. We use bone marrow, peripheral blood or umbilical cord blood as sources of stem cells for transplant. As an academic medical center, we also offer clinical trials to treat rare diseases using the latest scientific discoveries. In April 2016, we developed a program for genetically modified cells and changed our name to UNC BMT and Cellular Therapy Program.

Our program is a fully accredited collection and transplant center for the National Marrow Donor Program (NMDP). We are also accredited by the Foundation for the Accreditation of Cellular Therapy (FACT) for adults, teens and children. This allows us to offer you unrelated stem cell transplants and a higher chance of finding a donor. This accreditation is awarded to select programs that meet the highest standards in bone marrow transplant.

## Our Physicians

“Our bone marrow transplant physicians have diverse backgrounds that include training and prior faculty positions at Stanford University, St. Jude Children’s Research Hospital, University of Chicago, University of Minnesota, Dana Farber Cancer Institute, Moffitt Cancer Center, MD Anderson, and Fred Hutchinson Cancer Center in Seattle. Many of the faculty are members and hold leadership positions in the American Society of Oncology, the American Society of Hematology, the American Society for Blood and Bone Marrow Transplantation, The Cancer and Leukemia Group B, and the Center for International Blood and Marrow Transplant Research. This spectrum of skills and experience ensure that the care we provide is the finest and most advanced care available anywhere.”



Thomas C. Shea, M.D.  
Program Medical Director  
Founder, UNC BMT Program

UNC BMT and Cellular Therapy Program, 101 Manning Drive Chapel Hill, NC 27514

Monday—Friday: 984-974-0000 | [bmtprogram@unchealth.unc.edu](mailto:bmtprogram@unchealth.unc.edu)

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## Bone Marrow and Stem Cell Transplant Team Members

During your first visit, you will meet with various members of our program. Each BMT Program team member plays a different role in the preparation for your transplant treatment. You will be given direct contact information for your assigned transplant team. Remember that we are all here for you and your family. Please let us know how we can help.

### Program Team Members

- New Patient Intake Coordinator
- Bone Marrow Transplant and Cellular Therapy Program Clinical Program Director
- Bone Marrow Transplant Unit (BMTU) Staff
- BMT Outpatient Clinic/Infusion Staff
- Adult BMT Doctors
- Advanced Practice Providers (APPs): Nurse Practitioners and Physician Assistants
- Pharmacists
- Transplant Nurse Coordinators: Pre-transplant, Post-Transplant, Related Donor and Quality Management.
- Social Workers and Case Management
- Data Managers
- Financial Coordinator
- Administrative Assistants
- Recreational Therapy, Nutritionist, Chaplains
- Cancer Comprehensive Support Program (CCSP) Staff

### Program Phone Numbers

BMT Clinic Monday—Friday From 8:00 AM—4:00 PM Call 984-974-0000 Ask for the BMT Clinic	Bone Marrow Transplant Unit On Nights, Weekends and Holidays Call 984-974-8280 Ask to speak to a Nurse
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**Call 911 in an emergency, or go to a nearby Emergency Room**

## Who can get a Stem Cell Transplant?

You can have a stem cell transplant to treat many diseases. If you have a blood disease and your bone marrow does not work properly, a transplant can help by replacing your damaged bone marrow with healthy bone marrow cells. Your transplant doctor will let you know what type of stem cells you should receive.

If you have any of the following diseases or inherited disorders, you may be considered for allogeneic transplant:

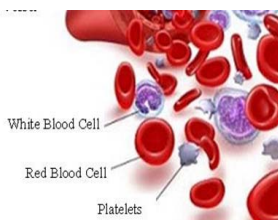
- ◆ Aplastic Anemia
- ◆ Hodgkin's Disease
- ◆ Inherited disorders of bone marrow function
- ◆ Leukemia (chronic and acute)
- ◆ MDS (Myelodysplastic Syndrome)
- ◆ Multiple Myeloma
- ◆ Non-Hodgkin's Lymphoma

## Allogeneic Transplant

- An **Allogeneic transplant** means that you will receive stem cells from someone else. This person is called a donor. The donor's bone marrow type (**Human Leukocyte Antigen** or HLA) needs to match or be a close match to your bone marrow type.
- This donor may be a family member (related donor) or someone else (unrelated donor).
- Healthy **hematopoietic** or blood making stem cells are infused into a person who has diseased or damaged bone marrow.

There are three types of donor cells used in transplants:

1. **Bone Marrow:** Bone marrow stem cells are collected directly from the donor's bone marrow space (hip bones). This is done in the operating room under **general anesthesia** which puts you into a deep sleep.
2. **Peripheral Blood Stem Cells:** Peripheral blood stem cell transplant (PBSC) uses cells that are collected from the donor's blood through an apheresis machine. The donor will receive a medicine called **G-CSF** for five days that will help release the stem cells into their blood so we can collect them.
3. **Umbilical Cord Blood:** The umbilical cord is rich in stem cells. Blood stem cells are collected from a baby's umbilical cord at the time of birth. They are donated to a cord blood bank and placed in special storage called **cryopreservation**. These cord blood units need to meet special standards. The National Marrow Donor Program (NMDP) has a registry with the HLA typing of the cord blood units available for unrelated donor transplants.



Regardless of the type of transplant that you will have, these are all stem cells that grow to become healthy:

- a) white blood cells
- b) red blood cells
- c) and platelets start in the bone marrow and into the bloodstream.

### Types of blood cells

## Your First Visit



- During your first visit, a Transplant Doctor and a Transplant Nurse Coordinator will meet with you and your family members. The Doctor will go over your medical history and do a physical exam. The Doctor and Transplant Nurse Coordinator will talk to you about what is involved in having a bone marrow transplant.



- Your Transplant Nurse Coordinator will spend more time with you and your family to provide more education on the transplant process, describe our support services and answer any questions you may have.

- You may also meet with our Financial Coordinator who will explain your insurance benefits and provide you with applications for extra resources if needed. You may also meet with our Social Worker if decided by you, your family and your transplant team.



- If you would like a tour of the Bone Marrow Transplant Unit (BMTU) during this visit, please talk to the Transplant Nurse Coordinator. During inpatient treatment, adult patients stay in the BMTU located on the First Floor of the Neuroscience Hospital.
- Timing for the transplant may depend on your disease, clinical situation, or donor availability. The transplant team will talk with your primary oncologist. You may need more treatment during this time. If the transplant doctor recommends a transplant, and you and your family would like to proceed with this treatment, your Transplant Nurse Coordinator will talk to you about the next steps.

## Transplant Resources

- We will give you more education materials from the National Marrow Donor Program and other transplant sources. You can visit the National Marrow Donor Website at [www.BeTheMatch.org](http://www.BeTheMatch.org).
- You can also visit the Leukemia and Lymphoma Society Website at [www.LLS.org](http://www.LLS.org) and the BMT Infonet website at [www.bmtinfonet.org](http://www.bmtinfonet.org).
- Other books, pamphlets, videos and internet access are available in the Patient and Family Resource Center. It is located on the ground floor of the North Carolina Cancer Hospital (NCCH). If you would like more information or resources, please contact your Transplant Nurse Coordinator.
- A BMT Social Worker will also meet with you and your family and may provide you with other resources.

