

# **ALLOGENEIC BLOOD AND MARROW TRANSPLANTATION**

## **A PATIENT AND CAREGIVER GUIDE**

## Welcome

On behalf of a dedicated group of professionals, I would like to welcome you and your family and caregivers to the Blood and Marrow Transplant Program at NYU Langone Health's Perlmutter Cancer Program.

We feel privileged that you have chosen us to provide you with the care you need. Our goal is to make sure you receive the best possible care in an environment where you feel safe and where you are treated with the upmost consideration and respect.

We look forward to working with you. We know that this time can be exciting and overwhelming for you and your family. Our team is committed to providing you with quality care based on your individual needs. Our multi-disciplinary team will guide you through the pre-transplant, transplant and post-transplant periods.

This education book is intended to act as a reference for you, your family and your caregivers. Education is a powerful tool and we want to ensure you understand each step of the transplant process. We are here as your partner in health and look forward to helping you reach your goals. Your role is equally important. Therefore, we invite you to be as engaged as possible. The success of your transplant depends on it.

We work daily to improve our services, guided by your feedback. I appreciate hearing from you throughout your transplant course. Please contact me with any feedback you may have.

We appreciate your trust in our Transplant Team on this journey. Remember, you are never alone.

Sincerely,

A. Samer Al-Homsi MD, MBA

Director, Blood and Marrow Transplantation Program



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## **Transplant Team**

The Transplant Team is a specially trained group of individuals from multiple specialties that work together to provide comprehensive care to the patient, family and caregivers.

### **Physicians**

Our doctors are trained in hematology and specialize in the field of transplantation. They will see patients prior to transplant, during the transplant stay and after discharge. You may or may not see your specific transplant doctor during your hospital stay but they will continue to be an active member of your team and involved in your care.

### **Advanced Practice Providers (APPs)**

APP refers to both Nurse Practitioners (NP) and Physician's Assistants. APPs work with your transplant doctor throughout the transplant process.

### **Transplant Coordinators**

Transplant coordinators are nurses who help you, your family and your caregivers navigate through the transplant process. This includes arranging necessary tests and procedures for all patients considering transplant and potential donors prior to transplant. They will provide education to you, your family and your caregivers about pre-transplant evaluation, donor search, HLA typing, the transplant process (including your hospital stay) and long-term follow-up care.

### **Social Workers**

A social worker will meet with you, your family and caregivers prior to transplant to discuss concerns you may have about your transplant and your personal situation. Social workers provide education, discuss lifestyle changes and coping and social support throughout the transplant process. It is important that you have good support throughout this process and the social worker will help you to identify this support and make sure you have a plan prior to proceeding with transplant. While hospitalized, a social worker will also provide psychosocial support.

### **Pharmacists**

In coordination with your physician and/or APP, the pharmacist will adjust your medications and their doses. Along with other members of the Transplant Team, they will provide you education about your medications.

### **Registered Nurses (RNs)**

Provide care for patients, both in the hospital and in the clinic. RNs work with the Transplant Team to deliver your plan of care. RNs perform assessments, administer medications, provide education and help to prepare you for discharge.

### **Dietitian**

Registered dietitians (specialists in nutrition) will meet with you prior to transplant to provide education and support. They will also be seeing you in the hospital and after discharge, as needed.

## **Financial Counselor**

Financial counselors work with your insurance provider to obtain approval for transplant services before you have your transplant. They work with you and the Transplant Team to determine what your insurance and benefits will cover.

## **Physical Rehabilitation Specialists**

This includes both physical therapists and occupational therapists. Physical therapy is a process used to help increase your mobility (movement) and function. Occupational therapy is a process used to help improve or restore your ability to perform your daily activities. Mobility and function can be altered by disease, treatment and deconditioning, among other causes. Our rehabilitation specialists are here to help you to set and reach your goals.

## **Integrative Health Professionals**

Integrative health uses conventional treatment together with complementary approaches to improve your care. Complementary approaches may include relaxation techniques, breathing, imagery, tai chi, movement therapy, amongst many others.

## **Chaplain Services**

Chaplain services are available to provide comfort and support, spiritual guidance, prayers, blessings, rituals, and may help you connect with other resources.

## **Palliative Care Specialists**

Palliative care is provided by team of doctors, nurses and other specialists, designed to reduce stress and symptoms from illnesses. The goal of their involvement in your care is to ease your burden symptoms of your illness or treatment.

There are many members of the Transplant Team working with you and behind the scenes to ensure the transplant process is smooth and seamless, based on your individual needs.

## Terms

Throughout transplant, you will become accustomed to hearing many terms. Below are frequently used terms and their meaning.

Absolute Neutrophil Count (ANC)	The total number of neutrophils. Neutrophils are part of your white blood count (WBC). These are important because they are the first line of defense against infections.
Allogeneic Transplant	A type of transplant where the patient (also call the recipient) get their transplant from a donor or someone other than themselves.
Alopecia	Hair loss, this can be partial or complete.
Anemia	A deficient number of red blood cells.
Apheresis	A process by which hematopoietic progenitor cells (HPC), stem cells or donor lymphocytes are collected via the bloodstream.
Autologous Transplant	A type of transplant where the cells are the patient (also called recipient) gets their own cells; they donate to themselves.
Bone Marrow	The spongy tissue inside of bones where blood cells are made.
Bone Marrow Harvest	The procedure done to collect the HPC or stem cells from the bone marrow.
Bone Marrow Transplant	The process of receiving HPC or stems cells after receiving a conditioning regimen.
Central Line	A line that allows for access to the bloodstream. It is used to give the patient their conditioning regimen, HPC or stem cells and medications, as needed. It is also used to draw blood from for lab tests.
Chemotherapy	Drugs used to eliminate cancers cells and to suppress or eliminate the bone marrow.
Conditioning Regimen	A combination of chemotherapy, immunosuppressive agents and/or radiation that get the patient's (recipient's) body ready to for transplant.
Colony Stimulating Factor	A medication (usually an injection) to increase the stem cells or white blood cells. This is also called growth factor, G-CSF, filgrastim or Neupogen®
Confirmatory Typing	A DNA (genetic information) test done in allogeneic transplant to check the patient and donor match. See Human leukocyte antigen (HLA).

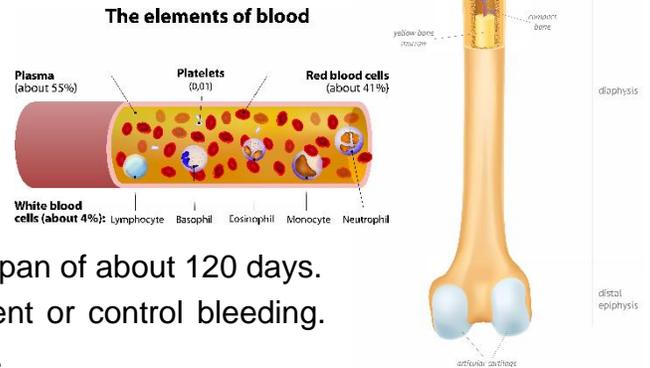
Cord Blood	Blood cells from newborns' umbilical cord that contain a large amount of HPC or stem cells.
Cytomegalovirus (CMV)	A virus that many people carry but may cause more problems when the patient is immune-compromised.
Dehydration	When the body loses too much water to work well. Severe vomiting or diarrhea may cause dehydration.
Donor	A person who gives HPCs or stem cells for a recipient of a transplant.
Engraftment	After transplant, when the HPC or stem cells begin to produce new cells, such as, white blood cells, red blood cells and platelets.
Graft Failure	A complication after transplant when the HPC or stem cells fail to engraft or are lost over time.
Graft versus Host Disease (GvHD)	A response, in allogeneic transplants, where the donor's HPCs (stem cells) attack the patient's (host or recipient) cells or body.
Graft versus Tumor Effect (GvT)	A response, in allogeneic transplants, where the donor cells attack and fight the recipient's cancer.
Hematopoiesis	The formation of blood cells.
Hematopoietic Progenitor Cells (HPC)	Stem cells capable of producing what makes up the blood and marrow.
Human Leukocyte Antigen (HLA)	Proteins on cells that make each person different.
HLA Typing	A test done to look a recipient and/or donor's DNA. Used to determine best donor for the recipient.
Immuno-compromised	A reduced ability to fight infections because the immune system is weakened.
Lymphocytes	A type of white blood cell that identifies organism that are foreign to the body.
Mobilization	The process of moving HPC or stem cells from the bone marrow to the blood stream (also called peripheral blood).
Myeloablative Conditioning	A type of transplant that uses high doses of chemotherapy to destroy your bone marrow and any remaining cancer cells.
National Marrow Donor Program	NMDP. An organization that manages a registry of volunteer donors.
Neutropenia	A low neutrophil count.

Non-myeloablative Conditioning	A type of conditioning regimen that uses a less aggressive chemotherapy and/or radiation therapy to prepare you for transplant.
Peripheral Blood Stem Cells (PBSC)	A source of HPCs that are obtained from the blood stream.
Platelets	Blood cells that help clot the blood and prevent bleeding.
Protocol	A specifically designed treatment plan.
Radiation	Treatment that destroys cancer cells or suppresses or eliminates the bone marrow using high-energy rays from x-rays, electron beams, or radioactive isotopes.
Red Blood Cells	Cells that carry oxygen to all parts of the body.
Reduced Intensity Conditioning	Chemotherapy and medications that suppress the immune system are used to prepare a patient for transplant. It relies on the donor's immune system to kill the disease. See graft versus tumor (GvT).
Relapse	The return of the disease after treatment and/or transplant.
Recipient	Person who receives a transplant.
Remission	Complete or partial absence of cancer cells and symptoms after treatment.
Syngeneic Transplant	A transplant where the donor is an identical twin of the recipient.
Thrombocytopenia	A low platelet count.
Total Body Irradiation (TBI)	This is a type of radiation treatment given to the patient before they receive the donor cells. It is given to suppress or eliminate the bone marrow cells. This is done by a radiation doctor (Radiation Oncologist).
Transmittable Disease Testing (TDT)	A blood test to determine if a person has been exposed to certain infectious diseases.
White blood count	Cells that help fight infection.

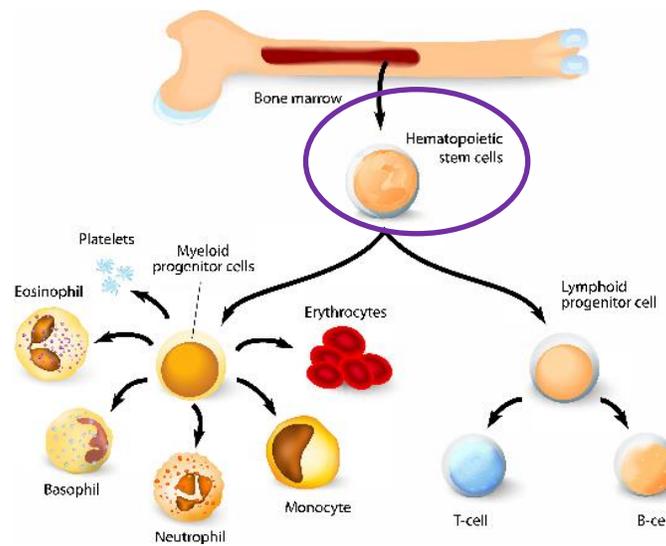
## Information about Transplant Bone Marrow

The bone marrow is the soft, spongy tissue inside bones that makes blood-forming cells. These blood-forming cells are called hematopoietic progenitor cells (HPCs), sometimes called stem cells and can grow into:

- White blood cells. White blood cells (which is made up of many types of cells) make up part of your immune system and help to fight infections. They have an average lifespan of 13 to 20 days.
- Red blood cells. Red blood cells carry oxygen throughout the body. They have an average lifespan of about 120 days.
- Platelets. Platelets help to clot blood and prevent or control bleeding. They have an average lifespan of about 10 days.



The bone marrow is a highly regulated system and is constantly producing these types of cells depending on what your body needs.



## Transplant

Transplant is the infusion of HPCs into the recipient after a conditioning regimen. These cells have a marker on their surface, which is CD34+, which is how they are differentiated from other cells.

