



YOUR GUIDE TO

# Allogeneic Blood and Marrow Transplant





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# 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.
- Reporting changes in your condition or symptoms, including pain, to a member of the health care team.

### **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.
- 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.
- Notifying a member of the health care team if you do not understand information about your care and treatment.

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# 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.

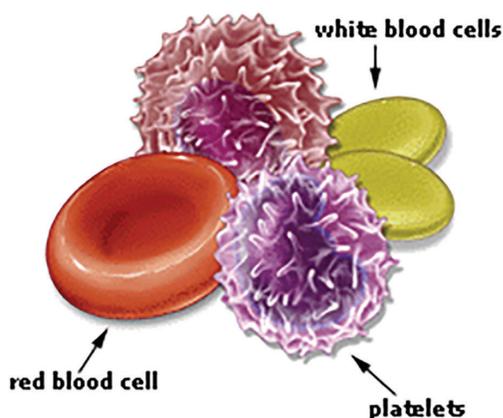
The Children's Hospital provides state-of-the-art care in a home-like setting. Because the family is an important part of a hospitalized child's recovery, the hospital rooms are designed to enable a parent to spend the night in the room with his or her child.

# 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.

# 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

## APHERESIS .....216.444.2633

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 Referra . . . . .	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

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# 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.

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# Donor Health History Screening Questionnaire

When a donor is scheduled for harvest of stem cells by either apheresis or bone marrow harvest, he or she will need to complete a donor health history screening questionnaire. Allogeneic transplant donors will be asked to complete the form when donating cells intended for use by another patient/recipient. Autologous transplant patients donating cells for their own future use will also need to complete the form.

The donor health history and screening questionnaire contains some specific questions and you may wonder why your answers to these questions are needed. Federal law requires that blood or marrow donors answer these questions, which are similar to the ones asked when donating blood. The answers are used to ensure the safety of the patient receiving the cells for transplant since infection may be carried in them. The questions gather information in two main areas:

1. Donor's own health and safety
2. Exposure to infections by vaccinations, sexual contact with others in a high risk group or travel to countries where particular infectious diseases are prevalent.

Your answers to these questions will remain confidential and will not become part of your or another's medical record. Often, a particular behavior may increase one's risk of infection, but the infection might not be detectable by a blood test for a longer period of time. Review of your answers to these questions allows your physician to assess any risk to you or to others.

Your BMT nurse coordinator will review the completed questionnaire with you at your scheduled appointment. Please answer every question and enter any additional information needed on the form to complete your answer. If you have any questions, please discuss them with your nurse coordinator or your physician.

You will be informed of any answer that may increase the risk of infection to another person. If you are an allogeneic transplant donor, your physician will seek your permission to share information about the disease that may be transmitted to the recipient with your cells. Only the infectious disease and not your specific behaviors will be shared prior to the recipient beginning the transplant process. Autologous transplant patients are treated in a similar fashion to prevent any infection in others during stem cell collection, processing and storage.

Your BMT nurse coordinator will ask if any of your answers have changed when there are delays in your harvest schedule and more than 30 days have passed since you initially completed the questionnaire. If more than 60 days have passed, then you will be asked to complete a new questionnaire. The collection staff either in the apheresis unit or in the operating room will also verify that your answers have not changed since the last review.

For additional information, you may view any of the resources listed below:

- FDA Guidance for Industry: Eligibility Determination for Donors of Human Cells, Tissues, and Cellular and Tissue-based Products: <https://www.fda.gov/downloads/BiologicsBloodVaccines/GuidanceComplianceRegulatoryInformation/Guidances/Tissue/UCM091345.pdf>
- Centers for Disease Control and Prevention. Travelers' Health. Vaccines. Medicines. Advice. <http://wwwnc.cdc.gov/travel/>

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**Dental Clearance for BMT****Patient Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_**Date of Dental Exam:** \_\_\_\_\_ **Planned Central Line Placement:** \_\_\_\_\_

We are currently working with the above listed patient as they prepare for a Blood or Marrow Transplant. Given the significant degree of immune suppression associated with this procedure and its aftermath, a thorough dental examination is necessary, with related radiographs as indicated. This is to exclude the presence of occult infection prior to the transplant. Specifically, we would like you to address the following issues:

1. Cleaning (if not done in the last 6 months or if the patient is symptomatic). If the patient is neutropenic, please consider antibiotic prophylaxis if indicated.
  - Date of Last Dental Cleaning: \_\_\_\_\_
2. Exclusion or definitive treatment of dental abscesses. Yes / No
  - Finding: \_\_\_\_\_
3. Exclusion of significant caries and active gingival or mucosal lesions. Yes / No
  - Finding: \_\_\_\_\_
4. Completion of major dental repairs or extractions if there is a significant risk for breakdown or infection within the next 3 to 6 months. We will delay admission for the transplant until at least one week following any extractions (longer if complications arise, or if otherwise advised by you). Yes / No / NA
  - Finding: \_\_\_\_\_
5. Clearance for bisphosphonates use around 100 days post-transplant. Yes / No
  - Finding: \_\_\_\_\_

Dentist Name: (please print) \_\_\_\_\_

Dentist Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Please fax completed form and/or summary of your findings to 216.445.7444**

# 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?

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# 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](http://www.fertilehope.org).

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

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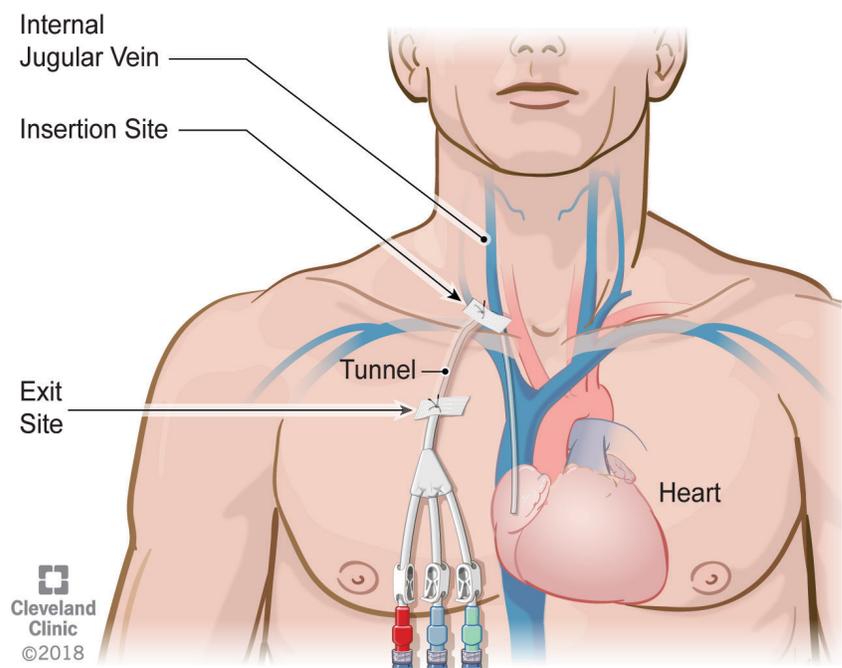
# Your Central Venous Catheter

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

>> continued

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

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

## 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!**

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# 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.**

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# 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<sup>®</sup>, to prevent the transfer of any bacteria from the old bandage to the new dressing.

**8. Clean the exit site with ChloroPrep<sup>®</sup>**

- Remove one swab from the ChloroPrep<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup> to air dry for 30 seconds. Do not pat, fan or blow on the area.
- Throw away any leftover ChloroPrep<sup>®</sup> 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.

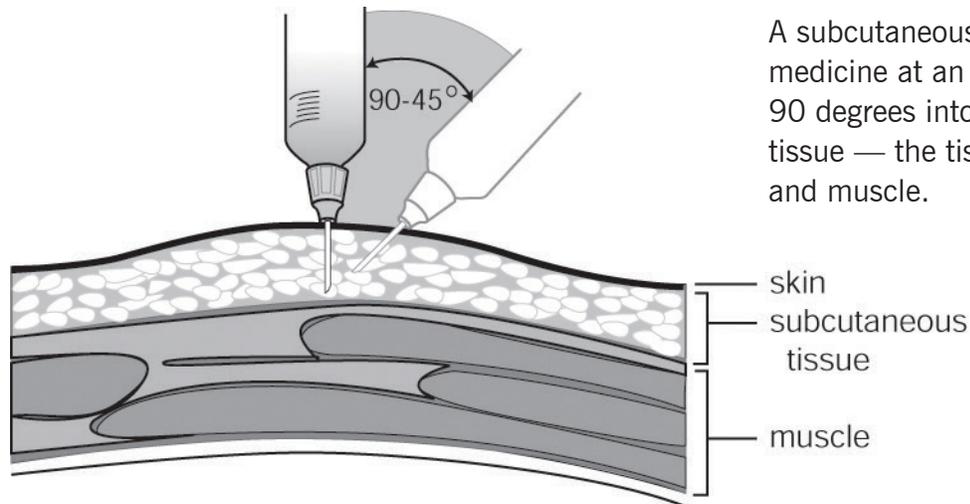
### Remember

- 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.

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# 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.

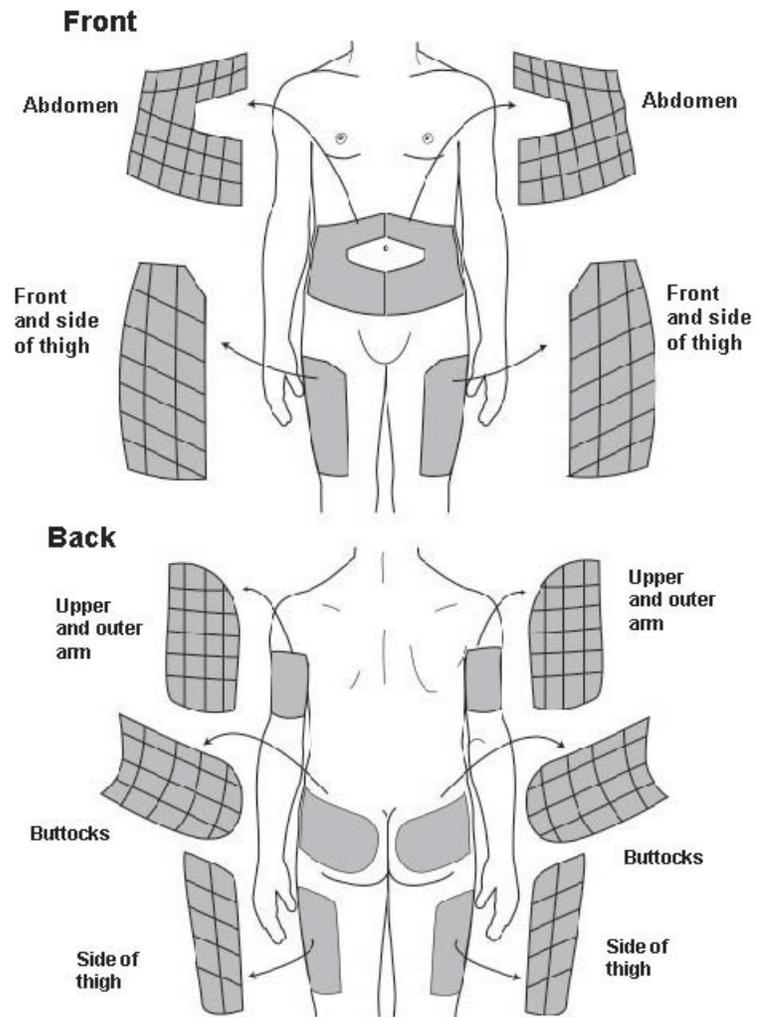
## 3. Select and clean the injection site.

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<sup>®</sup>, Zarxio<sup>®</sup>, Granix<sup>®</sup>

**Synonyms:** Filgrastim-SNDZ<sup>®</sup>, G-CSF<sup>®</sup>, Granulocyte-Colony Stimulating Factor<sup>®</sup>

## 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

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## 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](http://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

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# 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:

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# 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.

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# 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.

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# 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](http://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.themmr.org](http://www.themmr.org)

*Provides information about multiple myeloma. Funds myeloma specific research.*

**Aplastic Anemia & MDS International Foundation, Inc.** [www.aamds.org](http://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](http://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.cancer.org](http://www.cancer.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](http://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](http://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](http://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](http://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](http://www.bonemarrow.org)

*Provides education, resources and financial assistance to individuals undergoing blood and marrow transplantation. 1.800.365.13336 [patientservices@bone marrow.org](mailto:patientservices@bone marrow.org)*

## **Fertility**

### **Fertile HOPE**

[www.fertilehope.org](http://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](http://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](http://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](http://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](http://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](http://www.insurance.ohio.gov)

### **Cancer and Careers**

[www.cancerandcareers.org](http://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](http://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](http://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](http://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](http://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](http://www.rxassist.org)

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

### Rx for Ohio

[www.rxforohio.org](http://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](http://www.healthjourneys.com)

### National Center for Complementary and Alternative Medicine (NCCAM)

[www.nccam.nih.gov/](http://www.nccam.nih.gov/)

### The Center for Integrative Medicine at the Cleveland Clinic

[www.clevelandclinic.org](http://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](http://www.transplants.org)

1102 Brookfield - Suite 200, Memphis, TN 38119

1.800.489.3863 or 901.684.1697

### Help Hope Live

[www.helphopelive.org](http://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](http://www.clevelandclinic.org), click on “Patients and Visitors” and then “Parking, Lodging & Travel.”

## 4. The Allogeneic Blood or Marrow Transplant Process

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# The Allogeneic Blood or Marrow Transplant Process

## Waiting for the “Big Day”

Waiting for your blood or marrow transplant day to arrive might seem to last forever. By now, you have completed your pre-transplant evaluation and screening, and your donor has already been identified. Your donor is being scheduled for the work-up day within 30 days of the blood or marrow collection.

During this time, your nurse coordinator is gathering all of your test results. Some of the viral studies can take up to 5 days to complete. After all of the test results are received, they are submitted to your insurance company for transplant approval. This process takes about 7 to 10 working days. Your financial counselor can also answer any questions you might have about insurance coverage and benefits related to your transplant and care.

Don't forget that your nurse coordinator still needs a letter from your dentist stating that your mouth is healthy and free of infection. Please be prompt in sending this letter to your nurse by fax or hand delivery.

While you are waiting, it is not unusual for you to follow up with your referring doctor for assessments, labs, and blood transfusions. In most cases, this is appropriate because of your geographic location. Even though you might be following up with your referring doctor, please continue to notify your BMT nurse coordinator of any changes in your medical condition that occur during this time.

## Getting started: catheter placement

After your health insurance company approves your transplant, your catheter placement appointment will be scheduled in the Department of Interventional Radiology.

The **central venous catheter** will be placed during an outpatient surgical procedure. All

transplant patients must have a triple lumen central venous catheter. The catheter is used to draw blood and to infuse your chemotherapy, your donor's cells, and other IV medicines. You can learn more about the catheter in the section entitled “Pre-Transplant /Central Line Care.”

The day after the catheter placement, your nurse will give you catheter supplies and teach you how to care for your catheter. Your catheter will remain in place for at least 100 days after your transplant.

## Arriving for the Big Day

Your next visit to Cleveland Clinic is the “Big Day,” your hospital admission. Please follow your calendar that instructs you what time to report J1-1 Admitting desk.

## Admission to the Transplant Unit

Upon your admission to the Transplant Unit, you and your family will have time to tour the nursing floor, if you haven't done so already. You will also be able to ask the nurses, advanced practice providers, and doctors any questions you might have.

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

After you have been admitted to G110, the Transplant Unit, please be aware you might not see your nurse coordinator. The nurse coordinator has left your care in the expert hands of the inpatient BMT Team and will be notified when you are preparing for discharge.

## Preparative regimen

Your **preparative regimen** consists of **chemotherapy** and possibly **radiation therapy** used to destroy your own marrow and tumor cells.

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

- cyclophosphamide (Cytoxan®)
- busulfan (Busulfex, Myleran®)
- etoposide (VP-16, Etopophos®)
- cladribine (Leustatin®)
- antithymocyte globulin (Atgam®)
- fludarabine (Fludara®)

## Countdown days

The days you receive your preparative regimen are called countdown days.

The days before you receive your donor's cells are Day -1, Day -2, etc. The day you receive your donor cells is referred to as **Day 0**. The days after you receive your donor's cells are Day +1, Day +2, etc.

## Day -1

The day before you receive your donor cells (Day -1), you will begin your **immunosuppressive therapy**, cyclosporine (Neoral®) or tacrolimus (Prograf®). This medicine will suppress your immune system and allow your new donor cells to **engraft**, or grow.

## Day 0: Your infusion

**Day 0** is the day you will receive your donor cells. You will be given pre-medicines about 30 minutes before the cells are infused. When your donor cells are ready for infusion, a technologist from the transplant laboratory transports your cells to your room.

The timing of your **infusion** will depend on your donor. If your donor is related, the cells will be processed in the lab immediately after **harvesting** here at Cleveland Clinic. This means your donor cells will be ready to be infused in the late morning. Cord blood

transfusions usually occur late morning since those cells are delivered to our lab prior to your transplant.

Remember, the difference in time is due to the donor's location and the amount of time it takes for the cells to be transported and manipulated in the lab.

Your donor cells look similar to a bag of blood and are infused through your central venous catheter. Every patient will have a different quantity of cells, but it is usually between 1½ and 5 ounces. The infusion of your donor's cells usually only takes about 20 minutes. During the infusion, your blood pressure, pulse, and breathing will be monitored.

## After your infusion

### Monitoring your blood counts

Your donor cells will make their way to your bone marrow immediately after being infused. Your current blood counts will be affected by the high-dose chemotherapy and for some, radiation therapy. Therefore, your blood counts will continue to decrease in the days following your donor cell infusion.

It takes about 14 to 24 days for your donor cells to engraft, mature, and be released into the bloodstream. From the time your blood counts fall to the time when they recover (called **neutropenia**) is a very critical time. Special precautions, called **neutropenic and thrombocytopenic precautions**, will be used to protect you from infections and bleeding during this time.

*You can learn more about these precautions later in this section.*

Your inpatient nurse will inform you of 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.

## Monitoring GvHD

As your donor's cells are engrafting, your transplant team will be checking you daily for signs of **graft versus host disease (GvHD)**. Please refer to the section in this manual on GvHD so you can become familiar with this complication and know its early symptoms.

## Monitoring your recovery

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

If your **hemoglobin** and **platelet counts** are too low, you will receive blood and platelet transfusions. Blood work is drawn daily to monitor your kidney, liver, and nutrition status. If your transplant team feels you are not meeting your body's nutritional requirements, it might be necessary to supplement your diet by daily infusions of total parental nutrition (TPN) through your central venous catheter.

Other tests, such as a chest X-ray or CT scan, will be done if the Transplant Team believes these tests are needed.

## Daily activities

It is important to stay active during this time. A daily walk in the hall or on the treadmill is definitely encouraged. It is also very important to keep up with your daily hygiene by showering and being committed to doing your mouth care. This routine will also help to prevent infection.

Once your donor's cells have engrafted, any GvHD is controlled (if you even have any), and you don't have any fevers, your discharge will be considered.

At this time, your follow-up care will be arranged by your nurse coordinator. He or she will come to the Transplant Unit to discuss post-transplant outpatient care with you and your care partner.

## Hospital discharge

You and your care partner will be required to live in the Cleveland Metropolitan area — within a 1-hour drive from Cleveland Clinic — for about 3 months after your transplant. If your permanent residence is beyond this driving time, the BMT Team will help you make arrangements for your stay in the Cleveland Metropolitan area.

It is important for you to stay within this distance to Cleveland Clinic after your transplant so your BMT Team can monitor you for any treatment-related side effects. Your home doctor or hospital might not be trained to treat transplant patients.

If a sudden change in your medical condition occurs, you will be directed to come to the Cleveland Clinic Emergency Room, or we will arrange for re-admission to Cleveland Clinic.

Your inpatient team will tell you when you are close to being discharged so you can make plans. Your discharge instructions will be reviewed with you and your care partner several days before you are actually discharged. On the day of discharge, your care partner should arrive by 10 am for final review of the instructions with your nurse and the pharmacist. Your care partner will be sent to the pharmacy to pick up all the medicines you will need at home. Discharge time is noon. You will require a 24-hour care partner for the first 100 days after discharge.

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# The Related Allogeneic Bone Marrow Donor Experience

After your doctor has determined you are a good candidate for an allogeneic bone marrow transplant and a suitable **donor** has been found, the donor will begin his or her own part of the process. Your transplant would not be possible without the help of your donor. This section will help you better understand your donor's experience and give you an appreciation of the donor's involvement in your transplantation process.

Although your donor will receive a packet in the mail that provides information about the upcoming visits to Cleveland Clinic, we thought you would want to know what your donor will experience.

## Donor evaluation

Your donor will be scheduled to come to Cleveland Clinic for a day filled with appointments within 30 days of the actual bone marrow donation day. This time frame is mandated (required) by the Food and Drug Administration (FDA). The purpose of the donor evaluation is to ensure:

- Your donor meets medical criteria for blood or marrow donation.
- We will be infusing healthy marrow.

Having your donor complete the appointments at Cleveland Clinic ensures that billing will be processed appropriately. All of your donor's bills are the responsibility of your insurance company.

## Donor work-up day: Tests needed

- Chest X-ray (picture of the lungs)
- Electrocardiogram (a graph of the electrical impulses travelling through the heart to evaluate heart function)
- Blood tests. Samples of blood will be drawn

from a vein in the donor's arm and the following laboratory tests will be performed:

- CBC (complete blood count)
- CMP (comprehensive metabolic panel)
- Pregnancy test (if needed)
- Bleeding times
- ABO blood type
- Infectious disease tests. Human immunodeficiency virus (HIV), cytomegalovirus (CMV), toxoplasmosis, hepatitis, Epstein-Barr virus (EBV), herpes, HTLV I/II, varicella, syphilis, West Nile virus and Chagas.

## Donor work-up: Meetings with the BMT Team

- **Meeting with a transplant doctor.** The appointment will begin when your donor meets with one of the BMT doctors — usually the doctor who will be harvesting your donor's marrow. The doctor will review the process of harvesting the marrow and will discuss the tests that will be performed later in the day. Also included in this appointment is a review of the donor's past medical history and a physical exam.

After the doctor receives all of the test results from the work-up, he or she will decide if any additional tests need to be scheduled. It can take from 7 to 12 days to receive these results. If any tests or lab results are abnormal, it is possible that your donor will be expected to return to Cleveland Clinic for further testing and for possible consultations with other specialists. Again, this is to ensure the safety of the donation and the health of both you and your donor.

The doctor will meet with your donor a second time to review the test results and discuss any abnormal findings on the tests. Your donor will be able to ask any questions during this time. This appointment will usually be scheduled the week prior to your hospital admission and start of chemotherapy.

- **Meeting with your nurse coordinator.** Your donor will meet with the nurse coordinator to review the process of donation and discuss surgery preparation.

Your donor will be asked to complete a Health History Survey, as required by the FDA, to assess for risk of exposure to communicable diseases (diseases that can be passed from person to person). The nurse coordinator will review the survey and answer any questions your donor might have.

- **Meeting with the financial counselor.** Your donor will have the opportunity to meet with the financial counselor to discuss the process of billing and to answer any questions about insurance coverage for the marrow donation. All of your donor's bills are the responsibility of your insurance company.

## Harvest Day

Your donor will be expected to arrive very early on the day of harvest. An IV line will be started to provide intravenous fluid, both during and after the procedure.

The procedure will be performed in the operating room where the doctors and advanced practice providers (physician assistants/nurse practitioners) wear gowns and masks. The anesthesiologist will have your donor breathe into an oxygen mask and will inject medicine into your donor's IV. This will make your donor fall asleep.

The bone marrow is obtained by withdrawing (aspirating) special stem cells, along with some blood, through a needle. The needle is inserted through the skin into the marrow cavity of the hip bones, called the iliac crests. Your donor will have about 2 to 3 skin punctures on each rear hip, but there will be numerous bone punctures underneath the skin.

The procedure takes about 1 hour to collect enough cells. Usually 1 to 2 quarts of marrow are collected, which is only about 5percent of your donor's total marrow cells. Once the procedure is completed, a dressing will be placed over the needle marks to protect them.

## Recovery

Your donor will stay in a recovery room for about an hour, where a nurse will assist in waking your donor. The nurse will also frequently check your donor's vital signs (blood pressure, pulse, etc.) and check the hip dressings for bleeding.

When your donor is fully awake, he or she will be taken back to the recovery room. Around 2 pm to 4 pm, the BMT advanced practice provider will be called to visit your donor and explain the discharge instructions. The donor goes home the same day.

After they are discharged, many donors prefer to visit you in the BMT Unit. This is welcomed!

