



YOUR GUIDE TO

Autologous Blood and Marrow Transplant





1. Welcome to the Autologous Blood and Marrow Transplant Program

- › Welcome to the Blood and Marrow Transplant Program
- › Blood and Marrow Transplant Program Overview
- › Blood and Marrow Transplantation
- › Blood and Marrow Transplant Team Phone Numbers
- › Important Cleveland Clinic Phone Numbers

2. Pre-Transplant

- › Pre-Transplant Evaluation Required Tests and Appointments
- › Financial Questions to Ask
- › Reproductive Issues
- › Your Central Venous Catheter
- › How to Avoid Problems With Your Central Venous Catheter
- › Injection Cap Change
- › Central Venous Catheter Transparent Dressing Change
- › Daily Catheter Flushing With Prefilled Syringes
- › How to Give Yourself Subcutaneous Injections
- › Filgrastim
- › Plerixafor

3. Preparing for Your Hospital Stay

- › Social Work
- › Preparing for Your Hospital Stay
- › Packing for Your Hospital Stay
- › Care Partner
- › Advance Directives
- › Blood and Marrow Transplant Resources

4. The Autologous Blood or Marrow Transplant Process

- › The Autologous Peripheral Blood Stem Cell Transplant Process
- › Sample Calendar for Neupogen & Plerixafor Primed Autologous Transplant
- › Sample Calendar for Chemotherapy Primed Autologous Transplant
- › Common Inpatient Medicines for Autologous Transplant Patients
- › What to Expect During Your Hospital Stay
- › Staying Active During Your Hospital Stay
- › Music Therapy
- › Mouth Care Schedule
- › How to Cope With Side Effects
- › Blood Transfusions
- › Preventing Central-line Associated Bloodstream Infections (CLABSIs) While in the Hospital

- › Neutropenic Precautions For Autologous BMT Patients
- › Thrombocytopenic Precautions for Autologous and Allogeneic Patients

5. Transplant Medicines

- › Transplant Medicines Overview
- › Acyclovir
- › Antacids
- › Ciprofloxacin
- › Magnesium
- › Nystatin
- › Steroids

6. After Transplant

- › Contacting the Transplant Team
- › Autologous Transplant Patients and Care Partners: Things to Know Before You are Discharged
- › Follow-Up Appointments For Autologous Transplant Patients
- › Taking Your Temperature (Twice a Day)
- › Taking Your Blood Pressure (Twice a Day)
- › Preventing Infection After Blood and Marrow Transplant
- › Nutrition After Blood and Marrow Transplant
- › Food Safety Guidelines
- › Resuming Sexual Activity
- › Frequent Laboratory Testing
- › Daily Recordkeeping Log
- › Vaccinating Recipients of Hematopoietic Stem Cell Transplants
- › Definition of Terms

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- › Blood and Marrow Transplantation
- › Blood and Marrow Transplant Team Phone Numbers
- › Important Cleveland Clinic Phone Numbers

Welcome to the Blood and Marrow Transplant Program

Welcome to the Blood and Marrow Transplant (BMT) Program. The BMT Team at Cleveland Clinic's Taussig Cancer Institute is here to help you regain your health.

Learn about the transplantation process

We have designed an extensive teaching program to help you learn about the transplantation process and your individual health needs, as well as your medical care before and after the transplant.

We know that learning about the transplantation process and how to care for your health might be overwhelming at first. But remember, you can learn a little each day. You'll also have this notebook as a reference during your transplant experience.

We understand you are both excited and nervous about your transplant. These are normal reactions. Being prepared in advance by learning and understanding what to expect will help ease your fears of the unknown.

Always discuss your questions and expectations with your healthcare providers.

Be an active partner in your health care

We believe it is important for you to be an active participant in your health care. You will need to assume much responsibility in your own care by doing whatever is necessary to build and maintain your strength for the transplant.

It is also important for you to recognize and report any changes in the way you feel. No one knows how you feel except you.

Patient rights

Cleveland Clinic supports the following patient rights:

- Reasonable access to care in a safe environment, which will not be denied due to race, creed, color, national origin, sex, age, sexual orientation, disability, or source of payment.
- Access to information about your diagnosis, condition, and treatment in terms you can understand so you can participate in the decisions regarding your care.
- Considerate care that respects your personal value and belief systems.
- Participation in the consideration of ethical issues that arise in the provision of your care.
- Personal privacy and confidentiality of information.
- Designation of a representative decision maker in the event you are incapable of understanding a proposed treatment or procedure, or are unable to communicate your wishes regarding care.
- Ability to refuse treatment to the extent permitted by law and to be informed of the possible consequences of your refusal and the ability to consent or refuse to participate in experimental treatment or research.
- To know the names and professional titles of all your caregivers (Cleveland Clinic is a teaching institution. Resident doctors, fellows and other supervised healthcare providers in training might become involved in your care and treatment.)

- To be provided with information about your continuing health care needs and planning for care after you leave the hospital and, as appropriate, after an appointment with your doctor or other caregiver.

Patient responsibilities

Your responsibilities as a patient at Cleveland Clinic include:

- Providing accurate and complete information about all matters pertaining to your health, including medicines and past or present medical problems.
- Notifying a member of the health care team if you do not understand information about your care and treatment.
- Reporting changes in your condition or symptoms, including pain, to a member of the health care team.
- Acting in a considerate and cooperative manner, and respecting the rights and property of others.
- Following the rules and regulations of the health care facility, as well as following the instructions and advice of your health care team.
- Keeping scheduled appointments or canceling them in advance if at all possible.

Index 9546 | Review Date: 8/8/2019

Blood and Marrow Transplant Program Overview

Cleveland Clinic performed its first bone marrow transplant in 1977. Since then, the Blood & Marrow Transplant (BMT) Team has performed more than 4,000 transplants.

The Blood & Marrow Transplant Program offers state-of-the-art transplantation in both autologous and allogeneic transplants. We are one of the world's leading authorities on peripheral blood stem cell mobilization and transplantation of autologous peripheral stem cells. We were one of the founding members of the National Marrow Donor Program in the use of unrelated donors for allogeneic transplants.

The Blood & Marrow Transplant Program is accredited by The Foundation for the Accreditation of Cellular Therapy (FACT), American Association of Blood Banking, the National Marrow Donor Program, the Ohio Bone Marrow Consortium and Southwest Oncology Group.

Cleveland Clinic has designated facilities and support services available to assist patients and their families throughout the entire transplant process. Transplant patients at Cleveland Clinic receive the highest quality medical and nursing care.

Blood and Marrow Transplant Team offers comprehensive care

The Blood & Marrow Transplant Team at Cleveland Clinic is specially trained in meeting the needs of transplant patients. The team is committed to providing comprehensive care in a compassionate setting. The BMT Team members include:

- Transplant doctors
- Physician assistants and Nurse Practitioners
- Transplant nurse coordinators

- Infectious disease team
- Clinical pharmacists
- Transplant fellows and residents
- Administrative coordinators
- Nurse manager and assistant nurse manager
- Registered nurses
- Nursing assistants
- Administrator
- Dietitians
- Social workers
- Financial counselors

Transplant doctors

BMT doctors are staff doctors with extensive training and experience in hematology/oncology and blood or marrow transplant. The transplant doctor on service will be caring for you during your stay in the hospital and will check your progress daily. Since Cleveland Clinic is a teaching facility, the transplant doctors rotate caring for inpatient transplant recipients. Therefore, your transplant doctor may or may not be on service while you are in the hospital, but will continue to be an active member in the decision-making process. Your transplant doctor continues to care for your health and follows you closely during your follow-up visits.

Physician assistants and nurse practitioners

Physician assistants and nurse practitioners are advanced practice providers that play an active role in your treatment. The inpatient BMT unit is staffed with physician assistants and nurse practitioners who will follow your medical care, along with the transplant doctor. An advanced

practice provider and transplant doctor will perform physical exams, review treatment and follow laboratory and X-ray results on a daily basis.

Transplant coordinators

The transplant coordinator is a registered nurse who helps coordinate all the events leading up to and following your transplant. He or she teaches you how to prepare for your transplant and will find you a suitable blood or marrow donor should you require one.

Along with other members of the Transplant Team, your transplant coordinator teaches you how to take care of yourself after transplantation in order to maintain your health. After you are discharged from the hospital, your transplant coordinator will continue to be directly involved in all aspects of your care.

Infectious disease team

This team of doctors is specially trained in infectious disease and how it relates to the transplant process. Before your transplant, you will have multiple tests to detect any signs of infection.

The team will help control your hospital environment to protect you against harmful sources of infection. Before approaching you, visitors and others will be asked to wash their hands with antimicrobial soap or instant hand sanitizing foam located outside and inside each room. In addition, your temperature will be taken every 4 hours to detect early signs of infection.

Transplant fellows

Transplant fellows are doctors who are training to become specialists in hematology and oncology. They work under the guidance of your transplant doctor and will visit you daily along with your transplant doctor and the rest of the BMT Team.

Clinical pharmacists

Along with your transplant doctor, your clinical pharmacist will make adjustments in your medicine dosage as needed. The clinical pharmacist might assist your nurses and transplant coordinator in teaching you about your transplant medicines.

Administrative coordinators

Your administrative coordinator will make sure all of your appointments are scheduled before and after your transplant. He or she will work closely with your referring doctor to make sure all necessary medical records are available. The coordinator also stays in close contact with your insurance company for medical review and approval of your treatment plan.

Nurse manager and assistant nurse manager

The nurse manager and assistant nurse manager are responsible for the overall daily management while you are on the BMT Unit (G110) or the Leukemia Unit (G111). The nurse manager and the assistant nurse manager work with the registered nurses and nursing assistants on all nursing units to assure you are receiving the best care.

If you have any questions or concerns about the condition of your room or the nursing care you are receiving, you may ask to speak with either the nurse manager or assistant nurse manager.

Registered nurses

Registered nurses provide you with individual care during your outpatient appointments at the Taussig Cancer Center and 24-hours-a-day while you are hospitalized. Registered nurses work together with your doctor and the rest of the BMT Team to plan your daily care. In the hospital, registered nurses also:

- Check your progress at frequent intervals throughout the day and night
- Administer your medicines

- Tell your doctor of any changes in your condition
- Educate you and your family about the medicines you will be taking
- Teach you how to care for your health after transplantation
- Prepare you for your discharge

Nursing assistants

Nursing assistants work with the registered nurses to provide your daily care. They might take your temperature, blood pressure and daily weight. They also assist with your personal care and help make you comfortable during your hospital stay.

Administrator

The BMT administrator oversees the daily operations of the Blood & Marrow Transplant Program. The administrator works with nursing, engineering, research, technical, laboratory, financial, social work and clerical personnel within the BMT Program. The goal of all is to ensure the highest quality of patient care.

Dietitians

Registered dietitians (nutrition experts) are available to help you maintain good nutrition during your transplant recovery. They work closely with you and your doctor to provide individualized nutritional counseling. They are available to answer any nutrition questions you might have.

Social workers

A social worker will be assigned to you and your family and will discuss any concerns you might have about your transplant or your personal situation.

Your social worker will be a primary source of support during the transplant process. Social workers provide education, counseling regarding

lifestyle changes and coping with treatment demands, referrals to community or national agencies and support groups, help with local lodging needs and any other assistance you or your family might need.

Financial counselors

Your financial counselor can answer any questions you might have about insurance coverage and benefits related to your transplant and care. They will help obtain insurance approval for your transplant. Transplant patients will be scheduled to meet with the financial counselor prior to their transplant.

Some transplant patients might be eligible for certain government programs, depending on their individual financial situation.

Other BMT transplant team members

A chaplain is available to provide spiritual guidance or counseling for all faiths. There are many other professionals such as a music therapist, physical therapists and respiratory therapists, laboratory technicians and support staff who work as members of the BMT team to meet your medical and personal needs.

Special care for pediatric patients

Pediatric patients receiving a blood or marrow transplant are admitted to the Children's Hospital at Cleveland Clinic. There, they are under the care of specialists, nurses, social workers, child-life workers, and other health-care professionals who are trained to meet the unique needs of children and their families.

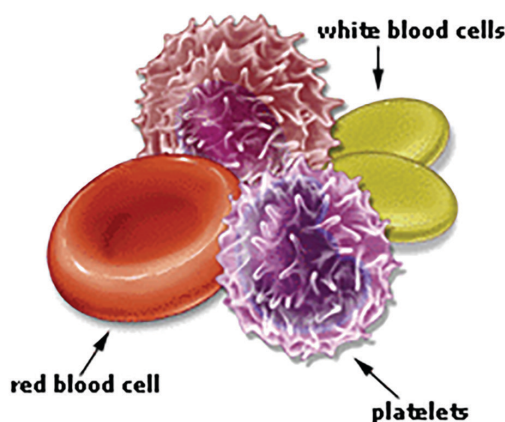
The Children's Hospital provides state-of-the-art care in a home-like setting. Because the family is an important part of a hospitalized child's recovery, the hospital rooms are designed to enable a parent to spend the night in the room with his or her child.

Blood and Marrow Transplantation

How the bone marrow functions

Hematopoietic stem cells are found in the peripheral blood and the bone marrow. These stem cells develop into all types of blood cells, including white blood cells, red blood cells and platelets.

- White blood cells of various kinds make up part of your immune system for fighting infections.
- Red blood cells are responsible for carrying oxygen throughout your body.
- Platelets clot your blood to prevent bleeding.



Stem cells are constantly being produced by your bone marrow and will develop into the types of cells your body needs.

Types of blood or marrow transplants

Most people who need to undergo a **blood or marrow transplant** have cancer, such as **leukemia, lymphoma or multiple myeloma**. There are different types of transplants. The type and severity of your disease determine what type of transplant you will need.

An **allogeneic transplant** involves receiving donor bone marrow, umbilical cord stem cells or peripheral stem cells. This donor is genetically matched and can be related or unrelated to you.

An **autologous transplant** involves receiving your own peripheral blood stem cells. A syngeneic transplant involves receiving your identical twin's bone marrow or peripheral stem cells.

The following is more information about three specific types of blood or marrow transplants:

- An **allogeneic transplant** involves receiving very high doses of **chemotherapy** and/or **radiation therapy**, followed by the infusion of your donor's bone marrow or peripheral blood stem cells. The high-dose cancer-fighting treatments are given to eliminate the cancer in your body.

The infusion of the new marrow, cord blood or peripheral stem cells from the donor replaces the bone marrow destroyed by the chemotherapy and/or radiation therapy. Allogeneic transplant patients have the risk of developing a complication called graft-versus-host disease or GvHD. GvHD is a condition where donor cells from the graft attack the patient's (or host's) organs or tissues. The condition can be mild and treated on an outpatient basis, or it can be severe and require treatment in the hospital.

You might be a potential candidate for an allogeneic transplant if you have leukemia, aplastic anemia, myelodysplasia, myelofibrosis, high-grade lymphoma or other types of cancers.

- A **reduced intensity allogeneic transplant** involves receiving lower doses of chemotherapy and radiation therapy followed by the infusion of your donor's bone marrow or peripheral blood stem cells. The objective is to suppress your own bone marrow by receiving just enough chemotherapy and radiation therapy to allow your donor cells to engraft and grow within you. The hope is these donor cells will mount an immunologic

attack against your underlying cancer, generating a response called the “**graft-versus-leukemia**” effect or “**graft-versus-cancer**” effect.

You might be a potential candidate for this type of transplant if you have a slow-growing (“indolent”) disorder, such as chronic leukemia, multiple myeloma, myelodysplasia, and low-grade lymphoma.

- An **autologous bone marrow transplant** involves receiving very high-dose chemotherapy followed by the infusion of your previously collected peripheral stem cells or bone marrow.

The high-dose chemotherapy treatments are given to eliminate the cancer in your body. The infusion of your new marrow or peripheral stem cells replaces the bone marrow destroyed by the chemotherapy and/or radiation therapy.

You might be a potential candidate for an autologous transplant if you have lymphoma, multiple myeloma, Hodgkin’s disease, germ cell cancer or certain types of leukemia.

Pre-transplant evaluation

Before a blood or marrow transplant can be approved as a treatment option, you will have a pre-transplant evaluation. This evaluation includes a complete physical, consultations with members of the Transplant Team and a comprehensive series of tests. A pre-transplant evaluation provides complete information about your overall health and helps determine if you are eligible for a blood or marrow transplant.

Blood or marrow transplantation as a treatment option

After your transplant doctor has determined you are a good candidate for a transplant, a date for the transplant will be determined and the process of insurance clearance will begin.

Please understand that insurance reimbursement for transplantation is not automatic.

If you are to be admitted to the hospital for your transplant, you can expect your stay to be about 3 to 4 weeks, depending on your recovery. During your recovery, you will learn about your new medicines, how to recognize signs of complications and infections and when you can return to your normal activities.

If an allogeneic transplant or inpatient reduced intensity transplant has been approved for you, you and your designated care partner will be required to stay within a 1-hour drive of Cleveland Clinic’s main campus for approximately 100 days after your transplant. After you go home, you can expect to recover gradually.

If an outpatient reduced intensity allogeneic transplant has been approved for you, you and your care-partner will be required to stay within a 1-hour drive of Cleveland Clinic’s main campus for at least 100 days after your transplant. At that time, your doctor will evaluate your medical condition to determine where you can continue your follow-up care.

Follow-up care after your transplant includes appointments with your transplant or local doctor and tests to assess how you are recovering.

References

- National Heart Lung and Blood Institute. Blood and Bone Marrow Transplant (<https://www.nhlbi.nih.gov/health-topics/blood-and-bone-marrow-transplant>). Accessed 8/8/2019.
- National Marrow Donor Program. How bone marrow transplants work. (<https://bethematch.org/transplant-basics/how-transplants-work/>). Accessed 8/8/2019.

Index # 4752 | Review Date: 8/8/2019

Blood and Marrow Transplant Team Phone Numbers

ADULT TRANSPLANT DOCTORS

Craig Sauter, MD, Director.....	216.444.2199
Faiz Anwer, MD.....	216.445.1469
Claudio Brunstein, MD.....	216.445.0910
Paolo Caimi, MD.....	216.445.4635
Robert Dean, MD.....	216.445.5365
Aaron Gerds, MD.....	216.445.9840
Betty Ky Hamilton, MD.....	216.445.7580
Brian Hill, MD.....	216.445.9451
Deepa Jagadeesh, MD.....	216.444.0857
Matt Kalaycio, MD.....	216.444.3705
Jack Khouri, MD.....	216.444.8360
Brad Pohlman, MD.....	216.445.6070
Shahzad Raza, MD.....	216.444.4960
Ronald Sobecks, MD.....	216.445.4626
Louis Williams, MD.....	216.444.2390
Allison Winter, MD.....	216.445.4782

BLOOD & MARROW TRANSPLANT UNIT (G110)..... 216.444.4173

Debra Scott, RN, Nurse Manager

Ally Farrell, Assistant Nurse Manager

Katherine King, Assistant Nurse Manager

Molly Klominek, Assistant Nurse Manager

ADVANCED PRACTICE PROVIDERS

Anita Bias, CNP, Inpatient Coordinator.....	216.444.1978
Christina Ferraro, CNP, Outpatient Coordinator.....	216.444.3990
Megan Corrao, CNP.....	216.445.6418
Kayla Giannetti, CNP.....	216.445.2031
Katie Mohr, CNP.....	216.445.6504
Jill O'Brien, PA.....	216.445.5602
Tina Piks, CNP.....	216.444.6236
Danielle DePhillipo, CNP.....	216.217.4744
Grace Paik.....	216.442.3352

APHERESIS216.444.2633

Swati Srivastava, MD, Medical Director

AFTER HOURS OR ON WEEKENDS

Call 216-444-2200 and ask for the Hematology/Oncology Fellow on call.
Note: since you will be directing your questions or concerns to your BMT nurse coordinator or the Fellow on call, please do not call the G110 nursing unit. If you are unable to reach the Hematology/Oncology Fellow, please page your nurse coordinator.

BLOOD & MARROW TRANSPLANT ADMINISTRATION.....216.445.5600

Julie Coffman, Administrator.....	216.445.3794
Joe Farinella, Quality Director.....	216.444.0054
Tiffany Addis, Department Coordinator.....	216.445.5600

NURSE COORDINATORS

Laura Bernhard, RN, Clinical Manager.....	216.445.6373
Brittany Hodgeman, RN, Lead Transplant Coordinator.....	216.444.0312
Sarah Basurto, RN.....	216.445.9128
Lisa Chiancone, RN.....	216.444.4652
Kerry Cross, RN.....	216.444.5839
Danijela Davis, RN.....	216.445.4360
Amy Healy, RN.....	216.444.0829
Jenn Kosar, RN.....	216.442.3345
Katie Krieger, RN.....	216.444.9276
Amy Masek, RN.....	216.442.1303
Kelley Murphy, RN.....	216.445.4231
Jamie Starn, RN.....	216.445.4942
Megan Tamburiello, RN.....	216.445.7163
Karen Willett, RN.....	216.444.9107

ADMINISTRATIVE COORDINATORS

Kay Pierson.....	216.445.6538
Domonic Rini.....	216.445.7453
Gerri Robinson.....	216.445.4941
Mark Stimpert.....	216.445.0333
Greg Jurecki.....	216.445.3334

FINANCIAL SUPPORT STAFF

Vanessa Hudson, Reimbursement Specialist.....	216.445.6559
Patient Financial Advocate.....	216.445.6775

SOCIAL WORK

Jane Dabney, LISW-S.....	216.445.2483
Caitlin Garcia, LISW-S.....	216.444.8576
Azia Morgan, LISW-S.....	216.445.6211

Important Cleveland Clinic Phone Numbers

Admitting (Patient Registration)	216.444.2029
Ambassadors (Volunteer Services)	216.445.6986
American Cancer Society	1.800.ACS.2345
Apheresis	216.444.2633
BMT Laboratory	216.444.9289
BMT Administration Office	216.445.5600
Cancer Answer Line	216.444.7923 or 1.800.862.7798
Cancer Information Service	1.800.4.cancer
Cashier	216.444.6848
Concierge Services	216.445.5580
Cleveland Clinic Information	1.800.223.2273 or 216.444.2000
Directions to the Cleveland Clinic	216.444.9500
Emergency Assistance (Fire, Security)	216.444.2222
Financial Ombudsman	216.445.5134
Food Services, Patient (Menu Hotline)	216.444.6659
Food Services, Retail	216.444.6660
General Counsel (Legal Affairs)	216.448.0200
Guest Services Desk	216.445.3114
Joseph Beth Gift Shop	216.444-1700
Hearing Impaired Interpreter Referral	216.444.2273
Cleveland Clinic Home Care	216.444.home or 1.800.263.0403
Hope Lodge	216.844.4673
Hospice of the Cleveland Clinic	216.444.9819
Infection Control	216.444.5194
International Center	216.444.6404
Laboratory (Taussig Cancer Center)	216.444.7126
Leukemia & Lymphoma Society	1.800.589.5721

Lost and Found	216.444.2253
Nurse on Call	216.444.1234
Nutrition Hotline	216.445.2710
Nutrition Therapy Appointments	216.444.4660
Ombudsman	216.444.2544
Parking Services	216.444.2255
Patient Helpline (24 hours a day)	216.444.6589
Patient Shuttle Bus	216.444.8484
Poison Control Center (Greater Cleveland Area)	216.231.4455
Police/Security	216.444.2250
Prayer Line	216.445.7200
Pharmacy (Outpatient -Euclid Ave Lobby of Parking #1).	216.444.2100
Pharmacy (Taussig Cancer Center)	216.445.2124
Reflections Wellness Program	216.444.3527
Social Work.	216.444.6552
Spiritual Care	216.444.2518
Telegram/Telex Service	216.444.7988
Transplant Housing	216.445.5618
TV Service.	216.444.5124
Vehicle Assistance	216.444.8484

Index # 9609 | Review Date: 8/8/2019

2. Pre-Transplant

- › Pre-Transplant Evaluation Required Tests and Appointments
- › Financial Questions to Ask
- › Reproductive Issues
- › Your Central Venous Catheter
- › How to Avoid Problems With Your Central Venous Catheter
- › Injection Cap Change
- › Central Venous Catheter Transparent Dressing Change
- › Daily Catheter Flushing With Prefilled Syringes
- › How to Give Yourself Subcutaneous Injections
- › Filgrastim
- › Plerixafor

Pre-Transplant Evaluation Required Tests and Appointments

Pre-Transplant Evaluation

Your transplantation process began with an initial consult with your transplant doctor. You and your doctor have determined that a transplant is the right treatment for you. The next step in the process is your pre-transplant evaluation.

What is a pre-transplant evaluation?

Your pre-transplant evaluation includes a variety of medical tests and appointments that will provide complete information about your overall health. These medical tests and appointments help the BMT team identify any potential problems before your transplant and avoid any potential complications during and after your transplant. These tests are also required by your insurance company in order to approve the medical necessity of your transplant.

About 4 to 6 weeks before your transplant, you will be scheduled for your pre-transplant evaluation. While each patient may not have the same tests, most of the tests listed in this section are common for all transplant patients. Your nurse and administrative coordinators will help arrange the testing for you.

If you have an allergy to the contrast dye used for CT scans, or have been told that you need to be premedicated before CT scans, please notify your nurse coordinator. You will need a prescription sent to your pharmacy before your scheduled test date.

If you have had a PET scan, CT scan or skeletal survey done within 6 to 9 months prior to your pre-transplant evaluation, please bring a copy of the films or CD – along with the report – to your pre-transplant evaluation appointments. The radiologist will use them as a comparison when reading your pre-transplant evaluation scans.



If special instructions are required before any of these tests, you will receive written instructions that explain how to prepare. After the tests are completed, your transplant doctor will review the results with you.

Required tests and appointments

Your pre-transplant evaluation will be scheduled at Cleveland Clinic (main campus), usually over a few days. In addition to your required medical tests, you will also be scheduled to meet with members of the BMT team. The next few pages provide information about upcoming tests and appointments that are part of your pre-transplant evaluation.

Meeting with the transplant team

As part of your evaluation for transplant, you will meet with a nurse coordinator, social worker and financial counselor to learn more about the BMT process.

- **Nurse coordinator.** Your nurse coordinator will meet with you to review the calendar of events related to transplant, including the chemotherapy, with or without radiation, and informed consents. This appointment usually lasts about 2 hours. The nurse coordinator will discuss potential side effects of chemotherapy /radiation and what you can expect during your BMT experience.

- **Social worker.** Your social worker will complete a thorough psychosocial assessment, which helps to identify the needs and concerns of patients, families and significant others. All patients will have an in-person assessment with the social worker that usually lasts about 1-1/2 hours. Your care partner(s) should attend this appointment with you. Most insurance companies require an assessment by a social worker to be completed before approval of your BMT.

All patients are asked to complete the enclosed social worker questionnaire and return it in the envelope provided.

If you are receiving a transplant from a donor (allogeneic or reduced intensity), you and your care partner will be required to stay in the Cleveland Metropolitan area, within a 1 hour drive of the Cleveland Clinic Main Campus. Most autologous transplant patients (patients receiving their own stem cells) will be required to stay within 1 hour of Cleveland Clinic Main Campus during the stem cell collection period, which can be up to 3 weeks.

In some cases, autologous stem cell patients may also be required to stay within 1 hour of Cleveland Clinic after being discharged.

Your social worker can help identify local housing options and provide assistance with other concerns that you may have.

- **Radiation oncologist.** If you require radiation as part of your preparative regimen, you will meet with a radiation oncologist. The radiation oncologist will assess your history of previous radiation exposure to ensure you are able to receive radiation for transplant. He or she will also explain possible side effects that can be caused by radiation, as well as how radiation is given.

- **Financial counselor.** All transplant patients will meet with a financial counselor who can review insurance coverage for pre- and post-transplant expenses.

- **Dentist.** All allogeneic transplant patients require a dental assessment as part of your pre-transplant screening to ensure that your mouth is free of potential infection.

Autologous transplant patients may be required to have a dental assessment. This will be determined by your insurance company and/or your transplant physician. Check with your nurse coordinator if you are unsure.

A dental assessment may be scheduled at your personal dentist's office or at Cleveland Clinic. If the assessment is done at your local dentist's office, please ask the dentist to fax a letter stating that your mouth is free from any source of potential infection.

The letter needs to be faxed to the BMT office at Fax: 216.445.7444 or hand delivered prior to your transplant. (Feel free to use the handout "Instructions for Your Dentist" as a guide.)

If dental work is required before the start of your preparative regimen, please notify your nurse coordinator to determine if preventive antibiotic therapy is needed before the dental work is performed.

If you would like a dental assessment to be scheduled at Cleveland Clinic, please notify your nurse coordinator and verify that your insurance will cover a dental consult at Cleveland Clinic. Medical insurance does not typically cover dental clearance.

Blood tests

Your healthcare provider or a technician will take a sample of blood from your arm or central venous catheter (if one is in place). The blood is sent to a lab where the following tests are performed:

- **Tissue typing (needed for allogeneic patients only).** This was done at or before your initial consultation appointment with your BMT doctor. Tissue typing is a series of blood tests that evaluate the compatibility or closeness of tissue between the donor and recipient. From your blood samples, the tissue typing lab can identify and compare information about your antigens (the “markers” in cells that stimulate antibody production) so they can match a bone marrow or peripheral blood stem cell donor to you. All donors are carefully screened to prevent any transmissible diseases or detect other medical problems that might prevent them from donating bone marrow or peripheral blood stem cells.
- **Other blood tests.** In the laboratory, a series of tests will be performed to detect certain substances in your blood and to evaluate your general health. These blood tests might include:

Infectious disease screening for:

- Hepatitis
- HIV (human immunodeficiency virus)
- RPR (syphilis)
- Toxoplasmosis
- Varicella Zoster
- CMV (cytomegalovirus)
- EBV (Epstein-Barr virus)
- HSV (Herpes Simplex virus)
- West Nile Virus

- HTLV1/11 (Human T-Cell lymphotropic virus)
- Chagas

Blood work to check your organ function:

- Complete Metabolic Panel
- Bleeding times
- CBC, diff, platelets

Other possible blood work:

- Ferritin
- Disease-specific labs for multiple myeloma, including a 24-hour urine
- Pregnancy test
- Research samples
- Hemoglobin Solubility
- ABO blood type

Heart and lung tests

Chemotherapy and/or radiation therapy that you may have received in the past as well as chemotherapy and/or radiation that you will receive for your transplant may affect your heart and lungs. Because of this, you will need heart and lung tests to identify and treat any potential problems before your transplant procedure.

Heart tests include:

- **Electrocardiogram (ECG).** An ECG is used to evaluate your heart rhythm. Before the test, electrodes (small, flat, sticky patches) are placed on your chest. The electrodes are attached to an electrocardiograph monitor that charts your heart's electrical activity (heart rhythm).
- **Echocardiogram.** An echocardiogram is a graphic outline of your heart's movement. During the test, a wand, or transducer, is

placed on your chest. The transducer emits ultrasound (high-frequency sound wave) vibrations so the doctor can see the outline of the heart's movement. The echocardiogram provides pictures of the heart's valves and chambers so the pumping action of the heart can be evaluated. Echocardiogram is often combined with Doppler ultrasound to evaluate blood flow across the heart's valves.