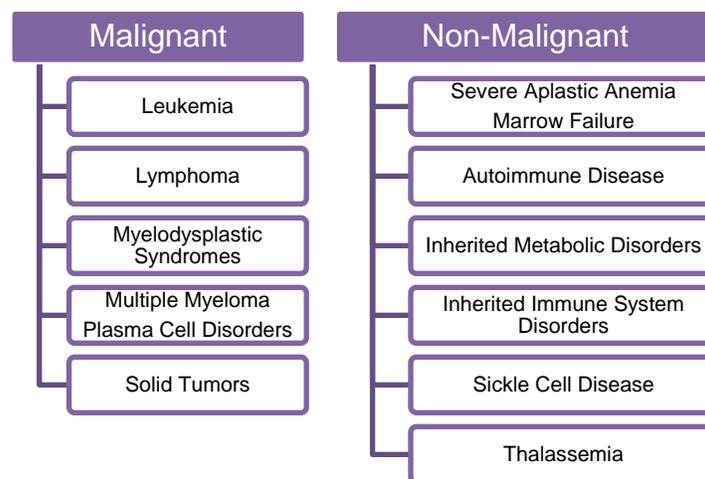
Transplant is done by using healthy HPCs or stem cells to replace damaged bone marrow. Bone marrow may be damaged because of bone marrow failure, disease, and/or chemotherapy and radiation. These transplanted cells are used to restore hematopoiesis (the production of blood cells) and immunity. Transplant can be used to allow a recipient to receive high doses of chemotherapy to kill cancer cells and then the transplant is used to restore blood-forming cells.

HPCs can be obtained through several sources, including the peripheral blood, bone marrow and umbilical cord blood.

- **Bone Marrow**

- Bone marrow is obtained through a bone marrow harvest. This procedure is done in the hospital under general anesthesia. The donor typically lies on their stomach and an incision (cut) is made over the pelvic (hip) bone. A needle is inserted into the pelvic bone and marrow is drawn out.
- **Peripheral Blood**
  - Peripheral blood HPCs are collected through a process called apheresis. The donor receives mobilization medications before apheresis collection to move stem cells to the blood stream. Blood is taken from an intravenous (IV) catheter, which is usually placed in the arm or chest. The blood is run through the apheresis machine where the stem cells are “picked up” and put in a collection bag. The remaining blood is returned to the donor through a second IV.
- **Cord Blood**
  - Blood is taken directly from the umbilical cord right after a baby is born in the hospital. This blood is rich in HPCs.

Transplant is used to treat both malignant and non-malignant conditions. Based on the recipient’s disease, different types of transplant are used. Autologous transplants use the recipients’ own bone marrow or peripheral blood cells. Allogeneic transplants use a donor’s bone marrow, peripheral blood or umbilical cord blood cells.



## Types of Transplant

### Autologous

Autologous transplant uses the patient’s own peripheral blood or bone marrow’s HPCs. This allows the patient to receive high dose anti-tumor therapy (the conditioning regimen) to work on the remaining cancer cells. The previously collected HPCs then “rescue” the marrow to restore blood-forming cells.

### Allogeneic

Allogeneic transplant uses someone else’s bone marrow, peripheral blood or cord blood HPCs. This allows for the safe delivery of high dose anti-tumor therapy (the conditioning regimen). It is followed by the infusion of the donor’s cells to restore blood-forming cells and immune reactive cells.

## The Transplant Process



## Information about the Transplant Process

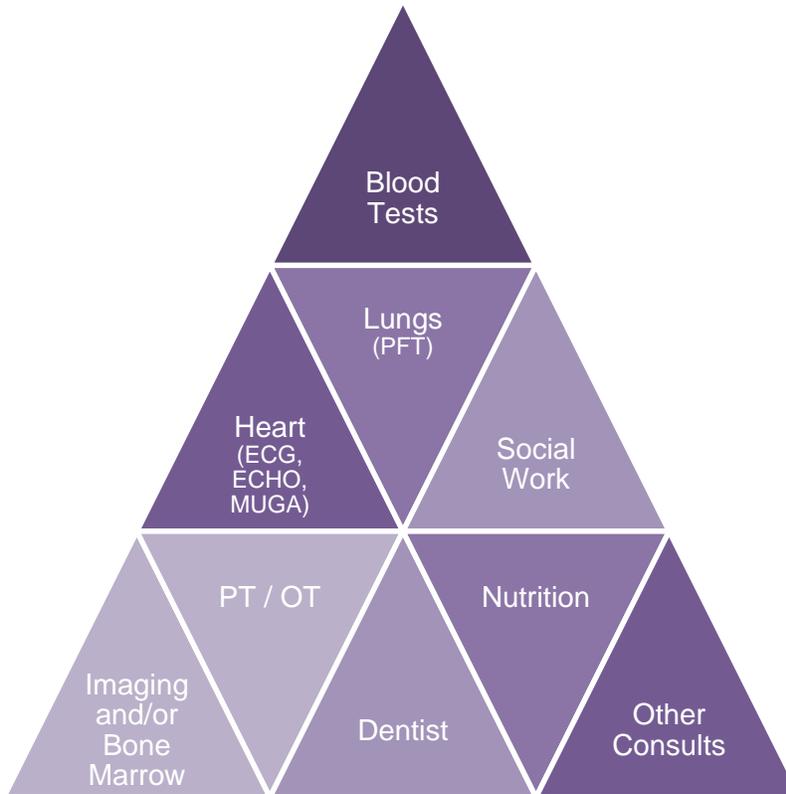
### Pre-Transplant Evaluation

Your transplant process begins with a consult with your transplant doctor. If it is determined you are a candidate for transplant, you will decide if transplant is a treatment you would like to pursue.

Prior to having a transplant, you will have a full health evaluation. This includes a medical history, physical exam, health history questionnaire, chest x-ray, electrocardiogram (EKG or ECG), an echocardiogram, pulmonary function tests (PFTs), lab tests and other tests. We will also test your blood for certain infections. Your blood will also be tested to see if your red blood cells are normal. Your Transplant Team orders other tests, such as a bone marrow biopsy, lab tests and imaging (for example, CT and/or PET), based on your disease. The Transplant Team does this to look at your disease status and make sure you are physically able to have a transplant. You will also need to have a dental evaluation within six (6) months before transplant. This is done to ensure that you do not have a possible source of infection. It may also help you avoid procedures in your post-transplant phase. All parts of the pre-transplant evaluation can help the Transplant Team identify and treat any possible problems before transplant and avoid complications during the transplant process.

Once this evaluation is complete, your transplant doctor will review the results with you and discuss the risks and benefits of transplant. Together you will discuss if transplant is the right treatment for you. Please understand that abnormal test results might require us to perform further investigation.

During the pre-transplant process, you will meet with many other members of the Transplant Team. These include a transplant coordinator, social worker, dietitian and a financial counselor. Based on your individual situation, you may need to meet with other team members such as radiation oncology, physical therapy, etc. The transplant coordinator will help you schedule and manage these tests and visits. They will stay in contact with you during the pre-transplant process.



Blood tests. You may need to have additional clinic visits for testing. These are done to check how well your body and organs are working. They also check for disease status (in certain types of diseases), exposure to viruses and infectious diseases, vaccination status, blood type, etc. Some of the testing needs to be repeated within one month of transplant.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_  
 Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Bone marrow biopsy, if needed, to assess disease status.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Electrocardiogram (ECG), to look at your heart's rhythm.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Chest x-ray provides a picture of your heart and lungs. We look at this to see their structure. Sometimes we can tell if there is evidence of lung disease or infection.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Imaging (PET scan, CT scan, etc., as needed). The imaging tests you have will depend on your disease. Sometimes we order these tests to give us more detail based on findings during your work-up.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_  
 Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_  
 Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

ECHO or MUGA scan gives us a picture of your heart and tells us more about the heart's movement and function.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Pulmonary function tests (PFTs) tell us about your lung capacity and function. They also tell us about your body's ability to carry oxygen.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Social Work Consult

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Nutrition Consult

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Physical Therapy/Occupational Therapy consult, as needed.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Radiation Oncology, as needed.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Dental Clearance

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

## Notes

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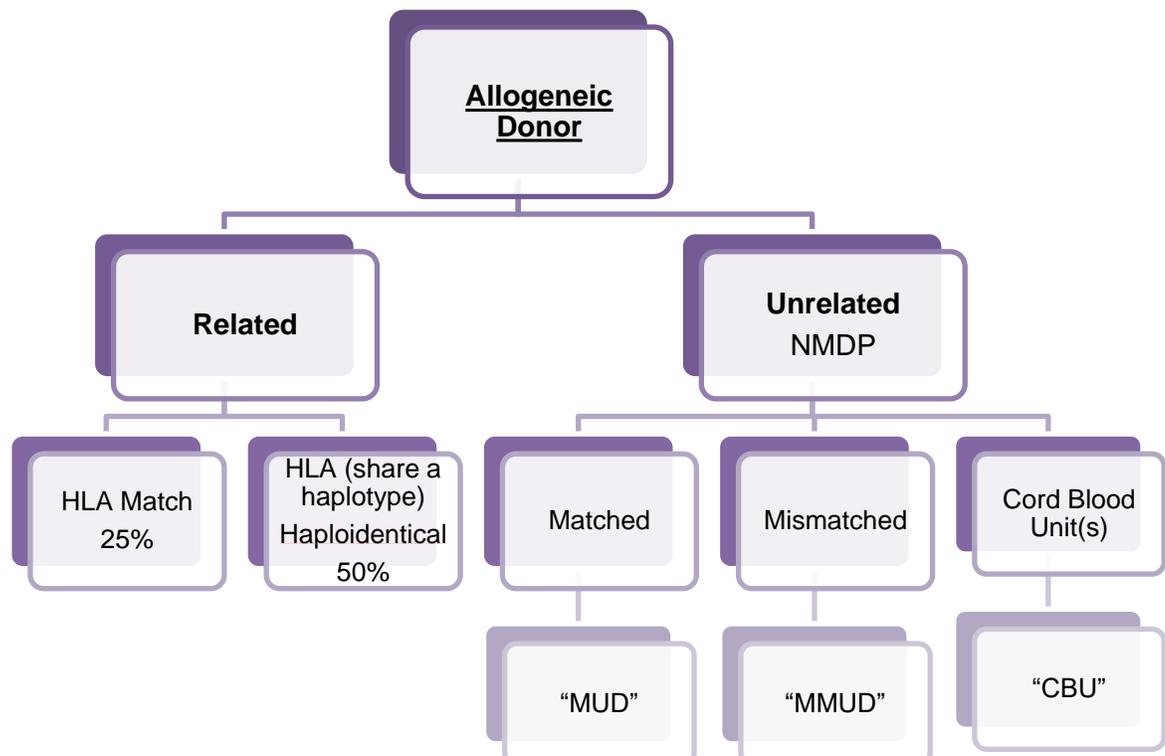
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## Allogeneic Transplant – Donor Information

Allogeneic transplant uses someone else's bone marrow, peripheral blood or cord blood HPCs. This allows for the safe delivery of high dose anti-tumor therapy (the conditioning regimen), followed by the infusion of the donor's cells to restore blood-forming cells and immune reactive cells.

When patients get stem cells from someone else, there are different donor types:

- **Related:** the donor is related to the patient
  - MRD: matched related donor, DNA matches the recipient
  - Syngeneic: identical twin donor
  - Haplo-identical: share at least half a haplotype
- **Unrelated:** the donor is someone not related to the patient
  - MUD: matched unrelated donor, DNA match to the patient
  - MMUD: mismatched unrelated donor, an almost match to the patient
  - CBU: cord blood unit(s), will allow for less matching
- **Human Leukocyte Antigens (HLA)**
  - What is it?
    - Proteins found on the surface of most cells in the body
    - Immune system uses HLA to verify that a given cell is part of the body and not foreign
    - A suitably-matched donor is important to reduce the risk of post-transplant complications
  - Why is it important?
    - Improves the chance for a successful transplant
    - Promotes engraftment
    - Reduces the risk of Graft Versus Host Disease (GVHD)



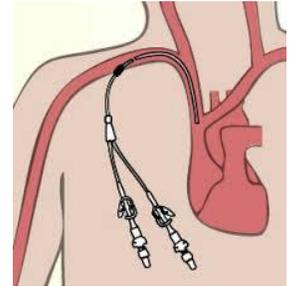
- Donor Selection. Many factors go into selecting the right donor for you. Among other factors, we look at:
  - Your disease and stage of disease
  - The HLA typing of you and the donor
    - We look at 6 pairs of HLA markers (for a total of twelve (12))
  - Donor availability
  - Age of you and the donor
  - Donor gender
  - CMV status of you and the donor
  - The number of pregnancies the donor has had
  - The number of blood transfusions the donor has had
- Donor Commitment. It is important that your donor be committed to the process.
  - Work up
    - History and physical
    - Health history questionnaire
    - Lab tests (at least 2) to test for each of the following:
      - HLA typing and confirmatory HLA typing
      - Blood type (ABO), Rh and antibody testing
      - Transmittable disease testing
  - Donating is entirely voluntary and the donor can decide not to donate at any time
  - Strict privacy laws to protect both the donor and recipient
  - Depending on where the cells come from (for unrelated donors) different rules can apply

## Allogeneic Pre-Transplant Information

### Central Venous Catheter

If you do not already have one, we will place a central venous catheter prior to transplant. A central venous catheter is a line that allows for access to the bloodstream. It is used to give you your conditioning regimen, HPCs and medications, as needed. It is also used to draw blood for lab tests. This catheter is a thin, flexible tube that is placed into a large vein in the chest. The tube will come out through the skin. The line may be removed before discharge or stay in place for a time after transplant. This will depend on your IV needs after transplant. Your catheter will be placed and removed during visits at the interventional radiology department.