## Finding A Donor

- We will ask if we can test your siblings with a cheek swab or a blood test. This test is called **Human Leukocyte Antigen (HLA)**. HLA typing is different from the blood type. This test identifies genetic codes that appear on your white blood cells. You get those codes from your parents. You inherit half from your father and half from your mother. If you have a sibling from the same mother and father, there is a 25% (or one in four) chance that they will be a match for you. If your sibling or siblings are a match for you, the Related Donor Coordinator will let them know their results.
- If you do not have any matched siblings, your transplant team will discuss with you if it is suitable to test other family members, such as your mother, father or children. The chance that other relatives would match is very low. Depending on your disease, a half-matched sibling, parent or child may be considered to be your donor. If you have a related donor match, the Related Donor Coordinator will help your family member with the stem cell donation process.
- We can also search for your donor in the NMDP, also known as Be The Match Registry. This unrelated donor registry tries to match your HLA type with the HLA type of volunteer donors all over the world a 18 years and older. Your Transplant Nurse Coordinator will talk to you about your donor search and potential matches in the NMDP Registry.
- Finding a donor in the registry may take several months. During this time, your referring doctor will continue to treat your disease. Your Transplant Nurse Coordinator will update you and your family with the search results regularly.

## Donor Medical Clearance

- First, your donor is identified (related or unrelated). Then your donor gets an appointment for a thorough medical checkup. If you have a related donor, their appointment will usually take place at the NC Cancer Hospital. If you have an unrelated donor, the donor checkup is handled by the NMDP.
- Your donor will complete the following steps to prepare for the stem cell donation:
  - ✓ a health history screening questionnaire
  - ✓ a physical exam from a BMT provider
  - ✓ a chest X-ray (if needed)
  - ✓ an electrocardiogram (ECG) of the heart (if needed)
  - ✓ blood work with screening for infectious disease
- Your donor is taught about the donation process and what type of stem cells they are donating: bone marrow or peripheral blood stem cells. A member of our team will review paperwork with your donor that gives us permission to collect their stem cells.
- We complete donor screening and tests before you are admitted for your transplant. Your Transplant Nurse Coordinator will inform you about your donor's medical clearance. Sometimes, a donor is not medically cleared to donate stem cells. If this happens, your transplant team will talk to you about other options.



## Preparing for Your Transplant Admission



**Clinical Testing:** Several medical tests are needed before starting your bone marrow transplant treatment. This pre-transplant work-up includes checking your heart, lungs, liver and kidney function, detailed blood work and a physical exam. Most often these tests are also used to get the insurance approval for your transplant.



**Psychosocial Evaluation and Caregiver Requirement:** Our BMT social worker will meet with you and your caregiver/family. They will help you plan family arrangements needed before admission to the hospital. You will need to have a BMT caregiver and a back-up caregiver(s). A caregiver can be a family member, partner or friend. We encourage them to be here with you during your hospital stay. They may also be asked to meet with the team before your admission is finalized.



While you are inpatient, a lot of teaching happens that is important when you go home. This is also important information for your caregiver. If your caregiver also cares for children at home, please let your transplant team know as other childcare arrangements are needed. We want to make sure that you have a dedicated caregiver when you leave the hospital.



**Housing:** If you live more than 45 minutes away from the UNC hospital, you will need to stay in the local Chapel Hill area for at least 100 days after your transplant. The social worker will talk to you about local housing options available when you leave the hospital. If you have travel and lodging benefits through your insurance company, we will review that with you as well.



**Living Will and Health Care Power of Attorney:** An Advance Directive is a decision that you make now about your medical care in case you are too sick to make those decisions later on. You may give your wishes about the use of artificial treatments to prolong your life if you are seriously ill. An Advance Directive is a form with two parts; a living will and a health care power of attorney. For more information, you can talk to your social worker. It is also important to think about Short-term Disability and FMLA (Family & Medical Leave Act) forms. A member of the transplant team can help you with these forms.

**Fertility:** High dose chemotherapy and radiation treatments are likely to cause infertility. You may wish to discuss fertility issues so that you may possibly have children in the future. Depending on your previous therapy and other factors, preserving your fertility may not be possible. Please talk with your Transplant Doctor or Transplant Nurse Coordinator about this as early in your evaluation as possible. We will provide information on fertility options for both men and women. We can also refer you to a specialist.

## Preparing for Your Transplant Admission



**Transplant Consent:** Before your transplant, we will ask you to sign a permission form that is called an **informed written consent**. You will get one for your transplant therapy and/or each research study in which you participate. By signing, it shows that the therapy has been explained to you, that you understand the risks and benefits, and that you had a chance to ask questions. A blood product consent will be reviewed and needs to be signed as well.

- We will also ask you to sign a consent form that gives our BMT Program permission to send information about your transplant to an international data registry called the Center for International Blood and Marrow Transplant Research (CIBMTR). Information about your transplant will be given to the registry, but your name will be kept private.
- This registry collects information on transplants from around the world. This helps the doctors and researchers who are working to make transplants better for patients like you. There are other consent forms that you will need to sign before admission. Your Transplant Nurse Coordinator will review those with you.



**Central Line Placement:** You will need central line access for your treatments and for the infusion of the stem cells. It may be placed in the Vascular Intervention Radiology (VIR) department or at another UNC facility. The line may be placed before your hospital stay or on the same day that you are admitted.

- If you already have a central line, your Transplant Nurse Coordinator will check if it is the right type of catheter for the transplant. There is a chance that either a different type of line or an extra line will need to be placed. The central line is placed under your skin into a large blood vessel. You and your caregiver(s) will learn how to care for your central line.

## BMT Final Agreement Form

The decision to receive a bone marrow or stem cell transplant (a BMT) can be a very hard one for many patients and family members. Our BMT Program will help you plan for the best possible result from your transplant. In our experience, the items listed below are essential in making your decision and preparing for transplant. We will discuss them with you and answer your questions. After that, you and a Program staff member will sign this form to show that these items have been reviewed to your satisfaction. You will receive a copy of the form and the original one will go into your BMT file. Topics on this form include:

1. **Housing Arrangements**
2. **Financial Issues**
3. **Family Conference and Caregiver Support**
4. **Treatment Adherence**
5. **Communication**
6. **Substance and Tobacco Use**



## Transplant Admission Day

- Your Transplant Nurse Coordinator will let you know your admission date and give you and your caregiver a calendar. There are times that we do not know what time the admission will happen until the day you are admitted . Your transplant nurse coordinator will call you and let you know what time you should arrive.
- Usually, you will go to the **Admissions** area. Your Transplant Nurse Coordinator will let you know where you should go to register. You will then go the Bone Marrow Transplant Unit. You may need to come to the BMT Clinic before admission.
- When you arrive on the BMTU, your inpatient BMT team will help you and your caregiver get settled in the room and orient you to the unit. The BMT provider will give you a physical checkup. You will begin your treatment, which is called **conditioning or preparatory regimen**. The days are counted down such as Day -8, Day -7, etc., until the day of your stem cell infusion with is called “Day 0”. This treatment includes chemotherapy and, sometimes, immunosuppressive therapy and/or radiation therapy. There are treatments that do not include radiation. If your treatment plan includes radiation, your BMT doctor will refer you to a Radiation Oncologist before your transplant.
- The chemotherapy may be stronger than any other chemotherapy you may have had before. This chemotherapy will get rid of all the blood making cells in your bone marrow to make room for the donor cells and get rid of any remaining cancer cells. The immune-suppressive medicine and radiation will get rid of your own bone marrow blood cells and immune system to prevent rejection. This treatment will not be harmful to the new cells.