Lung tests include:

- **Chest X-ray.** A chest X-ray provides a picture of your heart and lungs. This X-ray provides information about the size of your heart and lungs, and might detect the presence of lung disease or infection.
- **Pulmonary function tests (PFTs, lung tests).** Pulmonary function tests measure the capacity and function of your lungs, as well as your blood's ability to carry oxygen. During the tests, you will be asked to breathe into a device called a spirometer.

Here are some guidelines to follow before your scheduled pulmonary function tests:

- Be sure to get plenty of sleep the night before.
- Plan to wear loose clothing during the test so you can give your greatest breathing effort.
- Limit your liquids and eat a light meal before the test. Drinking or eating too much before the test might make you feel bloated and unable to breathe deeply.

Radiology Tests

Depending on the type of disease you have, you may be scheduled for radiology tests. Your transplant physician may request a computed tomography scan (CT scan), a Positron emission tomography (PET) scan, or a combination PET/CT scan. Patients with multiple myeloma may be required to have a skeletal survey.

- **Computed tomography scan (CT Scan).**

A CT scan, uses X-rays and computers to produce a detailed image of the body. Depending on the type of scan you need, an oral and/or IV contrast material might be used so the radiologist can see the extent of your disease. CT scans also might reveal the presence of other abnormalities.

If you had a CT scan within 6 months before your pre-transplant evaluation, bring the CT scan films or disc, along with a copy of the report, with you. The radiologist will use them as a comparison when reading these new scans.

Depending on your illness, your doctor might order additional CT scans.

- **Positron emission tomography (PET) scan.**

A PET scan is a unique type of imaging test that helps doctors see how the organs and tissues inside your body are actually functioning.

The test involves injecting a very small dose of radioactive chemical, called a radiotracer, into a vein. The tracer travels through the body and is absorbed by the organs and tissues being studied. Next, you will be asked to lie down on a flat examination table that is moved into the center of a PET scanner – a doughnut-like shaped machine. This machine detects and records the energy given off by the tracer substance. The PET scan can measure such vital function as glucose metabolism, which helps doctors identify abnormal from normal functioning organs and tissues.

One of the main differences between PET scans and other imaging tests like CT scan or magnetic resonance imaging (MRI) is that the PET scan reveals the cellular level metabolism changes occurring in an organ or tissue, or the activity of cells.

Depending on your illness, your doctor may order a PET scan.

- **Bone marrow biopsy.** A bone marrow biopsy is a procedure to collect and examine bone marrow – the spongy tissue inside some of your larger bones. A bone marrow biopsy shows if your bone marrow is healthy and making normal amounts of blood cells, as well as monitor for abnormal cells. The area of your back hip bone will be numbed with a local anesthetic or pain relieving medication before a needle is inserted to remove a sample of your bone marrow. You might be given oral medicine, prior to the procedure, to help you relax. You should plan to have a driver take you home after this procedure, since the medication can make you drowsy.

Additional Tests

Some insurance companies require additional testing as part of your pre-transplant evaluation. These may include: a colonoscopy, mammogram, dental exam, or gynecology exam. Your nurse coordinator will let you know if these tests are required.

After your BMT physician reviews your evaluation testing, additional appointments or consultations may be necessary. Your nurse and administrative coordinator will assist you in scheduling these appointments at Cleveland Clinic.

After my pre-transplant evaluation

At the end of your pre-transplant evaluation and after the test results are complete, the BMT doctor will decide if a transplant is the appropriate treatment for you.

Your test results will also be sent to your insurance company for the insurance approval process. Usually the insurance company will make a determination in 7 to 10 days after receiving the test results.

Please understand that abnormal test results may require further investigation.

The goal of pre-transplant testing is to ensure that you will be able to undergo the transplant and recover without increased risk of complications.

Donor pre-transplant testing

For allogeneic and reduced intensity allogeneic transplant patients, your blood or marrow donor will also have a medical evaluation with many of the same tests. The donor must be cleared and determined medically fit to proceed as your donor.

Index # 9606 | Review Date: 8/8/2019

Financial Questions to Ask

If you have been approved for a bone marrow transplant, you will need to prepare yourself financially and clarify your insurance coverage while you wait for your transplant.

The transplant financial counselor is available to answer your questions and concerns.

The following questions will help you sort out your insurance coverage and will help you plan for the expenses of transplantation.

Questions for your insurance company

- What is my deductible and out-of-pocket maximum for medical benefits?
- What is the maximum on my insurance coverage? What happens if my financial coverage runs out?
- Do I have a transplant maximum separate from my lifetime max?
- How does my plan determine transplant approval?
- If transplant coverage is denied, am I able to appeal? What is the process?
- If I have a question regarding my Explanation of Benefits (EOB), who should I call?
- How will a change in my job status affect my insurance? What would the increase be in my deductible?
- What pre- and post-transplant tests are covered? Do I need to go to a certain facility for these tests to be covered?
- Does my plan cover donor searching expenses?
- Does my plan cover the expenses incurred by my bone marrow donor?
- Are expenses for meals, lodging and transportation covered while I wait for my transplant? Are there maximums placed on the reimbursement for these items?
- Do I report to you if I have a secondary insurance?
- What are my possible out-of-pocket expenses for prescriptions?
- At which participating pharmacies can I fill my prescriptions?
- Does my insurance provide coverage for home health services? Is there a maximum on my home health service coverage?
- Is there a co-pay for a specialist office visit?

Questions for your transplant financial counselor

- What financial coverage is accepted by the hospital (such as Medicare, Medicaid, private insurance)?
- How much will the transplant cost? How much will I have to pay?
- Should I inform you if I am an active or retired veteran?

Index 10411 | Review Date: 8/8/2019

Blood and Marrow Transplants and Reproductive Issues

Blood & Marrow Transplant preparative regimens use high-dose chemotherapy and (sometimes) radiation to destroy cancer cells. Side effects of this life-saving therapy occur when normal cells in the body are also destroyed by the treatment. Cells in the male and female reproductive systems fall into this category, and BMT survivors may experience temporary or permanent damage affecting future fertility. Little research has been done to provide statistics about fertility after transplant, but quality-of-life issues, such as fertility/infertility, have been identified as major concerns for cancer survivors.

Recovery after BMT can take months to years, so many patients are not physically or psychologically ready to consider parenthood for several years after transplant. However, a pre-transplant discussion of options to preserve fertility might help you plan for your family's future.

Male fertility issues

You might choose to preserve your fertility before BMT by having your sperm frozen or banked for future use in either artificial insemination or in vitro fertilization. If you are interested in sperm banking, please tell your nurse coordinator, who can schedule an appointment in the Andrology Lab. The Andrology Lab will perform an analysis on a fresh semen sample to examine both quality and quantity of the sperm. If the results are acceptable, the Andrology Lab will schedule appointments to collect and freeze your sperm. This will be done before the start of your BMT preparative regimen. If you have already received chemotherapy or radiation therapy, you may or may not still be fertile. Sperm may be frozen indefinitely and annual storage fees are usually charged, which may or may not be covered by medical insurance.

If you do not wish to father children after BMT, the use of contraception is recommended because we cannot predict if or when fertility will return. Several options exist if your infertility is prolonged or permanent and you wish to become a parent once you have recovered from BMT. Alternatives include an assessment by a urologic surgeon who specializes in infertility for possible testicular sperm extraction and for use in specialized in vitro fertilization. Other options include the use of donor-banked sperm.

Female fertility issues

Most female patients experience temporary or permanent menopause, also known as premature ovarian failure, as a side effect of transplantation. If you have already received chemotherapy or radiation therapy, you may or may not still be fertile. If you are interested in attempting to preserve your fertility before transplant, please tell your nurse coordinator, who can schedule an appointment with a gynecologist who is an infertility expert. This is done before the start of your preparative regimen. The gynecologist will use lab tests to assess your current ovarian reserve, review your prior chemotherapy drugs and dosages, and discuss options that might be available to you. Barriers to consider include cost — since insurance companies may not cover these treatments — and your age, since fertility decreases as a woman ages.

Options to preserve fertility might include:

All of the following options have an unknown chance of success in producing a viable (living) egg or sperm.

- **Embryo freezing.** Mature eggs are stimulated with hormones, removed, fertilized with sperm, and then frozen and stored. This

method can take several weeks to achieve and might not be an option for a cancer patient who needs immediate treatment for active disease. Other factors to consider include the availability of a partner to donate sperm, and the ethical decision of what to do with the frozen embryos that might not be used as planned.

- **Egg freezing.** Mature eggs are stimulated, removed, and frozen unfertilized. This method can take several weeks to achieve, depending on your menstrual cycle, but might be an option for a woman currently without a partner to fertilize the eggs. Live births have been reported with this method, but it is still considered experimental.
- **Testicular tissue freezing.** Sperm-bearing tissue is removed from the testicle during this outpatient procedure and frozen for future use.
- **Ovarian tissue freezing.** Ovarian tissue is removed during an outpatient surgical procedure and frozen for future transplantation back into your body. This method is considered experimental, but the goal is to preserve immature eggs and the tissue that makes female hormones to potentially preserve female fertility.

If you do not wish to have children after BMT, the use of contraception is recommended because we cannot predict if or when fertility will return.

If your infertility lasts for a long period of time or is permanent and you wish to become a parent once you have recovered from BMT, other options exist. These include in vitro fertilization with donor eggs or adopted embryos or surrogacy.

Resources

Fertile HOPE is a non-profit organization that offers fertility resources for cancer patients. You can visit their Web site at www.fertilehope.org.

Your BMT social worker is available for counseling to assist with decision-making.

Index # 11927 | Review Date: 8/8/2019

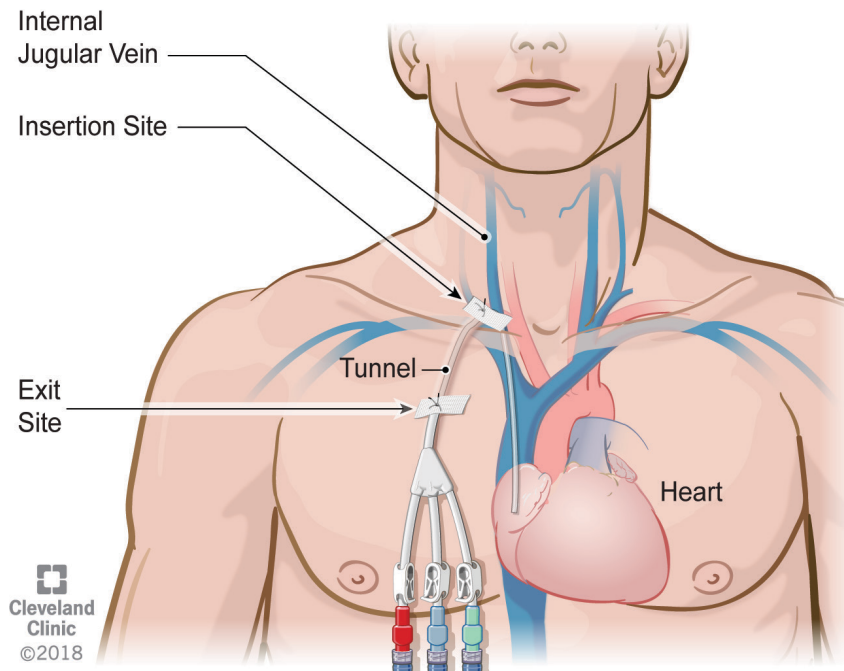
Your Central Venous Catheter

A **central venous catheter** is a slender, hollow, flexible tube (catheter) that is placed in your upper chest and goes into a large vein above your heart. **Hickman** and **Trifusion** are two types of central venous catheters. A central venous catheter has one central catheter that enters your body. On the outside of your body, the catheter divides into two or three lumens (the hollow opening of the tubings). Each lumen has a clamp and injection cap.

Why do I need to have a central venous catheter and what is it used for?

Central venous catheters have many uses. These include:

- To safely receive IV fluids, chemotherapy, blood products, and other medicines with less chance of irritation to your smaller veins
- To receive your stem cell or bone marrow infusion (transplant)
- To draw blood for blood work (labs)
- To collect stem cells during apheresis for patients receiving autologous stem cell transplant



What are the advantages to having a central venous catheter during transplant?

Advantages include:

- The catheter stays in longer than a regular IV line.
- You won't need to have as many needle sticks.
- You will be able to receive more than one medication or IV at a time because the catheter has two or three lumens.

If you have a port, the port will stay in place and can be used after your transplant team feels your central line can be removed.

What do I need to know before my central venous catheter is placed?

- **Ask about your medications.** You may need to stop taking or adjust the dose of some of your medications before your central line catheter is placed.
- **Blood thinners.** If you take medication to thin your blood, notify your BMT nurse or physician. Your dosage may need to be stopped temporarily or changed. Blood thinners are used to treat blood clots, or prevent heart attacks or strokes. Common blood thinners include aspirin, ibuprofen, warfarin (Coumadin), enoxaparin

(Lovenox®), rivaroxaban (Xarelto®), apixaban (Eliquis®), dabigatran (Pradaxa®), clopidogrel (Plavix®). If you are unsure if you are on a blood thinner, contact your BMT nurse.

- **Insulin.** If you take insulin or other medication for diabetes, your dosage may need to change before your procedure. Speak with the doctor that prescribes your diabetes medication about what you do the morning of your procedure.
- **Arrange for a driver.** You must have a responsible adult with you the day of your central line catheter procedure who can drive you home. If this is a problem, discuss with the BMT team as soon as possible.

The day BEFORE your catheter insertion

- Do NOT eat any solid food after midnight the night before your procedure.
- If you are on a blood thinner, hold your medication as instructed by your BMT team. If you are unsure, contact your BMT nurse.

The day of your catheter insertion

- Take your medications as directed with a sip of water.
- You may have clear liquids ONLY up to 2 hours before your scheduled procedure; then nothing to drink.
- You will be checking in about an hour before your actual procedure time. Although the procedure itself is less than an hour, plan on being at Cleveland Clinic for about 3 to 4 hours to allow for your preparation and recovery.
- **You are not being admitted to the hospital for this procedure. This is the just the check in desk for your procedure.**
- You must have a responsible adult with you who can drive you home.

What should I expect during the catheter placement?

- The placement of your central venous catheter is a minor procedure that is done in the interventional radiology department.
- An area on your chest and neck will be numbed with a local medication.
- You will also receive medication so you don't feel discomfort during the procedure.
- You will not receive general anesthesia or be put to sleep for this procedure.

How is the catheter placed?

- Two small incisions will be made, one in the upper chest near the neck and the other on your chest below your collar bone.
- The catheter is inserted through the small incision under your collar bone then tunneled underneath your skin to the incision above the collar bone, where it is inserted into a large vein.

What should I expect after the catheter is placed?

- You will have a small bandage and steri strips or surgical glue over the small incision at the base of your neck.
- You will have a bandage over the small incision below the collar bone where the catheter and lumens exit through your skin. This is also called "the exit site." There will also be a few stitches to help keep the catheter in place.
- You may feel a small bump under your skin where a small cuff is located. This cuff, which is part of the catheter, helps to hold the catheter in place and helps to prevent bacteria from moving up your catheter into your blood stream.

What will the catheter site feel like after it is inserted?

- Your shoulder and chest area may be sore for a few days after your catheter is inserted. You may also have some bruising.
- It helps to move your shoulder and neck right after the procedure to prevent it from getting stiff.
- Before taking any over-the-counter pain medicine, such as acetaminophen (Tylenol®) or ibuprofen (Advil®, Motrin®), speak with your BMT nurse or physician.
- Healing takes place over a few weeks. During this time you may slowly restart your usual activities as long as they do not cause pain.
- While the catheter is healing, avoid any physical work or lifting anything greater than 25 pounds.

If you have any questions, speak with your BMT nurse.

Things to remember the first 24 hours after your catheter is placed

- **If you have questions or problems with your catheter, contact your BMT nurse coordinator before 5:00 pm.**
- **After 5 pm, call 216-444-2200 and ask the operator to page the interventional radiologist on call.**
- If you have heavy bleeding from your catheter site, using clean towels or gauze pads, hold pressure on the site and have someone take you to the nearest emergency room or call 911.
- If you are having extreme pain, shortness of breath, or a temperature above 100.4

degree Fahrenheit, contact your nurse coordinator or the interventional radiologist on call.

- You can take a sponge bath as long as you keep the area at the bottom of your neck and dressing over the exit site dry.

How do I care for my catheter when I am away from the hospital?

- You will need to be able to take care of your catheter when you are at home and away from the hospital.
- Your outpatient BMT nurse coordinator will arrange a time to meet with you and your caregiver the day after your catheter is placed to make sure your catheter is working properly and to review how to take care of your catheter.
- If you are in the hospital when your catheter is placed, the inpatient nurses will arrange a time with you and your caregiver to provide catheter care instructions.
- You and your caregiver will learn to:
 - Clean the catheter exit site and apply a clean dressing every 7 days or sooner if the dressing gets wet or dirty or starts to fall off.
 - Flush each catheter lumen with normal saline daily.
 - Clamp each lumen.
 - Change the injection caps on each lumen weekly.
 - Be able to detect potential problems and learn what to do to prevent or treat them.
- Included in your BMT educational guide are individual instruction sheets on each of the procedures mentioned above so you can

perform your catheter care safely when you are away from the hospital. Your BMT nurse will be reviewing each of the procedures with you.

- The way your BMT outpatient nurse coordinator or inpatient nurse teaches you to care for your catheter at home may be slightly different from the way that your catheter is cared for when you are in the hospital or in the Taussig outpatient treatment area. Catheter care while you are in the hospital or in the Taussig outpatient treatment area follow hospital policy, which is slightly different than the home care policy. Both ways are correct.
 - Example. The use of bio patch, green caps and shower guard are currently not part of home catheter care.
- If you have any questions regarding how to properly take care of your central line catheter, please contact your outpatient BMT nurse coordinator.

Things to remember

- If your central line dressing becomes wet or starts to come off, you must change it.
- Avoid changing your dressing in the bathroom after you have showered because the moisture may prevent the dressing from sticking properly.
- Once you have been told that it is okay to shower, make sure that you cover your dressing with clear plastic wrap like Press N Seal® to keep the dressing dry. If it gets wet, you must change it.
- Do not let your caps or central line catheter become submerged in bath water.
- Never use scissors near your central line catheter.

Index # 4753 | Review Date: 8/8/2019

How to Avoid Problems With Your Central Venous Catheter

Do not expect problems with the central venous catheter, but be prepared if they occur. Read the information contained in this handout carefully so you'll know how to treat a problem or prevent it from happening.

PROBLEM	SIGNS/SYMPTOMS	WHAT TO DO	HOW TO AVOID
Infection	<ul style="list-style-type: none"> • Fever of 100.4°F • Chills • Sweats • Swelling or oozing at the exit site • Foul odor • Pain, warmth, or redness at the exit site or tunnel area • Fatigue; lack of energy • Decreased activity 	<ul style="list-style-type: none"> • Call your healthcare provider for instructions. 	<ul style="list-style-type: none"> • Check your temperature daily. • Wash your hands before any procedure. • Wear a mask during any procedure if you have a cold and when changing the bandage.
Clotting or catheter blockage	<ul style="list-style-type: none"> • Unable to flush catheter using normal pressure 	<ul style="list-style-type: none"> • Do not apply extra pressure. • Call your healthcare provider to assess the blockage. 	<ul style="list-style-type: none"> • Flush the catheter once a day and after every injection using the push pause method.
Broken screw adapter at the end of the catheter	<ul style="list-style-type: none"> • Catheter cap does not fit securely • Saline leaks out during flushing procedure 	<ul style="list-style-type: none"> • Call your healthcare provider for instructions. 	<ul style="list-style-type: none"> • Do not over-twist the catheter cap when changing. • Do not clamp near the catheter adapter.
Skin rash or irritation over the Dacron cuff	<ul style="list-style-type: none"> • Redness and tenderness at exit site without drainage or fever 	<ul style="list-style-type: none"> • Call your healthcare provider for instructions. 	<ul style="list-style-type: none"> • Do not wear constrictive clothing over the bulge of the cuff.

>> *continued*

PROBLEM	SIGNS/SYMPTOMS	WHAT TO DO	HOW TO AVOID
<p>Air embolus. Presence of air in the cardio-vascular system that could result in blocked blood flow. (This can occur if the cap or IV tubing becomes disconnected. It might occur within hours after the catheter has been inserted.)</p>	<ul style="list-style-type: none"> • Shortness of breath or chest pain 	<p>THIS IS AN EMERGENCY</p> <ul style="list-style-type: none"> • Clamp the catheter near the exit site • Call 9-1-1. • Lie on your left side while waiting to be seen by a health care provider 	<ul style="list-style-type: none"> • Never leave the catheter cap off without first clamping the catheter.
<p>Thrombosis. Blockage in the vein in which the catheter has been placed</p>	<ul style="list-style-type: none"> • Difficulty flushing the catheter • Swelling in the arm, shoulder, or neck on the same side of the catheter • Facial swelling • Enlarged vein on the chest or neck that was not noticeable before the catheter was inserted • Excessive tearing or runny nose • Dizziness • Confusion • Throat pain 	<p>THIS IS AN EMERGENCY</p> <ul style="list-style-type: none"> • Do not put any fluid in the catheter. • Call 9-1-1 or have someone take you to the emergency room. 	<ul style="list-style-type: none"> • Flush the catheter once a day and after every procedure. • Drink plenty of fluids to prevent dehydration. • You should never need to use force to flush the catheter.

Additional information

- Notify your doctor if you are to have any dental or surgical procedures since additional antibiotics might be needed prior to your appointment.

PROBLEM	SIGNS/SYMPTOMS	WHAT TO DO	HOW TO AVOID
<p>Catheter dislodgement (This occurs when the tip of the catheter moves from its proper location.)</p>	<ul style="list-style-type: none"> • Pain or discomfort in the neck or shoulder • Swelling in the chest • Exposed cuff 	<ul style="list-style-type: none"> • Call your healthcare provider for instructions (You will need to have an X-ray so your healthcare provider can locate the catheter tip.) • Do not use the catheter until you are told it is okay. 	<ul style="list-style-type: none"> • For longer catheters, loop the catheter and tape it and all of the connections to your chest. • Do not pull on the catheter. • Do not use force when flushing. • Handle the catheter with care.
<p>Blood back-up</p>	<ul style="list-style-type: none"> • Leakage of blood where the catheter cap is improperly connected 	<ul style="list-style-type: none"> • Clamp the catheter near the exit site. • Flush the catheter with saline solution after unclamping it. 	<ul style="list-style-type: none"> • Flush the catheter once a day and after all procedures. • CLOSE THE CLAMP before removing the saline syringe after you flush the catheter. • Leave at least 1cc of saline in the syringe when you flush (don't bottom out the plunger).

DO'S AND DON'TS

Do

- Wash your hands before any procedure.
- Clean and change the site if the dressing becomes soiled, wet, or loose.
- Have everything ready before you start.
- Flush the catheter at least once in 24 hours, unless IV fluid is being administered. Use a new syringe to flush each lumen daily.
- When in doubt about the sterility of a piece of equipment, consider it contaminated and use a new, sterile piece of equipment.

Don't

- Do not exert stress on the end of the catheter.
- Do not bend, pull, or kink the catheter.
- Do not re-use syringes or IV tubing.
- Do not touch the catheter exit site with your fingers.
- Do not leave the catheter end open to the air.
- Do not use scissors near the catheter.

Your catheter should flush easily.

Never force the saline into the catheter!

Injection Cap Change

The injection cap needs to be changed once a week.

1. Gather the following supplies:

- 70% alcohol
- 3 new, sterile injection caps
- Paper towel
- 6 alcohol wipes, 2 per lumen
- Liquid soap
- 3 prefilled saline syringes

2. To begin:

- Using a paper towel and alcohol or antibacterial wipes, clean the work surface.
- Wash your hands for 30 seconds using warm water and soap. Rinse your hands completely, and dry them with a clean paper towel. Turn the water faucet off using a paper towel. (Don't touch the faucet with your clean hands.)

3. Open all supplies.

- Carefully open all supplies without touching the inside surface of the kits or wrappers.
- Place supplies on clean surface.

4. Prepare the saline syringes.

- Examine the 3 prefilled syringes, making sure they contain saline and that they have not expired.
- Remove the cap on the end of the prefilled syringe. Do not touch the open end of the syringe.
- Pull back on the plunger to release the seal. Note: Do not push up on the plunger before breaking the seal. This action may reduce the amount of saline needed for flushing.
- Check the syringe for air bubbles. Tap the syringe so the bubbles rise to the top. While holding the syringe straight up, push up on the plunger to remove any air bubbles.

5. Attach saline filled syringe to the MicroCLAVE[®] Connector Cap by twisting and turning clockwise.

- Slowly push a small amount of saline into cap.
- Gently place the cap with syringe attached back into the cap wrapper.
- Keep the syringe attached during the cap exchange to make handling easier.

- 6. Make sure all lumens are clamped.**
- 7. Pick up one lumen of the catheter.** Using an alcohol wipe, clean the injection cap connection where the cap is connected to the catheter. Rub vigorously for 15 seconds; then let dry completely (about 15 seconds).
- 8. Remove the old injection cap** by turning counterclockwise and throw it away.
- 9. Using the second alcohol pad,** clean the catheter where the cap was connected. Rub vigorously for 15 seconds; then let dry completely (about 15 seconds).
- 10. Pick up the saline syringe that is connected to the new injection cap and remove the protective cover.** Do not touch the sterile area under the protective cover.
- 11. Attach the new injection cap by turning clockwise onto the catheter.**
- 12. Inject the saline into the catheter, using a push-pause method, until about 1 ml or cc of saline is left in the saline syringe.**
- 13. Clamp the catheter.**
- 14. Remove the syringe** by twisting the syringe counterclockwise while holding onto the cap with your non-dominant hand.
- 15. Repeat with the other two lumens.**

Central Venous Catheter Transparent Dressing Change

Changing the dressing helps to prevent infection and allows for routine inspection of the exit site. Change the dressing every 7 days, or sooner if it becomes wet, loosened or soiled.

1. Gather the following supplies (these may be found in a central line dressing change kit or separately)

- Mask
- 1 ChloroPrep® One-Step
- Tegaderm® transparent dressing
- 70% alcohol and paper towels or antibacterial wipes
- Liquid soap and waterless hand sanitizer
- Clean paper towel
- Mirror

2. Prepare your work surface and supplies

- Moisten a paper towel with alcohol, or use antibacterial wipes and clean your work surface.
- Wash your hands for 30 seconds using warm water and liquid soap. Rinse your hands completely, and dry them with a clean paper towel. Turn off the water faucet using a paper towel. (Don't touch the faucet with your clean hands.)

3. Open supplies

- Open the ChloroPrep® swabs and Tegaderm® dressing. Place them on your clean surface. Keep them in the packages.

4. Put mask on now

- If a caregiver is doing the dressing change, they will put the mask on and you will turn your head away from the catheter. (or you can both wear a mask.)

5. Remove the old dressing

- Remove the old dressing by gently loosening the edges. Hold down the catheter with your non-dominant hand. Slowly remove the dressing.

6. Inspect the exit site

- Look carefully at the exit site and the skin around it. If you notice unusual skin coloring, redness, swelling, bleeding, drainage or blistering, finish changing the dressing and call your BMT nurse coordinator.

7. Rewash your hands or you can use a waterless hand sanitizer, such as Purel®, to prevent the transfer of any bacteria from the old bandage to the new dressing.

8. Clean the exit site with ChloroPrep®

- Remove one swab from the ChloroPrep® package.
- Using both sides of the swab, clean the exit site and the skin around it, extending about 4 inches away from the exit site. Apply the ChloroPrep® in an up-and-down and back-and-forth motion for 30 seconds. Avoid rubbing over your catheter tubing. Instead, use half-circle motions to clean around the top and bottom of where your catheter comes out from the skin.
- Allow the ChloroPrep® to air dry for 30 seconds. Do not pat, fan or blow on the area.
- Throw away any leftover ChloroPrep® swabs.

9. Apply the transparent dressing

- Peel the paper backing from the back of the dressing, exposing the adhesive sticky side.
- Center the dressing so the area where the catheter comes through the skin is clearly visible.
- Align the slit on the dressing so the catheter tubing lies in between the slit.
- Smooth edges of dressing under catheter near the slit. Once secure, remove the outer paper border from the dressing.

10. Write date of dressing change on the label. You can use the adhesive strips left on the paper frame to write the date you changed the dressing. This is a reminder of when new dressing change is due.

Things to know:

- To increase the chance of having your transparent dressing last a week, cover it with plastic wrap extending over the shoulder when showering. Shower facing away from the water source to avoid direct contact with spray.
- If dressing becomes loose or wet, change it.
- Your stitches (sutures) will be removed about 4 weeks after your catheter is put in.
- Talk to your nurse if your skin becomes irritated or sensitive. A different type of bandage may be suggested.
- Never use scissors near the catheter.

Daily Catheter Flushing With Prefilled Syringes

It is necessary to flush all lumens (the hollow opening) of your catheter daily. This is done to make sure the lumens stay open and work properly.

1. Gather the following supplies:

- 70% alcohol and paper towels or antibacterial wipes
- Liquid soap
- 3 prefilled saline syringes
- 3 alcohol wipes

2. Prepare your work surface:

- Wipe down your work surface with alcohol and paper towel or antibacterial wipes.
- Wash your hands for 30 seconds using warm water and soap. Rinse your hands completely, and dry them with a clean paper towel. Turn the water faucet off using a paper towel. (Don't touch the faucet with your clean hands.)
- Carefully open all prefilled syringes and alcohol wipes and place on your clean surface.

3. Prepare the saline syringe:

- You will use a separate syringe and alcohol for each lumen.
- To release the small air bubbles in the syringe, point the syringe up and gently tap on the side of the syringe.
- Twist off the cap on the syringe.
- Pull back the black plunger slightly, then push the plunger up to release any air bubbles.
- Make sure nothing touches the end of the syringe after the cap is removed.

4. Clean the catheter cap:

- Pick up one lumen and wipe the end of the cap with an alcohol wipe. Rub vigorously for 15 seconds and allow it to dry for 15 seconds. **Do not touch the cap or blow it dry.**
- Once the catheter cap is cleaned, make sure it doesn't touch your skin or clothing.

5. Inject the saline into the catheter:

- Grasp the cap and firmly push and twist syringe tip into the cap until it feels secure. (clockwise to the right)
- Unclamp the clamp.
- Use the push pause method to flush the lumen.