Generally, allogeneic patients have a triple lumen central venous catheter. Lumens are the part of catheter that are on the outside of the body that you can see.



Central venous catheters have many names, based on their type. They may be called a central line, Mediports®, Permacaths®, or PICCs, among other names. These central venous catheters need extra care. Here is how we can work together to safely care for your central venous catheter during the hospital admission. You are a vital part of the healthcare team.

What can you do?	What does the healthcare team do?
<p><b>Wash hands. Wash hands. Wash hands.</b> Ask visitors to wash their hands in the hospital and at home.</p>	<p><b>We wash</b> our hands.</p>
<p>Wear masks. You will put on masks for procedures that involve touching or using the central venous catheter. For example:</p> <ul style="list-style-type: none"> <li>• Changing the dressing</li> <li>• Changing the backflow cap</li> <li>• Accessing a Mediport® with a needle</li> </ul>	<p>We wear masks and gloves during procedures that involve touching or using central venous catheter, like:</p> <ul style="list-style-type: none"> <li>• Changing the dressing</li> <li>• Changing the backflow cap</li> <li>• Accessing a Mediport® with a needle</li> </ul>
<p>Tell a nurse right away if the line becomes disconnected or the dressing is dirty or peeling.</p>	<p>We use dressings to cover the central line site. We check to make sure the dressing is clean, dry, and stays in place. We change the dressing every 7 days or when it becomes dirty or is peeling.</p>
<p>Work with staff to bathe yourself with medicated wipes every day. These wipes get rid of germs on your skin.</p>	<p>We work with you to make sure you bathe with medicated wipes every day.</p>
<p>Check with nurse before using any soap, lotions, or deodorants. Some products can stop the medication in the wipes from working.</p>	<p>We use caps with alcohol to keep the site clean.</p>

Ask questions if something does not look or feel right. Please tell a member of the Transplant Team if you notice something new, such as redness, tenderness or warmth in the area of the central venous catheter. Let us know if your dressing is dirty or peeling, or if you have any concerns.

## **Getting Ready for Transplant and Admission into the Hospital**

Things you can do to get ready for your transplant:

- Trim your fingernails and toenails
- Remove fake nails and nail polish
- Consider cutting your hair short
- Consider shaving your beard or mustache

Depending on the type of transplant you will receive, you can expect to stay in the hospital 2 to 4 weeks. Some patients may be able to leave the hospital earlier, while others will stay in the hospital longer due to complications. We want you to be prepared and comfortable during your admission.

We suggest bringing:

- A copy of your Medical Durable Power of Attorney for Healthcare
- Your Blood and Marrow Transplant – A Patient and Caregiver Guide Notebook
- Comfortable clothing such as sweaters, zip-up hoodies, long pants or pajamas to change daily
- Shoes with good traction for walking in halls
- Turbans, scarves, or hats
- Extra pillows and/or blankets. These should be washed before bringing them into your hospital room.
- Toothbrush and toothbrush holder

Patients find it helpful to bring items to help pass the time. Suggestions include:

- Books, magazines, playing cards, puzzles, coloring books, arts and crafts, knitting supplies
- Small radio or CD player
- Electronics, such as a laptop, iPad, tablet, handheld personal game system
- Cell phone and charger
- Family photos, favorite posters

## The Inpatient Unit: Kimmel 18

### Who will be taking care of me?

- Our inpatient team cares for you during your stay. A transplant doctor leads the inpatient team and they are called the Service Attending. This may or may not be the doctor who usually treats you as an outpatient. You may have more than one Service Attending during your stay.
- Our team works together to ensure you receive safe, quality care. We want to make sure you are satisfied with your hospital stay. If you have any questions, suggestions, or concerns please ask to speak with the Nurse Manager, Assistant Nurse Manager or Charge Nurse. We will do everything we can do to accommodate you during your stay with us. When you go home after discharge, please remember to return your patient satisfaction survey. We strive for excellence and value your feedback.

### The BMT Environment

- While you are in the hospital, you will be in your own private room. To prevent the spread of infections, we take special steps to maintain a clean environment. You can help us by keeping the surfaces in your room free of clutter. This allows housekeeping to thoroughly clean your room. Additional precautions include:
  - No fresh flowers or plants.
  - You will be given a special mask to wear when you leave your room and remain on the BMT unit.
  - When you need to leave the BMT unit, usually for tests and procedures, you will be given a special mask, gown, and gloves to wear. It is important to perform good hand hygiene, always, wash your hands when returning to your room.

### Visiting Policy

- Family members, friends and other guests with signs of a cold or infection are not allowed to visit the BMT unit.
- Adult family members and friends may visit at any time but only one person can stay overnight.
- Children under 12 years old should not visit without permission from your Transplant Team.
- Please tell visiting family members and friends to check in with your nurse. Everyone must wash their hands before entering the room.
- Visiting family members and friends must use the bathroom in the hallway. They should not use the one in your room. This helps prevent the spread of bacteria.
- Visiting family members and friends need to keep their belongings outside your room.

### Hospital Routine

- You will be cared for by a nurse, 24 hours a day. Nurses work 12-hour shifts. The nurses change shift and give report at 7:00 am and 7:00 pm every day. You will have a call bell in your room that will be answered promptly 24 hours a day. If you need any help at all, please use your call bell.
- Each morning before 6:00 am, the nurse will draw your blood and take your weight.
  - Your blood will be checked for white blood cells, red blood cells and platelet values.
    - If your red blood cells or hemoglobin is low, we may decide you need a transfusion.

- If your platelets are low, we may decide you need a transfusion.
  - We will also check your electrolytes and kidney function.
    - We may decide to give you electrolytes based on your results.
  - This guide contains a chart that you can use to track your own lab values.
- Your vital signs (blood pressure, temperature, pulse, pulse ox, respirations and pain score) will be taken every 4 hours, 24 hours a day. There are times that we may need to check these more often.
- While you are in the hospital, you will be offered meals three (3) times a day. A Registered Dietitian will meet with you daily to take your meal choices. If you would like to have a snack outside of meal hours, please tell the nursing staff. Your caregivers may also bring you home cooked meals. You can store these in the BMT unit refrigerator. All home cooked meals must follow the dietary guidelines in this book.
- Your urine and bowel movements are monitored while in the hospital. You need to save your urine and stool in the measuring device provided. Let the nurse know about any changes in your bowel function. We will also be tracking how much you drink. Be sure to tell your nurse how much you are drinking. This information helps the Transplant Team accurately monitor your intake and output status.

## Precautions during Your Admission

At NYU Langone Health, your safety is one of our biggest concerns. Let us work together to keep you safe.

### **Fall Precautions: Call, Do not Fall!**

- You may fall if you:
  - Have fallen before
  - Have had a surgery or medical issue. Examples are changes in blood pressure, pain, fluid loss, seizures, visual changes or other issues specific to you.
  - Have a fever and/or infection
  - Are taking medications that cause you to feel sleepy, dizzy, lightheaded, or make you have to go to the bathroom more often
  - Are experiencing neurological changes such as loss of feeling or numbness and tingling of the hands or feet, changes in balance, or if you sometimes become confused.
  - Have medical equipment with tubes or wires which might cause you to trip
  - Feel unsure of your environment
  - Walk in socks or slippery shoes
  - Rush from one place to another
- Staff will help you by:
  - Looking at your risk for falling and teaching you ways to stay safe
  - Checking on you often
  - Giving you a safety bracelet or special colored socks. When you wear these items, it helps everyone keep you safe
  - Using a bed alarm if you need to be reminded to call for help
  - Keeping your belongings and call bell where you can reach them

- Staying with you in the bathroom where falls may happen
- You and your visitors can help by:
  - Always using the call bell when you need help
  - Having the nursing staff accompany you to the bathroom
  - Keeping your belongings and call bell within reach
  - Wearing the non-skid socks (provided by the hospital) or supportive shoes
  - Bringing or sending home anything you don't need
  - Keeping bedrails raised as instructed by your nurse
  - Asking for help with medical equipment, tubes, or wires when getting out of bed.

## Bleeding Precautions

- What are bleeding precautions?
  - Bleeding precautions are safety measures used to protect you if you have a high risk for bleeding. You are at a high risk for bleeding when the platelet count in your blood is low or if your platelets are not working the way they should.
  - Platelets are cells that help the blood clot and prevent bleeding if you have an injury. Whether an injury is internal (inside your body) or external (on the surface or outer part of your body), platelets travel to the area and form a clot or scab that stops bleeding. If your platelet levels are low or your platelets are not working the way they should, you may not form scabs or clots. This means you are at risk for bleeding even when your platelet count is normal.
  - The only way to check your platelet count is with a blood test. While you are in the hospital, we will do a blood test and check your platelets every day. After you leave the hospital, your health care provider will tell you how often you need to have it checked.
    - A normal platelet count is 150,000 to 400,000
    - Below 100,000, you may be at risk for increased bleeding from injury. This condition is called thrombocytopenia.
    - Below 50,000, you are at increased risk for bruising or bleeding from everyday activities. You will need to follow the guidelines below.
- Why am I on bleeding precautions?
  - Some medical conditions and/or medications can lower your platelet count. Others affect the way platelets work and increase your risk of bleeding even when your platelet count is normal.
  - The best way to reduce your risk for bleeding is to avoid being cut or injured.
    - **Do Not** participate in any activity that may cause you to bang or injure your head, chest, or belly area (abdomen). If you have questions about participating in an activity, ask your Transplant Team.
    - **Do Not** play contact sports or go climbing. If you have questions about participating in a sport, ask your Transplant Team.
    - **Do Not** shave with a straight edge razor. Use only an electric razor.
    - **Do Not** hold, handle, or use sharp objects if possible.
    - **Do Not** use a firm toothbrush. Use only a soft bristle toothbrush or a Water-Pik

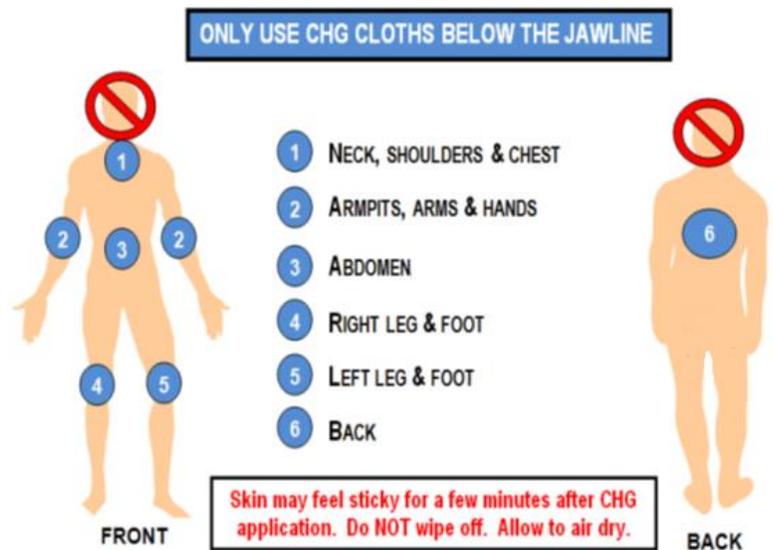
- **Do Not** take aspirin or products containing aspirin.
- **Do Not** blow your nose forcefully. If you have to blow your nose, make sure to blow it gently.
- **Do Not** use enemas, suppositories or rectal thermometers
- **Do Not** strain during or force bowel movements. Use stool softeners (laxatives) if you are constipated or having trouble with bowel movements. Speak with your health care provider before taking any medication.
- **Do Not** use tampons.
- What symptoms do I need to report?
  - Any type of fall
  - Headache
  - Blurry vision
  - A nose bleed
  - More bruises than usual or tiny red or purple spots on your skin
  - Vomiting or coughing up blood
  - Black stools, blood in your stool or rectal bleeding
  - Blood in your urine
  - Vaginal bleeding that is not a menstrual period or a period that is heavier than usual.

## Hygiene

Hygiene refers to keeping your body clean. It helps reduce the amount of bacteria you carry. Good hygiene can prevent infections.