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# Matched Unrelated Donor (MUD) Allogeneic Transplant

After your doctor has determined you are a candidate for a **Matched Unrelated Donor (MUD) transplant**, your nurse coordinator will complete a donor search through the **National Marrow Donor Program (NMDP)**.

## Finding a donor

Your nurse coordinator will submit your demographics, disease status, and high resolution typing antigens to the NMDP via computer. The computer will then display all possible matches. Your nurse coordinator will select the best possible donors and request the NMDP to contact them. This process is called the **confirmatory typing (CT) stage**. If there are no potential donors in the NMDP, your nurse coordinator might conduct the donor search at international centers.

The potential donors will send a blood sample to our lab for further compatibility testing using **crossmatch** and **DNA** methods. At this time, the donor's blood is also tested for infectious diseases. The donor's health history is evaluated to determine if there are any potential risks that would endanger either you or the potential donor during the transplant/donor process.

## Receiving updates about the donor search

You will receive a letter from the Office of Patient Advocacy at the NMDP when the donor search is formalized. This information is provided to help you understand the process and other resources available to you. Your nurse coordinator will mail you monthly updates. However, you may call the nurse coordinator at any time with questions or concerns.

## Donor work-up

Once a donor is confirmed as a match, the donor is requested to have a **“donor work-up.”** The purposes of the donor work up are to ensure:

- Your donor meets medical criteria for blood (peripheral blood stem cells) or marrow donation.
- We will be infusing healthy marrow or stem cells.

The complete work-up process might take 30 to 60 days, depending on the donor's availability and health.

## Support is available

While you are waiting for a matched donor, you and your family might benefit from joining a **BMT support group**. Awaiting a transplant can cause stress and anxiety, but support resources can help you and your family deal with the emotional aspects of the transplant process. A list of available BMT resources is available from your BMT Social Worker and in the “Social Work” section of this manual.

## Information session

After a potential donor has been identified, the donor center contacts the donor to explain the donation procedure. At that time, the donor receives information about your disease and the usual treatment options for this disease, as well as general information about you including your age, sex, and medical status. No other identifying information is given out.

## Physical exam

The physical exam ensures that the donor is not at risk for developing anesthesia problems (during the marrow collections). The physical exam is also performed to make sure the donor does not have any health problems that could

be passed along to you through the marrow or stem cells.

The physical exam might reveal medical problems that might lead to the rejection of the donor (such as pregnancy, infectious disease, or high risk for anesthesia problems.)

### **If a donor is not cleared**

If the original donor is not accepted, the transplant center will select another donor, if available, and the donor work-up process starts over. If a donor is not available, the search process will continue.

### **Donor clearance**

Once the donor is mentally and physically ready, he or she is “cleared.” Remember, your donor must be cleared by both the donor center and the collection center before you may be admitted to the Transplant Unit to begin your preparative regimen. Your BMT nurse coordinator will be calling you with the news when your donor has been “cleared.”

### **Harvest/stem cell collection**

Your unrelated donor’s bone marrow or peripheral blood stem cells will be harvested the day before your cells will be infused (T-O). This means the marrow or stem cells will be hand-carried on an airplane and cab to get it from the collection center to Cleveland Clinic, where it will then be processed before infusion.

### **Confidentiality**

Many of the steps taken in the search process are designed to ensure the safety and confidentiality of the donor and recipient. By law, the NMDP is required to keep the donor’s and recipient’s identities in confidence, at least until a year after the transplant, when the two parties can give informed consent for the release of their identity to each other. The NMDP has standards that ensure the donor’s right to privacy while making the decision to donate, just as it ensures your right to privacy during your recovery.

The NMDP allows cards and gifts to be exchanged between the donor and recipient, with the understanding that specific identifying information is not included. Some international centers do not allow the exchange of any information between the donor and recipient. The transplant center coordinators and the donor center coordinators screen cards and gifts and will remove identifying information.

Here is some information you might want to include in your correspondence to the donor:

- Thank the donor for the gift of blood or marrow
- How long you waited for a transplant and how the wait affected you and your family
- How the transplant has improved your health and changed your life
- What has happened in your life since the transplant
- If you are married, have children, grandchildren, etc.
- Your hobbies or interests

Here's the information you should **NOT** include in your correspondence to the donor:

- Do not include your name, address, city, state or phone number.
- Do not include the name or location of the hospital where your transplant surgery was performed, nor the names of your transplant healthcare providers.

Your letter will be reviewed prior to giving it to your donor, so do not seal the envelope. You can give the letter to your BMT nurse coordinator who will send it to the National Marrow Donor Program to deliver it to your donor.

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# Common Inpatient Medicines for Allogeneic Transplant Patients

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

- **Acyclovir (Zovirax®)** is used to prevent or treat infections caused by certain viruses. This medicine is started on admission and given every 12 hours, or twice a day. You will be prescribed either acyclovir or ganciclovir at one time. Possible side effects include dizziness, headache, nausea, vomiting, muscle or joint pain.
- **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 on admission. Possible side effects include dizziness, drowsiness, confusion, increase in heart rate, decrease in blood pressure, dry mouth, and blurred vision.
- **Sulfamethoxazole/Trimethoprim (Bactrim®)** is used to prevent or treat bacterial infections. This medicine is started on admission and is usually given every 12 hours, or 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 busulfan.
- **Hydromorphone (Dilaudid®), Morphine, Oxycodone (Oxycontin®)** 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 the ears, blurred vision, nausea, vomiting, urinary retention, rash, and cramps.
- **Electrolytes (calcium, magnesium, phosphorus, potassium)** are chemical substances in your body that are involved in metabolic activities and are essential to the normal function of all cells. Certain medicines, diarrhea, and nutritional status deplete your body of its normal levels of electrolytes. You will be given electrolytes to replace what has been lost.
- **Valganciclovir (Valcyte®)** is used to prevent or treat CMV (cytomegalovirus) while your immune system is suppressed. You will be prescribed either acyclovir or Valcyte® at one time. Possible side effects include decrease in platelet and white blood cell counts, nausea, vomiting, diarrhea, fever, confusion, rash, and headache.
- **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®)** are used to stimulate the growth of white blood cells (neutrophils). These are given daily, beginning a certain number of days after your stem cell infusion. Possible side effects include fever and bone pain.
- **Immunoglobulins, IVIG, (Gammagard®)** are used to boost the immune system. This medicine increases the ability of the body to fight off viruses, bacteria, and other toxins. Possible side effects include rash, chills, fever, headache, fatigue, and joint 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 sent to check for 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 release excess fluid in the body. Your transplant team will assess your weight, fluid retention, and blood pressure, as well as the amount of fluid you take in and put out every day to determine whether 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.
- **Mycophenolate mofetil (CellCept®), cyclosporine (Neoral®, Sandimmune®), tacrolimus (Prograf®), methotrexate and antithymocyte globulin** are used to help suppress the immune system, thereby helping to prevent rejection of your new bone marrow. They are also used to prevent the complications of graft-versus-host disease (GvHD). Possible side effects include headaches, tremors, diarrhea, nausea, confusion, decrease in kidney function, and increase in blood pressure.
- **Nystatin (Mycostatin®)** are used to help prevent mouth sores and fungal infections in patients receiving chemotherapy and antibiotics. These medicines 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 these medicines, you should not eat or drink anything for 15 minutes after taking them.
- **Esomeprazole (Nexium®), famotidine (Pepcid®), omeprazole (Prilosec®), pantoprazole (Protonix®) and lansoprazole (Prevacid®)** reduce acid production thereby reducing heartburn and nausea. Possible side effects include headache, dizziness, and constipation.
- **Prednisone (Deltasone®)** is used to reduce inflammation or to help suppress the immune system to prevent or treat graft-versus-host disease (GvHD). Possible side effects include increased susceptibility to infection, nausea, headache, increase in blood pressure, increase in appetite, decrease in platelet count, weakness, and edema.
- **Itraconazole (Sporanox®), voriconazole (Vfend®), fluconazole (Diflucan®) and posaconazole (Noxafil®)** are used to treat or prevent infections caused by fungi. It is usually started the day after your transplant. Possible side effects include nausea, vomiting, abdominal cramping, fatigue, high blood pressure, headache, or decrease in electrolytes.

# 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.

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# 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.

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# 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	
<b>9:00 a.m.</b>	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 <sup>®</sup> swish and swallow (if prescribed).
<b>1:00 p.m.</b>	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 <sup>®</sup> swish and swallow (if prescribed).
<b>6:00 p.m.</b>	Rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin <sup>®</sup> swish and swallow (if prescribed).
<b>9:00 p.m.</b>	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 <sup>®</sup> 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<sup>®</sup> + Maalox<sup>®</sup> + 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><b>Dehydration</b></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"> <li>• When you are in the hospital you will receive intravenous fluids.</li> <li>• 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"> <li>- Dark urine</li> <li>- Small amount of urine</li> <li>- Rapid heart rate</li> <li>- Headaches</li> <li>- Flushed (face/upper chest feels hot or changes color) or dry skin</li> <li>- Coated tongue</li> <li>- Irritability and confusion</li> <li>- Dizziness with position changes</li> </ul> </li> </ul>

Discomfort	Recommendations
<p><b>Skin Rash</b></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"> <li>• Gently cleanse the affected area using lukewarm water and mild soap. Do not rub your skin. Pat your skin dry with a soft towel.</li> <li>• Do not scratch or rub the affected area.</li> <li>• Do not apply any ointment, cream, lotion or powder to the affected area unless it has been prescribed.</li> <li>• Do not apply cosmetics, shaving lotions, perfumes or deodorants on the affected area.</li> <li>• Use only an electric razor if you need to shave within the affected area.</li> <li>• 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.</li> <li>• Do not apply medical tape or bandages to the affected area unless you are told to do so by your health care provider.</li> <li>• Do not expose the affected area to extreme heat or cold. Avoid using an electric heating pad, hot water bottle or ice pack.</li> <li>• 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.</li> </ul>

Discomfort	Recommendations
<p><b>Hair Loss</b></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"> <li>• This side effect can be very upsetting. Talk to your nurse or social worker about wearing scarves, hats or a wig.</li> <li>• 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.</li> <li>• Avoid frequent shampooing. Use a mild shampoo (such as baby shampoo) without any perfumes.</li> <li>• Wash your scalp with warm water. Avoid rubbing and do not scratch. Pat dry with a soft towel.</li> <li>• Avoid excessively combing or brushing your hair.</li> <li>• Avoid using hair spray, oils or creams.</li> <li>• Avoid using heat sources on your hair (including hair dryers, rollers, or curling irons).</li> <li>• Do not perm or color your hair. Ask your health care provider when you can go back to coloring or perming your hair.</li> <li>• 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).</li> </ul>

Discomfort	Recommendations
<p><b>Fatigue</b></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"> <li>• <b>Evaluate your level of energy.</b> 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. <ul style="list-style-type: none"> <li>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.</li> </ul> </li> <li>• <b>Be alert to your personal warning signs of fatigue.</b> 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.</li> <li>• <b>Plan ahead, organize and prioritize your daily activities.</b> 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.</li> <li>• <b>Schedule rest.</b> Balance periods of rest and work. Rest before you become fatigued. Frequent, short rests are beneficial.</li> <li>• <b>Pace yourself.</b> A moderate pace is better than rushing through activities.</li> <li>• <b>Exercise daily.</b> Walking is an excellent way for you to regain your strength and stamina.</li> <li>• <b>Eat a well balanced, nutritious diet.</b></li> <li>• <b>Manage stress.</b> Managing stress can play an important role in combatting fatigue. Adjust your expectations and ask others for support and help.</li> </ul>

Discomfort	Recommendations
<p><b>Fatigue</b> <i>continued</i></p>	<ul style="list-style-type: none"> <li>• 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"> <li>- Increased shortness of breath with minimal exertion</li> <li>- Uncontrolled pain</li> <li>- Inability to control side effects (such as nausea, vomiting, diarrhea, or loss of appetite) from treatments</li> <li>- Uncontrollable anxiety or nervousness</li> <li>- Ongoing depression</li> </ul> </li> </ul>

Discomfort	Recommendations
<p><b>Insomnia (difficulty sleeping)</b></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"> <li>• If necessary, you may be given a prescription medicine to help you fall asleep.</li> <li>• Practice relaxation techniques such as mental imagery, deep breathing, reading or listening to calming music.</li> <li>• Make sure you are comfortable. Arrange your pillows so you can maintain a comfortable position.</li> <li>• Avoid napping too much during the day. At the same time, remember to balance activity with rest.</li> <li>• 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.</li> </ul>

Discomfort	Recommendations
<p><b>Sexual Side Effects</b></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"> <li>• Discuss your concerns about fertility and your desire to have children after treatment with your doctor <b>before</b> you begin cancer treatment.</li> <li>• Concerns about being biologically able to have children might be distressing, so it might help to seek counseling with your BMT social worker.</li> <li>• It might help to talk about fertility loss and its impact on you and your partner or future partner.</li> <li>• 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.</li> <li>• 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).</li> <li>• 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.</li> </ul>

Discomfort	Recommendations
<b>Sexual Side Effects</b> <i>continued</i>	<ul style="list-style-type: none"><li>• 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.</li></ul>

# 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)

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# 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”)

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# Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is a common virus that infects most people at some time during their lives but rarely causes obvious illness. It is a member of the herpes virus family. Other members of the herpes virus family cause chickenpox, infectious mononucleosis, fever blisters (herpes I) and genital herpes (herpes II). Like other herpes viruses, CMV infection can become dormant (temporarily inactive) for a while and may reactivate at a later time. The virus is carried by people and is not associated with food, water or animals.

People who have had a blood or marrow transplant and who are on immunosuppressive medication can have CMV reactivate. This reactivation can cause many different infections. If untreated, these infections can be life-threatening. A transplant patient who received donor cells may be at risk for developing an active CMV infection if he or she or the donor was exposed to the virus in the past.

Your transplant team will be monitoring you often for CMV with frequent blood tests. This test will indicate if the virus has become active. You will have these tests drawn weekly for the first three months after your transplant. For the following three months (until 6 months after your transplant), these tests will need to be drawn every 2 weeks.

After 6 months, your CMV blood test will be checked at each physician appointment. If you have active graft-vs-host disease, if you are on prednisone, or if you have had a CMV infection, your transplant physician may have you continue to check more frequently.

If you get an infection cause by CMV or your CMV becomes active, you will be treated with antiviral medications. These medications can be either oral pills or IV infusions. This will be determined by your transplant physician.

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# Neutropenic Precautions For Allogeneic 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 mask when outside G110 or G111 inpatient units.
4. Minimize venipunctures and invasive procedures.
5. 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.
6. Cooked food from outside can be brought in after patient/family receive food safety education from a dietitian
7. Change your central line catheter dressing once a week.
8. 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.
9. Do not use the following products. They can increase your risk of infection.  
Do not use:
  - Tampons
  - Suppositories or enemas.
  - Cotton swabs (Q-Tips®).
10. Do not engage in 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.

# 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.

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## 5. Transplant Medicines

- › Transplant Medicines Overview
- › What You Should Know About Your Medications and Prescription Coverage

# 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)?

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# What You Should Know About Your Medications and Prescription Coverage

## Formulary vs. non-formulary

A formulary is a list of medications (brand and generic/"off-brand") that are preferred by your prescription plan. Your plan may only pay for medications that are on this preferred list, or if they cover them, it may be at a higher cost to you. The purpose of a formulary is to provide you with the least expensive medications that are effective for treating your health condition. Each prescription plan has a unique formulary; this may be available on your insurance company's website. Additionally, some plans require you to fill your prescriptions at preferred pharmacies. Talk to your local pharmacist and/or insurance company to obtain a list of preferred pharmacies and medications.

## Co-payments or "co-pays"

A co-pay is the amount, or portion of the cost, you are required to pay out-of-pocket for your prescription medication after your insurance has paid their part. Another term that is frequently used is "coinsurance" which means you are responsible for a percentage of the cost of your medication (for example, 10 percent of all generic medications) instead of a flat fee.

## Formulary tiers

Medications on the formulary are categorized into three categories:

**1. Generic.** These "off-brand" medications have the lowest co-pays and are generally referred to as "Tier 1 medications" (generic medications are FDA approved to be equivalent to their brand name counterparts).

**2. Formulary brand name.** These medications, which are only available as the brand product because their generic form is not yet available, have a higher co-pay and are generally referred to as "Tier 2 medications."

**3. Non-formulary.** These medications have the highest co-pays because there may be a similar drug available on a lower tier of the formulary. Alternatively, a medication may be non-formulary if it is new or extremely expensive. These are generally considered "Tier 3 medications."

## Prior authorization or "PA"

If a medication is not included on your prescription plan's formulary, it is sometimes possible to obtain coverage. Your doctor must complete this process, also known as a prior authorization, by submitting the proper forms and documentation to your insurance plan. It is important for you to determine if you need a PA for your medication before you attempt to have it filled for the first time, because the PA process may take a few days to complete. Additionally, some medications may require a PA every month, whereas others require your doctor to complete the process only one time.

This worksheet was created so you are aware of the potential financial impact of several expensive medications you may require following transplant. Every patient's insurance coverage is different. You should contact your insurance company to ask what you will be required to pay for these medicines IF they are needed.

## Medication list

The list only includes the most common and most expensive medications that typical patients require following transplant — not all of the possible medications are included. Your medication list will be determined by your doctor based on your specific needs and circumstances. Cash prices listed reflect only the current prices offered by the Cleveland Clinic as of March 13, 2019.

Cash prices for other pharmacies may vary. The “cash price” is the cost of the medication WITHOUT prescription coverage.

### Allogeneic Blood and Marrow Transplant Patient Medication Cost Worksheet

NOTE: Drug prices can change dramatically at any time and without notice.

Drug Name *(Indicates brand only)	Dose	Monthly Quantity	Indication	Cash Price (Monthly)	Monthly Cost to Patient (co-pay)	Prior Auth Needed Y or N	Mail Order or Retail Pharmacy M or P
Voriconazole	200	60 tablets	Prevent/treat fungal infection	\$4,294			
Itraconazole (Sporanox*)	10 mg/ mL solution	600 mL (4 bottles)	Prevent/treat fungal infection	\$1,395			
Posaconazole (Noxafil*)	40 mg/ mL	630 mL (6 bottles)	Prevent/treat fungal infection	\$9,847			
Posaconazole (Noxafil*)	100 mg	90 tablets	Prevent/treat fungal infection	\$7,031			
Valganciclovir	450 mg	120 tablets	Prevent/treat fungal infection	\$7,841			
Sirolimus	1 mg	30 tablets	Immuno- suppressant	\$458			
Sirolimus (Rapamune*)	1 mg/ mL solution	60 mL (1 bottle)	Immuno- suppressant	\$2,000			
Tacrolimus (Mylan)	1 mg	120 capsules	Immuno- suppressant	\$464			

## Allogeneic Blood and Marrow Transplant Patient Medication Cost Worksheet

NOTE: Drug prices can change dramatically at any time and without notice.

Drug Name *(Indicates brand only)	Dose	Monthly Quantity	Indication	Cash Price (Monthly)	Monthly Cost to Patient (co-pay)	Prior Auth Needed Y or N	Mail Order or Retail Pharmacy M or P
Cyclosporine, modified	100 mg	120 capsules	Immuno-suppressant	\$594			
Mycophenolate mofetil	500 mg	120 tablets	Immuno-suppressant	\$818			
Letermovir (Prevymis*)	480 mg	28 tablets (must be dispensed in multiples of 7)	Prevent cytomegalovirus (CMV) infection	\$6,536			

Are there restrictions on what pharmacy I may use to fill these prescriptions?  YES  NO

Am I required to use a mail order pharmacy for any of these prescriptions?  YES  NO

Prescription Insurance Information\*\*

Plan Name: \_\_\_\_\_

Policy Holder Name: \_\_\_\_\_

RX ID \_\_\_\_\_

Relationship to Policy Holder: \_\_\_\_\_

RX BIN: \_\_\_\_\_

Customer Service Phone No.: \_\_\_\_\_

RXPCN: \_\_\_\_\_

Date of Contact \_\_\_\_\_

RX Group: \_\_\_\_\_

\*\*This information can be found on your prescription insurance card

## 6. After Transplant

- › Contacting the Transplant Team
- › Allogeneic Transplant Patients and Care Partners:  
Things to Know Before You are Discharged
- › Follow-Up Appointments For Allogeneic 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
- › Sample: Daily Medication Log
- › Daily Medication Log
- › Vaccinating Recipients of Hematopoietic Stem Cell Transplants

# 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:

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

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

- Know how to take care of your triple lumen Hickman catheter. This includes dressing changes and changing caps once a week and flushing all lumens daily.
- Your blood pressure cuff should be checked for accuracy before discharge.
- Know how to use the blood pressure cuff. You should know abnormal blood pressure ranges to report and whom to tell. You should keep a log of all blood pressure readings after discharge, and bring the log with you to every appointment with your doctor.
- 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 how and where to log your daily blood pressure and temperature readings.
- Know low white blood cell (neutropenic) precautions and restrictions, and how long to follow these restrictions.
- Know low platelet (thrombocytopenic) precautions and restrictions, and how long to follow these 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.
- The pharmacist and nurse will review your medicine list before you are discharged. This will include medicine administration times to avoid medicine interactions.
- Your care partner should pick up your prescriptions before discharge so you can review them before leaving the hospital.
- Know when to follow-up with the doctor.
- Know when you are having follow-up labs drawn and where.
- Know when to have vaccinations redone.
- Recognize graft-versus-host disease (GvHD) signs and symptoms.
- Understand nutrition after transplant.
- Understand sexuality after transplant.
- Understand adjustments to life after transplant.
- Know when you should see your nurse coordinator.
- Provide local numbers, including cell phone number (if available) to your nurse coordinator.
- Your care partner should arrive on your day of discharge at 9 am.
- Discharge is before noon.

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# Follow-Up Appointments For Allogeneic Transplant Patients

## Staying in Cleveland

After your allogeneic transplant, you and your care partner will be required to live in the Cleveland Metropolitan area — within a 1-hour drive from Cleveland Clinic — for a minimum of 100 days after your transplant. It is important for you to stay in the Cleveland Metropolitan area after your transplant so you can be monitored closely.

If your permanent residence is beyond this distance, you will be required to make arrangements to stay locally. Your social worker can provide you with resources.

## Where will I go for my follow-up appointments?

Your follow-up appointments will be scheduled in the Blood & Marrow Transplant Outpatient Clinic, located on the Taussig Cancer Institute. You may park in the Visitor's Parking Garage located on E. 100th boulevard between Cedar and Carnegie Avenues. Discounted parking vouchers are available at the attendant's booth in the parking garage or at the Cashier's Office in the H area of the Cleveland Clinic. Unfortunately, we are not able to validate your parking tickets.

## How often do I need to go to follow-up appointments?

Your follow-up appointments will be scheduled frequently (several times a week) for the first few weeks after your transplant. Although Clinic visits are frequent at first, they will gradually taper off as your condition improves.

If at any time you develop a fever or complications, you might have more frequent appointments, or you might need to be admitted to the hospital until your condition

improves. It is important that your symptoms are closely monitored. Although re-admissions might be discouraging, they are very common.

Because these appointments play a vital role in monitoring your progress, it is very important you attend all appointments as scheduled.

Your appointment days might vary, depending upon your doctor's schedule.

## How long are the follow-up appointments?

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

## What should I bring?

- Bring your morning dose of cyclosporine (Neoral®) or tacrolimus (Prograf®) on these days. (Do not take it before your appointment.)
- You might want to bring a book, video or activities with you. A television and DVD player are available in most treatment rooms.
- Please bring your BMT education manual so we can review your patient record of temperature, blood pressure and medicines.
- You may bring food or snacks from home. The treatment area offers soups, crackers, and beverages. There is also a Bistro in the Taussig Cancer Institute where you can buy breakfast and lunch.
- Bring any medications you need to take throughout the day while here.

## What happens during my follow-up appointments?

You will be assessed and have blood tests at each appointment. Many times, these are the only ways GvHD, infections or other complications can be detected.

### Blood tests

In order for the Transplant Team to effectively monitor your health, blood tests — including a complete blood count and chemistry profile — will be performed. Additional blood tests may be ordered and your treatment plan modified according to your condition. If your condition is stable, your lab work might become less frequent, but it will always be necessary.

### Other tests

In addition to blood tests, other tests or treatments may be performed during your follow-up appointments:

- **Chest X-rays.** These are performed as needed to check your lungs and to detect the possible development of a lung infection.
- **Immunoglobulins (Iveegam<sup>®</sup>, Gammagard<sup>®</sup>).** This medicine is infused over several hours to boost your immune system. The frequency of the infusions will be determined by a blood test that measures your immunoglobulin levels.
- **Blood transfusions.** Depending on the results of your complete blood count, you may receive a red blood cell transfusion and/or platelet transfusion.
- **Electrolyte infusion.** If, for example, your potassium or magnesium levels are low, you may receive either or both of these important minerals infused into your central venous catheter. If you eat foods high in electrolytes, you might be able to help decrease the need for intravenous electrolyte replacement.