## Types of Preparative Regimen

There are different types of preparative regimens:

1. Myeloablative Regimen
2. Non-ablative Regimen
3. Reduced Intensity Regimen

The type of regimen that is chosen for your treatment will depend on your type of disease, organ function and history of prior transplant. These regimens may include radiation as part of the treatment. Your transplant doctor and pharmacist will talk to you in more detail about the regimen that is chosen for you.

**Notes:**

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# BMT: Inpatient Care

Allogeneic Transplant

UNC Bone Marrow Transplant and Cellular Therapy Program



UNC CANCER CARE

Your Transplant Nurse Coordinator will let you know your admission date. If you have any questions about your calendar or schedule, please call your Transplant Nurse Coordinator. On the day of your admission, the nurse will orient you and your caregiver to the unit.

## BMT Team Members

**Attending Physician.** The attending physician has completed training in bone marrow transplant that makes him or her an expert in the field. The attending you see during your hospital stay may be a different doctor than you saw in the BMT clinic for your consult. You may see more than one attending physician during your stay.

**Oncology Fellow.** The oncology fellow is a licensed doctor who is completing specialized training in cancer care or oncology. He or she works closely with the BMT doctors and the rest of the team to manage your care.

**Advanced Practice Professional (APP).** An APP is either a doctor of nursing practice, a nurse practitioner, or a physician assistant. APPs move between the inpatient and clinic setting. Our APPs work closely with the attending physicians and fellows to guide your care throughout the transplant process.

**Pharmacist.** The pharmacist works with the BMT team to help manage your medicines. The pharmacist will meet with you at different times during your transplant. You will have a detailed visit with the team pharmacist before you are discharged from the hospital. At that time, they will go over all your medicines with you. The pharmacist will remain available to you in the outpatient clinic.

**Nurse.** You will have a nurse who will be assigned to you on day shift and night shift. Your nurse will be your caregiver when you are in the hospital. A nurse's duties include: taking vital signs, height, and weight; drawing blood; giving you IV fluids, chemotherapy, and blood products; and providing other supportive care medicines and treatments.

**Nursing Assistant (NA).** The NA helps the nurse with his or her duties. Your NA may take your vital signs and weight, record your intake and output, and assist with other activities of daily living such as toileting, bathing/showering, and changing your bed linens daily.

**Recreational Therapy (RT).** RT's role is to keep you active during your hospital stay. The RTs will help you set up a daily schedule that includes physical activity. They will share coping tools and resources that can help you reach your goals. For example, a group meets several times a week on the BMT unit to perform stretches, participate in activities, and walk around the unit together. They sponsor the "Healthy Heels" program in which you can win medals for completing a marathon.

## BMT Team Members

**Unit Clerk.** Our unit clerk answers the phone, orders supplies, and often answers your call bell. He or she will help the nurse get you the items and help you need.

**Social Worker.** You and your family will meet with a social worker before, during and after your transplant. He or she will provide support during your inpatient stay and help you prepare to leave the hospital.

**Comprehensive Cancer Support Staff.** This team provides additional emotional support for you and your family as needed during the transplant process.

**Chaplain.** The chaplain is available to you and your family for spiritual and emotional support. There is a hospital chaplain available to support all religious preferences. If you would like a visit from the chaplain, please let a member of your team know.

**Nutrition Services.** The hospital dietician follows your nutritional needs during the transplant process. You will meet with them before admission, when you are admitted, and as needed. They can arrange special diet requests.

**Interpreter Services.** Interpreter services are provided by the hospital for non-English speaking or limited English-speaking patients and their families.

## Caregiver and Guests Guidelines

- Before entering, all caregivers and guests need to pick up the phone that is outside the unit and say who they are and who they are visiting. It is helpful to your BMT team if your caregiver or a family member leaves a phone number where we can easily reach them when they are not at the hospital with you.
- No more than 4 guests can be in your room at one time; this includes your caregiver. Only one caregiver can spend the night with you. They must be 18 years or older. Guests/caregivers will need to use the toilet in the family waiting area. For safety, children under the age of 2 years are not allowed to visit BMT patients in the hospital.

## Hand Washing



**Hand washing is the single most important way to prevent infections.** Healthcare workers, support staff, patients, caregivers and guests must wash their hands every time they enter the BMT unit, enter a patient's room or leave a patient's room. Everyone should wash their hands for at least 20 seconds. It is best to use soap and water to wash your hands, but you can also use an alcohol based hand rub.

There may be times that your caregiver and your guests will need to use only soap and water for washing their hands. This is often due to a specific infection. Your BMT team will let you know if this happens. A special sign will also be placed on the door giving your caregivers and guests instructions.

## We Provide the Following During Your Stay:

**Regular size pillows.** If you bring a larger size pillow, please bring several clean pillowcases.

**Linens.** Sheets, blankets, pillowcases, towels and washcloths are available for you and your caregiver.

**Toiletries.** (toothbrush, toothpaste, face wash, soap). Because you will be at an increased risk for bleeding and infection during your treatment, any toiletries you bring must be new and unopened. You can bring an electric razor but leave other razors at home. Nail clippers, metal nail files, needles, and sharp tools should also stay at home.

**Hospital Gown.** You may bring loose, comfortable clothes like sweatpants, pajamas, and shirts with buttons (this makes it easier to get to your central line). Clothes can get soiled during your stay, so only bring items that you do not mind throwing away.

**Telephone.** You may bring your own answering machine.

**Wii Gaming System & DVD Player.** You may want to bring games and movies from home.

**Masks.** You will have to wear a mask when you are not in your room.

**Clock Radio.** Our radios play music and nature sounds.

**Washing machine and dryer.** We also provide detergent for you to use.

**Refrigerator.** You may keep individually wrapped snacks and drinks in your room. Loose items, like cereal or candies, must be kept in closed containers. A larger patient refrigerator and freezer is located in the Nourishment Room. Food stored here must be labeled with your name and room number.

**Food.** The hospital provides patients with a menu of foods that are delivered directly to your room. They are aware of food restrictions that may result from your transplant status and will help guide your choices. Additionally, you may have *cooked* food from home; leftovers must be thrown away after 24 hours. You may eat fresh fruit and vegetables from UNC Hospital's Nutrition and Food Services *only*. You cannot eat fruit and vegetables from the cafeteria or home. You also cannot eat pepper, honey or fresh-fruit smoothies. Guests may eat these items in your room but cannot leave them.