## CHG Wipes

- During your hospital stay, you must bathe with an anti-bacterial wipe every day. This decreases your risk of infection. If you wish to shower, use the wipes after your shower. Check with your nurse before using any of your own soaps or lotions because they may stop the medication in the wipes from working.
- To use the wipes:
  - Wipe each body area with a vigorous back and forth motion. Be sure to wipe thoroughly. Follow the steps below.
  - Use one clean cloth to prep each area of the body. (See below.) **Do not use wipes on your face.**
    1. Neck and chest
    2. Both arms, starting at the shoulder and ending at fingertips.
    3. Abdomen, right and left hip, followed by the groin. Be sure to wipe folds in the abdominal and groin areas well.
    4. and 5. Both legs, starting at the thigh and ending at the toes. Be sure to wipe behind the knees
    6. Back, starting at the base of the neck and ending at the waistline



## Mouth Care

- Chemotherapy can cause many side effects, including mucositis, or mouth sores. Mucositis, also known as mouth sores, can be painful and affect your ability to eat and drink.
- Chemotherapy also weakens your immune system. This makes it harder for your body to fight off infections. Your mouth is an entry point for many harmful organisms. Open sores in your mouth give these organisms a place to enter your blood and cause infections. Therefore, mucositis can also lead to longer hospital stays and even life-threatening infections.
- You can help reduce infections related to mucositis during your hospital stay. By doing frequent mouth care, your mouth stays cleaner and lowers the number of bad bacteria entering your body.
- Your nurse will teach you a mouth care routine that should be done every 4 hours while you are awake. If your mucositis becomes worse, perform mouth care more often. If you cannot do your own mouth care, we will help you.
- The mouth care routine we give you will **not** stop mucositis from occurring. However, we hope it will keep you comfortable enough to allow you to keep eating and drinking and protect you from dangerous infections.
- Gentle flossing is allowed when your platelet level count is normal. If your platelet level is low, flossing can cause extensive bleeding. You should always talk with your nurse to know if it is safe for you to floss.

## Telemetry

- You may need telemetry during your hospital stay. Telemetry is a way of monitoring your heart. It uses a battery-operated unit called a “tele box.”
- This unit has 5 wires (leads) that are connected to pads (electrodes) which are placed on your chest. The wires pick up electrical signals from your heart and send the signal to the telemetry box. The box changes these signals from your heart into pictures of each heartbeat. These pictures are sent to the central monitoring station. If there is a change in your heart’s activity, your nurse will receive an alert on their phone or at the central monitoring station. It is important to know that the telemetry box does not correct any problems your heart might be having. It cannot check your blood pressure or “shock” your heart.
- Telemetry Frequently Asked Questions
  - What should I do if the leads or electrodes fall off?
    - Do not try to replace them yourself. Let your nurse know so he or she can put them in the right place on your chest.
  - I notice a beeping noise coming from the box when I leave the unit. What does that mean?
    - This means you are “out of range.” The nurses are unable to monitor you and see what your heart is doing if you are out of range. It is very important to stay on the unit while you are being monitor.
  - When is the telemetry box cleaned?
    - The wires are changed for each patient. The telemetry box is disinfected between patients.
- Important Facts to Remember
  - Call your nurse right away, if you feel chest pain, shortness of breath, dizziness, nausea, or discomfort.
  - Electrodes are changed daily. Your nurses will note the date on each set of electrodes used.
  - Telemetry allows you to walk around the unit and still be monitored. It should not limit your movements.
  - Do not take off telemetry pads or wires.
  - Do not get the telemetry box wet. If you would like to shower, ask your nurse to remove the pads and telemetry box.
  - Do not place your cell phone or other electronic devices near your telemetry box. This can cause interference with the signal.



## Incentive Spirometry

- An **incentive spirometer** is a device that measures how deeply you can inhale (breathe in). It helps you take slow, deep breaths to expand and fill your lungs with air. This helps prevent lung problems, such as pneumonia. Your nurse will teach you how to do coughing and deep breathing exercises with the incentive spirometer.
- Use your incentive spirometer at least 10 times each hour while you are awake.



## Activity Guidelines

During your stay, you will have physical therapy (PT) and occupational therapy (OT) about once a week. This schedule will continue unless we feel you need to be seen more often. On the days that you are not having therapy, there are many activities you can and should do to promote strength, mobility and wellness. Listed below are tips and guidelines to stay mobile every day.

Your therapist will let you know the best activity level for your exercises. The activity level set by your therapist is chosen to help you be safe while you are getting stronger. Use the following guidelines:

	Green	Yellow	Red
	Exercise Series	Exercise Series	Exercise Series
Strengthening	Standing exercise program	Seated exercise program	Lying down exercise program
Endurance	Independent bike or walking with RN approval	Requiring staff's assistance for bike or walking	Need Transplant Team approval for bike or walking
Activity Level and Limitations	No activity restriction	<ul style="list-style-type: none"> <li>• You need the assistance of one staff member for safe mobility.</li> <li>• You need to learn more about exercise safety. Your therapist may have noticed a change in your ability to exercise safely.</li> </ul>	You may demonstrate one of the following: fever, unstable vital signs, abnormal lab values, Transplant Team orders or significant changes in your condition.

## Strengthening

We have given you a list of exercises that can be performed daily while standing, lying down or sitting, based on your ability and medical condition. During each physical and occupational therapy session, your therapist will update the recommended exercises that are safe for you to do independently.

Number of times to perform each exercise	Number of times to repeat exercise series
8 to 20	2 to 3

Tip: To conserve energy, break up your exercises throughout the day and spread out the number of times you repeat them.

## Endurance

You should try to walk around the units several times each day. You could also use the stationary bike, which is available to you during your hospital stay. These activities help you maintain the strength you are gaining by exercising. Always exercise according to the activity level set by your therapist.

Walking	Biking
At least 3 to 5 laps each day	At least 20 minutes each day

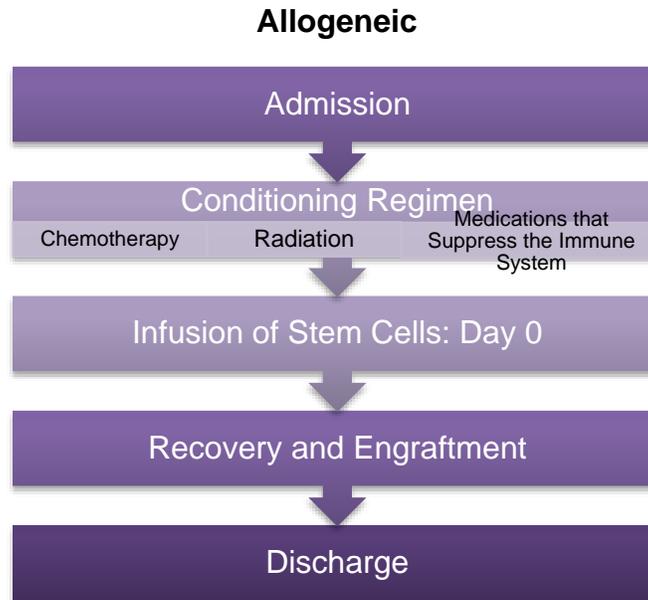
Tip: Break up the time you spend walking or using the bike into several short sessions each day. This can make it easier to reach for the total amount of time spent walking or biking.

## Physical activity

- Increase your activity level gradually.
- Continue light exercise, such as, walking while you are in the hospital and after you are discharged.
- Get plenty of rest and take breaks between activities but do try to push your activities.

If you are having trouble with activity or you need to talk to a physical therapist, the Transplant Team can help set up a referral.

# Transplant



You need to know how transplant days are counted. This number tells us about where you are in the transplant process and what you may be expected based on the timeframe.

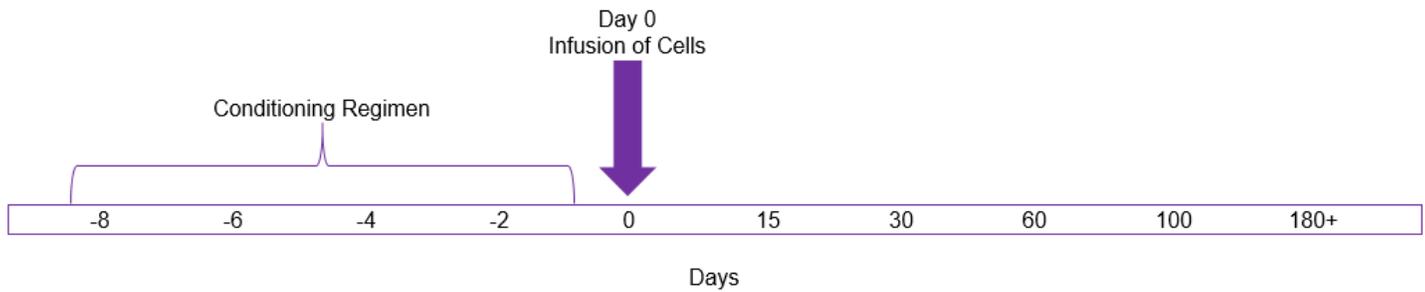
- Before the transplant days count down as minus (-) days (Day -7, -6, -5, etc.)
- Transplant day is Day 0. This is the day when the HPCs will be infused into your body.
- After the transplant, days count as plus (+) days (Day +1, +2, +3, etc.)

## Conditioning Regimen

The conditioning regimen is counted in negative numbers (-7, -6, -5...). It prepares your body and your bone marrow for the transplant. The conditioning regimen is given over one (1) to ten (10) days. The length of the conditioning regimen depends on:

- Transplant type
- Disease
- Age
- Previous treatment
- Coexisting conditions or diseases you may have before transplant
- Treatment protocol

Your Transplant Coordinator will give you a calendar prior to admission. It will show which day(s) you will be given each medicine and when you will have your transplant.



## Side Effects of the Conditioning Regimen

- Chemotherapy and radiation attack both healthy and unhealthy cells. This causes side effects. Every patient is different and the severity of these side effects varies. Your Transplant Team is experienced in giving these treatments and in managing their side effects. You will be carefully watched for signs of any serious side effects. Always tell your Transplant Team if you are experiencing side effects.

Common	Serious
<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Diarrhea</li> <li>• Lack of appetite</li> <li>• Mouth sores (mucositis)</li> <li>• Hair loss</li> <li>• Skin rash</li> </ul>	<ul style="list-style-type: none"> <li>• Sinusoidal obstruction syndrome (damage to the liver)</li> <li>• Damage to the lungs</li> <li>• Damage to the heart muscle</li> </ul>

## Allogeneic Transplant Conditioning Regimens

Allogeneic transplant patients may receive different types of conditioning regimens. These include:

- Myeloablative
  - This involves using higher doses of chemotherapy with or without radiation.
  - The intent of the myeloablative conditioning is to destroy your immune system, which destroys both diseased and healthy cells. Conditioning regimens make space in the bone marrow to allow donor cells to engraft.
  - This type of conditioning is used in:
    - Aggressive diseases
    - Patients with residual disease at the time of transplant
    - Diseases that do not respond as well to the Graft versus Tumor effect (GvT)
  - In myeloablative conditioning, your own bone marrow would not produce new cells without donor cells.
- Reduced Intensity

- This involves using lower doses of chemotherapy than a myeloablative conditioning regimen.
- The intent of the reduced intensity conditioning is to weaken the immune system. This allows donor cells to engraft and fight your disease (Graft versus Tumor effect, or GvT). Conditioning regimens make space in the bone marrow to allow donor cells to engraft.
- This type of conditioning is used in:
  - Patients who are less likely to tolerate the effects of myeloablative conditioning
  - Diseases that typically respond to the graft versus tumor effect
- In reduced intensity conditioning, your own bone marrow may or may not produce new cells without donor cells.
- Non-myeloablative
  - This involves using lower doses of chemotherapy. It usually done in combination with lower doses of radiation.
  - The intent of the reduced intensity conditioning is to weaken the immune system. This allows donor cells to engraft and fight your disease (Graft versus Tumor effect, or GvT). Conditioning regimens make space in the bone marrow to allow donor cells to engraft.
  - This type of conditioning is used in:
    - Patients who are less likely to tolerate the effects of higher doses of chemotherapy
    - Diseases that respond to GvT
  - In non-myeloablative conditioning, your own bone marrow would reproduce new cells without donor cells.
- Total Body Irradiation
  - Your conditioning regimen may also include the use of total body irradiation (TBI). This is a type of treatment given to weaken (non-myeloablative) or destroy (myeloablative) your bone marrow cells before you receive your donor cells. This is done by a Radiation Oncologist (radiation doctor). You will have a consult with the Radiation Oncologist before the treatment. They will take measurements and sometimes mark your body with a marker. This appointment generally takes about two (2) hours.
  - If you are receiving myeloablative conditioning, TBI is usually done twice a day for four (4) days. In non-myeloablative conditioning, TBI is usually done once prior to the transplant. Each treatment usually lasts about 20 minutes.

### Allogeneic Transplant Immuno-suppressant Medications

Allogeneic transplant patients are given medications that weaken their immune system to prevent them from rejecting the donor cells. They also help to prevent Graft versus Host Disease (GvHD), which is a reaction of the donor cells against your body. These medications are vital to your transplant. You must take them as prescribed and on a consistent schedule.