Note: There is more information in this guide about foods high in specific electrolytes.

### Consultation with the doctor and nurse

You will meet weekly with your doctor and nurse coordinator to assess your health, address your concerns, and provide you with resources you might need. Your social worker can be contacted if there are any concerns that you may need to discuss with her. Notify your nurse or doctor of your request.

These appointments become less frequent as you recover.

There are many times when you will be receiving treatment at the same time your doctor appointment is scheduled. If this occurs, and you are not receiving blood or platelets, please take your IV pump/ medicine to the CA-2 front desk to check in for your doctor appointment.

\*Please notify your treatment nurse when you leave and return to treatment.

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# 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.**

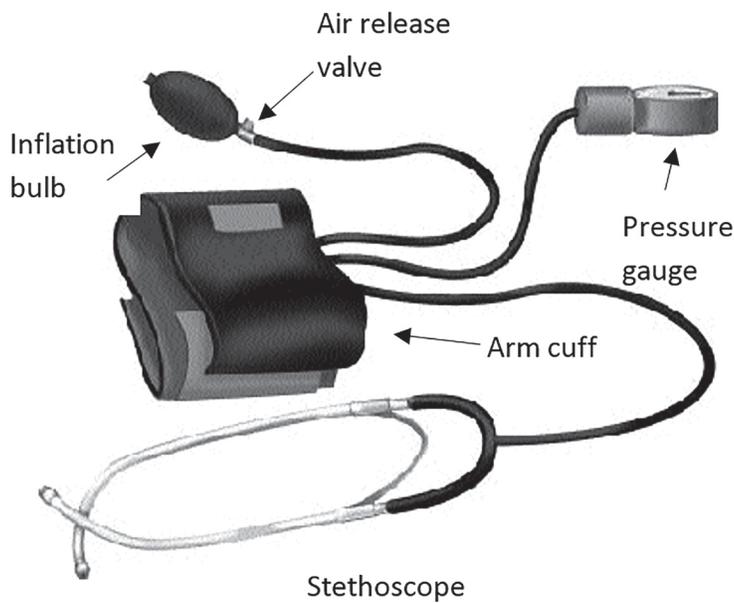
### **How to Take Your Blood Pressure**

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

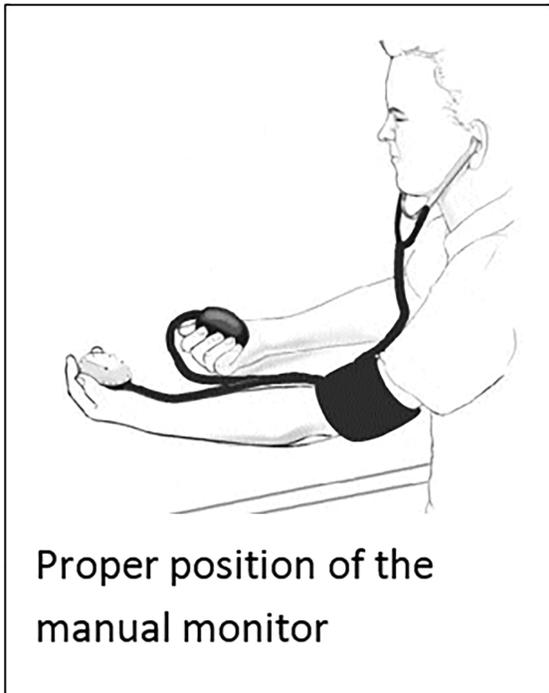
Locate your pulse by lightly pressing your index and middle fingers slightly to the inside center of the bend of your elbow. Here you can feel the pulse of the brachial artery.

### 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- $\mu$ 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](http://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](http://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<sup>®</sup>, Boost<sup>®</sup>, Resource<sup>®</sup>, Carnation Instant Breakfast<sup>®</sup>, Boost<sup>®</sup> bars and Boost<sup>®</sup> puddings. If you have diabetes, Glucerna<sup>®</sup> and Boost<sup>®</sup> 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.

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# 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

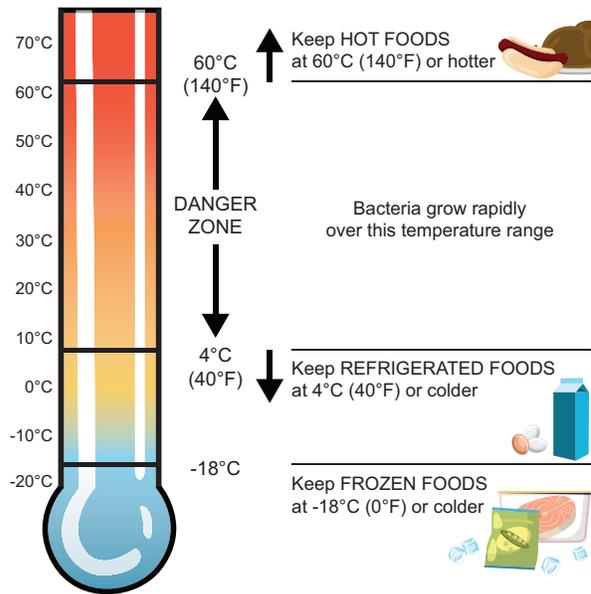
- Use a food thermometer to be sure foods are at a safe internal temperature.
- Reheat leftovers to an internal temperature of 165° F throughout before serving.
- Bring leftover soups, sauces, and gravies to a rolling boil before serving.
- Throw away any leftovers after they have been reheated once. 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](http://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"> <li>• Meat, poultry, fish, and seafood cooked to proper temperature</li> <li>• Hot lunch meats and hot dogs</li> <li>• Well-cooked (solid white and yolk) or pasteurized eggs</li> <li>• Well-cooked or pasteurized tofu and tempeh</li> <li>• Cooked or roasted nuts</li> </ul>	<ul style="list-style-type: none"> <li>• Raw, undercooked, or cold smoked meat, poultry, fish, and seafood</li> <li>• Cold lunch meats and hot dogs</li> <li>• Undercooked or raw unpasteurized eggs (i.e. dippy, over-easy, and poached eggs)</li> <li>• Raw or unpasteurized tofu and tempeh</li> <li>• Raw nuts</li> <li>• Prepared foods from deli counter (i.e. tuna salad, egg salad)</li> </ul>
Fruits	<ul style="list-style-type: none"> <li>• Washed fresh fruit</li> <li>• Pasteurized fruit juices</li> <li>• Cooked, frozen, dried or canned fruit</li> </ul>	<ul style="list-style-type: none"> <li>• Unwashed fresh fruit</li> <li>• Unpasteurized fruit juices</li> </ul>
Vegetables	<ul style="list-style-type: none"> <li>• Washed raw vegetables and herbs</li> <li>• Cooked vegetables and herbs</li> <li>• Frozen and canned vegetables</li> <li>• Pasteurized vegetable juice</li> </ul>	<ul style="list-style-type: none"> <li>• Unwashed raw vegetables and herbs</li> <li>• Salads from salad bars or delis</li> <li>• Unpasteurized vegetable juice</li> <li>• Raw sprouts</li> </ul>
Grains	<ul style="list-style-type: none"> <li>• Cooked or ready-to-eat cereal, bread, pasta, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Raw flour, dough, and batter</li> <li>• Raw sprouted grains</li> <li>• Raw or undercooked yeast</li> </ul>
Milk and milk products	<ul style="list-style-type: none"> <li>• Pasteurized dairy products (i.e. milk, cheese, cream, butter, yogurt, whipped cream)</li> <li>• Cheese made with pasteurized milk</li> <li>• Packaged ice cream/bars, frozen yogurt, sherbet</li> <li>• Pasteurized eggnog</li> <li>• Packaged protein shakes nutrition shakes</li> </ul>	<ul style="list-style-type: none"> <li>• Unpasteurized dairy products</li> <li>• Any cheese if made from unpasteurized milk (i.e. brie, feta, camembert, and farmers cheese)</li> <li>• Soft-serve ice cream, custard, or yogurt</li> <li>• Unpasteurized eggnog</li> <li>• Unrefrigerated cream or custard bakery products (i.e. cream pie, custard filled donut, cream puff, etc.)</li> </ul>
Beverages	<ul style="list-style-type: none"> <li>• Tea or coffee made with boiling water</li> <li>• City tap-water (boiled if told to do so)</li> <li>• Bottled distilled, spring, and natural waters from the store</li> <li>• Canned, bottled, powdered beverages</li> <li>• Pre-packaged, brewed herbal tea (i.e. Pure Leaf)</li> </ul>	<ul style="list-style-type: none"> <li>• Sun tea (sun-brewed)</li> <li>• Well-water</li> <li>• Unpasteurized cold-pressed juices</li> </ul>

Additional guidelines are available at:

[www.fsis.usda.gov](http://www.fsis.usda.gov)

[www.homefoodsafety.org](http://www.homefoodsafety.org)

Additional food safety information is available at:

[www.cdc.gov/foodsafety](http://www.cdc.gov/foodsafety)

[www.fightbac.org](http://www.fightbac.org)

[www.foodsafety.gov](http://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
<b>CBC (Complete Blood Count)</b>	<b>This lab test measures the following: WBC, RBC, HGB, HCT, PLT. (See below)</b>	
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
<b>DIFFERENTIAL</b>	<b>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.</b>	
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.	
<b>CMP (Comprehensive Metabolic Panel)</b>	<b>This is a group of lab tests (See Below) that measure chemical components in your blood. It might reflect the function of several organs.</b>	
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
<b>Other Lab Tests</b>		
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								

# Daily Medication Log (Sample)

*Before taking your medicines, please check the prescription labels to verify the medicine strength and correct dosage.*

In the spaces provided below, please record your prescribed medicine dose and scheduled times, and check the appropriate spaces after you've taken each medicine.

**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.**

*Important: Please notify your nurse coordinator via voice mail at least 2 weeks before you run out of your medicine so it can be refilled.*

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
<i>Medication</i>									
<b>Cellcept</b>	500 mg	9 am	✓	✓	✓	✓	✓	✓	✓
Take ½ hour before <u>itraconazole</u> .	500 mg	noon	✓	✓	✓	✓	✓	✓	✓
	500 mg	6 pm	✓	✓	✓	✓	✓	✓	✓
<i>Medication</i>									
<b>Prograf</b>	1 mg	8 am	✓	✓	✓			✓	✓
Take on an empty stomach. Take ½ hour before. <u>itraconazole</u> . Take at the same time/the same way every day.	1 mg	8 pm						✓	✓
<i>Medication</i>									
<b>Liquid <u>itraconazole</u></b>	20 ml/ 200 mg	5 pm	✓	✓	✓	✓	✓	✓	✓
Take on an empty stomach with cola.									
<b>OR <u>itraconazole</u> capsules</b>	200 mg	6 pm	✓	✓	✓	✓	✓	✓	✓
<i>Medication</i>									
<b>Prednisone</b>	30 mg	9 am	✓	✓	✓	✓	✓	✓	✓
Take with breakfast.									

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
<i>Medication</i>									
<b>Neoral</b> Take with breakfast.		9 am	✓	✓	✓	✓	✓	✓	✓
<i>Medication</i>									
<b>Antacid</b> Take at bedtime Take at least two hours after <u>itraconazole</u>		10 pm	✓	✓				✓	✓
<i>Medication</i>									
<i>Medication</i>									

SAMPLE

# Daily Medication Log

*Before taking your medicines, please check the prescription labels to verify the medicine strength and correct dosage.*

In the spaces provided below, please record your prescribed medicine dose and scheduled times, and check the appropriate spaces after you've taken each medicine.

**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.**

*Important: Please notify your nurse coordinator via voice mail at least 2 weeks before you run out of your medicine so it can be refilled.*

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
Medication									
Medication									
Medication									
Medication									

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									

Week of: (Date)	Dose	Time	M	TU	W	TH	F	SA	SU
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									
<b>Medication</b>									

# 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
ALLOGENEIC	COVID-19 <sup>1</sup>	Pevnar-20 <sup>2</sup> Hib <sup>3</sup> Tdap <sup>4</sup> Vaqta+Heplisav-B <sup>5</sup> HPV <sup>6</sup> Polio <sup>7</sup>	Pevnar-20 Hib Td <sup>8</sup> <u>Heplisav-B</u> HPV Polio	Pevnar-20 Hib Td Polio MenB <sup>9</sup> MenACWY <sup>10</sup> Shingrix <sup>11</sup>	Pevnar-20 <sup>12</sup> <u>MenB</u> <u>MenACWY</u> HPV <u>Vaqta</u> <u>Shingrix</u>	MMR <sup>13</sup> Varivax <sup>14</sup>

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

<sup>2</sup>Prevnar-20 = 20-valent conjugated pneumococcal vaccine

<sup>3</sup>Hib = *Haemophilus influenzae* conjugate vaccine

<sup>4</sup>Tdap = tetanus toxoid, diphtheria toxoid & acellular pertussis vaccine

<sup>5</sup>Vaqta (hepatitis A virus vaccine) and Heplisav-B (hepatitis B virus vaccine)

<sup>6</sup>HPV (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.

<sup>7</sup>Polio = inactivated polio vaccine

<sup>8</sup>Td = tetanus toxoid & diphtheria toxoid

<sup>9</sup>MenB = Meningococcal group B vaccine (Bexsero)

<sup>10</sup>MenACWY = MenQuadFi (MenACWY-TT)

<sup>11</sup>Shingrix = Recombinant Zoster Vaccine. Give if Varicella Zoster antibody is positive and patient is  $\geq 19$  years

<sup>12</sup>Give fourth dose of Pevnar-20 if ongoing chronic GVHD

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

<sup>14</sup>Varivax = 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

## 7. Graft Versus Host Disease (GvHD)

- › Graft Versus Host Disease (GvHD)
- › Nutrition Guidelines for GvHD
- › Definition of Terms

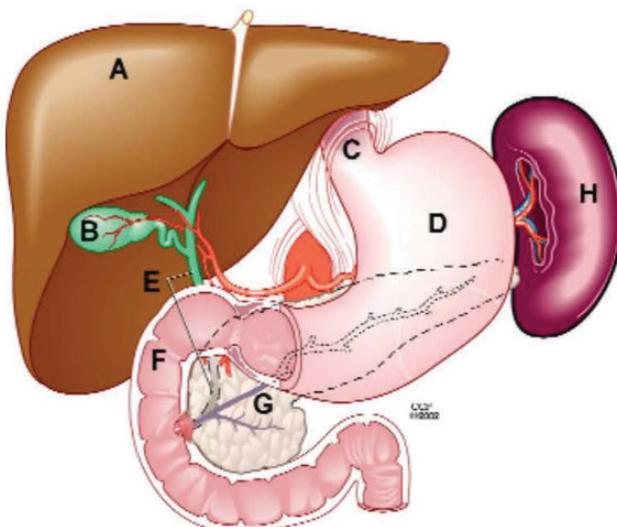
# Graft Versus Host Disease (GvHD) of the Liver

## What is graft versus host disease of the liver?

Graft versus host disease (GvHD) of the liver is one of the risks associated with an allogeneic transplant. In GvHD of the liver, the donor cells attack the liver.

GvHD of the liver can result in damage to the bile ducts, interfering with the flow of bile out of the liver. This damage can vary in severity. Doctors can determine the severity of the damage by performing diagnostic tests, such as a liver biopsy or blood tests.

To detect GvHD of the liver, each BMT patient is monitored closely throughout the transplant process. This monitoring includes regular physical exams — during which certain symptoms are evaluated — blood tests, and diagnostic tests.



A. Liver, B. Gallbladder, C. Cardia,  
D. Stomach, E. Common bile duct,  
F. Duodenum, G. Pancreas, H. Kidney

## Symptoms

Symptoms of GvHD of the liver may include any of the following:

- Abnormal blood test results that indicate the presence of increased liver enzymes in the blood (These abnormal liver enzymes include bilirubin, AST, ALT, GGT, and alkaline phosphate.)
- Pain or tenderness in the upper right abdomen
- Enlarged liver, detected during an abdominal exam
- Yellowing of the skin and/or eyes
- Rapid weight gain
- Swelling in the arms or legs (edema)
- Fluid build-up in the abdomen
- Confusion
- “Tea” colored urine

## Diagnosis

GvHD of the liver may be diagnosed with these tests:

- Blood tests, to measure the liver enzymes and proteins produced by the liver.
- Imaging tests, such as an ultrasound and/or CT scan, to provide a picture of the liver, its vessels and bile ducts, and to determine if there is a blockage.
- A liver biopsy, to obtain a sample of liver cells. These cells are then examined under a microscope to confirm the diagnosis of GvHD of the liver.

## Treatment

If GvHD of the liver is diagnosed, your doctor will discuss available treatment options with you and your family. Your treatment plan will be adjusted. Many patients are treated by suppressing their immune system with drugs such as cyclosporine, methotrexate, tacrolimus, prednisone, methylprednisolone, monoclonal antibodies or ATG.

Long-term treatment with immunosuppressive medicine for GvHD will require you to also take antibiotic, antifungal and antiviral medicines to prevent life-threatening infections. It is important to be aware of the signs and symptoms of infection, and report them to your BMT Team right away.

Long-term treatment with steroids may also increase your risk of developing osteoporosis, cataracts, or joint problems such as hip avascular necrosis (death of bone tissue). Your BMT doctor will constantly monitor for these potential side effects.

Report any bone or joint pain or vision changes to your BMT Team.

## Symptom management

You can help manage your treatment of liver GvHD by avoiding alcoholic beverages and medicines such as acetaminophen (Tylenol®) that can cause additional stress to your liver.

Index #10425 | Review Date: 11/30/2018

# Nutrition Guidelines for GvHD

Graft versus host disease (GvHD) is a condition that might occur after allogeneic bone marrow transplant where donated stem cells attack your own body’s cells. GvHD of the gastrointestinal (GI) tract (also known as “gut” GvHD) may cause these symptoms: nausea, vomiting, diarrhea, bloating, abdominal pain or cramping, and heartburn.

### Follow these tips:

- Before starting on solid foods your healthcare provider may start you on a clear liquid diet. You will need to avoid liquids containing citrus and caffeine. See the list of clear liquid foods and beverages under Clear Liquids/Beverages/Nutrition Supplements in the following pages.
- Aim for 8-12 cups per day of caffeine-free and citrus-free liquids to stay hydrated.
- When you are able to tolerate clear liquids, your healthcare provider will recommend a

trial of solid foods. Choose foods that are low in fat, low in fiber, and lactose-free. See the following list of food groups for recommended foods and foods to avoid.

- Avoid caffeine (regular coffee, regular tea, chocolate); citrus fruits/juices; mints (peppermint, spearmint); tomato products; and spicy foods.
- Try one new solid food at a time.
- Wait at least 3 hours before trying a new food.
- Each newly introduced food may be eaten with previously tolerated foods.
- Take a daily multivitamin. The multivitamin should NOT contain iron, contain more than 200% of the recommended daily allowance (RDA) for any vitamin or mineral, nor contain any herbs or plant supplements. Talk with your hematologist or dietitian about which vitamin supplement is right for you.

FOOD GROUP	RECOMMENDED	AVOID
<p><b>CLEAR LIQUIDS/BEVERAGES/ NUTRITION SUPPLEMENTS</b></p> <p>Aim for greater than 6-8 cups fluid per day</p> <ul style="list-style-type: none"> <li>• <b>Sip on beverages between meals to save room for meals.</b></li> <li>• <b>Juices and high sugar beverages may need to be diluted with water if you experience more diarrhea.</b></li> <li>• <b>Avoid very hot or very cold beverages. Beverages should be served close to room temperature.</b></li> <li>• <b>Avoid all citrus, caffeinated, and lactose containing beverages.</b></li> <li>• <b>Let carbonated beverages go flat before drinking if you experience nausea or heartburn.</b></li> </ul>	<ul style="list-style-type: none"> <li>• Clear liquids</li> <li>• Pulp-free juices and fruit-flavored drinks (made from allowed fruits)</li> <li>• Gingerale, lemon/lime soda, fruit flavored sodas</li> <li>• Sports drinks</li> <li>• Broth</li> <li>• Decaffeinated coffee or tea</li> <li>• Water, flavored water, ice chips or ice cubes</li> <li>• Fruit ices, popsicles</li> </ul>	<ul style="list-style-type: none"> <li>• Milk-based beverages</li> <li>• Hot cocoa</li> <li>• Tomato juice</li> <li>• Prune juice</li> <li>• Chocolate beverages (including supplements)</li> <li>• Caffeinated coffee, tea, colas, energy drinks</li> <li>• Peppermint</li> <li>• Alcohol</li> <li>• Unpasteurized beverages</li> <li>• Nutrition supplements that are made with milk or are not lactose-free</li> </ul>

FOOD GROUP	RECOMMENDED	AVOID
<p><b>GRAINS, STARCHES</b></p> <p>Aim for 6 or more servings per day.</p> <p>1 serving equals:</p> <p>1 slice bread</p> <p>1 oz crackers, chips</p> <p>½ cup cereal/potato/pasta/rice</p> <ul style="list-style-type: none"> <li>• <b>Aim for low-fiber foods (Must contain less than 2 grams dietary fiber per serving)</b></li> <li>• <b>Avoid foods with added nuts, seeds, dried fruit, coconuts</b></li> </ul>	<ul style="list-style-type: none"> <li>• White breads/rolls without seeds (French, Italian, potato, sourdough, cornbread, flour tortillas, seedless rye, seedless pumpernickel )</li> <li>• Plain bagels or English muffins</li> <li>• Plain pancakes or waffles</li> <li>• Crackers (animal, graham, saltines, pretzels)</li> <li>• Plain baked chips</li> <li>• Pasta/noodles made with refined flour</li> <li>• White rice</li> <li>• Hot cereal (cream of wheat, cream of rice, grits, farina)</li> <li>• Ready-to-eat cereal without bran, seeds, nuts, dried fruit, coconut</li> <li>• Plain baked potato without the skin or mashed potatoes made without milk (may use lactose free milk)</li> </ul>	<ul style="list-style-type: none"> <li>• Whole grain breads/roll (whole wheat, oatmeal, multigrain, seeded rye, seeded pumpernickel, raisin bread)</li> <li>• Any whole wheat/whole grain rice, pasta, tortillas, or crackers</li> <li>• Wheat bran or wheat germ</li> <li>• Popcorn, fried chips, french fries</li> <li>• Granola</li> <li>• Doughnuts, croissants, Danish, biscuits, pastry made with dried fruit or dairy</li> </ul>
<p><b>MEAT/MEAT SUBSTITUTES</b></p> <p>Aim for 6 oz per day</p> <p>1 serving equals:</p> <p>1 oz meat</p> <p>1 egg</p> <ul style="list-style-type: none"> <li>• Meat and meat substitutes may be baked, broiled, roasted, and boiled.</li> <li>• Do not fry meat or meat substitutes.</li> <li>• Use a non-stick pan and cooking spray to limit fat intake.</li> </ul>	<ul style="list-style-type: none"> <li>• Chicken or turkey without the skin</li> <li>• Lean cuts beef, pork, lamb without gristle</li> <li>• Flaky white fish, tuna, crab</li> <li>• Hard-boiled eggs</li> <li>• Creamy peanut butter or other nut butters</li> <li>• Cooked tofu</li> </ul>	<ul style="list-style-type: none"> <li>• Fried meat, fish or poultry</li> <li>• Meats seasoned with whole herbs/spices</li> <li>• Fatty or seasoned lunch meats (bologna, salami, pepperoni, olive loaf, pastrami)</li> <li>• Fried eggs, or eggs with undercooked yolks</li> <li>• Shellfish, clams, muscles</li> <li>• Nuts/seeds</li> <li>• All varieties of beans/legumes</li> </ul>

