

Autologous 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 under the direction of Thomas C. Shea, MD. Since then, our program has performed over 3,000 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, children and teens 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 with 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 Providers

“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 of Transplant and Cellular Therapy, ALLIANCE, 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.”

UNC BMT and Cellular Therapy Program, 101 Manning Drive Chapel Hill, NC 27514
Monday-Friday: 984-974-0000 | bmtprogram@unchealth.unc.edu

Table of Contents

Introduction

Welcome.....	1
Program Team Members & Phone Numbers	3

Before Your Transplant

About Autologous Transplants.....	4
Your First Visit.....	5
Preparing for Your Transplant Admission.....	6
Transplant Admission Day.....	8

Your Hospital Stay in BMTU

Team Members.....	9
Caregiver and Guest Guidelines.....	10
About the BMTU: Amenities & Routines	11
What to Expect on Transplant Day.....	13

After Your Transplant

Engraftment.....	14
Potential Complications.....	15
How We Care for You	16
Caring for Yourself.....	17

Preparing to Go Home

Discharge Planning.....	18
Returning Home and Follow-up Visits.....	18

Glossary

Commonly Used Medical Words.....	19
----------------------------------	----

Bone Marrow and Stem Cell Transplant Team Members

During your first visit, you will meet with various members of our program. Each BMTCTP 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 care team. 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, and Related Donor
- Quality and Organizational Excellence Leader
- Social Workers and Case Management
- Data Managers
- Financial Coordinators
- 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 to call BMT Clinic	Bone Marrow Transplant Unit On Nights, Weekends and Holidays Call 984-974-8280 Ask to speak to a Charge Nurse
--	--

Call 911 in an emergency, or go to a nearby Emergency Room

Autologous Stem Cell Transplant

- You can have an autologous stem cell transplant to treat different diseases. An **Autologous transplant** means that you will receive your own stem cells.

If you have any of the following diseases , you may be considered for Autologous transplant:

- ◆ Hodgkin's Disease
- ◆ Non-Hodgkin's Disease
- ◆ Multiple Myeloma
- ◆ Germ Cell Tumor

Peripheral Blood Stem Cell Collection

- **Central Line Placement:** You will need central line access for your treatments and for the infusion of the stem cells. 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. It may be placed in the Vascular Intervention Radiology (VIR) department at UNC Medical Center or at another UNC facility. The line will be placed before your hospital stay. 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.
- **Mobilization:** There are two ways to prepare your body for stem cell collection and the choice will depend on your disease or on what or how much therapy you have already received.
 1. You will receive a medicine called G-CSF for five days with an additional medication called Plerixafor that will help release the stem cells into their blood so we can collect them.
 2. You will receive a chemotherapy and then receive a medicine called G-CSF for approximately 10 days until collection.
- **Peripheral Blood Stem Cell Collection:** Peripheral blood stem cell transplant (PBSC) uses cells that are collected through an apheresis machine. This is done in the Apheresis Department. A Transplant Nurse Coordinator will provide you additional educational material and prepare you for the collection. During your mobilization, you will have multiple appointments in our clinic. You will be seen by a several providers including a Pharmacist who will review the mobilization process and your medications. You will also meet with a dietician who will provide education prior to your admission. A Transplant Nurse Coordinator will also meet with you to teach central line care and dressing changes, administration of subcutaneous injection teaching and preparations for admission.

Your First Visit



- During your first visit, a Transplant Doctor and a Transplant Nurse Coordinator will meet with you and your caregiver (s). 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.
- A Transplant Nurse Coordinator will provide you and your caregiver (s) more education on the transplant process, describe our support services, and answer any questions you may have.
- You will also meet with a Financial Coordinator who will explain your insurance benefits and provide applications for extra resources, if needed.
- 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 Neurosciences Hospital.
- Timing for the transplant may depend on your disease or clinical situation. 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

- You can visit the Leukemia and Lymphoma Society Website at **www.LLS.org** and the BMT Infonet website at **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).
- A BMT Social Worker will also meet with you and your caregiver (s) when you return for pre-transplant testing and can provide you with other resources as needed.

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. These tests will also be needed to submit to your insurance company for Autologous Transplant approval.



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. They may also be asked to meet with the team before your admission is finalized.

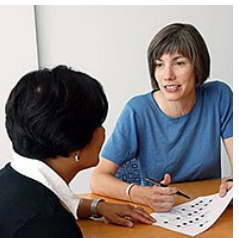


There is more teaching that will occur during your hospitalization. This is also important information for your caregiver. If your caregiver also cares for children at home, please let your transplant team know as other childcare arrangements are needed. We want to make sure that you have a **dedicated 24/7 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 two weeks after you are discharged from the hospital. 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. Please note that depending on your insurance carrier you may need to return to UNC Medical Center for care related to your transplant.