Different combinations of immune-suppressant medications are given, based on the type of transplant you receive. You will receive information specific to you prior to transplant.

We monitor you after transplant to make sure you are on the right dose of medications. This includes checking your levels for tacrolimus, cyclosporine and sirolimus. After discharge and on your clinic days, you will continue to have blood drawn to test these levels. On these clinic days, please bring all your

medications with you. Do not take your medication(s) until after the blood is drawn otherwise it will affect your lab results. If you received medication through your IV in the hospital, then blood draws for tacrolimus and cyclosporine levels are taken from your arm. This is because the medication adheres to your central venous catheter and may cause an error in the drug's level.

### Day 0: Transplant Day

You will get your transplant on Day 0. The cells arrive in bags like those that the ones used for blood transfusion. The cells are infused through your central venous catheter.

During the transplant, it is possible that you will have a fever, headache, chills, flushing, nausea, vomiting, scratchy throat, rash, trouble breathing or changes in your vital signs. We will give you medicines to help prevent any possible reactions. Your vital signs (temperature, pulse, blood pressure and other measures) will be taken frequently before, during and after your transplant.

If the cells have been processed and stored prior to transplant, that means they will have been frozen in a process called cryopreservation. Cryopreservation is done with an agent called dimethyl sulfoxide (DMSO). DMSO can cause some of the side effects listed above. Also, sometimes after transplant, patients may notice an odor. This odor is caused by their body getting rid of DMSO.

# Post-Transplant

## Early Post-Transplant

After the transplant is done, you will need time to recover. During this time, you will be watched closely. We will:

- Assess you each day. (And more often, if needed)
- Assess your vital signs several times each day
  - If you have a fever, we do testing to check for infection. This includes:
    - Chest x-ray
    - Blood cultures
    - Urine culture
    - We will also start you on antibiotics
- Your blood will be drawn each day
  - Lab tests will check for white blood cells, red blood cells and platelet values.
    - If your red blood cells or hemoglobin are low, we may decide you need a transfusion.
    - If your platelets are low, we may decide you need a transfusion.
  - We will also monitor your electrolytes and kidney function.
    - Based on your results, we may decide to give you IV fluids and/or electrolytes.
- Assess your fluid and nutritional intake
- Encourage activity
- Encourage hygiene
  - Daily showers and CHG wipes to get rid of bacteria on the skin
  - Perform mouth care, several times a day

Hand washing for you and anyone entering your room is the most important thing a patient can do to prevent infection.

After the transplant, you may experience side effects, which are different for everyone. Many side effects can be managed with medications and supportive care. Be sure to talk to your Transplant Team about the side effects you experience during the transplant process.

After transplant, you will be immuno-suppressed. This means you have a weakened immune system. Your system is especially suppressed before engraftment occurs. You will likely have:

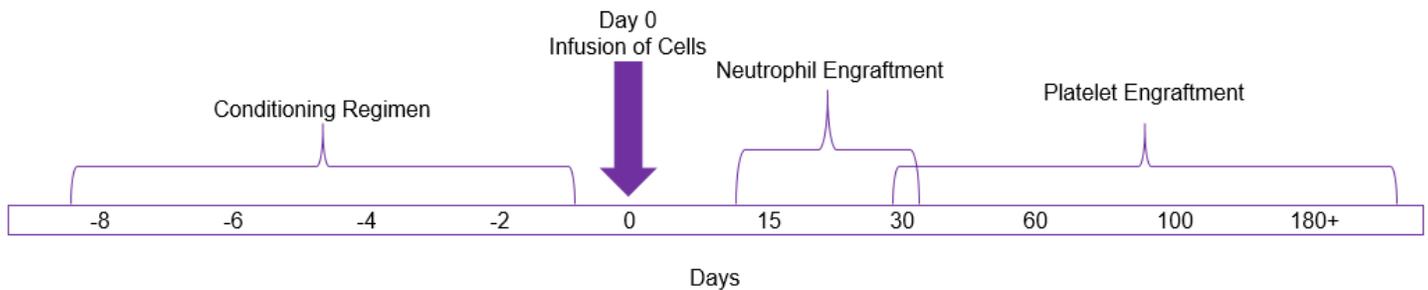
- Low blood counts
  - Low white blood count (WBC)
    - Your white blood cells, specifically your neutrophils, work to fight infection in your body. While these are low, you are at risk for infection.
    - You will start filgrastim (Neupogen®) following transplant. This helps to increase your WBCs. It is injected under your skin, one (1) time each day. The day this medication starts depends on your conditioning regimen and transplant type. The injections will continue until your white blood cell count increases to a good level.

- In addition, when your immune system is suppressed we will prescribe medications to prevent bacterial, viral and fungal infections. How long you continue these medications depends on your type of transplant and your recovery.
  - Low red blood cells (hemoglobin)
    - Your red blood cells carry oxygen to the rest of your body. If these are low after transplant, you may experience side effects such as fatigue, shortness of breath, and others. If your hemoglobin drops too low, we will give you a blood transfusion.
  - Low platelet count
    - Platelets prevent and help to control bleeding. When platelet counts drop after the conditioning regimen, you may be at risk for bleeding.
- Other possible side effects, include:

Early Transplant Phase (conditioning through day +100)			Late Transplant Phase (day +100 and beyond)
Hair loss	Mouth sores	Engraftment	Infections
Nausea and vomiting	Diarrhea	Infections	Endocrine issues
	Fevers	Kidney problems	Sterility
	SOS (liver)	Nutritional issues	Secondary cancers
	Electrolyte changes	Pneumonia	Chronic GvHD (allogeneic)
	Transfusions	Acute GvHD (allogeneic)	

Your lab results also tell the Transplant Team when you begin to engraft after transplant. Engraftment is the term used when the transplanted cells begin to make new blood-forming cells in bone marrow. The time from transplant to engraftment varies, depending on your body (for example, disease and prior treatments) and your transplant type. For engraftment, we monitor the absolute neutrophil count (ANC) and the platelets.

- Absolute Neutrophil Count (ANC)
  - Neutrophils make up a portion of the white blood count
  - Neutrophils are the body's main infection fighter
  - ANC recovery usually occurs:
    - Allogeneic transplants: 10 – 20 days after transplant
    - Allogeneic cord blood transplants: 20 – 30 days after transplant
- Platelet
  - Often happens a short time after neutrophil engraftment, usually within a couple weeks
  - Allogeneic cord blood transplants: can take 8 or more weeks after transplant



You can expect to stay in the hospital two (2) to four (4) weeks, depending on the type of transplant you have. Some patients may be able to leave the hospital earlier, while others will stay in the hospital longer for complications. Prior to discharge we expect you to have or be able to:

- No fever
- No evidence of infection or should be stable
- No evidence of GvHD or stable (allogeneic transplants)
- Engraftment of white blood cells
- Not need daily blood and platelet transfusions
- Eat and drink, show that your appetite is improving and you are not vomiting
- Take medications by mouth
- Mouth sores and diarrhea are controlled
- Be strong enough to function outside the hospital
- Discharge education is complete

### Preparing Your Home

We want you to be prepared for your return home. To reduce the potential for infection, we ask that your caregivers plan to take the following precautions before you return home:

- Steam clean the carpets
- Wash the curtains and blinds
- Clean all kitchen and bathroom surfaces
- Bleach the shower heads
- Change the furnace filters
- Dust and vacuum weekly
- Wash bed linens weekly
- Wash the inside of the car
- Live plants should be removed from rooms where the patient will be
- No fresh-cut flowers in the vases, as the water can carry bacteria

### Follow Up Visits

After transplant, you will be seen frequently in the clinic for follow-up. On these days, your labs will be drawn and we will go over the results with you. Based on your red blood cells (hemoglobin) and platelet counts, it may be possible that you will need to stay for a transfusion. Your lab results may also show that you need hydration (IV fluids) or medications to help replace your electrolytes. During your clinic visit, your Transplant Team will also review your medications with you. Be sure to bring your

medications to clinic. How often you are seen in clinic and how long you will stay during these follow up visits depends on your type of transplant, how you are doing and your lab results.

## Medications

After transplant, you will be on several medications. Take your medicines as prescribed by your Transplant Team. You must tell your Transplant Team if you are not able to take your medicines for any reason. Ask questions about any of your medicines and report any side effects to your Transplant Team.

- Do not take any medicines that are not prescribed by your Transplant Team. This includes over the counter drugs such as laxatives, herbal remedies, etc.
- Do not take “extra” vitamins without talking to your healthcare provider. You cannot take any vitamin A supplements.

We prescribe the following medications to help protect you against infection:

- Antibiotics
  - You will be on antibiotics while you are neutropenic.
  - After transplant, you will be on an antibiotic (for example, Bactrim, dapson, mepron) to take at home to prevent an infection of the lungs (pneumocystis jirovecii pneumonia). This type of lung infection can occur in people with badly weakened immune systems
    - This medication continues for one (1) year in allogeneic patients. This may be longer than one (1) year if you are on immune-suppressant medications.
- Anti-fungal
  - You will be on anti-fungal medications while you are neutropenic or, in cases of allogeneic transplant, when you are immuno-suppressed.
- Anti-viral (most often acyclovir)
  - You will be given this medication for at least one (1) year after transplant. If you have a history of herpes zoster (shingles), you will continue this medication indefinitely.

## Viral Monitoring

Depending on your transplant type, donor source and risk factors for certain infections after transplant we may monitor your blood for viruses. These viruses can be common in the community without causing harm, but while you are immune-compromised after transplant, they may cause complications for you. Often, we will start checking your blood for these viruses on a weekly basis.

- Cytomegalovirus (CMV)
  - We begin to check for this when there are signs of engraftment.
  - Some patients are positive for CMV before transplant and it may recur. Some allogeneic transplant patients have a donor that was positive for CMV.
  - Most people do not show signs and symptoms of CMV. In others, CMV may cause:
    - Decreased blood counts
    - Fever
    - Sore throat
    - Fatigue
    - Diarrhea

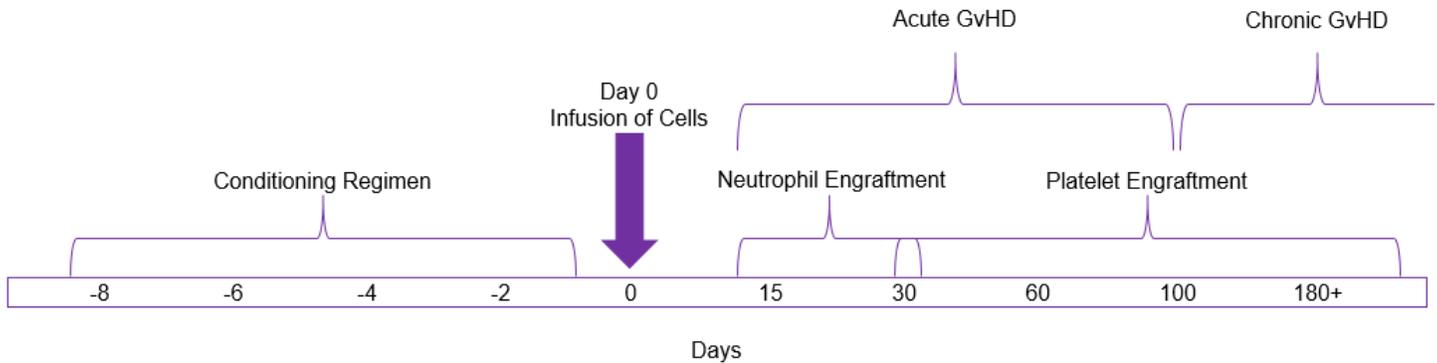
- Swollen lymph nodes
- In immune-compromised patients, CMV can cause symptoms that affect the following systems:
  - Eyes
  - Lungs
  - Liver
  - Esophagus
  - Stomach
  - Intestines
  - Blood counts
  - Bone marrow
- CMV is spread through direct contact (bodily fluids) so frequent handwashing is recommended. You may also get CMV through blood product transfusion(s) and your HPC infusion.
- If blood tests show that you have CMV, there are medications that we may start in order to kill this virus and stop the viral load from increasing.
  - There are times that the viral load may go down to zero but CMV may come back.
  - We will continue to monitor you depending on your transplant and post-transplant recovery.
- Epstein Barr Virus (EBV)
  - If we check for this, we will begin to do so at the time of transplant.
  - Some patients are positive for EBV before transplant and it may recur. Some allogeneic transplant patients have a donor that was positive for EBV.
  - EBV may cause the following symptoms:
    - Fever
    - Sore throat
    - Fatigue
    - Swollen lymph nodes
    - Rash
    - Enlarged spleen
    - Enlarged liver
  - In immune-compromised patients, EBV can cause complications. This includes symptoms that affect the following systems:
    - Nervous system
    - Increase in white blood cells, specifically lymphocytes
    - Lungs
    - Heart
    - Increased risk for infection
    - There are cancers associated with the EBV virus that include:
      - Burkitt's lymphoma
      - Nasopharyngeal carcinoma
      - Hodgkin's and Non-Hodgkin's lymphoma

- Post-transplant lymphoproliferative disorder (PTLD)
- EBV is spread through direct contact (bodily fluids) and frequent handwashing is recommended. You may also get EBV through blood product transfusion(s) and your HPC infusions.
- If blood tests show that you have EBV, we may try to decrease your immune-suppressant medications so your body can respond to the virus. We may also add rituximab, an IV medication, to your treatment.
  - There are times that the viral load may go down to zero but EBV may come back.
  - We will continue to monitor you depending on your transplant and post-transplant recovery.
- Adenovirus
  - If we need to check this, we will begin checking it at the time of transplant.
  - Adenovirus is most common cause of common colds and respiratory illnesses. Adenovirus can cause cold-like symptoms, as well as others, that may include:
    - Fever
    - Sore throat
    - Fatigue
    - Swollen lymph nodes
    - Rash
    - Blood in the urine
    - Enlarged spleen
    - Enlarged liver
  - In immune-compromised patients, adenovirus can cause complications. This includes symptoms that affect the following systems:
    - Fever
    - Pink eye
    - Sore throat
    - Bronchitis
    - Pneumonia
    - Diarrhea
  - Adenovirus is spread through direct contact with those who are infected. This could be through close personal contact, in the air by coughing and sneezing, touching objects that the adenovirus has contaminated. Avoiding others with any type of infection and performing frequent handwashing is recommended.
  - If blood tests show that you have adenovirus, we may try to decrease your immune-suppressant medications so your body can respond to the virus. You may require medications that can help you with your symptoms.
  - We will continue to monitor you depending on your transplant and post-transplant recovery.