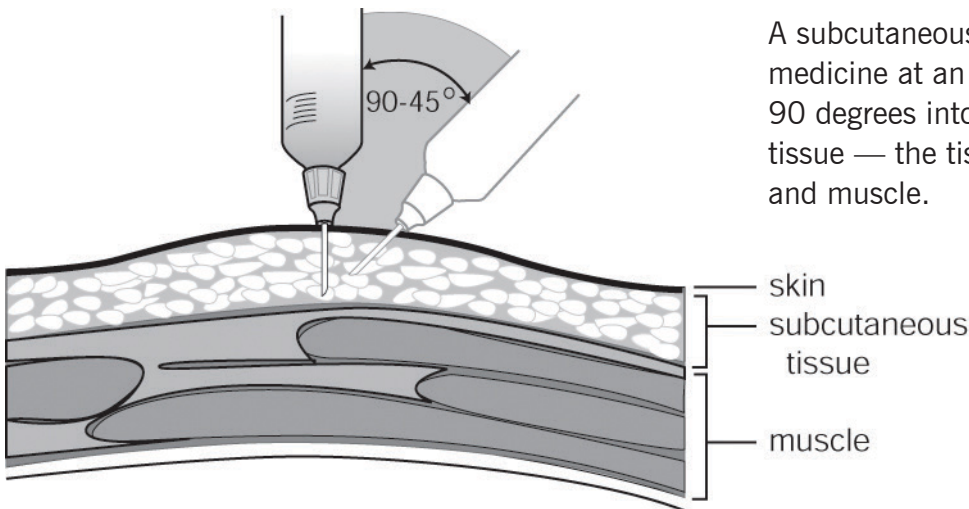
- Push pause method:
 - Inject 1/3 of the saline
 - Pause
 - Repeat
 - Leave a small amount of saline in the syringe
- Close your clamp.
- Remove the syringe while holding on to the cap, untwist the syringe (counter clockwise) and throw it away.
- Repeat steps 3 to 5 for each lumen.

Remember

- You never want to meet resistance as you inject the saline. If you do, check to make sure your clamp is open. If your clamp is already open, and you meet resistance, DO NOT FORCE the saline. Close the clamp. Remove the saline syringe and call your BMT nurse coordinator.
- All clamps should be closed when the catheter is not being used.

How to Give Yourself Subcutaneous Injections

The medicine: _____ has been prescribed for you. An injection is the best way to get this medicine into your body. This handout will teach you how to give yourself a subcutaneous injection.



A subcutaneous injection delivers medicine at an angle between 45 and 90 degrees into the subcutaneous tissue — the tissue between your skin and muscle.

1. Prepare the work area and gather your supplies.

- Select a clean/dry work surface.
- Note: If your medication has been refrigerated, remove from refrigerator about 15 minutes before you plan to give the injections.
- Prefilled syringes: Most patients will require more than 1 syringe to equal the full dose of medication prescribed by your physician. Your BMT nurse will review with you how many prefilled syringes you will need.
- Other supplies to gather:
 - Alcohol pads
 - Bandage
 - Needle box

2. Wash your hands for 30 seconds. Rinse and dry completely with a clean paper towel. Turn faucet off with your paper towel.

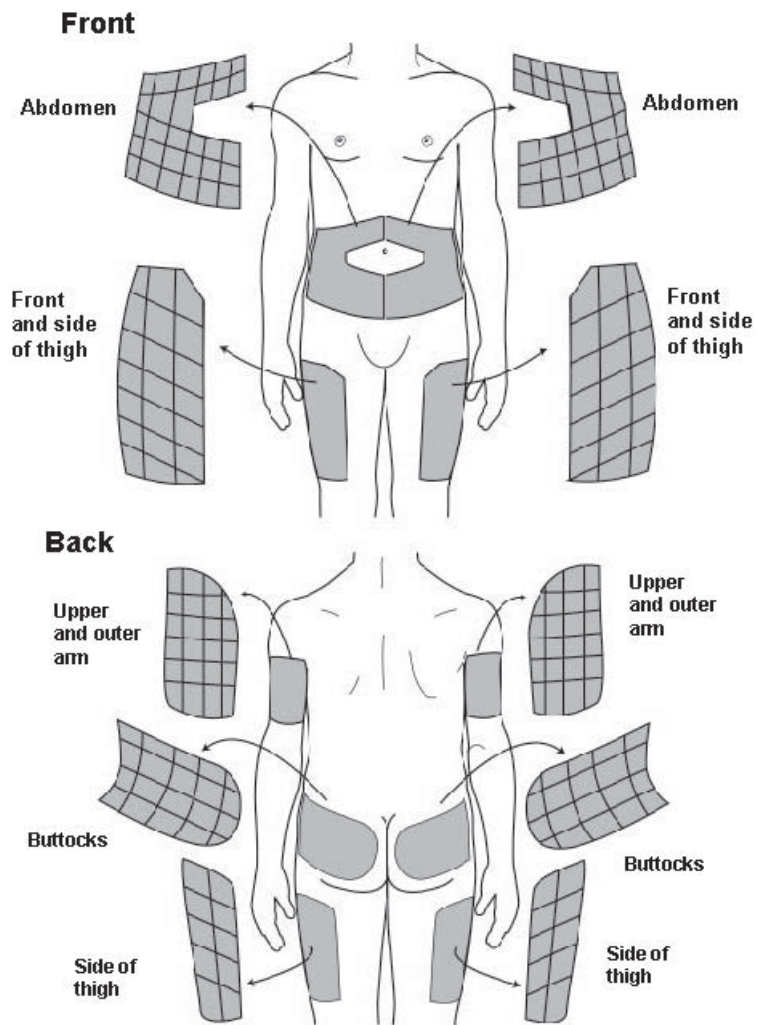
3. Select and clean the injection site.

See the illustration for possible injection sites.

- Do not inject near scar tissue, bruised or tender areas.
- Clean the injection site with an alcoholic pad. Wipe in a circular motion for a few seconds. Keep the alcohol pad nearby; you may need to use it again in step 4.
- Allow the alcohol to dry completely, do not fan or blow on the area.

4. Inject the medication.

- Using the hand that you write with, hold the syringe like a pencil with the needle end facing down.
- Remove the rubber cap on the tip of the syringe.
- With your other hand, pinch an area about 2 to 3 inches on either side of the clean skin that you selected for your injection.
- Still holding the syringe like you would hold a pencil, in a quick motion, insert the needle into your pinched skin at a 45-degree angle. The needle should be pushed all the way into your skin.
- Slowly push the plunger of the syringe until all of the medication is pushed out of the syringe. If you feel discomfort as the medication is being pushed in, slow down the push. This step should take less than 10 seconds.
- Count to 3 and pull the needle out.
- You might notice a small amount of bleeding after the needles are pulled out. If this happens, apply a little pressure with the alcohol pad you set aside.
- Cover the injection site with a bandaid if needed.



5. Dispose of the needle and syringe.

- Do not recap the needle.
- Immediately drop the needle and syringe into the needle box.

Repeat steps 3 thru 5 for your second injection as directed by your BMT nurse.

Rotating your injection sites

It is recommended that you move the site of each injection at least 1 and ½ inches away from the last injection site used to prevent that area from becoming tender or hardened. Your BMT nurse can talk with you about which sites may be the best for you to use.

Filgrastim

Brand name: Neupogen[®], Zarxio[®], Granix[®]

Synonyms: Filgrastim-SNDZ[®], G-CSF[®], Granulocyte-Colony Stimulating Factor[®]

What does it do?

Filgrastim increases the production and activity of different types of cells, such as white blood cells (specifically neutrophils) and stem cells, found in your blood and immune system.

With the increased number of stem cells in your bloodstream, we are able to collect them for use in your autologous transplant or for your donor's cells in your allogeneic transplant. The stem cells are collected in a process called apheresis or stem cell collection during which a cell separation machine is used. Apheresis involves taking blood from your central venous catheter, separating out the stem cells through the apheresis machine, and then returning the remaining blood components back to your body.

White blood cells fight infections. When your white blood cells are low, you have a higher risk for infection. Filgrastim is also given to help your white blood cells recover from chemotherapy and reduce the risk of infection. Your blood counts will be monitored on a regular basis during your filgrastim therapy.

How is it given?

Filgrastim is given by injection under the skin (subcutaneously) using a needle and syringe, or through a vein (intravenously). While you are an outpatient your filgrastim will be given by an injection under the skin.

What are some side effects I might experience?

- Mild to moderate bone pain
- Flu-like symptoms including muscle and joint aches, fever and chills, fatigue, weakness, and headaches
- Fluid retention
- Nausea
- Diarrhea
- Loss of appetite
- In rare instances, spleen enlargement and possible rupture may occur

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have questions about your personal situation.

What are some precautions or recommendations I should know when taking this medicine?

- Do not take aspirin or products containing aspirin unless your doctor prescribes them. These medicines are often referred to as blood-thinning pills.
- If you are experiencing pain, please contact your doctor or nurse coordinator.

Your Filgrastim dose is _____ mcg. You will need to take one injection of _____ mcg and one injection of _____ mcg to equal your total dose of _____ mcg. You will need to give yourself the injection(s) at the same time every day.

When should I call my doctor?

Call your doctor if you:

- Have a fever of 100.4°F (38°C) or higher
- Have a skin rash
- Severe abdominal pain
- Have shortness of breath
- Experience unusual sweating
- Have any other unusual symptoms
- Have any questions or concerns

Index # 9607 | Review Date: 8/8/2019

Plerixafor

Brand name: Mozobil®

Class of drugs: Hematopoietic Progenitor Cell Mobilizer

Why is it prescribed?

Plerixafor is given to you along with filgrastim (Neupogen®) to stimulate the bone marrow to produce more peripheral blood stem cells. The combination of these medications allows the HPCs to flow from the marrow spaces into your peripheral circulation where they can be harvested during apheresis for use in a future transplant. Apheresis involves taking blood from your central venous catheter, separating out the HPCs through the apheresis machine, and then returning the remaining blood components back to your body. The HPCs will be frozen until they are needed after your high-dose chemotherapy. Plerixafor is used in patients with lymphoma and multiple myeloma.

How is it taken?

Plerixafor is given by injection under the skin (subcutaneously) using a needle and syringe. It will be given approximately 15 hours before starting apheresis.

Plerixafor will be given to you in R10, the Chemotherapy Outpatient Department at Taussig Cancer Institute. You will be monitored for possible side effects for 30 minutes after the injection is given.

It is important that you are on time for this appointment. You may return for additional doses of Plerixafor until the desired amount of HPC's are collected. You may need to receive up to three doses of Plerixafor.

Are there special instructions that I should follow while using this drug?

Before your physician prescribes this medicine, tell your healthcare provider if you have ever had any unusual or allergic reactions to any medication. Also tell your healthcare provider if you are allergic to any other substances such as certain foods, preservatives or dyes. If you are allergic to some medicines or foods, plerixafor might not be the right medicine for you.

What are the common side effects of this drug?

- Fatigue, headache, dizziness
- Joint pain
- Insomnia
- Decrease in platelet count. Your labs will be checked daily when your stem cells are being collected.
- Facial tingling. This will resolve on its own without treatment within an hour or so.
- Redness, swelling or itching at injection site, which is usually relieved with Benadryl®.
- Diarrhea, flatulence (gas). Imodium® may be suggested to you by your BMT physician.
- Nausea/vomiting. Your BMT team may discuss anti-nausea medications for you to use.

When should I call my healthcare provider?

Call your health care provider if you:

- Have a temperature of 100.4 °F or higher
- Have a skin reaction
- Have more than five liquid stools (diarrhea) per day
- Have signs of dehydration including weakness, dizziness when standing from a sitting position, decreased urine output, and confusion
- Have dizziness, chest pain, or shortness of breath
- Have any sign of an allergic reaction
- Have numbness or tingling that continues or worsens after your injection
- Have severe abdominal pain (especially in left upper area)
- Experience persistent or severe side effects
- Develop new symptoms after starting this medication
- Have any other symptoms that cause concern
- Have any questions or concerns

Index # 14387 | Review Date: 11/30/2018

3. Preparing for Your Hospital Stay

- › Social Work
- › Preparing for Your Hospital Stay
- › Packing for Your Hospital Stay
- › Care Partner
- › Advance Directives
- › Blood and Marrow Transplant Resources

Introduction to Social Work

You will be assigned a Blood and Marrow Transplant (BMT) social worker who will complete a thorough in-person psychosocial assessment to help identify your needs and concerns, as well as those of your family members and significant others. Many insurance companies require this assessment as part of your pre-transplant evaluation.

What type of training does a social worker have?

BMT social workers have a Masters in Social Work (MSW) degree, which provides theoretical knowledge, clinical expertise, and practical experience with patients and families. In addition, BMT social workers receive specialized training in cancer care. The letters LISW (Licensed Independent Social Workers) after a social worker's name indicates the social worker has received a higher level of specialized training.

This information was adapted in part from the Association of Oncology Social Work (AOSW) Standards of Practice and the National Association of Social Worker (NASW) publication, "The Power of Social Work" (www.socialworkers.org).

Preparing for Your Hospital Stay

Staying in Cleveland

If you are from out of town, you and your loved ones might need temporary housing. Your condition will determine your length of stay in the Cleveland Metropolitan area.

- Allogeneic transplant patients must stay less than a 1-hour drive for a minimum of 100 days after transplant.
- Autologous transplant patients might have to stay less than a 1-hour drive during the pre-transplant phase of treatment. Occasionally, there might be a need to stay locally after discharge from the inpatient unit. Please check with your nurse coordinator.

Some insurance companies provide a travel and lodging benefit that will pay for such expenses. If your insurance company does not offer this benefit, you might choose to stay in a hotel or temporary apartment at your own expense, or ask your social worker to place you on the waiting list for Hope Lodge.

Please see the enclosed visitor travel guide for help in selecting local lodging options. You will need to make arrangements and obtain current rates.

Hospital tour

To arrange a tour of the inpatient Blood and Marrow Transplant Unit (G110), please contact your social worker.

Visitors

Having family and close friends visit can be very helpful. It is a good idea to think ahead about having your family and friends take turns visiting so you are not overwhelmed with company. You might want to ask others to call ahead before coming to see if you feel up to a visit.

It is important that visitors wash their hands before entering the G110 unit and your room. Visitors should not come if they have an infectious illness such as the flu or common cold.

Visiting hours

The Blood and Marrow Transplant Unit (G110) does not enforce strict visiting hours. However, the staff requests that the number of visitors at one time be limited.

Overnight visitation

One adult family member is permitted to stay in the hospital room overnight. A pull-out recliner is available in each room.

Children

Children who are immediate family members (own children, siblings or grandchildren) are permitted to visit in patient rooms. No child under 18 may be left unsupervised or spend the night in the hospital room. Children are not allowed in the communal rooms inside the unit. Your social worker can provide counseling to assist with any emotional concerns your children might experience.

Patient Lounge

The Patient Lounge area has comfortable seating, a television and DVD player, and a computer with Internet access. An exercise room is available for your use on the unit. A nutrition room is available for your use with small lockers to store non-refrigerated food items.

YOUR ROOM

Telephone

A telephone with an individual phone number is provided in all rooms. A daily fee for the telephone will appear on your home telephone account 30 days after you are discharged. Please talk to your social worker if this will be a financial burden for you. Please feel free to notify Admitting if you do not want the phone service. You may use your own cell phone while hospitalized.

Please note: You will not know your telephone number until you have checked into your room.

Television

A television and DVD player are provided in every room on G110. Limited cable, as well as several Cleveland Clinic channels, are free of charge.

What will my address be at Cleveland Clinic?

Your address during your stay at Cleveland Clinic will be:

Your Name

Cleveland Clinic G110

9500 Euclid Ave.

Cleveland, Ohio 44195-5232

Index # 5025 | Review Date: 8/82019

Packing for Your Hospital Stay

Clothing

- Bring loose, comfortable clothing.
- The temperature on the floor may vary, so it's best to bring clothes that can be layered.
- You may want to bring a robe if you wear one.
- Pack sneakers or comfortable walking shoes. For patients receiving total body irradiation, you will need to wear the same shoes for treatments as you wore when you were measured for the radiation therapy.
- Slippers are fine, but also bring hard-soled, closed-toe shoes for walking.
- A family member or friend may use the transplant unit's washer/dryer to do your laundry. Laundry soap is provided.
- Pack a soft, comfortable cap to keep your head warm when hair loss occurs.

Accessories

- Pack eye glasses or contacts if you have corrected vision.

Personal hygiene products

- Face washes, soaps, body washes, lotions, deodorants and makeup are all permitted. Please continue using your usual brands; it is not a good idea to experiment with new products during your hospital stay.

Miscellaneous

- Bring pictures of family, friends, pets or any other comforting scenes.
- Allogeneic BMT patients should bring a blood pressure monitoring device and a digital thermometer to have on hand when discharge planning is reviewed.

- Feel free to bring your own pillow and a blanket/comforter to make you more comfortable, but launder them first.
- Internet access is available for computers and wireless internet is available.
- Pack magazines, puzzles, word searches, books, or anything else that may help pass the time.
- Cell phone use is permitted. Calling cards are helpful for long distance calls if you do not have a cell phone.

Items to leave at home

- Valuable jewelry earrings and rings are not recommended.
- Credit cards, checks or large amounts of cash
- Nail polish and artificial nails should be removed.
- Pets and pet visitation are not allowed.

Things to bring:

Index # 13963 | Review Date: 8/8/2019

Care Partner

What is a care partner?

A **care partner** is a supportive person who helps a blood and marrow transplant (BMT) patient through the BMT process, sharing in the experience. Your care partner might be your spouse, significant other, a family member or trusted friend.

Patients who have a consistent care partner during their hospitalization have been found to have better outcomes.

Although the medical caregivers in the hospital unit will meet your physical needs for care, a care partner helps keep you – as a patient – focused on your goals and grounded in a meaningful relationship beyond the sometimes all-consuming illness experience.

Care partner requirements

While all blood and marrow transplant patients benefit from having a care partner with them during an inpatient hospital stay, care partner requirements vary in the outpatient setting, based on your type of transplant.

Allogeneic and reduced intensity allogeneic transplantation

All patients having an allogeneic BMT must have a care partner stay with them 24-hours a day when they are discharged from the hospital. For reduced intensity allogeneic outpatient patients, your care partner must be with you when you start your daily outpatient treatment. Patients and care partners must stay less than a 1-hour drive of the Cleveland Clinic main campus. Your care partner should be supportive, as well as willing to provide hands-on care such as caring for your central venous catheter, assisting with intravenous medicines and assisting with your nutritional needs.

Autologous transplantation

At certain time frames during your treatment, you may have to stay within a 1-hour drive of Cleveland Clinic. If you are being chemotherapy primed, having a care partner is highly recommended during the outpatient phase of your treatment, prior to your hospital admission. After you are discharged from the inpatient hospital unit, you are typically able to return directly home. However, you might require some temporary assistance at home.

Helpful hints for care partners

Care partners play a critical role in the transplant process. Caring for a transplant patient not only challenges your physical needs but your emotional needs as well.

Here are some tips to help you – the care partner – prepare for this role:

- **Ask the transplant team questions.** Learn as much as you can about your loved one's treatment, medicines, and possible side effects.
- **Plan a network of support before the transplant.** Having a few people lined up that you can rely on will be very helpful. Delegate one or two people to communicate medical progress to others so you don't have to update everyone daily.
- **Be prepared for changes in your loved one's behavior.** Medicines, discomfort and stress can cause your loved one to become depressed or angry. These changes are temporary.
- **Take care of yourself.** Be realistic about your own needs. Get enough sleep, eat properly and take some time for yourself. You can't offer much help if you are exhausted or overwhelmed.

- **Maintain a balance.** Try to maintain a balance between helping your loved one accomplish a task and actually doing the task for him or her. Allow your loved one enough time to complete activities on his or her own.
- **Set attainable goals for you and your loved one.** Do not attempt to do everything. By setting attainable goals, you are setting everyone up for success rather than disappointment.
- **Ask other family members and friends for help.** Often, they want to help but don't want to interfere. While family and friends might not be able to help out at the hospital, let them help with daily errands or chores at home. Your family and friends will appreciate the opportunity to lend a helping hand.
- **Have someone you can talk to.** You are there for your loved one to listen and to offer support, but you also need a support person. Talk openly and honestly with a friend or family member.
- **Consider joining a support group or talking to a social worker.** This might help you address specific concerns you might have about caring for your loved one. Understanding you are not alone and there are others in similar situations will help you cope.
- **Talk to your loved one about making health care decisions.** Although it's not easy to discuss these topics, you should be informed of your loved one's wishes regarding a Living Will and Durable Power of Attorney for Health Care.

Index # 10413 | Review Date: 8/8/2019

Advance Directives

What are advance directives?

Advance directives are legal documents prepared and signed in advance to let your doctor and family members know your wishes concerning medical treatment at the end of life. These documents include a Living Will and/or Durable Power of Attorney for Health Care. Ask your social worker for additional information.

The Living Will

A **Living Will** is a document that allows you to state what kind of medical care you desire to receive or what life-support procedures you would like to have withheld if you become terminally ill and unable to make your wishes known or if you become permanently unconscious.

Durable Power of Attorney for Health Care

When you complete a **Durable Power of Attorney for Health Care** (or whatever similar document is available in your state), you are naming a person to act as your attorney-in-fact to make health care decisions for you if you become unable to make them for yourself.

You may cancel a Durable Power of Attorney at any time and in any manner. However, to avoid confusion, you should notify the relevant people, including your personal doctor and anyone given legal responsibility to act on your behalf.

Index 10415 | Review Date: 8/8/2019

Blood and Marrow Transplant Resources

Getting in touch with community services may be helpful to you and your family. These organizations and programs represent just some of the resources available to you. Individual counseling with a social worker is also available and may be useful in helping you cope with the demands of treatment. Please contact your social worker if you need more assistance.

Cancer & Disease-Specific Organizations

BMT infonet (Blood and Marrow Transplant Information Network) www.bmtinfonet.org

BMT Infonet provides parents, survivors and their loved ones with emotional support and high quality, easy to understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

nbmtLink (National Bone Marrow Transplant Link) <http://www.nbmtlink.org/>

The mission of the National Bone Marrow Transplant Link is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

The Multiple Myeloma Research Foundation www.themmrff.org

Provides information about multiple myeloma. Funds myeloma specific research.

Aplastic Anemia & MDS International Foundation, Inc. www.aamds.org

A patient advocate and support organization providing hope, knowledge and support to patients and families. Offers the expertise of medical experts, scientific researchers, doctors, nurses, counselors, information specialists, government agencies, political advocates and pharmaceutical companies.

LiveStrong Foundation www.livestrong.org

We empower the cancer community to address the unmet needs of cancer survivors. To do so we encourage collaboration, knowledge-sharing and partnership. Then, we develop evidence-based solutions to address both the common and unique problems survivors are facing around the world.

CancerCare www.cancercares.org

CancerCare is a national nonprofit, 501(c)(3) organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved. CancerCare programs – including counseling and support groups, education, financial assistance and practical help – are provided by professional oncology social workers and are completely free of charge.

National Marrow Donor Program (NMDP) www.marrow.org
Also known as Be the Match Registry

This program facilitates marrow and blood stem cell transplants for patients who do not have a matched donor in their family. It is a network of national and foreign donation centers, collection centers, transplant centers and minority recruitment groups.

Lymphoma Research Foundation

www.lymphoma.org

The Lymphoma Research Foundation (LRF) is the nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and health care professionals with critical information on the disease. LRF's mission is to eradicate lymphoma and serve those touched by this disease.

Online & Telephone Communication Resources

Lotsa Helping Hands

www.lotsahelpinghands.com

A simple, immediate way for friends, family, colleagues, and neighbors to assist loved ones in need. It's an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meal delivery, rides, and other tasks necessary for life to run smoothly during a crisis.

Caringbridge

www.caringbridge.org

A website designed to help patients keep in touch with loved ones during treatment. Patients create their own web page free of charge. News about the patient's progress can be posted to keep loved ones informed.

The Bone Marrow Foundation

www.bonemarrow.org

Provides education, resources and financial assistance to individuals undergoing blood and marrow transplantation. 1.800.365.13336 patientservices@bone marrow.org

Fertility

Fertile HOPE

www.fertilehope.org

A national LIVESTRONG initiative dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Children and Family

Kidskonnected.org

www.kidskonnected.org

Kids Konnected provides complimentary counseling, summer camps, bereavement workshops and cancer educational tools for children and teens with a parent with cancer, or who have lost a parent to cancer. Kids Konnected was founded on the premise that when a parent gets cancer, the entire family is affected, especially the children.

Young Adult

Ulman Cancer Fund for Young Adults

www.ulmanfund.org

Provides support programs, education and resources, free of charge, to benefit young adults, their families and friends who are affected by cancer and to promote awareness and prevention of cancer. Also has a national college scholarship program.

Planet Cancer

<http://myplanet.planetcancer.org>

Support cancer patients through all aspects of their journey.

Stupid Cancer

www.stupidcancer.org

Helps to decrease isolation of adolescents and young adults with cancer by providing information on resources, support organizations, scholarships and financial aid, online forums and chat rooms, excursions, camps and retreats, young adult blogosphere, coping literature, advocacy tools and more!

Financial/Insurance

Social Security Administration

www.ssa.gov

If a person is likely to be unable to work for 12 months while undergoing treatment, applying for Social Security Disability is an option.

Ohio Department of Insurance

www.insurance.ohio.gov

Cancer and Careers

www.cancerandcareers.org

A resource for individuals with cancer in the workforce or re-entering the workforce.

Centers for Medicare & Medicaid Services (CMS)

- **Medicare**

www.medicare.gov

1.800.MEDICARE (1.800.633.4227)

Provides helpful information about Medicare, Medicare health plans, prescription drug plans and consumer rights and protections.

- **Medicaid**

Medicaid.ohio.gov

1.800.324.8680

Ohio Medicaid Consumer Hotline can direct you to your local Office of Job & Family Services

A State and Federally funded health care coverage plan providing assistance to certain low-income and medically vulnerable people. Ohioans eligible for Medicaid are entitled to all medically necessary services.

Medicare Rights Center

www.medicarerights.org

The largest independent source of health care information and assistance in the United States for people with Medicare. Services include enrollment projects, telephone hotline services, education department, public policy efforts and media communications.

Medication Assistance

Needy Meds

www.needymeds.org

This site lists pharmaceutical manufacturers who provide drugs free of charge to patients with limited financial resources.

Rx Assist

www.rxassist.org

This provides information about public and private pharmaceutical patient assistance programs, including drug discount cards.

Rx for Ohio

www.rxforohio.org

A website designed to help low-income, uninsured Ohio residents get free or discounted brandname medicines.

Complementary and Alternative Medicine

Health Journeys: The Guided Imagery Resource Center

www.healthjourneys.com

National Center for Complementary and Alternative Medicine (NCCAM)

www.nccam.nih.gov/

The Center for Integrative Medicine at the Cleveland Clinic

www.clevelandclinic.org

216.986.HEAL (4325)

Practitioners that address lifestyle, emotional, spiritual as well as physical needs. Provides educational programs for patients and staff. Works towards improving quality of life by integrating practices that address the needs of the whole person.

Fund-Raising Organizations

National Foundation for Transplants

www.transplants.org

1102 Brookfield - Suite 200, Memphis, TN 38119

1.800.489.3863 or 901.684.1697

Help Hope Live

www.helphopelive.org

Suite 230, 3475 West Chester Pike, Newtown Square, PA 19073

1.800.642.8399 or 610.353.9684

BMT Support Groups

Support groups provide a very useful sharing experience. They offer an environment where you can learn new ways of dealing with your illness. You might want to share approaches you have discovered with others. You will also gain strength in knowing you are not facing hardships alone.

- **Post-Transplant Preparation Group**

This inpatient education group meets on the first Tuesday of the month in the G110 lounge. This group is facilitated by a social worker, nutritionist and nurse coordinator from the Program and provides necessary information to prepare patients and caregivers for care after transplant. Contact Jane Dabney, LISW-S, at 216.445.2483 or 1.800.223.2273 ext. 52483.

Lodging Information

For lodging suggestions, please see the “Visitors Travel Guide to University Circle and Downtown Cleveland.”

Hope Lodge

OhioACS@cancer.org

The American Cancer Society’s Hope Lodge is a unique option for adults who need temporary, no-cost accommodations while receiving outpatient cancer treatment and who live a distance from Cleveland.

The Hope Lodge is located about 1 mile away from Cleveland Clinic. Oncology patients and their adult care-partners can stay here while receiving treatment in Cleveland. Patients must have a care partner stay with them at Hope Lodge. Your social worker can place you on the waiting list for this facility. If you do plan to stay at Hope Lodge, it is recommended that you make back-up lodging arrangements because there is a waiting list, and room availability will not be known until just before your treatment begins.

For additional lodging information, visit Cleveland Clinic’s website at www.clevelandclinic.org, click on “Patients and Visitors” and then “Parking, Lodging & Travel.”

4. The Autologous Blood or Marrow Transplant Process

- › The Autologous Peripheral Blood Stem Cell Transplant Process
- › Sample Calendar for Neupogen & Plerixafor Primed Autologous Transplant
- › Sample Calendar for Chemotherapy Primed Autologous Transplant
- › Common Inpatient Medicines for Autologous Transplant Patients
- › What to Expect During Your Hospital Stay
- › Staying Active During Your Hospital Stay
- › Music Therapy
- › Mouth Care Schedule
- › How to Cope With Side Effects
- › Blood Transfusions
- › Preventing Central-line Associated Bloodstream Infections (CLABSIs) While in the Hospital
- › Neutropenic Precautions For Autologous BMT Patients
- › Thrombocytopenic Precautions for Autologous and Allogeneic Patients

The Autologous Peripheral Blood Stem Cell Transplant Process

Your doctor has determined that an **autologous transplant** is the best treatment for you. An autologous transplant means you will receive your own **peripheral blood stem cells** back after receiving high-dose chemotherapy.

The first step in the autologous transplant process is to collect, preserve, and store (in frozen form) some of your peripheral blood stem cells from your bloodstream (a process called **harvesting**). Your peripheral blood stem cells will be collected and stored before you are admitted to the hospital for your transplant.

After you complete your high-dose chemotherapy regimen in the hospital, your stem cells will be thawed and re-infused into your blood to replace the cells that were destroyed by the high-dose chemotherapy.

Starting the transplant process

You will be assigned a nurse coordinator who will contact you to discuss the transplant process and answer your questions. Your nurse coordinator will schedule your pre-transplant tests (a process called **evaluation**) and will set a tentative calendar for your transplant that outlines your important tests and appointments. You will receive a copy of this calendar in the mail. **Remember, this calendar is tentative and is likely to change.**

Your nurse coordinator may need a letter from your dentist stating your mouth is healthy and free from infection. You will be notified if your insurance requires this letter for transplant approval or if your transplant physician feels that a dental assessment is needed.

Approval

At the end of your **pre-transplant evaluation** and after the test results are complete, your BMT doctor will review the results to confirm that a transplant is the appropriate treatment for you.

Next, your pre-transplant results are submitted to your insurance company for approval. The approval process takes 7 to 10 working days.

Getting started

After the **evaluation** process has been completed and your insurance company has approved your transplant, you will begin the treatment process.

