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The information provided in this guidebook is for educational use only. This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about your specific medical condition.
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Definitions 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 Bone Marrow Transplant** — A type of bone 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, that induces a specific immune response.

**Apheresis** — The process by which peripheral blood HPC’s (blood stem cells) are collected.

**Autologous Transplant** — A type of bone marrow transplant during which the patient receives his or her own bone marrow/stem cells.

**Blood Count** — A measurement of the different components that make up the blood.

**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.

**Bone Marrow Transplant (BMT)** — A procedure during which bone marrow or peripheral stem cells are infused following chemotherapy. (See “autologous, allogeneic, and syngeneic.”)

**Blood Stem Cells** — See “Hematopoietic progenitor cells”

**Central Line or Central Venous Catheter** — A small, plastic tube inserted in a large vein. The central line used in a stem cell 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 of peripheral stem cells and bone marrow.

**Colony Stimulating Factor or Growth Factor** — The drug given to increase the number of stem cells in the blood. Also called Filgrastim, Neupogen®, G-CSF®.

**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.”

**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 HPC's)

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 Lymphotrophic 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 4 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 thrombocytosis, 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 bone 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.

Non-Myeloablative Transplant — See “reduced-intensity bone marrow transplant.”

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 ” Bone Marrow Transplant (Non-Myeloablative Allogeneic BMT) — A bone 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. Reduced intensity transplants require an HLA matched donor. (also referred to as “mini” transplant)

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.

Renal Cell Carcinoma — Cancer of the kidney.

Staging — Extensive testing done to determine if a patient is a candidate for a bone marrow transplant.

Stem Cell Transplant — See “bone marrow transplant.”

Syngeneic Bone Marrow Transplant — A type of bone 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 Bone Marrow Transplant — A type of transplant where the donor is not related to the patient.

Volunteer Donor — Usually refers to an unrelated bone marrow donor who is an acceptable HLA match and who is willing to donate bone marrow anonymously to a recipient in need of a bone marrow transplant. Related bone 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.”
Bone Marrow Transplant Team
Phone Numbers

ADULT TRANSPLANT DOCTORS
Matt Kalaycio, MD, Director ..................................................216.444.3705
Steven Andresen, DO ..........................................................216.444.3737
Brian Bolwell, MD ..............................................................216.444.6922
Robert Dean, MD ...............................................................216.445.5365
Hien Duong, MD .................................................................216.445.5531
Brian Hill, MD .................................................................216.445.9451
Deepa Jagadeesh, MD ..........................................................216.444.0857
Brad Pohlman, MD .............................................................216.445.6070
Ronald Sobecks, MD ...........................................................216.445.4626

MID-LEVEL PRACTITIONERS
Vanessa Farrow, PA-C, Physician Assistant ..........................216.445.6413
Shannon Jarancik, PA-C, Physician Assistant .........................216.445.6504
Heather Kasberg, CNP, Nurse Practitioner .............................216.445.6681
Joe Kohuth, PA-C, Physician Assistant .................................216.445.6502

APHERESIS (M12) .................................................................216.444.2633
Anna Koo, MD, Co-Medical Director
Hien Duong, MD, Co-Medical Director

BONE MARROW TRANSPLANT UNIT (G110) .........................216.444.4173
Patti Akins, RN, Nurse Manager
Debra Scott, RN, Assistant Nurse Manager
Maureen Tarbuck, RN, Assistant Nurse Manager
Carolyn Best, RN, Assistant Nurse Manager

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.
ADMINISTRATIVE SUPPORT STAFF

Julie Curtis, RN, Program Administrator. ................................................. 216.445.3794

NURSE COORDINATORS

Mary Serafin, RN, Clinical Manager......................................................... 216.445.6373
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Karen Sands, RN ......................................................................................... 216.444.4652
Jamie Starn, RN ......................................................................................... 216.445.4942

ADMINISTRATIVE COORDINATORS

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Maria Daw ................................................................................................. 216.445.5873
Kay Pierson ................................................................................................. 216.445.6538
Domonic Rini ............................................................................................. 216.445.7453
Gerri Robinson .......................................................................................... 216.445.4941

FINANCIAL SUPPORT STAFF

Vanessa Hudson, Reimbursement Specialist ............................................. 216.445.6659
Cynthia Robinson, Financial Counselor .................................................. 216.445.6775

SOCIAL WORK

Michele Cooper, LISW-S ........................................................................ 216.445.5193
Jane Dabney, LISW-S ............................................................................ 216.445.2483
Linda McLellan, LISW-S ........................................................................ 216.444.5079
Welcome to the Bone Marrow Transplant Program

Welcome to the Bone Marrow Transplant Program. The Bone Marrow Transplant Team at Cleveland Clinic’s Taussig Cancer Center 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 health care 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 health care providers in training might become involved in your care and treatment.)

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

Patient responsibilities

Your responsibilities as a patient at Cleveland Clinic include:

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

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Bone Marrow Transplant Program Overview

Cleveland Clinic performed its first bone marrow transplant in 1977. Since then, the Bone Marrow Transplant (BMT) Team has performed more than 3,000 bone marrow transplants.

The Bone Marrow Transplant Program offers state-of-the-art transplantation in both autologous and allogeneic bone marrow transplants. We are one of the world’s leading authorities on peripheral 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 bone marrow transplants.

The Bone 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.

Bone Marrow Transplant Team offers comprehensive care

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

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

Transplant doctors

Bone marrow transplant doctors are staff doctors with extensive training and experience in hematology/oncology and bone 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 might or might 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
Physician assistants play an active role in your treatment. The inpatient BMT unit is staffed with physician assistants who will follow your medical care, along with the transplant doctor. A physician assistant and the staff 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 bone 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 bone marrow transplant process. Before your transplant, you will have multiple tests to detect any signs of infection.

Once you are admitted to the hospital, the infectious disease doctors will round every day with the rest of the BMT Team. They will help control your 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 staff transplant doctor and will visit you daily along with your transplant doctor and the rest of the BMT Team.

Pharmacologists
Along with your transplant doctor, your pharmacologist will make adjustments in your medicine dosage as needed. The pharmacologist 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 Bone Marrow Transplant 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 bone marrow transplant administrator oversees the daily operations of the Bone Marrow Transplant (BMT) Program to ensure maximum operating efficiency while ensuring quality care of all patients. The administrator manages the nursing, engineering, research, technical, laboratory, financial, social work, and clerical personnel within the BMT Program.

**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. Bone marrow 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 bone 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.

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Bone Marrow and Transplantation

How the bone marrow functions

Bone marrow is the soft, spongy center of your bone where blood is produced. Marrow is filled with blood-producing cells, called hematopoietic progenitor cells (HPCs), which develop into mature white blood cells, red blood cells, or 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.

HPCs are constantly being produced by your bone marrow, and will develop into the types of cells your body needs. HPCs are sometimes called stem cells.

Types of bone marrow transplants

Most people who need to undergo a bone marrow transplant have cancer, such as leukemia, lymphoma or multiple myeloma. There are different types of bone marrow 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 bone marrow or peripheral stem cells. A syngeneic transplant involves receiving your identical twin’s bone marrow or peripheral stem cells. Here is more information about the specific types of bone marrow transplants:
An **allogeneic bone marrow transplant** involves receiving very high-doses of **chemotherapy** and/or **radiation therapy**, followed by the infusion of your donor’s bone marrow or peripheral 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.

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 bone 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 Bone Marrow 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 bone marrow transplant.

**Bone marrow transplantation as a treatment option**

After your transplant doctor has determined you are a good candidate for a bone marrow transplant, a date for the transplant will be determined and the process of insurance clearance will begin. Please understand that insurance reimbursement for bone marrow transplantation is **not** automatic.

If you are to be admitted to the hospital for your bone marrow 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 \textbf{inpatient} “mini” transplant has been approved for you, you and your designated care-partner might 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, usually over 3 to 6 months.

If an \textbf{outpatient} “mini” allogeneic transplant has been approved for you, you might be required to stay within a 1-hour drive of Cleveland Clinic’s main campus for at least 30 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.
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/R-2 Library......................... 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
Joseph Beth Gift Shop .................................. 216.444-1700
Health Information Library .......................... 216.444.3771
Hearing Impaired Interpreter Referral .............. 216.444.2273
Cleveland Clinic Home Care ......................... 216.444.HOME
.......................................................... or 1.800.263.0403
Hope Lodge ................................................... 216.844.4673
Hospice of the Cleveland Clinic ........................................ 216.444.9819
Infection Control .............................................................. 216.444.5194
International Center .......................................................... 216.444.6404
Laboratory (R21) ............................................................... 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
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 Hospitality Unit (Guest House Hotel) ................. 216.444.8511
TV Service ................................................................. 216.444.5124
Vehicle Assistance ........................................................ 216.444.8484

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Dear Patient:

As the financial coordinator for your bone marrow transplant, I am here to assist you with the financial aspects of your transplant. My responsibility is to obtain your hospital insurance benefits and written approval for your transplant. This takes several steps and the approval may take 4-6 weeks to be obtained. The Cleveland Clinic Bone Marrow Transplant Program (BMT) will initiate this process and provide your insurance company with all the necessary information they require; however, if your insurance carrier requires you to obtain a referral for services at the Cleveland Clinic, you must contact your Primary Care Physician (PCP) to obtain this. In any event, if you have trouble obtaining your referral, please feel free to contact me directly; and I will be more than happy to assist you with obtaining your referral.

The bone marrow transplant includes charges associated with care in the hospital, care as an outpatient, and professional fees (physician fees). If you have any questions regarding the status of your deductibles, co-pay limitations or referrals, your best resource will be a customer service representative from your insurance company. They will be able to answer questions regarding these issues.

A written approval must be in our office prior to your admission for transplant. If we are unsuccessful with getting your transplant approved upon initial request, we will immediately file an appeal, after obtaining your permission, with the insurance company to have the transplant approved. We realize a transplant is a costly procedure, and we will assist you in your decision making for further arrangements or actions if needed.

If your insurance should change at any time during your transplant process, please notify me immediately to avoid incorrect billing matters.

If you have questions regarding the status of your insurance coverage, you may contact me in the BMT office at (216) 445-6775.

Valerie Fetzer
Financial Coordinator
Bone Marrow Transplant Program
Pre-Transplant Screening and 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.

During the pre-transplant screening

About 4 weeks before your transplant, you will be scheduled for a pre-transplant screening. Depending on your insurance company, these tests may need to be scheduled at Cleveland Clinic. During the pre-transplant screening, or staging, you will have several laboratory tests, chest X-ray, echocardiogram, electrocardiogram (EKG), pulmonary function tests (PFTs), and a bone marrow biopsy. CT and/or PET scans and skeletal surveys might be scheduled at your doctor’s request. If this will be the first time you have had CT and/or PET scans at Cleveland Clinic, to assist in comparing films, bring a copy of the CT or PET scans on film or disc, along with a copy of the report. The purpose of staging tests is to make sure you are eligible for a transplant.

The pre-transplant screening will take most of the day to complete, but might be scheduled over a couple of days, depending on scheduling conflicts.

This screening is performed to make sure you are physically able to undergo a transplant. It also helps the transplant team identify and treat any potential problems before the transplant, as well as avoid potential complications after the transplant.

Once the staging has been completed, you will be scheduled with your BMT doctor to review the screening results and discuss the specific risks and benefits of a bone marrow transplant.

Meeting with the transplant team

You will also 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, the chemotherapy/radiation preparative regimen, and informed consents, which can take up to 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, family, and significant others. All patients planning to undergo an allogeneic or mini-allogeneic bone marrow transplant have a scheduled in-person assessment with the BMT social worker, which usually lasts about 1½ hours. Your care-partner should attend this appointment with you. All patients planning on undergoing an autologous BMT are assessed on the phone or in person in the outpatient area before the transplant. Most insurance companies require this assessment to be completed prior to being approved for the BMT.

All patients are requested to complete the enclosed social work questionnaire and return it in the envelope provided. If you are receiving an allogeneic or “mini”allogeneic transplant, you and your designated care partner will be required to live in the Cleveland Metropolitan area within a 1-hour drive of the Cleveland Clinic main campus. In some cases, autologous transplant recipients might be required to stay in the Cleveland Metropolitan area. The social worker can help identify local housing options and provide assistance with other concerns you might have. The social worker is available to provide personal support to you and your family throughout the transplant process.

Social workers also offer:
- Counseling regarding lifestyle changes
- Referrals to community and national agencies and support groups that offer both information and support to transplant patients.
- Information about Social security disability, supplemental security income, Medicaid, or other financial assistance programs

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.

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

Hearing Impaired (TTY) Assistance 216.444.0261
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When a donor is scheduled for harvest of hematopoietic progenitor cells (HPCs) 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 HPC 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 from your planned HPC harvest.

Your 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 either your nurse coordinator or your physician.

You will be informed of any answer that may increase 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 your planned HPC harvest and prior to the recipient beginning the transplant process. Autologous transplant patients are treated in a similar fashion to prevent any infection in others during HPC collection, processing, and storage.
Your transplant 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 gone by since you initially completed the questionnaire. If more than 60 days have gone by, 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:

- Centers for Disease Control and Prevention: http://wwwnc.cdc.gov/travel/

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Instructions For Your Dentist

Patient's name: ___________________________________________________________

Tentative date of central venous catheter placement: _________________________

Prior chemotherapy: ______________________________________________________

Prior radiation to oral cavity: ______________________________________________

Transplant Coordinators to contact for more information:
- Kelly Cherni — 216.444.9276
- Elaina Corbett — 216.444.5839
- Christina Ferraro — 216.445.3773
- Gina Green — 216.445.4231
- Shirley Mobley — 216.445.4360
- Karen Sands — 216.444.4652
- Jamie Starn — 216.445.4942

Please complete the following evaluation before this patient's bone marrow transplant:
- Panorex or bitewing X-ray as indicated
- Evaluation of oral cavity
- Dental prophylaxis, if appropriate
- Restorations, if necessary
- Letter from dentist stating that the patient has obtained dental clearance and the patient's mouth is free of infection. Please fax dental clearance letter to 216.445.7444. This letter must be received prior to the start of the patient's transplant preparative regimen.

Antibiotic prophylaxis is required for all patients who have a central venous catheter device. Dr. ________________________________ has prescribed ________________________________
Pre-Transplant Screening: Required Tests

Why do I need to have pre-transplant evaluation tests?

Your pre-transplant evaluation includes a variety of medical tests that provide complete information about your overall health. These medical tests help the bone marrow transplant team identify any potential problems before your transplant and avoid potential complications after your transplant.

While each patient does not have the same tests, most of the tests included in this handout are common for all transplant patients. The tests required before the transplant are usually done on an outpatient basis. Your nurse and administrative coordinator will help arrange these for you. Please ask your nurse coordinator any questions you have.

If special instructions are required before any of these tests, you will receive a written form that explains how to prepare. After the tests are completed, your doctor will review the results with you. These results are also required by your insurance company in order to approve the medical necessity of your transplant.

Blood tests

Your health care 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 organ 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 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.

☐ **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**
- Ferritin
- Pregnancy test
- Complete Metabolic Panel
- Hemoglobin Solubility
- ABO blood type
- Bleeding times
- CBC, diff, platelets
- Quantitative immunoglobulins

**Other Possible Blood Work**
- Disease-specific labs for multiple myeloma
- Research samples

**Other tests**

- **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.

- **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 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.

- **Heart tests** — Because prior chemotherapy and/or radiation therapy, and the chemotherapy/radiation therapy you will receive for transplant can affect your heart, you will need heart tests to identify and treat any potential problems before the transplant procedure. The heart tests include:
  
  - **Electrocardiogram (EKG)** — An EKG 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.

- **Bone marrow biopsy** — A bone marrow biopsy is performed to evaluate your marrow’s function and to assess for disease involvement. A needle is placed in your posterior hip bone to remove a sample of bone marrow. The area will be numbed with a local anesthetic, or pain-relieving medicine, to make you feel less discomfort during the procedure. You might be given oral medicine to help you relax prior to the procedure. You should plan to have a driver take you home after this procedure since the medicine can make you drowsy.

- **Skeletal survey** — This is a series of X-rays of the skull and long bones to assess disease involvement for patients with multiple myeloma.

- **Other Tests** — may be required by your insurance company or your physician for example: colonoscopy, PAP smear, dental exam, or mammograms.

**Additional tests**

After the pre-transplant evaluation appointment, the BMT team may decide if you will need any other tests. Additional tests or consultations will be performed at Cleveland Clinic. Your nurse and administrative coordinator will help you make these arrangements.
After my pre-transplant evaluation

At the end of your pre-transplant evaluation and after the test results are complete, the bone marrow transplant doctor will decide whether or not a bone marrow 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 might 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 mini allogeneic transplant patients, your bone 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.

Notes

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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 be 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?
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 notify you if I am an active or retired veteran?

Notes

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Common Reproductive Issues

Bone 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 might suffer temporary or permanent damage affecting future fertility. Little research has been done to provide statistics about fertility after bone marrow 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 see if viable sperm are present. If your sperm production is adequate, 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 might or might not still be fertile. Sperm may be frozen indefinitely and annual storage fees are usually charged, which might or might 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 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 bone marrow transplantation. If you
have already received chemotherapy or radiation therapy, you might or might not still be fertile. If you are interested in attempting to preserve your fertility after bone marrow 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.

All of the following options should be considered experimental with an unknown chance of success in producing a viable egg.

**Options to preserve fertility might include:**

- **Embryo freezing** — Mature eggs are stimulated with hormones, removed, fertilized with sperm, and then frozen and stored. This method can require several weeks to accomplish and so might not be feasible 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 require several weeks to accomplish, 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** — Outpatient procedure to remove sperm-bearing tissue from the testicle and freeze it 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 is prolonged or 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 may visit their Web site at www.fertilehope.org or contact them at 1.888.994.HOPE (4673). Along with information about treatment options, this organization provides excellent suggestions to help overcome some of the financial barriers you might meet.

The Oncofertility Consortium is funded by the National Institutes of Health and has excellent patient education material. They can be reached by calling (866)728-FERT or by viewing their website at Myoncofertility.org.

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

What is a clinical trial?

A clinical trial, also called a research study, is a research program conducted with patients to evaluate a new medical treatment, drug, or device — such as new approaches to surgery or radiation therapy, new combinations of treatments, or new methods. The purpose of clinical trials is to find new and improved methods of treating cancer.

Phases of a clinical trial

Clinical trials are conducted in phases, each designed to find out specific information. Each new phase of a clinical trial builds on information from previous stages and answers different questions about the new treatment.

Participants might be eligible for clinical trials in different phases, depending on their overall condition. Most clinical trial participants take part in phases III and IV.

- **Phase I** clinical trials involve a small number of participants. The researchers determine the best way to give the new treatment and how much of it can be given safely. These trials have a limited number of participants who would not be helped by other known treatments.

- **Phase II** clinical trials focus on learning whether the new treatment has an anti-cancer effect on a specific cancer. Additional information regarding the side effects of the treatment is also obtained. A small number of people are included because of the risks and unknowns involved.

- **Phase III** clinical trials compare the new treatment with the standard treatment. A question asked in a phase III trial is which group has better survival rates or fewer side effects?

Clinical trial participants are assigned at random (a process similar to flipping a coin) to either the new treatment (treatment group) or the current standard treatment (control group). Randomization helps to avoid bias (having the study’s results affected by human choices or other factors not related to the treatments being tested). When no standard treatment exists for a cancer, some studies compare a new treatment with a placebo (a look-alike pill/infusion that contains no active drug). However, a person is told this is a possibility before deciding whether or not to take part in a study.
Comparing similar groups of people taking different treatments for the same type of cancer is another way to make sure the study results are real and caused by the treatment rather than by chance or other factors. These trials might include hundreds of people from different centers around the country.

Phase IV clinical trials, also called post-marketing studies, are trials conducted after a treatment has been approved. The purpose of these trials is to provide an opportunity to learn more details about the treatment, such as the mechanism of action, fine points regarding toxicity, quality of life, and questions that might have come up during other phases of trials. These "post-marketing" trials might be conducted in a phase I, II or III format.

What happens in a clinical trial?

In a clinical trial, patients receive treatment, and doctors carry out research on how the treatment affects patients. A person's progress is closely monitored during the trial. Once the treatment portion of the trial has been completed, patients might continue to be followed in order to gather information regarding specific endpoints. These endpoints are defined prior to the start of the study and might include time to disease progression and/or overall survival.

While clinical trials have risks for the people who take part, each study also takes steps to protect patients.

Informed consent is an ongoing process during a clinical trial in which all of the available information about the specific trial is discussed with the person participating in the trial. The doctor or nurse reviews the treatment plan with the participant, including potential risks and benefits of the treatment. This information is also written in a document (consent form) that is presented to the participant before treatment can begin.

After the potential study participant reads the document, he or she can ask questions about any parts of the form that are unclear. If the person agrees to participate in the study, the consent form is signed. Signing the form indicates that the study participant read the form and the doctor or study nurse answered any questions about the information contained in the form that might have been unclear.

Signing a consent form does not mean a person must stay in the study. In fact, a person may leave the study at any time. If a participant chooses to leave the study, he or she is given a chance to discuss other treatments and care with his or her doctor. A person might also choose not to participate in the study. If so, his or her care will not be affected in any way.

Clinical trial protocol

The protocol is the action plan for a clinical trial. The plan states what will be done in the study and why. It outlines how many people will take part in the study, what types of patients might take part, what tests they will receive and how often, as well as the treatment plan. Each doctor that treats patients in the study uses the same protocol, and must follow the guidelines that are specified. The federal Food and Drug Administration (FDA) has general guidelines that must be followed by any doctor or institution conducting clinical trials. Before the FDA can approve a treatment, the study results are audited to ensure the trial was conducted safely and according to these guidelines.

For patient safety, each protocol must also be approved by the organization that sponsors the study. The Scientific Review Committee — a group of individuals from the institution including doctors, scientists, nurses, and administrators — review the protocol for scientific merit and feasibility of the protocol.