FOOD GROUP	RECOMMENDED	AVOID
<p><b>FRUIT AND FRUIT JUICES</b> Aim for 2-4 servings per day. 1 serving equals: ½ cup juice or canned fruit</p> <ul style="list-style-type: none"> <li>• <b>All fruits (except banana) should be peeled, cooked, and without skins or seeds.</b></li> <li>• <b>Choose pulp-free juices and avoid citrus juices.</b></li> </ul>	<ul style="list-style-type: none"> <li>• Fruit juice (apple, grape, cranberry, fruit punch)</li> <li>• Fruit nectars (pear, apricot)</li> <li>• Strained vegetable juice</li> <li>• Canned fruit (peaches, pears, apricots, applesauce)</li> <li>• Baked and peeled apples and pears; poached pears</li> <li>• Fruit jelly and seedless jam</li> <li>• Banana</li> <li>• Soft seedless melon</li> </ul>	<ul style="list-style-type: none"> <li>• Citrus fruits or juice (orange, lemon, lime, grapefruit)</li> <li>• Prune juice</li> <li>• Tomato juice, V8® Juice, V8-Splash® juice</li> <li>• Cooked or raw grapes, cherries, pineapples, rhubarb, berries (strawberries, blueberries, raspberries)</li> <li>• All dried fruits (raisins, dates, currants, prunes)</li> <li>• Coconut</li> </ul>
<p><b>VEGETABLES</b> Aim for 3-5 servings per day. 1 serving equals: ½ cup cooked vegetable</p> <ul style="list-style-type: none"> <li>• <b>Cook all vegetables until very soft.</b></li> <li>• <b>Vegetables with skins must be peeled.</b></li> <li>• <b>Avoid vegetables that contain seeds or have stringy/fibrous textures.</b></li> </ul>	<ul style="list-style-type: none"> <li>• Cooked and peeled: asparagus tips, beets, carrots, green or yellow beans, mushrooms.</li> <li>• Peeled: pumpkin, sweet potatoes, turnip, yams, winter squash, potatoes</li> </ul>	<ul style="list-style-type: none"> <li>• Gas producing vegetables: cabbage, cauliflower, broccoli, Brussels sprouts, sauerkraut</li> <li>• Raw or cooked vegetables with skins or seeds: corn, peas, peppers, eggplant, summer squash, zucchini squash, tomatoes, lima beans</li> <li>• Stringy fibrous vegetables: artichokes, asparagus stalks, celery, greens, onion</li> <li>• Fresh herbs or dried herbs unless finely ground: parsley, basil, Italian seasoning, chives</li> </ul>
<p><b>MILK/DAIRY/DAIRY SUBSTITUTES</b> Aim for 2-3 servings lactose-free or low-lactose dairy per day. 1 serving equals: - ½ cup lactose-free milk, yogurt, or dairy free substitute - 1 oz cheese</p> <ul style="list-style-type: none"> <li>• Choose only lactose-free items.</li> <li>• Avoid foods containing dairy or milk ingredients.</li> </ul>	<ul style="list-style-type: none"> <li>• Lactose-free milk (such as Lactaid®, Lactase®, Dairy Ease®, and Sure-Lac®).</li> <li>• Non-dairy creamer</li> <li>• Lactose- or dairy-free (vegan) cheese, pudding, yogurt, ice cream, cottage cheese</li> <li>• Milk substitutes (soy milk, rice milk, almond milk, cashew milk)</li> </ul> <p>The following foods may be trialed 4-6 weeks after symptoms resolve:</p> <ul style="list-style-type: none"> <li>• Milk, treated with lactase enzyme</li> <li>• Sherbet</li> <li>• Hard cheeses such as brick, cheddar, Colby, Swiss, Parmesan)</li> <li>• Processed cheese</li> <li>• Butter or margarine</li> </ul>	<ul style="list-style-type: none"> <li>• Milk, milkshakes and other milkbased beverages</li> <li>• Whipping cream and coffee creamer</li> <li>• Sour cream</li> <li>• Yogurt</li> <li>• Cottage cheese, ricotta cheese, cream cheese</li> <li>• Ice cream, ice milk, sherbet</li> <li>• Butter</li> <li>• Puddings, custards</li> <li>• Cream soups, cream sauces</li> <li>• Foods made with milk</li> </ul>

FOOD GROUP	RECOMMENDED	AVOID
<p><b>FATS</b></p> <p><b>Aim for low-fat or fat-free products as tolerated</b></p> <p><b>1 serving equals</b> (See boxes for serving sizes)</p> <ul style="list-style-type: none"> <li>• <b>Limit to one serving for high-fat foods at each meal/snack</b></li> </ul>	<ul style="list-style-type: none"> <li>• Margarine, shortening, oil, mayonnaise – limit 1 tsp serving per meal/snack</li> <li>• Smooth nut butters – 2 tsp</li> <li>• High-fat sauce/gravy – ¼ cup</li> <li>• Light margarine or mayonnaise - limit 1 Tbsp per meal or snack</li> </ul>	<ul style="list-style-type: none"> <li>• Dairy fats (butter, cream, cheese)</li> <li>• High-fat or fried meats (sausage, hot dogs, poultry skins, meats with greater than 5 grams fat per ounce)</li> <li>• Fried pastries (Danish, doughnuts, fritters)</li> </ul>
<p><b>DESSERTS</b></p>	<ul style="list-style-type: none"> <li>• Plain cake without frosting (avoid chocolate cake)</li> <li>• Angel food cakes</li> <li>• Gelatin</li> <li>• Fruit ice, popsicles, sorbet</li> <li>• Plain cookies (vanilla wafers, shortbread/sugar cookies)</li> <li>• Apple, peach cobblers/pies made with allowed ingredients</li> </ul>	<ul style="list-style-type: none"> <li>• Desserts made with dried fruits, nuts, seeds, chocolate, coconut, milk</li> <li>• Milk-based puddings, ice creams, frozen yogurt, sherbet</li> </ul>
<p><b>MISCELLANEOUS</b></p>	<ul style="list-style-type: none"> <li>• Fruited hard candy, gum drops, jelly beans, marshmallows</li> <li>• Finely ground spices, salt, sugar</li> <li>• Dried (not fresh) herbs – such as basil, oregano, thyme</li> <li>• Clear jelly, pasteurized honey, syrup</li> <li>• Vinegar</li> <li>• Plain baked chips</li> </ul>	<ul style="list-style-type: none"> <li>• Dried fruits, coconut</li> <li>• Chocolate</li> <li>• Candy made with not allowed ingredients</li> <li>• Black or red pepper, chili powder, cumin, garlic, nutmeg, curry spices, coarsely ground or whole herbs/spices</li> <li>• Nuts, seeds</li> <li>• Fried snacks – corn chips, potato chips, popcorn</li> <li>• Pickled vegetables/fruits</li> <li>• Hot sauce, ketchup, chili sauce, mustard, horseradish</li> <li>• Jams or jellies made with seeds or skins</li> </ul>

**References:**

- American Cancer Society. Nutrition for the Person with Cancer During Treatment: A Guide for Patients and Families. 2015. <http://www.cancer.org>
- National Cancer Institute. Eating Hints Before, During, and After Cancer Treatment. 2011. <http://www.cancer.gov>
- American Institute for Cancer Research. Nutrition During Cancer Treatment. 2015. <http://www.aicr.org>

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## 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<sup>®</sup>, G-CSF<sup>®</sup>, Zarxio<sup>®</sup>.

**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."

**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.

**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.”

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# Basics of Graft-Versus-Host Disease

Graft-versus-host disease (GVHD) is a common and serious side effect of an allogeneic transplant. An allogeneic transplant uses blood-forming cells donated by someone else. GVHD can range from mild to severe.

## THIS FACT SHEET TELLS YOU:

- The main types of GVHD
- How to lower your risk of getting GVHD
- Signs and symptoms of GVHD
- Treatment for GVHD

## WHAT IS GVHD?

GVHD happens because of differences between the donated cells (graft) and your body's cells (host). Your new cells from your donor (graft) might see your body's cells (host) as different and attack them.

### Types of GVHD:

- **Acute** – Typically develops in the early weeks and months after transplant. It's called Late Acute GVHD when it develops 3 or more months after transplant.
- **Chronic** – Typically develops within 1 year of transplant but can happen later. It's called Overlap Chronic GVHD when signs and symptoms of chronic and acute GVHD appear together.

## HOW TO LOWER YOUR RISK

1. **Take your medicine.** Your doctor will give you medicine to help prevent GVHD. Take it as directed, even if you feel healthy. Call your doctor right away if you can't take the medicine for any reason.
2. **Watch for early warning signs and tell your doctor.** Early treatment of GVHD, infections and other side effects from treatment can help you recover faster.

3. **Protect yourself from the sun.** Exposing yourself to the sun's ultraviolet (UV) rays increases your risk of getting GVHD. To limit your exposure to the sun:
  - Avoid the sun as much as possible.
  - Use an umbrella when you're in the sun.
  - Wear a hat, sunglasses, long sleeves and pants when you go outside.
  - Apply SPF 50 or higher sunscreen on any skin that is not covered. You can also wear SPF clothing.

Even on a cool, cloudy day the sun is just as harmful as on a hot, bright day.

## WATCH FOR SIGNS OF GVHD

Tell your doctor right away if you have any of these signs or symptoms.

### Acute GVHD

- **Skin**
  - Very faint to severe sunburn-like rashes
  - Blisters
  - Redness
- **Stomach**
  - Nausea or vomiting
  - Loss of appetite
  - Weight loss
- **Intestines**
  - Diarrhea
  - Belly pain or cramping
  - Feeling bloated, or full of gas
  - Blood in your stool
- **Liver**
  - Jaundice (your skin or eyes look yellow)
  - Dark (tea-colored) urine
  - Pain in the upper part of your belly
  - Swelling in your legs or belly

## Chronic GVHD

- **Skin and nails**
  - Skin thickening or rash
  - Nail changes
  - Unusual hair loss or thinning
  - Itchy skin
- **Joints and muscles**
  - Arthritis-like symptoms (pain and stiffness)
  - Muscle pain, cramps or weakness
  - Joints don't move properly
- **Eyes**
  - Dry or teary eyes
  - Redness or irritation
  - Pain or sensitivity to light
  - Blurred vision
- **Mouth**
  - Trouble opening your mouth
  - Sores, irritation or pain
  - Chapped lips or dry mouth
  - Difficulty swallowing or sore throat
- **Lungs**
  - Feeling winded or short winded
  - Less able to exercise
  - Trouble breathing or shortness of breath
  - Cough
- **Stomach and intestines**
  - Nausea, vomiting or diarrhea
  - Weight loss
  - Belly pain or cramping
- **Genitals**
  - Irritation, dryness or itching
  - Redness, sores, swelling or burning
  - Dryness or pain with sexual activity

Many of the early warning signs for GVHD could also be caused by infection or another side effect. Tell your doctor right away if you notice any changes in your body.

### For Parents

- Look for early warning signs of chronic GVHD every day.
- Ask your child specific questions about any changes or problems he or she may be having.
- Tell your child to tell you right away about any changes in their body.

## TREATMENT FOR GVHD

- Starting treatment for GVHD **early** leads to the best results.
- Treatment typically includes medicines that hold back your immune system, also called immunosuppressants. These medicines help your new donor cells accept your body.
- Many times, the first treatment is a steroid, like prednisone.
- During treatment for GVHD you may have limitations on what you can do, even if your transplant was more than 1 year ago. For example, you may need to avoid yard work and large crowds. Ask your transplant team what you may need to avoid.
- Follow your doctor's instructions carefully when taking GVHD medicines. If you can't take them for any reason, tell your doctor.
- Treatment for GVHD takes time. You may need to take GVHD medicine for many months. It can take time to find the best type and dose of medicine with the fewest side effects to treat your GVHD.

## QUESTIONS TO ASK YOUR DOCTOR

- What is my risk for GVHD after transplant?
- Is there anything I can do to lower my risk for GVHD?
- What signs and symptoms should I watch for?

## RESOURCES FOR YOU

Talk to someone who can help:

- Contact a BMT Patient Navigator:
  - Call: 1 (888) 999-6743
  - Email: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)
  - Visit: [BeTheMatch.org/one-on-one](https://www.bethematch.org/one-on-one)

Order free resources at [BeTheMatch.org/request](https://www.bethematch.org/request).

Here are some you might find helpful:

- BOOKLET: *Allogeneic Transplant Process*
- FACT SHEET: *Coping with Chronic GVHD*
- VIDEO: *Basics of BMT*



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# Fast Facts: GVHD of the Stomach & Intestines

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

## THIS FACT SHEET TELLS YOU:

- What GVHD of the stomach and intestines is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS **GVHD** OF THE STOMACH AND INTESTINES?

- GVHD of the stomach and intestines happens when the donor's cells attack and damage these organs. When the stomach and intestines aren't working properly, you may have nausea, loss of appetite, a feeling of fullness, indigestion, gas, bloating, diarrhea, pain and weight loss.
- To diagnose this type of GVHD, doctors look at the tissues in the stomach and intestines. These procedures are called:
  - **EDG** (Esophagogastroduodenoscopy) – A doctor places a tube with a small camera through your mouth and into your stomach and small intestine.
  - **Colonoscopy or sigmoidoscopy** – A doctor places a flexible tube through your bottom (rectum) and into your large intestine (colon).

## HOW CAN I **DECREASE SYMPTOMS**?

- Be careful about what you eat. Some foods are more likely to cause symptoms. This may include spicy, oily, or fatty foods and foods that have milk in them.
- Keep a list of what you eat and your symptoms. Avoid foods that seem to cause symptoms.

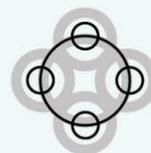
- Take anti-nausea medicines before you eat.
- Talk to your doctor about anti-diarrhea medicines.
- See a dietitian if you're losing weight. They can give you advice to ease symptoms and help you eat healthy foods.

## WHAT **TREATMENTS** ARE AVAILABLE?

- Medicines, like topical steroids that you swallow, can ease symptoms. These coat your stomach and intestines without affecting the rest of your body (for example, beclomethasone in corn oil and budesonide pills).
- Most people with this type of GVHD will also need medicines that treat the entire body. This may include prednisone.
- Your doctor might give you medicines to ease nausea (for example, Zofran or Compazine) and diarrhea (for example, Imodium<sup>®</sup> or Lomotil).

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- If your pancreas isn't working, your doctor may give you enzymes. Enzymes are substances that help you digest food, particularly fats and oils. If you don't have enough enzymes, you may have gas, bloating, pain, oily and smelly stools and weight loss. One example of this treatment is a pill called Creon®.
- If you lose weight because of GVHD of the stomach or intestines, you may need food through an intravenous line (IV) or feeding tube. You may heal more slowly and have a higher risk of infection if you aren't able to eat enough.

### WHAT ELSE SHOULD I KNOW?

- Symptoms of GVHD of the stomach and intestines may get better with treatment. But it can take a long time. Some people need treatment for years or for the rest of their lives.
- If your pancreas isn't working, you will likely need treatment with enzymes for a long time.
- There are other things that can cause symptoms that seem like GVHD. For example, nausea and diarrhea may be caused by pain medicines, antibiotics, or other treatments. Infections can cause diarrhea and stomach pain. Hormone changes from taking steroids for a long time can cause nausea, diarrhea and stomach pain.

### WHEN SHOULD I CALL MY DOCTOR?

- Your stomach or intestines hurt
- You notice changes in your appetite, stool or weight

### FREE SUPPORT & RESOURCES

- For information and help coping with GVHD, call the Be The Match Patient Support Center:
  - Call: 1 (888) 999-6743
  - Email: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)
  - Visit: [BeTheMatch.org/one-on-one](http://BeTheMatch.org/one-on-one)
- For help finding and joining GVHD clinical trials, call the Jason Carter Clinical Trials Program:
  - Call: 1 (888) 814-8610
  - Email: [clinicaltrials@jcctp.org](mailto:clinicaltrials@jcctp.org)
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# FAST FACTS: CHRONIC GVHD OF THE SKIN AND DEEPER TISSUES

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

## THIS FACT SHEET TELLS YOU:

- What chronic GVHD of the skin is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS CHRONIC GVHD OF THE SKIN?

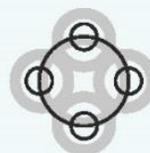
- Chronic GVHD of the skin happens when the donor's cells attack your skin. It is the most common type of chronic GVHD.
- Chronic GVHD of the skin can cause color changes (red, pink, purple, brown, or white), thinning or thickening, hardening, rashes, scaly areas, bumps, sores or blisters (small pockets of fluid). The skin may itch, feel like a sunburn, feel "woody" like a stick, or you may have a pulling or tightening feeling underneath your skin.
- Sclerotic chronic GVHD is a specific type of skin GVHD. "Sclerotic" means hardening or thickening. This form of skin GVHD causes thickening, tightness, and hardening of the skin and deeper tissues. Sclerosis can also make it hard to move your joints.
- Sclerotic chronic GVHD is more common on arms, legs, lower belly and lower back. But it can happen anywhere. Sclerosis on the belly may make it harder to take a deep breath.
- Some people with sclerotic chronic GVHD have difficulty moving their joints. You might notice this more in your wrists, elbows, shoulders and ankles.
- Sclerotic chronic GVHD may cause skin sores to heal slowly. Skin sores are more common on the legs.

## HOW CAN I DECREASE SYMPTOMS?

- If your skin is dry, keep it moisturized. This will help to keep your skin flexible and ease itching. Apply moisturizer right after you shower or bathe to keep moisture from the water in your skin. Ointments and creams are better than lotions.
- If your skin or tissues are tight, gentle stretching exercises, massage, or physical therapy may help loosen the tightness. These activities should be gentle and not hurt much, otherwise you may be causing more irritation that could worsen GVHD.
- Avoid the sun, particularly during peak hours of ultraviolet radiation (10am-4pm). Use sunscreen and wear sun protective clothes. Sun exposure can worsen chronic GVHD and cause skin cancer and wrinkles.
- If you have sores on your skin, keep the sores clean and protected from further injury. Ask your doctor if bandages or medicines applied to your skin may help.
- Avoid positions that decrease blood flow to your legs (for example, crossing your legs or sitting for a long time).

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## WHAT TREATMENTS ARE AVAILABLE?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) that you take by mouth or by injection for your skin may help reduce inflammation (redness and swelling), decrease sclerosis you already have and prevent new sclerosis.
- Your doctor might also prescribe topical immunosuppressive medicines that you put directly on your skin (for example, corticosteroids, tacrolimus, or pimecrolimus). These medicines can sometimes ease symptoms, such as itch or rash. But steroids can also cause side effects, like thinning of your skin, so don't use them for longer or on different areas than prescribed.
- If your skin is itchy, anti-itch lotions or antihistamine pills (for example, diphenhydramine, or hydroxyzine) may decrease symptoms.
- Your doctor might prescribe extracorporeal photopheresis (ECP) to treat your chronic GVHD of the skin. ECP is a treatment where blood is removed from you, treated under light, then given back to you.

## WHAT ELSE SHOULD I KNOW?

- Thickening of your skin and tightness of your deeper tissues may be permanent.
- It's important to tell your doctor about any skin changes and follow their instructions. This will help your skin, joints and tissues stay as healthy as possible.
- People with chronic GVHD have a higher risk of skin cancer. See your doctor regularly and report any changes in the color or texture of your skin. For example, you should tell your doctor about a sore that doesn't heal or a new bump in your skin.
- You cannot spread GVHD of the skin to other people.

## WHEN SHOULD I CALL MY DOCTOR?

- Your skin symptoms worsen
- You have less joint flexibility
- You notice any new bumps or changes in your skin.

## FREE SUPPORT & RESOURCES

- For information and help coping with GVHD, call the Be The Match® Patient Support Center at 1 (888) 999-6743.
- For help finding and joining GVHD clinical trials, call the Jason Carter Clinical Trials Program at 1 (888) 814-8610.



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# FAST FACTS: CHRONIC GVHD OF THE LUNGS

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

## THIS FACT SHEET TELLS YOU:

- What chronic GVHD of the lungs is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS CHRONIC GVHD OF THE LUNGS?

- Chronic GVHD of the lungs happens when the donor's cells attack the small airways (tubes) in your lungs. This can make your lungs inflamed (red and swollen) and cause scarring.
- When this happens, your lungs do not work properly. You might feel short of breath, or less able to exercise. It can cause coughing, chest tightness, or feeling like you cannot take a deep breath. In young children they may play less or breathe harder during play.
- With chronic GVHD of the lungs, you also have a higher risk of lung infections.
- In early chronic GVHD of the lungs, you may not notice any symptoms. Pulmonary (lung) function tests, also called PFTs, are the only tests that can find chronic GVHD of the lungs early. If your doctor suspects chronic GVHD of the lungs, you may also need a special CT (or CAT) scan that takes pictures of your lungs when you breathe in or out.
- Treatment may work better if your doctor starts treatment early, before you have symptoms. Ask your doctor about doing PFTs periodically to watch for GVHD of the lungs, especially if you already have chronic GVHD in other parts of your body.

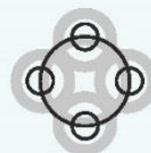
- To diagnose chronic GVHD of the lungs, your doctor may need to do a bronchoscopy. During this procedure your doctor takes samples from your airway and lungs using a small tube. They may look for infections that can cause symptoms similar to chronic GVHD of the lungs.

## HOW CAN I DECREASE SYMPTOMS?

- Lower your risk of infections by:
  - Washing your hands
  - Avoiding sick people, especially those with cold, flu, or lung infections
  - Getting vaccines (immunizations) that your doctor recommends
  - Talking to your doctor right away if you have new symptoms, like coughing, shortness of breath, or chest tightness
  - Ask your doctor if it's safe to garden, mow the lawn or do other activities with dirt, soil or plants. Some people have gotten lung infections after these activities.
  - For children, talk to the doctor about where they can play outside.
- Take medicines as directed by your doctor.
- Be as active as you can. Weak muscles will make shortness of breath seem worse. Be patient. Your lungs may not let you be as active as you'd like.

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- Pulmonary rehabilitation has helped some people with severe chronic GVHD of the lungs.

## WHAT TREATMENTS ARE AVAILABLE?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) for your lungs may help reduce inflammation and decrease scarring.
- Your doctor might prescribe an inhaler. This is a medicine that you inhale (breathe) into your lungs. Be sure you know how to take your inhalers. If they are taken wrong, they will not work.
- Your doctor might also prescribe medicines used for asthma (such as montelukast) or antibiotics (such as azithromycin).
- Sometimes, doctors prescribe extracorporeal photopheresis (ECP) to treat GVHD of the lungs. ECP is a treatment where blood is removed from you, treated with light, and then given back to you.
- Sometimes chronic GVHD of the lungs gets worse even with treatment. In that case, you may need an oxygen tank to help you breathe. Some patients have had lung transplants.

## WHAT ELSE SHOULD I KNOW?

- Sometimes you might not feel short of breath but your doctor may still order PFTs. The PFTs help your doctor see how your lungs are working and if you might need treatment.



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- Your doctor will measure whether your lungs are getting better with treatment by doing pulmonary function tests (PFTs). PFTs are the best tests to measure GVHD of the lungs.
- Symptoms of chronic GVHD of the lungs are often permanent. The goal of treatment is usually to keep your lungs from getting worse.
- Lung infections, particularly viruses like the flu, seem to make GVHD of the lungs worse. It is very important to take precautions against infections.
- Ask your doctor if you might be eligible to participate in clinical trials (research studies) for treatment of chronic GVHD of the lungs. Clinical trials help doctors find better treatments for patients in the future.

## WHEN SHOULD I **CALL MY DOCTOR?**

- Your shortness of breath gets worse
- You have a fever, or pain when you breathe
- Your phlegm or mucus from your throat isn't clear (for example, it's brownish or greenish)
- Your cough gets worse or you're less able to take a deep breath

## FREE **SUPPORT & RESOURCES**

- For information and help coping with GVHD, call the Be The Match® Patient Support Center at 1 (888) 999-6743.
- For help finding and joining GVHD clinical trials, call the Jason Carter Clinical Trials Program at 1 (888) 814-8610.



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# FAST FACTS: CHRONIC GVHD OF THE MOUTH

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

## THIS FACT SHEET TELLS YOU:

- What chronic GVHD of the mouth is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS CHRONIC GVHD OF THE MOUTH?

- Chronic GVHD of the mouth happens when the donor's cells attack the saliva (spit) glands and soft tissues in your mouth.
- Glands in your mouth make saliva that helps your mouth stay moist and smooth. Saliva also helps you swallow your food and helps protect your teeth from decay. If the glands are destroyed or don't work because of chronic GVHD, your mouth may be very dry and you may get more cavities.
- Chronic GVHD of the mouth can cause white patches, redness, pain, sores, and mucocles (painless bumps in the mouth). It may make eating painful or cause taste changes. It might cause your mouth to be more sensitive to spicy foods, acidic foods (like orange juice or tomatoes), and carbonated drinks (like soda or ginger ale). It can also make your lips chapped and sore.
- Chronic GVHD can also cause scarring over time that makes it difficult to open your mouth wide.

## HOW CAN I DECREASE SYMPTOMS?

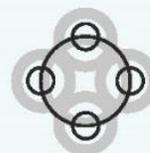
- Drink water often to keep your mouth moist and reduce dryness. Do not get dehydrated.
- If you have difficulty swallowing due to dry mouth, take small bites, chew food completely, and drink fluids frequently while eating.
- If swallowing is still difficult, talk to your doctor. Chronic GVHD of the mouth can also make your esophagus very dry. Your esophagus is the tube that moves food from your mouth to your stomach. A very dry esophagus can cause difficulty swallowing.
- Suck on sugarless candy or chew sugarless gum to decrease the feeling of a dry mouth.