First, a **central venous catheter** will be placed during an outpatient surgical procedure in the Interventional Radiology Department. This type of catheter is referred to as a 'trifusion catheter.' All transplant patients must have a central venous catheter. The catheter is used to draw blood and to infuse your chemotherapy, collect your peripheral blood stem cells, and provide other IV medicines. You can learn more about the catheter in the section entitled "*Your Central Venous Catheter*"

Your nurse will order your catheter supplies and teach you how to care for your catheter. Your central line catheter is usually removed before your hospital discharge.

Preparing for stem cell collection

Before your stem cells can be collected, they need to be “moved” out of your bone marrow and into your bloodstream. This process is called “mobilization.”

There are three methods of mobilization, described below. Your doctor will decide which method is best for you. Depending on the method your physician chooses, you will have 1 to 3 weeks of daily outpatient appointments.

- **Filgrastim priming.** Filgrastim is a colony-stimulating factor, a type of drug that help increase the number of stem cells in your bloodstream (a process called priming). This is given as a subcutaneous injection (into the fat under your skin). If this is your method of priming, you will begin the injections four days before your first stem cell collection. The stem cell collection process will then continue until the targeted number of cells is collected (usually five days).
- **Plerixafor (Mozobil®) and Filgrastim priming.** Plerixafor given with filgrastim helps increase the number of stem cells in the blood stream. Plerixafor is given in our outpatient clinic (CA2) at 5:00 pm the night before stem cell collection begins. Plerixafor is given as a subcutaneous injection. You will also have filgrastim injections that will begin four days before your first stem cell collection.
- **Chemotherapy and Filgrastim priming.** This method involves collecting stem cells after you receive chemotherapy and filgrastim. The number of stem cells circulating in your blood during recovery from chemotherapy might be up to 25 times higher than normal. The specific type of chemotherapy you will receive depends on the type of disease you have. Chemotherapy is typically given over several hours during

an outpatient appointment. Forty eight hours after you receive the chemotherapy infusion, you will begin daily injections of filgrastim until enough stem cells are collected.

Your blood counts will become very low the week after the chemotherapy infusion. You will have daily appointments for about a week in the Taussig Cancer Institute outpatient clinic to monitor your condition. During these appointments, your blood will be drawn daily to evaluate your blood counts. Blood products will be given to replace what is needed. If you show clinical signs of dehydration, you will receive fluids intravenously (IV).

While you are being treated in the outpatient clinic, you will be required to stay within a 1-hour drive of Cleveland Clinic. The social worker can help you with any lodging issues. Also refer to the Lodging Information in the Social Work section.

If you develop a fever of 100.4 degrees F at any time during your outpatient follow-up, you will be admitted to Cleveland Clinic where you will remain until your white blood cell count recovers.

As soon as your white blood cell count recovers, the stem cell collection process will begin. Stem cell collection is usually done about 12 to 20 days after you receive the chemotherapy infusion.

Stem cell collection process

Stem cells are collected in a process called **apheresis** or **stem cell collection**.

Apheresis is an outpatient procedure. If you live within driving distance, you can commute each day. This procedure does not require you to stay within a 1-hour drive of Cleveland Clinic.

During apheresis one lumen of your central venous catheter is hooked up to a 'cell separation' machine. Your blood is filtered through the machine and stem cells needed for your transplant are removed. The rest of your blood is reinfused through another lumen of your central venous catheter.

Each stem cell collection is stored in a separate bag and kept frozen until it is returned to your bloodstream.

The apheresis collection lasts about 4 hours and will take place on 5 separate days, or until enough stem cells have been collected. A minimum number of stem cells must be collected before you can be admitted to the hospital for your transplant. You will be scheduled to arrive at CA2 at 7:30 AM daily to start your apheresis collection.

How will I feel during the apheresis process?

Apheresis is a painless procedure. Changes in blood volume occasionally cause some people to feel dizzy or light-headed. Also, you might feel cold, experience a tingling sensation around your lips or fingers, or might even feel cramps in your legs. Tell your apheresis nurse if you experience any of these symptoms, and he or she will help relieve your discomfort.

Hospital admission and meeting with the Transplant Team

When enough stem cells have been collected, the next step is your admission to Cleveland Clinic for your peripheral stem cell transplant. This usually occurs the week following stem cell collection. Please follow your calendar instructions that will direct you to Desk J1-1, the Admissions Desk.

Once you are admitted to G110 or G111 (both are specialized **oncology** nursing units), you and your family will have time to tour the nursing floor, if you haven't done so already.

You will have the opportunity to ask nurses, physician assistants, and doctors any questions you might have.

You might also meet other members of your transplant team, including the social worker, nutritionist, chaplain, nursing assistants, and unit secretaries.

Please be aware that you usually do not see your nurse coordinator when you are admitted to the hospital. He or she has left your care in the expert hands of the inpatient BMT Team. Usually you do not see your nurse coordinator again until you are preparing for discharge.

Preparative regimen

The first step of your peripheral stem cell transplant is the preparative regimen, also called marrow ablation. Your preparative regimen consists of high-dose chemotherapy, which is used to destroy your own bone marrow and tumor cells.

Your preparative regimen is based on the type and stage of your disease. The preparative regimen you receive might include:

- carmustine (BiCNU®)
- cytarabine ([ara-c], Cytosar-U®)
- cyclophosphamide (Cytoxan®)
- busulfan (Busulfex®, Myleran®)
- etoposide (VP-16, Etopophos®)
- melphalan (Alkeran®)

Other chemotherapy drugs may be used depending on your disease.

Countdown days

The days you will be receiving your preparative regimen are called "countdown days (Day -3, Day -2, Day -1). The days following your stem cell infusion are referred to as Day +1, Day +2, Day +3.

Infusion: Day 0

The day you receive the re-infusion of your stem cells is referred to as “**Day 0.**”

You will receive an anti-anxiety/anti-nausea medicine (Ativan®), an antihistamine medicine (Benadryl®) and Tylenol® about 30 minutes before your stem cells are re-infused. Your stem cells are carefully thawed in the laboratory and brought to your room. The stem cells look similar to a bag of blood.

Your nurse will re-infuse each bag of stem cells through your central venous catheter. Each patient will have a different quantity of stem cells, but it is usually between 3 and 12 ounces. The reinfusion is similar to receiving a blood transfusion. It takes about 1 hour for each bag of stem cells to be infused.

During your infusion, your blood pressure, pulse, and breathing will be monitored.

How will I feel during the infusion?

You may experience a bad taste in your mouth, stomach cramping, nausea, vomiting, fever, chills, or a garlic-like odor.

The preservative, DMSO, which is placed in with your stem cells before they are frozen, causes most of the side effects. The side effects usually don't last longer than the infusion. The garlic-like odor can last for one or two days.

The color of your urine may be red after your stem cell infusion. This is caused by the breakdown of red blood cells that were in the stem cell bag. Your urine should turn back to its normal color within 6 hours. Your Transplant Team will monitor your urine output.

After your infusion

After your infusion, you will be monitored closely.

Your stem cells make their way to your bone marrow immediately after being infused. However, your current blood counts will continue to decrease in the days following your stem cell infusion. This is due to the high dose chemotherapy you received. It takes at least 7 to 10 days for the new stem cells to mature and be released into the bloodstream. This is called engraftment.

The time frame during which your blood counts fall (called **neutropenia**) until they recover is a very critical time. Special precautions, called **neutropenic and thrombocytopenic precautions**, will be used to protect you from infections and bleeding. You can learn more about these precautions later in this section.

You will be monitored for any changes in your condition many times throughout the day. You will receive intravenous **antibiotics, antifungal and antiviral** medicines to protect you from infections.

You will receive **blood and platelet transfusions** when your counts fall too low. Blood tests are taken daily to monitor your kidney and liver function. Other tests, such as a chest x-ray or CT scan, will be done if the Transplant Team feels these tests are needed.

It is important to stay active during this time. A daily walk in the hall or on the treadmill is definitely encouraged.

Blood counts

Your nurse can tell you your **blood counts** on a daily basis. There will be a calendar in your room so you can keep track of your daily blood counts and see the progress. Usually around 12 days after your stem cell infusion, your blood counts will be high enough for you to be safely discharged. You also must meet certain discharge criteria before you are released, including have no fevers, and be able to drink an adequate amount of fluid.

Hospital discharge

Your transplant nurse coordinator will meet with you on the day of your discharge or the day before discharge to review your discharge instructions and will help arrange your follow-up appointments. Please make arrangements for your family to pick you up by noon on the day of your discharge.

Under most circumstances, you will be able to return home when discharged. You will need to get your blood counts checked following your discharge, and have weekly labs locally for the first month. You will need to see your transplant doctor within 2 to 4 days following discharge.

Your transplant nurse coordinator will speak with you by phone at least weekly for the first month and then periodically for the next year.

Post-discharge evaluation

You will need to return to Cleveland Clinic about 1 month after your discharge for a post-transplant evaluation with your Cleveland Clinic transplant doctor. This post-discharge evaluation will include pulmonary function tests and blood work. This post-transplant evaluation is essential to evaluate any side effects you might still be experiencing. After your 1 month follow-up appointment, your local oncologist may resume managing your follow-up care.

Index #10251 | Review Date: 8/8/2019

Sample Calendar for Neupogen & Plerixafor Primed Autologous Transplant

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	Appointment with your Transplant Physician			Central Line Catheter Placement Follow All Instructions	Central Line Teaching with your Transplant Coordinator Neupogen Injection	Neupogen Injection
Neupogen Injection	Neupogen Injection Treatment 4:30 pm Plerixafor	Stem Cell Collection 7:30 am Neupogen Injection Treatment 4:30 pm Plerixafor	Stem Cell Collection 7:30 am Neupogen Injection Treatment 4:30 pm Plerixafor	Stem Cell Collection 7:30 am Neupogen Injection Treatment 4:30 pm Plerixafor	Stem Cell Collection 7:30 am	
		Admit to Hospital Melphalan -2	Day of Rest -1	Stem Cell Infusion 0	+1	+2
+3	+4	+5	+6	+7	+8	+9
+10	+11	+12	+13	+14	+15	+16

SAMPLE

Sample Calendar for Chemotherapy Primed Autologous Transplant

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	Appointment With Your Transplant Physician Central Line Catheter Placement	Central Line Teaching with your Transplant Coordinator Treatment – Chemotherapy		Neupogen Injection	Neupogen Injection Treatment – IV Antibiotic	Neupogen Injection Treatment – IV Antibiotic
Neupogen Injection	Neupogen Injection Lab & Treatment – IV Antibiotic	Neupogen Injection Lab & Treatment – IV Antibiotic	Neupogen Injection Lab & Treatment – IV Antibiotic	Neupogen Injection Lab & Treatment – IV Antibiotic	Neupogen Injection Lab & Treatment – IV Antibiotic	Neupogen Injection Lab & Treatment – IV Antibiotic
Neupogen Injection	Neupogen Injection Stem Cell Collection 7:30 am	Neupogen Injection Stem Cell Collection 7:30 am	Neupogen Injection Stem Cell Collection 7:30 am	Neupogen Injection Stem Cell Collection 7:30 am	Stem Cell Collection 7:30 am	
		Admission to Hospital Busulfan -9	Busulfan -3	Busulfan -7	Busulfan -6	Etoposide -5
Etoposide -4	Cyclophosphamide -3	Cyclophosphamide -2	Day of Rest -1	Stem Cell Infusion 0	+1	+2
+3	+4	+5	+6	+7	+8	+9
+10	+11	+12	+13	+14	+15	+16

SAMPLE

Common Inpatient Medicines for Autologous Transplant Patients

You can refer to this list as your nurse administers new medicines to you while you are in the hospital. Please do not hesitate to talk to your nurse if you have questions about your medicine. Always notify your nurse if you experience any unusual or new symptoms.

- **Acyclovir (Zovirax®)** is used to prevent or treat infections caused by certain viruses. This medicine is started upon admission and given every 12 hours (twice a day) for 6 to 12 months following your auto stem cell transplant. Possible side effects include dizziness, headache, nausea, vomiting, muscle or joint pain.
- **Allopurinol (Aloprim®, Zyloprim®)** is used to control uric acid levels. Uric acid is found inside both normal and cancerous cells. Chemotherapy kills cancer cells and their contents are released into the bloodstream. Kidney problems can occur if uric acid levels get too high. This drug is given once a day. The most common side effect is skin rash.
- **Atenolol (Tenormin®), clonidine (Catapres®), amlodipine (Norvasc®), enalapril (Vasotec®), and metoprolol (Lopressor®, Toprol XL®)** are used to control high blood pressure (hypertension). Possible side effects include dizziness, insomnia, low blood pressure, ringing in the ears, headache, dry mouth, and drowsiness.
- **Lorazepam (Ativan®), aprepitant (Emend®), prochlorperazine (Compazine®), ondansetron (Zofran®), and dexamethasone (Decadron®)** are commonly used to prevent or treat nausea and vomiting related to chemotherapy. These medicines are started upon admission. Possible side effects include dizziness, drowsiness, confusion, increase in heart rate, decrease in blood pressure, dry mouth, and blurred vision.
- **Ciprofloxacin (Cipro®)** is used to prevent or treat bacterial infections. This medicine is started upon admission and is usually given every 12 hours (twice a day). Possible side effects include nausea, vomiting, abdominal pain, diarrhea, rash, headache, and fever.
- **Phenytoin (Dilantin®)** is used to prevent seizures. If busulfan is part of your preparative regimen, you will receive Dilantin® to reduce the risk of seizures associated with this drug.
- **Hydromorphone (Dilaudid®), Morphine, Oxycodone** are used to control pain related to mouth and throat sores, abdominal pain, and headaches. Possible side effects include drowsiness, confusion, dizziness, headache, increase or decrease in heart rate, ringing in ears, blurred vision, nausea, vomiting, urinary retention, rash, and cramps.
- **Electrolytes (Calcium, Magnesium, Phosphorus, Potassium)** are chemical substances in your body that are essential to the normal function of all cells. Certain medicine, diarrhea, and nutritional status deplete your body of its normal levels of electrolytes. You will be given electrolytes to replace what has been lost.
- **Gentamicin (Gentak®), vancomycin (Valcocin®), piperacillin/tazobactam (Zosyn®)** are common antibiotics used to prevent or treat serious bacterial infections. These medicines are usually started when your white blood cell count is low or with your first fever. Possible side effects include nausea, vomiting, rash, diarrhea, hearing loss, and decrease in kidney function.

- **G-CSF, filgrastim (Neupogen®)** is used to stimulate the growth of white blood cells (neutrophils). It is given daily beginning 5 days after your stem cell infusion. Possible side effects include fever, low platelet count, nausea, vomiting, and bone pain.
- **Loperamide (Imodium®), atropine/diphenoxylate (Lomotil®)** are used to prevent and treat diarrhea. Chemotherapy and certain medicines can cause an increase in diarrhea. If you have (significant) diarrhea, a stool sample will be collected to check for a bacteria called *Clostridium difficile* (C-diff). If the bacteria is not present, these medicines will be started and given after each loose stool. Possible side effects include dizziness, drowsiness, lightheadedness, headache, nausea, vomiting, and dry mouth.
- **Furosemide (Lasix®)** is used to rid the body of excess fluid. Your Transplant Team will monitor your weight, fluid retention, and blood pressure, as well as the amount of fluid you take in and put out every day to determine if you need this medicine. Possible side effects include headache; dizziness; decrease in blood pressure; decrease in potassium, magnesium and calcium levels; rash; and decrease in kidney function.
- **Nystatin (Mycostatin®)** is used to help prevent mouth sores and fungal infections in patients receiving chemotherapy and antibiotics. This medicine can be taken in liquid form, which you swish around in your mouth and swallow, or by placing a troche (similar to a lozenge) in your mouth and letting it dissolve. To increase the effectiveness of this medicine, you should not eat or drink anything for 15 minutes after taking it.
- **Esomeprazole (Nexium®), famotidine (Pepcid®), omeprazole (Prilosec®), pantoprazole (Protonix®) and lansoprazole (Prevacid®)** are used to reduce heartburn and nausea by reducing acid production. Possible side effects include headache, dizziness, and constipation
- **Temazepam (Restoril®)** is used to help you sleep, if needed.

What to Expect During Your Hospital Stay

Our goal is to provide you with the best possible care in an atmosphere that is pleasant, educational, and supportive. If there is anything we can do to improve your hospital stay, please do not hesitate to ask.

Daily routine

Your hospital routine starts the day you arrive.

Weight and vital signs

You will be weighed once or twice a day. Your temperature, heart rate, breathing, and blood pressure will be monitored at least every 4 hours around the clock.

Blood draws

Every morning at 4 am, your nurse will take a blood sample from your central line catheter. This sample will be evaluated in the lab. Taking the blood sample at this time ensures your lab test results will be completed in time for your morning visits with the Transplant Team. It might also be necessary to draw blood samples at various other times of the day.

Chest X-ray

All transplant patients will have a chest X-ray when medically indicated. For example, a chest X-ray might be performed if you have a fever to rule out possible infection.

Medicines

During your hospital stay, you will be required to take medicines several times a day. Your nurse will be responsible for giving you your medicine at the prescribed times. Please bring a list of your current medicines when you are admitted. You do not need to bring in medications from home.

Hygiene

Keeping yourself clean is very important to help prevent infection. You are encouraged to bathe every day. Soap and lotion can be provided. However, feel free to bring your own soap and lotion.

Mouth care

Mouth care is a very important daily routine. Keeping your mouth clean helps prevent mouth sores and infection. The day you are admitted to the hospital, your nurse will review mouth care instructions (protocol). Mouth care supplies will be provided. Bring your own very soft/soft bristle toothbrush and fluoride toothpaste.

Transplant Team rounds

Every day your Transplant Team will assess and monitor your health. Keep in mind that the transplant doctor who sees you daily during your hospital stay might be different than your primary transplant doctor. They will communicate about your care and progress.

Index 10435 | Review Date: 8/8/2019

Staying Active During Your Hospital Stay

During your hospital stay, it is extremely important to stay active. The more active you are, the stronger your body will be, and the more prepared you will be to return home. Exercise has numerous benefits, such as strengthening muscles and bones, improving balance and reducing stress. Activity will also help reduce your risk of developing pneumonia.

Below is a list of things that you can do each day to make sure you are staying active.

- Walk in the hallways 4 to 6 times a day
- Sit in a chair for all your meals
- Walk to the bathroom to perform your daily grooming activities
- Use the exercise room on a regular basis
- Read, play games, work on the computer and visit with family and friends

A physical or occupational therapist may be consulted to show you different exercises and ways to stay active during your hospital stay.



Music Therapy

What is music therapy?

Music therapy, conducted by a board-certified music therapist, uses music to improve the physical, mental, emotional, and social well-being of an individual during the treatment of an illness.

How can music therapy benefit me?

Music therapy may help with physical discomfort by decreasing your feelings of pain, nausea, agitation or restlessness. Music therapy may address emotional distress, such as symptoms of depression, anxiety or feelings of isolation. Music therapy may help to fulfill a need for social support by providing opportunities for self-expression, comfort, distraction, and by providing additional support to you and your family members.

What happens in a music therapy session?

The music therapist completes a brief assessment, related to your music preferences and experiences, as well as symptom scales (for pain and nausea), then works with you to develop goals for the session. Music therapy interventions are based on the goals of the session. Following the session, goals will be re-assessed and plans for future sessions may be made.

The most commonly used music therapy interventions include: Music Listening (usually live), Active Music Engagement (instrument playing, singing, humming, etc.), Music-Assisted Relaxation Exercises (breathing, progressive muscle, music and imagery), and Songwriting. However, other music therapy interventions may be tried, depending on the goals of the music therapy session and the interests of the patient and/or family.

Where does a music therapy session take place?

Music therapy sessions take place in your room. You can lie in bed or sit in a chair – whatever is most comfortable for you.

What else do I need to know?

You do not need to have prior musical skills to benefit from music therapy. If you play an instrument regularly, you are encouraged to bring it with you while you are hospitalized. You are also encouraged to bring some of your favorite recorded music. Your family members are welcome to participate in music therapy sessions with you at your discretion.

How do I request music therapy services?

Any staff member, patient, or family member can make a music therapy referral. You can ask any staff member to call or page the music therapist to request music therapy services. We have a dedicated music therapist for our BMT Program because we want to provide the best services available.

Index # 14674 | Review Date: 8/8/2019

Mouth Care Schedule

Some treatment protocols restrict the use of certain mouth rinses. Your inpatient team will review your specific regimen. An example is listed below:

Mouth Care Schedule	
9:00 a.m.	Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin [®] swish and swallow (if prescribed).
1:00 p.m.	Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin [®] swish and swallow (if prescribed).
6:00 p.m.	Rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin [®] swish and swallow (if prescribed).
9:00 p.m.	Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin [®] swish and swallow (if prescribed).

*If you experience mouth discomfort, you will be given a bottle of BMX solution to keep at your bedside. Use 10 cc to swish and swallow every 4 hours as needed to soothe your mouth and throat. (BMX = Benadryl[®] + Maalox[®] + Lidocaine)

How to Cope With Side Effects

There are side effects associated with radiation therapy and high-dose chemotherapy. Some of the most common side effects and ways to relieve them are described in this handout.

Every person's reaction to treatment is unique, and some of these side effects may not affect you, or you may have a side effect not listed here. No one can predict which side effects will affect you or how severe they might be. Please discuss any concerns about your side effects with your health care team.

Following your preparative regimen, there may be days when you feel very sick. Please be sure to tell your nurse, physician assistant, or doctor how you are feeling so he or she can intervene early to try to make you feel better. Only you know how you feel.

Chemotherapy and radiation destroy cancer cells. They also destroy normal cells in the process. These include cells of the protective lining of the mouth and the gastrointestinal

tract. This can cause sores in the mouth and/or throat that are painful. The pain can be mild to severe. The gastrointestinal tract can become irritated, which causes nausea, vomiting and diarrhea. These conditions are not permanent, and you might receive medicines to help relieve your symptoms. As your blood counts begin to recover after your infusion of stem cells, your mouth and throat will begin to heal, and the nausea and vomiting will also improve.

Certain side effects can happen months or years after your transplant. They can be caused by radiation or chemotherapy, and some can be permanent, such as sterility. Secondary malignancies (cancers) have been reported in some patients receiving radiation and certain types of chemotherapy. Ask your doctor for your specific risk. The risk varies depending on your age, menopausal status for women, previous history of radiation, type and doses of chemotherapy, type of transplant and disease.

Discomfort	Recommendations
<p>Dehydration</p> <p>Persistent (ongoing) vomiting and diarrhea cause the body to lose large amounts of water and nutrients. If you are vomiting or having diarrhea more than 3 times a day and you are not drinking enough fluids, you could become dehydrated. Dehydration is the loss of water from body tissues, and it disturbs the balance of essential substances in your body. Dehydration can cause serious complications if it is not treated.</p>	<ul style="list-style-type: none">• When you are in the hospital you will receive intravenous fluids.• When you are an outpatient, please tell your health care provider if you are vomiting persistently or have persistent diarrhea and experience any of these signs of dehydration:<ul style="list-style-type: none">- Dark urine- Small amount of urine- Rapid heart rate- Headaches- Flushed (face/upper chest feels hot or changes color) or dry skin- Coated tongue- Irritability and confusion- Dizziness with position changes

Discomfort	Recommendations
<p>Skin Rash</p> <p>A skin rash or other irritation might occur because of chemotherapy, an allergic reaction to a medicine, or from an infection. Allogeneic transplant patients may also experience skin rashes from graft-versus-host disease. (See section on GvHD for more information.) A skin biopsy, during which a small sample of skin is removed and examined under a microscope, might be required to diagnose your skin rash.</p> <p>Most skin rashes improve but require time for healing.</p>	<ul style="list-style-type: none"> • Gently cleanse the affected area using lukewarm water and mild soap. Do not rub your skin. Pat your skin dry with a soft towel. • Do not scratch or rub the affected area. • Do not apply any ointment, cream, lotion or powder to the affected area unless it has been prescribed. • Do not apply cosmetics, shaving lotions, perfumes or deodorants on the affected area. • Use only an electric razor if you need to shave within the affected area. • Do not wear tight-fitting clothing or clothes made from harsh fabrics such as wool or corduroy. These fabrics can irritate the skin. Instead, choose clothes made from natural fibers such as cotton. • Do not apply medical tape or bandages to the affected area unless you are told to do so by your health care provider. • Do not expose the affected area to extreme heat or cold. Avoid using an electric heating pad, hot water bottle or ice pack. • Do not expose the affected area to direct sunlight. Sun exposure might intensify your skin reaction and lead to severe sunburn. Wear a large-brimmed hat or protective clothing to minimize sun exposure. Choose a sunblock/sunscreen of SPF 30 or higher. Continue to protect yourself from the sun even after your course of treatment has been completed.

Discomfort	Recommendations
<p>Hair Loss</p> <p>Hair follicles are very sensitive to radiation and chemotherapy. Both of these treatments cause hair loss.</p> <p>Hair loss might be temporary or permanent. If your hair loss is temporary, it may start to re-grow hair about 3 to 6 months after your transplant. You may notice that when your hair begins to re-grow, the texture or color is different than before.</p>	<ul style="list-style-type: none"> • This side effect can be very upsetting. Talk to your nurse or social worker about wearing scarves, hats or a wig. • Ask about “The Look Good, Feel Better program,” which is sponsored jointly by the American Cancer Society; the Cosmetic, Toiletry and Fragrance Association; the National Cosmetology Association and the Cleveland Clinic Cancer Center. All participating patients receive a complimentary gift bag of skin care and cosmetic products. • Avoid frequent shampooing. Use a mild shampoo (such as baby shampoo) without any perfumes. • Wash your scalp with warm water. Avoid rubbing and do not scratch. Pat dry with a soft towel. • Avoid excessively combing or brushing your hair. • Avoid using hair spray, oils or creams. • Avoid using heat sources on your hair (including hair dryers, rollers, or curling irons). • Do not perm or color your hair. Ask your health care provider when you can go back to coloring or perming your hair. • Protect your head from the sun, cold, and wind by wearing a head covering (such as a cap, turban, scarf, or hat made of cotton or a cotton blend).

Discomfort	Recommendations
<p>Fatigue</p> <p>Everyone has a different level of energy, so BMT will affect each patient differently. Many patients might require a full year to recover physically and psychologically from their transplant. Even after that, life might not return to the “normal” you had experienced before your transplant. You might find that you need to permanently change your lifestyle to prevent fatigue, avoid infections and cope with the long-term effects of treatment.</p> <p>During your recovery, you will feel fatigued and weak. You will also have a decreased appetite. It will take some time to regain your strength and ability to participate in daily activities. Each person’s recovery varies. You might find that it takes several weeks to many months to resume your daily activities.</p> <p>The time following your transplant is a time of cell recovery and growth of your new marrow and re-growth of cells in your mouth, stomach, intestines, hair and muscles. This growth requires calories and energy, and may explain why you feel more tired than you anticipated.</p>	<ul style="list-style-type: none"> • Evaluate your level of energy. Think of your personal energy stores as a “bank.” Deposits and withdrawals have to be made over the course of the day or the week to balance energy conservation, restoration and expenditure. Keep a diary for 1 week to identify the time of day when you are either most fatigued or have the most energy. Note what you think may be contributing factors. • Be alert to your personal warning signs of fatigue. Fatigue warning signs might include tired eyes, tired legs, whole-body tiredness, stiff shoulders, decreased energy or a lack of energy, inability to concentrate, weakness or malaise, boredom or lack of motivation, sleepiness, increased irritability, nervousness anxiety, or impatience. • Plan ahead, organize and prioritize your daily activities. Change storage of items to reduce trips or reaching. Decide which activities are important to you, and delegate other tasks/activities when needed. Combine activities and simplify details. • Schedule rest. Balance periods of rest and work. Rest before you become fatigued. Frequent, short rests are beneficial. • Pace yourself. A moderate pace is better than rushing through activities. • Exercise daily. Walking is an excellent way for you to regain your strength and stamina. • Eat a well balanced, nutritious diet. • Manage stress. Managing stress can play an important role in combatting fatigue. Adjust your expectations and ask others for support and help.

Discomfort	Recommendations
<p>Fatigue <i>continued</i></p>	<ul style="list-style-type: none"> • Talk to your health care providers. Although fatigue is a common, and often expected, side effect of cancer and its treatments, mention your concerns to your healthcare providers. Fatigue may be a symptom of a different medical problem. Also, there may be ways to control some of the causes of fatigue. Finally, there may be suggestions to help combat your specific cause(s) of fatigue. Be sure to let your doctor or nurse know if you have: <ul style="list-style-type: none"> - Increased shortness of breath with minimal exertion - Uncontrolled pain - Inability to control side effects (such as nausea, vomiting, diarrhea, or loss of appetite) from treatments - Uncontrollable anxiety or nervousness - Ongoing depression

Discomfort	Recommendations
<p>Insomnia (difficulty sleeping)</p> <p>Many patients have trouble sleeping during their hospital stay. You may experience insomnia because of discomfort from nausea, mouth sores or other problems. Changes in your daily routine or stress from your personal concerns might also be factors.</p>	<ul style="list-style-type: none"> • If necessary, you may be given a prescription medicine to help you fall asleep. • Practice relaxation techniques such as mental imagery, deep breathing, reading or listening to calming music. • Make sure you are comfortable. Arrange your pillows so you can maintain a comfortable position. • Avoid napping too much during the day. At the same time, remember to balance activity with rest. • If you feel nervous or anxious, talk to your spouse, partner or a trusted friend. Get your troubles off your mind. Your social worker can meet with you for individualized counseling and is available to meet with you on the BMT unit.

Discomfort	Recommendations
<p>Sexual Side Effects</p> <p>Chemotherapy and radiation therapy can affect your ability to have children (fertility) in the future. Factors that impact sexual desire — such as hormonal changes, excessive fatigue, cancer pain or treatment or changes in a person’s self-image — also might affect a person’s ability to have children after cancer treatment.</p> <p>Some women stop having their menstrual cycles after a blood or marrow transplant and may benefit from hormone replacement therapy to relieve menopausal symptoms. Talk to your doctor about this treatment option.</p> <p>Some men may experience a decreased or absent sperm count after cancer treatment.</p>	<ul style="list-style-type: none"> • Discuss your concerns about fertility and your desire to have children after treatment with your doctor before you begin cancer treatment. • Concerns about being biologically able to have children might be distressing, so it might help to seek counseling with your BMT social worker. • It might help to talk about fertility loss and its impact on you and your partner or future partner. • Even though infertility (the inability to have children) might occur after cancer treatment, it is still possible to get pregnant, so both men and women should use birth control after treatment. If you do wish to start a family after cancer treatment, talk to your health care provider about the timing of a pregnancy after treatment. • Some ways to increase your chances of having children after cancer treatment include: sperm banking and cryopreservation (freezing sperm samples so it can later be used to fertilize a woman’s egg); assisted reproduction techniques such as in vitro fertilization (a procedure in which thousands of sperm are placed in a laboratory dish with an egg); and intracytoplasmic sperm injection (a procedure in which sperm is injected directly into an egg). • Researchers are also looking at new methods of treatment that spare the reproductive system, including hormonal suppression of the reproductive organs, new surgical techniques and tissue transfer.