The Institutional Review Board (IRB) of the hospital must also approve it. This board includes consumers, clergy, and health professionals. They review the protocol to try to be sure that the research will not expose patients to extreme or unethical risks.

Eligibility criteria are guidelines from the protocol that describe the characteristics that all participants in the study must have. These criteria
differ from study to study, depending on the purpose of the research. Examples are: age, gender, the type and stage of cancer, and whether cancer patients who have had prior cancer treatment or have other health problems can participate.

Possible benefits of clinical trials
- Clinical trials offer high quality cancer care.
- You might be among the first to benefit from a new treatment.
- By looking at the pros and cons of clinical trials and other treatment choices, you are taking an active role in a decision that affects your life.
- You have the chance to help others and improve cancer treatment.

Possible drawbacks of clinical trials
- New treatments being studied are not always better than or even as good as standard care. They might have side effects that are unexpected or that are worse than those of standard care.
- Even if a new treatment has benefits, it might not work in your case. Even standard treatments, proven effective for many people, do not help everyone.
- If you receive the standard treatment rather than the new treatment being tested, it might not be as effective as the new approach.
- Insurance companies do not always cover all patient care costs in a study. What is covered varies by plan and by study.

Questions you should ask your referring doctor about the clinical trial
- What is the purpose of the study?
- What has previous research of this treatment shown?
- What is likely to happen in my case with or without the treatment?
- Are there standard treatments for my type of cancer?
- How does this study compare with standard treatment options?

Questions you should ask the doctor or study nurse
- What Phase is this clinical trial?
- What are the possible short- and long-term risks, side effects, and benefits of the treatment?
- What kinds of treatments, medical tests, or procedures will I have during the study? How do they compare with what I would receive outside of the study?
- How long will the study last? Will there be a follow-up after the study?
- Where will my treatment take place?
Will I have to be in the hospital?

How will I know the treatment is working?

How could the study affect my daily life?

Will my records be kept confidential?

Will the study cost me anything?

If I decide to withdraw from the study, will my care be affected? Will I need to change doctors?

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
A central venous catheter is a slender, hollow, flexible tube (catheter) that is inserted through a large vein and into your heart. Hickman and horizon are two types of central venous catheters. 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 venous catheter?

Your doctor has chosen this type of catheter so fluids, nutrition solutions, antibiotics, chemotherapy, or blood products can be delivered directly into your bloodstream without frequently having to insert a needle into your vein. The catheter can also be used to collect blood samples. Patients having an autologous stem cell transplant will have a horizon catheter placed. The horizon catheter is a stiffer catheter which will allow us to collect your peripheral stem cells for your transplant.

How is the catheter inserted?

The catheter is inserted during a simple surgical procedure. Your central venous catheter will be placed in the Angiography Section of Radiology, located in Hb6.

During the surgery, one end of the catheter is placed through a small incision in your
neck (called the insertion site) and is threaded carefully through your vein until it reaches your heart. The other end of the catheter is threaded through a “tunnel” beneath your skin where it exits on your chest through another incision called the exit site.

Guidelines before the catheter placement

☐ Do NOT eat any solid food after midnight the night before your procedure. You may have clear liquids ONLY up to 2 hours prior to your procedure. Clear liquids consist of anything you can see through, such as apple juice, ginger ale, broth, and gelatin.

☐ You may take your medicines with a small sip of water.

☐ You must be accompanied by a responsible adult who can drive you home.

☐ You will be at Cleveland Clinic for about 4 hours for this procedure.

How will the catheter feel after it is inserted?

You might feel a slight bulge under your skin where the Dacron® cuff is located. The Dacron® cuff surrounds the catheter to prevent infection and keep it from moving out of place. You might also feel mild soreness around the insertion and exit sites (where there will be a few stitches) immediately following the procedure.

Guidelines for the first 24 hours after the procedure

☐ If you have any questions or problems within the first 24 hours after the catheter placement, contact your nurse coordinator during business hours or the radiologist. To contact Radiology, call 216.444.6640 or 1.800.223.2273, ext. 46640, Mondays through Fridays, 8 a.m. to 5 p.m. Any other times, please call 216.444.2200 or 1.800.223.2273 and ask the operator to page the radiologist on call.

☐ Do not shower for the first 5 days after the catheter is inserted.

☐ You can take a sponge bath as long as you keep the dressing and insertion site dry and do not soak above the insertion site.

☐ If you have heavy bleeding from the catheter site, remain sitting upright (unless you feel faint), hold pressure at the site, and have someone take you to the nearest emergency room or call 9-1-1.

☐ If you experience extreme pain, bleeding, or drainage from the catheter insertion site, fever of 100.5 degrees Fahrenheit (100 degrees for allogeneic patients), or shortness of breath, contact your nurse coordinator or radiologist.

☐ Keep the dressing clean and dry. If your dressing falls off or becomes loose, cover the catheter site with a sterile pad.

☐ You can expect some soreness in the area of insertion.

☐ You might notice a black and blue mark on your chest and possibly your neck.
Your nurse coordinator will meet with you the day after the central venous catheter placement to provide you with catheter care instructions.

How do I care for the insertion site?

You may have surgical glue or steri-strips over the insertion site. The steri-strips will remain in place for at least 1 week after the catheter is inserted. Do not pull the steri-strips off. They should fall off after the incision has healed. Keep the area dry and clean. The insertion site will heal within a few days after the procedure.

Your nurse coordinator will teach you how to care for the catheter and will practice these instructions with you. There are several things you will need to do to care for your catheter, including:

- Clean the exit site and apply a clean dressing every 7 days or sooner if dressing gets soiled or wet.
- Clamp the catheter.
- Flush each lumen of the catheter with normal saline every day.
- Change the injection caps every week.
- Be able to detect potential problems and learn what to do to prevent or treat them.

You will receive individual instruction sheets on each of the procedures described above so you can perform the procedures correctly. Your nurse coordinator also will review these instructions with you.
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.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Signs/Symptoms</th>
<th>What to do</th>
<th>How to avoid</th>
</tr>
</thead>
</table>
| Infection                      | • Fever over 100 F for allogeneic, 100.5 F for autologous  
• Chills  
• Sweats  
• Swelling or oozing at the exit site  
• Foul odor  
• Pain, warmth, or redness at the exit site or tunnel area  
• Fatigue; lack of energy  
• Decreased activity | • Call your health care provider for instructions | • Check your temperature daily.  
• Wash your hands before any procedure.  
• Wear a mask during any procedure if you have a cold and when changing the bandage. |
| Clotting or catheter blockage  | • Unable to flush catheter using normal pressure | • Do not apply extra pressure.  
• Call your health care provider to assess the blockage. | • Flush the catheter once a day and after every injection. |
| Broken screw adapter at the end of the catheter | • Catheter cap does not fit securely  
• Saline leaks out during flushing procedure | • Clamp the catheter  
• Call your health care provider. The end will need to be replaced. | • Do not over-twist the catheter cap when changing.  
• Do not clamp near the catheter adapter. |
<p>| Skin rash or irritation over the Dacron cuff | • Redness and tenderness at exit site without drainage or fever | • Call your health care provider for instructions | • Do not wear constrictive clothing over the bulge of the cuff. |</p>
<table>
<thead>
<tr>
<th>Problem</th>
<th>Signs/Symptoms</th>
<th>What to do</th>
<th>How to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Break or accidental cut in the catheter</td>
<td>• Leaking fluid</td>
<td>• Immediately clamp the catheter between the break and exit site.</td>
<td>• Only clamp the reinforced sleeve of the catheter.</td>
</tr>
<tr>
<td></td>
<td>• Puncture or split in the catheter</td>
<td>• Call your health care provider for instructions</td>
<td>• Rotate the clamping site.</td>
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<td></td>
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<td></td>
<td>• Never use scissors near the catheter.</td>
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<td></td>
<td></td>
<td></td>
<td>• Do not use force when flushing the catheter.</td>
</tr>
<tr>
<td><strong>Air embolus</strong></td>
<td>• Shortness of breath or chest pain.</td>
<td><strong>THIS IS AN EMERGENCY</strong></td>
<td>• Never leave the catheter cap off without first clamping the catheter.</td>
</tr>
<tr>
<td>presence of air in the cardiovascular system</td>
<td></td>
<td>• Clamp the catheter near the exit site</td>
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<td>that could result in blocked blood flow (This</td>
<td></td>
<td>• Call 9-1-1.</td>
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<tr>
<td>can occur if the cap or IV tubing becomes</td>
<td></td>
<td>• Lie on your left side while waiting to be seen by a health care provider</td>
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<td>disconnected. It might occur within hours</td>
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<td>after the catheter has been inserted.)</td>
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<tr>
<td><strong>Thrombosis</strong></td>
<td>• Difficulty flushing the catheter</td>
<td><strong>THIS IS AN EMERGENCY</strong></td>
<td>• Flush the catheter once a day and after every procedure.</td>
</tr>
<tr>
<td>blockage in the vein in which the catheter has</td>
<td>• Swelling in the arm shoulder, or neck on the same side of the catheter</td>
<td>• Do not put any fluid in the catheter.</td>
<td>• Drink plenty of fluids to prevent dehydration.</td>
</tr>
<tr>
<td>been placed</td>
<td>• Facial swelling</td>
<td>• Call 9-1-1 or have someone take you to the emergency room.</td>
<td>• You should never need to use force to flush the catheter.</td>
</tr>
<tr>
<td></td>
<td>• Enlarged vein on the chest or neck that was not noticeable before the</td>
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<td></td>
<td>catheter was inserted</td>
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<tr>
<td></td>
<td>• Excessive tearing or runny nose</td>
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<td></td>
<td>• Dizziness</td>
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<td></td>
<td>• Confusion</td>
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<td></td>
<td>• Throat pain</td>
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</table>

**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.
# Avoiding Problems With Your Central Venous Catheter

<table>
<thead>
<tr>
<th>Problem</th>
<th>Signs/Symptoms</th>
<th>What to do</th>
<th>How to Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catheter dislodgement</td>
<td>• Pain or discomfort in the neck or shoulder</td>
<td>• Call your health care provider for instructions (You will need to have an X-ray so your health care provider can assess the location of the catheter tip.)</td>
<td>• For longer catheters, loop the catheter and tape it and all of the connections to your chest.</td>
</tr>
<tr>
<td>(This occurs when the tip of the catheter moves from its proper location.)</td>
<td>• Swelling in the chest</td>
<td>• Do not use the catheter until you are told it is OK.</td>
<td>• Do not pull on the catheter.</td>
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<td></td>
<td>• Exposed cuff</td>
<td></td>
<td>• Do not use force when flushing.</td>
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<td></td>
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<td>• Handle the catheter with care.</td>
</tr>
<tr>
<td>Blood back-up</td>
<td>• Leakage of blood where the catheter cap is improperly connected</td>
<td>• Clamp the catheter near the exit site.</td>
<td>• Take time when changing the catheter cap.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Change or replace a sterile injection cap.</td>
<td>• Flush the catheter once a day and after all procedures.</td>
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<tr>
<td></td>
<td></td>
<td>• Flush the catheter with saline solution after unclamping it</td>
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<tr>
<td><strong>Do’s and Don’ts</strong></td>
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<tr>
<td><strong>Do</strong></td>
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<tr>
<td>• Wash your hands before any procedure.</td>
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<tr>
<td>• Clean and change the site if the dressing becomes soiled, wet, or loose.</td>
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<tr>
<td>• Have everything ready before you start.</td>
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<tr>
<td>• Flush the catheter at least once in 24 hours, unless IV fluid is being administered. Use a new syringe to flush each lumen daily.</td>
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<tr>
<td>• When in doubt about the sterility of a piece of equipment, consider it contaminated and use a new, sterile piece of equipment.</td>
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<tr>
<td><strong>Don’t</strong></td>
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<tr>
<td>• Exert stress on the end of the catheter.</td>
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<tr>
<td>• Bend, pull, or kink the catheter.</td>
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<tr>
<td>• Re-use syringes or IV tubing.</td>
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<tr>
<td>• Touch the catheter exit site with your fingers.</td>
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<tr>
<td>• Leave the catheter end open to the air.</td>
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<tr>
<td>• Use scissors near the catheter.</td>
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<tr>
<td>• Your catheter should flush easily. Never force the saline into the catheter!</td>
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</table>
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 antibacterial soap
   - 3 prefilled saline syringes

2. To begin:
   - Moisten a paper towel with alcohol, and wipe the work surface with it.
   - Wash your hands for 30 seconds using warm water and liquid antibacterial 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. Avoid touching the area under the cap.
   - Pull back on the plunger to release the seal. Note: pushing up on the plunger before breaking the seal might 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 at a 90 degree angle, push up on the plunger to remove any air bubbles.

5. Attach saline filled syringe to the MicroCLAVE® Connector Cap by screwing the two pieces together and turning clockwise. Hold vertically so that the cap tip is on top of the syringe then push the syringe plunger so that the saline fills the cap and expels the air. Place cap back in cap wrapper with saline syringe attached. Keep the syringe attached during the cap exchange to make handling easier.
6. Make sure all lumens are clamped.

7. **Clean the injection cap connection** where the cap is connected to the catheter with an alcohol wipe for 15 seconds, vigorously, and let dry completely (about 15 seconds)

8. **Remove the old injection cap and discard.**

9. **Clean the catheter** where the cap was connected with the second alcohol wipe for 15 seconds, vigorously, then allow to dry completely (about 15 seconds).

10. **Remove the protective cover** from the injection cap. Avoid touching the sterile area under the protective cover.

11. **Screw the new injection cap onto the catheter.**

12. Inject the saline into the catheter until all of the saline is out of the syringe.

13. Clamp the catheter.

14. Remove the syringe by twisting the syringe counterclockwise.

15. Dispose of syringe.

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**Notes**

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Index #10140

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

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Hearing Impaired (TTY) Assistance
216.444.0261

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Produced by Center for the Consumer Health Information Rev. 02/11
Central Venous Catheter Transparent Dressing Change

Changing the dressing helps to prevent infection and allows for routine inspection of the exit site. It is necessary to 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 ChloraPrep® One-Step
     (contains chlorhexidine gluconate 2% and isopropyl alcohol 70%)
   - Tegaderm™ transparent dressing
   - Label
   - If you have a kit, it may contain additional supplies that will not be needed and will not be described in these instructions.
     
     You will need to gather these additional supplies:
     - Liquid antibacterial soap and waterless hand sanitizer
     - Clean paper towel

2. To begin:
   - Moisten a paper towel with alcohol and wipe your ‘work area’ with it.
   - Wash your hands for 30 seconds using warm water and liquid antibacterial 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 or Central Line Dressing Change Kit
   - 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.)

4. Remove the old dressing.
   - Start at the bottom or notched edge of the dressing. Loosen the transparent dressing and gently lift and stretch the dressing toward the opposite edge, making sure to stabilize the tubing with a non-dominant finger. Do not use scissors. They can damage the catheter.
5. **Inspect the exit site.**
   - Your health care provider will advise you on the process for removal of the sutures, which will occur in about 4 weeks.
   - Look carefully at the exit site and the skin around it. If you notice unusual discoloration, redness, swelling, bleeding, drainage or blistering, finish changing the dressing and notify your health care provider.

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

7. **Clean the exit site.**
   - Remove one swab from the ChloraPrep package and discard any remaining swabs.
   - 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 ChloraPrep® 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 ChloraPrep® to air dry for 30 seconds. Do not pat, fan or blow on the area.

8. **Apply the transparent dressing.**
   - Peel the printed backing from the back of the dressing. Center dressing over catheter insertion site.
   - 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.

9. **Write date of dressing change on the label,** remove backing to expose adhesive and place on top of new dressing as a reminder of when new dressing change is due.

10. **To extend the likelihood that your transparent dressing will 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.

11. **If dressing becomes loose or wet,** it will need to be changed.

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

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Hearing Impaired (TTY) Assistance 216.444.0261

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Produced by the Center for Consumer Health Information
Rev. 5/11
Central Venous Catheter
ChloraPrep® Dressing Change

Changing the dressing helps to prevent infection and allows for inspection of the exit site. It is necessary to change the dressing at least daily.

1. **Gather the following supplies for each dressing change.**
   - 70% alcohol
   - Liquid antibacterial soap and waterless hand sanitizer
   - 1 ChloraPrep® One-Step
     (contains chlorhexidine gluconate 2% and isopropyl alcohol 70%)
   - Sterile 2" x 2" gauze pad
   - Skin prep/protective dressing
   - Paper tape

2. **To begin:**
   - Moisten a paper towel with alcohol, and wipe the work surface with it.
   - Wash your hands for 30 seconds using warm water and liquid antibacterial 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 all supplies.**
   - Carefully open all supplies without touching the inside surface of the kits or wrappers.
   - Place supplies on clean surface.

4. **Remove the old dressing.**
   - Starting at the top corners of the dressing, loosen all the edges, and gently lift the dressing down toward the bottom. **Do not use scissors. They can damage the catheter.**
5. **Inspect the exit site.**
   - Look carefully at the exit site and the skin around it. If you notice unusual discoloration, redness, swelling, bleeding, drainage or blistering, finish changing the dressing and call your health care provider.

6. **Rewash your hands** or you can use a waterless hand sanitizer such as Purel®

7. **Clean the exit site with ChloraPrep®**
   - Remove one swab from the package and discard any remaining swabs.
   - Clean the exit site and the skin around it, extending about 2 inches away from the exit site. Apply the ChloraPrep® in an up-and-down and back-and-forth motion for 30 seconds. Avoid rubbing over your line. Instead, use half-circle motions to clean around the top and bottom of where your line comes out from the skin.
   - Allow the ChloraPrep® to air dry for 30 seconds. Do not pat, fan or blow on the area.

8. **Apply the sterile dressing.**
   - Cover the exit site with the 2x2 gauze pad. Touch only the corners of the dressing, or pinch in the middle of the side of the gauze that will not touch the skin.
   - Apply the skin prep/protective dressing around the 2x2 gauze pad (hold the gauze pad in place while applying the skin prep/protective dressing). Allow the skin prep to dry.
   - Tape the gauze pad in place, using the paper tape.
Catheter Flushing With Prefilled Syringes

Saline is a neutral salt water solution used to maintain the patency (ie, quality) of your catheter. It is necessary to flush all lumens (the hollow opening) of your catheter daily.

1. Gather the following supplies.
   - 70% alcohol
   - Liquid antibacterial soap
   - Paper towels
   - 3 prefilled saline syringes
   - 3 alcohol wipes

2. To begin:
   - Moisten a paper towel with alcohol and wipe the work surface with it.
   - Wash your hands for 30 seconds using warm water and liquid antibacterial 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 prefilled syringes and alcohol wipes.
   - Place the supplies on a 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. Avoid touching the area under the cap.
   - Pull back on the plunger to release the seal. Note: pushing up on the plunger before breaking the seal might 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 at a 90 degree angle, push up on the plunger to remove any air bubbles.

☐ Use a separate syringe for each lumen of your central venous catheter

☐ Do not put the syringe down.

5. **Clean the catheter cap.**

☐ Wipe the end of the cap with an alcohol wipe, vigorously for 15 seconds and allow it to dry for 15 seconds. **Do not touch the cap or blow it dry.**

6. **Inject the saline into the catheter.**

☐ Grasp cap and firmly push and twist syringe tip into the cap until secure.

☐ Unclamp the catheter.

☐ Push down slowly on the plunger of the syringe until all of the saline is out of the syringe.

☐ Clamp the catheter. Note: The catheter must always be clamped when not in use.

☐ Remove the syringe by twisting the syringe in the opposite direction (counter clockwise).

☐ Dispose of the syringes.

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

Prepare the work area and gather your supplies

1. Gather the following supplies:
   - Liquid antimicrobial soap
   - Bottle of medicine — NOTE: if your medicine requires refrigeration, take it out of the refrigerator 30 minutes before your injection time.
   - ______cc syringe with wrapper removed — Note: You will need more than 1 syringe if you require multiple injections.
   - 25-gauge needle
   - Two alcohol wipes (or cotton balls and a bottle of rubbing alcohol)
   - Bandage
   - One container for used equipment (such as a hard plastic or metal container with a screw-on or tightly secured lid or a commercial “sharps” container)

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

2a. Select a clean, dry work area.

2b. Wash your hands for 30 seconds with antibacterial soap. Rinse your hands completely, and dry them with a clean paper towel. Turn the water faucet off using a paper towel. Do not turn the faucet off with your hands.

Prepare your medicine and syringe

1. Examine your medicine bottle(s), verifying the correct medicine, dosage and expiration date.

2. Remove the plastic cap from your medicine bottle(s).

3. Wipe off the rubber part on the top of the medicine bottle(s) with an alcohol pad or an alcohol-soaked cotton ball.

4. Set your medicine bottle(s) nearby on a flat surface.

5. Remove the wrapper from the 25-gauge needle and screw it onto the syringe.

6. Remove the cap from the 25-gauge needle and place on a flat surface on its side so it can be used to re-cap your needle if necessary.

7. Draw ________ cc. of air into the syringe by pulling the plunger back.

8. Insert the needle into the rubber stopper of the medicine bottle.

9. Push the plunger down to inject air into the bottle (this allows the medicine to be drawn more easily). Leave the needle in the bottle.

10. While holding the plunger down, turn the bottle and syringe upside-down. Be sure the medicine covers the needle.

11. Pull back on the plunger to ______.cc

12. Check the syringe for air bubbles. Air bubbles in the syringe can reduce the amount of medicine in the syringe. To remove air bubbles, tap the syringe so the air bubbles rise to the top. While holding the syringe at a 90-degree angle, push up on the plunger to remove the air bubbles. Recheck the dose and add more medicine to the syringe if necessary.

13. Remove the needle from the medicine bottle. Carefully replace the cap on the needle.

Rotate your injection sites

Since you will be injecting your medicine on a regular basis, you need to know where to inject the medicine and how to rotate (move) your injection sites. By rotating your injection sites, you will make your injections easier, safer, and more comfortable.