### Allogeneic Post-Transplant

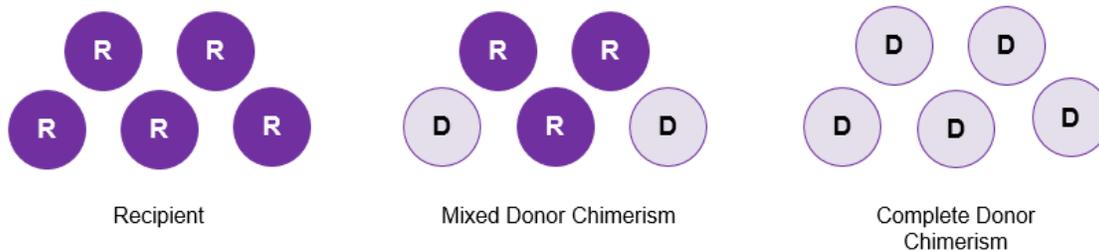
The post-transplant course is different for allogeneic transplants. You will be watched closely for engraftment and signs of graft versus host disease (GvHD). Engraftment is when the HPC or stem cells

begin to produce new cells, such as, white blood cells, red blood cells and platelets. We watch for engraftment through lab tests. We look at your white blood cells, red blood cells and platelets. This is a sign that your transplanted cells are taking over and producing new cells in the bone marrow. We can also look at a blood test called chimerism. Chimerism is a blood test that tells us how much of your cells are yours and how much is your donor's.



### Chimerism

Chimerism is two or more cell populations of different chromosomal make up, derived from different people. In your case, you the patient (sometimes referred to as the host) and your donor. This test tells us what percent donor make up you are. Depending on your type of transplant and conditioning regimen in may take longer for your donor chimerism to increase. We will follow this throughout your post-transplant course and watch for trends.



### Graft versus Host Disease (GvHD)

After your transplant, you will also be watch closely for signs of graph versus host disease (GvHD). GvHD occurs when your new donor cells recognize your body as foreign and react against you. GvHD can be mild and be treated in the outpatient setting or may be severe and require you to be in the hospital. Many factors may affect GvHD from occurring. The Transplant Team looks at these factors when selecting donors, based on you, your disease and prior treatment.

- Patient (may also be referred to as the recipient or host) factors:
  - Your age
  - Prior infections you may have had
  - Prior treatments you may have received
  - Receiving a myeloablative conditioning regimen
- Donor (graft) factors
  - Donor's age
  - Degree of HLA match between you and your donor
  - Having a female donor for a male recipient

- Number of pregnancies the donor has experienced
- Amount of T-cells in your HPC product

Based on the type of transplant you receive your Transplant Team will give you medications called immune-suppressants. These medications help to suppress your immune system, which prevents you from rejecting your donor cells. These medications are also used to prevent GvHD. You must take these medications as prescribed. Do not stop any of these medications, unless directed by your Transplant Team. While you are on these medications, you are at a higher risk for infection because we are suppressing your immune system. These medications may include:

- Mycophenolate mofetil (also called, MMF or Cellcept®)
- Cyclosporine
- Tacrolimus
- Sirolimus

Some of these medications (cyclosporine, tacrolimus and sirolimus) require us to monitor their levels in your blood. We monitor these drug levels through a blood test to make sure you are on a dose that is right for you. It is important to remember on the days that you come to clinic that we will be checking these drug levels. Do not take your dose on the morning you come to clinic. We will be checking these drug levels and it may affect the lab results. If you have received cyclosporine or tacrolimus through your central venous catheter we will take this blood test through a venipuncture (drawing blood from your arm). We do this because these two drugs can adhere to the lining of your central venous catheter and may affect the results of the drug level.

A small amount of GvHD can be a good sign after transplant by producing a graft versus tumor (GvT) effect. The GvT effect is when the donor's immune system works to destroy remaining cancer cells. Patients who have some GvHD can have a lower risk of relapse.

There are two types of GvHD that may occur after allogeneic transplants: acute GvHD and chronic GvHD. It is very important that you watch for signs of GvHD and tell your Transplant Team if you notice any changes.

### **Acute GvHD**

Acute GvHD generally occurs in the first 100 days after transplant. It may also happen when we stop or decrease your immune-suppressant medications. Acute GvHD may affect the skin, the gastrointestinal tract (gut), and/or the liver.

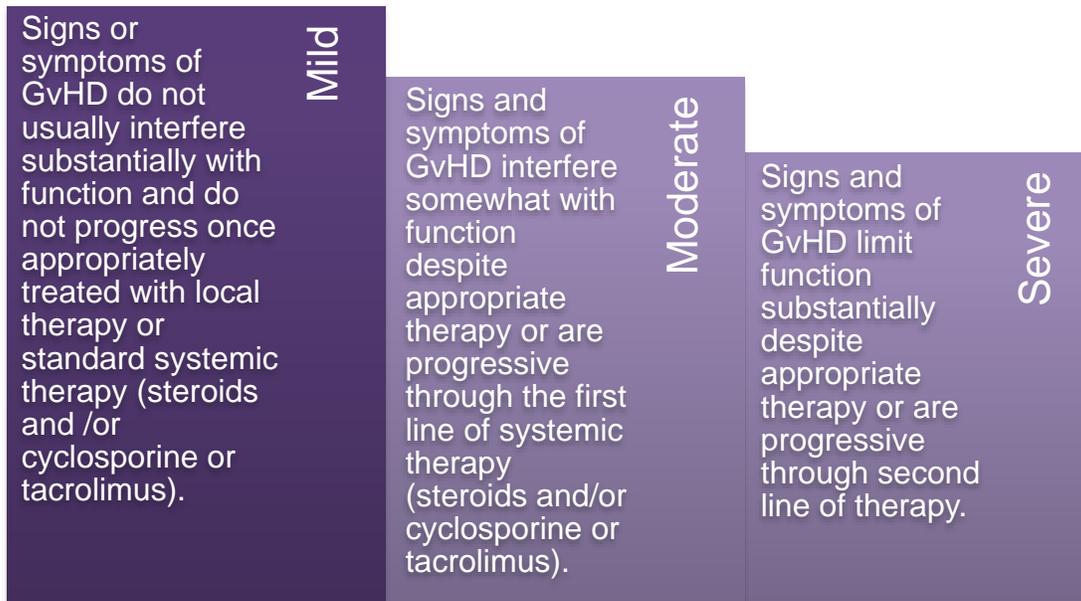
- Skin: changes in the skin, often looks like a rash. It is important to look at your skin regularly.
- Gastrointestinal: symptoms may include nausea, vomiting, pain or cramping, and/or diarrhea. It is important if you notice diarrhea that you keep track of how frequently this happens and about how much you are having.
- Liver: you may have an increase in liver function tests (LFTs). We monitor these blood tests frequently after transplant.

### **Chronic GvHD**

Chronic GvHD usually occurs after day +100, after transplant. The symptoms may come and go with time and treatment or they may persist (be chronic). Chronic GvHD can affect almost any organ or system. The effects of chronic GvHD may include:

- Changes to the skin. These may include:
  - Thickening of the skin
  - Tightness
  - Ulceration
  - Rash, changes in pigmentation or color changes
- Changes to the fingernails and toenails. This may include texture changes or brittleness
- Changes to the eyes, which may include:
  - Dryness
  - Irritation
  - Blurred or double vision
- Changes to the mouth, which may include:
  - Dryness
  - Sores or ulceration
  - Sensitivity or pain
  - Trouble swallowing
- Changes is to the gut, which may include nausea or changes in weight.
- Difficulty or discomfort with urination
- Changes to the lungs, include may include symptoms of:
  - Coughing
  - Shortness of breath
  - Chest pain
- Changes to the liver that may increase liver functions tests (LFTs)
- Changes to the muscles or joints, which may include:
  - Pain
  - Stiffness
  - Tightness and/or decreased range of motion (movement ability) at joints (such as wrists, elbows, ankles and knees).
- Severe fatigue

The symptoms of chronic GvHD can be mild, moderate or severe.



Everyone is different. We cannot predict if you will develop GvHD or how severe the GvHD may be. It is very important to tell the Transplant Team if you notice any of the symptoms for acute or chronic GvHD. You should report any and all new symptoms. You may need to return to the hospital for diagnosis and management or you may be able to have some GvHD managed in the clinic setting. We may need to do a biopsy to see if GvHD is present. How severe the symptoms of GvHD are and how GvHD is treated varies. Most of the time, though, GvHD can be treated. However, sometimes it can be life threatening.

Treatment of GvHD is specific to you. It depends on the type of GvHD you have and the how bad the symptoms are. Approaches to treatment are described below. Your Transplant Team may use these alone or in combination to treat your GvHD. There are additional approaches they may use. This will all be discussed with you before treatment.

- The use of immuno-suppressants. As discussed, these include cyclosporine, tacrolimus and sirolimus. Depending on your post-transplant course, these may be restarted, changed or doses altered for treatment.
- Steroids
- Extra-corporeal photopheresis (ECP).
  - ECP is a procedure that takes blood from your body (usually through a central venous catheter) and processes it through a machine. The machine separates and treats the lymphocytes. Lymphocytes are type of white blood cell that can start the GvHD process. The goal of ECP is to suppress the donor lymphocytes to control that process. All the blood, including the treated lymphocytes, is then returned to the body through a separate IV catheter.
  - ECP
    - Extra = doing a procedure outside the body
    - Corporeal = refers to the patient's blood cells
    - Photopheresis = ultraviolet "light" therapy

## Donor Lymphocyte Infusion (DLI)

After transplant, there is a chance that your chimerism may decrease or your disease may relapse, or come back. In some cases, we use what is called donor lymphocyte infusions or DLI. DLI is taking small doses of lymphocytes from your donor. These cells may have been previously collected, cryopreserved (frozen) and stored at the original time of collection. If these were not previously collected, we would ask the donor if they would be willing to donate DLI. Lymphocytes are a type of white blood cell that can cause the graft versus tumor (GvT) effect. DLI is used to:

- Preserve or regain donor chimerism
- Preserve or regain GvT effect and help fight disease relapse

These donor lymphocytes are given to you much as the transplant was given, through an IV catheter. There are risks to receiving DLI. These may include:

- Pancytopenia (low blood counts)
- Severe acute GvHD

To prevent or lessen these risks we give DLI in small, increasing doses. We watch you closely for side effects. If you are given more than one DLI, you will usually have them 6 to 8 weeks apart. There are times that DLI cannot stop your disease from progressing. Your Transplant Team will discuss the possible benefits and risks of DLI with you in detail, specific to your situation.

## Recovery

Recovery is the long-term process of regaining blood cell production and immune function as well as strength, energy, and appetite after a transplant. This process begins in the hospital and continues after you are discharged from the hospital. The recovery process may last for months, even years, until your body has regained its highest possible level of functioning.

Your Transplant Team will tell you when to return for clinic visits. You should expect these to be at least once a week and more often based on your need. They will arrange for home health care, if you need it. Please call your Transplant Team's office if you have questions or need referrals for social service, physical and occupational therapists, dietitians, and other services. Your Transplant Team will be glad to answer questions at any time.