Discomfort	Recommendations
Sexual Side Effects <i>continued</i>	<ul style="list-style-type: none"> For more information, please refer to the booklet, "Sexuality and Cancer" provided by the American Cancer Society. Also talk to your social worker who can refer you to several agencies or support groups for more information.

Blood Transfusions

What is a blood transfusion?

A blood transfusion is the delivery of whole blood or blood components to replace blood lost through trauma, surgery or disease.

All patients receiving a blood or marrow transplant will receive blood products during their hospital stay.

Blood transfusions at Cleveland Clinic

About one of every three patients hospitalized at Cleveland Clinic will receive a blood transfusion during his or her stay. More than 7,500 Cleveland Clinic patients receive a total of about 120,000 units of blood annually. Experience has shown that transfusion is a very safe procedure.

The possibility of a blood transfusion concerns some patients who worry about contracting AIDS or another infectious disease from the blood. If you require a transfusion during your hospitalization, be assured that the entire transfusion process will be expertly performed to protect your safety and health.

Components of blood products

Donated whole blood is typically divided into four different components, including:

- 1. Red blood cells**, the primary carrier of oxygen
- 2. Platelets**, substances that help form clots to control bleeding
- 3. Plasma**, replaces blood volume and clotting factors
- 4. Clotting factors**, substances in the blood that help it thicken (clot)

You may receive one or all of these different components during your hospital stay.



What are the benefits of blood transfusions?

Red blood cells are usually transfused to a patient to prevent anemia. Anemia is a deficiency of hemoglobin, the primary carrier of oxygen in red blood cells. A substantial loss of hemoglobin in the body can cause injury to vital organs such as the brain and heart.

Platelets, plasma and clotting factors are transfused to prevent bleeding. If a patient lacks platelets or clotting factors, profuse (severe) bleeding could occur during surgery or treatment, causing a loss of red blood cells (which could result in anemia).

Platelets are severely depleted in people with leukemia, aplastic anemia and other blood disorders. These disorders, as well as their treatment, reduce a patient's ability to manufacture platelets. Severe bleeding might result from a lack of platelets, making platelet transfusions necessary.

How safe is the blood supply?

Cleveland blood donors have one of the lowest rates in the country of diseases that can be transmitted through blood. In addition, about 80 percent of the blood comes from people who have donated blood in the past. This is important because these people have established a record of safety with us.

Every unit of blood used for transfusion at Cleveland Clinic has been donated by a healthy individual, and each unit has passed eight different tests for infectious diseases, such as hepatitis (a viral infection of the liver) and AIDS, which attacks the immune system.

Donated blood that tests positive for an infectious disease is discarded, and the donor is never permitted to donate blood again.

Despite the best efforts of modern technology, however, there remains a brief period of time during which a healthy but potentially infectious donor might test negative. This is called the window period. Currently, screening tests used by Cleveland Clinic and other institutions will detect an infection after a window period of several days.

The risk of receiving an infection such as HIV (the virus that causes AIDS) through a transfusion is less than 1 in 500,000. In other words, fewer than 1 in 500,000 transfusions will transmit the HIV virus from a donor to a recipient; similar to the risk of being struck by lightning (1 in 600,000 per year).

Every unit of blood is carefully tested in the laboratory for compatibility with the patient's own blood before it is approved for use. The label on every unit is checked and double-checked at the patient's bedside before it is given.

Where will the blood I receive come from?

Most of the blood used at Cleveland Clinic comes from the American Red Cross. Donors are volunteers who care enough about someone else's medical needs to give a pint of their own blood.

Every donor is screened in detail before each donation. Donors are asked questions about their medical history and their lifestyles (sexual history) before blood is collected. This information is used to identify people who

might be at high risk for a disease that could be transmitted (spread) through their donated blood.

Should I provide my own donors?

This is not advisable for most people. Patients who want to choose their own donors (called directed donors) usually believe this will make blood transfusion safer. It will not. Often, the friends or relatives a patient chooses are first-time donors. Unlike the majority of Red Cross donors, their blood has no proven "track record" of safety.

Most people who learn the facts about the safety of blood transfusion choose to let their doctors select the blood that will be used. Such selections are always based on the best scientific information available. However, if a directed donation program is important to you, discuss it with an American Red Cross representative by calling 1.800.448.3543.

Directed donors must meet the same strict standards that community blood donors meet. Blood from directed donors must pass tests for hepatitis, AIDS, and syphilis, as well as other blood-borne viruses. Each unit must be shown to match the intended recipient's blood type before it will be issued. Processing these tests can take three full working days after the pint is drawn, so arrangements should be made well in advance to avoid unnecessary delays. Any directed units remaining after the intended patient is discharged will be released for general use.

Friends and family members can be encouraged to donate blood products at an American Red Cross donation center.

What are the costs of blood transfusions?

The costs for a normal blood transfusion include the fees for the collection and storage of the blood unit plus fees for the compatibility test. Blood from directed donors is more

expensive because of fees from processing costs. Blood collected from donors who are out of town might include additional shipping fees.

What can I expect during the transfusion?

First, a nurse will check your blood pressure, temperature and pulse. An intravenous line will be started with saline (salt) solution. While this is being completed, the blood or blood products will be retrieved from the Blood Bank.

Red blood cells are kept under 50 degrees Fahrenheit to prevent contamination, so you might feel a cold sensation during a red blood cell transfusion. A nurse will periodically check your blood pressure, pulse and temperature throughout the procedure.

How long will the transfusion take?

Blood typing and matching to your own blood will take approximately 2 hours. Red blood cell transfusions generally take about 3 to 4 hours. Your blood transfusion might be slightly shorter or longer. Platelet transfusions take approximately 1 hour, which includes a half-hour observation period after the platelets have been infused.

How will I feel after the transfusion?

Most patients who receive a blood transfusion feel better within a few days. Once the transfusion has been completed you may return to your normal activities. Benefits from the red blood cell transfusion might not be noticed immediately.

Will I notice any reactions?

Reactions from transfusions happen very rarely. A reaction can occur during, immediately after, or even several hours or days following the transfusion. Your nurse will watch for reactions during the transfusion. If a reaction occurs, the transfusion will be stopped, and pre-medicines might be required for future transfusions.

Tell your health care provider immediately if you have any of the following symptoms during or after your transfusion:

- Fever of 100.4 degrees F (38 degrees C) or higher
- Shivering or chills
- Headache
- Nausea and/or vomiting
- Chest pain
- Back pain
- Shortness of breath
- Itching or hives
- Reddish urine
- Yellowing of the skin (jaundice)

Index 10254 | Review Date: 8/8/2019

Preventing Central Line-Associated Bloodstream Infections (CLABSIs) While in the Hospital

What is a central line?

A “central line” or “central venous catheter” is a slender, hollow, flexible tube (catheter) that is inserted through a large vein, usually in the neck, chest, arm or groin. The catheter is made of silicone that is hypoallergenic and well-tolerated in the body for several years.

Why do I need to have a central line?

Your doctor has chosen this type of catheter so fluids, nutrition solutions, antibiotics, chemotherapy, or blood products can be delivered directly into your bloodstream. This catheter is also used to collect blood samples, if needed.

What is a CLABSI?

A bloodstream infection can occur when bacteria or other germs travel down a “central line” and enter the blood. This is called a central-line associated bloodstream infection (CLABSI). If you develop a CLABSI, you may become ill with fevers and chills or the skin around the catheter may become sore and red.

Why is a CLABSI dangerous?

A CLABSI can cause high fevers and a dangerous drop in blood pressure. The infection can be life-threatening.

Can a CLABSI be treated?

These infections are serious, but often can be successfully treated with antibiotics. The catheter might need to be removed if you develop an infection.

What actions can be taken to prevent CLABSIs?

The doctors and nurses will:

- Clean their hands with soap and water or an alcohol-based hand rub before and after caring for you.

- Clean the catheter or tubing with alcohol for at least 15 seconds before putting anything into it or taking blood out.
- Carefully handle medications and fluids that are given through the catheter.
- Discuss the plan of care for your catheter. The catheter will be removed as soon as it is no longer needed.
- Change the dressing and the caps on the end of the catheter once a week. The dressing will also be changed if it becomes dirty, wet or loose.
- Wear a mask and sterile gloves when changing the dressing.

What can you do to prevent CLABSIs?

- Tell your nurse or doctor if the dressing becomes dirty, wet or loose.
- Remind all caregivers to clean their hands with soap and water or an alcohol-based hand rub before and after caring for you. Some sinks and hand rub dispensers are located outside of patient rooms. It is okay to ask your caregivers if they washed their hands before entering your room.
- Do not let family and friends who visit touch the catheter or tubing.
- Make sure family and friends clean their hands with soap and water or an alcohol-based hand rub before and after visiting you.
- Wash your hands with soap and water or an alcohol-based hand rub before eating and especially after you have gone to the bathroom.

References:

World Health Organization. WHO guidelines on hand hygiene in health care. <http://www.who.int/gpsc/5may/tools/9789241597906/en/>

Centers for Disease Control and Prevention (CDC). Guidelines for the prevention of intravascular catheter related infections. <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5110a1.htm?vm=r>

Tartari E, Weterings V, Gastmeier P, et al. Patient engagement with surgical site infection prevention: An expert panel perspective. *Antimicrob Resist Infect Control* 2017;6:45. 10.1186/s13756-017-0202-3 (New Good article with specific info for patients “what can patient do”)

Index # 15532 | Review Date: 8/8/2019

Neutropenic Precautions For Autologous BMT Patients

1. Ask all visitors to wash their hands before entering your room. (Use proper hand washing technique, which is to lather and rub for at least 20 seconds.)
2. Single room isolation with laminar air flow.
3. Wear a mask when outside G110 or G111 inpatient units.
4. Do not take aspirin or nonsteroidal anti-inflammatory drugs (eg, ibuprofen [Advil[®], Motril[®]], naproxen [Aleve[®]]). These products can mask fevers; an indicator of your health that needs to be watched for and reported.
5. Change your central line catheter dressing once a week.
6. Limit visitors (no more than a few at a time). Visitors with infection, upper respiratory infection, diarrhea, or other signs of sickness, should not visit.
7. Do not use tampons.
8. Do not use suppositories or enemas.
9. Do not use cotton swabs (Q-Tips[®]).
10. No intimate contact (sexual intercourse).
11. Only you should use the bathroom in your room. Visitors can wash their hands in your bathroom but need to use the visitors' bathroom.
12. Only the patient is to occupy the bed.
13. Avoid contact with new animals. If you have pets at home, allow another person to clean up after them. Do not handle pet waste yourself.

Index #10259 | Review Date: 8/8/2019

Thrombocytopenic Precautions For Autologous and Allogeneic Patients

The following are tips:

1. Minimize venipunctures and invasive procedures.
2. Do not take aspirin or other nonsteroidal anti-inflammatory drugs (NSAIDS), such as ibuprofen (Advil, Motrin) or celecoxib (Celebrex). These drugs may increase your risk of bleeding.
3. Do not floss or use toothpicks
4. Do not use straight razors, fingernail or toe clippers. Use a file.
5. Do not use suppositories or enemas.
6. Do not use tampons.
7. Do not blow your nose. Dab your nose if it drips.
8. Do not use cotton swabs (Q-Tips®) in your ears.
9. Do not have intimate contact (sexual intercourse) until your platelet count is greater than 50.

Index #13585 | Review Date: 2019

5. Transplant Medicines

- › Transplant Medicines Overview
- › Acyclovir
- › Antacids
- › Ciprofloxacin
- › Magnesium
- › Nystatin
- › Steroids

Transplant Medicines Overview

The most important step in maintaining your health after your transplant is to take your medicines exactly as prescribed. These drugs help prevent rejection, graft-vs-host disease and infection. You might need to take some of these medicines for the rest of your life.

What should I know about taking my medicines?

Before your doctor prescribes any medicine, he or she will ask you:

- If you are allergic to any medicines
- If you are currently taking any other medicines (including over-the-counter medicines, vitamins and herbal supplements)
- If you have problems taking any medicines

The type of medicines, the dosage, and side effects might be different for each patient.

Your BMT Team will teach you about your medicines and give you information sheets describing each drug and how to take it. You should always know:

- The name of the drugs prescribed and their action (**Please note:** all medicines have two names — the generic or chemical name and the brand name.)
- The dosages, how to take them, and the time of day to take them
- The side effects and how you can treat or prevent them

Your family members are encouraged to learn about your medicines.

Where will I get my prescriptions?

Autologous. Patients will receive written prescriptions at the time of discharge that can be filled at your preferred pharmacy. We also offer bedside delivery of your medicines before you leave the hospital. You will be asked during your stay if you would like to use this service.

Allogeneic. If approved by your prescription plan, most prescriptions are provided by the Taussig Cancer Center Pharmacy. These prescriptions usually include a 1-month supply with refills. When your discharge medications are ready, they will be delivered to your bedside. If you are not able to use the Taussig pharmacy, please send a family member, along with your prescription card, to pick up your medicines. Before you go home, you, your care partner and your nurse must verify the medicine dosages. Please review the information on your prescription labels. This includes the medicine name, dose, instructions on how to take, and remaining refills. You can also use the bedside delivery service.

Prescription refills. Do not wait until you are completely out of medicine before filling your prescriptions.

If there are no remaining refills, notify your nurse coordinator at least 1 week before the medicine will run out.

Mail-order programs. Many prescription benefits plans offer a mail-order program. These are provided to decrease your prescription co-pay.

It is necessary to plan ahead, since initial prescriptions can take up to 3 weeks to receive. Notify your nurse coordinator if you plan to use this benefit.

Will the drugs I'm taking cause any side effects?

Some of the drugs prescribed for you might cause unwanted side effects such as weight gain, acne or excess hair growth. **Despite these side effects, never change the dose or stop taking your medicines without first checking with your doctor.** Many of the side effects can be controlled. Your doctor might adjust your dosage or offer other suggestions for managing the side effects. Keep all appointments with your doctor so your response to the drug can be monitored.

The individual drug information sheets contained in this notebook describe the common side effects of each drug and how to manage them.

Call your health care provider if you become sick and vomit soon after taking your medicine. If you vomit within 30 minutes of taking the medicine, repeat the dose. If you are unable to keep down the second dose, call your healthcare provider. Also call if you have any other symptoms that are persistent (ongoing) or severe.

Does it really matter if I miss a dose?

Yes. It is very important to always follow the instructions for your medicines every day to prevent rejection, graft-vs-host disease or infection.

What if I forget to take my medicines at the scheduled time?

If you miss a dose of your medicine at the scheduled time, don't panic. Take it as soon as you remember. **(However, if it is almost time for your next dose, skip the missed dose and return to your regular medicine schedule.)**

As you begin to feel well, it might be easy to forget to take your medicines, but always remember that your body never stops requiring the transplant medicines. By taking your medicines consistently and following-up with

your doctor routinely, you are assuming the most important job after your transplant.

Dose changes

Your doctor will change the dosage of your medicines from time to time. The dosage might be changed because you are having uncomfortable side effects or because blood test results indicate that a different dosage is needed.

You will receive a medicine dosage record to write down your medicines and dosages. Every time your doctor tells you to change the dose of your medicine, cross out the previous dose and write in the new dose. (Use ink, not pencil, and do not erase previous information so you have a record of your earlier doses). Remember, never change the dosage of your medicine unless your doctor has told you to do it.

Other medicines

Never take other medicines without first talking to your doctor, including over-the-counter drugs (those you can buy without a prescription). Some over-the-counter drugs — including aspirin, ibuprofen (Advil[®], Motrin[®]), naproxen (Aleve[®]), vitamins, cold medicine, antihistamines, antacids, herbs, laxatives, and sleeping pills — may decrease the effectiveness of your transplant medicines and can cause unwanted side effects.

Will any new medicines be available?

Exciting developments in drug research are creating new immunosuppressive medicines. Cleveland Clinic's Bone Marrow Transplant Program participates in new drug studies on a continuous basis. You might be asked to participate in one of these programs after your transplant. All programs are strictly voluntary and have no influence on your transplant status.

General medicine guidelines

Note: these are general guidelines. Be sure to ask your doctor or pharmacist for guidelines specific to your medicine.

- **Keep a list of your medicines and their dosages with you.**
- **Take your medicines exactly as prescribed, at the same time(s) every day.** Do not stop taking or change your medicines or the dosages unless you first talk with your doctor. Even if you feel good, continue to take your medicines. Stopping some medicines suddenly might make your condition worse.
- **Have a routine for taking your medicines.** Consider getting a pill box that is marked with the days of the week. Fill the pill box at the beginning of each week to make it easier for you to remember. If you are taking cyclosporine (Neoral®) keep this medicine in its original packaging.
- **Keep a medicine calendar** and note every time you take a dose. Your prescription label tells you how much to take at each dose, but your doctor might change your dosage periodically, depending on your response to the medicine. On your medicine calendar, you can list any changes in your medicine dosages as prescribed by your doctor.
- If your doctor has discontinued a medicine, **place the discontinued medicine in a separate area away from your current medicines.** Your doctor might re-prescribe this medicine at a later date.
- **Wash your hands** before preparing or taking medicines.
- **Take your time.** Double check the name and dosage of all your medicines before using them.
- **Regularly fill your prescriptions** and ask your pharmacist any questions you have about refilling your prescription. Know your pharmacy phone number, prescription number, medicine name and dose so you can easily call for refills. Try to fill all your prescriptions at the same pharmacy so the pharmacist can monitor for interactions, and provide proper dosing and refills. **If your refill medicine does not look right, ask your pharmacist to verify that you have received the correct prescription.**
- **Do not decrease your medicine dosage** to save money. You must take the full amount to get the full benefits. Talk with your doctor about ways you can reduce the costs of your medicines.
- If you have prescription coverage, **make sure you know the terms of your policy.** Remind your doctor about the type of insurance coverage you have.
- **Do not stop taking a medicine.** Talk to your doctor if you have concerns about a medicine and how it is working.
- Keep medicines **stored in sealed containers.** Store according to the instructions given with the prescription.
- **Check liquid medicines often.** If they have changed color or formed crystals, throw them away and get new ones.
- **When traveling,** keep your medicines with you so you can take them as scheduled. On longer trips, take an extra week's supply of medicines and copies of your prescriptions in case you need to get a refill.
- **Always keep medicines out of the reach of children.**
- **Never give your medicine to others.**

Questions to Ask About Your Medicines

Be sure you know the answers to these questions before you start taking any new medicine:

- What is the name of the medicine?
- Why do I need to take it?
- How often should I take it?
- What time of day should I take it?
- Should I take it on an empty stomach or with meals?
- Where should I store the medicine?
- What should I do if I forget to take a dose?
- How long should I expect to take the medicine?
- How will I know it is working?
- What side effects should I expect?
- Will the medicine interfere with driving, working, or other activities?
- Does the medicine interact with any foods, alcohol, or other medicines (including over-the-counter medicines)?

Index #10422 | Review Date: 8/8/2019

Acyclovir

Brand name: Zovirax®

Class of drugs: Antiviral

Why is acyclovir prescribed?

Acyclovir is used to prevent infections caused by viruses, especially the herpes virus. Herpes virus infections can affect the skin, brain, genitals (sex organs), lips, and mouth (“cold sores” or ulcers). Although acyclovir will not cure herpes, it will help relieve the pain and discomfort faster, and will help the sores (if any) heal faster. Acyclovir is also used to suppress the virus that causes chickenpox and shingles.

Allogeneic transplant patients might develop these viruses due to the large amount of immunosuppressive drugs they must take to prevent graft-versus-host disease (GvHD).

Autologous transplant patients remain on acyclovir prophylaxis for 6 to 12 months following transplant. They are given a prescription for a 6 to 12-month supply when they are discharged from the hospital.

How is acyclovir taken?

Acyclovir is generally taken in the form of tablets, capsules, or suspension liquid (with small particles in it). It can be given intravenously in the hospital, if necessary.

In order to suppress the infection, acyclovir is generally taken twice a day. It might be prescribed to be taken more frequently if you develop an active viral infection.

Your prescription label tells you how much to take at each dose and how often to take it. Follow these instructions carefully and ask your pharmacist or doctor to explain anything you do not understand. It is important that you take this medicine regularly as prescribed. Do not stop taking it without talking to your doctor.

What special instructions should I follow while using this drug?

- Take acyclovir for the entire time it is prescribed for you.
- Take this medicine with or without food. Take it with food if it upsets your stomach.
- Be sure you always have enough medicine on hand. Check your supply before holidays or other occasions when you might be unable to fill your prescription.
- Shake the liquid well before use. Measure the correct amount using a specially marked measuring spoon.

What should I do if I forget to take a dose?

If you forget to take a dose, take it as soon as you remember. However, if it is almost time for your next dose, skip the missed dose and continue your regular dosing schedule. Do not take a double dose.

What storage conditions are necessary for this drug?

- Store capsules, tablets, and liquid at room temperature.
- Do NOT store this medicine in direct sunlight or in the bathroom, near the kitchen sink, or in other damp places. Heat or moisture might cause it to break down.
- Keep this medicine in a tightly sealed container.
- Keep this and other medicines out of the reach of children.

What are the common side effects of this drug?

Acyclovir might result in any of the following side effects:

- Tiredness
- Lightheadedness
- Headache
- Nausea or vomiting
- Diarrhea
- Abdominal pain
- Skin reactions

When should I call my healthcare provider?

Call your health care provider **right away** if you:

- Develop a skin reaction
- Experience persistent or severe side effects
- Develop new symptoms after starting this medicine
- Have any other symptoms that cause concern
- Have any questions or concerns

Index # 10242 | Review Date:8/8/2019

Antacids

Common generic and brand names:

These medicines can be divided into three groups. All are used to prevent ulcers and reduce the acid in your stomach.

1. Antacids. Maalox[®], Mylanta[®], Tums[®]
2. Acid blockers (“Proton pump inhibitors”). Omeprazole (Prilosec[®]), lansoprazole (Prevacid[®]), esomeprazole (Nexium[®]), pantoprazole (Protonix[®]), rabeprazole (AcipHex[®]), dexlansoprazole (Dexilant[®])
3. Acid blockers (“H2 antagonists”). Famotidine (Pepcid[®]), cimetidine (Tagamet[®]), nizatidine (Axid[®]), ranitidine (Zantac[®])

Why are antacids prescribed?

Antacids are used to treat and prevent the recurrence of ulcers and other conditions where the stomach produces too much acid. Antacids work by decreasing the amount of acid produced in the stomach. Histamine (H2) receptor blockers are a type of commonly prescribed antacid that prevents the release of acid into the stomach. If you are taking steroids such as prednisone, dexamethasone, or methylprednisolone, your doctor may prescribe a daily antacid or H2 blocker to prevent indigestion.

How and when should antacids be used?

Many insurance companies cover only selected acid blockers. Discuss this with your BMT Team to ensure that the proper substitution is made, if necessary.

Prilosec[®], Prevacid[®], and Nexium[®] are available as delayed-release capsules and should be taken on an empty stomach at bedtime (at least 2 hours after meals).

Pepcid[®] is available as an intravenous solution (delivered into your vein in the hospital only),

tablets, chewable tablets, and suspension liquid (with small particles in it). Shake the liquid form before each use. Measure the liquid form with a specially marked measuring spoon to measure each dose accurately. Pepcid[®] can be taken with food.

If you have difficulty swallowing capsules, you can open Prevacid[®] or Nexium[®] capsules and sprinkle the contents on food or in a drink. However, do not chew or crush the contents inside the capsule. Do not open or chew Prilosec[®] capsules. Swallow them whole with a full glass of water. Antacids are usually taken once a day at bedtime or twice a day in the morning and at bedtime.

Your prescription label tells you how much to take at each dose. Follow these instructions carefully, and ask your doctor or pharmacist to explain anything you do not understand. Do not stop taking the medicine without consulting your doctor. Ask your pharmacist any questions you have about refilling your prescription.

What special instructions should I follow while using this drug?

- Keep all appointments with your doctor so your response to the drug can be monitored.
- Pepcid[®] might cause dizziness. Do not drive, operate machinery, or participate in any potentially dangerous activity until you know how the medicine affects you.
- Do not smoke. Cigarette smoking can decrease the effectiveness of antacids. Ask your doctor for advice on how to quit smoking.
- If you are also taking itraconazole (Sporanox[®]), take your antacid medicine at least 2 hours **after** taking the itraconazole dose or as directed.

- Carbonated beverages might cause further stomach irritation. You might want to avoid carbonated beverages while taking antacids.
- If you are also taking ciprofloxin, take your ciprofloxin two hours before or six hours after your antacid.

What are the common side effects? What can I do about them?

Although side effects are not common when antacids are taken properly, they can occur.

Some side effects might include:

- Headache
- Dizziness
- Diarrhea or constipation

Call your healthcare provider if these symptoms are persistent or severe.

What should I do if I forget to take a dose?

Take the missed dose as soon as you remember. If you miss two or more doses of antacids in a row, contact your healthcare provider for advice.

What storage conditions are necessary for this drug?

- Keep antacids in a tightly sealed container.
- Store tablets at room temperature, away from direct sunlight.
- Store liquid antacids in the refrigerator, but do not allow it to freeze. Discard liquid that is older than 30 days.
- Keep antacids out of the reach of children.

When should I call my healthcare provider?

Call your healthcare provider right away if you:

- Develop a skin rash or skin irritation
- Have any other symptoms that cause concern

Index #10424 | Review Date: 8/8/2019

Ciprofloxacin

Brand name: Cipro®

How is ciprofloxacin prescribed?

Ciprofloxacin is mainly used to prevent or treat bacterial infections caused by gram-negative organisms. These infections include urinary tract infections; acute sinusitis; and lower respiratory tract, skin, bone, and joint infections.

Allogeneic transplant patients might develop infections because the chemotherapy or the immunosuppressive medicines they must take to prevent graft-versus-host disease keep their immune system from functioning as it normally would.

Autologous patients who receive chemotherapy before the collection of stem cells will be on ciprofloxacin when their blood counts are low.

How is ciprofloxacin taken?

Ciprofloxacin is generally taken in the form of tablets in 250 mg, 500 mg and 750 mg doses. In the hospital, this medicine can be given intravenously. A liquid form is available if you have difficulty swallowing tablets.

It is usually taken twice a day. This medicine works best when there is a constant amount of it in the bloodstream. Ciprofloxacin must be taken for the entire length of treatment to achieve the best results. It is important that you take this medicine regularly as prescribed. Do not stop taking it without talking to your doctor first.

The dose of this medicine will be different for each patient. The prescription label tells you how much to take at each dose and how often to take it. Follow these instructions carefully, and ask your pharmacist or doctor to explain anything you do not understand.

What special instructions should I follow while using this drug?

- **Take this medicine with a full glass of water.**
- Limit caffeine while taking this medicine. Its use might cause nervousness, shakiness, and fast heartbeat.
- BEFORE your doctor prescribes this medicine, tell him or her if you have ever had any unusual or allergic reactions to quinolone medicines such as Levaquin®, Tequin®, and Avelox®.
- If you are taking medicines called anticoagulants, such as warfarin (Coumadin®), to prevent blood clots, it is important to tell your doctor. Ciprofloxacin can increase the effect of the anticoagulant, so it might be necessary to have blood tests more frequently.
- Because of absorption, it is important to take your dose of ciprofloxacin at least 2 hours before or 6 hours after dairy products or taking antacid, calcium, magnesium, zinc, or iron.
- Keep taking ciprofloxacin for the full time of your treatment.
- Be sure you always have enough medicine on hand. Check your supply before holidays or other occasions when you might be unable to fill your prescription.
- This medicine might make your skin more sensitive to sunlight. Use a sunscreen when you are outdoors. Avoid sunlamps and tanning beds, and wear protective clothing.

What should I do if I forget to take a dose?

If you forget to take a dose, take it as soon as you remember. However, if it is almost time for your next dose, skip the missed dose and continue your regular dosing schedule. Do not take a double dose.

What storage conditions are necessary for this drug?

- Store the tablets at room temperature.
- The liquid can be stored at room temperature or in the refrigerator.
- DO NOT store the tablets in direct sunlight or in the bathroom, near the kitchen sink, or in other damp places. Heat or moisture might cause them to break down.
- Keep this medicine in a tightly sealed container.
- Keep this and other medicines out of the reach of children.

What are the common side effects?

Ciprofloxacin might cause any of the following side effects:

- Headache
- Restlessness
- Diarrhea. If you have diarrhea, drink more fluids to replace fluid lost in your stool and to prevent dehydration. You can become dehydrated quickly. Signs of dehydration might include weakness, dizziness when standing from a sitting position, decreased urine output, and confusion. If any of these symptoms occur, tell your nurse coordinator. Also tell your nurse coordinator if you have more than 5 liquid stools daily.

- Nausea and/or vomiting. Tell your nurse coordinator if your symptoms persist.
- Skin rash. Tell your nurse coordinator as soon as you notice a rash. If it is severe, and you also have breathing problems, call 9-1-1. This might be a sign of an allergic reaction.

When should I call my healthcare provider?

Call your healthcare provider right away if you:

- Have tightness in the chest or trouble breathing
- Have vaginal itching
- Have a “furry” or white coating on your tongue.
- Have a skin rash or itching
- Have more than 5 liquid stools (diarrhea) per day
- Have signs of dehydration including weakness, dizziness when standing from a sitting position, decreased urine output, and confusion
- Experience persistent or severe side effects
- Develop new symptoms after starting this medicine
- Have any other symptoms that cause concern
- Have any questions or concerns

Index #10992 | Review Date:8/8/2019

Magnesium

Generic and brand names:

Magnesium is available as many different forms. Common names include:

Magnesium L-lactate (Mag-Tab[®] SR)

Magnesium Oxide (Mag-Ox[®] 400)

Magnesium Gluconate (Magonate[®], Magtrate[®], Mag[®]-G)

Magnesium Chloride (Chloromag[®], Mag Delay, Slow-Mag[®])

Why is magnesium prescribed?

Magnesium is a necessary mineral used by your body to promote proper growth and good health. Magnesium supplements are often prescribed to BMT patients when the magnesium levels in the blood are lower than normal. Certain medications that are necessary for BMT can cause low magnesium levels.

How is magnesium taken?

Magnesium is most commonly taken in the form of tablets and capsules. In the hospital, magnesium can also be given intravenously.

The dose of the medication is different for every patient. It is most commonly given two or three times per day.

The prescription label tells you how much to take at each dose. Follow these instructions carefully and ask your doctor or pharmacist to explain anything you do not understand. Do not stop taking the medicine without consulting your doctor. Ask your pharmacist any questions you have about refilling your prescription.

What special instructions should I follow while using this drug?

- Magnesium can affect the absorption of certain antibiotics such as ciprofloxacin (Cipro[®]), levofloxacin (Levaquin[®]), and moxifloxacin (Avelox[®]). It is important to take these antibiotics at least 2 hours before or 6 hours after magnesium.
- Magnesium should be taken with food to reduce stomach upset.
- Certain magnesium tablets and capsules cannot be split, crushed, chewed, or opened. Check with your pharmacist or doctor if you are having difficulty swallowing the tablets or capsules whole.
- Be sure you always have enough medicine on hand. Check your supply before holidays or other occasions when you might be unable to fill your prescription.
- Keep all appointments with your doctor and the laboratory so your response to the drug can be monitored.