If the same injection site is used over and over again, you might develop hardened areas under the skin that keep the medicine from being used properly.

Follow these guidelines:

☐ Move the site of each injection, ensuring that the injection is at least 1 1/2 inches away from the last injection site.

☐ Ask your doctor, nurse, or health educator which sites you should use. (See the next page of this handout for general guidelines.)

☐ Keep a record of which injection sites you have used. Every time you give yourself an injection, record the date, time, and site.
Injection sites

**FRONT**
- abdomen
- injection rotation sites
- front and side of thigh

**BACK**
- upper and outer arm
- buttocks
- injection rotation sites
- side of thigh

**Subcutaneous Self-Injections**
Select and clean the injection site

1. Choose an injection site. Do not inject near joints, groin area, navel, middle of abdomen, and scar tissue. A picture of the injection sites that can be used is included in this section. These sites are away from nerves, joints, and large blood vessels.

2. Clean the injection site (about 2 inches of your skin) in a circular motion with an alcohol wipe. Leave the alcohol wipe nearby. Allow alcohol to dry completely.

Inject the medicine

1. Using the hand you write with, hold the syringe like a pen or pencil, with the needle end down.

2. Remove the needle cap.

3. With your other hand, pinch about 2 to 3 inches on either side of the cleaned skin.

4. Insert the needle with a quick motion into the pinched skin at a 45- to 90-degree angle. The needle should be all the way into your skin.

5. Slowly push the plunger of the syringe until all of the medicine is pushed out of the syringe. This step should take less than 10 seconds. If the medication is stinging as it goes in, slow down the push.

6. Count to 3 and then pull the needle out.

7. You might or might not bleed at the injection site. If you notice bleeding, apply pressure with the alcohol wipe. Cover the injection site with a bandage if necessary.

8. Do not rub the injection site.

Dispose of the needle

1. Do not cap the needle.

2. Drop the entire syringe and needle into your container for used “sharps” equipment.
Neupogen®

What are some other names for this medicine?

Neupogen® is also called a granulocyte colony stimulating factor (G-CSF), or filgrastim.

What does it do?

Neupogen® 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 bone marrow transplant or for your donor’s cells in your allogeneic bone marrow 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 you.

Neupogen® might also be given to boost your white blood cell counts that have been lowered by chemotherapy. White blood cells fight infections. When your white blood cells are low, you have a higher risk for infection. Neupogen® 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 Neupogen® therapy.

Your Neupogen® 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.
How is it given?

Neupogen® is given by injection under the skin (subcutaneously) using a needle and syringe, or through a vein (intravenously). While you are an outpatient your Neupogen 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
- Nausea
- Diarrhea
- Loss of appetite

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.

When should I call my doctor?

Call your doctor if you:

- Have a fever of 100.5°F (38°C) or higher (autologous patients or donors).
- Have a fever of 100.0 °F (37.8°C) or higher (allogeneic patients).
- Have a skin rash.
- Have shortness of breath.
- Experience unusual sweating.
- Have any other unusual symptoms.
- Have any questions or concerns.
Introduction to Social Work

What is a social worker?
A social worker is a professional trained in the treatment of social and emotional (psychosocial) concerns.

What services does a BMT social worker provide?
A bone marrow transplant (BMT) social worker provides psychosocial services to patients, families, and care partners facing the impact of their cancer diagnosis and bone marrow transplant. BMT social workers are an integral part of the health care team. They work with other Cleveland Clinic specialists to contribute to your overall treatment plan. They provide:

- Individual, family, and group counseling to help with coping and adjusting to lifestyle changes
- Referrals to local community and national organizations and support groups that offer information and support to bone marrow transplant patients
- Lodging information
- Information about financial assistance programs including Supplemental Security Income (SSI), Social Security Disability (SSD), Medicaid, and other programs
- Information about employment and disability benefits
- Assistance with governmental agencies and programs that help people with disabilities, including the Social Security Administration and Medicare
- Advocacy (They strive to ensure access to needed information, services, and resources.)
- Psychosocial research

Assessment
BMT social workers complete a thorough psychosocial assessment to help identify your needs and concerns, as well as those of your family members and significant others. Every patient receiving a bone marrow transplant has a scheduled in-person assessment with a BMT social worker. Many insurance companies require this assessment as part of your pre-transplant evaluation.
What type of training does a social worker have?

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

*This information was adapted in part from the Association of Oncology Social Work (AOSW) Standards of Practice and the National Association of Social Worker (NASW) publication, “The Power of Social Work” (www.socialworkers.org).*
Preparing For Your Hospital Stay

Staying in Cleveland

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

☐ Allogeneic transplant patients must stay less than a 1-hour drive for a minimum of 100 days after transplant.

☐ Mini allogeneic transplant (outpatient) patients must stay less than a 1-hour drive for a minimum of 30 days after transplant.

☐ Autologous/tandem 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 (ohioACS@cancer.org).

Please see the enclosed visitor travel guide for help in selecting local lodging options. You will need to make arrangements and obtain current rates. You may also contact the American Express Travel office through Cleveland Clinic. They can be reached at 216-444-2564 or by email at amexclinictravel@aexp.com.

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 cancer treatment and who live a distance from Cleveland. The Hope Lodge is located about 1 mile away from Cleveland Clinic. Oncology patients and/or 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 register you 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 bone marrow transplant.
Discounted parking
Discounted parking tickets are available at the cashiers' booths in the parking garages, or at any valet stand. Please refer to the Cleveland Clinic map for parking garage locations. More information including current rates is available on our internet site found at: my.clevelandclinic.org/patients-visitors/parking-lodging-transportation

Hospital tour
To arrange a tour of the inpatient Bone 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 Bone 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
Having a family member stay in the hospital room overnight is possible. Please discuss this with your social worker.

Children
Children of any age are allowed to visit you during your inpatient stay. Children of immediate family members (own children, siblings or grandchildren) are permitted to visit in patient rooms and lounges outside of the unit on G110. No child under 18 may be left unsupervised or spend the night. 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.

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. A television schedule is available on the nursing unit. The Patient Lounge on G110 has a selection of DVDs available for loan.

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

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 do your laundry on the unit in the washer/dryer.
- 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 an automated 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.
- Radios, CD players, MP3 players, and video game sets are permitted.
- Internet access is available for computers and wireless internet is available.
- Pack magazines, puzzles, word searches, books, DVDs, 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.

## Notes

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Care-Partner

What is a care-partner?

A *care-partner* is a supportive person who helps a bone 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 bone 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 mini-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 mini-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 typically are able to return directly home, but 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 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 to help you understand what is happening.

- **Plan a network of support before the transplant** — Having a few people lined up that you can rely on will be very helpful. Delegate 1 or 2 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.
Coping

Although bone marrow transplantation offers hope for many patients, going through the BMT process is a difficult experience for patients and their families. Treatment is physically and emotionally challenging.

Dealing with changes and loss of control

Facing the reality of a serious illness, fearing what is involved in bone marrow transplantation, dealing with complex and unfamiliar medical information, and facing separation from family and friends can be overwhelming and difficult to endure. You and your family might experience anxiety regarding the uncertainty of what lies ahead.

You will experience changes and might not be as independent as you want to be. People will experience some changes and role losses that are temporary, and some longer-term changes in lifestyle might occur. While going through transplantation, common role changes might involve employment or work, parenting and family responsibilities, and physical activity. People who are used to being independent and like to feel in control might find such changes very frustrating and might find it difficult to cope.

A person’s ability to cope is strongly influenced by his or her perceptions of a situation. If you believe challenges facing you are insurmountable, you might feel helpless or hopeless. Obtaining more information, asking about how other people have coped, and turning to others for support are helpful coping strategies and might change the way you view your situation.

Give yourself permission to have bad days. You are only human and will have times when you feel discouraged or are in a bad mood. Just guard yourself against getting stuck in negative thinking and feelings.

Helpful coping strategies

Review what has been helpful and not helpful to you in the past when dealing with stressful or difficult situations. Focus on building on your strengths, and stay open to new ideas and strategies. Here are some positive coping strategies:

- **Utilize your support network of friends and family** — Having loved ones or friends visit or call you can be very comforting. Discuss your feelings about what is happening with your friends and family. Allow family and friends to help you sort through the information you receive.

- **Talk with other patients and families about bone marrow transplantation** — Talk with your social worker about the 4th Angel Mentoring Program through the Scott Hamilton Cares Initiative. (Please see the section, “Support Groups” for more information.)

- **Make use of resources and support services** — These include resources at Cleveland Clinic and in the community. This notebook contains information about available resources that can help you learn about your disease and help you feel comfortable with your treatment.

- **Actively participate in your treatment plan** — You are a valuable and key person in
your treatment plan. Stay informed and communicate your questions and ideas to the medical team. Do not be afraid to ask your doctor, nurse, or other health care provider to repeat any instructions or medical terms you don’t understand. Your Bone Marrow Transplant Team is always available to answer your questions and address your concerns.

☐ **Focus on things you can influence** — Let go of things you can’t change or control, and focus on doing things that will help your situation.

☐ **Focus on what needs to be done here and now** — It is easy to get overwhelmed if you think about everything you might eventually have to deal with. Focus on what you are currently dealing with and can work on now.

☐ **Accept your reactions and your natural pace** — Accept how you feel about events, and give yourself time to adjust and process thoughts and feelings about what is happening.

☐ **Give yourself things to look forward to** — Your energy has been focused on treatment, but there are still things you can enjoy, and you need to plan simple pleasures to which you can look forward.

☐ **Focus on what you have** — Try to focus on what you still have and have gained rather than what you have lost or haven’t accomplished yet.

☐ **Accept the unexpected** — Accept that there are events you cannot control. Few things will happen exactly as expected. Plan for delays, setbacks, and surprises.

☐ **Reduce stress** — When you are facing BMT, stress can build up and affect how you feel about life. Prolonged stress can lead to frustration, anger, hopelessness and, at times, depression.

Here are some tips for reducing stress:

-- Be assertive instead of aggressive. “Assert” your feelings, opinions, or beliefs instead of becoming angry, combative, or passive.
-- Learn to relax.
-- Exercise as often as you can.
-- Eat well-balanced meals.
-- Rest and sleep. Your body needs time to recover from stressful events.

☐ **Learn to Relax** — There are a number of exercises you can do to relax. These exercises include breathing, muscle and mind relaxation, relaxation to music, and biofeedback. A few for you to try are listed below. First, be sure you have a quiet, distraction-free location. Try to find a comfortable body position. Sit or recline on a chair or sofa. Also, have a good state of mind. Try to block out worries and troubling thoughts.

**Two-minute relaxation**

Switch your thoughts to yourself and your breathing. Take a few deep breaths, exhaling slowly. Mentally scan your body. Notice areas that feel tense or cramped. Loosen up these areas, letting go of as much tension as you can. Rotate your head in a smooth, circular motion once or twice. (If any movement causes pain, stop immediately.) Roll your shoulders forward and backward several times. Let all of your muscles completely relax. Recall a pleasant thought for a few seconds. Take another deep breath and exhale slowly. You should feel relaxed.

**Mind Relaxation**

Close your eyes. Breathe normally through your nose. As you exhale, silently say to yourself the word “one,” a short word such as “peaceful,” or a short phrase such as “I feel quiet.” Continue for 10 minutes. If your mind wanders, gently remind yourself to think about your breathing and your chosen word or phrase. Let your breathing become slow and steady.

**Deep breathing relaxation**

Imagine a spot just below your navel. Breathe into that spot and fill your stomach with air. Let the air fill you from the stomach up, then let it out, like deflating a balloon. With every long, slow breath out, you should feel more relaxed.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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, including a Living Will 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.
Support Groups

For more information about other support groups at Cleveland Clinic, please call the Social Work Department at 216.444.6552 or 1.800.223.2273 ext. 46552.

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.

Taussig Cancer Center Support Groups

Post-Transplant Preparation Group
This inpatient education group meets on the first Wednesday of the month in the G110 lounge. This group is facilitated by a social worker and nurse coordinator from the BMT 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.

Multiple Myeloma Support and Education Group
This group is for patients with multiple myeloma, their families and friends. The group meets Quarterly in the Taussig Cancer Institute, Room R3-002. Contact Barb Savage LISW-S at 216.444.6465 or 1.800.223.2273, ext. 46465.

Caregiver Support Group
“Circle of Friends” is a support group that offers a series of educational and supportive sessions for adults responsible for caring for a loved one with cancer. Meetings will offer information that will assist you in your role as a caregiver and also provide an opportunity for you to receive support in a safe environment with others dealing with similar issues. Meetings are held monthly. Contact Christa Poole, LISW-S at 216.445.2148

Leukemia & Lymphoma Society Support Group Meetings

Life After Bone Marrow/Stem Cell Transplant
The Leukemia & Lymphoma Society sponsors this quarterly group for adults who have undergone a bone marrow or stem cell transplant. Participants learn the latest information and have an opportunity to discuss the unique issues faced by those who have had a transplant. Family members are welcome. Contact Linda McLellan, LISW-S, at 216.444.5079 or 1.800.223.2273, ext. 45079, or the Leukemia & Lymphoma Society at 1.800.589.5721.
Other Leukemia & Lymphoma Society Support Groups
For a complete listing, please contact the Leukemia and Lymphoma Society at 1.800.589.5721.

The Gathering Place Support Group Meetings
For a complete listing of adult and children/family support groups, please contact this wellness community at 216.595.9546.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Bone Marrow Transplant Resources

Getting in touch with community services might 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 might be useful in helping you cope with the demands of treatment. Please contact your social worker if you need more assistance.

**Cleveland Clinic Web site**
**www.clevelandclinic.org**

Cleveland Clinic’s Web site provides an online Health Information Center where you can look up a variety of topics, including a physician directory. For additional Web sites and resource information specific to the Taussig Cancer Center and the Social Work Department, go to www.clevelandclinic.org/socialwork/cancercenterresources.htm

**ExploreBMT**
**www.explorebmt.org**

ExploreBMT is a great place to start when you are looking for information and support about blood and marrow transplantation. You can use ExploreBMT, an easy-to-search web portal, to browse resources and services from many respected organizations. You can then connect to the resources that you need most throughout your transplant journey, from diagnosis through survivorship.

**Cleveland Clinic Cancer Answer Line:** 1.800.862.7798
Oncology clinical nurse specialists and their staff can provide information and answer questions about cancer.

**Reflections at Cleveland Clinic**
**216.444.3527 or 1.800.223.2273 ext. 43527**

*The is a free service to patients undergoing cancer treatment. Sessions are private with a licensed aesthetician and include: one-hour facial, massage, make-up application with instruction, Reiki for relaxation, guided imagery, and reflexology.*
Healing Services
216.445.9543 or 59543 from your bedside phone.

A free service offered at the Cleveland Clinic, Healing Services, supports your well being during your hospital stay by offering complimentary services to naturally help you relax and heal. They offer the following services to both patients and family:

- Reiki, Healing Touch
- Light Massage (10 Minutes with physician approval)
- Guided Imagery
- Spiritual Counseling
- Personal aromatherapy

Wellness Organizations

The Gathering Place-East
23300 Commerce Park
Cleveland, OH 44122
216.595.9546
E-mail: info@touchedbycancer.org
www.touchedbycancer.org

The Gathering Place-West
800 Sharon Drive
Westlake, OH 44145
E-mail: info@touchedbycancer.org
www.touchedbycancer.org

The mission of the Gathering Place is to support, educate, and encourage people working to overcome the effects of cancer in their lives. All programs and services are provided free of charge.

Center for Body, Mind & Spirit
41201 Schaden Road
Elyria, OH 44035
440.324.0480

Offers extensive support services designed to complement cancer treatment and enhance quality of life by focusing on the psychological, emotional, spiritual, and social aspects of healing.

Stewart’s Caring Place
2955 W. Market Street
Akron, OH 44333
330.836.1772
www.stewartscaringplace.org

Offers support, information, and an array of programs and services to families and individuals touched by cancer. All services are free of charge.

The Victory Center
5532 West Central Avenue, Suite B
Toledo, OH 43615
419.531.7600
www.thevictorycenter.org

Provides non-medical support services to individuals living with cancer, in support of their pursuit of recovery and to promote education and prevention techniques for healthy living.

Cancer & Disease Specific Organizations

The Leukemia and Lymphoma Society
1311 Mamaroneck Ave.
White Plains, NY 10605
1.800.955.4572 or 914.949.5213
E-mail: lsa2000@aol.com
www.lls.org

The Leukemia and Lymphoma Society
Northern Ohio Chapter
23297 Commerce Park Road
Beachwood, OH 44122
800.589.5721

Services include health education, peer-to-peer support, support groups, and patient financial aid for certain treatment-related expenses. It supports cancer research and provides information and support to patients with leukemia, lymphoma, and multiple myeloma.
BMT Infonet
(Blood and Marrow Transplant Information Network)
2310 Skokie Valley Road, Suite 104
Highland Park, IL 60035
1.888.597.7674 Fax: 847.433.4599
E-Mail: help@bmtinfonet.org
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)
1-800-LINK-BMT (800-546-5268)
248.358.1886
20411 W. 12 Mile Road, Suite 108
Southfield, MI 48076
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
P. O. Box 613
Annapolis, MD 21404-0613
www.aamds.org

Provides information about multiple myeloma. Funds myeloma specific research.

Aplastic Anemia & MDS International Foundation, Inc.
383 Main Avenue, 5th Floor
Norwalk, CT 06851
203.229.0464
www.multiplemyeloma.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.

Lance Armstrong Foundation
877.236.8820 or for Cancer Support call: LIVESTRONG SurvivorCare 866.673.7205
www.LIVESTRONG.org
2201 E. Sixth Street
Austin, Texas 78702

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
1.800.813.HOPE (4673)
www.cancercare.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)
Also known as Be the Match Registry
3001 Broadway Street NE, Suite 100
Minneapolis, MN 55413-1753
1.800.526.7809 or 612.627.5800
1.800.MARROW2 (Donor Information)
www.marrow.org

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.

Office of Patient Advocacy
1.888.999.6743

Assists patients who lack funding for unrelated donor search and/or procurement.

Lymphoma Research Foundation
New York Office:
115 Broadway, 13th Floor
New York, NY 10006
Phone: 212.349.2910, 800.235.6848
Fax: 212.349.2886
lrf@lymphoma.org

Los Angeles Office:
8800 Venice Blvd. Suite 207
Los Angeles, CA 90034
Phone: 310.204.7040 800.500.9976
Fax: 310.204.7043
helpline@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.

American Cancer Society
1599 Clifton Rd., NE

Atlanta, GA 30329
1.800.227.2345 or 404.320.3333
www.cancer.org

This organization supports cancer research, conducts educational programs, “Look Good, Feel Better,” to patients and families. It also provides free printed information about cancer.

Online & Telephone Communication Resources

The Status.com
Public Knowledge Systems, LLC
P. O. Box 111586
Anchorage, AK 99511-1586
1.877.725.1500 or 1.907.646.4523
www.thestatus.com

This Web site keeps family and friends updated on the patient’s condition. Family and friends can write messages to patients. It requires a secured password to protect patient confidentiality.

Lotsa Helping Hands
www.lotsahelpinghands.com

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

Caringbridge
www.caringbridge.org

A Web site 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.

Fertility

Fertile HOPE
1.866.965.7205
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.

**Peer Support**

**4th Angel Mentoring Program**
216.445.8734 or 1.800.223.2273, ext. 52573
www.scottcares.com

A program of the Cleveland Clinic Scott Hamilton CARES Initiative that offers one-on-one, confidential outreach and support from other cancer survivors. Specially trained volunteer cancer survivors offer comfort, reassurance, information, coping techniques, and practical advice.

**First Connection**

First Connection through the Leukemia and Lymphoma Society is a peer-to-peer telephone support program linking patients and their families with a trained volunteer who has experienced a similar situation.
www.lls.org
1.800.955.4572

**Children & Family**

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.

**Bear Essentials**
314.996.5517
www.bear-essentials.org

This program provides age-appropriate support and tools to help children and parents cope with a parent’s diagnosis and treatment of cancer. Addresses the needs of children ages 4 to 12.

**Young Adult**

**Ulman Cancer Fund for Young Adults**
410.964.0202 or 1.888.393-FUND
E-mail: info@ulmanfund.org
Web: 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**
www.planetcancer.org

This is a community of young adults with cancer who share insights, explore fears, and approach cancer with a sense of humor.

**I’m too [young] for this (i[2]y)**
www.imtooyoungforthisto.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!

**The Stupid Cancer Show**
The voice of young adults with cancer
www.stupidcancershow.com
Live weekly streaming interactive, unscripted, unrehearsed, unapologetic show for young adults with cancer.

Financial/Insurance

Social Security Administration
Contact your local office or 1.800.772.1213
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
2100 Stella Court
Columbus, OH 43215
1.800.686.1578
www.ins.state.oh.us/

Cancer and Careers
www.cancerandcareers.org
A resource for working women with cancer.

Patient Advocate Foundation
700 Thimble Shoals Blvd, Suite 200
Newport News, VA 23606
1.800.532.5274 or 757.873.6668
E-mail: info@patientadvocate.org
www.patientadvocate.org
This serves as an active liaison between the patient and his or her insurer, employer, or creditors to resolve insurance, job discrimination, and/or debt crisis matters relative to their diagnosis.

Centers for Medicare & Medicaid Services (CMS)

Medicare
1.800.MEDICARE (1.800.633.4227)
www.medicare.gov
Provides helpful information about Medicare, Medicare health plans, prescription drug plans, and consumer rights and protections.

Medicaid
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
212.869.3850 or 202.544.5561
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

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

Partnership for Prescription Assistance
1.888.4PPA.NOW (477.2669) www.phrma.org
(see patient assistance programs)
This site brings together America’s pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them. Many will get them free or nearly free.