**Coffee Pot & Microwave.** These items are in the nutrition room.

## Other Reminders

- Everything you bring from home must be clean. Wash and dry any clothes, bedding or stuffed animals before you come. Your nurse can give you special wipes to clean picture frames, hard cover books or other things from home. Please leave any valuables at home.
- Leave your contact lenses at home. Bring glasses if needed.
- If you have an Intra Uterine Device (IUD), you need to have it removed before your stay.
- Staff can help you send mail, please make sure to bring stamps.
- We want you to stay active during your stay, so bring good walking shoes or sneakers. You may also want to bring slippers with non-skid soles.
- Bring items that you enjoy such as books and games.

Your hospital stay may be anywhere from 2-6 weeks. The length of your stay will depend on the type of transplant (Autologous or Allogeneic) you have and how quickly you recover.

There are special air filters on the BMT unit that allow you to leave your room and walk in the hallway. However, the door will need to stay closed while you are in your room.

When walking around the BMT unit you will need to wear a light surgical mask to give you extra protection from infection. During your transplant stay you will not be able to leave the unit unless it is for a test or procedure. For tests and procedures, you will need to wear an **N95 mask** for extra protection.

**Call Bell.** Please use your nurse call button in your room when you need something or when an IV pump is beeping. Requests made over the call button are private so please be specific about your needs. It is helpful to the staff if you speak slowly and clearly.

**BMT team rounds.** The BMT team rounds on patients in the morning. This is a good time for you or your family to ask your team questions. You may find it helpful to keep a notebook by your bedside to write down any questions you may have.

**Nursing report.** Nursing report happens twice a day at shift change. This occurs between 7AM-8AM and 7PM-8PM and usually takes place at your bedside.

**Chest X-Ray and EKG.** You will have these tests before admission. They may be repeated during your hospital stay depending on your health.

**Vital Signs and Assessment.** Your vital signs will be taken every 4 hours. Some treatments, such as blood

product transfusions, chemotherapy infusions, and your stem cell infusion may require vital sign checks more often than every 4 hours. Your BMT Team will give you a full physical exam each day.

**Weight.** Your weight will be taken at least once a day. Daily weights help your medical team know your fluid status. Remove your shoes before stepping on the scale.

**Intake and Output.** We must record the amount of food and drink you take in each day. Please keep track of all the liquids you drink. Your urine, vomit and liquid stool must also be measured. We will give you a paper log for your bathroom door.

We will give you a urinal and/or place a urine or stool hat on your toilet so that it can be measured. Please do not flush your urine, vomit or liquid stool down the toilet without writing down the amount on your paper log. Your nurse or nursing assistant can also help keep track of your input and output.

**Labs.** We will use your central line to draw your blood each day. Your nurse will collect blood for tests around midnight. This way, results are back for your BMT team to review before unit rounds in the morning. In addition to routine morning lab tests, your BMT Medical Provider may request more blood tests at other times during your stay.

**Central line care.** Your central line dressing will be changed when you are admitted and at least once a week. If your dressing becomes wet or soiled, then it needs to be changed. You and your caregiver will receive teaching on central line care. You will also receive a central line booklet during your stay.

## What to Expect during your Preparative Regimen

### **Chemotherapy**

Before your transplant day, you will get very high doses of chemotherapy that will wipe out your bone marrow cells. This allows the new, transplanted cells to grow in your body. It is possible that your blood counts will not have completely reached zero on the day of your transplant. The number of days you receive chemotherapy will depend on your disease, your donor, and the type of transplant and stem cells you are receiving. You will be given IV fluids to help flush the chemotherapy from your body. It is common to use the bathroom more often than you normally do.

**Possible Side Effects:** Chemotherapy can also cause nausea and vomiting. You will be given nausea medicine before your chemotherapy infusion(s). There are several medicines that can be given to you around the clock for your nausea. These medicines may make you feel drowsy or more sleepy than usual. Other side effects may include diarrhea, fatigue, fever, chills, loss of appetite, a drop in all of your blood counts, mouth sores, changes with your taste buds, and hair loss. These side effects usually get better when your new cells start to grow in your body. Your hair will grow back, but it may be a different color or texture.

### **Immunosuppressive Therapy**

Allogeneic transplant patients may get an immunosuppressive medicine called **ATG** or **Campath**. These medicines help wipe out your immune system and lower the chance of stem cell rejection.

**Possible Side Effects:** This type of treatment can cause infusion reactions like fever, chills, blood pressure changes or trouble breathing. We may place you on a special monitor and give you medicine before your infusion to help prevent a reaction.

### **Radiation Therapy**

Depending on your disease, your transplant doctor may include radiation as part of your treatment. The radiation treatment will be like getting an x-ray and will not be painful.

**Possible Side Effects:** Some of the side effects that may occur with radiation therapy are darkening of the skin, increased sensitivity to the sun, infertility, dry mouth and changes in your lungs. You will see the radiation doctor before your admission to talk about your treatment plan. They will review the possible short term and long term side effects of radiation treatment in detail. They may also measure your body so that the radiation team can plan your therapy.

**Radiation Visits:** You may receive a special medicine several days before your first radiation treatment. It is given again after your radiation treatment is over. This medicine helps to lower your chances of getting severe mouth sores. You will go to the radiation department for your treatments. Your caregiver may come with you but cannot stay in the radiation room during treatment. While you will be alone in the radiation room during the treatment, the radiation team can see you on a camera monitor. They can also talk with you over an intercom. It is important that you stay very still during radiation treatment.



## What to Expect on the Day of Your Transplant (“Day 0”)

- We recommend only eating a light meal before transplant because the infusion can cause nausea and vomiting. Your nurse will give you medicines before your cell infusion to help prevent side effects. These medicines may include Tylenol<sup>®</sup>, Benadryl<sup>®</sup>, anti-nausea drugs, and sometimes, a type of steroid.
- The BMT Nurse and our stem cell lab will coordinate the time of infusion. The stem cell product will be infused through your central line, very similar to a blood transfusion. We will check your vital signs often during your infusion and watch you closely to make sure you are tolerating the infusion without a problem. The time of infusion will depend on what type of stem cells you are receiving. Your nurse will let you know what to expect.

## Transplant Day (Day “0”-day of stem cell infusion)



- The day of your transplant (stem cell infusion) is **Day 0**. The transplant is the infusion of the donated stem cells—it is not surgery. This infusion is done in your hospital room. The stem cells look like blood and are given through your central line. You will feel no pain and may visit with your family, rest or watch TV.



- You will be given medicines before the transplant to prevent any serious reactions. This medicine may make you feel sleepy. The nurse will watch you closely to treat any reactions you may have.



- Sometimes, a patient may get chills, a mild fever or a skin rash. It is normal for your urine to turn pink for a day. Your body is getting rid of extra red blood cells that are mixed in with the stem cells.
- You may taste or smell an odd odor if your donor’s cells have been frozen and are thawed just before your transplant. This is from the preservative that is used during the freezing process. It is called **Dimethyl Sulfoxide (DMSO)**. Sucking on hard candy in your mouth may help the taste go away. This taste or smell will go away 24 to 48 hours after the infusion.