Living Will and Health Care Power of Attorney: An Advanced 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 can give your wishes about the use of artificial treatments to prolong your life if you are seriously ill. An Advanced Directive is a form with two parts: a living will and a health care power of attorney. For more information, you can discuss this with your social worker. It is also important to consider Short-term Disability and FMLA 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 stem cell product storage consent and blood product consent will be reviewed and signed.
- 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.

BMT Final Agreement Form

The decision to receive a stem cell transplant 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. On the morning of your planned admission, your transplant nurse coordinator will call you and let you know what time you should arrive and where you need to register.
- You will then go to the Bone Marrow Transplant Unit (BMTU). Depending on the time that a bed is available for you on day of admission, you may need to come to the BMT Clinic before admission.
- When you arrive on the BMTU, a member of the BMT team will help you and your caregiver get settled in the room and orient you to the unit. The BMT provider will also perform a physical exam. The admission day can become very busy. You will have many team members starting your teaching about transplant, medicines, procedures and unit routine. You will have many members obtaining history, drawing blood work and making sure you are ready for chemotherapy and transplant.
- 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 which is called “Day 0”. 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 your new cells and with the goal to get rid of any remaining cancer cells.

Types of Preparative Regimens

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:

BMT: Inpatient Care

Autologous Transplant

UNC Bone Marrow Transplant and Cellular Therapy



Your Transplant Nurse Coordinator will let you know your admission date. If you have any questions regarding 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 clinic for your BMT consultation. 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 oncology. He or she works closely with the BMT doctors and the rest of the team in managing your care.

Advanced Practice Professional (APP). An APP is either a doctor of nursing practice, a nurse practitioner, or a physician assistant. APPs rotate between the inpatient and clinic settings. Our APPs work closely with the Attending Physicians and Fellows, to help 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 meeting with the team pharmacist before you are discharged from the hospital, during which time they will go over all your medicines with you and your caregiver. 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. Some of 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 on the BMTU is to help you maintain a consistent level of activity during your admission, as well as help you identify strategies to aide with coping/adjustment. Upon admission, you will be provided with various tools to assist with establishing your daily activity routine which will include a walking log, lap counter and information about our Healthy Heels program. The Healthy Heels program offers incentives, including a marathon medal, for meeting your physical goals during admission. Occasionally there will be small groups offered that can focus on exercise, stress management/coping and positive peer/social support.

BMT Team Members

Unit Clerk. Our unit clerk does different jobs on the unit, including: greeting visitors, answering the phone, answering the call bell, and ordering supplies. This person will notify other staff members about your needs when you use the call bell.

Social Worker/Case Management. You and your family will meet with a social worker and/or case manager before, during and after your transplant. He or she will provide support during your inpatient stay and help you transition to discharge from 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.

Caregiver and Guests Guidelines

- It is important that visitors to the BMTU are not sick, which places all patients at risk. The Unit Clerk will help remind visitors of this, but it is helpful if you notify any of your visitors of this rule before they come and visit. All caregivers and guests will need to pick up the phone that is outside of 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 they can easily be reached when they are not at the hospital with you.
- No more than 4 guests (including your caregiver) are able to be in your room from 6:00 am until 9:00 pm. Only one caregiver can spend the night with you (from 9:00 pm until 6:00 am) and 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.
- During the Flu season (approx. Oct/Nov-April/May, children under 12 years old will not be allowed to visit the unit.

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 and 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. You should always wash your hands after touching the door handle of a room.

There may be times that your caregiver and your guests will need to use only soap and water for washing their hands. Most often this is 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, toiletries you bring must be new and unopened. You will likely not be able to use your toothbrush at some point due to infection and bleeding risks, but your medical team will discuss this with you during your stay. You can bring an electric razor but leave other razors at home. Nail clippers, metal nail files, needles, and sharp tools should also stay home. Special wipes will be given to you to use daily to help prevent you from getting an infection while in the hospital.

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

Wii Gaming System & DVD Player. You may want to bring games and movies from home, but a selection is also available on the unit. Just ask the unit team. You may also bring your own streaming device, such as a Roku or Amazon Fire stick, that can be connected to the TV.

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

Clock Radio/Telephone. Our radios play music and our sound machines play nature sounds.

Washing machine and dryer. We also provide detergent for you to use. There is a sign-up sheet for your use.

Refrigerator. Each room has a small dorm size refrigerator. You can keep non-perishable 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, date and room number.