Rx Assist
www.rxassist.org
Volunteers in Health Care: 1.877.844.8442
This provides information about public and private pharmaceutical patient assistance programs, including drug discount cards.
**Rx for Ohio**
www.rxforohio.org

*A Web site designed to help low-income, uninsured Ohio residents get free or discounted brand-name medicines.*

**Complementary and Alternative Medicine**

**Health Journeys: The Guided Imagery Resource Center**
E-mail: info@healthjourneys.com
www.healthjourneys.com

**National Center for Complementary and Alternative Medicine (NCCAM)**
NCCAM Clearinghouse
P.O. Box 7923
Gaithersburg, MD 20898
E-mail: info@nccam.nih.gov
1.888.644.6226 or 301.519.3153
TTY: 1.866.464.3615 (for hearing impaired)
www.nccam.nih.gov/

**The Center for Integrative Medicine at the Cleveland Clinic**
216.986.HEAL (4325)
www.clevelandclinic.org

*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**
1102 Brookfield - Suite 200
Memphis, TN 38119
1.800.489.3863 or 901.684.1697
E-mail: jhill@transplants.org
www.transplants.org

**National Transplant Assistance Fund**
Suit 230, 3475 West Chester Pike
Newtown Square, PA 19073
1.800.642.8399 or 610.353.9684
E-mail: NTAF@transplantfund.org
www.transplantfund.org
Lodging Information for Patients and Family Members

The expense of lodging while undergoing treatment in Cleveland can be burdensome. Therefore, we recommend you check with your health insurance to determine if your policy offers a lodging and travel benefit associated with your transplant. For lodging suggestions, please see the “Visitors Travel Guide to University Circle and Downtown Cleveland” located in the front pocket of this notebook.

There are 2 other lodging options. The American Cancer Society's Hope Lodge offers no-cost lodging for patients who are undergoing cancer treatment and their families. Please talk with your social worker if you are interested in being placed on the waiting list for Hope Lodge.

Cleveland Clinic also offers an outpatient housing unit for transplant patients located in Cleveland Clinic's Guest House Hotel. The cost for this option is $60 per night. The phone number is 216.444.8511.

For additional lodging information, you may contact your social worker or visit Cleveland Clinic's Web site at www.clevelandclinic.org, click on “Patients and Visitors” and then “Parking, Lodging & Transportation.

Cleveland Clinic also has an American Express Travel bureau that offers assistance with lodging reservations. Discounted hotel rates are offered through this agency. They can be reached at 1.800.955.6111 or at amexclinictravel@aexp.com.
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 will provide information about the upcoming visits to Cleveland Clinic, we thought you would want to know what your loved one will be experiencing.

Donor work-up

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 work-up is to ensure:

- Your donor meets medical criteria for bone marrow/stem cell 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)
- Urinalysis
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
- 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 Bone Marrow Nurse Coordinator — Your donor will meet with the nurse coordinator to review the process of donation and discuss the anesthesia clearance process called “Routing.” The arrival time and preparation needed before surgery will also be discussed.

Your donor will be asked to complete a Health History Survey, as required by the FDA.

The nurse coordinator will provide and explain the consent form for being a bone marrow donor. The coordinator will also be able to 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.

Day of Routing

The surgery scheduler will make an appointment for your donor to be assessed less than or equal to seven days prior to your admission date. This will include an interview to discuss your donor’s past medical history, blood work drawn by a phlebotomist, and possibly additional questions or physical exam by a member of the anesthesia team. Usually this involves only half a day, and its primary purpose is to provide the anesthesiologist with necessary information prior to giving anesthesia. We want to make sure that your donor is able to proceed with the planned harvest BEFORE you begin your chemotherapy. If there is any question about the donor’s ability to proceed, your admission may be delayed until it is safe to proceed.

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 Physician Assistants 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 5% of your donor's total marrow cells. Once the procedure is finished, 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 M22, the recovery room. Around 2 p.m. to 4 p.m., the BMT Physician Assistant 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 Bone Marrow Transplant Unit. This is welcomed!
The Allogeneic Bone Marrow/Stem Cell Transplant Process

Waiting for the “Big Day”

Waiting for your bone marrow/stem cell 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 bone marrow harvest/stem cell 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 bone marrow 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 Angiography and 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 6 months 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 to report to Radiology in J1 for a chest X-ray as your first stop.

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, physician assistants, 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 Bone Marrow Transplant Team and will be notified when you are preparing for discharge.

Preparative regimen

Your preparative regimen, also called marrow ablation, consists of high doses 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 high doses of cyclophosphamide (Cytoxan®), busulfan (Busulfex, Myleran®), etoposide (VP-16, Etopophos®), cladribine (Leustatin®), or antithymocyte globulin (Atgam®).

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 bone marrow 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 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 with you and your care-partner how your care will be continued on an outpatient basis.

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 Bone Marrow Transplant Team will help you make arrangements for your stay in the Cleveland Metropolitan area. It is important for you to stay in the Cleveland area after your transplant so your BMT Team can monitor you for any treatment-related side effects.

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. For this reason, the BMT service wants you to stay within a safe driving distance to our institution, as your local doctor or hospital might not be trained to treat transplant patients.

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 a.m. 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.

Please refer to the handouts, “Follow-Up Appointments” and “Lodging Information” in this book for more information.
Matched Unrelated Donor (MUD) Allogeneic Transplant

After your doctor has determined you are a candidate for a **Matched unrelated donor (MUD) bone marrow 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

If 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 bone marrow/stem cell donation.
- We will be infusing healthy marrow.

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.

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
Your unrelated donor’s bone marrow or peripheral stem cells will be harvested the same day your cells will be infused (T-0). This means the marrow 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 bone 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 health care 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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Please visit your dentist before your first appointment. Your nurse will explain more.
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** 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.

- **Amphotericin B** is used to prevent or treat fungal infections. This medicine is started the day after your transplant and generally given once a day. It is given intravenously over 2 hours. Most people require premedicines to help counteract side effects. Common premedicines are Benadryl®, Tylenol® or hydrocortisone. Possible side effects include fever, chills, electrolyte imbalance, headache, nausea, vomiting, diarrhea, and fatigue. Later side effects might include decreased kidney and liver function.

- **Atenolol, Clonidine, Norvasc®, Vasotec®, and Metoprolol** 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.

- **Ativan®, Aprepitant, Compazine®, Halodol®, Zofran®, and 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.

- **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.

- **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.
**Dilaudid®, Morphine, Oxycodone** are used to control pain related to mouth and throat sores, abdominal pain, and headaches. Possible side effects include drowsiness, confusion, dizziness, headache, increase or decrease in heart rate, ringing in 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 in order to replace what has been lost.

**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.

**Gentamycin, Vancomycin, 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, Neupogen®** are used to stimulate the growth of white blood cells (neutrophils). These are given daily beginning 5 day 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.

**Imodium®, 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.

**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, cyclosporine, Tacrolimus, 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.

**Mycostatin®, Nystatin** 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.

**Nexium®, Pepcid®, Prilosec®, and Prevacid®** reduce acid production thereby reducing heartburn and nausea. Possible side effects include headache, dizziness, and constipation.
- **Prednisone** 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, voriconazole, and posaconazole** are used to treat or prevent infections caused by fungi. It is usually started when amphotericin B is stopped or reduced. 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 a.m., your nurse will take a blood sample from your triple lumen 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 will 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.

Daily activity

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 quickly you will recover. Activity will also help reduce your risk of developing pneumonia.

Walking in the halls several times per day is strongly encouraged. There is exercise equipment in the exercise room that you may use during your hospital stay. If you are having difficulty walking, getting out of bed and sitting in a chair can be beneficial. Reading, playing games, working on the computer and visiting with family and friends are all ways you can stay active and prevent boredom.

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

<table>
<thead>
<tr>
<th>Time</th>
<th>Instructions</th>
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<tbody>
<tr>
<td>9:00 a.m.</td>
<td>Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin swish and swallow.</td>
</tr>
<tr>
<td>1:00 p.m.</td>
<td>Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin swish and swallow.</td>
</tr>
<tr>
<td>6:00 p.m.</td>
<td>Rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin swish and swallow.</td>
</tr>
<tr>
<td>9:00 p.m.</td>
<td>Cleanse your mouth with a soft toothbrush and fluoride toothpaste. Then rinse your mouth with a 10 cc salt and soda solution, swish for 30 seconds and spit. Follow with 5 cc Nystatin swish and swallow.</td>
</tr>
</tbody>
</table>

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

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

Every person's reaction to treatment is unique, and some of these side effects might not affect you, or you might 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 might be days when you feel very sick. Please make 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 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.
### Diarrhea

Diarrhea is common during your treatment and can continue after your bone marrow transplant. Your treatments might cause you to have:

- Abdominal bloating or cramps
- Thin or loose stools
- Watery diarrhea
- Sense of urgency to have a bowel movement

Chemotherapy can cause patients to be temporarily 'lactose intolerant'. If you notice more diarrhea or loose stools with milk or milk products, you may want to decrease or cut out these foods or drinks until your diarrhea is controlled.

Tell your nurse or doctor if you have diarrhea more than 2 or 3 times per day or if you notice mucus or blood when you have a bowel movement. Your health care provider might prescribe medicine for you.

- Drink at least six 8-ounce glasses of fluids per day. Choose beverages without caffeine such as pulpless fruit juices, broths, or flat sodas.
- Instead of drinking liquids with your meals, drink liquids **between** meals.
- Tell your health care provider if you think you need an anti-diarrheal medicine. You might be instructed to take an over-the-counter anti-diarrheal medicine after each bowel movement to control mild diarrhea. (Please note: Follow the directions on the medicine container.)
- Eat cooked, peeled, or canned fruits and vegetables. Avoid fruits or vegetables with skins or seeds such as berries and grapes. Avoid cabbage, broccoli, corn and peas, as these vegetables can cause you to have gas.
- Eat small, frequent meals instead of 3 large meals. Chew foods thoroughly. Eat warm food rather than very hot or very cold food.
- Avoid eating spicy foods or foods that are high in fat. Milk and foods high in sugar also cause diarrhea for some people.
- If your rectal area becomes sore because of frequent bowel movements, or if you experience itching, burning, or pain during bowel movements, try warm sitz baths (sit in a few inches of warm water in a bathtub). You might be instructed to add Epsom® salts or another type of tablet to the water. Afterward, pat the area dry (do not rub) with a clean, soft towel. Check with your health care provider to determine if medicated creams or pads are appropriate treatments for you.
- If you have severe or persistent diarrhea, you might become dehydrated. (See “Dehydration” section of this handout.)

### Changes in your sense of taste

After a bone marrow transplant, many patients will complain that foods just do not taste the same as they did before treatment. A metallic taste in your mouth is common. This will resolve over time.

- Tart fruits or fruit-flavored sourballs might decrease the metallic taste in your mouth.
- Foods that are chilled might be better tolerated, such as milkshakes, flavored gelatin, pudding, and applesauce.
- Clean your mouth thoroughly before you eat to help improve the taste of food.
- Try using strong flavorings or seasonings, such as salad dressings, to help provide food with more pleasant flavor.
- If your taste is really dulled, you can try increasing the aroma of the foods you eat. Usually if the food smells good, it will also taste good.
- Liquid nutritional drinks might be helpful.
<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Recommendations</th>
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</table>
| **Nausea and vomiting**     | □ Some patients find relaxation methods or self-hypnosis are helpful in decreasing nausea. Talk with your social worker about audiotapes that have relaxation techniques.  
□ Eat small, frequent meals throughout the day instead of 3 large meals. Nausea is often worse if your stomach is empty.  
□ Eat slowly and chew your food completely.  
□ Eat foods that are cold or at room temperature. The smell of hot or warm foods might make you more nauseous.  
□ Do not mix hot and cold foods, drink liquids rapidly, or eat too fast. These might bring on vomiting.  
□ Avoid eating foods that are hard to digest such as spicy foods, fried foods, or other high-fat foods (including rich sweets and sauces).  
□ Avoid completing mouth care for 2 hours after eating to prevent nausea.  
□ Rest after eating. If you need to lie down, lay on your right side and keep your head elevated about 12 inches above your feet.  
□ Instead of drinking beverages with your meals, drink beverages **between** meals.  
□ Drink 6 to 8 eight-ounce glasses of fluid per day to prevent dehydration. Choose cold beverages such as flat soda or flavored drink mixes. You can also choose ice cubes, popsicles, or gelatin.  
□ Try to eat more food at a time of day when you feel less nauseous. If you feel nauseous when you first wake up, keep a box of crackers on your night stand and eat a few before getting out of bed. Or, try eating a high-protein snack such as lean meat or cheese before going to bed (protein takes longer to digest). |

Reducing or preventing nausea is one of the main goals of your BMT Team. If a certain medicine is not helping your nausea, tell your nurse, and a different anti-nausea medicine can be prescribed. (cont.)↓
<table>
<thead>
<tr>
<th>Discomfort</th>
<th>Recommendations</th>
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</table>
| **Nausea and vomiting (cont.)** | - If your health care provider prescribes an anti-nausea medicine for you, take it ½ hour to 1 hour before eating.  
- After every episode of vomiting, gargle with a baking soda solution (1 teaspoon of baking soda in 8 ounces of warm water) to cleanse your mouth.  
- Tell your health care providers immediately if your nausea causes vomiting that is persistent or severe (if you can’t keep fluid or foods down on a continual basis). Persistent vomiting can cause dehydration. |
| **Dehydration**            | - When you are in the hospital, you will receive intravenous fluids.  
- When you are an outpatient, please tell your health care provider if you are vomiting persistently or have persistent diarrhea and experience any of these signs of dehydration:  
  - Dark urine  
  - Small amount of urine  
  - Rapid heart rate  
  - Headaches  
  - Flushed or dry skin  
  - Coated tongue  
  - Irritability and confusion  
  - Dizziness with position changes |
| **Loss of appetite**       | - During your hospital stay, you might be unable to eat a well-balanced diet due to nausea, vomiting, mouth sores, or loss of appetite. If these side effects prevent you from maintaining proper nutrition, your doctor might want to give you intravenous nutrition, depending on your specific nutritional deficiencies.  
- After you are discharged from the hospital, you might continue to have side effects from your treatment (such as decreased appetite, taste changes, mouth sores, dry mouth, or diarrhea). These side effects might prevent you from trying to maintain good nutrition. Over time, many of these problems will improve.  
**Here are some suggestions to increase your appetite:**  
  - Eat small, frequent meals or snacks from 6 to 8 times a day.  
  - Drink beverages after meals instead of before or during a meal so you do not feel as full.  
  - Try to eat more protein and fat and fewer simple sugars. Eggs, fish, and high-protein puddings will provide you with high nutritional content and high protein in small portions. Custards, peanut butter, ice cream, yogurt, peas, beans, and nuts are also high in protein.  
  - Don’t waste your energy eating foods that provide little or no nutritional value (such as potato chips, candy, colas, and other snack foods). |
<table>
<thead>
<tr>
<th>Discomfort</th>
<th>Recommendations</th>
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</thead>
<tbody>
<tr>
<td>Dry mouth</td>
<td>- Rinse your mouth with water before meals.</td>
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<td></td>
<td>- Chew your food completely. Sip liquids frequently while eating to keep food</td>
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<td></td>
<td>moist and to help with swallowing.</td>
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<td></td>
<td>- Drink 6 to 8 eight-ounce glasses of fluid per day.</td>
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<td></td>
<td>- Gargle with club soda or add lemon or lime to water to thin saliva.</td>
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<td>- Try to eat soft foods with sauces, dressings, broths, sour cream, or gravies</td>
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<td>to make the food easier to swallow.</td>
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<td></td>
<td>- Try dunking your foods, such as bread, into soups to moisten them.</td>
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<td></td>
<td>- Suck on ice chips or sugar-free gum or candies to keep your mouth moist.</td>
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<td>- Liquid nutritional drinks might be helpful when your mouth is most dry.</td>
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<td>- Artificial saliva and Biotene® products might relieve a dry mouth. Ask your</td>
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<td>health care provider for more information.</td>
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</table>

**Mouth sores**

Mouth sores are common after chemotherapy. They can make it difficult to eat and drink. You will be instructed on how to perform daily mouth care. It is important to perform this mouth care as instructed. The healthier you can keep your mouth, the less likely an infection will occur. (cont.)

<table>
<thead>
<tr>
<th>To prevent mouth sores:</th>
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<tbody>
<tr>
<td>- In the hospital, you will be given mouth care products and instructions on how to</td>
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<td>use them. You will use two types of mouth rinses daily to keep your mouth clean.</td>
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<td>You are expected to perform your mouth care independently several times a day.</td>
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<tr>
<td>- Do not use commercial mouthwashes or lozenges.</td>
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<tr>
<td>- Patients can brush their teeth after each meal with a small, soft toothbrush and</td>
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<td>fluoride toothpaste.</td>
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<tr>
<td>- Prepare a gargle by dissolving $\frac{1}{4}$ teaspoon each of salt and baking</td>
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<tr>
<td>soda into 8 ounces of warm water. Rinse your mouth and gargle with this solution at</td>
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<tr>
<td>least 4 to 6 times a day, especially after meals and before going to bed.</td>
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<tr>
<td>- Use dental floss daily, if allowed by your doctor.</td>
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<tr>
<td>Discomfort</td>
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<tr>
<td><strong>Mouth sores (cont.)</strong></td>
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<td><strong>Skin rash</strong></td>
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</table>
## Discomfort

### Hair loss
Hair follicles are very sensitive to radiation and chemotherapy. Both of these treatments cause hair loss. Hair loss might be temporary or permanent. If your hair loss is temporary, it might start to re-grow about 3 to 6 months after your transplant. You might notice that when your hair begins to re-grow, the texture or color is different than before.

- This side effect can be very upsetting. Talk to your nurse or social worker about wearing scarves, hats, or a wig.
- Ask about “The Look Good, Feel Better program,” which is sponsored jointly by the American Cancer Society; the Cosmetic, Toiletry and Fragrance Association; the National Cosmetology Association; and the Cleveland Clinic Cancer Center. All participating patients receive a complimentary gift bag of skin care and cosmetic products.
- Avoid frequent shampooing. Use a mild shampoo (such as baby shampoo) without any perfumes.
- Wash your scalp with warm water. Avoid rubbing and do not scratch. Pat dry with a soft towel.
- Avoid excessively combing or brushing your hair.
- Avoid using hair spray, oils, or creams.
- Avoid using heat sources on your hair (including hair dryers, rollers, or curling irons).
- Do not perm or color your hair. Ask your health care provider when you can go back to coloring or perming your hair.
- Protect your head from the sun, cold, and wind by wearing a head covering (such as a cap, turban, scarf, or hat made of cotton or a cotton blend).

### Fatigue
Everyone has a different level of energy, so bone marrow transplantation will affect each patient differently. Many patients might require a full year to recover physically (cont.)

- **Evaluate your level of energy.** Think of your personal energy stores as a “bank.” Deposits and withdrawals have to be made over the course of the day or the week to balance energy conservation, restoration, and expenditure.

  Keep a diary for 1 week to identify the time of day when you are either most fatigued or have the most energy. Note what you think might be contributing factors.
<table>
<thead>
<tr>
<th>Discomfort</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Fatigue (cont.) and psychologically from their transplant. Even after that, life might not return to the “normal” you had experienced before your bone marrow 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.</td>
<td>□ <strong>Be alert to your personal warning signs of fatigue.</strong> 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.</td>
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<tr>
<td>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.</td>
<td>□ <strong>Plan ahead, organize and prioritize your daily activities.</strong> 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.</td>
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<tr>
<td>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 might explain why you feel more tired than you anticipated.</td>
<td>□ <strong>Schedule rest.</strong> Balance periods of rest and work. Rest before you become fatigued. Frequent, short rests are beneficial.</td>
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<tr>
<td>□ <strong>Pace yourself.</strong> A moderate pace is better than rushing through activities.</td>
<td>□ <strong>Exercise daily.</strong> Walking is an excellent way for you to regain your strength and stamina.</td>
</tr>
<tr>
<td>□ <strong>Eat a well balanced, nutritious diet.</strong></td>
<td>□ <strong>Manage stress.</strong> Managing stress can play an important role in combatting fatigue. Adjust your expectations and ask others for support and help.</td>
</tr>
</tbody>
</table>
| □ **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 health care providers. There are times when fatigue might indicate an underlying medical problem. Other times, there might be medical interventions to assist in controlling some of the causes of fatigue. Finally, there might be suggestions that are more specific to your situation that would help in combatting your fatigue. Be sure to let your doctor or nurse know if you have: | □ Increased shortness of breath with minimal exertion  
□ Uncontrolled pain  
□ Inability to control side effects from treatments (such as nausea, vomiting, diarrhea, or loss of appetite)  
□ Uncontrollable anxiety or nervousness  
□ Ongoing depression |
### Discomfort

<table>
<thead>
<tr>
<th>Insomnia (difficulty sleeping)</th>
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</thead>
<tbody>
<tr>
<td>Many patients have trouble sleeping during their hospital stay. You might 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.</td>
</tr>
<tr>
<td>Recommendations</td>
</tr>
<tr>
<td>If necessary, you might be given a prescription medicine to help you fall asleep.</td>
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<tr>
<td>Practice relaxation techniques such as mental imagery, deep breathing, reading, or listening to calming music.</td>
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<td>Make sure you are comfortable. Arrange your pillows so you can maintain a comfortable position.</td>
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<tr>
<td>Avoid napping too much during the day. At the same time, remember to balance activity with rest.</td>
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<tr>
<td>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.</td>
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</tbody>
</table>

### Sexual side effects

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>| Recommendations |
| Discuss your concerns about fertility and your desire to have children after treatment with your doctor before you begin cancer treatment. |
| Concerns about being biologically able to have children might be distressing, so it might help to seek counseling with your BMT social worker. |
| It might help to talk about fertility loss and its impact on you and your partner or future partner. |
| Even though infertility (the inability to have children) might occur after cancer treatment, it is still possible to get pregnant, so both men and women should use birth control after treatment. If you do wish to start a family after cancer treatment, talk to your health care provider about the timing of a pregnancy after treatment. |</p>
<table>
<thead>
<tr>
<th>Discomfort</th>
<th>Recommendations</th>
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<tr>
<td><strong>Sexual side effects (cont.)</strong></td>
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<tr>
<td>Some women stop having their menstrual cycles after a bone marrow transplant and might benefit from hormone replacement therapy to relieve menopausal symptoms. Talk to your doctor about this treatment option.</td>
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<tr>
<td>Some men might experience a decreased or absent sperm count after cancer treatment.</td>
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<tr>
<td>□ 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).</td>
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<tr>
<td>□ 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.</td>
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<tr>
<td>□ 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.</td>
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</tbody>
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*This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.*
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 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 bone marrow transplant and who are on immunosuppressive medication can have CMV reactivate. This reactivation can cause a variety of different infections. If untreated these infections can be life threatening. A bone marrow transplant 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.