## HOW CAN I KEEP MY TEETH AND GUMS HEALTHY?

- Keep your teeth clean. Brush your teeth at least 2 times each day with a soft toothbrush. If toothpaste bothers your mouth, use toothpaste made for sensitive teeth or for use by children.
- Floss once every day.

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- See your dentist for regular cleanings. Ask your dentist if you need to take medicines before dental work to prevent infections.
- You may need fluoride treatments or prescription toothpaste to protect your teeth from cavities.

### WHAT TREATMENTS ARE AVAILABLE?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) for your mouth may help reduce inflammation (redness and swelling). They may also make it easier to eat and drink. Examples include steroid solutions that you swish and spit or gels that you apply to painful areas. These treatments can cause yeast infections of the mouth so tell your doctor if you feel burning, or notice new white patches in your mouth or throat pain.
- Pain medicines taken before eating and topical anesthetics (medicine that you put directly on painful areas) can decrease pain.
- Prescription medicines that help your body make more saliva may help ease dryness. Examples include cevimeline or pilocarpine.
- Ask your doctor or pharmacist if any of your other medicines could be making your dry mouth worse. Some medicines, like pain medicine, antihistamines, antidepressants, and sleeping pills, may cause dry mouth.

### WHAT ELSE SHOULD I KNOW?

- You cannot spread GVHD of the mouth to other people by kissing or sharing food.
- Symptoms of chronic GVHD of the mouth often get better with treatment.
- Severe dry mouth is often permanent.
- Some infections can cause symptoms similar to chronic GVHD. Your dentist or doctor may need to do tests to see if you have an infection.
- People with chronic GVHD have a higher risk of mouth cancer. See your dentist every 6 months and report any changes in the color or texture of your mouth. For example, a sore that doesn't heal or a new bump in your mouth.

### WHEN SHOULD I CALL MY DOCTOR?

- Your mouth gets drier.
- You have a hard time opening your mouth wide.
- Your mouth or throat hurts, burns, or you feel intense pain.
- You notice any new bumps or changes in your mouth.

### FREE SUPPORT & RESOURCES

- For information and help coping with GVHD, call the Be The Match® Patient Support Center at 1 (888) 999-6743.
- For help finding and joining GVHD clinical trials, call the Jason Carter Clinical Trials Program at 1 (888) 814-8610.



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# FAST FACTS: CHRONIC GVHD OF THE EYES

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

## THIS FACT SHEET TELLS YOU:

- What chronic GVHD of the eye is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS CHRONIC GVHD OF THE EYES?

- Chronic GVHD of the eye happens when the donor's cells attack the surface of your eyes, including the conjunctiva and tear glands. The conjunctiva is the clear tissue that covers the white part of your eye and the inside of your eyelids. Tear glands make tears that keep your eye surface moist and smooth.
- First, the conjunctiva and tear glands get inflamed (red, swollen and painful with discharge). Then the damaged glands stop making tears, causing dry eyes. When this happens, your eyes may feel itchy, gritty, painful, sticky and your vision blurry and glary.
- Later the conjunctiva and tear glands may become scarred and damaged. When this happens your eye can't make enough tears to keep your eyes moist and smooth. Your eyes may become very irritated and painful.

## HOW CAN I DECREASE SYMPTOMS?

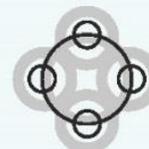
- Keep your eyes moist with lubricating eye drops to reduce dryness and to avoid damage to your eyes. Lubricating or artificial tear drops are available over the counter without prescription. Non-preserved eye drops are best because some preservatives in eye drops may irritate your eyes if used too often.
- Keep away from blowers, fans and blowing wind that can dry your eyes. Wear Air Shields or protective sun glasses with ultraviolet light protection when you go out of doors for UV and wind protection.
- To keep your eyes moist while you sleep, use eye gel or ointment at night. This is especially important if you don't close your eyes completely when you sleep.
- Take flaxseed oil. Mix 2 tablespoons with your juice or food every day. You may also use Omega-3 fatty acid pills instead.

## WHAT TREATMENTS ARE AVAILABLE?

- An ophthalmologist can prescribe medicated eye drops to protect your eyes. These drops help reduce and reverse damage. They include cyclosporine, tacrolimus, lifitegrast and steroid eye drops.

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- Sometimes, prescription pills (for example, cevimeline or pilocarpine) help your undamaged tear glands make more tears.
- Punctal plugs block the tiny tubes that drain your tears from your eyes. This makes your tears last longer. Punctal plugs can be temporary or permanent.
- Ask your doctor or pharmacist if any of your other medicines could be making your dry eyes worse. Some pain medicines, antihistamines, antidepressants, and sleeping pills, may cause dry eyes.
- Autologous serum eye drops are special eye drops made from your own blood by a specialized pharmacy. The liquid portion of your blood is separated out and sterilized and put into vials for you to put in your eyes like eye drops. The liquid part of your blood contains a lot of nutrients, antibodies, hormones and proteins that help the eye heal.
- Special bandage contact lenses or PROSE or other scleral lenses may help relieve the eye pain and protect the eye from damage from dryness. Ask your eye doctor (ophthalmologist or optometrist) or transplant doctor if these could be an option for you. They however, may be costly and need a special fitting process.

## WHAT ELSE SHOULD I KNOW?

- Chronic GVHD of the eye often gets better with treatment over time.
- Severe dry eyes, if untreated, may become permanent.
- Vision is usually not affected permanently unless the surface of the eye is very damaged.
- Sometimes eyesight is blurry because of dry eyes and irritation. This gets better when the eye is treated properly and lubricated.
- Chronic GVHD usually does not affect the inner eye structures responsible for vision. However, side effects from medicines to treat GVHD, such as steroids, may cause cataracts or glaucoma. These can be treated by an ophthalmologist.

## WHEN SHOULD I CALL MY DOCTOR?

- Your eyes get more dry.
- Your eyes hurt.
- Your vision changes.

## FREE SUPPORT & RESOURCES

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# Fast Facts: Chronic GVHD of the Vulva & Vagina

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage with symptoms.

## THIS FACT SHEET TELLS YOU:

- What chronic GVHD of the vulva and vagina is
- How to ease symptoms
- How it can be treated
- When to call your doctor

## WHAT IS CHRONIC GVHD OF THE VULVA AND VAGINA?

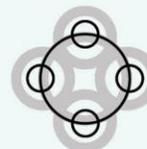
- Chronic GVHD of the vulva and vagina happens when the donor cells attack these tissues. The vulva is the outer part of the vagina (birth canal).
- It commonly happens within 2-3 years after transplant.
- People with chronic GVHD of the vulva and vagina may feel dryness, burning or itching. They may develop open sores, cracks, and redness on the vulva or vagina. Some people have external genital (vulvar) pain at rest or when they wear tight clothing. Others have pain with urination, pain with vaginal sex, or bleeding after sex.
- Symptoms of chronic GVHD of the vulva and vagina can also seem like symptoms of vaginal infection or menopause.
- Without treatment, chronic GVHD of the vulva and vagina can cause permanent tissue changes. This could lead to scarring or even complete closure of the vagina.
- Doctors need to do a pelvic exam to diagnose this type of GVHD. Sometimes they need to take a small piece of vaginal tissue to look at more closely under a microscope.

## HOW CAN I DECREASE SYMPTOMS?

- If you are near or have gone through menopause, ask your doctor about using low-dose topical estrogen. Estrogen can be used as a pill, cream or vaginal ring. This is different from hormone replacement therapy where people take estrogen as a pill or patch. Estrogen may ease vaginal dryness and other menopause symptoms.
- Clean your vulva and vagina gently with warm water only. Don't use perfumed washes or lotions in the area, even gentle ones.
- Let soap and water from washing other parts of your body rinse over your vulva. Pat the area dry.
- Wear loose-fitting cotton underwear.
- Don't douche. This can cause irritation and infections.
- Use a water or silicone-based lubricant before vaginal sex. Use one that doesn't have perfumes or dyes or alcohol. Vaginal moisturizers, such as Replens, may also help. Some people find that silicone-based lubricants last longer during sex. Olive or coconut oil lubricants are safe, too.

*Continued on back*

The information in this fact sheet was developed jointly by Be The Match and the Chronic Graft Versus Host Disease Consortium.



**C H R O N I C  
G R A F T V E R S U S  
H O S T D I S E A S E  
C O N S O R T I U M**

- Look at your vulva with a handheld mirror every week. Tell your doctor about any changes.
- Have vaginal sex or use a dilator at least once a month. Tell your doctor if you have any pain. You can order dilators anonymously on the internet.

## WHAT TREATMENTS ARE AVAILABLE?

- The first treatment is usually a strong steroid ointment or gel used 2 times each day for a few weeks. Your doctor will check your symptoms and do pelvic exams often to make sure the GVHD is getting better.
- Avoid steroid creams. They can cause irritation.
- If steroid ointment or gel doesn't heal the GVHD, you may need a topical immunosuppressant medicine. These are medicines, such as Cyclosporine and Tacrolimus, that hold back your immune system). They may cause vaginal burning.
- Dilators or regular vaginal sex can keep your vagina from narrowing or closing.
- If your vagina narrows or closes off, you may need surgery to open up the vagina. Even if you aren't sexually active, you'll need regular pelvic exams and Pap smears. After surgery, you'll need to use vaginal dilators regularly.

## WHAT ELSE SHOULD I KNOW?

- When GVHD of the vagina or vulva is found early, it often gets better quickly with topical medicines. If it isn't treated early, you may have long-term or even permanent changes to your vagina or vulva and your quality of life may suffer.
- Have a doctor with experience doing pelvic exams check your vulva and vagina 3 months after transplant and then yearly, even if you don't have any symptoms. If possible, see a gynecologist with experience caring for people after transplant.

- Tell your doctor about new symptoms right away so they can treat them.
- Vulvar or vaginal infections can be more common during treatment.
- You can't spread GVHD of the vulva and vagina to other people through touching or sex.
- Some people feel embarrassed talking about their vulva or vagina with their doctor. Remember, your doctor wants to help you. It's important to tell your doctor what's happening with your body.
- Tell your doctor if you have lower interest or less satisfaction with sex.
- Other things can cause symptoms that seem like chronic GVHD of the vulva and vagina. Examples include vulvar or vaginal infections and genital atrophy, which is a symptom of early menopause. Tell your doctor about any new symptoms right away.

## WHEN SHOULD I CALL MY DOCTOR?

- You have new symptoms in your vulva or vagina
- Your vulvar or vaginal symptoms get worse
- You have a fever or other signs of infection
- It's too painful to have vaginal sex or use a dilator
- You have unexpected genital bleeding

## FREE SUPPORT & RESOURCES

- For information and help coping with GVHD, call the Be The Match Patient Support Center:
  - Call: 1 (888) 999-6743
  - Email: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)
  - Visit: [BeTheMatch.org/one-on-one](http://BeTheMatch.org/one-on-one)
- For help finding and joining GVHD clinical trials, call the Jason Carter Clinical Trials Program:
  - Call: 1 (888) 814-8610
  - Email: [clinicaltrials@jcctp.org](mailto:clinicaltrials@jcctp.org)
  - Visit: [JCCTP.org](http://JCCTP.org)



Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.

# Frequently Asked Questions Regarding the BMT Cancer Survivorship Program

## **Why am I being scheduled for a “survivorship visit?”**

Patients undergoing blood and marrow stem cell transplants are living longer and we know that important issues may come up that are unique to cancer and transplant survivors. This visit will provide a summary of your treatment history and a care plan for your future health maintenance. We will review what is important as you continue to live life after transplant.

## **Who is appropriate for a survivorship clinic visit?**

At this time, we are offering these visits to any patients who have had an allogeneic stem cell transplant and are being followed at the Cleveland Clinic.

## **When will my first survivorship clinic visit take place? Will there be more than one such visit?**

Your first survivorship visit will typically occur around day +100 after your transplant. This visit is designed to review your past treatment and side effects, and discuss what to look for and expect with your ongoing future post-transplant care and health maintenance. You will also have survivorship visits around 1, 2, and 5 years after transplant. You may also have additional visits if there are ongoing concerns or if you would like to be seen yearly.

## **Will I need to come in for a special appointment, separate from my regular follow up appointments?**

No, these visits are not intended to make you come for an additional visit. They will be scheduled at the time of your routine follow up and typically replace that visit.

## **What, if anything, do I need to do to prepare for such a visit?**

There is no preparation required, although it may be helpful to make a list of questions or concerns you may have that we can answer in person during your visit

## **Who will I see during my visit?**

You will see one of our Nurse Practitioners, Chris Ferraro, CNP or Kayla Giannetti, CNP, who are specialized in transplant and cellular therapy and survivorship care. You may already know them from your other transplant appointments, as they work closely with our

physicians and nurse coordinators to help with your care during your transplant course. They are knowledgeable regarding BMT, survivorship concerns, late effects of treatment and are qualified to do a clinical exam as would be done by your physician.

You will also see our survivorship/clinical research coordinator (Clarence Williams) who will have certain screening exams to be done on that day, including a short cognitive screen and a 2-minute walk test. We also take photographs of your skin, mouth, and joint range of motion to evaluate for any potential graft versus host disease (GVHD). These photos are kept in your secure medical record.

You will see your social worker to allow you the opportunity to ask and address any psychosocial concerns or questions you may have.

### **What is involved with this visit?**

Prior to your visit, a thorough chart review is completed and a personalized treatment summary and care plan is developed, which includes your diagnosis, imaging and treatments that you underwent.

We will review during your visit and we will discuss any questions or concerns you have had along your journey.

We will review testing done and any treatment that may be needed.

You will be asked to fill out a complete review of symptoms so that we cover all possible side effects and late effects of transplant, including signs and symptoms of chronic GVHD.

You will be asked to change into a gown as we complete a full skin assessment and look for sign and symptoms of chronic GVHD or skin cancer.

### **How long is a survivorship clinic visit?**

They usually last 1.5 hours, but may be shorter or longer depending on your needs and questions.

### **Will the visit be covered by insurance?**

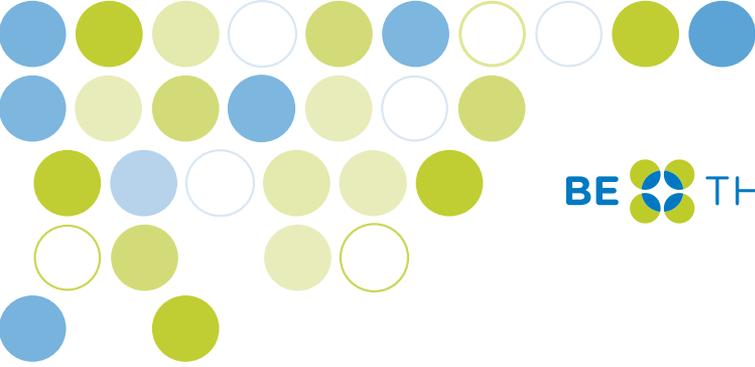
This is a routine follow up visit, so it should be covered by most insurance policies.

### **Who do I need to call if I need to reschedule my survivorship visit?**

You may call the BMT appointment line directly, 216-445-0333.

### **Who do I call if I have additional questions or concerns regarding this visit?**

You may call your nurse coordinator.



BE  THE MATCH®

# 6 MONTH

## After Transplant Care Guide

The 6-month anniversary of your transplant is an important milestone in your recovery. This guide has a list of tests and questions to ask to help you prepare for your 6-month checkup. Guidelines for your yearly appointments are also available. These recommendations are from doctors who specialize in after-transplant care.\*

## Why your 6-month checkup matters

Whether you had an **autologous** or **allogeneic** transplant, follow-up care is important. It helps your doctors find any changes in your health, such as:

- The disease coming back (relapse)
- Problems due to your treatment
- Changes in quality of life

When issues are caught early, there may be more options for treatment, and those treatments may work better.

*Even if you're feeling well, checkups after transplant are very important to staying healthy.*

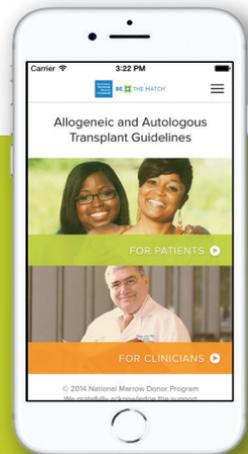
## About this guide

This guide is based on after-transplant care recommendations developed by doctors and researchers from around the world.\* This information is not intended to replace the recommendations of your transplant doctor. You may need different tests or evaluations based on your unique situation. **Your transplant doctor knows you best, so follow his or her recommendations carefully.**

## FREE MOBILE APP

### Use it to:

- Access these guidelines anytime, anyplace
- Make a list of tests and evaluations customized to your unique situation
- Email information to yourself or your health care team
- Identify possible symptoms of chronic GVHD
- Set reminders, like appointments, taking medicines and exercising



Search “transplant guide” in the Apple® or Android™ app stores to download.

Available online at [BeTheMatch.org/CareGuide](https://www.bethematch.org/CareGuide)

## Take action: prepare for your checkup

- Schedule 6-month checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests and evaluations listed on the pages inside this brochure
- Write down questions or issues you'd like to talk to your doctor about
- Ask your doctors if there are other suggestions unique to your situation
- At your checkup, ask your doctor if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist or other specialists)
- Bring this guide to your checkup

## Share with your doctor

There are 2 easy ways to share these guidelines with your doctors or dentist:

- Review this guide with them at your next appointment
- Point them to [BeTheMatchClinical.org/guidelines](https://www.bethematchclinical.org/guidelines) for free clinical guidelines in print or through a mobile app



\* Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; Center for International Blood and Marrow Transplant Research (CIBMTR), American Society for Blood and Marrow Transplantation (ASBMT), European Group for Blood and Marrow Transplantation (EBMT), Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO). Co-published in Biol Blood Marrow Transplant. 2012; 18(3): 348-371; Bone Marrow Transplant (2012) 47, 337-341; and Hematol Oncol Stem Cell Ther 2012; 5(1): 1-30.

# 6-MONTH CHECKUP GUIDE

Below, you'll find information on the physical exams and tests that are recommended 6 months after transplant. You can use this information to help you prepare any questions or concerns you'd like to talk about with your doctor. **Words in bold are defined in the glossary.**

## Bones

- Talk about ways to prevent **bone density loss**—including exercise, vitamin D and calcium supplements

*If you have **GVHD** or are taking **immunosuppressants** you may need:*

- Bone density measurement (using **DEXA scan**)

## Cancer Screening

- Talk to your doctor about your risk of getting another cancer

*If you have **GVHD** you may need:*

- More frequent oral cancer screening

## Emotional Health

- Tell your doctor about your general well-being or quality of life
- Talk about your feelings
- Talk about your family and caregiver's emotional health
- Ask about counselors and support groups in your area
- Ask any questions you may have about your sexual health

## Endocrine System *(thyroid, growth, sex hormones)*

*Tests for children:*

- Talk to your child's doctor about sexual development. Your child may need blood tests to measure sex hormone levels
- **Growth rate evaluation**
- Your child may need blood tests to check **thyroid** and **growth hormone function** and may need to see an endocrine doctor

*If you have **GVHD** or are taking **immunosuppressants** you may need:*

- To take more doses of steroids (like prednisone) if you become very sick
- To have your dose of steroids gradually lowered when it's time to stop taking them

## Eyes

- Check for eye symptoms like pain or dryness
- Check how well you can see (vision screening)
- If you have eye symptoms or problems seeing, ask to see an eye specialist (**ophthalmologist**)

*If you have **GVHD** you may need:*

- To see an eye specialist more often

## Fertility

- Ask your doctor for advice about birth control

## General Health

- Get regular screenings for:
  - Cancer
  - Depression
  - Diabetes
  - High blood pressure
  - High cholesterol
  - Osteoporosis
  - Sexually transmitted infections (STIs)

## Heart and Blood Vessels

- Talk about a “heart healthy” lifestyle (exercise, healthy weight, healthy foods, smoke-free)
- If needed, get treatment for diabetes, high blood pressure and high cholesterol

## Immune System

- Talk about medicines to prevent infections, such as **pneumocystis**
- Ask if you need vaccines to prevent infection and disease

*If you have **GVHD** or are taking immunosuppressants you may need:*

- Medicine to prevent infections such as **meningitis** and **pneumonia**
- Blood tests to screen for **cytomegalovirus (CMV)**

## Kidneys

- Blood pressure test
- If you have high blood pressure, start treatment and have regular follow-up
- **Urine protein levels test** to see how well your kidneys are working
- **Kidney filtration levels test** (BUN/Creatinine test) to see how well your kidneys are working
- If your kidneys aren’t working well, you may need more tests (kidney ultrasound or biopsy)
- If you have chronic kidney disease that is getting worse, don’t take medicines, herbs or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

## Liver

- **Liver function blood tests** to see if your liver is working properly
- If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor

## Lungs

- Regular lung exam
- Tell your doctor if you have shortness of breath or a cough that doesn’t go away
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- **Lung function tests** and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

*If you have **GVHD** you may need:*

- Lung exams and **lung function tests** earlier and more often

## Mouth

- Exam of the mouth and teeth
- Oral cancer screening
- Talk to your doctor about symptoms like dry mouth
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves

*If you have **GVHD** you may need:*

- To have exams of the mouth and teeth, and oral cancer screening more often

## Muscles

- Talk about current exercises

*If you have **GVHD** or are taking **immunosuppressants** you may need to:*

- Test if your muscles are weak (**myopathy**)
- See a physical therapist if you have **myopathy, fasciitis** or **scleroderma**
- Have a **range of motion** exam to look for **sclerotic changes**
- Learn how to test your own **range of motion**

## Nervous System *(brain, spinal cord and nerves)*

- You may need tests of your **nervous system**
- If you have trouble with things such as memory, concentration or decision-making, you may need more tests

## Skin and Genitals

- Learn how to do a routine self-exam of your skin
- Talk about risks of being in the sun without proper protection
- Tell your doctor if you have any pain or other problems with sexual activity

*If you have **GVHD** or had **total body irradiation**, you may need to:*

- Ask your doctor how often you need gynecologic or genital exams



# GLOSSARY

**Bone density loss**—Bones become weak and brittle. Bones can break more easily.

**Cytomegalovirus (CMV)**—A type of herpes virus that can cause infections (like **pneumonia**).

**DEXA scan**—A test to measure bone density. Often called dual photon densitometry or a DXA scan.

**Endocrine system**—Glands that release hormones into your body. Hormones affect your mood and growth.

**Fasciitis**—Inflammation (redness and swelling) of the connective tissue that surrounds muscles, blood vessels and nerves. Often happens with hardening of the skin (see **scleroderma**).

**Graft-versus-host disease (GVHD)**—A common side effect after an allogeneic transplant when the new donor cells attack your body's cells.

**Growth hormone function**—Test to see if there is enough growth hormone in your body to grow normally.

**Growth rate evaluation**—Comparing a person's growth to average growth in the general population in people of the same age and sex.

**Immunosuppressants**—Medicines that lower your body's ability to fight infection. These medicines also help to prevent and treat GVHD.

**Kidney filtration levels test**—Measures the flow rate of filtered fluid through the kidneys. Used to detect chronic kidney disease.

**Liver function blood tests**—Tests to see how well your liver is working.

**Lung function tests**—A group of tests to measure how well your lungs are working.

**Meningitis**—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

**Myopathy**—Muscle disease and weakness. Steroids used for chronic GVHD may cause muscle weakness, especially in your legs and feet.

**Nervous system**—The parts of your body that control your movements and thinking. The nervous system includes your brain, spinal cord (inside the back bone) and nerves.

**Ophthalmologist**—A medical doctor who treats diseases that affect the eyes.

**Pneumocystis**—A form of **pneumonia** caused by a yeast-like fungus.

**Pneumonia**—Inflammation (redness and swelling) of the lungs caused by infection.

**Range of motion**—A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

**Scleroderma**—When your skin becomes hard, thick and tight. This can lead to weak muscles, stiff joints or pain in your joints.

**Sclerotic changes**—Hardening of the skin and other tissues such as connective tissues, muscles and joints.

**Thyroid**—A gland that controls your body's metabolism (how quickly your body uses energy).

**Total body irradiation (TBI)**—Radiation before your transplant to kill cancer cells throughout your body.

**Urine protein levels test**—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.

## We are here to help

Be The Match® Patient Support Center is offers reliable, easy-to-understand information from diagnosis through recovery. All of our programs and resources are **FREE**.