## Potential Side Effects of Transplant Treatment

1. **Gastrointestinal problems.** You may have nausea, vomiting or diarrhea.
2. **Loss of appetite.** You may need extra nutritional support during this time. This includes special protein shakes or liquid nutrition that is given through your central line.
3. **Interstitial Pneumonitis.** This is a reaction that can prevent your lungs from using oxygen well. You may have trouble breathing, coughing, fevers, and feel more tired than normal.
4. **Sinusoidal Obstructive Syndrome.** This is also called **veno-occlusive disease** of the liver. With this disease, blood flow in the liver becomes sluggish. This can lead to weight gain, an increase in your liver enzymes, yellow skin and eyes, and belly pain.

## Engraftment

- After the stem cells are given to you, they circulate in your blood vessels. Then they settle back in the bone marrow space where they begin to grow. This is called **engraftment**. On average, it takes 14 to 21 days for your new bone marrow to engraft or to begin making new stem cells. Your bone marrow may engraft as early as Day +14, but it is not unusual for this to happen as late as Day +30.
- It depends on the type of stem cells that you received: whether bone marrow, peripheral blood stem cells or cord blood stem cells. A cord blood transplant takes the longest time to engraft. So you may be in the hospital longer than the usual 3 to 6 weeks.
- During this time, you will receive antibiotics, antivirals and antifungal medicine to protect you from infection. These are also called “**antimicrobials**.”
- You may need red blood cell and platelet transfusions until your new bone marrow makes enough new cells. When your white blood cell count is below normal, you have a high risk of getting an infection. Germs that would not usually bother you can make you very sick at this time. We will watch you very closely and give you antibiotics to prevent infection.
- If you have a fever or any other signs of an infection, you may receive different or additional antimicrobials. It is important for you to tell your doctor or nurse if you notice any changes in your body. Your BMT medical team will let you know how long you will need to take these medicines.
- To help keep you safe from infection, all hospital staff members and guests need to follow our strict handwashing rules. No one should visit if they have a cough, fever or other signs of infection. Your Transplant Nurse Coordinator and your transplant team on the unit will talk to you and your family about ways to help prevent infection.

### Notes:

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## Potential Complications of Allogeneic Transplant

Allogeneic transplant may result in complications or problems. Your BMT medical team will monitor and treat you if any problems occur. These complications include:

- Graft versus Host Disease (GVHD)
- Graft failure
- Infections
- Interstitial Pneumonia
- Sinusoidal Obstructive Syndrome (SOS) also called Veno-occlusive Disease (VOD)

### Graft versus Host Disease (GVHD)

**This is seen more often in Allogeneic transplant.** Graft versus host disease happens your new cells attack your body. There are two forms of GVHD. The “acute” form occurs early in the transplant period, usually within the first 30 to 90 days. The “chronic” form occurs later in the transplant course, usually 90 days and as late as 1 to 2 years after transplant. Patients who have acute GVHD are more likely to get the chronic form of GVHD. Older patients or patients that have a partially matched donor are at higher risk for GVHD.

#### Acute GVHD

- Acute GVHD usually affects your skin, liver, or gastrointestinal (GI) tract and can happen suddenly. Patients may notice an itchy, red rash that develops over a few days.
- They may also have nausea or vomiting which starts suddenly and does not get better with anti-nausea medicines that worked before.
- Diarrhea is common with acute GVHD. Patients can have frequent large, watery and sometimes bloody stool.

#### Chronic GVHD

- Chronic GVHD is a slower process. Patients who get chronic GVHD commonly complain of decreased appetite, weight loss, dry mouth, dry scaly skin and mild constant nausea.
- Some patients may also have a change in skin color, tea-colored urine, dry crusty eyes, and a sandy or grainy feeling in their eyes.

**Always report these changes to your transplant nurse or doctor.**

### Medicines

You will receive medicines to prevent GVHD. These medicines are monitored by blood levels. Sometimes your dose may go up or down depending on the drug level in your body or clinical condition. It is very important for you to take these medicines as instructed. Never stop taking these medicines unless instructed by your transplant medical team.

## Potential Complications of Allogeneic Transplant

**GVHD Symptoms:** The symptoms of GVHD may be mild or severe. It is important for you to make your BMT team aware of any new symptoms or changes you notice. Your BMT team will also watch you closely for changes. We will teach you more about GVHD while you are in the hospital and immediately before your discharge home.

### Signs and Symptoms of GVHD:

- Skin rash or discoloration on any part of the skin
- Itching
- Dry, thick scaly skin
- Diarrhea. Watery, frequent, bloody or large amount of stools
- Abdominal pain or cramping
- Constant nausea or vomiting
- Dry mouth, thick plaques in the mouth
- Dry eyes, crusting of the eyes in the morning
- Burning or sandy feeling in the eyes
- Burning or redness of the palms and soles
- Tea-colored urine
- Low grade fevers: 99°- 100°F without chills

### Graft Failure

- Graft failure may occur when the patient's body rejects the donated marrow or stem cells. This leads to very low blood counts and a higher risk of bleeding and infection. A second infusion of donor bone marrow or peripheral stem cells and sometimes a second transplant may be done.

### Interstitial Pneumonitis

- Your lungs are sensitive to certain chemotherapy medicines and total body irradiation which are used sometimes during **conditioning** for bone marrow transplant. A reaction called **interstitial pneumonitis** (IP) may occur. It can prevent your lungs from using oxygen well.
- The signs are shortness of breath, cough, fevers and feeling unusually tired. Always tell your doctor if you experience any of these symptoms. This problem that may happen after you are discharged from the hospital, so be sure to tell your clinic provider if you notice these symptoms.

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# Potential Complications of Allogeneic Transplant

## Infections

- Chemotherapy and radiation therapy kills cancer cells. They also help decrease your immune function to help prevent rejection of the donated stem cells. This may leave you with a weakened immune system that cannot fight infections. Antibiotics and other drugs are given to prevent and to treat these infections.
- One of the most common and severe infections is from a virus called the *Cytomegalovirus* or *CMV*. Most of us have already been exposed to it. Like all viruses, it 'hides' in our system because our immune system protects us with antibodies to the virus. However, after your transplant, the CMV virus can reactivate or 'turn back on' and cause serious problems.
- We will give you antiviral medicines to help prevent this. If it is not treated, CMV in a patient after transplant can cause pneumonia or other very serious problems.

## Sinusoidal Obstructive Syndrome (SOS) also called Veno-occlusive Disease (VOD)

- Chemotherapy and/or radiation therapy can cause deposits of thread-like material in the tiny blood vessels of the liver. This can block blood flow out of the liver. This condition is known as **veno-occlusive disease** (VOD). Always tell your physician if you experience any of these symptoms.

### Signs and Symptoms of VOD:

- Pain and swelling in your belly
- Liver problems: yellowing of the skin and eyes (jaundice)
- Light colored stool
- Dark urine
- Sudden weight gain

## IMPORTANT!

- **Infection:** During your treatment and for several months afterward, you will be at high risk for bacterial, viral and fungal infections. Infections may be found in your blood, urine, stool or organs like your lungs.
- Your team will check for these infections often during your hospital stay. It is very important to:
  1. Practice good hand washing and hygiene.
  2. Stay as healthy and active as possible during this time.
  3. Take your medicines as instructed. These include: antivirals, antibiotics, and anti-fungal medicines.