Your bone marrow transplant team will be monitoring you often for CMV with frequent blood tests. This test will indicate whether the virus has become active. You will have these tests drawn weekly for the first three months after your bone marrow transplant. For the following three months (until 6 months after your bone marrow 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 bone marrow transplant physician may have you continue to check more frequently.

CMV blood tests need to be run at the Cleveland Clinic; therefore, if you are at home, a kit with tubes will be provided to you. Your transplant nurse coordinator will either give you kits at your appointment or you will receive them in the mail at your home. This kit can be taken to your local lab to be drawn and mailed to the Cleveland Clinic lab. Please plan to have blood drawn Monday through Thursday so that samples are returned to our labs for processing on a weekday. You will be provided with a standing order from your transplant physician to take with you and give to your local lab.

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.
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 4-6 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.
This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Music Therapy

What is music therapy?
Music therapy, conducted by a board-certified music therapist, uses music and music interventions within a therapeutic relationship to promote physiological, psychological, emotional, and social well-being of the 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 (i.e. pain, 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 implemented, 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 Bone Marrow Transplant Program because we want to provide the best services available.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 bone marrow transplant will receive blood products during their hospital stay.

Blood transfusions at Cleveland Clinic

About 1 of every 3 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 4 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 might 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% 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 8 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 3 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 100.5 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)

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Neutropenic Precautions
For Allogeneic Bone Marrow Transplant Patients

1. Good hand washing for all who enter the room.

2. Single room isolation with laminar air flow.

3. Wear mask when outside the G110 or G111 inpatient units.

4. Minimize venipunctures and invasive procedures.

5. No aspirin or non-steroids, as they might mask fevers.

6. No cooked food from outside unless approved by the nutritionist.

7. Weekly dressing change of Hickman catheter.

8. Minimize visitors and screen for infection, upper respiratory infection, diarrhea, etc.

9. No tampons.

10. No suppositories or enemas.

11. No cotton swabs. (Q-Tips®)

12. No pierced earrings.

13. No intimate contact. (sexual intercourse).

14. Except for handwashing, only the patient is to use the bathroom. Only the patient is to occupy the bed.

15. Avoid contact with new animals. If you have pets at home, do not clean up after them.
This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Thrombocytopenic Precautions
For Autologous and Allogeneic Patients

1. Minimize venipunctures and invasive procedures
2. No aspirin or non-steroids, as they might increase your risk of bleeding
3. No flossing or toothpicks
4. No straight razors, fingernail or toe clippers (use a file)
5. No suppositories or enemas
6. No tampons
7. No nose blowing
8. No cotton swabs (Q-Tips®)
9. No intimate contact (sexual intercourse) until your platelet count is greater than 50
This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
**Antithymocyte Globulin (ATG)**

**BRAND NAME:** Atgam®

**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 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 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
☐ 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.
**Busulfan**

**BRAND NAME:** Myleran®, Busulfex®

**What does it do?**

Busulfan stops the growth of cancer cells by attaching to the DNA molecule that gives the cell the ability to reproduce. Therefore, the cell can no longer reproduce. Busulfan belongs to a group of medicines known as “alkylating agents."

**How is it given?**

Busulfan is given as an intravenous solution through your central venous catheter. Busulfan is given every 6 hours around the clock for a specific number of doses.

(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?**

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

- Decreased blood counts
- Nausea and vomiting — Nausea might increase as more doses of busulfan are taken. Anti-nausea medicines can be given before each dose.
- Loss of appetite
- Rash, itching
- Mucositis — The lining of your mouth and throat, as well as your gums (called the oral mucosa), might become inflamed or sore during treatments. You might have a dry mouth with thick, sticky saliva; discomfort when chewing or swallowing; or sores in your mouth.
- Esophagitis — The lining of your esophagus (food pipe) might become inflamed and sore during treatments. You might feel a burning sensation in your throat or chest, or you might feel as if you have a “lump” in your throat. You might also feel pain when swallowing.
Seizures — The risk of developing this side effect is minimal. However, to further reduce the risk of developing seizures, you will be given an anti-seizure medicine called Dilantin® once a day while you are taking busulfan.

- Diarrhea
- Loss of fertility
- Discoloration of the skin and nails
- Scarring of the lung tissue (called pulmonary fibrosis) — To monitor this side effect, you will have a pulmonary function test 1 month after you are discharged from the hospital. (This is rare.)
- Hair loss
- Increased risk of infection

What do I need to know when I go home?

- Nausea and vomiting might continue for a length of time after you are discharged.
- Call your doctor if you have a persistent, dry, hacking cough.
Cyclophosphamide

**BRAND NAMES:** Cytoxan® 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 preparative regimen. 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 binder.)

**What are some side effects I might experience?**

- Decreased blood counts — This usually occurs in about 7 days and lasts about 21 days.
- Nausea and vomiting (NOTE: You will be given an antinausea 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 (brand name 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 necessary, 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.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Etoposide (VP-16)

**BRAND NAMES:** VePesid®, Etopophos®, Toposar®

**What are some other names for this medicine?**

Etoposide is commonly called VP-16.

**What does it do?**

Etoposide inhibits cell division. It belongs to a group of agents known as “plant alkaloids,” meaning it is derived from a plant source.

**Why is it given?**

Etoposide can be given as part of the preparative regimen for autologous and allogeneic transplants. It is also sometimes used as a “priming” agent for autologous transplant patients prior to stem cell collection, to help make more stem cells.

**How is it given?**

If given as part of a preparative regimen, Etoposide is an intravenous solution given through your central venous catheter continuously for 18 to 36 hours at a time (depending on your body weight), or for 2 hours at a time, twice a day for 3 days in a row. The amount of etoposide you receive will depend on your specific preparative regimen.

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 binder.)

**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 any questions about your personal situation.

What do I need to know when I go home?

If you experience a skin reaction, your skin color will return to normal over time. Lotion is recommended to treat dry skin. Sunscreen is also recommended, as your skin might be more sensitive to the sun.

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

**BRAND NAME:** 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 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.*
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. You may be able to use acetaminophen (Tylenol®) for pain if approved by your doctor.

☐ Take anti-nausea medicines only as prescribed by your doctor. Ask your doctor which over-the-counter medicines you can take.

☐ Do not have any vaccinations without your doctor's approval.

☐ If you can, avoid people with infections (because the risk of infection is higher when your blood count is low). Your doctor might also ask you to avoid eating fresh fruits and vegetables.

When should I call my doctor?

Call your doctor if you:

☐ Have a fever of 100°F (37.8°C) or higher

☐ Have black stools

☐ Have difficulty urinating

☐ Notice blood in your urine

☐ Notice a faint, red rash

☐ Have any unusual bruising or bleeding

☐ Have chest pain, shortness of breath, or difficulty breathing

☐ Have any other unusual symptoms

☐ Have any questions or concerns

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

What is photopheresis?

Photopheresis or extracorporeal photimmune 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 Desk M12. Televisions are available for viewing during the procedure. Visitors are limited in this area. 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 prior.

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.

When your blood first enters the machine, it is mixed with an anticoagulant medicine called heparin 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 to 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° 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.

*This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.*
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 minimizing 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 T28 or R28, 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 might or might 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 minimize 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 Name: 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 post-transplant for severe graft versus host disease (GvHD) in allogeneic patients.

How is rituximab 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 binder.)

What are some common side effects of this drug?
- 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.*

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

Call your health care provider if you:

- Have a fever of 100.5°F (38°C) or chills
- Have shortness of breath
- Have chest pain or discomfort
- Have swelling of your lips or throat
- Are confused
- Develop a rash or sore joints
- Have nausea or vomiting not otherwise relieved with your prescribed medicines
- Show other signs of infection such as sore throat, cough, redness, inflammation, or pain with urination
- Have any questions or concerns
- Have any other unusual symptoms

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

☐ 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 nurse and/or pharmacist will provide you with a medicine sheet describing each medicine and how you should take it.

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.
**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 you are notified that your prescriptions are ready, 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.

**Prescription refills** — When your initial supply of medicine is running low, you may call your nurse coordinator with your preferred pharmacy’s phone number and your prescription number so the refill can be called in.

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 health care provider. Also call if you have any other symptoms that are persistent 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 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 periodically change the dose of your medicines. The dose might be changed because you are having uncomfortable side effects or because blood test results indicate that a different dose 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 dose 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®, Nuprin®), naproxen (Aleve®), vitamins, cold medicine, antihistamines, antacids, herbs, laxatives, and sleeping pills — might 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 Neoral® or cyclosporine, keep these medicines in their 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**.

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

Brand names: Amoxil®, Trimox®, Wymox®

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 in order 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. 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 health care provider if you have ever had any unusual or allergic reactions to penicillin or cephalosporin medicines. Also tell your health care 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
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 duration of treatment in order 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 transplants 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 prevent or minimize 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 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 health care provider adjusts your dosage.

When should I notify my health care provider?

If you have any of these symptoms, please tell your health care 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

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

**Brand names:** Zithromax®, AzaSite®, Zmax®

**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 duration of treatment in order 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 he or she prescribes this medicine, tell your health care provider if you have ever had any unusual or allergic reactions to macrolide antibiotics. Also tell your health care 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 2-3 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 the 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. Notify your nurse coordinator if you are having more than five liquid stools daily.

• **Nausea and/or vomiting** – Notify 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 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 or severe side effects

• Develop new symptoms after starting this medication

• Have any other symptoms that cause concern

• Have any questions or concerns

*This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.*
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 suppressed. Amphotericin B lipid complex will suppress 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 for the entire duration of treatment in order 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 time 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 minimize 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 health care provider adjusts your dosage.

When should I notify my health care provider?
If you have any of these symptoms, please tell your health care 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

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

Common generic and brand names:
These medicines can be divided into 3 groups. All are used to prevent ulcers and reduce the acid in your stomach.

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

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

How and when should antacids be used?
Many insurance companies cover only selected acid blockers. Discuss this with your BMT Team to ensure that the proper substitution is made, if necessary.

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

Pepcid® is available as an intravenous solution (delivered into your vein in the hospital only), tablets, chewable tablets, and suspension liquid (with small particles in it). Shake the liquid form before each use. Measure the liquid form with a specially marked measuring spoon to measure each dose accurately. Pepcid® can be taken with food.

If you have difficulty swallowing capsules, you can open Prevacid® or Nexium® capsules and sprinkle the contents on food or in a drink. However, do not chew or crush the contents inside the capsule. Do not open or chew Prilosec® capsules. Swallow them whole with a full glass of water. Antacids are usually taken once a day at bedtime or twice a day in the morning and at bedtime.
Your prescription label tells you how much to take at each dose. Follow these instructions carefully, and ask your doctor or pharmacist to explain anything you do not understand. Do not stop taking the medicine without consulting your doctor. Ask your pharmacist any questions you have about refilling your prescription.

What special instructions should I follow while using this drug?

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

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 health care provider if these symptoms are persistent or severe.

When should I call my health care provider?

Call your health care provider right away if you:

- Have a fever of 100°F (37.8°C) for allogeneic patients, or 100.5°F (38°C) or higher for autologous patients
- Develop a skin rash or skin irritation
- Have any other symptoms that cause concern

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

Take the missed dose as soon as you remember. If you miss 2 or more doses of antacids in a row, contact your health care 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.

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

Common brand names: Neoral®, Sandimmune®, Gengraf®

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 2 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 bone marrow 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 sensing 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 the suggestions on the next page.

Notes

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<table>
<thead>
<tr>
<th>Possible Side Effect</th>
<th>What You Should Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased risk of infection</td>
<td>Avoid anyone who might have an infection, and report any signs or symptoms of infection to your health care provider.</td>
</tr>
<tr>
<td>Swollen or bleeding gums</td>
<td>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 health care provider. Notify your BMT Team before any dental procedures.</td>
</tr>
<tr>
<td>Excess hair growth</td>
<td>To remove unwanted hair, use safe bleaching techniques or creams. Please check with your BMT Team before using these products.</td>
</tr>
<tr>
<td>Liver damage</td>
<td>Visit your doctor regularly and have your blood drawn as scheduled. Report any changes in the color of your urine, eyes, or skin.</td>
</tr>
<tr>
<td>Kidney damage</td>
<td>Report any changes in urine output, weight, or swelling during your regular doctor visits.</td>
</tr>
<tr>
<td>Tremors or seizures</td>
<td>Report any trembling, shaking, or seizures to your doctor. Your dosage might need to be adjusted.</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>Take your medicine as prescribed and limit salt in your diet.</td>
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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 duration of treatment in order 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 a medicine called cimetidine (Tagamet®), which is an antacid. Cimetidine can decrease the effect of fluconazole.
- It is important to tell your doctor if you are taking medicines called anticoagulants, 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, 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 a medicine called 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, notify 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 health care provider?**

Call your health care 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

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

Brand names: Cytovene®

Class of drugs: 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 bone marrow transplant 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 duration of treatment in order 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 taking this medicine?

- Please refer to the separate information sheet about chemotherapy precautions under the Medication tab in this binder.
- 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 health care provider before taking this medicine.
- Keep taking ganciclovir for the full time 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 health care 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 and what can I do to treat them?

While you are taking ganciclovir, frequent blood tests will be taken to prevent or minimize 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 health care provider if you develop any of these symptoms:
  - Fever 100°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 health care provider?

If you have any of these symptoms, please tell your health care 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 health care 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
Immune Globulins (IVIG)

Other Names: Sandoglobulin®, GammImmune®, Iveegam®, Gammagard®, Polygam®, Venoglobulin®

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 the control of 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 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®, diphenhydramine, and/or hydrocortisone. These drugs are given to prevent further infusion reactions.

**When should I call my health care 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.
Immunosuppressant Medicines

Why do I need to suppress my immune system?

In order for your donor’s cells to establish themselves in your body, the cells involved with recognizing “foreign” cells must be suppressed. You will be on 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 notify your Transplant Team immediately at the first sign.

When should I call my health care provider?

Call your health care provider RIGHT AWAY if you have any of these warning signs of infection:

- Fever of 100°F (37.8°C) for allogeneic patients
- 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 health care provider if you have any other symptoms that cause concern or if you have any questions.

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

Brand name: Sporanox®

Class of drugs: 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 duration of treatment in order 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 taking this medicine?

- Itraconazole should be taken at least 2 hours before taking magnesium supplements and antacids — such as Peptic®, 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 time 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 and what can I do to treat them?
While you are taking itraconazole, frequent blood tests will be taken to prevent or minimize 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 health care provider?
If you have any of these symptoms, please tell your health care 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 health care 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

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

**Brand names:** Folex®, Folex PFS®, Mexate®, Mexate-AQ®, Rheumatrex®, Trexall®

**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.*
Mycophenolate Mofetil

Common brand name: CellCept®

Type of medicine: Immunosuppressant

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 2 to 3 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 treatment ends.

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
• Mycophenolate mofetil can cause birth defects. Therefore, you should 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.
• There is an increased risk of infection. Avoid anyone who might have an infection, and report any signs or symptoms of infection to your health care provider.
• This medicine might cause a change in the white blood cell count. Have your blood drawn regularly so your health care providers can monitor your white blood cell count.

• High blood pressure
• Headache
• Swelling

What storage conditions are necessary for 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.
Nystatin

Common brand name: 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 systems are 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 4 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 health care provider?

Call your health care 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, deceased 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

Notes

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 R10 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 health care provider?
Call your health care provider immediately or call 911 if you experience any of the following symptoms:
- Chest pain
- Constant coughing
- Difficulty breathing
**Steroids**

**Generic names:** Prednisone, methylprednisolone

**Common brand names:** Deltasone®, Meticorten®, Orasone®, Prednicen-M®, Prednisone Intensol®, Solu-Cortef®, Solu-Medrol®, Sterapred DS®

**Why is this drug 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 duration of treatment in order 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 this drug?**

- 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 the Transplant Center 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 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 occur, 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.

<table>
<thead>
<tr>
<th>Possible Side Effect</th>
<th>What You Should Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>This can be caused by increased fluid retention. Take your medicine as prescribed, and reduce the amount of salt and fluid you use. Also, measure your blood pressure and record it every day. Ask your health care provider what your blood pressure range should be.</td>
</tr>
<tr>
<td>Increased appetite</td>
<td>Eat well-balanced, nutritious meals, and visit a dietitian regularly to discuss excess weight gain and ways you can maintain a healthy lifestyle.</td>
</tr>
<tr>
<td>Steroid-induced diabetes</td>
<td>If you formerly controlled your pre-existing diabetes without medicine, you might now need to take insulin or pills to control diabetes.</td>
</tr>
<tr>
<td>Vision changes, cataracts, glaucoma</td>
<td>Visit an ophthalmologist yearly. Check with your BMT Team before getting a new prescription for glasses.</td>
</tr>
<tr>
<td>Acne</td>
<td>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.</td>
</tr>
<tr>
<td>Easy bruising</td>
<td>Avoid accidental bumps and cuts by taking extra safety precautions before beginning any task.</td>
</tr>
<tr>
<td>Increased sensitivity to the sun</td>
<td>Avoid the sun whenever possible. When outdoors, wear a sunblock with an SPF of at least 30. Report any skin changes to your doctor.</td>
</tr>
<tr>
<td>Increased swelling of the face, hands, or ankles</td>
<td>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.</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>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.</td>
</tr>
</tbody>
</table>
**When should I call my health care provider?**

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

- Fever of 100°F for allogeneic patients or 100.5°F for autologous patients
- 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

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

<table>
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<th>Possible Side Effect</th>
<th>What You Should Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach irritation, ulcers</td>
<td>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.</td>
</tr>
<tr>
<td>Mood swings</td>
<td>Try relaxation techniques. Your social worker can recommend materials that can help.</td>
</tr>
<tr>
<td>Increased risk of infection</td>
<td>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.</td>
</tr>
<tr>
<td>Joint pain, increased risk of osteoporosis</td>
<td>Avoid gaining excess weight and include low-impact exercises in your daily schedule to avoid a possible need for joint replacement.</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Talk to your health care provider about taking steroids in the morning. Avoid napping too much during the day and balance activity with rest.</td>
</tr>
<tr>
<td>Excess hair growth</td>
<td>To remove unwanted hair, use safe bleaching techniques or creams. Please contact your BMT before using.</td>
</tr>
</tbody>
</table>

**Possible Side Effect**

- 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 health care provider if you have any other symptoms that cause concern or if you have any questions.

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Sulfamethoxazole and Trimethoprim Double Strength

Brand name: Bactrim® DS

Class of drugs: Antibiotic

Why is Bactrim DS® prescribed?

Bactrim® DS is usually prescribed to prevent or treat a specific bacterial infection called *Pneumocystis carinii* 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 systems are 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 health care provider if you have ever had any unusual or allergic reactions to any of these medicines: sulfamethoxazole, furosemide (Lasix®), thiazide diuretics (water pills), oral diabetes medicines, glaucoma medicine, dichlorphenamid (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 a.m. to 3 p.m., 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 time 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

• Headache

• Diarrhea

• Headache

• Diarrhea

• Headache

• Diarrhea

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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.

When should I call my health care 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

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

Common brand name: Prograf® (FK506)

Type of medicine: 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 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 health care provider for specific instructions.

What are the common side effects?
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.
• **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.
Valganciclovir

Brand Name: Valcyte®

Class of Drugs: 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 bone marrow transplant 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 duration of treatment in order 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 health care 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 are the common side effects of this drug?

While you are taking valganciclovir, frequent blood tests will be taken to prevent or minimize 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 health care provider?

Call your health care 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

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 given?
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 drug 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 bone marrow transplant team.
- Take voriconazole for the entire duration 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.

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 health care provider?
If you have any of the following symptoms, please tell your health care provider at your next follow-up appointments:
• Diarrhea
• Nausea that doesn’t improve after changing your eating habits

Call your health care provider immediately if you experience any of the following symptoms:
• Fever or chills
• Skin rash or itching
• Sore throat
• Changes in your vision
• 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

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

Brand name: Noxafil®

Why is posaconazole prescribed?
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 liquid three times a day (for prophylaxis) or four times a day (for treatment). 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, preferably with fatty meals (sour cream, whole milk, ice-cream).

- 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®) or cyclosporine (Neoral®, Sandimmune®), your doctor might order more frequent checks of tacrolimus or cyclosporine blood levels.
and might possibly change your dose of tacrolimus or cyclosporine.

- 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 some possible side effects of this medicine?**

- 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 rarely occur. You will have frequent blood tests while taking posaconazole to monitor the development of altered liver function, a serious side effect of this medicine.

**When should I call my health care 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.
- 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

*This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.*
Contacting the Team After Transplant

You have just completed an intense period in the hospital for bone marrow 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 your discharge: **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 as an outpatient for several months. You will receive detailed instructions for your follow-up appointments, which will be designed to meet your specific needs.