Our services include:

- Telephone counseling and confidential, one-on-one support
- Financial grants for patients
- Support groups and telephone workshops
- Caregiver support
- Tips for talking with your health care team
- Educational books, DVDs, newsletters and fact sheets
- Information and support in many languages

Contact us at [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) or 1 (888) 999-6743

## Notes:

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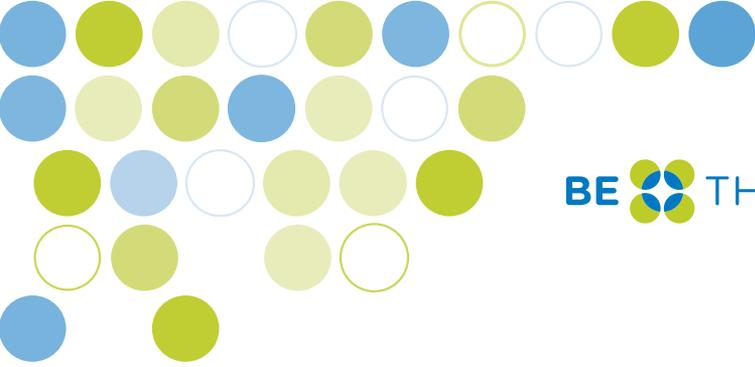
## Resources just for you

**ONLINE:** [BeTheMatch.org/AfterTransplant](http://BeTheMatch.org/AfterTransplant)

**E-NEWS:** [BeTheMatch.org/patient-eneews](http://BeTheMatch.org/patient-eneews)

**FACEBOOK:** [Facebook.com/BeTheMatchPatient](https://Facebook.com/BeTheMatchPatient)





BE  THE MATCH®

12+  
MONTH

**After  
Transplant  
Care** Guide

The 1-year anniversary of your transplant is an important milestone in your recovery. This guide has a list of tests and questions to ask to help you prepare for your yearly checkups. These recommendations are from doctors who specialize in after-transplant care.\*

## Why your yearly checkups matter

Whether you had an **autologous** or **allogeneic** transplant, follow-up care is important. It helps your doctors find any changes in your health, such as:

- The disease coming back (relapse)
- Problems due to your treatment
- Differences in quality of life

When issues are caught early, there may be more options for treatment, and those treatments may work better.

*Even if you're feeling well, checkups after transplant are very important to staying healthy.*

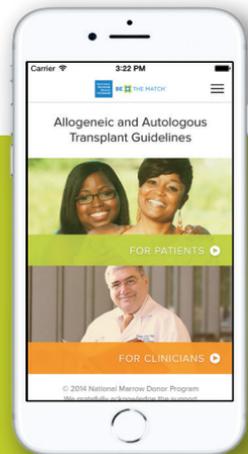
## About this guide

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## FREE MOBILE APP

### Use it to:

- Access our guidelines anytime, anyplace
- Make a list of tests and evaluations customized to your unique situation
- Email information to yourself or your health care team
- Identify possible symptoms of chronic GVHD
- Set reminders, like appointments, taking medicines and exercising



Search “transplant guide” in the Apple® or Android™ app stores to download.

Available online at [BeTheMatch.org/CareGuide](http://BeTheMatch.org/CareGuide)

## Take action: Prepare for your checkup

- Schedule 12-month checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests listed on the pages inside this brochure
- Write down questions or issues you'd like to talk to your doctor about
- Ask your doctors if there are other suggestions unique to your situation
- At your checkup, ask your doctor if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist or other specialists)
- Bring this guide to your checkup

## Share with your doctor

There are 2 easy ways to share these guidelines with your doctors or dentist:

- Review this guide with them at your next appointment
- Point them to [BeTheMatchClinical.org/guidelines](https://www.bethematchclinical.org/guidelines) for free clinical guidelines in print or through a mobile app



\* Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; Center for International Blood and Marrow Transplant Research (CIBMTR), American Society for Blood and Marrow Transplantation (ASBMT), European Group for Blood and Marrow Transplantation (EBMT), Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO). Co-published in Biol Blood Marrow Transplant. 2012; 18(3): 348-371; Bone Marrow Transplant (2012) 47, 337-341; and Hematol Oncol Stem Cell Ther 2012; 5(1): 1-30.

# YEARLY CHECKUP GUIDE

Below, you'll find information on the physical exams and tests that are recommended yearly after transplant. You can use this information to help you prepare any questions or concerns you'd like to talk about with your doctor. **Words in bold are defined in the glossary.**

## Bones

- Talk about ways to prevent **bone density loss**—including exercise, vitamin D and calcium supplements

*If you're a woman, an allogeneic transplant recipient, have **GVHD**, are taking **immunosuppressants** or are at a high risk for bone loss, you may need:*

- Bone density measurement (using **DEXA scan**)

## Cancer Screening

- Talk to your doctor about your risk of getting another cancer
- Learn how to do self-exams for cancer, including skin and testicular exams
- Follow cancer screening recommendations for the general population
- If you're a woman, ask your doctor if you need a **mammogram** or other breast screening tests and how often they should be done

## Emotional Health

- Tell your doctor about your general well-being or quality of life
- Talk about your feelings
- Talk about your family and caregiver's emotional health
- Ask about counselors and support groups in your area
- Ask any questions you may have about your sexual health

## Endocrine System *(thyroid, growth, sex hormones)*

- Blood tests to check your **thyroid**
- Blood tests to check your sex hormone levels
- Additional tests for women who haven't gone through menopause

*Additional tests for children:*

- Blood tests to measure sex hormone levels
- **Growth rate evaluation**
- Blood tests to check **thyroid** and **growth hormone function** (which an endocrine doctor can perform)

*If you have **GVHD** or are taking **immunosuppressants**, you may need to:*

- Take more doses of steroids (like prednisone) if you become very sick
- Have your dose of steroids gradually lowered when it is time to stop taking them

## Eyes

- Check for symptoms like pain or dryness
- Have an eye specialist (**ophthalmologist**) perform a vision screening and retina exam

*If you have **GVHD**, you may need to:*

- See an eye specialist more often

## Fertility

- Ask your doctor for advice about birth control
- If you want to have a baby, ask to see a fertility specialist

## General Health

- Get regular screenings for:
  - Cancer
  - Depression
  - Diabetes
  - High blood pressure
  - High cholesterol
  - Osteoporosis
  - Sexually transmitted infections (STIs)

## Heart and Blood Vessels

- Check for risk factors, such as cholesterol, high blood pressure, obesity or history of smoking
- Talk about a “heart healthy” lifestyle (i.e., exercise, healthy weight, healthy foods, smoke-free)
- If needed, get treatment for diabetes, high blood pressure and high cholesterol

## Immune System

- Ask if you need vaccines to prevent infection and disease

*If you have **GVHD** or are taking immunosuppressants, you may need:*

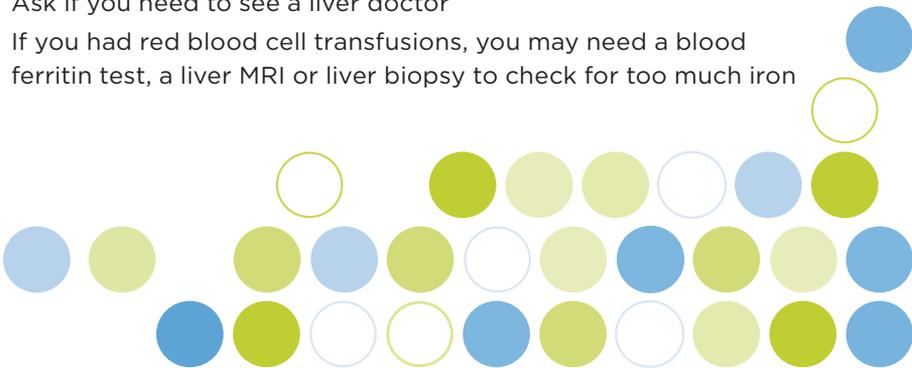
- Medicine to prevent infections such as **meningitis** and **pneumonia**
- Medicine to prevent an infection called **pneumocystis** for as long as you are taking **immunosuppressants**
- Blood tests to screen for **cytomegalovirus (CMV)**

## Kidneys

- Blood pressure test
- If you have high blood pressure, start treatment and have regular follow-up
- **Urine protein levels test** to see how well your kidneys are working
- **Kidney filtration levels test** (BUN/Creatinine test) to see how well your kidneys are working
- If your kidneys aren't working well, you may need more tests (e.g., kidney ultrasound or biopsy)
- If you have chronic kidney disease that is getting worse, don't take medicines, herbs or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

## Liver

- **Liver function blood tests** to see if your liver is working properly
- If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor
- If you had red blood cell transfusions, you may need a blood ferritin test, a liver MRI or liver biopsy to check for too much iron



## Lungs

- Have your doctor listen to your lungs at least 1 time every year
- Tell your doctor if you have shortness of breath or a cough that doesn't go away
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- **Lung function tests** and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

*If you have **GVHD**, you may need:*

- Lung exams and **lung function tests** earlier and more often

## Mouth

- Exam of the mouth and teeth
- Oral cancer screening
- Talk to your doctor about symptoms like dry mouth
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- See your dentist for a complete dental checkup (exam of your head, neck, mouth and teeth)
- Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves

*If you have **GVHD**, you may need:*

- To have exams of the mouth and teeth and oral cancer screenings more often

*Additional test for children:*

- A dentist will check how well your child's teeth are growing

## Muscles

- Talk about current exercises

*If you have **GVHD** or are taking immunosuppressants, you may need to:*

- Test if your muscles are weak (**myopathy**)
- See a physical therapist if you have **myopathy, fasciitis** or **scleroderma**
- Have a **range of motion** exam to look for **sclerotic changes**
- Learn how to test your own **range of motion**

## Nervous System *(brain, spinal cord and nerves)*

- Tests of your **nervous system**
- If you have trouble with things such as memory, concentration or decision-making, you may need more tests

*Additional test for children:*

- Check cognitive development (ability to think and reason) for your child's age

## Skin and Genitals

- Learn how to do a routine self-exam of your skin
- Talk about the risks of being in the sun without proper protection
- Have a yearly gynecologic exam if you're a woman
- Tell your doctor if you have any pain or other problems with sexual activity

*If you have **GVHD** or had total body irradiation, you may need to:*

- Ask your doctor how often you need gynecologic or genital exams

# GLOSSARY

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**Growth hormone function**—Test to see if there is enough growth hormone in your body to grow normally.

**Growth rate evaluation**—Comparing a person's growth to average growth in the general population in people of the same age and sex.

**Immunosuppressants**—Medicines that lower your body's ability to fight infection. These medicines also help to prevent and treat GVHD.

**Kidney filtration levels test**—Measures the flow rate of filtered fluid through the kidneys. Used to detect chronic kidney disease.

**Liver function blood tests**—Tests to see how well your liver is working.

**Lung function tests**—A group of tests to measure how well your lungs are working.

**Mammogram**—A test to detect breast cancer.

**Meningitis**—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

**Myopathy**—Muscle disease and weakness. Steroids used for chronic GVHD may cause muscle weakness, especially in your legs and feet.

**Nervous system**—The parts of your body that control your movements and thinking. The nervous system includes your brain, spinal cord (inside the back bone) and nerves.

**Ophthalmologist**—A medical doctor who treats diseases that affect the eyes.

**Pneumocystis**—A form of **pneumonia** caused by a yeast-like fungus.

**Pneumonia**—Inflammation (redness and swelling) of the lungs caused by infection.

**Range of motion**—A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

**Scleroderma**—When your skin becomes hard, thick and tight. This can lead to weak muscles, stiff joints or pain in your joints.

**Sclerotic changes**—Hardening of the skin and other tissues such as connective tissues, muscles and joints.

**Thyroid**—A gland that controls your body's metabolism (how quickly your body uses energy).

**Urine protein levels test**—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.

## We are here to help

Be The Match® Patient Support Center offers reliable, easy-to-understand information from diagnosis through recovery. All of our programs and resources are **FREE**.

Our services include:

- Telephone counseling and confidential, one-on-one support
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- Support groups and telephone workshops
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- Educational books, DVDs, newsletters and fact sheets
- Information and support in many languages

Contact us at [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) or **1 (888) 999-6743**

## Notes:

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## Resources just for you

**ONLINE:** [BeTheMatch.org/AfterTransplant](https://www.BeTheMatch.org/AfterTransplant)

**E-NEWS:** [BeTheMatch.org/patient-eneews](https://www.BeTheMatch.org/patient-eneews)

**FACEBOOK:** [Facebook.com/BeTheMatchPatient](https://www.Facebook.com/BeTheMatchPatient)



**1 (888) 999-6743 | [BeTheMatch.org/one-on-one](https://www.BeTheMatch.org/one-on-one)**

# Antithymocyte Globulin (ATG)

**Brand names:** Atgam®, Thymoglobulin®

## What are some other names for this medicine?

This medicine might also be called ATG.

## What does it do?

In patients with aplastic anemia, ATG might increase the production and activity of lymphocytes (a type of white blood cell).

ATG acts to suppress the immune system and might be used to prevent and/or treat graft-vs-host disease (GvHD) or graft rejection.

ATG also appears to have some ability to destroy malignant (cancerous) lymphomas.

## How is it given?

ATG is an intravenous solution given through your central venous catheter over 4 to 6 hours for 3 to 10 days, depending on your doctor's treatment guidelines.

To prevent side effects during the infusion, steroids, diphenhydramine (Benadryl®) and acetaminophen (Tylenol®) are administered before the infusion of ATG.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this binder.)

## What are some common side effects I might experience?

- Shortness of breath
- Pain in the chest, back, or sides
- Muscle aches
- Low blood pressure
- Nausea
- Chills or fever
- Diarrhea
- Itching and/or skin redness, rash
- Decreased blood counts
- Headache
- Tiredness

Some side effects might occur as long as 3 weeks after you receive ATG.

These include:

- Fever
- Swollen spleen
- Swollen lymph nodes
- Skin rash
- Joint pain

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 10419 | Review Date: 8/8/2019

# Busulfan

**Brand names:** Myleran<sup>®</sup>, Busulfex<sup>®</sup>

## 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<sup>®</sup> 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<sup>®</sup>, Etopophos<sup>®</sup>, Toposar<sup>®</sup>

## 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

# Fludarabine Phosphate

**Brand names:** Fludara®

## What are some other names for this medicine?

Fludarabine phosphate belongs to the group of medicines called “antimetabolites.”

## What does it do?

Fludarabine phosphate interferes with the growth of cancer cells, which are eventually destroyed.

## How is it given?

Fludarabine phosphate is injected directly into your vein through an IV (intravenously), usually for 30 minutes or longer.

## What are some common side effects I might experience?

### EARLY SIDE EFFECTS

These might occur within 1 week after treatment.

- Drowsiness while the medicine is being given. Drowsiness usually stops after the injection is complete.
- Mild nausea and vomiting

- Taste changes, metallic taste
- Vomiting
- Rash
- Weakness and fatigue (more likely with 5-day infusions)
- Low blood counts
- Poor appetite
- Numbness and tingling of the hands and feet
- Chills, sweating
- Loss of fertility

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 4835 | 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

# Photopheresis

## What is photopheresis?

**Photopheresis** or **extracorporeal photoimmune therapy** is a procedure that might be recommended by your doctor to prevent or to treat **graft versus host disease (GvHD)**. This procedure offers another way to try to suppress the donor lymphocytes (type of white blood cells) that stimulate immune reactions and aid in the development of GvHD.

## Where is photopheresis done?

The photopheresis procedure is performed in the Therapeutic Apheresis Department located at on the second floor of the Taussig Cancer Center. Televisions are available for viewing during the procedure. Please eat breakfast or lunch prior to your scheduled appointment. Please try to drink plenty of fluids in the days before your scheduled appointment and try to eat a low-fat diet beginning the evening before the procedure.

## How long does the procedure last?

The photopheresis process lasts about 3 to 4 hours. You might require several photopheresis sessions before the desired results are achieved. Your doctor will develop an individual treatment plan for you based on your disease.

## How is photopheresis done?

During photopheresis, blood is taken from one lumen of your central venous catheter and processed through a cell separation machine. This machine removes and treats your lymphocytes and then returns them and the rest of your blood to your body.

When your blood first enters the machine, it is mixed with an anticoagulant medicine to prevent it from clotting. Then, the cell separation machine collects the lymphocytes from your blood and mixes them with the drug 8-methoxypsoralen or UVADEX. This is a photosensitizing agent that becomes active when it is exposed to ultraviolet light. The lymphocytes and UVADEX are next exposed to ultraviolet A light inside the machine. Lastly, the lymphocytes and the rest of your blood are re-infused back into you.

## How can this procedure help me?

By treating your lymphocytes during photopheresis, their function is altered. When the treated lymphocytes are re-infused, they will stimulate an immune response in your body to fight the development or progression of GvHD.

Your doctor might use photopheresis alone or in combination with other treatments.

## How will I feel during the photopheresis process?

You will lay comfortably in bed during the photopheresis procedure while your blood is taken, processed, and then re-infused. Photopheresis is a painless procedure.

Changes in blood volume might cause you to feel dizzy, light-headed or cold. Tell your nurse if you experience any of these symptoms, and he or she will help relieve your discomfort.

## What are the side effects?

A few patients might experience a slight drop in blood pressure during the procedure. This is easily corrected by receiving intravenous fluids.

Another possible side effect is fever about 6 to 8 hours after the procedure. Please tell your doctor if you have a temperature over 100.4° F. Your doctor might recommend you take additional medicines such as acetaminophen (Tylenol®).

## Precautions after treatment

You must avoid sunlight, even if it's indirect sunlight, for 24 hours after each procedure since you will be more sensitive to the sun. If you go outside, please apply sunscreen with at least SPF 30. Please wear UVA protective sunglasses in a “wraparound” style to protect the sides of your eyes. UVA sunglasses are available in many colors, including clear, at most drug stores for about \$20. It is recommended that you wear these both inside and outside for 24 hours after each procedure.

Index 10252 | 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

# Radiation Therapy

You will have an appointment prior to your first day of radiation so they can take measurements. These measurements will be used to protect your organs during your radiation treatments.

## What is radiation therapy?

Radiation therapy is a form of cancer treatment that uses high levels of radiation to kill cancer cells or keep them from growing and dividing — while limiting damage to healthy cells.

You can expect to receive small daily doses of radiation over a period of 1 to several days.

More information regarding this therapy will be provided by the Radiation Therapy Department.

## What happens on treatment day?

The radiation therapist will escort you into the treatment room. The therapist will help place you in the correct treatment position. Once the therapist is sure you are positioned correctly, he or she will leave the room and start the radiation treatment.

You will be under constant observation during the treatment. Cameras and an intercom are in the treatment room, so the therapist can always see and hear you. If you should have a problem, you can let the therapist know. It is very important that during treatment, you remain still and relaxed.

The therapist will be in and out of the room to reposition the machine and change your position. The treatment machine will not touch you and you will feel nothing during the treatment. Once your treatment is complete, the therapist will help you out of the treatment room.

## Where should I go on the first day of treatment?

On the first day of treatment, check in at Desk CA-LL, according to your schedule. Plan to arrive a few minutes before your scheduled appointment. The receptionist will give you instructions on where you can wait, and you will be asked to change into a hospital gown. When the radiation therapist is ready, your name will be called. The therapist will meet you in the waiting area and escort you to the treatment area.

Your family and friends will be asked to wait in the waiting area until you finish your treatment.

## Common Side Effects of Radiation Therapy

### Skin reactions

During your treatment, radiation must pass through your skin. You might notice some skin changes in the area exposed to radiation. Your skin might become red, warm, and sensitive — as if you had a sunburn. It might also become darker and appear tanned. It might peel or become moist and tender. Depending on the dose of radiation you receive, you might notice a loss of hair or decreased perspiration within the treated area.

These skin reactions are common and temporary. They will subside gradually within 2 to 4 weeks of completing treatment. If skin changes appear outside the treated area, tell your doctor or primary nurse.

For information on how to reduce skin reactions caused by radiation therapy, see the section entitled, “How to Cope with Side Effects.”

## **Nausea and vomiting**

Radiation treatment might cause nausea (a sensation often leading to the urge to vomit). If nausea occurs, it usually happens from 2 to 6 hours after your treatment. Nausea may or may not be accompanied by vomiting.

For information on how to manage nausea and vomiting caused by radiation therapy, see the section entitled, “How to Cope with Side Effects.”

## **Fatigue**

Everyone has a different level of energy, so radiation treatment will affect each patient differently. For most patients, this fatigue is mild. However, a loss of energy might require other patients to change their daily routine.

To lessen fatigue while you are receiving radiation treatment:

- Be sure to get enough rest.
- Eat a well-balanced, nutritious diet.
- Pace your activities and plan frequent rest periods.

# Rituximab

**Brand names:** Rituxan®

## What does rituximab do?

Rituximab is a drug that attaches itself to specific cancer cells and “marks” them for destruction by your body’s immune system. It belongs to a class of medicines known as “monoclonal antibodies.”

## What is rituximab used for?

Rituximab is given to treat certain types of non-Hodgkin’s lymphoma. It is sometimes given after allogeneic transplant for severe graft versus host disease (GvHD).

## How is it given?

Rituximab is given as an infusion into a vein (intravenous, IV) over about 6 hours.

(Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.)

## What are some common side effects of this drug?

### EARLY SIDE EFFECTS

These might occur within 1 week after treatment.

- Fever and chills
- Weakness
- Nausea
- Headache
- Cough
- Runny nose, shortness of breath, swollen or inflamed sinuses

- Throat irritation
- Temporary low blood pressure
- Irregular heartbeat or heart pain. This is a rare side effect and is most often seen in patients who have experienced heart irregularities in the past.
- Kidney irregularities. These have been seen with the rapid destruction of cancer cells.

In addition, there is a potential to develop a severe infusion reaction during your first dose of rituximab. This side effect is rare and is usually seen within the first 30 to 120 minutes of the infusion. To prevent this side effect, you will be given medicine before your infusion, and you will be closely monitored. If this reaction occurs, the infusion will be stopped and can usually be restarted as a slower rate.

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 condition.

Index #11034 | 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

# Amoxicillin

**Brand names:** Amoxil<sup>®</sup>, Trimox<sup>®</sup>, Wymox<sup>®</sup>

**Class of drugs:** Antibiotic

## Why is amoxicillin prescribed?

Amoxicillin is a type of penicillin prescribed to prevent or treat infections caused by bacteria.

## How is amoxicillin taken?

Amoxicillin is available in capsules, tablets, chewable tablets, and suspension liquid (with small particles in it). The chewable tablet form of this medicine should be chewed thoroughly or crushed before swallowed. The oral liquid form of this medicine should be shaken well before use and measured with a specially marked measuring spoon to measure each dose accurately. The liquid form can be taken by itself or mixed with milk, juice, water, ginger ale, or other cold drinks. If you mix the liquid form of the medicine with another liquid, drink it as soon as you mix it. This medicine may be taken on a full or empty stomach.

This medicine works best when there is a constant amount of it in the bloodstream. Amoxicillin must be taken for the entire duration 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.

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 it, generally twice a day. 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?

- BEFORE he or she prescribes this medicine, tell your healthcare provider if you have ever

had any unusual or allergic reactions to penicillin or cephalosporin medicines. 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 any of these medicines or foods, amoxicillin might not be the right medicine for you. Another antibiotic might be prescribed instead.

- This medicine might change the effectiveness of oral contraceptives (birth control pills) containing estrogen. Use a second method of birth control while taking this medicine.
- If you have diabetes, amoxicillin might change the results of your blood glucose tests. Check with your doctor before changing your diet or the dosage of your diabetes medicine.
- 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.

## 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 capsule or tablet form of this medicine at room temperature.
- Store the liquid form of this medicine in the refrigerator, but keep the liquid from freezing. Discard liquid that is older than 14 days.

- Do NOT store the capsule or tablet form of 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?

Amoxicillin might cause any of the following side effects:

- **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. 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 a severe allergic reaction.

### When should I call my health care provider?

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

- Have a skin rash
- 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 or have any questions or concerns

Index # 10425 | Review Date: 8/82019

# Amphotericin B

**Brand name:** Fungizone®

**Class of drugs:** Antifungal

## Why is amphotericin B prescribed?

Amphotericin B is prescribed to transplant patients to treat or prevent the development of aspergillus infection, a type of fungal infection. A transplant patient has an increased risk of developing infections because the immune system is suppressed. Amphotericin B will suppress the infection and help keep the symptoms from becoming worse.

## How is amphotericin B given?

This medicine is given by infusion (IV). This drug works best when there is a constant amount of it in the bloodstream. In order to achieve this, allo transplant patients will receive amphotericin B daily in the hospital, starting the day after your transplant. Amphotericin B must be taken for the entire length of treatment to achieve the best results. The dose of this drug will be different for each patient. A home care nurse will teach you how to give yourself this medicine if it is needed on an outpatient basis. Auto transplant patients may receive amphotericin B on an as needed basis as directed by your physician.

## What special instructions should I follow while using this drug?

- Drink plenty of fluids every day. (We recommend at least six to eight, 8-ounce glasses of fluid a day.)
- Keep taking this medicine for the full time of treatment.

- Keep all appointments with your doctor and the laboratory so your response to the drug can be monitored.
- Keep refrigerated. Do not freeze.