What should I do if I forget to take a dose?

If you forget to take a dose, take it as soon as you remember. However, if it is almost time for your next dose, skip the missed dose and continue your regular dosing schedule. Do not take a double dose.

How should I store this medicine?

- Store magnesium tablets or capsules at room temperature, away from direct sunlight.
- Keep magnesium out of the reach of children.
- Do not use this medication after expiration on packaging.

What are some possible side effects of this medicine?

- Diarrhea
- Upset stomach

When should I call my healthcare provider?

Call your healthcare provider if you:

- Have more than 5 liquid stools (diarrhea) per day.
- Have signs of dehydration including weakness, dizziness when standing from a sitting position, decreased urine output, and confusion.
- Have any other symptoms that cause concern.

Index #14680 | Review Date: 8/8/2019

Nystatin

Brand names: Mycostatin®

Why is nystatin prescribed?

Nystatin is used to prevent or treat fungus infections. These infections are caused by a fungus called Candida. Candida can affect many parts of the body, including the mouth, throat, esophagus, and stomach.

Transplant patients might develop infections because their immune system is suppressed by either chemotherapy or by the immunosuppressant medicines they must take to prevent graft-versus-host disease (for allogeneic patients).

How is nystatin taken?

Nystatin is generally taken in a liquid form. There is also a troche (lozenge) form available. It is usually taken four times a day after meals and at bedtime.

The dose of this medicine will be different for each patient. Your prescription label tells you how much to take at each dose and how often to take the medicine. Follow these instructions carefully, and ask your pharmacist or doctor to explain anything you do not understand.

What special instructions should I follow while using this drug?

- If you wear dentures, remove them before using this medicine. Make sure to wash the dentures carefully to prevent your mouth from getting the infection again.
- Shake this medicine well before using.

- Swish nystatin around in your mouth and hold it there as long as possible (several minutes) before swallowing.
- If you are using troches, it is important to hold the troche in your mouth until it has completely dissolved.
- Do not eat or drink anything for at least 15 minutes after using this medicine.
- If you are having difficulty swallowing for any reason, please tell your doctor.

What should I do if I forget to take a dose?

If you forget to take a dose, take it as soon as you remember. However, if it is almost time for your next dose, skip the missed dose and continue your regular dosing schedule. Do not take a double dose.

What storage conditions are necessary for this drug?

- Store the liquid and the troches at room temperature.
- Do not store the troches or liquid in direct sunlight or in the bathroom, near the kitchen sink, or in other damp places. Heat and moisture might cause them to break down.
- Keep this medicine in a tightly sealed container.
- Keep this and other medicines out of the reach of children.

What are the common side effects of this drug?

Nystatin might cause any of the following side effects:

- Diarrhea. If you have diarrhea, drink more fluids to replace the fluid lost in your stool and to prevent dehydration. You can become dehydrated quickly. Signs of dehydration might include weakness, dizziness when standing from a sitting position, decreased urine output, and confusion. Tell your nurse coordinator if you are having more than 5 liquid stools daily.
- Nausea and/or vomiting. Tell your nurse coordinator if your symptoms persist.
- Stomach pain
- Rash

When should I call my healthcare provider?

Call your healthcare provider if you:

- Have a skin reaction
- Have more than 5 liquid stools (diarrhea) per day
- Have signs of dehydration, including weakness, dizziness when standing from a sitting position, decreased urine output, and confusion
- Experience persistent or severe side effects
- Develop new symptoms after starting this medicine
- Have any other symptoms that cause concern
- Have any questions or concerns

Index #5654 | Review Date: 8/8/2019

Steroids

Generic names: Prednisone, Methylprednisolone, Dexamethasone

Brand names: Deltasone[®], Meticorten[®], Orasone[®], Prednicen-M[®], Prednisone Intensol[®], Solu-Cortef[®], Solu-Medrol[®], Sterapred DS[®]

Why are these drugs prescribed?

Classified as corticosteroids or steroid hormones, prednisone and methylprednisolone are similar to the steroid hormone your body produces naturally. Steroids might be given along with other immunosuppressive medicines to prevent or treat graft-versus-host disease (GvHD).

How are steroids taken?

Prednisone is available in many generic brands and in several dosages. Generally, you will be prescribed the pill form of prednisone. Methylprednisolone is given by infusion (IV) in the hospital.

These drugs work best when there is a constant amount of it in the bloodstream. Steroids must be taken for the entire length of treatment to achieve the best results. It is important you take this medicine regularly as prescribed. **Do not stop taking your steroids.**

The dose of these drugs will be different for each patient. Your prescription label tells you how much to take at each dose and how often to take it. Follow these instructions carefully and ask your pharmacist or doctor to explain anything you do not understand.

Once prescribed prednisone/methylprednisolone, your doctor will gradually decrease the dosage over a period of time. This is called a taper schedule. Taper schedules are individualized to meet each person's special needs. Never change the dose of your prednisone/methylprednisolone without the advice of your doctor.

What special instructions should I follow while using these drugs?

- Take prednisone early in the day to prevent insomnia (difficulty sleeping).
- Take this medicine with food.
- You **MUST** take all of the prescribed amount of prednisone/methylprednisolone to maintain enough immunosuppression to prevent/treat GvHD. Follow your dosage schedule carefully.
- For prednisone. Be sure you always have enough medicine on hand. Check your supply before holidays or other occasions when you might be unable to fill your prescription.
- Keep all appointments with your doctor and the laboratory so your response to the drug can be monitored.
- Do not have any immunizations or vaccinations without your doctor's approval.
- Do not drink alcohol while taking this medicine. Alcohol can interfere with the effectiveness of this medicine and cause serious side effects.
- Do not take any new medicines (prescription or non-prescription) without telling your health care provider first. Several drugs might interfere with the effectiveness of prednisone.
- Take precautions to avoid infection while taking this medicine.

What should I do if I forget to take a dose?

DON'T FORGET TO TAKE THIS MEDICINE.

Your body gets used to having this medicine in your system. If you forget to take a dose, take it immediately.

If you have forgotten more than one dose, contact your nurse coordinator for instructions.

What storage conditions are necessary for this drug?

- Store this medicine at room temperature. Do NOT store this medicine in direct heat or light.
- Do NOT store this medicine in the bathroom, near the kitchen sink, or in other damp places. Heat or moisture might cause it to break down.
- Keep this medicine in a tightly sealed container.
- Keep this and other medicines out of the reach of children.

What are the common side effects of this drug?

Even though the side effects of prednisone/methylprednisolone could be serious, remember that this drug is necessary to prevent/treat GvHD. We will take precautions to detect these side effects and treat them before they become harmful.

Prednisone/methylprednisolone might cause dose-related side effects, which will subside as your dosage is reduced. If any of the following symptoms occurs, report them to your health-care provider.

- Increase in blood pressure
- Increased swelling of the face (chipmunk cheeks), hands, or ankles due to sodium (salt) retention
- Dowager's hump (curve in the back of the neck)
- Increased appetite. This might result in weight gain. These medicines alter brain chemicals that can increase hunger and fluid retention.
- "Steroid-induced diabetes." This might result from high doses of these medicines, which may or may not require treatment. If you currently have diabetes, your medicines may need to be adjusted to control your blood glucose.
- Vision changes, cataracts, or glaucoma
- Skin changes including acne, easy bruising, thinning of the skin, stretch marks, and increased sensitivity to the sun
- Excess hair growth on the face, back, arms, and legs
- Mouth sores
- Stomach irritation or ulcers
- Mood swings and depression
- Joint pain and muscle weakness
- Increased risk of infection
- Increased risk of developing osteoporosis
- Insomnia (difficulty sleeping or falling asleep)

Please see the guidelines on the next page for information on what you can do to help treat these symptoms.

What can I do to reduce the side effects of steroid medicines?

To reduce troublesome side effects, your dosage might be decreased as soon as it is safe. In the meantime, there are some daily practices that can help you prevent or decrease the side effects of steroids.

Possible Side Effect	What You Should Do
High blood pressure	This can be caused by increased fluid retention. Take your medicine as prescribed, and reduce the amount of salt and fluid consumed. Also, measure your blood pressure and record it every day. Ask your health care provider what your blood pressure range should be.
Increased appetite	Eat well-balanced, nutritious meals, and visit a dietitian regularly to discuss excess weight gain and ways you can maintain a healthy lifestyle.
Steroid-induced diabetes	If you formerly controlled your pre-existing diabetes without medicine, you might now need to take insulin or pills to control diabetes.
Vision changes, cataracts, glaucoma	Visit an ophthalmologist yearly. Check with your BMT Team before getting a new prescription for glasses.
Acne	Practice good hygiene. Wash your face with an antibacterial soap to control acne and reduce the risk of infection. Avoid soaps with lanolin or cold cream, which tend to clog pores. Acne might be controlled with medicines such as benzoyl peroxide (Clearasil®). Acne subsides when your dosage is lowered.
Easy bruising	Avoid accidental bumps and cuts by taking extra safety precautions before beginning any task.
Increased sensitivity to the sun	Avoid the sun whenever possible. When outdoors, wear a sunblock with an SPF of at least 30. Report any skin changes to your doctor.
Increased swelling of the face, hands, or ankles	Swelling is caused by fluid retention. Swelling will subside in 3 to 4 months if weight is maintained. Monitor your weight and discuss any concerns with your BMT Team.
Mouth sores	Practice good oral hygiene to prevent mouth sores and oral infections. Report any sores to your health care provider. Visit your dentist every 6 months, and notify your transplant doctor before any dental procedures.

Possible Side Effect	What You Should Do
Stomach irritation, ulcers	Take your medicine after meals (with a full stomach) and use antacids (as directed) between meals. Report any stomach problems to your health care provider.
Mood swings	Try relaxation techniques. Your social worker can recommend materials that can help.
Increased risk of infection	Avoid anyone who might have an infection, and report any signs or symptoms of infection to your doctor or nurse. Steroids might mask a fever so it is important to report any signs of infection to your BMT Team.
Joint pain, increased risk of osteoporosis	Avoid gaining excess weight and include low-impact exercises in your daily schedule to avoid a possible need for joint replacement.
Insomnia	Talk to your health care provider about taking steroids in the morning. Avoid napping too much during the day and balance activity with rest.
Excess hair growth	To remove unwanted hair, use safe bleaching techniques or creams. Please contact your BMT Nurse Coordinator before using.

When should I call my healthcare provider?

Call your healthcare provider **right away** if you have any of these warning signs of infection:

- Fever of 100.4oF
- Sweats or chills
- Skin rash
- Pain, tenderness, redness, or swelling
- Wound or cut that won't heal
- Red, warm, or draining sore
- Sore throat, scratchy throat, or pain when swallowing
- Sinus drainage, nasal congestion, headaches, or tenderness along upper cheekbones
- Persistent dry or moist cough that lasts more than 2 days
- White patches in your mouth or on your tongue
- Nausea, vomiting, or diarrhea
- Flu-like symptoms (chills, aches, headache, or fatigue), or generally feeling “lousy”
- Trouble urinating: pain or burning, constant urge, or frequent urination
- Bloody, cloudy, or foul-smelling urine, or black, tarry stools
- Irregular heartbeat or shortness of breath
- Sudden confusion
- Dizziness, light-headedness, or “feeling faint”

Also contact your healthcare provider if you have any other symptoms that cause concern or if you have any questions.

6. After Transplant

- › Contacting the Transplant Team
- › Autologous Transplant Patients and Care Partners: Things to Know Before You are Discharged
- › Follow-Up Appointments For Autologous Transplant Patients
- › Taking Your Temperature (Twice a Day)
- › Taking Your Blood Pressure (Twice a Day)
- › Preventing Infection After Blood and Marrow Transplant
- › Nutrition After Blood and Marrow Transplant
- › Food Safety Guidelines
- › Resuming Sexual Activity
- › Frequent Laboratory Testing
- › Daily Recordkeeping Log
- › Vaccinating Recipients of Hematopoietic Stem Cell Transplants
- › Definition of Terms

Contacting the Team After Transplant

You have just completed an intense period in the hospital for blood or marrow cell transplantation. You are probably excited about being able to leave the hospital because “there’s no place like home.” You might also feel uneasy about leaving the constant support and supervision you’ve had during your hospitalization.

Please remember two things:

1. The Transplant Team would not discharge you unless you were ready to leave the hospital.
2. Support does not stop here. Doctors, nurses, social workers, dietitians, financial counselors and others are available to help you. Our goal is to keep you out of the hospital and free of complications.

Please ask questions

You are the best judge of how you feel. This simple rule is essential after you are discharged: When in doubt, check it out. We are here to help you. Your questions are our concern. Please see the list of phone numbers on the back of this page. You and your support group of family and friends are the most important members of the Transplant Team.

Follow-up appointments

You will be monitored closely in the outpatient setting. You will receive detailed instructions for your follow-up appointments, which are designed to meet your specific needs.

Feel free to ask questions

The BMT Team wants to serve you and care for your unique health needs in the best possible way. Members of the BMT Team are always available. Please feel free to talk to the Team members about any medical or personal questions and concerns. In order to avoid any miscommunications, we will not respond to electronic media communication such as Facebook. Please call or discuss directly with your BMT Team

If you have questions at any time, please call your nurse coordinator:

Sarah Basurto, RN	216.636.7276 or 1.800.223.2273 ext 45839 Pager 216.444.2200, ask for pager #80918
Lisa Chiancone, RN	216.444.4652 or 1.800.223.2273 ext 44652 Pager: 216.444.2200, ask for pager #81453
Jamie Elberson, RN	216.445.3773 or 1.800.223.2273 ext. 53773 Pager: 216.444.2200, ask for pager #24729
Amy Healy, RN	216.445.4231 or 1.800.223.2273 ext. 54231 Pager: 216.444.2200, ask for pager #25619
Brittany Hodgeman, RN	216.445.4360 or 1.800.223.2273 ext. 54360 Pager: 216.444.2200, ask for pager # 22795
Jennifer Kosar, RN	216.442.3345 or 1.800.223.2273 ext 45839 Pager 216.444.2200, ask for pager #24122
Katie Krieger, RN	216.444.9276 or 1.800.223.2273 ext. 49276 Pager: 216.444.2200, ask for pager #81488
Kerry Monreal, RN	216.444.5839 or 1.800.223.2273 ext 45839 Pager 216.444.2200, ask for pager #81478
Jamie Starn, RN	216.445.4942 or 1.800.223.2273 ext. 54942 Pager: 216.444.2200, ask for pager #23199
Karen Willett	216.442.3345 or 1.800.223.2273 ext 45839 Pager 216.444.2200, ask for pager #23667

After Hours or on Weekends:

Call 216.444.2200 and ask for the Hematology/Oncology fellow on call. Note: since you will be directing your questions or concerns to your BMT nurse coordinator or the fellow on call, please do not call the G110 or any other nursing unit. If you are unable to reach the Hematology/Oncology fellow, please page your nurse coordinator.

In an Emergency:

Call 9-1-1 or go to the nearest Emergency Department. If time allows, bring a list of your current medicines and the name and phone number of your BMT doctor or nurse coordinator.

Autologous Transplant Patients and Care Partners: Things to Know Before You are Discharged

- Know how to take your temperature, how often to take it, what is considered a fever, and whom to call when you have one.
- Know and follow the low white blood cell (neutropenic) precautions and restrictions.
- Know and follow the low platelet (thrombocytopenic) precautions and restrictions.
- Know when to call the Transplant Team and whom to call.
- Understand your medicines, why you are taking each medicine, what the dose is, how often to take it, and how to take it.
- Make sure you have all the prescriptions orders for all medicines.
- Know the date of your initial follow up appointment at Taussig Cancer Center.
- Know when to follow up with your BMT doctor.
- Know when you are having follow-up labs drawn and where and how often to have them drawn.
- Understand nutrition after transplant.
- Understand sexuality after transplant.
- Understand adjustments to life after transplant.
- Know when you should see or talk to your nurse coordinator.

If you are being discharged on blood pressure medications:

- Your blood pressure cuff should be checked for accuracy before discharge.
- Know how to use the blood pressure cuff. You should know normal range and who to call if your blood pressure reading is outside the normal range. You should keep a log of all blood pressure readings and bring the log with you to each outpatient appointment.

Index # 13593 | Review Date: 10/10/2018

Follow-Up Appointments For Autologous Transplant Patients

Meeting with your nurse coordinator

Before you are discharged, your nurse coordinator will discuss all your post-transplant needs, including your follow-up appointments.

Your nurse coordinator will contact your local oncologist to update him or her on your hospital stay and to discuss all of your discharge needs. Your test results, lab results, discharge summary, and discharge instructions will be faxed to your local oncologist.

Your insurance company will also be notified of your discharge and follow-up plan.

Where will I go for my follow-up appointments?

Within 2 to 3 days of your discharge, you will have an appointment in the Taussig Cancer Institute. You will see the transplant nurse practitioner or your transplant physician. You will also have blood work drawn. You may need blood products, electrolytes, or IV fluids. A member of the BMT team will speak with you to discuss any symptoms or problems you may be having. They will also review your medications and answer any questions you or your family members may have. The BMT team may decide that additional appointments need to be scheduled at Taussig Cancer Institute depending on how quickly you are recovering.

When you return home, if your primary oncologist is local, he/she may need to see you within a week to check for signs of dehydration or infection. You might need to have blood work drawn weekly, with the results faxed to your BMT coordinator.

If you are taking medications for your blood pressure or you are being discharged on new medications for blood pressure, please have a family member bring in a blood pressure cuff

to G110 a few days before you are discharged. The nurses on G110 will check the accuracy of your blood pressure cuff. You will be asked to check your blood pressure and temperature twice a day.

Nurse coordinator follow-up calls

Your nurse coordinator will initially call you at least once a week to check on your progress during your recovery period. During the phone conversation, your nurse will talk to you about your daily temperature record, fluid intake, appetite, nausea, vomiting, diarrhea, skin changes, lab results, medicines, blood pressure, and energy level.

You are expected to contact your nurse coordinator if there are any changes in your condition (for example, if you have a fever, increased nausea, increased diarrhea, changes in your normal breathing pattern, etc.). Following your one-month appointment at Cleveland Clinic, your nurse will contact you several times during the first year after your transplant to check on your ongoing recovery.

One-month follow-up appointment

One month after your discharge date, you will return to Cleveland Clinic to see your transplant doctor. This appointment is necessary to check on the progress of your transplant recovery and any remaining side effects. Your doctor might repeat breathing tests at this follow-up appointment and several times during the first year after your transplant if needed.

How long is the follow-up appointment?

Your follow-up appointments could last from 2 to 8 hours, depending upon the tests and treatment needed.

What happens during my follow-up appointment?

Blood tests

Blood tests, including a complete blood count and chemistry profile, will be ordered. Additional blood tests might be ordered. Your treatment plan may be changed based on the results of these tests.

Other tests

In addition to blood tests, other tests ordered include:

- **Chest X-rays.** Chest X-rays are taken as needed to detect the development of pneumonia or possible infection in your lungs.
- **Pulmonary function test (PFT).** If needed, this is done to check your lung function and to make sure the chemotherapy medicines have not caused any lung function changes.

Consultation with Infectious Disease doctor

You will meet with an Infectious Disease doctor to discuss reimmunization (vaccination) needs after transplant in accordance with CDC (Center for Disease Control) guidelines.

Consultation with Social Worker

You will meet with your transplant Social Worker for a brief follow-up assessment and to discuss life after transplant.

Consultation with the doctor and nurse

You will meet with your doctor and nurse coordinator to review your test results and your health, address your concerns, and to learn about resources you might need.

Follow-up appointments with your local oncologist

After your one-month follow up appointment at Cleveland Clinic, you will return to the care of your primary oncologist.

Even though you might not be in direct contact with your transplant doctor and nurse coordinator, we are still concerned about you. We are available should you require us in the future. Occasionally, a member of the BMT Team will contact your local oncologist for updates.

Index # 10431 | Review Date: 8/8/2019

Taking Your Temperature (Twice a Day)

Using a thermometer to monitor your temperature can help you manage an illness. A rise in your temperature is usually caused by an illness or infection and is usually one of the first signs of a potential problem.

For autologous transplant patients, you should check your temperature twice a day while you have central line and for 2 weeks after discharge.

For allogeneic transplant patients, you should check your temperature twice a day while you are taking immunosuppressive medicines and while you have a central line.

Normal body temperature

Normal body temperature is about 98.6 degrees Fahrenheit (or 37 degrees Celsius). Your temperature often varies by 1 to 2 degrees Fahrenheit (0.5 to 1 degrees Celsius) throughout the day. Your temperature is usually low in the morning and gradually increases during the day, reaching its high in the late afternoon or evening.

Electronic thermometers

We recommend that you purchase an oral electronic thermometer. Please follow the manufacturer's instructions for recommended use.

CONVERSION CHART

Fahrenheit	Centigrade (Celsius)
104.0	40.0
103.6	39.9
103.6	39.8
103.5	39.7
103.3	39.6
103.1	39.5
102.9	39.4
102.7	39.3
102.6	39.2
102.4	39.1
102.2	39.0
102.0	38.9
101.8	38.8
101.7	38.7
101.5	38.6
101.3	38.5
101.1	38.4
101.0	38.3
100.8	38.2
100.6	38.1
100.4	38.0
100.2	37.9
100.0	37.8
99.9	37.7
99.7	37.6
99.5	37.5
99.3	37.4
99.1	37.3
99.0	37.2
98.8	37.1

NORMAL

98.6 37.0

Taking Your Blood Pressure (Twice a Day)

You will need to have your own blood pressure cuff to check your blood pressure twice a day. There are many varieties, so it is important that you understand how to use yours. You will need to bring your blood pressure cuff to the hospital prior to discharge for instruction on your particular model.

What is blood pressure?

With each beat of the heart, blood is pumped out of the heart into the blood vessels, which carry the blood throughout the body. Blood pressure is the measurement of the pressure or force inside your blood vessels (arteries) with each beat of the heart.

Blood pressure is determined by the pumping action of the heart, ability of the artery walls to stretch and the amount of blood in the blood vessels.

How is blood pressure recorded?

Blood pressure is written as two numbers, such as 120/80. The first number is the systolic pressure. Systolic pressure is the pressure in the arteries when the heart beats and fills the arteries with blood. The second number is the diastolic pressure. Diastolic pressure is the pressure in the arteries when the heart rests between beats.

What is a normal blood pressure reading?

See chart below.

These are general guidelines for normal blood pressures. Your baseline blood pressure might be higher or lower, so it is important to watch for increases or decreases from your baseline blood pressure.

If you have received a transplant from a donor, (allogeneic transplant), you may be taking certain medications, such as Neoral® or Prograf®, that may cause high blood pressure. It is not unusual for transplant patients to take medications to lower blood pressure (anti-hypertensives).

When to call

Call your health care provider if you have:

- Diastolic blood pressure readings that remain in the mid-90s or higher over a 24- to 36-hour period.
- One systolic reading > 160 or < 90
- One diastolic reading > 110 or < 50

BLOOD PRESSURE

TYPE OF BLOOD PRESSURE READING	IDEAL BLOOD PRESSURE	HIGH BLOOD PRESSURE	LOW BLOOD PRESSURE
Systolic	120	Over 140	Under 90
Diastolic	80	Over 90	Under 50

What should I do if I have high blood pressure?

Hypertension (high blood pressure)

Most of the time there are no symptoms. People can develop heart disease and kidney problems without knowing they have high blood pressure. That is why it is so important to check your blood pressure twice a day until instructed otherwise.

If you have a severe headache, confusion, changes in your vision or nosebleeds, contact your doctor immediately or go to the emergency room

The goal of therapy, is to lower your blood pressure.

If you have high blood pressure:

- Eat healthy foods that are low in salt and fat.
- Lose weight, if you are overweight.
- Limit alcohol to no more than 1 drink (beer, wine, or whiskey) each day, if your doctor allows alcohol.
- Exercise regularly.
- Quit smoking.
- Take high blood pressure medicine if your healthcare provider prescribes it, and follow your healthcare providers' directions carefully.
- Have regular blood pressure checks, and check your own blood pressure at home as recommended by your healthcare provider.

Hypotension (low blood pressure)

Low blood pressure, or hypotension, occurs when blood pressure during and after each heartbeat is much lower than usual. This means the heart, brain, and other parts of the body do not get enough blood.

Causes:

- Dehydration
- Medications
- Sudden change in position/posture

Symptoms:

- Blurry vision
- Confusion
- Dizziness
- Fainting (syncope)
- Light-headedness
- Sleepiness
- Weakness
- Fast heart rate

Call your doctor immediately or go to the emergency room if you have any of the following symptoms:

- Black or maroon stools
- Chest pain
- Dizziness, light-headedness
- Fainting
- Fever higher than 100.4 degrees F
- Irregular heartbeat
- Shortness of breath

If you have low blood pressure, your doctor may recommend certain steps to prevent or reduce your symptoms.

These may include:

- Avoiding alcohol
- Avoiding standing for a long time
- Drinking plenty of fluids
- Getting up slowly after sitting or lying down
- Using compression stockings to increase blood pressure in the legs
- Avoiding hot showers or excessive heat

A member of the BMT Team will be checking you at your follow-up appointment, a few days after your hospital discharge, for low blood pressure (hypotension) and orthostatic hypotension. Orthostatic hypotension can be brought on by a sudden change in body position, most often when shifting from lying down to a standing position. This type of low blood pressure usually lasts only a few seconds or minutes. We will give you IV fluids if we find you have low blood pressure or orthostatic hypotension.

When should I check my blood pressure?

Follow your doctor's instructions for when and how often to check your blood pressure. Your blood pressure is usually lowest in the morning after you wake up from sleeping and is lower when lying down than when sitting or standing.

Keep in mind that certain factors can cause blood pressure to temporarily rise. Blood pressure normally rises as a result of:

- Stress, emotional upset
- Smoking
- Cold temperatures
- Exercise
- A full stomach
- Full bladder
- Caffeine
- Certain medicines

Avoid any of these factors you can when taking your blood pressure.

Measure your blood pressure in the morning and evening, and record it on the Daily Recordkeeping Log. Please bring this log with you to all of your follow-up appointments.

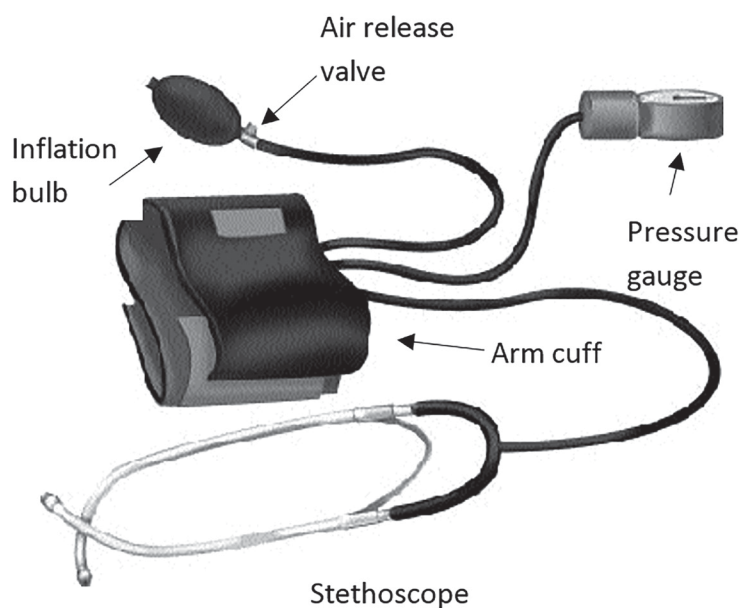
How to Take Your Blood Pressure

It is important to learn the proper technique for taking your blood pressure. With repeated practice, you will be able to determine an exact blood pressure reading.

What steps should I take while checking my blood pressure at home?

Before taking your blood pressure

- Find a quiet place.
- Check to be sure you have the correct size cuff. If you are not sure, or if you have questions, talk to your healthcare provider. (Avoid wrist and finger monitors to ensure an accurate blood pressure reading.)



Manual blood pressure monitor

A. Positioning

1. Find a quiet place. You will need to listen for your heart beat.
2. Sit in a chair next to a table that's at a height close to the level of your heart.
3. Relax for a few minutes before starting.
4. Roll up the sleeve on your left arm or remove any tight-sleeved clothing, if needed. (It's best to take your blood pressure from your left arm, if possible. The left arm is recommended because the largest artery coming from the heart, called the aorta, is on the left side of the body.)
5. Rest your left arm comfortably on the table, with your palm facing up.
6. Sit up straight with your back against the chair, legs uncrossed.
7. Rest your forearm on the table with the palm of your hand facing up.

B. Locate your pulse

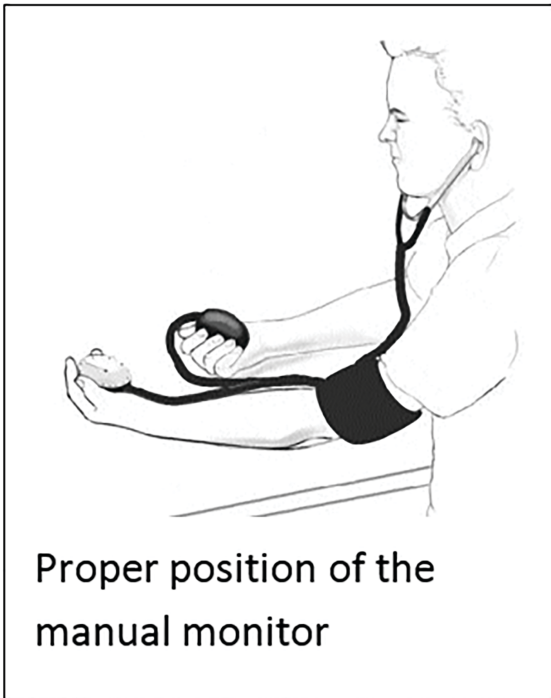
Locate your pulse by lightly pressing your index and middle fingers slightly to the inside center of the bend of your elbow. Here you can feel the pulse of the brachial artery.

C. Secure the cuff

1. Wrap the cuff around your upper arm. The lower edge of the cuff should be about 1 inch above the bend of your elbow. Your arm should be resting on the table with your palm up.
2. Place the stethoscope's circle sound piece inside the cuff, over the pulse felt in your upper arm.
3. Fasten the straps on the cuff tight enough to keep the sound piece in place.
4. Make sure the cuff is not too tight. You should be able to place 2 fingers between your arm and the cuff.
5. Place the earpieces of the stethoscope into your ears. Tilt the ear pieces slightly forward to get the best sound.

D. Closing the airflow valve and inflating the cuff

1. Hold the pressure gauge in your left hand and the bulb in your right (as shown at left).
2. Close the airflow valve on the bulb by turning the screw clockwise until you can't turn it further. Make sure the valve is not closed too tightly, so that it can be opened easily with one hand.
3. Inflate the cuff by squeezing the bulb with your right hand. You might hear your pulse in the stethoscope.
4. Watch the gauge. Keep inflating the cuff until the gauge reads about 20 to 30 points (mm Hg) above the last systolic (first) reading. At this point, you should not hear your pulse in the stethoscope. Inflating the cuff increases the pressure inside the cuff above the pressure in your arm. This temporarily stops the blood flow.