## Notes:

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## How We Care for You

**Safety.** Your BMT team will monitor your risk of falling throughout your stay. Transplant treatment may cause you to have generalized weakness. Medicines given in your IV for pain and nausea may make you dizzy or sleepy. It is very important that you ask for help when you get out of bed. If there is no one in the room with you, please press your call button and ask for a staff member to help you. We want to keep you safe from falls while you are getting out of the bed, a chair or in the bathroom.

**Pain Management.** If you feel any pain during your transplant treatment, your BMT Team will work with you to find the best way to control your pain. Medicines and other methods such as massage, music, repositioning, and distraction may help ease your pain. Expect your BMT Team to ask you about pain often. They may ask you to rate your pain level using a pain scale. Please talk to your BMT Team when the pain starts. If you get medicine for pain control, you will be asked how well the medicines are working for you.

Depending on your pain, your BMT Team may talk to you about a **PCA pump**. This is an IV pump that gives you a continuous amount of low dose pain medicine each hour. The pump can also be set up to let you press a button for more pain medicine when you need it. For safety, this pump will be locked so that you do not get more medicine than prescribed.

**Transplant Supportive Care.** During your visit, other medicines such as antivirals, antibiotics and antifungals will be given to help protect you from infections. We will also give you blood products if you need them.

**Special Precautions.** If you are placed on **Contact, Enteric (GI), or Droplet Isolation**, your inpatient nurse will let you know what special precautions are needed. There will also be signs on the door that will let guests know what special precautions they need to take.

**Vaccines.** Caregivers and guests who have not had chicken pox are not be allowed on the unit if they have come into contact with someone who has a confirmed case of chicken pox or a rash of unknown cause. They also will not be allowed on the unit if they had the chicken pox vaccine in the past 8 weeks and have a rash. Similarly, caregivers and guests who have had the smallpox vaccine in the past 8 weeks may not visit the unit. Caregivers and guests who get the **FLUMIST**<sup>®</sup> vaccine—the flu vaccine that is sprayed in the nose—will not be able to visit you unless:

- a) they are free of flu-like symptoms
- b) at least 1 week has passed since they got the vaccine

**Visitors.** Caregivers and guests must not have a fever, runny nose, sore throat, flu-like symptoms, vomiting, diarrhea or a rash. Staff will screen guests for infection. During flu season, the hospital does not allow children under the age of 12 to visit. While the BMT Team understands that this is hard for our patients and their families, it is for your safety. Your BMT Team will let you know if these restrictions are in place.



## Caring for Yourself

**Skin Care.** Taking a daily shower is very important. It is critical that areas such as your armpits, genital area and rectum are washed and dried carefully. We will give you the proper soap and lotion to help prevent dry skin. You should change your clothes daily. We prefer that you do not use liquid make-up or powders as your skin will be very sensitive and may develop rashes easily. If you must use make-up, it needs to be new and unopened. We recommend use of hypoallergenic make-up on your face. Do not use products with the PABA chemical. It is best to avoid wearing jewelry during your hospital stay.

**Mouth Care.** Chemotherapy and radiation therapy may cause sores in your mouth. Frequent and proper mouth care helps prevent infection, decreases pain, and helps with healing. We will give you oral saline rinses and special sponges, called toothettes, for your daily mouth care. Mouth care should be done every 2 hours when you are awake. Your team will let you know when it is okay to use a regular toothbrush. Please throw away your used toothbrushes. Plan to use a new, unopened brush when you are admitted. Dental floss and mouth rinses with alcohol are never allowed. If you wear dentures, bring a new unopened denture brush, denture container, and cleaner. The cleaner should be in a tablet form, not in a tube.

**Nails.** Make sure your toe nails and fingernails are cut short and straight before coming to the hospital. You may only use a nail file after you are admitted. Please remove any acrylic nails. It is also best if you do not wear nail polish. It is normal for fingernails and toenails to crack with your treatment. You may notice new nail growth under your old nails.

**Hair loss.** It is common for you to have hair loss during transplant. In addition to the hair on your head, you may lose hair in other parts of your body. You may wear scarves, hats and wigs or hair pieces. The Patient & Family Resource Center located on the main floor of the Cancer Hospital offers wigs and soft head coverings for men and women. If you decide to cut your hair while you are in the hospital, you may only use an electric razor.

**Activity.** Physical activity is very important during your treatment. It helps keep your muscles strong. The Recreational Therapist will help you come up with an exercise program and activities that are right for you. It is important to have a daily schedule that fits your needs and helps you reach your goals. You may be asked to use an exercise bicycle or treadmill in the patient lounge. Small weights are also available. Your nurse will also give you with a tool for your lungs called an **incentive spirometer**. It is important for you to use it at least 3-4 times a day. Your team may also order a physical therapy consult for you. We want your mind to stay occupied during your stay as well. Feel free to bring activities and projects that you enjoy to the hospital such as books, crafts and puzzles.

**Visitors.** Please let a member of your BMT Team know if there is someone you do not want visiting you. We will assist with keeping your privacy. Only one caregiver aged 18 years or older can spend the night with you. There can only be 4 guests in the room with you at one time. Guests and caregivers need to use the toilet in the family waiting area.

## Discharge Planning

Discharge from the hospital depends on many factors including:

1. Your blood count recovery
  2. If you have a fever or evidence of an infection
  3. If you are able to tolerate food and fluids
  4. If your Caregiver has attended our Caregiver Class
- You may need to continue therapy like IV fluids or antibiotics when you are discharged. The BMT Team will discuss this with you.
  - As you recover, members of the BMT Team will prepare you and your caregiver for discharge. Discharge teaching must be reviewed with both you and your caregiver. It may take several days so you are well prepared. If your caregiver is not staying with you on the unit, he or she should arrive at the hospital to pick you up by **no later than 10:00 AM** on the expected day of discharge.
  - **Allogenic Transplant Patients.** Unless your home is less than a one hour drive from UNC Hospital, you will need to stay in the local area for at least the first **100 days post transplant**. The BMT Social Worker will help you find living arrangements if this is the case. For your safety, you are required to have at least one caregiver with you during this time.

## Outpatient Follow-up

After discharge from the hospital, you will return to the outpatient clinic two to three times per week until approximately **Day +100**. Most of the time, you will see the Advanced Practice Professional (APP) working with your BMT Physician. A Post-Transplant Nurse Coordinator is also part of the team that manages your care when you leave the hospital. You may be re-admitted to the hospital after transplant to receive treatment for problems.

## Returning Home After Transplant

- If you are staying in local housing after transplant discharge, at approximately day +100, you will be allowed to return to your home. Please know that this timeframe varies and will depend on how you are doing. Your BMT Team will continue to update you during your clinic appointments.
- We will assess you before you go home and put a plan of care in place for you. Your referring physician will be given a copy of your transplant records. After your return home, your local referring physician will be responsible for most of your care.
- At this time, you will alternate visits between your local oncologist and your BMT provider. We will check up on you at least once a month, until you finish certain medicines. Follow-up visits with your BMT Provider will be less frequent over time. However, we will continue to see you for the next five years or more.