Food. The hospital provides its patients with a menu of foods that will be 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.

Single-cup Coffee Maker & Microwave. These items are provided in the nourishment room.

Room Safe. A mini-safe will be in your room to place valuable belonging. You will create your own code.

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. Leave any valuables at home.
- Leave your contact lenses at home. Bring glasses if needed.
- If you have an Intra Uterine Device (IUD), please discuss with your BMT Doctor.
- Staff can help you send mail, please make sure to bring stamps.
- We want you to stay active during your stay, 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.

BMT Unit Routines

Your hospital stay can 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 at all times.

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 with your needs. It is helpful to the staff if you speak slowly and clearly. If you use your staff member does not attend your needs, please use the call bell to let us know again, so we can know right away.

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

Patient Engaged Report. It is a nursing report happens twice a day at shift change. This occurs between 7AM-8AM and 7PM-8PM and usually takes place at your bedside. During this report, a safety check will be performed with you, and the nurses will discuss goals for your care. Please plan to be in your room during this time, so you can be involved in this nursing transition of care.

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 monitoring of vital signs more frequently than every 4 hours. Multiple physical exams will occur each day by nursing and your BMT provider.

Intake and Output. The amount you drink you each day must be recorded. We will give you a paper log for your bathroom door. Please keep track of all the liquids you drink. All liquid output must be measured (including urine, vomit and liquid stool).

You will be given a urinal and/or have a urine or stool hat placed on your toilet so that it can be measured. Please be sure to record your urine before flushing. Please let your staff know so they can look at any urine, vomit or liquid stool. For assistance tracking your input & output, please let your nursing staff know.

Chest X-Ray and EKG. You will have these tests before admission. There is a chance they may be repeated during your hospital stay depending on your clinical condition.

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

Labs. Your central line will be used to draw your blood for lab tests each day. Your nurse will collect blood for tests around midnight to make sure that results are back for your BMT team to review before unit rounds in the morning. In addition to routine morning lab tests, your Provider may find it necessary to request more blood tests at other times during your stay.

Blood Product Transfusions. Blood product replacements are typically done overnight to make sure there is prompt treatment in your care.

Central line care. Your central line dressing will be changed the day you are admitted, every seven days, and if your dressing becomes wet, soiled, or is no longer sticking well. You and your caregiver will receive teaching on catheter line care.

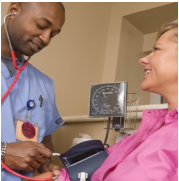
What to Expect on the Day of Your Transplant (“Day 0”)

- We recommend eating only 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, Benadryl, 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 stem cells—it is not surgery. This infusion is done in your hospital room. The stem cells look like blood and are given back to you through your central venous catheter. You will feel no pain and can 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 nursing staff 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 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 can help the taste go away. This taste or odor will go away 24-48 hours after the infusion.

Engraftment

- After the stem cells are given to you, they circulate in your blood vessels and then settle back in the bone marrow space where they begin to grow. This is called **engraftment**. How quickly the cells grow (engraft) depends upon how the cells are collected. For PBSC, you may engraft as early as Day +10 or Day +11, but it may be several days later. If we collect cells from your bone marrow, engraftment usually happens on Day + 14-21.
- 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 produces 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 will need to follow our strict hand washing rules. No one should come 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:

Side Effects and Potential Complications of Autologous Transplant

1. **Gastrointestinal problems.** You may have nausea, vomiting or diarrhea.
2. **Loss of appetite.** You may need extra nutritional support during this time such as special protein shakes or nutrition that is given to you through your central line.
3. **Mucositis.** Mouth sores, sore throat, or increased heartburn can be signs and symptoms of mucositis.
4. **Fatigue.** You can feel more tired or weak due to low blood counts and medications and eating less. It is important to get up and walk to keep your muscles strong.
5. **Infections.** Bacterial, viral and/or fungal.
6. **Engraftment failure.** This can occur when the patient's body rejects the stem cells. This results in very low blood counts and an increased risk of bleeding and infection. A second infusion of stem cells may be done. This is uncommon.

IMPORTANT!

- **Infection:** During your treatment and for several months afterward you will be at high risk for bacterial, viral and fungal infections. Infections can 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:

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 control can make you dizzy or sleepy. It is very important that you ask for help when you are getting 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 come and help you. We do not want you to fall while you are getting out of the bed, a chair or in the bathroom.