E. Deflating the cuff

Keeping your eyes on the gauge, slowly release the pressure in the cuff by turning the airflow valve counter clockwise. Allow the arrow on the gauge to move at a slow, steady pace. This permits time for you to get a reading.

F. Detecting measurements

1. As the pressure falls, the blood begins to flow, causing a beating sound.
2. When you hear the first clear beating sound, memorize the reading on the gauge. This reading is your systolic pressure.
3. Keep listening while the beating sound changes in loudness.
4. Remember the number on the gauge when the rhythmic beating stops. This is your diastolic pressure.

G. Opening the airflow valve

1. Turn the screw counter clockwise to open the valve.
2. Allow all of the air to flow out of the cuff.

H. Repeating the measurement

1. If you released the pressure too quickly or you could not hear the beating clearly, DO NOT try to inflate the cuff again right away.
2. Deflate the arm cuff completely by letting all the air out.
3. After waiting 1 minute, start again from the beginning by reapplying the cuff.

If you are using a digital monitor:

Follow steps A. positioning 1-7, B. Locate your Pulse, and C. Secure the cuff 1.

1. Hold the bulb in your right hand.
2. Press the power button. All display symbols should appear briefly, followed by a zero. This indicates that the monitor is ready.
3. Inflate the cuff by squeezing the bulb with your right hand. If you have a monitor with automatic cuff inflation, press the start button.
4. Watch the gauge. Keep inflating the cuff until the gauge reads about 30 points (mm Hg) above your expected systolic pressure.
5. Sit quietly and watch the monitor.
6. Pressure readings will be displayed on the screen. For some devices, values may appear on the left, then on the right. Most devices will also display your pulse rate.
7. Wait for a long beep. This means that the measurement is complete. Note the pressures on the display screen. Systolic pressure appears on the left and diastolic pressure on the right. Your pulse rate may also be displayed in between or after this reading.
8. Allow the cuff to deflate.

Important: If you did not get an accurate reading, DO NOT inflate the cuff right away. Wait one minute before repeating the measurement. Start by reapplying the cuff.

Record your blood pressure

Follow your doctor's orders on when to take your blood pressure and how often to take it. Note the date and time for each blood pressure reading. Record your readings by writing the systolic (first) pressure reading over the diastolic (last) pressure reading.

Systolic

Diastolic

Index # 10249 | Review Date: 8//8/2019

Preventing Infection After Blood and Marrow Transplant

After your transplant, your immune system is weak and you are at risk for infection. Even though your white blood cell count might be “normal,” your immune system is still recovering. Therefore, infections might still occur.

Causes of infection

The usual causes of infection after a transplant include:

- Month 1.** bacteria, fungi, herpes simplex virus
- Month 2.** cytomegalovirus (CMV), other viruses, bacteria, and fungi*
- Month 3.** varicella zoster virus, bacteria, fungi*, community-acquired respiratory virus

* These are more common after allogeneic transplants than autologous BMTs, particularly in patients with graft-versus-host-disease (GvHD).

Detecting infection

One of the easiest and most important ways to detect signs of infection is to take your temperature. **You should take and record your temperature twice a day.** For your convenience, you may use the temperature recording chart located in the “Follow-Up Care After Your Transplant” section of this binder.

Allogeneic transplant patients should continue to take your temperature twice a day until all of your immunosuppressive medicines have been discontinued by your transplant team and your central line has been removed. (Unless instructed otherwise by your transplant team).

Preventing Infection

Autologous transplant patients should follow these restrictions for six months. As long as you are on maintenance medications (such as rituximab or lenalidomide), follow these restrictions.

Allogeneic transplant patients should follow these restrictions while taking immunosuppressive medications and while the central line is in place.

Avoiding Environmental Exposures

Pay close attention to hygiene.

This is necessary to help prevent infection. You may shower or bathe normally, as long as you don't submerge your central venous catheter under water. Daily cleansing with soap and water is the first line of defense against bacteria on the skin. To help minimize infection and gum bleeding, daily oral (mouth) care is necessary. You may use a soft, nylon-bristled toothbrush or sponge toothette to care for your teeth and gums. Brush your teeth and gums thoroughly with fluoride toothpaste after each meal. Use a mouth wash or rinse as recommended by your health care provider.

Prevent infections transmitted by direct contact

Thorough hand washing is crucial, especially during the first 6 months after your BMT or while taking immunosuppressive medicines. Wash your hands with soap and warm water.

The use of hygienic hand rubs (hand sanitizer) is recommended when you are outside your home, if soap and warm water are not available. (Keep in mind that these hand sanitizers do not prevent transmission of the bacteria responsible for causing C diff. colitis.)

Handwashing is necessary:

- Before eating
- Before and after preparing food
- After touching pets or animals
- After sneezing, coughing or blowing your nose
- After going outdoors
- Before and after any central venous catheter care or intravenous infusions
- Before taking oral medicines
- After touching soiled linens or clothes
- After changing diapers
- After using the bathroom
- After sexual contact if hands touch genital or anal area

Remember to wash your hands even if you wear gloves.

Prevent infections transmitted by direct contact and respiratory transmission

Avoid gardening, mulching, raking, mowing, caving, farming or direct contact with soil and plants. Direct contact with soil and plants increases your exposure to potential pathogens (substances that can cause disease) including aspergillus and cryptococcus. These pathogens can cause serious fungal infections. If you must do any of these activities (for example, you are a farmer), wear a mask and gloves.

Avoid having anything in your yard that collects water, such as bird baths or empty buckets. Standing water attracts mosquitoes that can transmit West Nile Virus.

This does not mean you should avoid the outdoors. Walking, biking and many other outdoor activities are not only enjoyable but will promote good health.

Prevent respiratory infections

Avoid close contact with people who have respiratory illnesses (cough, cold, etc.). Be especially careful around school-aged children, since they are often exposed to other children who are ill.

Avoid crowded areas where you are unable to control the distance between you and others. Some might feel “safer” wearing a mask when they are outside the home. This is a personal choice, but you are **not** required to wear a mask when you go outside your home. If you choose to wear a mask, you should still avoid situations, such as crowds, that might increase your risk of infection. Consider wearing a mask on airplanes and buses.

Avoid construction sites, including homes or buildings that are being repaired or remodeled. These dusty environments increase your exposure to molds.

Avoid tobacco and marijuana use. The use of these substances, along with exposure to environmental tobacco smoke (second-hand smoke), increases your risk for bacterial, viral and fungal infections.

Avoid wood-burning fireplaces, stoves and pits since the wood can contain fungus.

Avoid house cleaning that will disturb dust and mold, causing it to move into the air (such as vacuum cleaning, dusting, and scrubbing down showers). Once you have the energy, it is not harmful to iron, wash clothes, dry clothes, wash dishes and cook.

Avoid using a room humidifier due to water-harboring bacteria.

Prevent pet-transmitted infections

It is not necessary to part with your pets. However, it is important to limit direct contact with animals, especially animals that are ill. Please delegate the care of your pets to other family members or friends.

Avoid contact with reptiles, ducklings, or chicks to prevent infection with salmonella. If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where food preparation and eating occur. In addition, have someone else clean the litter box during the first 6 months after transplant and while you are taking immunosuppressive medicines to reduce your chance of getting toxoplasmosis. Please keep your cats inside and do not adopt or handle stray cats.

If you have a dog, do not handle or clean up bowel movements. If hunting, do not gut animals and avoid prolonged contact with earth matter (for example, wild turkey hunting requires laying on earth surrounded by vegetative matter for cover). If fishing, avoid cleaning the fish.

Small children

If you have small children and are unable to avoid changing soiled diapers, you must wear gloves and a mask. After removing the changing the diaper and removing the gloves, wash your hands with soap and water. When possible have another person change diapers.

Water safety

After your transplant, avoid walking, wading, swimming, or playing in recreational water such as ponds, swimming pools, lakes, whirlpools, water fountains and hot tubs.

Avoid drinking well water from private wells or from public wells in small communities because tests for microbial contamination are performed too infrequently. Drinking well water from municipal wells serving highly

populated areas is thought to be safe because the water is tested 2 times/day for bacterial contamination.

If you drink tap water, routinely monitor the mass media (radio, television, and newspapers) in your area. Act immediately if a boil-water advisory is issued. A boil-water advisory means that all tap water should be boiled for at least 1 minute before drinking.

You may consume bottled water if it has been processed to remove cryptosporidium by one of three processes: reverse osmosis, distillation, or 1- μ m particulate absolute filtration.

The International Bottled Water Association can be contacted in the United States at (703) 683.5213 or at their website bottledwater.org to obtain contact information regarding water bottlers.

For a list of filters certified under National Sanitization Foundation (NSF) Standard 053 for Cyst (i.e., cryptosporidium) removal, contact the NSF International consumer line or NSF.org.

Travel safety

Please do not plan to travel to developing countries without first talking to your transplant doctor. Certain countries can pose significant risks for exposure to substances, such as viruses or microorganisms that can cause disease or infection.

Vaccinations

It is beneficial for family members and household contacts to be vaccinated to limit your exposure to vaccine-preventable diseases (such as tetanus, polio, measles, mumps, rubella, influenza, and pneumococcal.) Discuss influenza vaccines with your BMT team.

Recommendations for a possible revaccination schedule are included in this handout.

Children in the household of an immunocompromised patient should receive the MMR (measles, mumps, and rubella) vaccine. Although MMR is a live vaccine, household transmission does not occur. The varicella (chicken pox) vaccine is also a live vaccine. The American Academy of Pediatrics recommends that the child in the household receive the vaccine.

The varicella (chicken pox) vaccine poses a very small risk of household transmission, usually only if the vaccinated child develops a rash. If the vaccinated child develops a rash, the transplant patient might be placed on acyclovir (if not already on it). The transplant patient would be at a much greater risk if the child actually got the chicken pox virus.

When to call

Watch for early signs of infection. It is very important to notify the Blood and Marrow Transplant Team or your local doctor if any of these signs or symptoms of infection occur:

- Fever of 100.4°F (38.0°C) (even if you feel well).
- Shortness of breath
- Cough with yellow or green sputum (phlegm) or a dry, persistent (ongoing) cough
- Sweats or chills, even if you have a normal temperature.
- Sore throat, scratchy throat, or pain when swallowing
- Sinus drainage, nasal congestion, headaches, or tenderness along the upper cheekbones
- Trouble urinating: pain or burning, constant urge, or frequent urination. This might also be a side effect of chemotherapy called hemorrhagic cystitis. When this occurs, there might be blood or blood clots in your urine
- Cloudy or foul-smelling urine
- Redness, swelling, tenderness, or drainage at the site of your central venous catheter
- Diarrhea, with or without cramping
- Lesions (sores) or white patches in your mouth or on your tongue
- Skin rash
- Vaginal discomfort, itching, or unusual discharge
- If you become aware that you have been exposed to chickenpox, strep throat, herpes, or mononucleosis, the flu or any other respiratory virus.

Nutrition After Blood and Marrow Transplant

Good nutrition is a very important part of your recovery. It helps your body resist infection and repair tissue damage caused by chemotherapy and/or radiation therapy.

Losing interest in food after a long illness is to be expected. Some of the side effects you may have experienced while in the hospital may continue even after you go home. These side effects may include nausea, vomiting, loss of appetite, taste changes, and a sore or dry mouth. With these symptoms, it may be difficult for you to imagine eating high-calorie, nutrient-rich meals.

Nutrition supplements

When you are unable to eat a well-balanced diet, we recommend you try over-the-counter nutrition supplements to meet your nutritional needs, unless otherwise instructed. However, it is important to check the labels for the specific vitamin, mineral or nutrient levels. They can vary from different manufacturers. Examples of nutrition supplements are Ensure[®], Boost[®], Resource[®], Carnation Instant Breakfast[®], Boost[®] bars and Boost[®] puddings. If you have diabetes, Glucerna[®] and Boost[®] Glucose Control are options.

Several discount stores and drug stores have nutritional supplements packaged under their private label. Please check with the dietitian to determine if the particular product will meet your needs.

Multivitamins

After you are discharged, if you wish to take a daily multivitamin, ask your physician. You can take children's chewable multivitamins twice a day if better tolerated. Excess doses of some vitamins and minerals might be unsafe at this time. For instance, it is important to choose vitamins that do not contain iron or herbs. Also, due to your numerous red blood cell transfusions, additional iron supplementation is unnecessary. Your body does not eliminate iron. If you have questions regarding your preferred multivitamin, bring your labeled vitamin bottle to your appointment for your doctor's approval.

Follow food safety guidelines when choosing any of the following foods:

Calcium and phosphorus

Some of your medicines might deplete calcium, which is important for maintaining bone strength. When the staff reviews your medications and labs, they will inform you if this is likely to be a problem. Phosphorus is a mineral that helps to strengthen bones. Some transplant patients often need additional phosphorus. Unless you are following a special diet, we recommend you eat a diet high in calcium and phosphorus.

Dairy products high in calcium and phosphorus include:	Non-dairy products high in calcium include:
Creamer (pasteurized)	Calcium-enriched fruit juice
Milk (skim, low-fat, whole)	Roasted almonds
Natural cheese, processed cheese (pre-packaged)	Dried peas and beans (cooked thoroughly)*
Cottage cheese, ricotta cheese	Tofu (calcium enriched, cooked thoroughly)
Yogurt (regular, frozen or Greek)	Greens (kale, collard, mustard, turnip*)
Pudding, custard	Canned salmon with soft bones
Eggnog	Bok choy
Rice milk , calcium fortified	Calcium fortified cereal
Ice cream or ice milk	Sardines
Cream soup	Spinach
Buttermilk	* a good source of phosphorus
Evaporated milk	
Powdered milk	
Soy Milk	

Additional foods with significant amounts of phosphorus:			
Biscuit	Dried beans and peas	Oatmeal	Soybeans
Beef or veal -lean only	Fish – pollock, walleye, swordfish, cod, halibut, salmon, tuna	Peanut/nut butters	Soy milk
Cereal – bran	Granola	Pork loin	Tortillas
Cheese – American, cheddar, mozzarella, Swiss, Provolone	Milks	Potato – baked with skin	Tuna, canned in water
Cheese – ricotta	Milkshake	Pudding/custard	Turkey
Cheese – cottage	Nuts, most varieties	Seeds – sunflower or pumpkin	Veggie or soy patty
Chicken – white meat			Waffle or pancake
			Yogurt

Your doctor may recommend calcium supplements such as Tums®, Oscal +D®, or Caltrate®. Calcium supplements with vitamin D are essential for those who require long-term steroid therapy, such as prednisone. Steroids cause bone loss, called osteoporosis. Taking these supplements, as well as exercising, can help reduce bone loss and prevent fractures. An appointment with a rheumatologist may be advised to monitor your bone density.

Potassium and Magnesium

Antibiotics, diarrhea, and vomiting can cause electrolyte (mineral) imbalances. Even after your hospital discharge, it is common to require potassium and magnesium supplementation, which can be given by pill or intravenous infusion.

Potassium is an electrolyte (mineral) that maintains normal fluid balance, supports healthy nerve and muscle function and helps your heartbeat stay regular.

Fruit sources of potassium include:	Vegetables high in potassium include:	
Apricots	Artichokes	Spinach
Avocados	Avocado	Squash
Bananas	Bamboo shoots	Sweet potatoes
Dates, figs	Beets	Tomatoes
Honeydew/cantaloupe	Brussels sprouts	Tomato juice
Kiwi	Chard	V-8 Juice
Nectarines	Chick peas	White potatoes
Oranges	Dried beans	
Orange juice	Escarole	
Peaches	Kohlrabi	
Prunes	Parsnips	
Prune juice	Pumpkin	
Raisins	Rutabaga	

Magnesium is also an electrolyte (mineral) that is involved in bone mineralization, building of protein, transmission of nerve impulses, and normal muscular contraction.

Significant sources of magnesium include:	
Chocolate	Nuts
Halibut	Peanut butter
Legumes	Spinach
Leafy green vegetables	Tofu
Meat	Tuna
Milk	Whole grain cereal

Sodium

Sodium is an electrolyte essential for water regulation and electrical activities of the body, such as nerve impulse transmission and muscle contraction. Our diets rarely lack sodium. A healthy person requires about 200 mg of sodium daily, but the average sodium intake is estimated to be 6,000 to 18,000 mg daily. Excessive sodium intake can lead to high blood pressure (hypertension) and fluid retention. Reduce your sodium intake to less than 2,300 mg each day.

Since allogeneic transplant recipients might already be experiencing hypertension or fluid retention/swelling (edema) caused by steroids — such as prednisone, tacrolimus (Prograf®), or cyclosporine (Neoral®) — it is crucial to avoid a diet high in sodium.

Alcohol

After your transplant, you may have decreased liver function due to the effects of high-dose chemotherapy, graft-versus-host disease (GvHD) or metabolism of medicines. Since the liver metabolizes alcohol, avoid all alcoholic beverages. Alcohol can cause malnutrition by attacking the stomach lining, leading to malabsorption and excretion of many nutrients. Before drinking beer, wine, or other alcoholic beverages, ask your BMT doctor.

Index # 4382 | Review Date: 8/8/2019

Food Safety Guidelines

You are given this handout because your medical condition puts you at high risk for food borne illness. Following the tips in this handout will help you reduce your chances of getting sick from unsafe food or drinks.

This handout will review the 4-steps to food safety as recommended by the Centers for Disease Control and Prevention (CDC) in addition to other steps you can take to maintain food safety.



<https://www.cdc.gov/foodsafety/index.html>

SHOP

- Do not buy food that is past its “expiration” or “sell by” date.
- Do not buy dented, bulging, or rusted canned goods.
- Do not buy bruised or damaged produce.
- Do not buy unrefrigerated eggs or eggs with broken shells.
- Do not buy food from the bulk bins unless the food is to be cooked.
- Do not eat unpackaged food samples or drink open beverage samples in the store.
- Refrigerate food within 2 hours after purchasing. Refrigerate within 1 hour if the temperature outside is above 90°F.

CLEAN

- Wash hands using warm water and soap for 20 seconds before and after handling food.
- Wash countertops, tables, and cutting boards often.
- Wash utensils **before** and **after** each use.
- Wash dish cloths and kitchen towels often.
- Replace sponges or scrubbers often.
- Wash ALL produce before eating unless it is labeled as “pre-washed” or “ready-to eat.” For extra safety, wash produce with 2 parts water + 1 part vinegar.
- Wash the tops of cans before opening

SEPARATE

- Separate raw foods from other foods in your shopping cart and grocery bags.
- Separate raw foods from other foods in your refrigerator. Store raw foods below ready-to-eat foods.
- Use separate cutting boards for raw foods and ready-to-eat foods.



THAW

- Thaw foods in the refrigerator, in cold running water, or in the microwave.
- If thawed in the refrigerator, cook within 3-5 days.
- If thawed in cold running water, drain and refill the water every 30 minutes and cook immediately after.
- If thawed in the microwave, cook the food immediately after.
- Thaw all meat and poultry before adding it to a slow cooker.

COOK

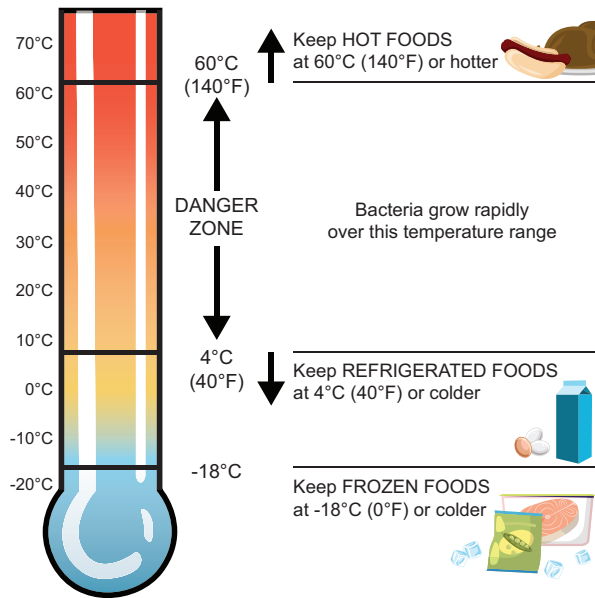
- Use a food thermometer to be sure foods are at a safe internal temperature.
- Reheat leftovers to an internal temperature of 165° F throughout before serving.
- Bring leftover soups, sauces, and gravies to a rolling boil before serving.
- Throw away any leftovers after they have been reheated once. Do not reheat a second time.
- Follow microwaving directions exactly if provided.

CUT OF MEAT	INTERNAL TEMPERATURE
Ground Meat (beef, pork, veal, lamb)	At least 160°F
Ground Poultry (turkey, chicken)	At least 165°F
Fresh beef, veal, lamb	At least 145°F 3 minute rest time
Poultry	At least 165°F
Pork and ham	At least 145°F 3 minute rest time
Fish	At least 145°F
Egg Dishes (casseroles, soufflé)	At least 160°F
Leftovers	At least 165°F

<https://www.foodsafety.gov/food-safety-charts/safe-minimum-cooking-temperature>

FOOD HOLDING & STORAGE

- Keep hot foods hot (above 140° F).
- Keep cold foods cold (below 40° F).
- Divide leftovers into small, shallow containers for quick cooling in the refrigerator.
- Refrigerate leftovers within 2 hours of cooking.
- Discard leftovers that were kept at room temperature for more than 2 hours.
- Save leftovers no more than 4 days in the refrigerator.
- Do not eat foods past the “expiration” date.



Food Banks Canada | <https://www.foodbankscanada.ca/>

USDA FoodKeeper App



The USDA FoodKeeper app is an easy way for consumers to keep their food safe by providing valuable advice on storing foods and beverages to maximize freshness and minimize food waste.

EATING OUT

- Avoid buffets, food vendors, potlucks, and any food service where there is a question about safe food handling and preparation.
- Order individually packaged foods, condiments, beverages, seasonings, etc., to minimize the risk of bacterial contamination when able.
- Ask the waiter/waitress how the food will be prepared.
- Request freshly made food rather than an item sitting under a heat lamp.
- Order food to be cooked until well-done.
- Send back foods if they are not well cooked, especially the meats.
- Ask for meals without garnish.

FOOD SAFETY RECALLS

- Stay informed of food safety recalls in your area.
- Find a list of food safety recalls and guidelines at www.cdc.gov/foodsafety



Below are 2 categories of food.

Choose foods from the Low-Risk column and avoid foods from the High-Risk column.

FOOD GROUP	LOW-RISK FOODS	HIGH-RISK FOODS
Meat and meat substitutes	<ul style="list-style-type: none"> • Meat, poultry, fish, and seafood cooked to proper temperature • Hot lunch meats and hot dogs • Well-cooked (solid white and yolk) or pasteurized eggs • Well-cooked or pasteurized tofu and tempeh • Cooked or roasted nuts 	<ul style="list-style-type: none"> • Raw, undercooked, or cold smoked meat, poultry, fish, and seafood • Cold lunch meats and hot dogs • Undercooked or raw unpasteurized eggs (i.e. dippy, over-easy, and poached eggs) • Raw or unpasteurized tofu and tempeh • Raw nuts • Prepared foods from deli counter (i.e. tuna salad, egg salad)
Fruits	<ul style="list-style-type: none"> • Washed fresh fruit • Pasteurized fruit juices • Cooked, frozen, dried or canned fruit 	<ul style="list-style-type: none"> • Unwashed fresh fruit • Unpasteurized fruit juices
Vegetables	<ul style="list-style-type: none"> • Washed raw vegetables and herbs • Cooked vegetables and herbs • Frozen and canned vegetables • Pasteurized vegetable juice 	<ul style="list-style-type: none"> • Unwashed raw vegetables and herbs • Salads from salad bars or delis • Unpasteurized vegetable juice • Raw sprouts
Grains	<ul style="list-style-type: none"> • Cooked or ready-to-eat cereal, bread, pasta, etc. 	<ul style="list-style-type: none"> • Raw flour, dough, and batter • Raw sprouted grains • Raw or undercooked yeast
Milk and milk products	<ul style="list-style-type: none"> • Pasteurized dairy products (i.e. milk, cheese, cream, butter, yogurt, whipped cream) • Cheese made with pasteurized milk • Packaged ice cream/bars, frozen yogurt, sherbet • Pasteurized eggnog • Packaged protein shakes nutrition shakes 	<ul style="list-style-type: none"> • Unpasteurized dairy products • Any cheese if made from unpasteurized milk (i.e. brie, feta, camembert, and farmers cheese) • Soft-serve ice cream, custard, or yogurt • Unpasteurized eggnog • Unrefrigerated cream or custard bakery products (i.e. cream pie, custard filled donut, cream puff, etc.)
Beverages	<ul style="list-style-type: none"> • Tea or coffee made with boiling water • City tap-water (boiled if told to do so) • Bottled distilled, spring, and natural waters from the store • Canned, bottled, powdered beverages • Pre-packaged, brewed herbal tea (i.e. Pure Leaf) 	<ul style="list-style-type: none"> • Sun tea (sun-brewed) • Well-water • Unpasteurized cold-pressed juices

Additional guidelines are available at:

www.fsis.usda.gov

www.homefoodsafety.org

Additional food safety information is available at:

www.cdc.gov/foodsafety

www.fightbac.org

www.foodsafety.gov



Center for Human Nutrition / Nutrition Therapy | Digestive Disease and Surgery Institute

9500 Euclid Avenue, Cleveland, Ohio 44195

Appointments: 216.444.3046 | 1.800.223.2273, ext. 43046

This information is not intended to replace the medical advice of your doctor or healthcare provider. Please consult your healthcare provider for advice about a specific medical condition.

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Resuming Sexual Activity

Sexuality is an important part of a loving relationship. Kissing, hugging, and touching are acts of love that may be resumed after you are discharged from the hospital.

Will my sexual desire change after my transplant?

You may notice a decrease in sexual desire after your transplant. Factors that can have an impact on sexual desire include hormonal changes, excessive fatigue, cancer pain or treatment or changes in your self-image.

As your hormone levels return to normal and as you regain your strength and endurance, your sexual desire should return to normal. If you have any concerns about the changes in your sexual desire, please discuss them with your doctor, nurse or social worker.

When can I have sex again after my transplant?

We recommend having a platelet count of at least 50,000 per cubic millimeter before engaging in sexual intercourse. Because your immune system is now weaker than normal, you should avoid sexual practices that could result in oral exposure to feces.

To reduce your risk of exposure to sexually-transmitted infections such as CMV, HIV, hepatitis and herpes, and because some medications can be passed to your partner during sexual activity, we recommend the use of latex condoms.

Will I have to take hormones after my transplant?

In women, chemotherapy and radiation therapy cause changes in ovarian function and decreased hormone levels. Because of these changes, you may receive a prescription for estrogen supplements after your transplant. Your primary care provider can discuss your specific estrogen treatment with you.

In addition, some women stop having their menstrual cycles after a transplant and may benefit from hormone replacement therapy to relieve menopausal symptoms.

What can I do to treat vaginal dryness?

Some women may experience vaginal dryness after transplant because of the changes in hormone levels. Water-soluble lubricants such as K-Y® Jelly or Astroglide® can be useful during intercourse to decrease the discomfort of vaginal dryness. Talk with your doctor. He or she may refer you to a gynecologist.

Communicate with your partner

Talk to your partner. Tell your partner how you feel, especially if you have mixed feelings about sex after your transplant. Encourage your partner to communicate with you, especially if you notice changes in your partner's responsiveness. Communicating with your partner can help you both better understand your feelings and desires.

Take time for intimacy

If your healthcare provider has told you to limit your sexual activity, or if you are not in the mood for intercourse, remember to take time for intimacy with your partner. Being intimate does not require having intercourse. Love and affection can be expressed in many ways.

Enjoy your time together. You can take long, romantic walks, have candlelit dinners, or give each other back rubs.

Will I be able to have children after my transplant?

The chemotherapy and radiation therapy you received as your preparative regime can affect your ability to have children (fertility) in the future.

Some men might experience a decreased or absent sperm count after cancer treatment. Some women stop having their menstrual cycles after a transplant and begin menopause. However, do not assume you are unable to father a child or get pregnant unless this has been medically verified. You may request testing from your doctors.

Concerns about being biologically able to have children might be distressing, so it might help to seek counseling with your BMT social worker. It might help you to talk about fertility loss and its impact on you and your partner or future partner.

If you do wish to start a family after cancer treatment, talk to your health care provider about the timing of a pregnancy after treatment.

Importance of birth control

Even though infertility (the inability to have children) might occur after cancer treatment, it is still possible to get pregnant, so both men and women should use birth control after treatment. Birth control is important after your transplant because the medicines you will be taking may be harmful to a developing fetus. Follow your healthcare provider's recommendations on the appropriate method of birth control to use.

Index # 10248 | Review Date: 8/8/2019

Frequent Laboratory Testing

You will have your blood drawn each day you are in the hospital and each time you come to the outpatient area for a physician or treatment appointment. This may seem excessive, but blood tests are a vital tool in monitoring your medical status during and after a transplant. Chemotherapy, infection, graft-versus-host disease (GvHD) and medications you are taking may affect your blood results.

The following is a list of blood tests that may be done frequently. This list is intended to help you understand what your physicians and nurses may be monitoring. Feel free to ask your nurse for copies of your test results at your appointments.

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
CBC (Complete Blood Count)	This lab test measures the following: WBC, RBC, HGB, HCT, PLT. (See below)	
WBC (White Blood Count)	These are the types of cells in your blood that fight infection. As you engraft after transplant, your total WBC number will increase. Often, infections and steroids will cause an elevated WBC.	If your WBC is low, your doctor might order Neupogen® or Neulasta® to boost your WBC count.
RBC (Red Blood Count)	RBC is a measure of the number of cells in your blood that are composed of hemoglobin. RBC circulate in your blood for 120 days before being replaced by new cells.	
HGB (Hemoglobin)	This is a protein that enables red blood cells to carry oxygen from the lungs to your tissues and carry carbon dioxide from the tissues to the lungs.	If your HGB is too low, you will receive a red blood cell transfusion. Your doctor might order Procrit®, Epogen® or Aranesp® as well.
HCT (Hematocrit)	HCT measures the percentage of RBC in your blood.	
PLT (Platelets or thrombocytes)	PLT are cells that help your blood clot. After an allogeneic transplant, low platelets might indicate the presence of GvHD or infection. Certain medications can also cause platelet counts to drop.	If your PLT count drops too low, you will receive a platelet transfusion.