Your BMT team will teach you a lot of new information at every stage of your transplant. This helps you and your family to stay informed and to make decisions about your care. Below are medical words that are used often before, during, and after your transplant. Talk to your team when you have questions.

- ◆ **Allogeneic transplant:** Using the stem cells from another person's blood, bone marrow or umbilical cord. Allogeneic transplants can be from a related family member, such as a sibling, or from an unrelated donor.
- ◆ **Absolute Neutrophil Count (ANC):** The number of neutrophils in your blood. Neutrophils are the most active white blood cell against infection. We use the ANC to tell us how well you can fight infection.
- ◆ **Advance Directives:** An advance directive is a form that you sign now to direct your future medical care in the event that you cannot speak for yourself when decisions need to be made about your care. You decide if you want to use artificial treatments to keep you alive for a long time. This legal document must be signed by you and witnessed by two people. Our social worker has this form and will help you fill it out.
- ◆ **Advanced Practice Professionals (APPs):** Nurse Practitioners and Physician Assistants, are a group of healthcare providers who are all under the Advanced Practice Professionals category.
- ◆ **Anemia:** A decrease in the number of red blood cells in the body.
- ◆ **Antiemetic:** A medicine to prevent or relieve nausea and vomiting.
- ◆ **Antibiotic:** A medicine used to prevent or treat bacterial infections.
- ◆ **Antifungal:** A medicine used to prevent or treat fungal infections.
- ◆ **Antiviral:** A medicine used to prevent or treat viral infections.
- ◆ **Apheresis:** The process of collecting stem cells from your blood. Blood from your central line catheter will be taken and circulated through the apheresis machine. The machine will filter out your stem cells and collect them. This is a painless procedure.
- ◆ **Autologous transplant:** A transplant using your own blood or marrow stem cells.
- ◆ **Blood Draws:** A sample of blood from your catheter to check your blood cell counts or other blood tests.
- ◆ **Bone Marrow:** A spongy tissue inside the bones. This is the "factory" where blood cells are made.
- ◆ **Bone Marrow Biopsy:** A bone marrow biopsy is a test to see your bone marrow function and the health of your white blood cells, red blood cells, and platelets. This test is also used to detect any tumor cells in your bone marrow. This test is routinely done before transplant. You will lie on your stomach and your back hip bone will be cleaned and numbed with a local anesthetic. A needle will be inserted into your bone and the liquid bone marrow will be collected. The needle is inserted again to collect a very small piece of the bone. In some cases, both hipbones will need to be examined. A large pressure bandage is applied to prevent any bleeding. The entire procedure will take 15-20 minutes.

## Glossary of Terms

- ◆ **Bone Marrow Harvest:** Process of collecting stem cells from the inside of the back hip bones under **general anesthesia**.
- ◆ **Chest X-ray (CXR):** A picture of your chest, which shows the condition of your lungs and may identify infection or fluid. During your transplant, chest x-rays may be done frequently if you have fevers.
- ◆ **Chimerism:** A test after stem cell transplant which involves identifying the genetic profiles of the recipient and the donor and evaluating the extent of mixture of each in the recipient's blood, marrow or tissue; this test is performed after an allogeneic transplant.
- ◆ **Clinical Trial:** An organized investigation of the effects of a treatment on a specific group of people with a particular disease. In cancer research, clinical trials are conducted with cancer patients, usually to evaluate a new treatment.
- ◆ **Complete Blood Count (CBC):** A blood test that measures the white blood cell count level, platelet count and red blood cell level.
- ◆ **Conditioning:** Treatment with high dose chemotherapy with or without radiation therapy, to destroy cancer cells throughout the body. Conditioning in allogeneic transplantation serves an additional purpose by destroying the cells of the immune system, reducing the risk that the recipient will reject the graft. Conditioning regimens vary according to the disease being treated and the medical center protocols being investigated.
- ◆ **Cytomegalovirus (CMV):** A type of virus that can cause infection in a transplant patient. Allogeneic patients are screened for CMV weekly with a blood test.
- ◆ **Cytogenetics:** A test on your bone marrow to evaluate the health of your chromosomes.
- ◆ **CAT Scan (Computerized Axial Tomography):** This process takes pictures of the inside of your body. To better visualize certain areas, you may receive an injection of dye into an IV line. You will lie still on an examination table while a machine circles around you to take the pictures. The test can take up to one hour depending on how many areas need to be imaged.
- ◆ **Central Line Catheter:** A catheter is a tube that is inserted through your skin and into a large blood vessel. Part of the tube will lie outside your chest. This catheter is necessary to have for the transplant because of the many medicines and blood products that you will be receiving at the same time. It is used to draw your blood samples without poking you with needles several times a day.
- ◆ **Day 0:** The day of your transplant (infusion of the stem cells).
- ◆ **Do Not Resuscitate (DNR):** DNR stands for "Do Not Resuscitate." This order tells the medical staff not to perform CPR, (Cardiopulmonary Resuscitation). CPR is used when you stop breathing or your heart stops. It is helpful to decide about CPR before you need it. In order to get a DNR order you must talk with your physician. A doctor will not write a DNR order without talking to you or your family. It is important to note that you will still receive all the medical care that you need even if you have a DNR order.

## Glossary of Terms

- ◆ **Echocardiogram (Echo):** This test uses sound waves to make a picture of your heart. A jelly-like substance is spread on your chest. A pen-like object is moved across your chest to make the picture.
- ◆ **Electrocardiogram (ECG):** An ECG will make a picture of the electrical currents of your heart. Stickers are placed on your chest, arms and legs and attached to wires which read your heart rate. The test will take approximately 10 minutes to complete.
- ◆ **Engraftment:** The process in which the transplanted bone marrow or the peripheral blood stem cells begin to grow in the bone marrow of the recipient and to manufacture new white blood cells, red blood cells and platelets.
- ◆ **Graft-versus-Host-Disease (GVHD):** The new marrow (graft) recognizes the patient as foreign and sends out lymphocytes (white blood cells) to attack the recipient (patient) organs. The most common areas of involvement are the skin, stomach, intestines and liver.
- ◆ **Growth Factors:** Growth factors are proteins normally produced by the body that stimulate the development of blood cells from stem cells. These substances can also be produced in the laboratory. Growth factors are commonly called GCSF and GMCSF. They are used in mobilizations and after transplant to increase the white blood cell count. They are given as an injection under the skin. Most common side effects include bone pain and low-grade fevers.
- ◆ **Haploidentical Transplant:** a type of allogeneic transplant (from someone other than yourself) when the HLA match is not 100% identical but is at least 50% identical. This type of transplant is used for patients in whom a full (100%) match cannot be found and the donor is a family member.
- ◆ **Hematocrit:** The amount of red blood cells in your body.
- ◆ **Hemoglobin:** A protein in red blood cells which carry oxygen and is used to measure how many red blood cells you have.
- ◆ **HLA (Human Leukocyte Antigen):** This is a series of proteins that are found on the surface of your cells, which are important in allogeneic transplantation. When an allogeneic stem cell transplant is being considered, the HLAs on the white blood cell of the patient and the potential donor are compared. The HLAs are inherited from each parent. Therefore, the best matches are found between full brothers and sisters.
- ◆ **Immunosuppression:** A weakened immune system can be caused by drugs or certain conditions. If you are immunosuppressed, you are at risk of developing an infection that your body cannot fight on its own. During this time, you will take medicines to help prevent infections. If you have an allogeneic transplant, you will be given medicines to suppress your immune system, which can decrease the chance of developing Graft-versus-host disease after the transplant.