## What are the common side effects and what can I do to treat them?

While you are taking amphotericin B, frequent blood tests will be taken to monitor for the following serious side effects:

- Electrolyte imbalance. Taking your prescribed oral potassium and magnesium will help with this side effect. It is not uncommon to require intravenous electrolyte replacement.
- Altered kidney function. Amphotericin B might be changed to Amphotericin B lipid complex at your doctor's discretion.
- Altered liver function
- Diarrhea
- Shaking, chills, fever. Medicine such as Tylenol® and Benadryl® will be given before amphotericin B to prevent the development of fever or chills. Other medicines might also be added if needed.
- Generalized muscle or joint pain

Many of the side effects of amphotericin B are dose-related and might go away when your healthcare provider adjusts your dosage.

## When should I call my healthcare provider?

If you have any of these symptoms, please tell your healthcare provider right away so the dosage of your medicine can be adjusted or additional medicine can be prescribed to prevent or treat these side effects:

- Chills, fever, or headache
- Nausea that does not improve after changing your eating habits
- Vomiting or diarrhea
- Changes in the color of your urine
- Increased or decreased urination
- Changes in your vision
- Unusual skin changes
- Unusual fatigue
- Extreme weight loss with unknown cause
- Decreased appetite
- Difficulty breathing
- Sore throat
- Stomach pain
- Numbness or tingling in hands/feet
- Pain or swelling at the infusion site
- Shortness of breath

Index #6982 | Review Date: 8/8/2019

# Azithromycin

**Brand names:** Zithromax<sup>®</sup>, AzaSite<sup>®</sup>, Zmax<sup>®</sup>

**Class of drugs:** Antibiotic (Macrolide)

## Why is azithromycin prescribed?

Azithromycin is prescribed to prevent or treat infections caused by certain bacteria.

## How is azithromycin taken?

Azithromycin is available in tablets, suspension liquid (with small particles in it) or can be injected through an IV. Immediate release azithromycin tablets and oral suspension can be taken on an empty or full stomach. If you are taking an extended-release suspension, you should take it on an empty stomach.

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

The dose of this medication 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.

## What special instructions should I follow while using this drug?

- Before your healthcare provider prescribes this medicine, tell them know if you have ever had any unusual or allergic reactions to macrolide antibiotics. 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 any of these medicines or foods, azithromycin might not be the right medicine for you. Another antibiotic might be prescribed instead.
- This medication might change the effectiveness of oral contraceptives (birth control pills) containing estrogen. Use a second method of birth control while taking this medicine.
- Drink 2 to 3 liters per day of fluid to stay hydrated while taking this medication.
- 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.

## 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?

- Keep this medicine in a tightly sealed container.
- Store this medication at room temperature.
- If you are taking the extended release suspension (liquid), you should take it within 12 hours of mixing.
- Keep this and other medicines out of the reach of children.

## What are some common side effects of this drug?

Azithromycin may cause any of the following side effects:

- **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 may include weakness, dizziness when standing from a sitting position, decreased urine output and confusion. Tell your nurse coordinator if you are having more than five 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 a severe allergic reaction.

## When should I call my healthcare provider?

Call your healthcare provider if you:

- 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
- Experience persistent (ongoing) or severe side effects
- Develop new symptoms after starting this medication
- Have any other symptoms that cause concern
- Have any questions or concerns

Index #14349 | Review Date: 8/8/2019

# Amphotericin B Lipid Complex

**Brand name:** Abelcet®

**Class of drugs:** Antifungal

## Why is amphotericin B lipid complex prescribed?

Amphotericin B lipid complex is prescribed to transplant patients to treat or prevent the development of aspergillus infection, a type of fungal infection. A transplant patient has an increased risk of developing infections because the immune system is not fully functioning. Amphotericin B lipid complex will fight the infection and help keep the symptoms from becoming worse.

## Is there any reason I should not use this medicine?

You should not use this medicine if you have ever had an allergic reaction to amphotericin B.

## How is amphotericin B given?

This medicine is given by infusion (IV). This drug works best when there is a constant amount of it in the bloodstream. In order to achieve this, allo transplant patients will receive amphotericin B lipid complex daily in the hospital, starting the day after your transplant. Amphotericin B lipid complex must be taken the entire length of treatment to achieve the best results. The dose of this drug will be different for each patient. A home care nurse will teach you how to give yourself this medicine if it is needed on an outpatient basis. Auto transplant patients may receive amphotericin B lipid complex on an as needed basis as directed by your physician.

## What special instructions should I follow while using this drug?

- Drink plenty of fluids every day. (We recommend at least six to eight, 8-ounce glasses of fluid a day.)
- Keep taking this medicine for the full length of treatment.
- Keep refrigerated. Do not freeze.
- Keep all appointments with your doctor and the laboratory so your response to the drug can be monitored.

## What are the common side effects?

While you are taking amphotericin B lipid complex, frequent blood tests will be taken to prevent or limit the development of the following serious side effects:

- Electrolyte imbalance. Taking your prescribed oral potassium and magnesium will help with this side effect. It is not uncommon to require intravenous electrolyte replacement.
- Altered kidney or liver function
- Diarrhea
- Nausea, stomach upset, vomiting
- Weakness, muscle cramps
- Shaking, chills, fever. Medicine such as Tylenol® and Benadryl® will be given before amphotericin B lipid complex to prevent the development of fever or chills. Additional medicines might also be added if needed.

- Generalized muscle or joint pain

Many of the side effects of amphotericin B lipid complex are dose-related and might go away when your healthcare provider adjusts your dosage.

### **When should I call my healthcare provider?**

If you have any of these symptoms, please tell your healthcare provider right away so the dosage of your medicine can be adjusted or additional medicine can be prescribed to prevent or treat these side effects:

- Chills, fever, or headache
- Nausea that does not improve after changing your eating habits
- Vomiting or diarrhea
- Changes in the color of your urine
- Increased or decreased urination
- Changes in your vision
- Unusual skin changes
- Unusual fatigue

- Decreased appetite
- Extreme weight loss with unknown cause
- Difficulty breathing
- Sore throat
- Stomach pain
- Numbness or tingling in hands/feet
- Pain or swelling at the infusion site
- Shortness of breath

Index #11053 | 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<sup>®</sup>, Mylanta<sup>®</sup>, Tums<sup>®</sup>
2. Acid blockers (“Proton pump inhibitors”). Omeprazole (Prilosec<sup>®</sup>), lansoprazole (Prevacid<sup>®</sup>), esomeprazole (Nexium<sup>®</sup>), pantoprazole (Protonix<sup>®</sup>), rabeprazole (AcipHex<sup>®</sup>), dexlansprazole (Dexilant<sup>®</sup>)
3. Acid blockers (“H2 antagonists”). Famotidine (Pepcid<sup>®</sup>), cimetidine (Tagamet<sup>®</sup>), nizatidine (Axid<sup>®</sup>), ranitidine (Zantac<sup>®</sup>)

## 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<sup>®</sup>, Prevacid<sup>®</sup>, and Nexium<sup>®</sup> are available as delayed-release capsules and should be taken on an empty stomach at bedtime (at least 2 hours after meals).

Pepcid<sup>®</sup> 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<sup>®</sup> can be taken with food.

If you have difficulty swallowing capsules, you can open Prevacid<sup>®</sup> or Nexium<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup>), 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 ciprofloxacin, take your ciprofloxacin 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

# Cyclosporine

**Brand names:** Neoral<sup>®</sup>, Sandimmune<sup>®</sup>, Gengraf<sup>®</sup>

## How do I take cyclosporine?

Cyclosporine is available as soft gelatin capsules or oral solution (an olive oil-based liquid). If you take the oral solution, it is best to mix it with milk, chocolate milk, apple juice, or orange juice. Use only glass containers. Refill the glass with more juice or milk after taking your dose, and drink the juice or milk to be sure you get all of the medicine.

The soft gelatin capsules are available in two strengths, 25 mg and 100 mg. Each is different in size and color. Packaged individually, these capsules should be left in the foil containers until used. Cyclosporine may be taken with water on an empty or full stomach. In the hospital, it can be given intravenously.

Cyclosporine is generally taken twice a day. Take the morning dose with breakfast. Take the second dose 12 hours after the first dose. Be sure to take the prescribed doses at the same time every day.

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 at the same time every day as prescribed. **Do not stop taking it.** You might need to take immunosuppressant drugs for the rest of your life to prevent or control graft-versus-host disease (GvHD).

## What special instructions should I follow while using this drug?

- Levels of cyclosporine in the blood can be measured. This is done to help your doctor monitor your therapy more closely.
- **It is important to schedule your regular lab work appointment before taking your daily dose of cyclosporine (preferably in the early morning). You must take the last dose of cyclosporine at least 12 hours before your blood tests. Bring your medicine with you to your appointment so you can take it immediately after your blood is drawn for the test.**
- You must take the entire prescribed amount of cyclosporine to maintain enough immunosuppression. Follow your dosage schedule carefully.
- 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 receive any vaccinations without your doctor's approval.
- Take precautions to avoid infection while taking this medicine.
- If you eat grapefruit or drink grapefruit juice products, it is important that you eat or drink the same amount every day, because this might affect your drug level.
- There are different formulations (brands) for cyclosporine. Please verify that your pharmacist is filling the correct brand.

## 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. If it is almost time for your next dose, you may take your missed along with your regular dose then return to your regular schedule. If you have forgotten more than 1 dose, contact your nurse coordinator for instructions.

## What are the common side effects of this drug?

Even though the side effects of cyclosporine could be very serious, remember that this drug is necessary. We will take precautions to detect these side effects and treat them before they become harmful. Cyclosporine might result in any of the following side effects:

- **Flushing.** This refers to a brief period of warmth and/or redness in your face for 1 to 2 hours after taking cyclosporine. This feeling disappears within a short time.
- **Hair growth.** Increased hair on your face, arms, and body is common, and can be controlled, if necessary, with bleaching creams or hair-removal products. Please discuss with your transplant doctor prior to using any of these products
- **Fine tremors of the hands.** Trembling of the hands is common, especially during the first month of taking cyclosporine. The tremor is usually mild and tends to disappear the longer you take the medicine or when your dosage is decreased.
- **Gum swelling and mouth sensitivity to cold or heat.** Extreme care in daily hygiene is necessary to keep gums in good health.
- **Hypertension (high blood pressure).** You will be asked to purchase a blood pressure cuff and to record your blood pressure twice daily while you are taking cyclosporine. You may be given appropriate medicine to

control your blood pressure, if needed. It is important to follow other recommendations to help lower your blood pressure.

- **Altered kidney function (nephrotoxicity).** You will have blood tests performed frequently to detect changes in kidney function.
- **Diarrhea**
- **Nausea or vomiting.** Small, frequent meals, good mouth care, and sucking on hard candy might help.
- **Neurological symptoms.** These include headache and memory loss.
- **Drug interactions.** Several drugs affect metabolism or excretion of cyclosporine and must be used with caution. You need to verify ALL new medicines with your doctor and nurse coordinator. This includes over-the-counter (OTC) and herbal products.
- **Increased risk of infection**

## What storage conditions are necessary for this drug?

- Store this medicine at room temperature. Do not freeze or expose to heat over 77°F. The liquid might gel at temperatures below 68°F, so bring to room temperature before drinking.
- If you are traveling, store your cyclosporine in an insulated container.
- 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 the capsule form of this medicine in the packaging it came in, tightly sealed. Cyclosporine might lose its strength if removed from its packaging far in advance of taking it.

- The liquid form of this medicine can be used for 60 days after opening.
- Do not use this medicine after the expiration date on the packaging.
- Keep it and other medicines out of the reach of children.

### Why are blood tests important?

Frequent blood tests allow your doctor to effectively monitor the levels of cyclosporine in your blood and prevent adverse side effects of the medicine.

### How can I reduce the side effects of cyclosporine?

To avoid or control the possible side effects of cyclosporine, follow these suggestions.

Index #10423 | Review Date: 8/8/2019

Possible Side Effect	What You Should Do
Increased risk of infection	A void anyone who might have an infection, and report any signs or symptoms of infection to your healthcare provider.
Swollen or bleeding gums	Practice good oral hygiene to prevent swollen gums from becoming infected. Brush your teeth and gums thoroughly after each meal with a small, soft toothbrush and fluoride toothpaste. Use foam sticks instead of a toothbrush if your gums are especially sore. Keep dentures clean and fitting properly. Report any mouth sores to your healthcare provider. Call your BMT Team before any dental procedures.
Excess hair growth	To remove unwanted hair, use safe bleaching techniques or creams. Please check with your BMT Team before using these products.
Liver damage	Visit your doctor regularly and have your blood drawn as scheduled. Report any changes in the color of your urine, eyes, or skin.
Kidney damage	Report any changes in urine output, weight, or swelling during your regular doctor visits.
Tremors or seizures	Report any trembling, shaking, or seizures to your doctor. Your dosage might need to be adjusted.
High blood pressure	Take your medicine as prescribed and limit salt in your diet.

# Fluconazole

**Brand name:** Diflucan®

## Why is fluconazole prescribed?

Fluconazole is used to prevent or treat fungal infections. Transplant patients might develop infections because their immune systems are suppressed by either chemotherapy or — in allogeneic patients — by the immunosuppressive medicines they must take to prevent graft-versus-host disease.

## How is fluconazole taken?

Fluconazole is generally taken in the form of tablets in 100 mg or 200 mg. It also comes in 50 mg, 150 mg, and suspension liquid. In the hospital, this medicine can be given intravenously.

It is usually taken once daily. Fluconazole must be taken for the entire length of treatment to achieve the best results. The dose of this drug will be different for each patient. It is possible you will take fluconazole as long as you are also taking immunosuppressive medicines. You might be taking this medicine and amphotericin B at the same time.

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 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?

- It is important to tell your doctor if you are taking cimetidine (Tagamet®), which is an antacid. Cimetidine can decrease the effect of fluconazole.
- It is important to tell your doctor if you are taking an anticoagulant (blood-thinning drug), such as warfarin (Coumadin®). Fluconazole can increase the effect of the anticoagulant, so it might be necessary to have blood tests more frequently.
- If you are taking tacrolimus (Prograf®), your doctor might order more frequent checks of tacrolimus blood levels and might possibly change your dose of tacrolimus.
- Please tell your health care provider if you are using tadalafil (Cialis®) sildenafil (Viagra®), or vardenafil (Levitra®) for erectile dysfunction. This drug combination might cause changes in your blood pressure.
- If you are taking cyclosporine (Neoral®), your doctor might order more frequent blood tests to check your renal (kidney) function.
- Keep taking fluconazole 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.
- 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.

### **What storage conditions are necessary for this drug?**

- Store the tablet form of this medicine at room temperature.
- The liquid form of this medicine can be stored either at room temperature or in the refrigerator. Do not freeze. Throw away any unused liquid after 2 weeks.
- 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 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?**

Fluconazole might cause any of the following side effects:

- 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.
- Headache

### **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
- 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 #10995 | Review Date: 8/8/2019

# Ganciclovir

**Brand name:** Cytovene®

**Drug class:** Antiviral

## Why is ganciclovir prescribed?

Ganciclovir is prescribed to transplant patients to treat or prevent the development of cytomegalovirus (CMV), a type of herpes virus that can cause a variety of different infections. Ganciclovir will suppress the infection and help keep the symptoms from becoming worse.

A BMT patient who received donor cells might be at risk for developing an active CMV infection if he or she or the donor was exposed to the virus in the past.

## How is ganciclovir given?

This medicine is given by infusion (IV). This drug works best when there is a constant amount of it in the bloodstream. You must take ganciclovir for the entire length of treatment to achieve the best results. The dose of this drug will be different for each patient. A home care nurse will teach you how to give yourself this medicine at home.

## What special instructions should I follow while using this drug?

- Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this guide.
- While taking this medicine, it is important for men and women to use barrier contraception (condom) if they are sexually active, since there might be an increased risk of birth defects if pregnancy occurred while taking this medicine. Continue using

barrier contraception for at least 90 days following ganciclovir treatment.

- This medicine might cause infertility in men or women. Discuss this risk with your healthcare provider before taking this medicine.
- Keep taking ganciclovir for the full length of treatment.
- Be sure you always have enough medicine on hand. Check your supply before holidays or other occasions when your home care pharmacy might be unable to deliver your supply.
- 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, call your healthcare provider for instructions.

## What storage conditions are necessary for this drug?

- Store this medicine in the refrigerator. Do not freeze.
- Keep this and other medicines out of the reach of children.

## What are the common side effects of this drug?

While you are taking ganciclovir, frequent blood tests will be taken to prevent or limit the development of these serious side effects:

- Neutropenia (low white blood cell count). If you are told your white blood cell count is at a critical level, call your healthcare provider if you develop any of these symptoms:
  - Fever 100.4° F or higher
  - Mild sore throat
  - Mild cough
- Anemia (low red blood cell count)
- Thrombocytopenia (low platelet count)
- Altered kidney function (nephrotoxicity). Blood tests will be performed frequently to detect any changes in kidney function.

Other common side effects include:

- Headache
- Diarrhea
- Nausea
- Vomiting
- Upset stomach
- Loss of appetite
- Dizziness
- Confusion
- Nervousness
- Rash

## When should I call my healthcare provider?

If you have any of these symptoms, please tell your healthcare provider at your next follow-up appointment:

- Changes in your urine output
- Swelling of the feet or ankles
- Nausea that does not improve after changing your eating habits

If you experience any of the following symptoms, call your healthcare provider immediately:

- Sore throat with fever, chills
- Diarrhea
- Unusual bleeding or bruising
- Black, tarry stools
- Pain or swelling at place of infusion
- Rash
- Unusual tiredness
- Mood or mental changes

Index #10247 | Review Date: 8/8/2019

# Immune Globulins (IVIG)

**Brand names:** Sandoglobulin<sup>®</sup>, GammlImmune<sup>®</sup>, Iveegam<sup>®</sup>, Gammagard<sup>®</sup>, Polygam<sup>®</sup>, Venoglobulin<sup>®</sup>

## What are immune globulins?

Immune globulins are substances normally found in your body that perform a variety of functions, the most important being to help fight infection. You will receive immune globulins intravenously to help boost your infection-fighting capabilities. Your BMT Team will determine how often you will receive the infusion.

Sometimes, people receive intravenous (IV) immune globulins because it seems to increase the length of survival of platelets, the cells responsible for controlling bleeding in your body. You may ask your doctor or nurse for the exact reason why you are receiving immune globulins.

## How are immune globulins given?

Immune globulins are given intravenously (directly in a vein) over a period of a few hours.

## What are the common side effects of immune globulins?

Although rare, you might experience some side effects from the IV immune globulins. These side effects might include:

- Chills
- Flushing
- Dizziness
- Nausea
- Fever
- Back, hip, or joint pain

- Headache
- Tiredness
- Shortness of breath, wheezing
- Chest tightness
- Rash or hives
- Problems urinating or urinating less often

Patients who experience some of these side effects might be pre-medicated with Tylenol<sup>®</sup>, diphenhydramine, and/or hydrocortisone. These drugs are given to prevent further infusion reactions.

## When should I call my healthcare provider?

If you experience any of these side effects or if you start to feel different in any way, call your nurse immediately.

If you have any other questions about this medicine, please ask your nurse or doctor.

Index #10639 | Review Date: 8/82019

# Immunosuppressant Medicines

## Why do I need to suppress my immune system?

In order for your donor's cells to develop and multiply in your body, the cells involved with recognizing "foreign" cells must be suppressed. (In other words, we must reduce the normal level of "combat" activity of your body's defense system.) You will be receiving several different immunosuppressant medicines at the same time because each medicine suppresses your immune system in a different way. They are used to prevent or control graft-versus-host disease (GvHD).

The Transplant Team will monitor the ratio of donor and recipient DNA on a routine basis through a blood test. Once your donor's cells are fully matured, your transplant doctor will determine the best taper schedule for you. You might be taking none, one, or several immunosuppressant medicines at different times after transplant. You might need to be taking immunosuppressant medicines for an indefinite length of time to control GvHD. While you are on any suppressive medicine, you are at risk for life-threatening infections. Your nurse coordinator will review precautions with you to prevent infection. You must always watch for signs of infection, and tell your BMT Team immediately at the first sign.

## 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 (38oC)
- Sweats or chills

- Skin rash
- Pain, tenderness, 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 the 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

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

Index #10418 | Review Date: 8/82019

# Itraconazole

**Brand name:** Sporanox®

**Drug class:** Antifungal

## Why is itraconazole prescribed?

Itraconazole is prescribed to transplant patients to treat or prevent the development of aspergillus infection, a type of fungal infection. A transplant patient has an increased risk of developing infections because the immune system is suppressed.

## How is itraconazole taken?

Itraconazole is generally taken in the form of capsules or liquid that is swallowed. If the liquid form of this medicine is prescribed, use a specially marked measuring cup to measure each dose accurately.

This drug works best when there is a constant amount of it in the bloodstream. You must take itraconazole for the entire length of treatment to achieve the best results. The dose of this drug will be different for each patient. You will probably take itraconazole as long as you are also taking immunosuppressive medicines. You might be taking this medicine and an additional antifungal (amphotericin B) at the same time.

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?

- Itraconazole should be taken at least 2 hours before taking magnesium supplements and antacids — such as Pepcid®, Prilosec®, and Nexium® — if these medicines are prescribed for you.
- Liquid itraconazole is best absorbed on an empty stomach with a glass of cola, which will increase your stomach's acidity, making the medicine more effective.
- Please tell your health care provider if you are using the drug tadalafil (Cialis®), sildenafil (Viagra®), or vardenafil (Levitra®) for erectile dysfunction. This drug combination might cause changes in your blood pressure.
- It is best to take the tablet form of itraconazole with food.
- Keep taking itraconazole for the full length of 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.
- 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.

## What storage conditions are necessary for this drug?

- Store this medicine at room temperature.
- Do not store the capsule form of 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.
- Store the liquid form of this medicine in the refrigerator, but make sure it does not freeze.
- 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?

While you are taking itraconazole, frequent blood tests will be taken to prevent or limit the development of altered liver function, a serious side effect of this medicine.

Nausea is a common side effect of itraconazole. To manage nausea, eat small, frequent meals and avoid spicy or greasy foods.

## When should I call my healthcare provider?

If you have any of these symptoms, please tell your healthcare provider at your next follow-up appointment:

- Changes in your urine output
- Nausea that does not improve after changing your eating habits
- Constipation, diarrhea
- Headache

If you experience any of the following symptoms, call your healthcare provider immediately:

- Fever or chills
- Skin rash, itching or unusual skin changes
- Sore throat
- Changes in the color of your urine
- Changes in your vision
- Unusual fatigue
- Extreme weight loss with unknown cause
- Unusual bleeding or bruising
- Stomach pain
- Loss of appetite

Index #9064 | Review Date: 8/8/2019

# Methotrexate

**Brand names:** Folex<sup>®</sup>, Folex PFS<sup>®</sup>, Mexate<sup>®</sup>, Mexate-AQ<sup>®</sup>, Rheumatrex<sup>®</sup>, Trexall<sup>®</sup>

## What are some other names for this medicine?

Methotrexate is also called MTX.

## What does it do?

Methotrexate blocks an enzyme needed by cancer cells to live. This interferes with the growth of cancer cells, which are eventually destroyed. Methotrexate is also used to prevent graft-versus-host disease in BMT patients receiving cells from a donor. This medicine is classified as an “antimetabolite.”

## How is it given?

Methotrexate is an intravenous solution that is injected through your central venous catheter.

## What are some side effects I might experience?

- Decreased blood counts
- Nausea and vomiting
- Poor appetite
- Diarrhea

- 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.
- Skin rash
- Increased sensitivity to the sun
- Hair loss
- Eye irritation
- Loss of fertility
- Kidney toxicity

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 #4884 | Review Date:8/8/2019

# Mycophenolate Mofetil

**Brand names:** CellCept®

## How is this medicine taken?

Mycophenolate mofetil is available in capsule or tablet form in 250 mg and 500 mg doses. It is also available in liquid form. In the hospital, this medicine can be given intravenously. Generally, mycophenolate mofetil is taken two to three times per day.

Swallow the capsules or tablets whole. Do not break, crush, chew, or open the capsules or tablets before swallowing. Mycophenolate mofetil may be taken with or without food.

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 at the same time every day as prescribed. **Do not stop taking it.** You might need to take immunosuppressant drugs for the rest of your life to prevent or control graft-versus-host disease (GvHD).

## What special instructions should I follow while using this drug?

- Do not take mycophenolate mofetil at the same time as an antacid, since absorption of this medicine will be decreased. Do not take antacids (Maalox®, Mylanta®, Tums®), cholestyramine, or iron within 2 hours of taking this medicine.