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**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:

**Kelly Cherni, R.N.** — 216.444.9276 or 1.800.223.2273 ext. 49276  
Pager: 216.444.2200, ask for pager #22539

**Elaina Corbett, R.N.** — 216.444.5839 or 1.800.223.2273 ext 45839  
Pager: 216.444.2200, ask for pager #80918

**Christina Ferraro, R.N.** — 216.445.3773 or 1.800.223.2273 ext. 53773  
Pager: 216.444.2200, ask for pager #24729

**Gina Green, R.N.** — 216.445.4231 or 1.800.223.2273 ext. 54231  
Pager: 216.444.2200, ask for pager #25619

**Shirley Mobley, R.N.** — 216.445.4360 or 1.800.223.2273, ext. 54360  
Pager: 216.444.2200, ask for pager #80174

**Karen Sands, R.N.** — 216.444.4652 or 1.800.223.2273 ext. 44652  
Pager: 216.444.2200, ask for pager #22795

**Mary Serafin, R.N.** — 216.445.6373 or 1.800.223.2273 ext. 56373  
Pager: 216.444.2200, ask for pager #24024

**Jamie Starn, R.N.** — 216.445.4942 or 1.800.223.2273 ext. 54942  
Pager: 216.444.2200, ask for pager #23199

**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.
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 bone marrow 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.

<table>
<thead>
<tr>
<th>Lab Test</th>
<th>What does it measure?</th>
<th>What might be done if the result is abnormal</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBC (Complete Blood Count)</td>
<td>This lab test measures the following: WBC, RBC, HGB, HCT, PLT. (See below)</td>
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</tr>
<tr>
<td>WBC (White Blood Count)</td>
<td>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. The use of Neupogen (G-CSF) or Neulasta can cause an elevated WBC.</td>
<td>If your WBC is low, your doctor might order Neupogen or Neulasta to boost your WBC count.</td>
</tr>
<tr>
<td>RBC (Red Blood Count)</td>
<td>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.</td>
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<tr>
<td>HGB (Hemoglobin)</td>
<td>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.</td>
<td>If your HGB is too low, you will receive a red blood cell transfusion. Your doctor might order Procrit, Epogen or Aranesp as well.</td>
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<tr>
<td>HCT (Hematocrit)</td>
<td>HCT measures the percentage of RBC in your blood.</td>
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<tr>
<td>PLT (Platelets or thrombocytes)</td>
<td>PLT are cells that help your blood clot. After an allo transplant, low platelets might indicate the presence of GVHD.</td>
<td>If your PLT count drops too low, you will receive a platelet transfusion.</td>
</tr>
<tr>
<td>DIFFERENTIAL</td>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>Neutrophils</td>
<td>These are a specific type of WBC that are the body's first line of defense against infection.</td>
<td>If this result is too low, your doctor might order a Neupogen (G-CSF) or Neulasta injection.</td>
</tr>
<tr>
<td>Lymphocytes</td>
<td>These are a specific type of WBC that attach to foreign antigens and destroys them. Together with neutrophils, lymphocytes make up the majority of your total WBC.</td>
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<tr>
<td>Eosinophils</td>
<td>These are a specific type of WBC that responds to allergic reactions. This lab value can increase with GVHD.</td>
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<tr>
<td>Basophils</td>
<td>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.</td>
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<tr>
<td>Monocytes</td>
<td>This is a specific type of WBC that is the body's second line of defense to fight off infection.</td>
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<tr>
<td>CMP (Comprehensive Metabolic Panel)</td>
<td>This is a group of lab tests (See Below) that measure chemical components in your blood. It might reflect the function of several organs.</td>
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<tr>
<td>Total Protein</td>
<td>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.</td>
<td>A dietitian might be consulted for caloric monitoring and possible dietary recommendations, including TPN.</td>
</tr>
<tr>
<td>Albumin</td>
<td>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.</td>
<td>A dietitian might be consulted for caloric monitoring and possible dietary recommendations, including TPN.</td>
</tr>
<tr>
<td>Calcium (Ca)</td>
<td>Calcium is an electrolyte that helps neuromuscular and enzyme activity, and skeletal development. 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.</td>
<td>If your calcium is too low or if you are on steroid therapy, your doctor might ask you to take a calcium supplement</td>
</tr>
<tr>
<td>Total Bilirubin (Total Bili)</td>
<td>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.</td>
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</tr>
<tr>
<td>Alkaline Phosphatase (Alk Phos)</td>
<td>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.</td>
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<tr>
<td>Aspartate aminotransferase (AST)</td>
<td>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.</td>
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<tr>
<td>Blood Urea Nitrogen (BUN)</td>
<td>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.</td>
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</tr>
<tr>
<td>Creatinine (Creat)</td>
<td>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.</td>
<td>Adjustments in your medicines might be made according to your creatinine levels.</td>
</tr>
<tr>
<td>Sodium (Na)</td>
<td>Sodium is an electrolyte that affects water distribution, helps maintain osmotic pressure, and helps promote neuromuscular function.</td>
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</tr>
<tr>
<td>Potassium (K)</td>
<td>This is an electrolyte that is essential to maintaining electrical conduction within the cardiac and skeletal muscles. Certain medicines such as IV amphotericin can affect potassium levels.</td>
<td>It is common to need potassium replacement during and after your BMT.</td>
</tr>
<tr>
<td>Chloride (Cl)</td>
<td>Chloride is an electrolyte that helps regulate blood volume and arterial pressure.</td>
<td></td>
</tr>
<tr>
<td>Anion Gap</td>
<td>This lab test helps to distinguish types of metabolic acidosis and kidney function.</td>
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<tr>
<td>Carbon Dioxide (CO2)</td>
<td>CO2 reflects the adequacy of gas exchange in the lungs. It evaluates acid-base balance.</td>
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<tr>
<td>Alanine transaminase (ALT)</td>
<td>ALT is an enzyme that detects acute liver tissue damage.</td>
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<tr>
<td>Glucose</td>
<td>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.</td>
<td>High glucose might be treated by adjusting your diet, or with medicines, such as insulin.</td>
</tr>
<tr>
<td>Lactic Dehydrogenase (LDH)</td>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>Gamma Glutamyl Transpeptidase (GGT)</td>
<td>GGT is an enzyme used to assess liver function. GGT is an indication of GVHD.</td>
<td></td>
</tr>
<tr>
<td>Uric Acid</td>
<td>Uric acid helps to detect gout or kidney dysfunction. It might become elevated soon after high-dose chemotherapy as cancer cells are destroyed</td>
<td>Medicines, including Allopurinal, might be prescribed</td>
</tr>
<tr>
<td>Magnesium (Mg)</td>
<td>Mg is an electrolyte that is vital to neuromuscular function. Certain medicines such as IV Amphotericin can affect your Mg levels.</td>
<td>It is common to need magnesium replacement during and after your BMT</td>
</tr>
<tr>
<td>Quantitative Immunoglobulins (IgG, IgA, IgM)</td>
<td>These are proteins that help evaluate immune function.</td>
<td>If you have an allogeneic BMT, your doctor might order immunoglobulin infusions until your levels return to normal.</td>
</tr>
<tr>
<td>Ferritin</td>
<td>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.</td>
<td>If your ferritin level is too high, your doctor might prescribe certain medicines</td>
</tr>
<tr>
<td>Lab Test</td>
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<tr>
<td>Prothrombin Time (PT or Pro time) /INR</td>
<td>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 coumadin.</td>
<td></td>
</tr>
<tr>
<td>Plasma Thrombin Time (PTT or Thrombin clotting time)</td>
<td>This is one of two blood tests done to evaluate your blood clotting system. This monitors the effectiveness of certain medicines, such as Heparin.</td>
<td></td>
</tr>
<tr>
<td>Cyclosporine (CSA) Neoral</td>
<td>This test indicates the amount of CSA in your blood.</td>
<td>If levels are too high or too low, your dose of CSA might be adjusted.</td>
</tr>
<tr>
<td>Prograf (Tacrolimus)</td>
<td>This test indicates the amount of Prograf in your blood.</td>
<td>If levels are too high or too low, your dose of Prograf might be adjusted.</td>
</tr>
<tr>
<td>CMV DNA detection</td>
<td>This blood test is done to determine the presence of a virus in your blood called CMV (cytomegalovirus).</td>
<td>If you have a positive CMV test result, your doctor will order certain medicines to treat the virus.</td>
</tr>
</tbody>
</table>

**Notes**

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

Hearing Impaired (TTY) Assistance 216.444.0261
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Rev.05/11
Follow-Up Appointments
For Allogeneic Bone Marrow Transplant Patients

Staying in Cleveland

After your allogeneic bone marrow 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, the Bone Marrow Transplant Team will help you make arrangements for your stay in Cleveland.

Where will I go for my follow-up appointments?

Your follow-up appointments will be scheduled in the Bone Marrow Transplant Outpatient Clinic, located at R20 in the Taussig Cancer Center. You may park in the Visitor’s Parking Garage located on E. 93rd between Euclid and Chester 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 bone marrow transplant. 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. Although re-admissions might be discouraging, they are very common and necessary for recovery.

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

Although Clinic visits are frequent at first, they will gradually taper off as your condition improves.

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 the tests and 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 VCR 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 Center where you can buy breakfast and lunch.

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 might be ordered and your treatment plan modified according to your condition. If your condition is stable, your labwork might become less frequent, but it will always be necessary.

**Other tests**

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

- **Chest X-Rays** — These are performed weekly at R22 to check your lungs to detect the development of pneumonia.
- **Immunoglobulins (Iveegam®, Gammagard®)** — This medicine is infused over several hours to boost your immune system. The frequency of the infusions will be determined by your immunoglobulin levels.
- **Blood transfusions** — Depending on the results of your complete blood count, you might receive a red blood cell transfusion and/or platelet transfusion.
- **Electrolyte infusion** — If, for example, your potassium or magnesium levels are low, you might 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 manual 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.

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 chart and IV pump/medicine to the R20 front desk to check in for your doctor appointment.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 Bone Marrow 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 caregiver should arrive on your day of discharge at 9 a.m.

☐ Discharge is before noon.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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, infection or injury.

For autologous bone marrow transplant patients, you should check your temperature twice a day for 2 weeks after discharge. For allogeneic bone marrow 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 from 1 to 2 degrees Fahrenheit (.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.

When to call your health care provider*

*For allogeneic bone marrow transplant patients, page your nurse coordinator if you have a temperature of 100.0 degrees Fahrenheit or higher. For autologous bone marrow transplant patients, page your nurse coordinator if you have a temperature of 100.5 degrees Fahrenheit or higher. This could be a sign of infection and should be treated right away. After hours or on weekends, call 216.444.2200 or 1.800.223.2273 and ask for the Hematology/Oncology fellow on call.

If you have a fever and any of these other signs, call your health care provider right away:

- Severe headache
- Stiff neck
- Severe swelling of your throat
- Mental confusion
### CONVERSION CHART

**Fahrenheit to Centigrade (Celsius)**

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<thead>
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</table>

**100.5*       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**

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Preventing Infection
After Bone Marrow Transplant

After your bone marrow 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 bone marrow 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*

* These are more common after allogeneic bone marrow 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 patients should continue to take your temperature twice a day until all of your immunosuppressive medicines have been discontinued by your health care provider and your central line has been removed.

**Preventing Infection**
The following restrictions are important for autologous patients for the first month after transplant to prevent infections. These restrictions are important to prevent infections while allogeneic patients are taking immunosuppressive medicines and while you still have central lines.

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. After you are discharged from the hospital, 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 mouthwash 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 antimicrobial (antibacterial) 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 gastrointestinal bacterial infections, such as C diff.)

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

**Prevent infections transmitted by direct contact and respiratory transmission**

Avoid gardening, mulching, raking, mowing, farming, or direct contact with soil and plants. Creating plant or soil aerosols increases exposure to potential pathogens (substances that can cause disease) including *aspergillus* and *cryptococcus*. These pathogens can cause serious fungal infections.

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 (such as at movie theaters or sporting events). 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.
- 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, since the wood contains fungus.
- Avoid house cleaning that will disturb dust and mold, causing it to aerosolize (such as vacuum cleaning, dusting, and scrubbing down showers). Once you have the energy, it is not harmful to iron, wash clothes, dry clothes, and wash dishes.
- Avoid the use of a room humidifier due to the water-harboring bacteria.
- **Prevent pet-transmitted infections**
  It is not necessary to part with your pets. However, it is important to minimize direct contact with animals, especially animals that are ill. Please delegate the care of your pets to other family members or friends.

  It is recommended to avoid contact with reptiles, ducklings, or chicks to prevent 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 handle the daily litter box cleaning during the first 6 months after transplant and when you are taking immunosuppressive medicines to reduce your risk of acquiring toxoplasmosis. Please keep your cats inside and do not adopt or handle stray cats.

- **Water safety**
  After your transplant, avoid walking, wading, swimming, or playing in recreational water such as ponds, swimming pools, lakes, whirlpools, 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 to immediately implement any boil-water advisory. 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 1 of 3 processes: reverse osmosis, distillation, or 1-µm particulate absolute filtration. You can contact the bottler directly to confirm that a specific bottled water has undergone one of these processes.

- **Travel safety**
  Please do not plan to travel to developing countries without first talking to your bone marrow 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 minimize exposure to vaccine-preventable diseases (such as tetanus, polio, measles, mumps, rubella, influenza, and pneumococcal.) Discuss influenza vaccines with your BMT team.
When to call

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

- Fever of 100°F (37.8°C) for allogeneic patients, or 100.5°F (38.0°C) for autologous patients (even if you feel well)
- Shortness of breath
- Cough with yellow or green sputum (phlegm) or a dry, persistent cough
- Sweats or chills
- 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
- 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

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 he or she is not already taking it. It would be much riskier for the transplant patient if the child got the actual chicken pox virus.

Recommendations for a possible revaccination schedule are included in this handout and are needed for allogeneic transplant patients.

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 he or she is not already taking it. It would be much riskier for the transplant patient if the child got the actual chicken pox virus.
Vaccinating Recipients of Hematopoietic Stem Cell Transplants

A hematopoietic stem cell transplant (HSCT) results in immunosuppression because of the hematopoietic ablative therapy administered before the 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

Date of my HSCT: 

<table>
<thead>
<tr>
<th>Months from HSCT</th>
<th>6 months</th>
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<th>10 months</th>
<th>12 months</th>
<th>24 months</th>
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</thead>
<tbody>
<tr>
<td>Approximate month &amp; year</td>
<td>/</td>
<td>/</td>
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</tbody>
</table>

- Inactivated influenza vaccine every Fall

<table>
<thead>
<tr>
<th></th>
<th>Prevnar¹</th>
<th>Hib²</th>
<th>Tdap³</th>
<th>Twinrix⁴</th>
<th>Polio⁵</th>
<th>Prevnar</th>
<th>Hib</th>
<th>Tdap</th>
<th>Twinrix</th>
<th>Polio</th>
<th>Prevnar or Pneumovax⁸</th>
<th>MMR⁹</th>
<th>Varivax¹⁰</th>
</tr>
</thead>
</table>

¹Prevnar = 13-valent conjugated pneumococcal vaccine
²Hib = Haemophilus influenzae conjugate vaccine
³Tdap = tetanus toxoid, diphtheria toxoid & acellular pertussis vaccine
⁴Twinrix = combined hepatitis B virus and hepatitis A virus vaccines
⁵Polio = inactivated polio vaccine
⁶Td = tetanus toxoid & diphtheria toxoid
⁷Meningococcal vaccine = Age ≤ 55 years: Menactra (quadrivalent meningococcal conjugate vaccine). Age > 55 years: Menomune (meningococcal polysaccharide vaccine)
⁸Pneumovax = 23-valent polysaccharide pneumococcal vaccine. Give Pneumovax if no chronic graft-versus-host disease (GVHD). Give Prevnar if ongoing chronic GVHD.
⁹MMR = mumps-measles-rubella. If measles antibody is unprotective, no ongoing GVHD & not on immunosuppressive medications.
¹⁰Varivax = varicella zoster (Chicken pox) vaccine. If varicella zoster antibody is unprotective, no ongoing GVHD & not on immunosuppressive medications. Please note that Zostavax (shingles vaccine) is contraindicated.

In addition to above schedule, if patient is planning to travel out of the United States of America, we recommend scheduling a visit in our International Travel Clinic several months in advance.
Nutrition After Bone 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 might 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. Examples of nutrition supplements are Ensure®, Boost®, Resource®, Carnation Instant Breakfast®, Boost® bars and Boost® puddings. If you have diabetes, Choice DM® and Glucerna® are options.

**Multivitamins**
We recommend you take a daily multivitamin, after you are discharged. 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 bone marrow transplant patients often need additional phosphorus. Unless you are following a special diet, we recommended you eat a diet high in calcium and phosphorus.

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

* a good source of phosphorus

Additiona foods with significant amounts of phosphorus:
- Brussels sprouts
- Peanut butter
- Beef and Chicken livers
- Whole grain breads
- Coconuts
- Hawaiian Punch®
- Tropicana Peach Papaya®
- Tropicana Fruit Punch®
- Tropicana Strawberry Melon®
- Fruitworks—all varieties except pink lemonade
- Cool Iced Tea—all varieties except lemonade iced tea

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:
- Legumes
- Leafy green vegetables
- Whole grain cereals
- Nuts
- Chocolate
- Milk
- Meat

Sodium
Sodium is an electrolyte essential for water regulation and electrical activities of the body, such as nerve impulse transmission and muscular 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 bone marrow 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 bone marrow transplant, you might 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.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Food Safety Guidelines

For autologous transplant patients

While there are no restrictions on food you are allowed to eat, choosing safe foods is important during the first month after discharge.

For allogeneic transplant patients

Food safety is important in preventing infections while you are taking immunosuppressive medicine and while your central line is in place.

You should always practice food safety guidelines. You cannot taste, see, or smell most bacteria that cause food-borne illness or infection. If you are not sure about a food's safety, throw it out.

You should choose foods that do not upset your stomach. You might still have some nausea/vomiting and diarrhea after you are discharged. Soft, bland foods can be more gentle on your stomach, whereas spicy foods will probably make an upset stomach worse. If you are still having diarrhea after discharge, avoid milk products. Chemotherapy can cause some people to become temporarily lactose intolerant.

Below are two categories of food.

1. **High risk** — Foods you should be aware are more risky while you are immunosuppressed

2. **Safe** — Foods you can eat any time

<table>
<thead>
<tr>
<th>Food Group</th>
<th>Safe Foods</th>
<th>High Risk Foods to Avoid</th>
</tr>
</thead>
</table>
| Fruits     | • Cooked, frozen, fresh and dried fruit  
              • Canned fruit  
              • Pasteurized fruit juices  
              • Well-washed fruit (after discharged)  
              • Washed and peeled fruit | • Fresh-squeezed, unpasteurized fruit juices  
              • Hard-to-clean fruits such as raspberries and blackberries |
| Grains     | • All cooked grains (i.e. breads, crackers, muffins, pancakes, baked goods, etc.)  
              • All cooked and ready-to-eat cereal | • Raw, uncooked grain products (i.e. whole oats, wheat germ) |
<table>
<thead>
<tr>
<th>Food Group</th>
<th>Safe Foods</th>
<th>High Risk Foods to Avoid</th>
</tr>
</thead>
</table>
| Meat and meat substitutes| • Well-done meats, well-cooked poultry, cooked fish, and seafood (See the Food Safety section related to the appropriate meat temperatures.)  
  • Packaged luncheon meats and luncheon meats/hotdogs cooked until steaming hot.  
  • Well-cooked eggs (whites and yolk firm, including hard-boiled eggs)  
  • Cooked tofu (To cook, cut tofu into 1-inch or smaller cubes, and boil for at least 5 minutes in water or broth before eating or using in recipes)  
  • Cooked nuts (nuts in baked products), peanut butter | • Raw and undercooked meat, poultry, pork, wild game, fish (including cold smoked salmon, lox, sushi, and pickled fish), and seafood  
  • Undercooked or raw eggs  
  • All meats from the deli counter (including hard, cured salami in natural wrap), undercooked hotdogs, and processed meats  
  • Undercooked or raw tofu  
  • Unroasted nuts, roasted nuts in the shell.  
  • All miso and tempeh products  
  • Prepared foods from the deli counter (i.e. seafood salad, tuna salad) |
| Milk and milk products    | • Pasteurized dairy products (milk, cheese, cream, butter, yogurt)  
  • Packaged cheese with pasteurized milk (mild/medium cheddar, mozzarella, Swiss, parmesan)  
  • Packaged ice cream/bars, frozen yogurt, sherbert, homemade milkshakes (following food safety guidelines)  
  • Pasteurized whipped topping- dry, refrigerated, and frozen  
  • Commercial pasteurized eggnog | • Unpasteurized dairy products (milk cheese, cream, butter, yogurt)  
  • Unpasteurized cheeses or cheese containing molds (bleu, stilton, gorgonzola, roquefort)  
  • Sharp cheddar, brie, feta, camembert, and farmer’s cheese  
  • Cheese from the deli counter, cheese with chili pepper or uncooked vegetables  
  • Soft serve ice cream or yogurt  
  • Unrefrigerated cream or custard bakery products e.g. cream pie, custard filled donut, cream puff, etc. unless shelf stable |
| Vegetables                | • Pasteurized vegetable juices  
  • Cooked frozen, fresh, and canned vegetables  
  • Well-washed raw vegetables (after discharge) | • Fresh, raw mushrooms  
  • Fresh-squeezed, unpasteurized vegetable juices  
  • Raw herbs, dried herbs, and spices (i.e. pepper, oregano) not cooked into a recipe  
  • Salads from salad bar, deli or restaurants (only while in the hospital)  
  • Prepared salads from the deli counter (i.e. potato salad, macaroni salad)  
  • Raw sprouts - alfalfa, clover or mung bean |
<table>
<thead>
<tr>
<th>Food Group</th>
<th>Safe Foods</th>
<th>High Risk Foods to Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrees</td>
<td>• Well-cooked entrees, cooked all the way through to the appropriate temperature (See Food Safety guidelines for cooking temperatures.)&lt;br&gt;• Cooked soups</td>
<td>• Foods containing raw or undercooked meat or meat substitutes (i.e. undercooked eggs in French Toast, omelets and salad dressing)&lt;br&gt;• Any uncooked or undercooked soup</td>
</tr>
<tr>
<td>Beverages</td>
<td>• Tea made with boiling water&lt;br&gt;• Commercially bottled distilled, spring, and natural waters&lt;br&gt;• Tap water (This is usually safe if from a city water supply. If in doubt, boil for at least one minute.)&lt;br&gt;• Canned, bottled, powdered, beverages&lt;br&gt;• Instant and brewed coffee or tea, cold brewed tea made with boiling water’&lt;br&gt;• Commercially packaged brewed herbal tea&lt;br&gt;• Nutrition supplement beverages, packaged or canned</td>
<td>• Mate tea (unless pasteurized)&lt;br&gt;• Cold brewed tea with warm or cold water&lt;br&gt;• Well water (unless tested yearly for coliforms or boiled for at least one minute)&lt;br&gt;• Unpasteurized beer (i.e. home-brewed and certain microbrewery beers)</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>• Packaged chips (i.e. potato chips, corn chips, pretzels, popcorn)&lt;br&gt;• Salt, granulated sugar, brown sugar&lt;br&gt;• Pasteurized honey&lt;br&gt;• Jam, jelly, syrup (refrigerated after opening)&lt;br&gt;• Oil, shortening, and refrigerated lard&lt;br&gt;• Margarine, butter, and cooked gravies/sauces&lt;br&gt;• Commercially packaged condiments (refrigerated after opening)&lt;br&gt;• Pickles, pickle relish, olives (refrigerated after opening)&lt;br&gt;• Candy, gum</td>
<td>• Raw or unpasteurized honey&lt;br&gt;• Yeast, including raw, uncooked brewer’s yeast (Avoid all contact with raw yeast, and do not make bread products.)&lt;br&gt;• Fresh salad dressing made with raw eggs, unacceptable cheeses (See Milk and Milk Products section.), or raw herbs and spices.&lt;br&gt;• All moldy, outdated food products&lt;br&gt;• All restaurant/fast foods, deli and vendor foods (only while in the hospital)&lt;br&gt;• All deli foods unless cooked until steaming hot&lt;br&gt;• Raw cookie dough&lt;br&gt;• Salsa in the refrigerated section</td>
</tr>
</tbody>
</table>
Shopping
- Avoid purchasing foods from the deli unless cooked until steaming hot.
- Check the expiration date and do not buy outdated food.
- Do not purchase bulging, dented or rusted cans.
- Avoid any eggs with cracked shells.
- Choose fresh produce with no mold or bruises.
- Do not purchase items from the bulk bins unless the item is individually wrapped e.g. candy or unless the food is to be cooked.
- Do not consume the food/beverage samples in the store.
- Check that the tamper resistant seals have not been destroyed.
- Make the grocery store the last stop before going home.
- Refrigerate the necessary items when you arrive home.