## Glossary of Terms

- ◆ **Informed Consent:** Informed Consent is the process in which you are educated about a clinical trial or treatment plan, including the risks and benefits of the treatment. If you sign an informed consent form and enter the trial, you are still free to leave the trial or the treatment at any time and will continue to receive medical care.
- ◆ **Incentive Spirometer:** Small, plastic device which will help you breathe deeply and keep your lungs healthy. You will be asked to use this device several times each day during the transplant.
- ◆ **Infertility** - Radiation and/or chemotherapy may make you sterile or unable to have children. The extent of this problem depends on your sex and age. It also depends on the dosage and duration of treatment. If you are planning to have children in the future, you need to discuss this before transplant.
- ◆ **Intravenous:** The administration of a drug or fluid directly into the vein.
- ◆ **Mobilization:** The process of increasing the number of stem cells in the circulation. This can be accomplished by using growth factors, chemotherapy or a combination of both.
- ◆ **Mucositis:** Inflammation and irritation of the fragile membranes throughout the gastrointestinal tract. The mouth is most often affected. Mouth sores, bleeding and pain are common.
- ◆ **MUGA Scan:** MUGA Scan measures the performance of your heart muscle. A dye is injected into your bloodstream through an IV, and then x-rays are taken of your heart while you lie still on a table and/or while you ride a bike. The test lasts about an hour. You will have this test before and after your transplant.
- ◆ **Neutropenia:** When your white blood cell level is below normal and your body does not have its normal infection-fighting abilities. You are considered to be neutropenic when your neutrophil count is less than 1000.
- ◆ **NMDP:** The National Marrow Donor Program (NMDP) was established in 1987 to coordinate bone marrow transplants. The NMDP is a network of donor centers, transplant centers, collection centers and recruitment groups. Volunteer donors can also join the NMDP through organized donor drives. The NMDP helps facilitate unrelated marrow or PBSC transplants in the US and worldwide.
- ◆ **Pancytopenia:** When all of the three major blood cell types (red cells, white cells and platelets) are below normal values.
- ◆ **Patient -Caregiver Contract:** a document signed by the patient and caregiver and approved by the BMT Team, confirming the commitment of an individual to be a caregiver for the patient.
- ◆ **Peripheral blood stem cells (PBSC):** Stem cells that circulate in the peripheral blood.
- ◆ **Petechiae:** pin-head size sites of bleeding in the skin resulting from a low platelet count, frequently seen on the legs, feet, trunk and arms. They disappear gradually when the platelet count increases.



## Glossary of Terms

- ◆ **Physical Therapist (PT):** A member of the BMT Team that helps you to exercise and stay fit while you're in the hospital.
- ◆ **Platelets:** Help to form clots to stop bleeding.
- ◆ **Power of Attorney:** In North Carolina, you can name a person to make medical care decisions for you if there comes a time when you are unable to make decisions yourself. In this legal document, you name a person as your “health care agent.” You can state what treatments you would want and not want to have. This form must be witnessed by two people and signed by you. Our social worker has this form and will help you fill it out.
- ◆ **Protocol:** The outline or plan of a course of treatment.
- ◆ **Protocol Nurse:** A registered nurse that specializes in the administration of protocols. The protocol nurse reviews your medical information to determine your eligibility for a clinical trial. He or she may also provide informed consent and manages the data collection.
- ◆ **Pulmonary Function Tests (PFTs):** PFTs measure how well your lungs work. You will be asked to breathe into a tube. You will have this test before and after your transplant.
- ◆ **Radiation Oncologist:** A doctor who specializes in using radiation to treat disease.
- ◆ **Radiation Therapy:** Treatment with high-energy rays to kill cancer cells, also called radiotherapy. It may be used in combination with chemotherapy as part of the conditioning regimen in transplant patients.
- ◆ **Recreational Therapist:** A member of the BMT team who helps you stay active during your inpatient stay.
- ◆ **Red blood cell (RBC):** A blood cell that carries oxygen (fuel) from your lungs to all parts of the body.
- ◆ **Reduced Intensity Regimen:** Also called a “non-ablative transplant” or a “mini transplant.” This type of transplant is an allogeneic transplant where you get your stem cells from a related or an unrelated donor. The goal is to give a moderate dose of chemotherapy to set up a mixed immune system. The new immune system will attack the cancer.
- ◆ **Patient-Family Conference:** A pre-transplant meeting to answer questions and sign the treatment/protocol consent forms. The patient and caregivers are requested to be present. The Caregiver must be present to sign the Patient-Caregiver Contract.
- ◆ **PCA (Patient-controlled analgesia):** This means you have control of your pain medicine. The doctor will program your PCA pump to deliver an amount of pain medicine that is safe for you. When you need pain medicine, instead of calling the nurse, you can push your PCA button. The pump will give you pain medicine through your IV.
- ◆ **Remission:** A complete or partial disappearance of the signs and symptoms of your cancer.

## Glossary of Terms

- ◆ **Staging:** A process to find out where the cancer may be present. The tests are different for each disease but may include blood work, a bone marrow evaluation or a variety of scans and x-rays.
- ◆ **Stem cells:** The "mother" cells. Their job is to produce baby cells that will grow up to become mature red blood cells, white blood cells and platelets. They can be collected from the bone marrow by a bone marrow harvest or from the blood by apheresis.
- ◆ **Total Body Irradiation (TBI):** Used as a treatment to condition the patient and to promote immunosuppression. It is used with chemotherapy and may be given over the course of several days and in most cases, twice daily (fractionated radiation). Fractionated schedules may decrease the risk of side effects.
- ◆ **T-cells:** white blood cells that mature in the thymus and perform important immune system functions, also known as T lymphocytes.
- ◆ **Thrombocytopenia:** A platelet count that is below normal. A platelet transfusion will generally be given when the platelet count is less than 10,000 if you're an inpatient and less than 20,000 when you are an outpatient or having bleeding.
- ◆ **TPN (Total Parenteral Nutrition):** A liquid with high nutritional content given through the central line catheter.
- ◆ **Ultrasound:** Study of the organs of the body by using sound waves. The technologist will apply a warm gel to your skin over the area to be examined then move an instrument across your body and images will be photographed.
- ◆ **Umbilical Cord Transplant:** A transplant using the stem cells collected from an umbilical cord.
- ◆ **White blood cells (WBC):** Infection fighting blood cells. They are the body's defense against infection and disease.

UNC Bone Marrow Transplant and Cellular Therapy Program

101 Manning Drive, Chapel Hill, NC 27514

Monday—Friday: 984-974-0000 | Nights, Weekends and Holidays: 984-974-8280

<https://unclineberger.org/patientcare/programs/bmt>