## When to Call

It is important that you call your Transplant Team with any questions or concerns. You know yourself better than anyone and we rely on you to keep us informed. **Always call your Transplant Team if you experience any of the following:**

- Fever of 100.4° Fahrenheit (38° Celsius) or higher
- Sweating or shaking chills
- Redness, tenderness or swelling anywhere. This includes your central venous catheter site.
- Trouble flushing your central venous catheter or chills when flushing it
- Coughing, sneezing, runny nose, shortness of breath, or chest discomfort
- Headaches that do not improve
- Blurred or double vision
- Trouble swallowing or new mouth sores
- Pain with urination and/or urinating more often than usual. Urine that smells bad or is cloudy
- Bleeding (nose, vomit, urine, stool)
- Bruising
- Red, swollen or painful areas
- Diarrhea, constipation, or vomiting
- Fever and chills or hives and itching after a blood transfusion
- New rash
- Abdominal cramping or pain with diarrhea
- Exposed to the flu, chickenpox, shingles or measles

If you develop any unusual symptoms, please call your Transplant Team right away. There is someone to answer your call 24 hours a day.

## Caregivers

Caregivers are a vital part of a patient's health and healing. A positive outcome depends on you and your caregivers following a treatment plan that includes clinic visits, outpatient hospital procedures, a special diet and taking medications as instructed by the Transplant Team. While we hope for a speedy recovery, many patients are in a weakened condition after transplant and may need assistance following transplant. The recovery process takes a long time and may make many demands on you

and your caregivers. You may need help with meals, medications and appointments. This is where the caregiver role is crucial. The Transplant Team's doctors, nurses and social workers are here to you and your caregivers every step of the way. If you have any concerns or questions, please do not hesitate to reach out to us.

## Your Central Venous Catheter

If you go home with a central venous catheter, there are precautions that you should take to avoid infection. These include:

- Do not let your central venous catheter soak in water while bathing or showering.
- Avoid swimming in ocean, lakes, pools and hot tubs, as they contain bacteria.
- Dressing changes will be done at least once a week (or more often if the dressing is loose or dirty) in the clinic or at home by a homecare nurse.
- Call your Transplant Team if you notice any redness, tenderness, or swelling at the catheter site.

## Precautions

You can expect that it will take at least six (6) months to one (1) year to develop your immune system. After transplant, it is important to prevent infections. Precautions we ask you to take after transplant include:

- **Please wash your hands frequently!** It is the best way to prevent infection.
- Make sure your visitors are washing their hands frequently and correctly.
- Wear a mask in public places for the first six (6) months after allogeneic transplant. This may be longer for allogeneic patient who are immuno-compromised (on immune-suppressants, receiving treatment for GvHD).
  - It is especially important to wear a mask on elevators. This includes when you are coming to your clinic visits.
- Have your family and caregivers get the seasonal flu vaccine.
- Avoid crowds for six (6) months for allogeneic patients.
- Avoid contact with anyone who is sick or who has been exposed to communicable disease (flu, chicken pox, shingles and measles).
  - Be informed of any communicable diseases in your child or grandchild's daycare and/or school.
- Avoid contact with anyone who recently received a "live" vaccine immunization.
  - "Live" vaccine immunizations include nasal flu mist, measles, mumps, rubella (MMR), varicella (chickenpox), zoster (shingles), rotavirus and some polio vaccinations.
  - If someone living with you needs vaccinations, they should be given inactivated vaccines (such as for polio). They should not have live or oral (by mouth) vaccines.
  - If someone living with you receives a live vaccine for polio, avoid contact with them for four (4) to six (6) weeks.

## Household Precautions

- Do not go back to doing your housecleaning chores until you have talked to your Transplant Team about when it is safe to do so.
- Wash your hands after handling trash.

- Do not begin any construction projects in your home. If there is currently construction taking place, avoid these areas.
- Avoid contact with chemicals and fumes. These may be found in cleaning supplies, gasoline, paints, pesticides, herbicides, fertilizers, etc.
- Avoid fresh plants or flowers by placing them in rooms you do not use. Do not touch soil or water that has been sitting in pots or buckets. It may contain large amounts of bacteria.
- Do not use vaporizers and dehumidifiers.
- Avoid dust, dirty and mold
- Avoid smoke-filled areas, secondhand smoke and wood burning fires.

### **Pets and Animals**

- Pets can stay in the home except for birds and reptiles.
  - Do not touch birds, reptiles or exotic pets (lizards, snakes, frogs, turtle and ferrets).
- Pets should be up to date on vaccinations and preventative care (for example, flea and tick prevention, intestinal worm prevention).
  - Before going home, have your cats and dogs tested for toxoplasmosis and parasites.
- Wash your hands after contact with animals.
- You should not kiss, hug or sleep with your pet.
  - If you can, have them sleep outside your bedroom.
- Avoid scratches and bites for the first 3-6 months after transplant and during time of immunosuppression.
- Feed your pet high quality, commercial pet food. Do not feed them table scraps or leftovers.
- Avoid direct contact with pet saliva, urine, and feces.
  - Do not clean yard waste, litter boxes, cages, turtle tanks, or aquariums.
- Talk to your Transplant Team first before getting any new pets after transplant.
- Do not come in close contact with outdoor or farm animals.

### **Physical Activity**

Physical activity is important to your recovery. The best way to improve symptoms of fatigue is to take part in physical activity. You should:

- Keep up the exercise program that was set up for you while you were in the hospital.
- Stay active to keep lungs, heart, bones and muscles stronger.
- Space out activities throughout the day. Give yourself time to rest in between activities.
- You know yourself best. Listen to your body. Avoid exhaustion. Remember that it could take up to 6 months or more before your stamina returns.

### **Hygiene**

Hygiene is another way to prevent the spread of infection. We recommend that you:

- Keep your hands clean by washing them often with soap and water, especially before eating and after using the bathroom. Hand washing is the most important thing you and your caregivers can do to prevent infections. Remind your caregivers and visitors to wash their hands often and before having any direct contact with you.

- Shower every day with your own soap, washcloth, and towel. This will reduce bacteria on the skin and lower your risk for infection. Use a gentle, nondrying soap such as Basis or Dove. Avoid harsh soaps such as Ivory, Irish Spring and Dial. Protect your central venous catheter dressing while showering or bathing.
- Use hypoallergenic lotion (such as Eucerin, Lubriderm and Cetaphil) twice a day to moisturize your skin. Avoid lotions containing alcohol. These can dry the skin. Avoid facial astringents.
- Wear eyeglasses rather than contact lenses, when possible. If you wear contact lenses, make sure they are cleaned thoroughly before wearing.
- Throw away makeup products used before transplant, especially eye makeup. Replace with new makeup. Make sure it is hypoallergenic and changed every three (3) months.
- Do not use acrylic nails for at least one (1) year
- Use sunscreen (with at least SPF 30), protective hat and sunglasses while you are outside. Avoid prolonged sun exposure after transplant.
- Clean all cuts and scratches. Call your Transplant Team if you have cuts or scratches that are reddened or non-healing.
- Hair and nails usually start to grow back about three months after transplant.

### **Mouth Care**

- Check your mouth and lips each day for blisters or sores. Check your tongue for any white patches, cracks or areas of bleeding. Tell your Transplant Team if you have any of these signs.
- Brush your teeth with a soft-bristled toothbrush. Use a non-flavored toothpaste with fluoride such as Biotene or Sensodyne.
- Use a mouthwash without alcohol such as Biotene or Oasis. You may also make your own mouth rinse with 1 teaspoon of baking soda in 1 quart of bottled water.
- Ask your Transplant Team when you may see your dentist. Ask if there are any precautions you should take before your dental appointments. These are usually scheduled within 6 months of transplant.
- If you need to have any dental work done, have your dentist speak with your Transplant Team first. You may need to take antibiotics to prevent infection while you are having this dental work.

### **Bleeding Precautions**

- Shave with only an electric razor
- Blow your nose gently
- Avoid contact sports or heavy exercise that may cause injury such as horseback riding, weight lifting, or skiing until your platelet level is greater than 50,000 without transfusions.
- Avoid using rectal thermometers, rectal suppositories, and enemas.
- Avoid sharp objects when possible.
- Use a soft-bristled toothbrush or Water Pik.
- You may floss your teeth when your platelet level is more than 50,000.
- Call your transplant team if you notice any excessive bruising, petechiae (tiny, pinpoint, purplish-red spots on the skin) or bleeding.
- Avoid aspirin and non-steroidal anti-inflammatory drugs (NSAIDs), such as Advil or Motrin. They can irritate your stomach and interfere with how well your platelets work.

## **Outside Your Home**

- Avoid traveling on a plane until your Transplant Team approves this. Discuss any travel with your Transplant Team beforehand.
- Carry your medical history information and a current medication list when traveling.
- Avoid public pools, hot tubs, ponds and lakes.
- Limit your exposure to the sun. Sit in the shade. Wear sunscreen with SPF of 30 or greater and reapply frequently. Wear protective clothing such as a wide-brimmed hat, long sleeved tops and long pants to prevent sunburn. Avoid lying out in the sun.
- Avoid construction areas.
- Take precautions to avoid tick bites. Wear long sleeve clothing, use DEET, do frequent body checks, etc.
- Avoid travel to developing countries for six (6) to 12 months after transplant and also during periods of intense immunosuppression.

## **Driving**

- You need to be strong and have quick reflexes for safe driving. The Transplant Team will discuss your progress and the medications you are taking before you should drive.
  - Certain medications can affect your ability to drive safely.
- You cannot drive for a period of time after transplant. This timeframe varies and you should talk to your Transplant Team before you begin driving again.

## **Work**

- Returning to work will depend on the type of transplant and your recovery.
- The decision of when to return to work should be made with your Transplant Team. This decision considers your physical condition, physical demands and work conditions.
  - Allogeneic patients should not expect to return to work for 6 to 12 months.

## **Seasonal Activities**

Patients should avoid the following activities for at least one (1) year after transplant and when on immune-suppressant medications:

- Hay rides
- Going to orchards
- Hunting
- Lawn mowing, landscaping, raking leaves, cutting trees and other activities that stir up soil and dust.
- A live Christmas tree. You may have an artificial Christmas tree.
- Fishing is okay if you do not handle any bait or fish
- Sledding and skiing are OK only after your platelets are recovered

## **Sexual Health**

The stress of illness, transplant, and being in the hospital may cause changes in the way you feel about intimacy. Sexuality is central to one's identity, self-esteem and quality of life. Intimacy can reduce stress and help you cope with other complications after transplant. Women may have vaginal changes, premature menopause, painful intercourse or changes in sex hormones. Men may have erectile or ejaculatory problems, or changes in sexual hormones. Both men and women may have a lower sex

drive or painful intercourse or infertility. Everyone's post-transplant course is different. We want to focus on your needs and desires. Feel free to discuss any questions or concerns with your Transplant Team.

- You can go back to sexual activity when you feel ready and feel healthy.
- Use a latex condom for six (6) months after allogeneic transplant.
- You should stay with one partner to reduce the risk of getting sexually transmitted infections (STIs).
  - It is recommended that condoms and dental dams be used during sex to reduce the risk for STIs.
- You should avoid contact with mouth and genital secretions.
- You should not have anal sex and should not come in contact with stool.
- Women:
  - Should use a water-based lubricant to help vaginal dryness.
  - Some women may need hormone replacement therapy to manage symptoms of menopause.

### **Immunizations**

During the transplant course, you will lose much of the immunity that you have built prior to transplant. This includes the immunity you have built from vaccinations. Vaccinations are important to protect you from preventable diseases. After transplant you will have to be revaccinated with all your previous vaccines. For allogeneic transplants, it may be possible that you gain some immunity from your donor. However, this is limited. You cannot rely on this to protect you from disease. If you experience chronic GvHD, there is a greater chance of losing immunity.

- Do not begin any vaccinations without first talking with your Transplant Team.
- Your immunization schedule usually begins a few months after your transplant. Your schedule is based on your type of transplant and treatment.
- You will be given the influenza ("flu") vaccine as early as three (3) months after transplant.
- You will receive inactivated vaccinations. Do **not** receive any live or active vaccinations without first talking with your Transplant Team.

### **Smoking and Alcohol**

- After transplant you are at a higher risk for lung damage and infections. Therefore, you should not smoke or be around secondhand smoke.
- Discuss drinking alcohol (wine, beer, mixed drinks) with your Transplant Team.
  - You should avoid alcohol for the first 6 months after transplant.
  - Do not drink alcohol until enough platelet and mucosal recovery has occurred.