Cleaning
Most food-related illnesses are caused by improper food handling. You can reduce your chances of getting food-borne illnesses or infections by properly cleaning, handling, and cooking foods, as well as controlling food temperature.

Keeping food and food preparation areas clean is an important part of preventing food from being contaminated. Keep shelves, counter tops, refrigerators, freezers, utensils, sponges, towels, and other kitchen items clean. In addition:

- Wash your hands with soap before handling food. Use warm water and wash with soap for 15 to 20 seconds, including all areas of the hands. Dry them with a clean cloth or paper towel, and turn off the faucet with a towel or paper towel.
- Wash your hands immediately after preparing raw foods.
- Use only clean utensils and work surfaces. Can openers should be washed after each use.
- Wash fresh produce thoroughly under running water before preparing them.
  - Use a clean vegetable scrubber to assure all soil has been removed from the outer skin or peel. It is important to remove bacteria from the outside and avoid transferring it to the inside flesh.
  - Be especially careful when cleaning lettuce leaves. Dirt or insects can be on the inside between the leaves. Be sure to wash each leaf well. Produce that is commercially packaged and “pre-washed” should still be washed well, following these guidelines, and discard after the “use by” date.
- Change dish cloths, sponges, and kitchen towels frequently.
- Rinse and clean the tops of cans before opening, especially beverage cans. (Avoid drinking from beverage cans.)

Food handling
- **Cutting boards** — Bacteria on raw foods can contaminate cooked foods if you use the same cutting board. To prevent contamination, use separate cutting boards for raw and cooked foods or sanitize the cutting boards thoroughly after each use. Cutting boards can be sanitized by first washing the board with warm, soapy water, then washing it again with a solution of 1 tablespoon of bleach to 4 cups of warm water. Let this solution sit on the board for 2 minutes, then rinse the board with clean, hot water. Avoid using plastic cutting boards, as they tend to harbor bacteria.
Thawing foods — Follow safe food thawing guidelines published by the U.S. Department of Agriculture. The guidelines state that there are 3 safe ways to defrost your food, which are:

- **In the refrigerator** — After thawing in the refrigerator, ground meat and poultry should remain safe for an additional day or 2 before cooking. Red meat should remain safe for an additional 3 to 5 days. Foods can be refrozen without cooking if they are defrosted in the refrigerator.

- **In cold running water** — When thawing food in cold water, be sure the food package or bag does not leak. Bacteria from the surrounding environment or air could be introduced into the food. It is necessary to check the tap water frequently to be sure it stays cold. Also, it is recommended to change the water every 30 minutes until the meat product is thawed. Foods that are thawed in cold tap water should be cooked before refreezing.

- **In the microwave** — When defrosting food in the microwave, remove the original packaging. It is important to cook the food immediately because some areas of the food might begin to cook while thawing. Foods thawed in the microwave should be cooked before refreezing.

### Cooking

Many bacteria that cause food-borne illnesses are destroyed by heat, so thorough cooking helps to prevent food-borne illnesses. Eggs and meat are especially prone to contamination.

### Food storage

- Divide leftovers into small units and store in shallow containers for quick cooling.
- Refrigerate leftovers within 2 hours of cooking.
- Discard leftovers that were kept at room temperature for more than 2 hours.
- Reheat leftovers or heat partially cooked foods to 165 degrees Fahrenheit (F) throughout before serving.
- Bring leftover soups, sauces, and gravies to a rolling boil before serving.
- Store cold foods in temperatures of less than 40 degrees F.

### Eggs

- Thoroughly cook eggs before you eat them.
- Don’t eat raw eggs or dishes made with raw eggs, such as raw cookie dough, homemade ice cream, Caesar salad dressing or eggnog.
Don’t eat eggs prepared “sunny-side up” or “over-easy,” or eggs that are runny.

You can substitute a pasteurized egg product (such as frozen pasteurized eggs or powdered egg whites) for raw eggs in most recipes.

**Meats**

1. Cook all meats and other dishes until they are well-done.
2. Avoid raw fish and seafood, such as sushi, oysters, or clams.
3. Use a meat thermometer when cooking at home to control the internal temperature of meats. The thermometer should be inserted at the thickest point in the flesh. See the chart below.

<table>
<thead>
<tr>
<th>Meat</th>
<th>Internal temperature</th>
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<tbody>
<tr>
<td>Beef</td>
<td>at least 160°F</td>
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<tr>
<td>Pork</td>
<td>at least 170°F</td>
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<tr>
<td>Poultry</td>
<td>at least 180°F</td>
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<tr>
<td>Lamb</td>
<td>at least 180°F</td>
</tr>
<tr>
<td>Fish</td>
<td>at least 160°F</td>
</tr>
<tr>
<td>Leftovers</td>
<td>at least 165°F</td>
</tr>
</tbody>
</table>

**Controlling temperature**

Bacteria grow fastest between 40° F and 140° F — a range that includes room temperature — so refrigerating foods or cooking them promptly helps prevent food-borne illnesses.

- Keep hot food hot (above 140° F).
- Keep cold food cold (below 40°F).
- Refrigerate all leftovers within 2 hours of cooking.
- Don’t save leftovers in the refrigerator for more than 2 days.
- Don’t purchase refrigerated foods after their expiration date.

**Eating away from home**

- Avoid buffets, food vendors, pot lucks and any food service where there is a question about safe food handling and preparation.
- When able, try ordering individually packaged foods, condiments, beverages, seasonings, etc to minimize the risk of bacterial contamination.
- You can 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.
- If foods are not well cooked, especially the meats, send them back.
- Ask for no garnish with the meals.

Additional guidelines are available at www.fsis.usda.gov and www.homefoodsafety.org

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
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 might notice a decrease in sexual desire after your bone marrow 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, it is common to 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 bone marrow transplant and might benefit from hormone replacement therapy to relieve menopausal symptoms.
What can I do to treat vaginal dryness?

Some women might experience vaginal dryness after bone marrow 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.

Communicate with your partner

Talk to your partner. Tell your partner how you feel, especially if you have mixed feelings about sex after your bone marrow 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 health care 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 bone marrow 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 bone marrow 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 bone marrow transplant because the medicines you will be taking might be harmful to a developing fetus. Follow your health care provider’s recommendations on the appropriate method of birth control to use.

For more information about sexuality after your bone marrow transplant, please read the booklet, "Sexuality and Cancer" provided by the American Cancer Society. A copy of this booklet is included in this manual.

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

<table>
<thead>
<tr>
<th>Type of blood pressure reading</th>
<th>Ideal blood pressure</th>
<th>High blood pressure</th>
<th>Low blood pressure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic</td>
<td>120</td>
<td>Over 140</td>
<td>90</td>
</tr>
<tr>
<td>Diastolic</td>
<td>80</td>
<td>Over 90</td>
<td>50</td>
</tr>
</tbody>
</table>

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, (allo transplant), you may be taking certain medications, such as Neoral or Prograf, that may cause high blood pressure. It is not unusual for bone marrow transplant patients to take medications to lower blood pressure (anti-hypertensives).

**When to call**

Call your health care provider if you have

- Consecutive diastolic blood pressure readings that remain in the mid-90s or higher over a 24- to 36-hour period.
- One systolic reading $\geq 160$ or $\leq 90$
- One diastolic reading $\geq 110$ or $\leq 50$

**What should I do if I have high blood pressure?**

**Hypertension** (high blood pressure)

**Symptoms**

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.

The goal of therapy, if you have high blood pressure, 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 health care provider prescribes it, and follow your health care providers directions carefully.
- Have regular blood pressure checks, and check your own blood pressure at home as recommended by your health care 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 if you have any of the following symptoms:

- Black or maroon stools
- Chest pain
- Dizziness, light-headedness
- Fainting
- Fever higher than 100.5 degrees F
- Irregular heartbeat
- Shortness of breath

**Prevention**

If you have low blood pressure, your doctor may recommend certain steps to prevent or reduce your symptoms.
This 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
- Avoid hot showers or excessive heat

A member of the Bone Marrow Transplant Team will be checking you at your follow-up appointment, a few days after your hospital discharge for low blood pressure 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 hypotension usually lasts only a few seconds or minutes. We will give you IV fluids if we find you have hypotension 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.**

**Manual blood pressure monitor**

**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.

**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.

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 above).
2. Close the airflow valve on the bulb by turning the screw clockwise until you can’t turn it in further. Make sure the valve is not closed too tightly, so that it can be opened easily with 1 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:
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.

Recording the measurement
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 putting the systolic (first) pressure reading over the diastolic (last) pressure reading.

Systolic
Diastolic

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# Daily Recordkeeping Log

In the spaces provided below, please record your daily weight, blood pressure (take and record twice a day), temperature (take and record twice a day), 24-hour intake and output (in ounces), 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.*

<table>
<thead>
<tr>
<th>Week of: (date)</th>
<th>Time</th>
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<tbody>
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<td>Weight</td>
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**DAILY MEDICATION LOG (Sample)**

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<tr>
<td>Cellcept</td>
<td>500 mg</td>
<td>9 a.m.</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td></td>
<td>500 mg</td>
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<td></td>
<td>500 mg</td>
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<tr>
<td>Prograf</td>
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<td></td>
<td>1 mg</td>
<td>8 p.m.</td>
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<tr>
<td>Liquid itraconazole</td>
<td>20mg/200mg</td>
<td>5 p.m.</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>OR itraconazole capsules</td>
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<td>✓</td>
<td>✓</td>
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<td>Prednisone</td>
<td>30 mg</td>
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<td>Neoral</td>
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<td>Antacid</td>
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<td>10 p.m.</td>
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## DAILY MEDICATION LOG

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Graft Versus Host Disease: An Overview

What is graft versus host disease?

Graft versus host disease (GvHD) is a condition that might occur after an allogeneic bone marrow transplant. In GvHD, the donated bone marrow or stem cells view the recipient’s body as foreign, and the donated cells/bone marrow attack the body.

There are two forms of GvHD:

- Acute graft versus host disease (aGvHD).
- Chronic graft versus host disease (cGvHD).

As an allogeneic transplant recipient, you might experience either form of GvHD, both forms, or neither.

Acute graft versus host disease

Risk factors

Several factors are thought to increase the development of acute GvHD. The most important factor is donor/recipient HLA (human leukocyte antigen) match, in which there are differences between you and your stem cell/bone marrow donor. The differences can cause donor cells to recognize your cells as foreign, and lead to an immune response against your tissues and organs.

Recipients who have received stem cells/bone marrow from an HLA mismatched related donor (or from an HLA matched unrelated donor) have an increased risk of developing acute GvHD.

Other donor/recipient factors that might increase the risk of developing aGvHD include:

- Differences between the sex of the donor and the recipient
- A female donor who has been pregnant in the past
- The advanced age of either the donor or the recipient

When/where it might occur

Acute GvHD might occur once the donor’s bone marrow/stem cells have engrafted in the transplant recipient. It might develop in your skin, liver, eyes, or gastrointestinal tract, and symptoms might appear within weeks after your transplant.
Diagnosis
Your BMT doctor can make the diagnosis of aGvHD during a physical exam by observing certain symptoms and/or by evaluating the results of site biopsies and lab values.

Symptoms to report
Because of the increased risk of developing infections, it is very important to report any fevers of 100 degrees or higher to your BMT Coordinator during business hours. After hours, contact the Oncology fellow on-call.

Please report any physical changes you might experience to your BMT Team. Symptoms of acute GvHD might include any of the following:

- Skin rash or reddened areas on the skin (signs of aGvHD of the skin) — Please report if your skin is itchy.
- Yellow discoloration of the skin and/or eyes, and abnormal blood test results (signs of aGvHD of the liver)
- Nausea, vomiting, diarrhea, or abdominal cramping (signs of aGvHD in the gastrointestinal tract, or “gut”)
- Increased dryness/irritation of the eyes (signs of GvHD of the eyes)

Treatment
If aGvHD occurs, your doctor will discuss available treatment options with you and your family. Many patients are successfully treated with increased immnosuppression in the form of oral or intravenous steroid medicines.

Chronic Graft versus Host Disease

Risk factors
Some doctors believe that cGvHD is a later phase of aGvHD, while others believe it is a separate condition that is similar to an autoimmune process.

Patients who have an increased risk of developing cGvHD are those who have received stem cells/bone marrow from an HLA (human leukocyte antigen) mismatched related donor or from an HLA matched unrelated donor, patients that may have already experienced acute GvHD, and older recipients.

When/where it might occur
Chronic GvHD can appear at any time after bone marrow transplant or several years after your transplant. Chronic GvHD might occur in the skin, liver, eyes, mouth, lungs, gastrointestinal tract, neuromuscular system, or genitourinary tract.

Diagnosis
Your BMT doctor might be able to make the diagnosis of cGvHD during a physical exam by observing certain symptoms and/or by evaluating the results of site biopsies and lab values.

Some symptoms of cGvHD might be very vague, which might make the diagnosis possible only after other causes are excluded.

Symptoms to report
Because of the increased risk of developing infections, it is very important to report any fevers of 100 degrees or higher to your BMT Coordinator during business hours. After hours, contact the Oncology fellow on-call.

Please report any physical changes you might experience to your BMT Team. Symptoms of chronic GvHD might include any of the following:

- Rash, raised, or discolored areas, skin thickening or tightening (signs of cGvHD of the skin)
- Abdominal swelling, yellow discoloration of the skin and/or eyes, and abnormal blood test results (signs of cGvHD of the liver)
- Dry eyes or vision changes (signs of cGvHD of the eyes)
- Dry mouth, white patches inside the mouth, pain or sensitivity to spicy foods (signs of oral cGvHD, of the mouth)
- Shortness of breath or changes seen on your chest X-ray (signs of pulmonary cGvHD — of the lungs)
- Difficulty swallowing, pain with swallowing, or weight loss (signs of cGvHD of the gastrointestinal tract or “gut”)
- Fatigue, muscle weakness, or pain (signs of neuromuscular cGvHD, of the nerves and muscles)
Increased need to urinate (urinary frequency), burning or bleeding with urination, vaginal dryness/tightening, or penile dysfunction (signs of cGvHD of the genitourinary system, bladder, or sexual organs)

**Treatment**
If cGvHD occurs, your doctor will discuss available treatment options with you and your family. Long-term immunosuppressive medicines are usually the treatment regimen for cGvHD. Fungal, bacterial, and viral infections are a major risk with this treatment option since your immune system will be suppressed for a very long time. Your doctor will prescribe several medicines to help prevent these life-threatening infections from occurring.

**Prevention**
Tissue typing labs have been developing and using more precise DNA level tests to enable your Bone Marrow Transplant Team to select the best HLA matched donor for you.

We try to lower your risk of developing GvHD by giving you preventive (prophylactic) immunosuppressive medicines after your bone marrow transplant. These medicines will decrease the ability of your donor’s T cells to start an immune response against your own tissues.

Fungal, bacterial, and viral infections are major risks with this prophylactic medicine regimen, since your immune system will be suppressed and have a decreased ability to fight infection.

**Research**
New, and hopefully better, methods to prevent GvHD are being studied in clinical trials. The use of photopheresis, different immunosuppressive drugs, and new monoclonal antibodies given to recipients after transplant, as well as methods to remove donor T cells prior to transplant, are examples of some of that research.

**IMPORTANT NOTE**
While GvHD can deeply impact your quality of life, it does have some benefit. The same immune response responsible for attacking your normal cells is also monitoring and destroying any surviving cancer cells. This is called the graft versus tumor effect. Patients who develop GvHD have lower disease relapse rates.
Graft Versus Host Disease of the Eyes

GvHD of the eyes is one of the risks associated with an allogeneic bone marrow transplant. In GvHD of the eyes, the donated bone marrow or stem cells (called the graft) view the recipient's body as foreign, and the donated cells/bone marrow attack the eyes (the host).

Symptoms of GvHD of the Eyes

Symptoms of GvHD of the eyes might include any of the following, and you should report them to your bone marrow transplant coordinator as soon as you notice them:

- Burning eyes
- Dry eyes
- “Gritty” feeling in the eyes
- Blurred vision
- Increased sensitivity to light
- Excessive tearing

In patients that have GvHD of the eyes, the tears produced are not effective at moisturizing the eyes. The severe dryness can be very uncomfortable and can make reading or watching television difficult.

If left untreated, GvHD of the eyes can cause permanent damage to eye tissues, scarring of the cornea and impairing vision.

NOTE: If you are experiencing any of these symptoms, wearing contact lenses is not recommended.

Diagnosis

To detect the development of GvHD of the eyes, each bone marrow transplant (BMT) patient is monitored closely throughout the BMT process. This monitoring includes regular physical exams during which certain symptoms are evaluated, and blood tests and diagnostic tests are performed.

If you have any symptoms of GvHD of the eyes, please report them to your Bone Marrow Transplant Team. Your bone marrow transplant doctor will perform a physical exam and will refer you to an ophthalmologist (eye specialist). A test to detect tear production, called a Schirmer's test, might be performed. During this test, a small strip of treated paper might be placed against the white of your eye to determine if your eyes are producing tears.
Treatment

If GvHD of the eyes is diagnosed, the ophthalmologist will discuss available treatment options with you and your family. Your treatment plan will be adjusted.

You might already be taking immunosuppressive drugs [such as cyclosporine, (Neoral®) or tacrolimus (Prograf®)] to prevent the onset of GvHD. These medicines might be changed to treat your condition.

To treat your dry eye condition, artificial tears or ointment might be recommended to keep your eyes moist. If these treatments are prescribed, here’s how to give yourself eye drops or ointment:

- Wash your hands with soap and warm water. Dry them with a clean towel.
- Use a mirror.
- Look up to the ceiling with both eyes.
- Pull the lower lid of your eye down with one hand. Hold the eye drops bottle in your other hand. (Rest part of your hand on your forehead if necessary to keep it steady.)
- Place a drop inside your lower lid. The tip of the bottle should not touch your eye.
- Close your eyes for a minute after putting in the drop.
- If you are prescribed both eye drops and eye ointment, use the eye drops first.
- If you have more than 1 eye medicine to put in your eyes, wait about 5 minutes after the first medicine before putting in the second medicine.

Another treatment method for dry eyes is called “Temporary punctal occlusion,” in which the ducts that drain tears out of the eyes are temporarily plugged to determine whether permanent “plugs” can provide an adequate supply of tears. If the temporary procedure works well, a permanent procedure will be performed during which silicone is used to keep the tears from draining so they can lubricate the eyes properly.

Symptom management

To manage the symptoms of eye Graft versus Host Disease, follow these guidelines:

- Wear protective eyewear to shield your eyes from the wind. Many sunglasses are now available in a “wraparound” style.
- Point car vents away from your eyes and point heating and cooling ducts away from the areas in which you spend a lot of time (especially in the bedroom).
- Remind yourself to blink more frequently when you are working on your computer or watching TV.
- Keep the air moist indoors when the furnace is on.
- Avoid the use of a hairdryer as much as possible.

Notify your nurse coordinator before using any over-the-counter medicines to relieve dry eye symptoms.

Early detection and prevention

To detect eye problems early and to prevent eye problems from becoming worse, visit your eye care specialist at least once per year. At an annual visit, your eye care specialist will check your corrective lens prescription (eyeglasses or contact lenses) and your overall eye health.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Graft Versus Host Disease 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 bone marrow transplant. In GvHD of the liver, the donated bone marrow or stem cells (called the graft) view the recipient’s body as foreign, and the donated cells/bone marrow attack the liver (the host).

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 bone marrow transplant (BMT) patient is monitored closely throughout the BMT process. This monitoring includes regular physical exams — during which certain symptoms are evaluated — blood tests, and diagnostic tests.