Pain Management. If you experience any pain during the course of your transplant, 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 can 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 pain first starts. If you are receiving 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 having a Patient Controlled Analgesia (PCA) pump. This is an IV pump that can be programmed to let you press a button that will give you more pain medicine when you feel you need it. This pump can also let you get a continuous amount of a low dose pain medicine each hour. For safety, this pump will be locked so that you do not get more medicine than is 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, 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 will 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 have had the chicken pox vaccine in the past 8 weeks or have a rash. Similarly, caregivers and guests who have had the small pox vaccine in the past 8 weeks may not visit the unit. Caregivers and guests who have had the FLUMIST vaccine—the flu vaccine that is sprayed in the nose—will not be able to visit on the unit unless they are free of flu like symptoms and at least one week has passed since they received 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 the Flu season (approx. Oct/Nov-April/May, children under 12 years old will not be allowed to visit the unit. While the BMT Team understands that this restriction is hard for our patients and their families, it is for your safety. Your BMT Team will let you know when these restrictions are in place.

Caring for Yourself

Skin Care. Taking a daily shower is very important. It is also very important for you to use the Chlorohexedine (CHG) body wipes after taking your shower daily to decrease your risk of infection. It is very important 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. 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 will develop rashes easily. If you must use make-up, it needs to be new and unopened. We do not recommend that you use of make-up during your transplant stay. It is best for you to avoid wearing jewelry during your hospital stay.

Mouth Care. Chemotherapy and/or radiation therapy may cause sores to develop in your mouth. Frequent and appropriate mouth care helps prevent infection, decreases pain, and helps with healing. We will provide you with small cups to rinse with tap water and special sponges, called toothettes, for your daily mouth care. Your nurse will give you instructions on your mouth care. Your nurse will give you instructions on your mouth care. Your team will let you know when it is okay to use a regular toothbrush. Please throw away your used toothbrushes and plan on using a new, unopened soft-bristle toothbrush when you are admitted. Dental floss and alcohol based rinses are not allowed. If you wear dentures/removable dental appliance, 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. Only a nail file can be used after you are admitted. Please remove any acrylic nails. Also it is 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 underneath 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. Scarves, hats and wigs or hair pieces can be worn. The Cancer Support Center located on the main floor of the Cancer Hospital makes loaner wigs and hairpieces available in some situations. If you decide to cut your hair while you are in the hospital only an electric razor may be used. Your nursing staff can provide an electric razor and help with this if you need.

Activity. It is important that you maintain a consistent physical activity routine during your admission to promote wellness and recovery. A Recreational Therapist will assist you with developing appropriate goals based on your abilities and will provide ongoing support throughout your admission. You will have access to various resources in the Wellness Room including a bicycle, treadmill, and an elliptical, There is also an air hockey table and Wii gaming system to promote increased activity through active leisure involvement. In some cases, the team may consult PT/OT for additional support if needed. Your nurse will provide you with a tool called an incentive spirometer that you will be asked to use 3-4 times a day. This will help to keep your lungs active as well. Feel free to bring various activities with you that you enjoy such as books, crafts, puzzles, etc. to allow opportunity for involvement in meaningful activity during your admission.

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, and
4. If your Caregiver has attended our Caregiver Class.

It is possible that 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, and it may take several days. If your caregiver is not staying with you on the unit, he or she should plan on arriving at the hospital to pick you up by **no later than 10:00 AM** on the expected day of discharge.

Returning Home After Transplant and Outpatient Follow-up

After discharge from the hospital, you will return to the outpatient clinic frequently for appointments for approximately two weeks after discharge. You will have additional follow-up visits for follow-up transplant related care including your vaccines. Most of the time you will see the Advanced Practice Professional (APP) working with your BMT Doctor A Post-Transplant Nurse Coordinator will be 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 complications.

- If you are staying in local housing after transplant discharge, **at approximately two weeks after discharge, you will be allowed to return to your home.** Please know that this timeframe can vary and will depend on how you are doing. Your BMT Team will continue to update you during your clinic appointments.
- We will evaluate you before you go home and put a plan of care in place for you. We will transfer care back to your local oncologist for follow-up of your cancer. How often you are seen will depend on how you are doing and on your disease. Your referring physician will be given a copy of your transplant records. Transplant specific follow-up like vaccines must be done at a Transplant Center.
- Please note that depending on your insurance carrier you may need to return to UNC Medical Center for all care that is related to your transplant.

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.

- ◆ **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 generally 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.
- ◆ **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.
- ◆ **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. This is rare after Autologous HCT.
- ◆ **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.
- ◆ **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.
- ◆ **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.

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.
- ◆ **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.
- ◆ **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.
- ◆ **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.
- ◆ **White blood cells (WBC):** Infection fighting blood cells. They are the body's defense against infection and disease.

HDF7031; 5/2020

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>

Approved by Oncology Patient Education Committee 5/2020