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
DIFFERENTIAL	This lab test is made up of several different components. (See Below). It indicates a percentage of the different types of WBCs making up the total WBC count.	
Neutrophils Absolute Neutrophil Count (ANC)	These are a specific type of WBC that are the body's first line of defense against infection.	If this result is too low, your doctor might order a Neupogen® (G-CSF) or Neulasta® injection.
Lymphocytes	These are a specific type of WBC that attach to foreign antigens and destroys them. Together with neutrophils, lymphocytes make up most of your total WBC.	
Basophils	These are a specific type of WBC that are thought to help the body resist severe allergic reaction states, although their function isn't completely understood.	
Monocytes	This is a specific type of WBC that is the body's second line of defense to fight off infection.	
CMP (Comprehensive Metabolic Panel)	This is a group of lab tests (See Below) that measure chemical components in your blood. It might reflect the function of several organs.	
Total Protein (TP)	Total protein can be an indicator of your nutritional status. This value can be affected by GvHD. If you are receiving TPN (IV nutrition), your medical team will monitor this number closely.	A dietitian may be consulted to monitor your calories and to make possible dietary recommendations, including TPN.

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
Albumin (ALB)	This is a protein that is mostly found in the liver. It maintains normal distribution of water in your body. A sharp decline in albumin leads to swelling (edema). This value can be affected by the presence of GvHD. If you are receiving TPN (IV nutrition), your medical team will monitor this number closely.	A dietitian may be consulted to monitor your calories and to make possible dietary recommendations, including TPN.
Calcium (Ca)	Calcium is important in keeping your bones strong. Our bodies excrete calcium daily so it is important to get your recommended daily allowance of calcium.	If your calcium is too low or if you are on steroid therapy, your doctor might ask you to take a calcium supplement.
Total Bilirubin (Total Bili)	Bilirubin is an indicator of your liver function and the condition of your red blood cells. This value can be elevated due to liver damage from chemotherapy or GvHD.	
Alkaline Phosphatase (Alk Phos)	Alk Phos is a liver enzyme that can be elevated in both skeletal and liver diseases. GVHD can also increase the level of Alk Phos in your blood.	
Aspartate Aminotransferase (AST)	AST is an enzyme that is released into the blood. It can reflect cellular damage. It can also help to assess heart and liver function.	
Blood Urea Nitrogen (BUN)	BUN reflects your protein intake and kidney function. An elevated value can reflect dehydration. This value will be monitored closely if you are on TPN.	

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
Creatinine (Creat)	Creatinine is a measurement of your kidney function. Certain medicines — such as antibiotics, Prograf® or cyclosporine — can affect your kidneys. If you are on these medicines, your creatinine will be measured closely.	Adjustments in your medicines might be made according to your creatinine levels.
Sodium (Na)	Sodium is an electrolyte that affects water distribution.	
Potassium (K)	This is an electrolyte that is essential to maintaining electrical conduction within the cardiac and skeletal muscles. Certain medicines can affect potassium levels.	It is common to need potassium replacement during and after your BMT.
Chloride (Cl)	Chloride is an electrolyte that helps regulate blood volume and arterial pressure.	
Carbon Dioxide (CO2)	CO2 reflects the adequacy of gas exchange in the lungs.	
Alanine transaminase (ALT)	ALT is an enzyme that detects acute liver tissue damage.	
Glucose	Glucose is the body's major source of energy. This test is a measurement of the amount of sugar in the blood. Steroid therapy affects your glucose levels.	High glucose might be treated by adjusting your diet, or with medicines, such as insulin.

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
Other Lab Tests		
Anion Gap	This lab test helps to distinguish types of metabolic acidosis and kidney function.	
Lactic Dehydrogenase (LDH)	LDH is an enzyme that detects tissue changes, including liver, lung and RBC damage. It can be affected by GvHD and certain cancer diagnoses such as lymphoma.	
Gamma Glutamyl Transpeptidase (GGT)	GGT is an enzyme used to assess liver function. An elevated GGT can be an indication of GvHD.	
Uric Acid	Uric acid helps to detect gout or kidney dysfunction. It might become elevated soon after high-dose chemotherapy as cancer cells are destroyed (tumor lysis).	Medicines, including Allopurinol, may be prescribed.
Magnesium (Mg)	Mg is an electrolyte that is vital to neuromuscular function. Certain medicines can affect your Mg levels.	It is common to need magnesium replacement during and after your BMT.
Quantitative Immunoglobulins (IgG, IgA, IgM)	These are proteins that help evaluate immune function.	If levels are low, your doctor might order immunoglobulin infusions; ie, IVIG
Ferritin	Ferritin is a major iron-storage protein directly related to the amount of available iron stored in the body. This lab value is monitored closely to evaluate possible iron overload from receiving multiple RBC transfusion.	If your ferritin level is too high, your doctor may prescribe certain medicines to help your body get rid of the extra iron.

LAB TEST	WHAT DOES IT MEASURE?	WHAT MIGHT BE DONE IF THE RESULT IS ABNORMAL
Prothrombin Time (PT or Pro time) /INR	This is one of two blood tests done to evaluate your blood clotting system. An abnormal value can show the potential for abnormal bleeding. This value can be affected by alcohol consumption. This monitors the effectiveness of certain medicines, such as warfarin.	If you are taking warfarin (Coumadin®) your dosage may be adjusted.
Plasma Thrombin Time (PTT or Thrombin clotting time)	This is one of two blood tests done to evaluate your blood clotting system. This monitors the effectiveness of certain medicines, such as Heparin.	
Cyclosporine (CSA) (Neoral®)	This test indicates the amount of CSA in your blood.	If levels are too high or too low, your dose of CSA might be adjusted.
Tacrolimus (Prograf®)	This test indicates the amount of Prograf® in your blood.	If levels are too high or too low, your dose of Prograf® might be adjusted.
CMV DNA detection	This blood test is done to determine the presence of a virus in your blood called CMV (cytomegalovirus).	If you have a positive CMV test result, your doctor will order certain medicines to treat the virus.

Daily Recordkeeping Log

In the spaces provided below, please record blood pressure (take and record twice a day), temperature (take and record twice a day), and the time you took these readings.

Always carry this sheet with you. Your doctor will need to see it during your appointments, and you might need it in case of an emergency.

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Week of: (Date)	Time	M	TU	W	TH	F	SA	SU
Blood pressure								
Temperature								

Vaccinating Recipients of Hematopoietic Stem Cell Transplants

A hematopoietic stem cell transplant (HSCT) results in immunosuppression because of the hematopoietic ablative therapy administered before transplant, drugs used to prevent or treat graft-versus-host disease, and in some cases, from the underlying disease process necessitating transplantation. As a result, HSCT recipients should be revaccinated routinely after HSCT, regardless of the source

of the transplanted stem cells. Taken from the CDC Centers for Disease Control and Prevention.

Please note that vaccination does not occur at your first appointment with the Infectious Disease physician but rather approximately six months after your transplant.

Date of HSCT _____

Months from HSCT	3	6	8	10	12	24
Approximate month and year	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
	GET YOUR	INACTIVATED	INFLUENZA	VACCINE	EVERY	FALL
AUTOLOGOUS	COVID-19 ¹	Pevnar-20 ² Hib ³ Tdap ⁴ Vaqta+Heplisav-B ⁵ HPV ⁶ Polio ⁷	Pevnar-20 Hib Td ⁸ Heplisav-B HPV Polio	Pevnar-20 Hib Td Polio Shingrix ¹¹	HPV Vaqta Shingrix	MMR ¹³ Varivax ¹⁴

¹Administer 3-dose primary bivalent mRNA COVID-19 vaccine series; Pfizer: 0, 21, 49 days, followed by bivalent booster at least 2 months later

²Prevnar-20 = 20-valent conjugated pneumococcal vaccine

³Hib = *Haemophilus influenzae* conjugate vaccine

⁴Tdap = tetanus toxoid, diphtheria toxoid & acellular pertussis vaccine

⁵Vaqta (hepatitis A virus vaccine) and Heplisav-B (hepatitis B virus vaccine)

⁶HPV (Gardasil) = nine-valent human papilloma virus vaccine; recommended for those 11-26 years old. Patients 27-45 years may receive HPV vaccination as part of shared clinical decision making.

⁷Polio = inactivated polio vaccine

⁸Td = tetanus toxoid & diphtheria toxoid

⁹MenB = Meningococcal group B vaccine (Bexsero)

¹⁰MenACWY = MenQuadFi (MenACWY-TT)

¹¹Shingrix = Recombinant Zoster Vaccine. Give if Varicella Zoster antibody is positive and patient is ≥ 19 years

¹²Give fourth dose of Pevnar-20 if ongoing chronic GVHD

¹³MMR = measles-mumps-rubella. If measles antibody is unprotective, no ongoing GVHD, not on immunosuppressive medications and no IVIG in the preceding 8-11 months.

¹⁴Varivax = varicella zoster (Chicken pox) vaccine. If varicella zoster antibody is negative, no ongoing GVHD, not on immunosuppressive medications and no IVIG in the preceding 8-11 months. May administer Shingrix 8 weeks following Varivax.

In addition to the above schedule, if the patient is planning to travel out of the United States of America, we recommend scheduling a visit to an International Travel Clinic several months in advance.

Review Date: 6/29/2023

Definition of Terms

Absolute Neutrophil Count (ANC). The total number of neutrophils in your white blood cell count. (See “neutrophils.”)

Acute Lymphoblastic Leukemia (ALL). A fast-growing cancer of the lymphocytes, one of the white blood cells. Also called acute lymphocytic leukemia. Appears most often in children, but can occur in adults.

Acute Myelogenous Leukemia (AML). A cancer of the myelocytes, one of the white blood cells. Also called acute non-lymphocytic leukemia. AML occurs in all ages and is the more common acute leukemia in adults.

Adjuvant Chemotherapy. Drugs used to kill cancer cells. They are given with other treatments, such as surgery or radiation, to destroy areas of tumor.

Allogeneic Blood or Marrow Transplant. A type of blood or marrow transplant where the cells a patient receives are not their own. The donor can be a related family member or a closely matched unrelated donor.

Alopecia. A partial or complete hair loss, usually a temporary side effect of the chemotherapy.

Anemia. A deficiency in the number of red blood cells. (See “red blood cells.”)

Antibody. A protein produced by the white blood cells (leukocytes) to battle foreign substances, such as bacteria, that enter the body.

Antigen. A foreign substance, such as bacteria or toxin, which induces a specific immune response.

Apheresis. The process by which peripheral blood HPCs (blood stem cells) are collected.

Autologous Transplant. A type of blood and marrow transplant during which the patient receives his or her own bone marrow/ stem cells.

Blood and Marrow Transplant (BMT). A procedure during which bone marrow, peripheral stem cells or umbilical cord stem cells are infused following chemotherapy. (See “autologous, allogeneic, and syngeneic reduced intensity and umbilical cord blood transplants.”)

Blood Count. A measurement of the different components that make up the blood.

Blood Stem Cells. See “Hematopoietic progenitor cells”

Bone Marrow. The spongy tissue found in the cavities of the body’s bones where all blood cells are produced.

Bone Marrow Harvest. The procedure of collecting stem cells from the bone marrow.

Central Line or Central Venous Catheter. A small, plastic tube inserted in a large vein. The central line used in a blood or marrow transplant allows blood samples to be drawn and drugs to be given, as well as the actual infusion of cells.

Chemotherapy. Treatment with one or more anti-cancer drugs to try to stop or slow the growth of cancer cells.

Chronic Lymphocytic Leukemia (CLL). A cancer of the lymphocytes, one of the white blood cells. CLL is more common in men over the age of 60.

Chronic Myelogenous Leukemia (CML). A cancer of the myelocytes, one of the white blood cells. CML can occur at any age but is most often found in people over the age of 45.

Clinical Trials. Research studies that test new treatments using devices or drugs.

Collection Centers. National Marrow Donor Program (NMDP) facilities that collect peripheral stem cells and bone marrow.

Colony Stimulating Factor or Growth Factor. The drug given to increase the number of stem cells in the blood. Also called Filgrastim, Neupogen®, G-CSF®, Zarxio®.

Conditioning. See “preparative regimen.”

Confirmatory Typing (CT). A tissue typing test done at the transplant center to make sure the donor and patient match.

Cord Blood. The blood of newborns found in the umbilical cord and placenta that contains large numbers of blood stem cells. (See umbilical cord blood stem cell.)

Cord Blood Bank. An organization that helps to collect and store umbilical cord blood for transplant.

Cytomegalovirus (CMV). A herpes virus that can occur in immunocompromised patients.

DNA (Deoxyribonucleic Acid). The material throughout the body that carries your cells’ genetic information.

DNA-Based HLA Typing. Human leukocyte antigen (HLA) is a system of markers found on white blood cells (leukocytes) that the immune system recognizes. DNA-based HLA typing uses precise (DNA) methods of testing to determine and report specific HLA antigens. This test is performed on recipients and donors to confirm an acceptable match exists.

Donor. A volunteer who has donated stem cells or bone marrow for a patient.

Donor Center. An NMDP-accredited organization with the experience, staff and facilities to recruit and manage interaction with volunteer stem cell donors.

Donor Workup. The process that a potential donor goes through to make sure he or she is healthy and ready to donate marrow or blood stem cells. A workup includes a detailed information session regarding the donation process, a complete physical exam, and blood tests.

Engraftment. The process during which transplanted stem cells begin to grow in the recipient’s bone marrow and produce new white blood cells, red blood cells, and platelets.

Epidural Anesthesia. A form of anesthesia in which medicine is inserted into the outer (epidural) layer of the spinal cord to block any painful sensations from the point of insertion to the lower extremities.

Erythrocytes. See “red blood cells.”

Filgrastim. See “colony stimulating factor.”

General Anesthesia. A form of anesthesia that causes temporary partial or complete loss of sensation. Bone marrow harvests are most commonly performed using general anesthesia.

Graft Failure. A complication after an allogeneic transplant in which the donor stem cells do not grow in the recipient’s bone marrow and fail to produce new white blood cells, red blood cells and platelets.

Graft Versus Host Disease (GvHD). A condition where transplanted stem cells attack the patient’s body.

Graft Versus Leukemia Effect (also called Graft Versus Cancer Effect). The phenomenon whereby the donor cells mount an attack against the recipient's underlying cancer.

Growth Factor or Colony Stimulating Factor. See "colony stimulating factor."

Haplotype. When the donor is only a half match to the recipient. These donors can be parents, siblings or children.

Harvest. See "stem cell harvest."

Hematopoiesis. The process of forming red blood cells, white blood cells and platelets.

Hematopoietic Progenitor Cells. Blood-forming stem cells capable of producing all the components of blood and marrow (abbreviated HPCs).

Hemoglobin. The part of the red blood cell that carries oxygen.

Histocompatibility. A system that determines how closely the patient and donor blood stem cells match.

HLA (Human Leukocyte Antigen). Proteins on white blood cells that make each person's tissue unique. The HLA A, B, C, and DR proteins are important in matching patients and donors for a marrow or blood stem cell transplant.

HLA Match. When both recipient and donor have had DNA-based HLA typing performed and share the same human leukocyte antigen results.

HLA typing. The identification of a person's key antigens used for determining compatible donors.

Hodgkin's Disease. A cancer found in the lymph tissue.

HPC collection. The process of collecting stem cells from the circulating bloodstream.

Human T-Cell Lymphotropic Virus (HTLV). A rare virus transmitted by cellular components of blood. Two forms of the virus have been identified, HTLV-I and HTLV-II.

Immune Compromised. A condition in which the patient has a much higher risk of infection due to a weak immune system.

Immune System. The group of organs and cells in the body that fight infection and other diseases.

Infectious Disease Markers. Elements in a person's blood that indicate if a person has been exposed to certain viruses.

Informed Consent. The process by which a person receives an explanation of the risks and benefits of a medical treatment or research study, agrees to participate, and indicates in writing that he or she understands and agrees to the information provided. A person can provide informed consent at age 18.

Infusion. The introduction of medicines, fluids, chemotherapy or blood products into a vein. Sometimes referred to as an intravenous infusion.

Leukemia. A group of cancers that involve the white blood cells. Leukemias can be acute (fast growing) or chronic (slow growing).

Leukocytes. See "white blood cells."

Lymphocytes. A type of white blood cell that is part of the immune system that helps protect the body from invading organisms. T-cells are a kind of lymphocyte that are involved in graft versus host disease.

Lymphoma. A cancer of the lymph tissue. Included in this disease category are Hodgkin's disease and non-Hodgkin's lymphoma

Malignant. Cancerous.

Marrow. See "bone marrow."

Preparative Regimen. The chemotherapy and/or radiation that is given to patients before the marrow or blood stem cell transplant.

Priming. See “mobilization.”

Prognosis. The predicted or likely outcome.

Protocol. A specifically designed treatment plan.

Radiation Therapy. Treatment to kill cancer cells using high-energy rays from X-rays, electron beams or radioactive isotopes.

Recruitment Group. An organization affiliated with the National Marrow Donor Program that recruits donors.

Red Blood Cells. Cells that carry oxygen to all parts of the body. Also known as erythrocytes.

Reduced Intensity Blood or Marrow Transplant. A blood or marrow transplant during which lower doses of chemotherapy and radiation are used to prepare a patient for transplant. It relies on the donor’s immune system to kill the disease. The donor can be a related family member or a closely matched unrelated donor.

Registry. A confidential national database of potential volunteer bone marrow/stem cell donors established and maintained by the National Marrow Donor Program.

Relapse. The return of the disease after treatment.

Remission. Complete or partial disappearance of cancer cells and symptoms after treatment.

Staging. Extensive testing done to determine if a patient is a candidate for a blood or marrow transplant. Also called evaluation.

Stem Cell Transplant. See “blood and marrow transplant.”

Syngeneic Blood or Marrow Transplant. A type of blood or marrow transplant where the donor is an identical twin.

T-cells (T-lymphocytes). A type of white blood cells that identifies organisms that do not belong in the body. The T-cells are involved in graft versus host disease (GvHD).

T-cell Depletion. Removing T-cells from the donor’s stem cells to significantly reduce the risk of developing serious GvHD.

Thrombocytopenia. Low platelet count.

Tissue Typing. A series of blood tests that evaluate the compatibility or closeness of tissue between the organ donor and recipient.

Umbilical Cord Blood Stem Cell. A stem cell from the blood of the umbilical cord and placenta. (See also “stem cell” and “cord blood.”)

Unrelated Blood or Marrow Transplant. A type of transplant where the donor is not related to the patient.

Volunteer Donor. Usually refers to an unrelated blood or marrow donor who is an acceptable HLA match and who is willing to donate blood or marrow anonymously to a recipient in need of a blood or marrow transplant. Related blood or marrow donors also may be referred to as volunteer donors.

White blood cells. Cells that help fight infection and disease (leukocytes).

Workup. See “donor workup.”

Index # 10638 | Review Date: 10/10/2018

Marrow donation. A surgical procedure by which a person donates a portion of their bone marrow for a patient who needs a bone marrow transplant.

Metastasis. The spread of cancer from one part of the body to another.

Mobilization. A process involving the movement of stem cells from the bone marrow into the bloodstream through chemotherapy and/or growth factor injections. Also called priming.

Molecular HLA Typing. See “DNA-based HLA typing.”

Monoclonal Antibodies. A form of treatment that only destroys a certain type of cell that is involved in cancer.

Multiple Myeloma. A cancer of the plasma cells in the blood.

Myelodysplastic Syndrome or Disorder (Myelodysplasia). A disease of the bone marrow in which too few platelets, red blood cells and white blood cells are made. Also called pre-leukemia or ‘smoldering’ leukemia.

Myelofibrosis. A disease that causes scar tissue to form in the bone marrow. As a result of the scar tissue, normal blood cell production is blocked. Normal blood cell production then moves to the spleen, which then becomes enlarged. Anemia results because blood production in the spleen does not work as well as in the bone marrow.

Myeloproliferative Disorders. A group of disorders caused by increased production of blood cells by the bone marrow. The four types of myeloproliferative disorders are: polycythemia vera, when too many red blood cells are formed; chronic myelomonocytic leukemia, when too many white blood cells are formed; primary thrombocythemia, when too many platelets are formed; and myelofibrosis, a disease that causes scar tissue to form in the bone marrow.

National Marrow Donor Program (NMDP).

The organization selected to manage the registry of volunteer unrelated blood or marrow donors in the United States.

Neutrophil. The type of white blood cell that is the first line of defense against infection.

Non-Hodgkin’s Lymphoma. A cancer that is found in the lymph tissue.

Peripheral Blood Stem Cells (PBSC). Cells found in the circulating bloodstream that have not become specialized.

Peripheral Blood Stem Cell Transplant. See “bone marrow transplant.”

Phlebotomy. Withdrawing blood from a vein for testing purposes.

Plasma. The liquid portion of unclotted blood that helps to replace blood volume.

Platelets. Blood cells that act as clotting agents to control bleeding.

Preliminary Search. The process by which a patient’s HLA type is sent to the NMDP and entered into the computer, where it is compared to the HLA types of all volunteers listed in the registry at that time. The preliminary search becomes formal when specific donors are requested for further testing on behalf of the patient.

Busulfan

Brand names: Myleran[®], Busulfex[®]

What does it do?

Busulfan stops the growth of cancer cells by attaching to the DNA molecule that gives the cell the ability to reproduce. Therefore, the cell can no longer reproduce. Busulfan belongs to a group of medicines known as “alkylating agents.”

How is it given?

Busulfan is given as an intravenous solution through your central venous catheter. Busulfan is given either once daily or every 6 hours around the clock for a specific number of doses.

Depending on your doctor’s treatment guidelines, your blood level of busulfan may need to be checked and the dose of busulfan may need to be adjusted.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

What are some common side effects I might experience?

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have any questions about your personal situation.

- Decreased blood counts
- Nausea and vomiting. Nausea might increase as more doses of busulfan are taken. Anti-nausea medicines can be given before each dose.
- Loss of appetite
- Rash, itching
- Mucositis. The lining of your mouth and throat, as well as your gums (called the oral mucosa), might become inflamed or sore during treatments. You might have a dry mouth with thick, sticky saliva; discomfort when chewing or swallowing; or sores in your mouth.
- Esophagitis. The lining of your esophagus (food pipe) might become inflamed and sore during treatments. You might feel a burning sensation in your throat or chest, or you might feel as if you have a “lump” in your throat. You might also feel pain when swallowing.
- Seizures. The risk of developing this side effect is minimal. However, to further reduce the risk of developing seizures, you will be given an anti-seizure medicine called Dilantin[®] once a day while you are taking busulfan.
- Diarrhea
- Loss of fertility
- Discoloration of the skin and nails
- Scarring of the lung tissue (called pulmonary fibrosis). To monitor this side effect, you will have a pulmonary function test 1 month after you are discharged from the hospital. (This is rare.)
- Hair loss
- Increased risk of infection

What do I need to know when I go home?

- Nausea and vomiting might continue for a length of time after you are discharged.
- Call your doctor if you have a persistent, dry, hacking cough.

Index # 10421 | Review Date: 8/8/2019

Carboplatin

Brand name: Paraplatin®

What does it do?

Carboplatin stops cancer cells from forming by interfering with DNA and RNA, the genetic material in cells. Carboplatin belongs to a group of medicines known as “alkylating agents.”

How is it given?

Carboplatin is an intravenous solution given through your central venous catheter continuously for 3 to 4 days, depending on your doctor’s treatment guideline.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

What are some common side effects I might experience?

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have any questions about your personal situation.

- Decreased blood counts
- Nausea and vomiting
- Loss of appetite
- Metallic taste or change in taste perception
- Hair loss on scalp and other areas of the body
- Decreased levels of electrolytes (potassium, magnesium, and calcium)

- Numbness and tingling or mild loss of muscle strength in arms and legs (called peripheral neuropathy)
- Hearing loss — rare
- Renal toxicity (kidneys affected by the medicine) — uncommon
- Liver function test changes
- Weakness, fatigue (feeling very tired)
- Diarrhea
- Mouth sores
- Risk of infection
- Skin irritation
- Loss of fertility

Index # 4794 | Review Date: 04/2019

Carmustine

Brand name: BiCNU®

What are some other names for this medicine?

Carmustine is commonly called BCNU.

What does it do?

Carmustine stops cells from dividing and multiplying. This medicine belongs to a group of agents known as “alkylating agents.”

How is it given?

Carmustine is usually given as an infusion into a vein (intravenous, IV) over 2 hours. The amount of carmustine is based on your doctor’s treatment guidelines.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

What are some common side effects I might experience?

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have any questions about your personal situation.

- Nausea and vomiting. Note: You will be given an anti-nausea medicine before receiving carmustine.
- Facial flushing
- Low blood counts. This might put you at increased risk for infection and/or bleeding until your blood counts recover.

- Increases in liver function tests. These usually return to normal once treatment is stopped.
- Dizziness
- Low blood pressure. This has been seen with high doses of carmustine.
- Pulmonary toxicity. This has been seen with high doses of carmustine. Scarring of the lung tissue (pulmonary fibrosis) may occur. To monitor this side effect, you will have a pulmonary function test one month after you are discharged from the hospital.
- Temporary redness or blurring of the eyes
- Pain and/or burning at injection site

Index # 11032 | Review Date: 04/2019

Cyclophosphamide

Brand names: Cytosan[®] and Neosar[®]

What are some other names for this medicine?

Cyclophosphamide might also be called CTX.

What does it do?

Cyclophosphamide destroys tumor cells and makes them unable to reproduce. It is known as an “alkylating agent.”

How is it given?

Cyclophosphamide is an intravenous solution given through your central venous catheter for four hours at a time, two days in a row, depending on your doctor’s treatment guidelines. It can also be used with Neupogen[®] to mobilize stem cells for autologous stem cell transplants. This is called a “priming” agent.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

What are some side effects I might experience?

- Decreased blood counts
- Nausea and vomiting. You will be given an anti-nausea medicine before receiving cyclophosphamide.
- Loss of appetite
- Mucositis. The lining of your mouth and throat, as well as your gums (called the oral mucosa), might become inflamed or sore during treatments. You might have a dry mouth with thick, sticky saliva; discomfort when chewing or swallowing; or sores in your mouth.
- Esophagitis. The lining of your esophagus (food pipe) might become inflamed and sore during treatments. You might feel a burning sensation in your throat or chest, or you might feel as if you have a “lump” in your throat. You might also feel pain when swallowing.
- Burning, painful feeling when urinating
- Facial flushing
- Blood in the urine (hemorrhagic cystitis). To help prevent this side effect, you might receive an intravenous medicine called mesna (Mesnex[®]). Additional preventive measures include extra IV fluid and close monitoring of urinary output. Drinking lots of fluids (2 to 3 quarts every 24 hours) and emptying your bladder frequently will also help prevent this effect.
- Change of taste
- Hair loss on scalp and other areas of the body
- Heart damage (cardiotoxicity). To help prevent this side effect from developing, you will have an electrocardiogram (EKG) to monitor the electrical activity of your heart before each dose of cyclophosphamide. If needed, the dosage of the medicine will be adjusted.
- Dizziness or nasal stuffiness or jaw pain while you are receiving the medicine
- Sensitivity to the sun. Avoid direct sunlight and wear sunscreen with an SPF of 30 or greater.

- Sterility in males and females
- Diarrhea
- Discoloration of skin or nails

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have questions about your personal situation.

What do I need to know when I go home?

Tell any new doctors or other health care providers, including dentists, that you received this medicine in the past.

Index # 4813 | Review Date: 8/8/2019

Etoposide (VP-16)

Brand names: VePesid[®], Etopophos[®], Toposar[®]

What are some other names for this medicine?

Etoposide is commonly called VP-16.

What does it do?

Etoposide inhibits cell division. It belongs to a group of agents known as “plant alkaloids,” meaning it is derived from a plant source.

Why is it given?

Etoposide can be given as part of the preparative regimen for autologous and allogeneic transplants. It is also sometimes used as a “priming” agent for autologous transplant patients prior to stem cell collection, to help make more stem cells.

How is it given?

If given as part of a preparative regimen, etoposide is an intravenous solution given through your central venous catheter continuously for 18 to 36 hours at a time (depending on your body weight), or for 2 hours at a time, twice a day for 3 days in a row. The amount of etoposide you receive will depend on your doctor’s treatment guidelines.

If given as a priming agent, etoposide is infused over 4 hours in the outpatient clinic.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

What are some common side effects I might experience?

- Decreased blood counts
- Nausea and vomiting. You will be given anti-nausea medicines as needed to treat this side effect.
- Loss of appetite
- Low blood pressure. You will be monitored closely for this effect.
- Headaches
- Mucositis. The lining of your mouth and throat, as well as your gums (called the oral mucosa), might become inflamed or sore during treatments. You might have a dry mouth with thick, sticky saliva; discomfort when chewing or swallowing; or sores in your mouth.
- Esophagitis. The lining of your esophagus (food pipe) might become inflamed and sore during treatments. You might feel a burning sensation in your throat or chest, or you might feel as if you have a “lump” in your throat. You might also feel pain when swallowing.
- Loss of hair on scalp and other areas of the body
- Skin changes similar to a severe sunburn. Your skin might become darker, extremely dry, and peel.
- Peripheral neuropathy: numbness, tingling and loss of muscle strength in the arms and legs. This generally improves over many months post-transplant.

- Loss of fertility
- Diarrhea
- Metallic taste during infusion. Sucking on hard candy or chewing gum might help alleviate this effect.

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have questions about your personal situation.

Index #4975 | Review Date: 8/8/2019

Ifosfamide

Brand name: IFEX®

What are some other names for this medicine?

Ifosfamide might also be called isophosphamide.

What does it do?

Ifosfamide kills cancer cells by interfering with their growth. Ifosfamide belongs to a group of medicines known as “alkylating agents.”

How is it given?

Ifosfamide is an intravenous solution given through your central venous catheter. It is administered over a 2-hour time period and given 4 days in a row.

What are some common side effects I might experience?

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have questions about your personal situation.

- Decreased blood counts.
- Nausea and vomiting. You will be given medicine to prevent this side effect.
- Loss of appetite.
- Inflammation and bleeding of the bladder. To prevent this side effect, you might receive an intravenous medicine called mesna. You will also receive more intravenous fluids and you be asked to urinate frequently.
- Confusion.
- Loss of hair on scalp and other areas of the body.
- Change in sense of taste.
- Loss of fertility.

Index #4855 | Review Date: 8/8/2019

Melphalan

Brand name: Alkeran®

What are some other names for this medicine?

Melphalan is also called L-PAM, L-sarcolysin, phenylalanine mustard.

What does it do?

Melphalan inhibits cell division. It belongs to a class of medicines known as “alkylating agents.”

How is it given?

Melphalan is given as an infusion into a vein (intravenous, IV). The amount of melphalan that is given is based on your doctor’s treatment guidelines.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

Cryotherapy: When you receive melphalan in the hospital, you will be asked to perform cryotherapy. This means sucking on ice chips before, during, and after the infusion. Cryotherapy can help reduce the severity of mucositis/mouth sores.

What are some common side effects I might experience?

Please note: The side effects listed are the most common. All possible side effects are not included. Always contact your doctor if you have questions about your personal situation.

- Decreased blood counts
- Nausea and vomiting
- Mouth sores
- Diarrhea
- Loss of fertility
- Hair loss
- Kidney toxicity. You will be monitored closely for this side effect.
- Heart irregularities. You will be monitored closely for this side effect.
- Allergic reactions. You will be monitored closely for this side effect.

Index #11033 | Review Date: 04/2019