Symptoms
Symptoms of GvHD of the liver might 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
- Yellow discoloration 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 might be diagnosed with these tests:

- Blood tests are done to measure the liver enzymes and proteins produced by the liver.
- Imaging tests — such as an ultrasound and/or CT scan — are done to provide a picture of the liver, its vessels and bile ducts, and to determine if there is an obstruction.
- A liver biopsy is done 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 might also increase your risk of developing osteoporosis, cataracts, or joint problems such as hip avascular necrosis. 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 Tylenol® that can cause additional stress to your liver.

Notes

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Notes

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Graft Versus Host Disease of the Skin

Graft versus host disease (GvHD) of the skin is one of the risks associated with an allogeneic bone marrow transplant. In GvHD of the skin, the donated bone marrow or stem cells (called the graft) view the recipient’s body as foreign, and the donated cells/bone marrow attack the skin (the host).

What is acute graft versus host disease of the skin?
Acute graft versus host disease (aGvHD) of the skin might occur once the donor’s bone marrow/stem cells have engrafted in the transplant recipient.

The skin is often the first organ affected by graft versus host disease and can occur any time after engraftment.

Symptoms of aGvHD
Symptoms of aGvHD of the skin might include any of the following. Report them to your bone marrow transplant coordinator as soon as you notice them:

- Reddened and raised rash
- Sunburn-like appearance that might be itchy and warm to the touch
- Reddened palms of the hands or soles of the feet that can be painful

These skin symptoms might also be caused by chemotherapy, drug allergies, or by viral infections.

What is chronic graft versus host disease of the skin?
Chronic graft versus host disease (cGvHD) of the skin can appear at any time after bone marrow transplant or several years after your transplant.

Symptoms of cGvHD
Symptoms of cGvHD of the skin might include any of the following. Report any of these symptoms to your bone marrow transplant coordinator as soon as you notice them:

- Dry, itchy rash
- Raised skin lesions (sores)
- Darkening of the skin
- Mottling (blotchiness)
- Redness
- Severe thickening or tightening of the skin that limits mobility
- Decreased or absent perspiration (because the sweat glands aren’t functioning properly)
- Possible thinning of body hair and nail loss
**Diagnosis**

To detect the development of GvHD of the skin, each bone marrow transplant (BMT) patient is monitored closely throughout the BMT process. This monitoring includes regular physical exams during which certain symptoms are evaluated and blood tests and diagnostic tests are performed.

If you have any symptoms of GvHD of the skin, please report them to your Bone Marrow Transplant Team. Your bone marrow transplant doctor will perform a physical exam and might be able to make a diagnosis, based on your symptoms.

If your doctor is unsure about the cause of your skin problem, he or she might refer you to a dermatologist for a test called a “punch” biopsy of the affected area.

During this test, a local anesthetic (pain-relieving) medicine will be applied to numb the area and then a small sample of tissue on the affected area will be removed and evaluated under a microscope in the Pathology laboratory. The biopsy area will be closed with 1 or 2 stitches that will be removed in about 10 days. You will need to keep the area clean and dry. This procedure is usually quick and painless.

If certain characteristics are present in the skin sample, a diagnosis of GvHD of the skin can be made.

**Treatment**

If GvHD of the skin is diagnosed, your doctor will discuss available treatment options with you and your family. Your treatment plan will be adjusted. You might already be taking immunosuppressive drugs [such as cyclosporine, (Neoral®) or tacrolimus (Prograf®)] to prevent the onset of GvHD. These medicines might be changed to treat your condition.

Steroid treatment for both acute and chronic GvHD usually begins once the diagnosis is made. Oral or intravenous steroids might be given. Steroids help suppress the immune system and decrease its ability to recognize the skin cells as foreign.

Other medicines that might be used to treat GvHD include mycophenolate (CellCept®), thalidomide, ATG, and experimental monoclonal antibodies.

Your doctor might recommend treatment procedures such as photopheresis or total lymphoid irradiation. These procedures will be explained to you in more detail if your doctor recommends these treatments.

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 might also increase your risk of developing osteoporosis, cataracts, or joint problems such as hip avascular necrosis. 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**

Skin graft versus host disease often causes dry, itchy skin. You can help decrease the discomfort of this symptom by keeping your skin well-moisturized. Drink plenty of fluids, apply Vaseline (petroleum jelly) to your lips, bathe with a non-drying soap such as Aveeno®, apply moisturizing lotion to your skin several times each day, and avoid all sun exposure, which can cause increased skin damage. Your BMT doctor might prescribe topical steroid medicine to apply to your skin.

**Skin GvHD and UV Sun Exposure**

UV ray sun exposure can be harmful to the skin, causing sunburns and/or skin cancers. Also, UV ray exposure to those who have had an allogeneic bone marrow transplant can trigger or worsen skin GvHD. It is recommended to wear a hat, long sleeves, long pants, and sunscreen with at least a SPF of 45 if you are outside in the sun. However, avoiding sun exposure is the best prevention. Please note that even on cloudy days, skin exposure to UV rays still occurs; therefore, precautions should still be taken.
Graft Versus Host Disease of the Gastrointestinal (GI) Tract

What is graft versus host disease of the gastrointestinal tract?

Graft versus host disease (GvHD) of the gastrointestinal (GI) tract is one of the risks associated with an allogeneic bone marrow transplant. In GvHD of the GI tract, (also referred to as the “intestines” or the “gut”), the donated bone marrow or stem cells (called the graft) view the recipient’s body as foreign, and the donated cells/bone marrow attack the GI tract (the host).

Symptoms

Report these symptoms of GvHD of the GI tract to your nurse coordinator as soon as you notice them so the proper diagnosis can be made and prompt treatment can be started:

- Increased nausea
- Severe diarrhea (The stools are usually green and watery, but blood might also be present in the stool in more severe cases.)
- Extreme weight loss
- Abdominal cramping and bloating

Later signs of GvHD of the GI tract might include:

- Decreased saliva causing dry mouth, difficulty swallowing, or mouth sores
- Chronic loose stools

Diagnosis

To detect GvHD of the GI tract, each bone marrow transplant (BMT) patient is monitored closely throughout the BMT process. This monitoring includes regular physical exams during which certain symptoms are evaluated, and blood tests and diagnostic tests are performed.
If you have any of the symptoms of GvHD of the GI tract, please report them to your BMT Team. Your bone marrow transplant doctor will perform a physical exam and might refer you to a gastroenterologist, a doctor who specializes in treating conditions of the GI tract.

The gastroenterologist will need to take a biopsy (tissue sample) of the area that is suspected of causing symptoms. The biopsy is performed during one of these procedures:

- **Colonoscopy** is an outpatient procedure during which the rectum and the inside of the lower large intestine (colon) are examined. During a colonoscopy, a doctor uses a colonoscope (a long, thin, flexible instrument about 1/2 inch in diameter) to view the lining of the colon. The colonoscope is inserted through the rectum and advanced to the large intestine.

- **Upper endoscopy (EGD)** is an outpatient procedure during which the inside of the upper digestive system is examined. During the procedure, a doctor uses an endoscope (a long, thin, flexible instrument about 1/2 inch in diameter) to examine the inside of the upper digestive system. The endoscope is inserted through the esophagus (the “food pipe” leading from your mouth into your stomach) and into your stomach.

The results of the biopsy might take several days to be evaluated and reported to your BMT doctor.

**Treatment**

If the diagnosis of GvHD of the GI tract is confirmed, your doctor will monitor your symptoms to make sure the condition is not getting worse. Some of the tests that might be performed to monitor your symptoms include a stool volume test, and an evaluation of the color and consistency of stool. You will be asked questions about the severity of your symptoms, especially nausea and abdominal cramping. Your doctor will also monitor your nutritional status to make sure you are not developing any deficiencies.

When the diagnosis of GvHD of the GI tract is confirmed, your doctor will discuss available treatment options with you and your family. The treatment you receive for GvHD of the GI tract will be determined by the severity of your symptoms.

Many patients are successfully treated with outpatient steroid therapy (prednisone, methylprednisolone) to suppress your immune system and reduce symptoms.

If your symptoms (weight loss, nausea, diarrhea, or cramping) worsen, inpatient treatment might be necessary. In the hospital, you will receive higher doses of steroids and IV hydration to prevent dehydration.

As a result of gastrointestinal GvHD, you lose important nutrients and protein, leading to malnourishment. One way to determine nutritional deficiencies is with blood work measuring total protein and albumin. Albumin helps to maintain the fluid in your veins. If your albumin level drops, the fluid will escape from your veins into your tissue, causing severe swelling, especially in your legs. This can be very uncomfortable, but is not permanent.

IV nutrition (called total parenteral nutrition or TPN) is given to help treat these nutrition deficiencies. During this time, you will not be allowed to eat or drink anything, which gives your GI tract a chance to heal.

Although TPN provides nutrients, it is not as effective as real food. When your transplant doctor determines your symptoms are under control, you will be taught to slowly introduce liquids and food into your diet. If your intestinal tract is not quite ready for liquid and food, your symptoms might return. If this happens, you might need to “rest your gut” a little longer. For this period of time, TPN will be your only source of nutrition.
If your volume of diarrhea is under control and you can tolerate pills but not food, the Transplant Team will begin to prepare you to go home. They do this by “cycling” your TPN. This means the TPN is infused while you sleep. After discharge, your BMT doctor will continually monitor your nutritional status and allow you to slowly reintroduce liquids and food. A homecare nurse will be actively involved in instructing you on home TPN.

If your GI tract tolerates reintroduction of liquids and foods, you might be able to discontinue TPN prior to being discharged. A dietician will be available to instruct you on following a “GvHD diet”: bland food, no dairy, no fresh fruits or vegetables, no citrus, and no caffeine. He or she will also help you with developing meal plans.

The recovery period from GvHD of the GI tract can be very slow and frustrating. Your hospitalization might be lengthy, but remember the goal is to return you to eating a normal diet. Try not to become discouraged. Refer to the “Nutritional Guidelines for GvHD” section.
This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.
Nutrition Guidelines for GvHD

After your bone marrow transplant, you might experience nausea, diarrhea, bloating, gas, or cramps after eating. These are all common symptoms caused by graft versus host disease (GvHD). GvHD is a condition that might occur after an allogeneic bone marrow transplant. In GvHD, the donated bone marrow or stem cells view the recipient's body as foreign, and the donated cells/bone marrow attack the body.

GvHD often affects the intestines. The guidelines in this handout might help you avoid irritating your intestines while they are healing from the GvHD.

“Trial of solids”

Before starting a solid GvHD diet, you will likely start with the GvHD clear liquid diet, avoiding citrus and caffeine. If this diet is tolerated, your doctor will determine when it is appropriate for you to begin a trial of solid food.

The “trial of solids” is usually started while in the hospital. It consists of foods that are lactose-free, low-fat, low-acid, low-fiber, and low in gastric irritants (i.e. chili, chocolate). The dietitian will meet with you prior to beginning solid food to explain the GvHD diet and to help you pick one new solid food for each of the next 3 meals. Each day of your trial, the dietitian will meet with you to evaluate your tolerance to the meals you’ve eaten. You may add one new solid food to all of the trialed foods that were tolerated. You will continue on this trial until your doctor tells you otherwise. If you have difficulty with this diet after you are at home, please let your BMT Coordinator know. She will arrange an appointment with a dietitian in the outpatient department.

The following guidelines for the solid GvHD diet should be followed to avoid gastrointestinal (GI) distress (i.e. nausea, vomiting, diarrhea) and to help assure your nutritional needs are being met.

SPECIAL INSTRUCTIONS – THE GvHD SOLID DIET

1. Try to eat the minimum number of servings from each food group in at least 5 to 6 small meals each day. Eating enough of a variety of foods is very important to the healing process.

2. Take a vitamin with minerals supplement each day until you are eating all foods again. Check with your doctor to see if your multivitamin should be without iron.
3. Avoid any foods that cause gastrointestinal upset (such as abdominal cramps, gas, bloating, nausea, diarrhea, and vomiting) or foods that you cannot tolerate. Please call your dietitian if you have a question about a food.

4. GvHD often causes lactose intolerance. Lactose intolerance is the inability to digest lactose, the sugar primarily found in milk and dairy products. Lactose intolerance is caused by a shortage of lactase in the body. Lactase is an enzyme produced by the small intestine that is needed to digest lactose. **Do not drink milk or eat dairy products.**

Initially, when started on a GvHD solid diet, it is recommended you follow a lactose-free diet due to the compromised gastrointestinal (GI) tract. Once you tolerate the solid diet for about 4 to 6 weeks (with minimal or no GI symptoms such as abdominal pain, nausea, vomiting, loose stools, etc.), you might be able to find a level of foods containing lactose that will not produce symptoms. **Contact your doctor or dietitian prior to adding lactose back into your diet.**

If, as you add dairy products back into your diet, you get symptoms from small amounts of lactose or have difficulty limiting your intake of foods containing lactose, lactase enzyme replacements (such as Dairy Ease® or Lactaid®) can be used to help tolerate the lactose in dairy. These enzyme replacements are available over the counter and come in liquid form to add to milk or in tablet form that can be taken when eating solid food containing lactose. Lactose-reduced milk and cheese, and other lactose-reduced dairy products are also available at many supermarkets. **Contact your dietitian with questions.**

5. Do not eat the following because they might cause symptoms of GvHD (i.e., nausea, vomiting, diarrhea, abdominal cramping, and bloating):

   - Fried or greasy foods
   - High fiber foods, including whole grains, raw fruits, and vegetables
   - Gas-producing foods, including cabbage, broccoli, cauliflower, and beans
   - Beverages containing caffeine, such as coffee, tea, or colas
   - Citrus foods or juices such as orange, grapefruit, lemon, or lime
     *(Your daily vitamin with minerals supplement should supply 100% of your daily Vitamin C.)*
   - Alcoholic beverages and drinks
   - Chocolate, pepper, chili powder, cumin, garlic, nutmeg, curry, tobacco, catsup, chili sauce, mustard, and horseradish

6. As you begin to heal and feel better, you might begin to eat some of the foods listed above that you were able to tolerate in the past. Try only one new food per day. If it bothers you, continue to avoid it for a few more weeks before trying it again.

7. If you experience diarrhea or GI distress from foods allowed on the GvHD diet, such as bacon or creamy peanut butter, you might have an intolerance to fat. Discuss these symptoms related to higher fat foods with your doctor or dietitian. A low-fat diet might be appropriate for you.

8. The meal plan for GvHD outlined on the next few pages contains about 2500 calories and 110 grams of protein.

   Your calorie needs are about
   ________________________________

   Your protein needs are about
   ________________________________ grams.

   If your calorie or protein needs are higher than this meal plan, your dietitian will instruct you to choose from the section labeled “Supplements” to add the additional calories and protein you need daily.
**GRAIN GROUP**

**Foods to Choose**

**6 or more servings each day**

- White, French, Italian, sourdough, or refined corn breads and rolls without seeds
- Plain bagels or English muffins
- Graham, saltine, or animal crackers
- Macaroni, noodles, and pasta made from refined flour
- White rice
- Couscous
- Corn or flour tortillas
- Pretzels
- Pancakes/Waffles
- Cooked cereals including Cream of Wheat, Cream of Rice, grits, farina, and ready-to-eat cereals that do not contain coarse grains or bran, dried fruits, coconut, or nuts

**Foods to Avoid**

- Whole grain breads, rolls, and crackers including rye, pumpernickel, or whole wheat
- Breads, rolls, and crackers that contain seeds, dried fruits or nuts
- Brown rice
- Oatmeal and all coarse whole grain cereals such as Shredded Wheat, bran cereals, granola-type cereal, or cereals with nuts, dried fruit, and coconut
- Macaroni, noodles, and pasta made with whole grain flours
- Doughnuts and pastries

**MEAT GROUP**

**Foods to Choose**

**3 or more 3-ounce servings each day**

Examples:

- Tender cuts of chicken, turkey, fish, beef, veal, pork, and lamb
- Canned tuna and seafood
- Crisp bacon, ham
- Eggs (may be hard-cooked, poached, scrambled, or pan-cooked using margarine or vegetable oil spray)
- Casseroles and soups using allowed foods only
• Creamy peanut butter
• Tofu

**NOTE:** Meat and meat substitutes may be baked, broiled, roasted, or boiled, NOT fried. Trim off the extra fat. Use a non-stick pan and a vegetable oil spray instead of frying meats.

**Foods to Avoid**

• Fried meat, fish, or poultry
• Luncheon meats, including bologna, salami, and pepperoni
• Heavily seasoned or smoked meats and fish, including hot dogs, sausage, kielbasa, corned beef, dried beef, or pickled herring
• Crunchy peanut butter
• Tomato or bean soup
• Chili

**FRUITS AND FRUIT JUICES**

**Foods to Choose**

2 or more ½ cup servings each day

Examples:
• Fruit juices such as apple, grape, cranberry, fruit punch (if made with allowed juices)
• Peach, pear, and apricot nectars
• Canned and peeled fruits: peaches, pears, apricots, applesauce, cherries, nectarines, plums, and fruit cocktail (without the pineapple)
• Apple (baked and peeled)
• Cranberry sauce and cranberry jelly (not whole cranberry sauce)
• Banana

**NOTE:** These fresh fruits may be eaten raw only if they are ripe, easy to chew, and peeled: banana, peaches, pears, apricots, and melon (cantaloupe, honeydew, or watermelon).

**Foods to Avoid**

• Orange, grapefruit, lemon, lime juice
• Prune juice
• Tomato juice
• Raw apples, grapes, pineapples, or figs
• Canned or fresh berries such as strawberries, raspberries, blackberries, or blueberries
• Fresh and canned grapefruit, orange, and other citrus fruit
• Dried raisins, dates, and prunes
• Coconut
**VEGETABLES**

**Foods to Choose**

3 or more ½ cup servings each day

Choose from these well-cooked and tender* vegetables:

- Beets, green beans, carrots, spinach, mushrooms, asparagus, de-veined celery, pumpkin, winter squash, and waxed beans

*A vegetable is considered tender if you can easily cut it with the side of the fork.

- Baked, mashed, or boiled potatoes: white, yams, or sweet. Do not eat the skin.

**Foods to Avoid**

- All raw vegetables. Do not eat these raw or cooked vegetables: cabbage, cauliflower, broccoli, Brussels sprouts, sauerkraut, corn, peas, eggplant, artichokes, bamboo shoots, rutabagas, turnips, lima beans, tomatoes, summer squash, lettuce, onions, parsley, chives, greens, bean sprouts, or rhubarb
- Lentils, beans, legumes.
- Fried potatoes or potato skins, potato chips

**MILK AND DAIRY**

**Foods to Choose**

3 or more cups each day

Examples: low-lactose or lactose-reduced milk, non-dairy creamer, lactose-free milk substitutes.

**Foods to Avoid**

Dairy products including milk, yogurt, cheese, and cottage cheese
**BEVERAGES**

**As Desired, Choose:**

- Caffeine-free carbonated beverages such as ginger ale, lemon-lime soda, and fruit-flavored sodas
- Fruit-flavored drinks (made from allowed juices)
- Decaffeinated coffee or tea

**Avoid**

- Beverages made with milk such as hot chocolate or chocolate milk
- Alcoholic beverages
- Regular coffee and tea
- Beverages containing caffeine such as colas and some lemon-lime sodas
- Cocoa
- Peppermint tea

**FATS**

**As Tolerated in Moderation, Choose:**

- Vegetable oil
- Mayonnaise
- Non-dairy cream substitutes

- Margarine
- Shortening
- Salad dressings with allowable ingredients

**Avoid:**

- Butter, cream, sour cream, cream cheese, and whipping cream

**DESSERTS**

**As Desired, Choose:**

- Plain cake with frosting (no chocolate)
- Angel food cake
- Gelatin
- Fruit ice, popsicles
- Plain cookies such as vanilla wafer, shortbread or sugar cookies
- Apple, peach, or cherry pie (made from allowable ingredients)

**Avoid:**

- Desserts made with dried fruits, nuts, seeds, chocolate, coconut or milk — including pudding, ice cream, frozen yogurt, and sherbet
**SUPPLEMENTS**

**Avoid**

- Breakfast drinks
- Milk shakes and puddings (unless labeled lactose-free)

**Notes:**

- Ask your dietitian which supplements would be best for you, where to purchase them and how often to take them.
- Choose from plain or fruit-flavored, lactose-free supplements

**MISCELLANEOUS FOODS**

**As Desired, Choose:**

- Gum drops
- Honey, syrups
- White or brown sugar
- Salt
- Herbs including basil, bay leaf, oregano, thyme
- Broth base soups with permitted meats and vegetables
- Hard candy, jelly beans
- Clear jelly
- Marshmallows
- Vinegar

**Avoid**

- Candy with nuts
- Chocolate
- Coconut or dried fruits
- Pepper, chili powder, cumin, garlic, nutmeg, and curry
- Nuts
- Pickles
- Popcorn
- Jams or jellies with seeds and skins
- Tabasco® sauce
- Fried snack foods including corn chips and potato chips
- Condiments including catsup, chili sauce, mustard, and horseradish
- Cream soups
BREAKFAST
1 poached egg
½ cup apple juice
2 slices toasted Italian bread
2 tsp. margarine
1-cup lactose-free milk

MORNING SNACK
2 Tbsp. creamy peanut butter
6 plain crackers

LUNCH
2 slices white bread with 3 ounces turkey
½ cup peeled and canned peaches
½ cup well-cooked carrots
1 tsp. margarine
1 Tbsp. mayonnaise
1 cup lactose-free milk

AFTERNOON SNACK
1 ripe and peeled banana
6 vanilla wafers

DINNER
3 ounces broiled fish
½ cup mashed potatoes
(made with low lactose milk)
½ cup well-cooked green beans
2 tsp. margarine
fruit-flavored soda

EVENING SNACK
1 slice bread with 2 ounces roast beef
1 cup lactose-free milk
1 Tbsp. mayonnaise