- Do not break, crush, chew, or open the capsules or tablets before swallowing. The powder in the capsule should not come in direct contact with your skin or mucous membranes, and inhalation should be avoided. If skin contact does occur, wash your skin immediately and thoroughly with soap and warm water.
- You must take all of the prescribed amount of mycophenolate mofetil to maintain enough immunosuppression. Follow your dosage schedule carefully.
- 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 vaccinations without your doctor's approval.
- Take precautions to avoid infection while taking this medicine.
- Use a reliable form of birth control during treatment and for 6 weeks after

## 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. If it has been more than 3 hours since your missed dose, call your nurse coordinator for advice. Taking your medicine doses too close together can be harmful.

## What are the common side effects of this drug?

- Diarrhea
- Nausea or vomiting
- Birth defects. Because this medicine can cause birth defects, use barrier contraception (condom) plus another form of birth control if you are sexually active, even if you are thought to be infertile. This practice should be continued for 6 weeks after your doctor discontinues this medicine. You should not try to get pregnant while you are taking this medicine.
- Increased risk of infection. Avoid anyone who might have an infection, and report any signs or symptoms of infection to your healthcare provider.
- Changes in white blood cell count. Have your blood drawn regularly so your healthcare providers can monitor your white blood cell count.
- High blood pressure
- Headache
- Swelling

## What storage conditions are necessary with this drug?

- Store this medicine, both pills and liquid, at room temperature. Do not freeze or expose to heat over 77° F. Liquid might be kept in the refrigerator as well.
- If you are traveling, store your medicine in an insulated container.
- 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
- The liquid form of this medicine can be used for 60 days after opening.
- Do not use this medicine after the expiration date on the packaging.
- Keep it and other medicines out of the reach of children.

Index #4679 | 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

# Pentamidine

**Brand names:** NebuPent®, Pentam 300®

## Why is pentamidine given?

Pentamidine is given to prevent the development of pneumonia caused by the bacteria *Pneumocystis carinii*. Allogeneic transplant patients who are unable to take sulfa drugs, such as Bactrim®, may be prescribed this treatment.

## How is pentamidine given?

A respiratory therapist will administer the pentamidine aerosol treatment using a device called a nebulizer (a plastic tube that is held between your lips). The pentamidine aerosol treatment is delivered through the nebulizer until the entire dose is gone, usually 30 to 40 minutes. The pentamidine treatments are given every 30 days. The aerosol treatments can be given in the Taussig Outpatient Department if you are receiving other prescribed treatments that day or at A90 in the Respiratory Therapy Department. Your treatments will be arranged by your BMT Team.

## What special instructions should I follow while taking this medicine?

This medicine can cause coughing, difficulty breathing, or wheezing. A bronchodilator (which opens your airways), such as albuterol, might be given with the pentamidine aerosol treatment. This will allow the medicine to be given more easily and to help prevent further adverse effects.

## What are the common side effects of this drug?

- Fatigue
- Dizziness
- Coughing
- Nausea
- Decreased appetite

## When should I call my healthcare provider?

Call your healthcare provider immediately or call 9-1-1 if you experience any of the following symptoms:

- Chest pain
- Constant coughing
- Difficulty breathing

Index # 10760 | Review Date: 8/8/2019

# Steroids

**Generic names:** Prednisone, Methylprednisolone, Dexamethasone

**Brand names:** Deltasone<sup>®</sup>, Meticorten<sup>®</sup>, Orasone<sup>®</sup>, Prednicen-M<sup>®</sup>, Prednisone Intensol<sup>®</sup>, Solu-Cortef<sup>®</sup>, Solu-Medrol<sup>®</sup>, Sterapred DS<sup>®</sup>

## 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.

# Sulfamethoxazole and Trimethoprim Double Strength

**Brand name:** Bactrim® DS

**Drug class:** Antibiotic

## Why is Bactrim DS® prescribed?

Bactrim® DS is usually prescribed to prevent or treat a specific bacterial infection called Pneumocystis jiroveci pneumonia. This infection can affect the lungs or brain. Bactrim® DS can also be used to treat a variety of bacterial infections including urinary tract infections.

Transplant patients might develop this infection because their immune system is suppressed by the immunosuppressive drugs they must take to prevent graft-versus-host disease (GvHD).

## How is Bactrim® DS taken?

Bactrim® DS is generally taken in the form of tablets or suspension liquid (with small particles in it). The tablet form of this medicine is taken with a full glass of water (8 ounces). The oral liquid form of this medicine should be shaken well before use and measured with a specially marked measuring spoon to measure each dose accurately.

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 consulting your doctor.

## What special instructions should I follow while using this drug?

- Review all of your allergies with your transplant physician including allergies to foods, preservatives, and dyes.
- Tell your healthcare provider if you have ever had any unusual or allergic reactions to any

of these medicines: **sulfa medicines**, furosemide (Lasix®), thiazide diuretics (water pills), oral diabetes medicines, glaucoma medicine, dichlorphenamide (Daranide®), methazolamide (Neptazane®), or trimethoprim (Trimprex®) BEFORE he or she prescribes Bactrim® DS. If you are allergic to any of these medicines, you should NOT take Bactrim® DS. Another antibiotic might be prescribed instead.

- This medicine causes increased sensitivity to sunlight. Avoid direct sunlight (especially from 10 am to 3 pm, if possible) and tanning beds. Wear a sunblock with an SPF of at least 30 and, wear protective clothing, including a hat and sunglasses. Sensitivity to sunlight might continue for many months after you stop taking Bactrim® DS.
- Keep taking Bactrim® DS for the full length of 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.
- 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.

### What storage conditions are necessary for this drug?

- Store this medicine (both 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?

Bactrim® DS might cause any of the following side effects. Some of these side effects (such as headache or nausea) can be avoided or relieved by drinking plenty of water daily.

- Anemia (blood problems resulting from a reduction in the number of red blood cells). Anemia is often a result of taking Bactrim®DS over a long period of time.
- Lowered white cell count
- Sensitivity to sunlight
- Dizziness
- Diarrhea
- Headache
- Loss of appetite
- Nausea with or without vomiting
- Skin rash

### When should I call my healthcare provider?

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

- Have skin reactions
- Have severe nausea or vomiting
- 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 #4675 | Review Date: 8/8/2019

# Tacrolimus, FK506

**Brand name:** Prograf®

**Type of medication:** Immunosuppressive agent

## How is tacrolimus taken?

Tacrolimus is available in capsule form in 0.5 mg, 1 mg, or 5 mg doses. In the hospital, this medicine can be given intravenously. It is also available as an ointment for the skin.

Take tacrolimus exactly as your doctor directs. Tacrolimus works best when it is constantly in the bloodstream. Try to take it around the same time each day. Levels of tacrolimus in the blood can be measured. This will help your doctor monitor your therapy closely.

Changes in your diet might affect absorption of this drug. Do not change the type or amount of food you eat without talking with your doctor.

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 at the same time every day as prescribed. **Do not stop taking it.** You might need to take immunosuppressant drugs for the rest of your life to prevent or control graft-versus-host disease (GvHD).

## What special instructions should I follow while using this drug?

- It is best to take tacrolimus on an empty stomach. Take it 1 hour before or 2 hours after meals.
- Swallow capsules whole. Do not chew, break, or crush capsules.
- **It is important to schedule your regular lab work appointment before taking your daily**

**dose of tacrolimus (preferably in the early morning). You must take the last dose of tacrolimus at least 12 hours before your blood tests. Bring your medicine with you to your appointment so you can take it immediately after your blood is drawn for the test.**

- You must take all of the prescribed amount of tacrolimus to maintain enough immunosuppression. Follow your dosage schedule carefully.
- 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 vaccinations without your doctor's approval.
- Take precautions to avoid infection while taking this medicine.
- Do not take antacids (Maalox®, Mylanta®, Tums®), cholestyramine, or colestipol within 2 hours of taking this medicine. Antacids could impair the absorption of tacrolimus.
- Do not take this medicine with any grapefruit or grapefruit juice products.
- Do not take St. John's wort while taking this medicine.

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

If it has been less than 3 hours since your missed dose, take the missed dose and return

to your regular schedule. However, if it is almost time to take your next scheduled dose, simply skip the missed dose and proceed with your regular schedule. Do not take a double dose. If you miss more than 1 dose, please call your BMT nurse coordinator for specific instructions.

### What are the common side effects of this drug?

The most common side effects include:

- **Hyperglycemia** (increased blood glucose level). Blood tests will be performed frequently to monitor your blood glucose level. Tell your nurse coordinator if you develop frequent urination or increased thirst. If your blood glucose levels are routinely high, you might be prescribed medicine to control your glucose levels.
- **Altered kidney function** (nephrotoxicity). Blood tests will be performed frequently to detect changes in kidney function. Your BMT doctor may decide to change or temporarily stop your tacrolimus dose if the blood tests indicate an altered kidney function. Do not stop taking this medicine without your doctor's approval.
- **Hyperkalemia** (increased potassium level). Blood tests will be performed frequently to measure your potassium level.
- **Neurotoxicity** such as tremors, headaches or confusion. These symptoms are usually associated with increased levels of tacrolimus in your blood. Therefore, frequent blood tests will be done to monitor your levels to prevent adverse side effects.
- **Increased risk of infection.** Avoid anyone who might have an infection, and report any signs or symptoms of infection to your health care provider.
- **Hypertension** (high blood pressure). You will be asked to purchase a blood pressure cuff and record your blood pressure twice daily

while you are taking tacrolimus. If needed, you might be prescribed medicine to control your blood pressure. It is important to follow other recommendations to help lower your blood pressure, such as following a low-sodium (low-salt) diet.

- **Hypomagnesemia** (low magnesium levels). Blood tests will be performed frequently to measure your magnesium level. You may need to take a magnesium supplement.
- Nausea or vomiting
- Diarrhea

### What storage conditions are necessary for this drug?

- Store this medicine at room temperature. Do not freeze or expose to heat over 77°F.
- If you are traveling, store your medicine in an insulated container.
- 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.
- Do not use this medicine after the expiration date on the packaging.
- Keep it and other medicines out of the reach of children.

### Why are blood tests important?

Frequent blood tests allow your doctor to effectively monitor the levels of tacrolimus in your blood and prevent adverse side effects of the medicine.

Index #10074 | Review Date: 8/8/2019

# Valganciclovir

**Brand name:** Valcyte®

**Drug class:** Antiviral

## Why is valganciclovir prescribed?

Valganciclovir is prescribed to transplant patients to treat or prevent the development of cytomegalovirus (CMV), a type of herpes virus that can cause a variety of different infections. Valganciclovir will suppress the infection and help keep the symptoms from becoming worse.

A BMT patient who received donor cells might be at risk for developing an active CMV infection if he/she or the donor was exposed to the virus in the past.

## How is valganciclovir taken?

Valganciclovir is generally taken as tablets. This drug works best when there is a constant amount of it in the bloodstream. Valganciclovir must be taken for the entire length of treatment to achieve the best results. The dose of this drug 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. It is important that you take this medicine regularly as prescribed. Do not stop taking it without talking to your doctor.

Your dosage might be decreased or even stopped after several months, or when the infection has subsided.

## What special instructions should I follow while using this drug?

- Take your tablet with food or milk so your body will absorb it completely.
- Throw away any tablet that is broken or crushed. Do not touch or allow anyone to touch a broken or crushed tablet. If you or someone else does touch the tablet, wash the medicine off of your hands completely, using warm water and soap.
- While taking this medicine, it is important for men and women to use barrier contraception if they are sexually active, since there might be an increased risk of birth defects if pregnancy occurred while taking this medicine. Continue using barrier contraception for at least 90 days following valganciclovir treatment.
- This medicine can cause drowsiness, dizziness, or changes in muscle coordination or control. Do not drive, operate machinery, or participate in any potentially dangerous activity until you know how the medicine affects you.
- This medicine might cause infertility. Discuss this risk with your healthcare provider before taking it.
- Take valganciclovir for the full length of treatment.
- Be sure that 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.
- This medicine might cause light sensitivity (photosensitivity). Avoid direct sunlight, and wear sunscreen with an SPF of 30 or greater.

## 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 this medicine 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?

While you are taking valganciclovir, frequent blood tests will be taken to prevent or limit the development of these serious side effects:

- Neutropenia (low white blood cell count)
- Anemia (low red blood cell count)
- Thrombocytopenia (low platelet count)

Valganciclovir might result in any of these other side effects:

- Drowsiness
- Dizziness
- Increase or decrease in urination
- Eye pain or changes in vision
- Changes in muscle coordination or control
- Fever or chills
- Sore throat
- Unusual tiredness or weakness
- Headache
- Nausea/vomiting
- Diarrhea
- Trouble sleeping

## When should I call my healthcare provider?

Call your healthcare provider **right away** if you:

- 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 #10308 | Review Date: 8/8/2019

# Voriconazole

**Brand name:** Vfend®

**Class of drugs:** Antifungal

## Why is voriconazole given?

Voriconazole is given to transplant patients to prevent or treat the development of aspergillus or other fungal infections. A transplant patient has an increased risk of developing infections because the immune system is suppressed.

## How is voriconazole taken?

Voriconazole is generally taken as tablets twice daily. Your prescription label tells you how many tablets to take and how often to take them. Follow these instructions carefully, and ask your doctor or pharmacist to explain anything you do not understand. It is important that you take this medicine as prescribed. Do not stop taking it without talking to your doctor.

## What special instructions should I follow while using this drug?

- Take voriconazole 1 hour before meals or 1 hour after a meal since food may interfere with absorption.
- Tell your health care team if you are taking sildenafil (Viagra®), vardenafil (Levitra®), or tadalafil (Cialis®). These are all medicines used to treat erectile dysfunction. These drugs combined with voriconazole might cause dangerous changes in your blood pressure.
- Visual changes are commonly associated with voriconazole, especially during the first few doses. These might include blurred vision, color changes, increased sensitivity to light (photophobia), and changes in visual acuity (sharpness). Avoid tasks such as driving or operating machinery if you

experience any of these changes. These changes are generally reversible and decrease with time. Discuss this with your transplant team.

- Take voriconazole for the entire length of treatment.
- Be sure you always have enough voriconazole on hand. Check your supply before a holiday or weekend, or other occasions when you might be unable to refill your prescription.
- Keep all appointments with your doctor and the lab so your response to the drug can be monitored.
- If you are taking tacrolimus (Prograf®), cyclosporine (Neoral®, Sandimmune®), or sirolimus (Rapamune®), your doctor might order more frequent checks of tacrolimus, cyclosporine or sirolimus blood levels and might possibly change your dose of tacrolimus, cyclosporine or sirolimus.
- Voriconazole may interact with several other medications. Check with your doctor before taking any new medication, including over-the-counter and herbal products.

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

- Take a missed dose as soon as possible.
- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.

### How should I store this medicine?

- Store it at room temperature.
- DO NOT store the capsule form of this medicine in direct sunlight, in the bathroom, near a sink, or in any damp place. Heat or moisture might cause the medicine 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?

- You will have frequent blood tests while taking voriconazole to monitor the development of altered liver function, a serious side effect of this medicine.
- Visual changes might occur while taking voriconazole. Discuss this with your BMT team.
- Voriconazole tablets contain lactose, which might cause increased diarrhea in patients who are lactose intolerant (patients who lack the enzyme to help break down lactose), which is found in dairy products. Discuss this with your BMT Team.

### When should I call my healthcare provider?

If you have any of the following symptoms, please tell your healthcare provider at your next follow-up appointments:

- Diarrhea
- Nausea that doesn't improve after changing your eating habits

Call your healthcare provider immediately if you experience any of the following symptoms:

- Fever or chills
- Skin rash or itching
- Sore throat
- Changes in your vision or hallucinations that are temporary
- Changes in the color of your urine
- Unusual fatigue
- Bleeding or unexplained bruising
- Stomach pain
- Loss of appetite

Call 911 or report to the nearest emergency room if you have:

- Chest pain
- Heart palpitations or a rapid heart rate

Index #12160 | Review Date: 8/8/2019

# Posaconazole

**Brand name:** Noxafil®

## Why is posaconazole given?

Posaconazole is used to treat or prevent infections with fungal organisms. A transplant patient has an increased risk of developing such infections because the immune system is suppressed.

## How is posaconazole taken?

Posaconazole is taken as a tablet. Your prescription tells you how often to take the medication. Follow these instructions carefully and ask your doctor or pharmacist to explain anything you do not understand. It is important that you take this medication as prescribed, even if feeling better (fungal infections may take weeks or months of therapy). Do not stop taking it without talking to your doctor.

## What special instructions should I follow while using this drug?

- Take this medication with food.
- Swallow tablets whole. Do not divide, crush, dissolve or chew.
- Avoid grapefruit juice while taking this medication.
- Avoid alcohol (includes wine, beer, and liquor).
- Shake well before use.
- Do not take any new prescriptions, over-the-counter medications, vitamins, or herbal products during therapy without consulting prescriber.

- Be sure you always have enough posaconazole on hand. Check your supply before a holiday or weekend, or other occasions when you might be unable to refill your prescription.
- Keep all appointments with your doctor and the lab so your response to the drug can be monitored.
- If you are taking tacrolimus (Prograf®), cyclosporine (Neoral®, Sandimmune®), or sirolimus (Rapamune®), your doctor might order more frequent checks of the blood levels of these drugs and might possibly change the dose of these drugs.
- Posaconazole may interact with several other medications. Check with your doctor before taking any new medications, including over-the-counter and herbal products.

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

- Take a missed dose as soon as possible.
- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.

## How should I store this medicine?

- Store this medicine at room temperature. Do not freeze.
- Protect from light.
- Keep this and other medicines out of the reach of children.

## What are the common side effects of this drug?

- Nausea or vomiting. Small frequent meals; frequent mouth care; sucking hard, sugar-free candy; or chewing sugar-free gum may help.
- Diarrhea
- Belly pain
- Headache
- Low potassium level. Signs include feeling tired, weak, numbness, or tingling; muscle cramps; constipation; vomiting; or fast heartbeat.
- Liver damage can occur (rare). You will have frequent blood tests while taking posaconazole to watch for changes in liver function, a serious side effect of this medicine.
- Difficulty breathing
- Severe swelling
- Fast heartbeat or passing out
- Severe belly pain
- Severe diarrhea
- Severe nausea or vomiting
- Not able to eat
- Signs of low potassium
- Significant weight gain
- Dark urine or yellow skin or eyes
- Feeling extremely tired or weak
- Any rash
- No improvement in condition or feeling worse

## When should I call my healthcare provider?

- If you suspect an overdose, call your local poison control center or emergency department immediately.
- Signs of a life-threatening reaction. These include wheezing; chest tightness; fever; itching; bad cough; blue skin color; fits; or swelling of face, lips, tongue, or throat.

Index #14679 | Review Date: 8/8/2019

# Leuprolide Acetate

**Brand name:** Lupron Depot®

## Why is leuprolide acetate prescribed?

Leuprolide acetate is used in pre-menopausal women to prevent severe menstrual bleeding during blood and marrow transplantation. Leuprolide acetate works by preventing the release of hormones that lead to ovulation and menstruation.

## How and when should leuprolide be used?

Leuprolide acetate is an intramuscular injection that is given prior to transplantation (approximately 2 to 4 weeks before hospital admission). The injection may be given during an office visit. Sites of administration include the buttocks area, front of the thigh, or deltoid muscle (muscle around the shoulder).

## What do I need to tell my doctor BEFORE I take this drug?

- If you are allergic to any medications or chemicals, including what happened when you were exposed to the substance
- If you are pregnant or may be pregnant
- If you are breastfeeding
- If you have unexplained vaginal bleeding

## 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
- Avoid driving or doing tasks that require your alertness until you see how this drug affects you

- Use barrier methods of contraception, such as condoms, while on this medication
- Notify your physician if you become pregnant while on this therapy
- Do not breastfeed while taking this medication

## What are the common side effects?

This drug may raise certain hormone levels in your body during the first few weeks of therapy. This may result in breakthrough bleeding. Call your doctor if this does not improve within a few weeks of starting therapy.

The most common side effects are due to the direct effects of the medication on menstruation. Most patients do not experience all of the side effects listed. Some side effects that may occur include:

- Hot flashes
- Headache
- Mood changes
- Vaginal dryness
- Change in breast size and breast soreness or tenderness
- Nausea and vomiting
- Injection site burning/pain
- Bone loss

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

## When should I call my healthcare provider?

Call your healthcare provider right away if you:

- Develop signs of an allergic reaction such as rash, hives, itching, wheezing, tightness in the chest or throat, or trouble breathing
- Develop signs of depressed mood, thoughts of killing yourself or others, nervousness, emotional ups and downs, anxiety, or lack of interest in life
- Have any other symptoms that are concerning

Index #15776 | 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<sup>®</sup> SR)

Magnesium Oxide (Mag-Ox<sup>®</sup> 400)

Magnesium Gluconate (Magonate<sup>®</sup>, Magtrate<sup>®</sup>, Mag<sup>®</sup>-G)

Magnesium Chloride (Chloromag<sup>®</sup>, Mag Delay, Slow-Mag<sup>®</sup>)

## 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<sup>®</sup>), levofloxacin (Levaquin<sup>®</sup>), and moxifloxacin (Avelox<sup>®</sup>). 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

# Cyclophosphamide (after stem cell transplant)

**Brand name:** Cytosan®

## What does it do?

Cyclophosphamide decreases the ability of transplanted stem cells to mount an immune response against the recipient. This is a condition known as graft-versus-host disease, or GVHD. Cyclophosphamide also has anti-cancer activity against many different types of cancer cells. It is thought that cyclophosphamide can help prevent GVHD after stem cell transplant.

## How is it given?

Cyclophosphamide is given as an intravenous infusion on two consecutive days starting on the third day after stem cell transplant. The infusion is given over two to four hours with increased intravenous fluids provided before and after each dose.

## What are some side effects of cyclophosphamide I may experience?

- Decreased blood counts
- Loss of appetite, nausea, vomiting, or diarrhea
- Mucositis. You may develop inflammation or sores on the inside of your mouth and throat (oral mucosa). This may coincide with dry, sticky saliva; discomfort when chewing or swallowing; or a burning sensation or feeling of a “lump” in your throat or chest.

- Burning or pain upon urination
- Blood in the urine. You will receive extra IV fluid and a medication called mesna to help prevent this side effect. Drinking lots of fluid and urinating frequently can also help prevent this side effect.
- Hair loss
- Heart damage. To help prevent this side effect you will have an EKG to monitor your heart’s electrical activity before each dose of cyclophosphamide
- Altered sensation of taste
- Feelings of dizziness, nasal congestion, or jaw pain during infusion of the drug
- Sterility in males and females
- Secondary malignancy

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 # 15623 | Review Date: 8/8/2019

# Isavuconazole /Isavuconazonium Sulfate

**Brand name:** Cresemba®

**Class of drug:** Antifungal

## Why is isavuconazole given?

Isavuconazole is prescribed to transplant patients to treat or prevent the development of aspergillus infection, a type of fungal infection. A transplant patient has an increased risk of developing infections because the immune system is suppressed.

## How is isavuconazole taken?

Isavuconazole is generally taken in the form of capsules that are swallowed.

This drug works best when there is a constant level of it in the bloodstream. You must take isavuconazole for the entire length of treatment to achieve the best results. The dose of this drug 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. It is important that you take this medicine as prescribed. Do not stop taking it without talking to your doctor.

## What special instructions should I follow while using this drug?

- Please tell your healthcare provider if you are taking tadalafil (Cialis®), sildenafil (Viagra®), or vardenafil (Levitra®) for erectile dysfunction. This drug combination might cause changes in your blood pressure.
- Swallow capsules whole. Do not crush, chew, dissolve or open.

- Keep taking isavuconazole for the full length of 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.
- Keep all appointments with your doctor and the laboratory so your response to the drug can be monitored.
- Isavuconazole may interact with several other medications. Check with your doctor before taking any new medication including over-the-counter and herbal products.

## 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 this medicine at room temperature.
- DO NOT store the capsule form of 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 its original container.
- Keep this and other medicines out of the reach of children.

## What are common side effects and what can I do to treat them?

While you are taking isavuconazole, frequent blood tests will be taken to prevent or reduce changes in your liver function, a serious side effect of this medicine.

Nausea is a common side effect of isavuconazole. To manage nausea, eat small, frequent meals and avoid spicy or greasy foods.

## When should I call my healthcare provider?

If you have any of the following symptoms, please tell your healthcare provider at your next follow-up appointment:

- Changes in your urine output
- Nausea that does not improve after changing your eating habits
- Constipation, diarrhea
- Headache
- Signs of low potassium like muscle pain or weakness, muscle cramps or a heartbeat that does not feel normal

If you experience any of the following symptoms, call your healthcare provider immediately:

- Fever or chills
- Skin rash, itching or unusual skin changes
- Sore throat
- Changes in the color of your urine
- Changes in your vision
- Unusual fatigue
- Extreme weight loss with unknown cause
- Unusual bleeding or bruising
- Stomach pain
- Loss of appetite
- Swelling
- Shortness of breath

Index #16711 | Review Date: 8/8/2019