# Immunocompromised Diet and Food Safety

## Managing Symptoms

Good nutrition is vital to your recovery. After you are discharged from the hospital, you may have a smaller appetite, nausea, changes to your taste, mouth sores, or diarrhea. These problems slowly improve over time. Some tips to help with these symptoms are:

- Eat smaller portions. Choose foods that are easy to chew and swallow. Eat every 2-3 hours. Doing this helps maintain your weight and prevents nausea. High fat foods may make nausea worse, so consider limiting them.
- Choose high protein foods such as chicken, meat, fish, turkey, eggs, peanut butter, yogurt, milk, cheese, peas, beans, tofu, nuts and seeds.
- Drink high calorie beverages. Good choices are milkshakes, smoothies, and nutritional supplements such as Ensure Plus®/Pediasure® or Boost Plus®/Boost Kid Essentials 1.5®.
- If you have diarrhea, focus on low-fiber foods. Good choices are white breads, rice, and pasta, cooked vegetables such as potato without the skin, fruits such as bananas or applesauce, and proteins such as chicken without the skin, eggs, tofu, or fish.
- Changes to your taste will slowly get better with time.
  - Practice good oral hygiene (mouth care). See “Mouth Care” section.
  - Put lemon, lime, or orange on foods or in beverages to improve taste.
  - Try vinegar or vinegar-based products (for example, pickles) before meals.
  - Suck on lemon-flavored candy before meals.
  - Mix ¼ tsp baking soda and ¼ tsp salt in 8 oz water. Use this as a mouth rinse before and after eating.
- A dietitian is available to help with any of your nutrition questions or concerns. Let your team know if you would like to meet with them at any time.

## Post-Transplant Dietary Guidelines

After your transplant, you may be more susceptible to illness from foods (foodborne illness). Certain foods may contain bacteria, viruses or parasites that can make you sick. This diet will help lower your risk of getting a foodborne illness.

- For **autologous** transplant patients: You will follow this diet for six (6) months after transplant or until your doctor tells you to stop.
- For **allogeneic** transplant patients: You will follow this diet for at least one (1) year after transplant and you are off all immunosuppressive therapy, or until your doctor tells you to stop. You may need to stay on the diet longer if you have chronic graft versus host disease (cGVHD), or it has been 8 weeks after you complete immunosuppressive therapy.

## Food Handling

Follow these guidelines and tips to avoid getting an infection from food (foodborne illness).

### Cleaning and preparing:

- Wash your hands for 20 seconds with soap and warm, running water before and after handling food<sup>1,6</sup>.
- Clean all surfaces where food is prepared, such as countertops and tables. Use different cutting boards, utensils, and plates for cooked and raw foods<sup>1</sup>.

- Clean cutting boards with a dilute bleach solution of *1 tablespoon unscented chlorine bleach per gallon of water* or run through the dishwasher.<sup>2,6</sup>
- Keep sponges and towels clean.
  - Sanitize sponges daily and after contact with raw meat, poultry, fish and eggs. To clean, soak in the above dilute bleach solution for 5 minutes, heat in microwave on high for 1 minute, or run through the dishwasher.<sup>3</sup>
- Wash all fruits and vegetables under cold, running water for 30 seconds<sup>1</sup>. Do not use soap. Use scrub brush as needed<sup>1</sup>.
- Clean lids of cans and can opener with hot, soapy water<sup>1</sup>.
- Do not purchase produce that is pre-cut, moldy, bruised or damaged<sup>4</sup>.
- Do not buy canned goods with dents, cracks, or bulging lids<sup>5</sup>.
- Avoid buying foods from self-service or bulk bins<sup>6</sup>.
- Check and abide by “use by” and “sell by” dates on food packages<sup>6</sup>.

**Food storage and cross-contamination:**

- Keep raw meats, poultry, seafood and eggs separate from raw fruits and vegetables<sup>6</sup>.
- Thaw frozen foods in the refrigerator or in cold water<sup>1</sup>. Never thaw food at room temperature<sup>1,6</sup>.
- Refrigerate or freeze leftovers within 2 hours<sup>1</sup>. Split larger entrees, such as soups and meats, into smaller portions to cool faster.
- Place leftovers in the refrigerator with a date. Throw leftovers away if not eaten in 72 hours (3 days)<sup>7</sup>.
- Avoid sharing food or drinks with other people<sup>9</sup>.

**Cooking to safe temperatures:**

- Avoid raw foods such as sushi, rare meats and runny eggs<sup>6</sup>.
- Cook meat, poultry (chicken, turkey), eggs and seafood fully through.
- Keep hot foods hot (over 140°F) and cold foods cold (under 40°F)<sup>6</sup>.
- For microwave cooking, rotate the dish a quarter of a turn once or twice during cooking to make sure no cold spots remain where bacteria can survive<sup>6</sup>.
- When heating leftovers in the microwave, cover with a lid and stir several times during reheating<sup>1</sup>. When the food is heated to a minimum of 165°F, cover and let sit for 2 minutes before serving.

**Safe Minimum Internal Cooking Temperatures**

Food	Temperature (°F) <sup>1</sup>
Ground beef, pork, veal, lamb	160
All poultry (chicken, turkey, duck, etc.)	165
Fresh beef, veal, lamb (steak, roast, chops)	145
Fresh pork, including fresh ham	145
Precooked ham (to reheat)	165
Leftovers and casseroles	165
Eggs	Until yolk and white are firm
Egg Dishes (for example, frittata, quiche)	160
Fish	145
Seafood	Until flesh is opaque or shells open

## Diet Guidelines

Food Group	Foods Allowed	Foods to Avoid
Milk and Dairy	<p>All <b>pasteurized</b> products:</p> <ul style="list-style-type: none"> <li>• Grade A milk and milk products:               <ul style="list-style-type: none"> <li>○ Ice cream, frozen yogurt, sherbet, ice cream bars, eggnog, milkshakes, yogurt, processed cheese slices and spreads, cream cheese, cottage cheese, ricotta cheese, kefir</li> </ul> </li> <li>• Dry, refrigerated or frozen pasteurized whipped topping</li> <li>• Commercially packaged hard and semisoft cheeses:               <ul style="list-style-type: none"> <li>○ Cheddar, Mozzarella, Parmesan, Swiss, Monterey Jack, etc.</li> </ul> </li> <li>• Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if ready-to-feed or liquid concentrate alternative is available)</li> </ul>	<p>All <b>unpasteurized</b> products:</p> <ul style="list-style-type: none"> <li>• Raw and unpasteurized milk, cheese, eggnog, yogurt or kefir</li> <li>• Cheeses from a deli</li> <li>• Milkshakes, soft serve ice cream, and frozen yogurt from a machine</li> <li>• Cheese that contains chili peppers or other uncooked vegetables</li> <li>• Cooked and uncooked cheese with molds:               <ul style="list-style-type: none"> <li>○ Blue cheese, Stilton, Roquefort, Gorgonzola</li> </ul> </li> <li>• Uncooked, unpasteurized soft cheeses (Can eat if cooked until melted.):               <ul style="list-style-type: none"> <li>○ Brie, Feta, Farmer's cheese, Camembert, goat cheese, fresh Mozzarella</li> </ul> </li> <li>• Unpasteurized Queso fresco, Queso blanco</li> </ul>
Eggs	<ul style="list-style-type: none"> <li>• Eggs cooked until yolk and white are firm</li> <li>• Pasteurized eggs and egg substitutes (such as Egg Beaters®), powdered egg whites</li> </ul>	<ul style="list-style-type: none"> <li>• Raw or undercooked eggs and unpasteurized egg substitutes:               <ul style="list-style-type: none"> <li>○ Eggs over easy, soft-boiled, poached</li> </ul> </li> </ul>

<p>Meat and Meat Substitutes</p>	<ul style="list-style-type: none"> <li>• All meats cooked to well done</li> <li>• Canned meats</li> <li>• Commercially packaged salami, bologna, hot dogs, ham, and other luncheon meats – <i>heated until steaming</i></li> <li>• Canned and shelf-stable smoked fish – <i>refrigerate after opening</i></li> <li>• Pasteurized or cooked tofu</li> <li>• Refrigerated smoked seafood: <ul style="list-style-type: none"> <li>○ Salmon or trout if fully cooked or cooked in casserole</li> </ul> </li> <li>• Cooked and pasteurized tempeh (fermented soybean cake) products</li> <li>• Prepackaged jerky</li> </ul>	<ul style="list-style-type: none"> <li>• Raw or undercooked meat, poultry, fish, game meats, carpaccio</li> <li>• Meats and luncheon meats from a deli</li> <li>• Unpasteurized tofu and tempeh</li> <li>• Unpackaged hard cured salami in natural wrap</li> <li>• Uncooked, refrigerated smoked seafood: <ul style="list-style-type: none"> <li>○ Salmon or trout labeled as “nova-style,” “lox,” “kippered,” “smoked”</li> </ul> </li> <li>• Raw fish and shellfish (for example, sushi, oysters, ceviche)</li> <li>• Pickled fish</li> </ul>
<p>Fruits and Nuts</p>	<ul style="list-style-type: none"> <li>• Well-washed raw fruits with no visible cuts, bruises or mold</li> <li>• Frozen, prepackaged berries</li> <li>• Cooked, canned, and frozen fruit</li> <li>• Pasteurized juices and frozen juice concentrates</li> <li>• Prepackaged dried fruits</li> <li>• Canned or bottled roasted nuts/seeds</li> <li>• Nuts/seeds in baked products</li> <li>• Commercially packaged nut/seed butters: <ul style="list-style-type: none"> <li>○ Peanut butter, almond butter, sunflower seed butter, soybean butter, etc.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Fresh berries: <ul style="list-style-type: none"> <li>○ Strawberries, blueberries, blackberries, raspberries</li> </ul> </li> <li>• Unpasteurized fruit juices (for example, apple cider)</li> <li>• Pre-cut fresh fruit found in the grocery store refrigerator case</li> <li>• Foods from “reach in” or “scoop” bulk food containers that will not be cooked prior to consumption</li> <li>• Raw nuts or seeds</li> <li>• Grapefruit</li> <li>• Pomegranate</li> </ul>
<p>Entrées, Soups and Vegetables</p>	<ul style="list-style-type: none"> <li>• Well-washed raw vegetables</li> <li>• Cooked vegetable sprouts</li> <li>• Well-washed fresh herbs</li> <li>• Dried herbs and spices cooked into foods</li> <li>• All cooked entrées and soups</li> <li>• All cooked fresh, frozen, or canned vegetables and potatoes</li> <li>• Shelf-stable bottled salsa – <i>refrigerate after opening</i></li> </ul>	<ul style="list-style-type: none"> <li>• Unwashed, raw vegetables</li> <li>• All raw vegetable sprouts<sup>4</sup>: <ul style="list-style-type: none"> <li>○ Alfalfa sprouts, clover sprouts, mung bean sprouts, etc.</li> </ul> </li> <li>• Salads from the deli or salad bar</li> <li>• Unpasteurized vegetable juices</li> <li>• Pre-cut vegetables or salsa found in the grocery store refrigerator case</li> </ul>

		<ul style="list-style-type: none"> <li>All miso (fermented soybean paste) products, such as miso soup and miso paste</li> </ul>
Breads, Grains and Cereals	<ul style="list-style-type: none"> <li>All breads, bagels, rolls, English muffins, muffins, pancakes, sweet rolls, waffles, French toast</li> <li>Potato chips, corn chips, tortilla chips, pretzels, popcorn</li> <li>Cooked grains and grain products, including pasta and rice</li> <li>All cereals, cooked and ready-to-eat</li> </ul>	<ul style="list-style-type: none"> <li>Raw oats and uncooked grains</li> <li>Breads, rolls and pastries from self-service bins or bakeries</li> <li>Do not handle or consume raw or uncooked yeast, brewer's yeast or nutritional yeast</li> </ul>
Desserts	<ul style="list-style-type: none"> <li>Refrigerated cakes, pies, pastries, pudding, cream-filled pastries</li> <li>Cookies, Candy, gum</li> <li>Commercially packaged shelf-stable cream filled cupcakes and fruit pies: <ul style="list-style-type: none"> <li>Twinkies®, Ding Dongs®, fruit pies, Pop-Tarts®, etc.</li> </ul> </li> <li>Prepackaged frosting – <i>refrigerate after opening</i></li> <li>Homemade frosting with approved ingredients – <i>refrigerate after preparing</i></li> <li>Ices, popsicles, and similar foods</li> </ul>	<ul style="list-style-type: none"> <li>Unrefrigerated cream-filled pastry foods (for example, cream-filled donuts, creampuffs)</li> <li>Milkshakes and soft serve ice cream and frozen yogurt from a machine</li> <li>Raw cookie dough</li> <li>Avoid bakeries/items packaged from a bakery</li> </ul>
Fats	<ul style="list-style-type: none"> <li>Vegetable oils and shortening, refrigerated lard, margarine, butter</li> <li>Commercial shelf-stable mayonnaise and salad dressings including blue cheese and other cheese-based dressings – <i>refrigerate after opening</i></li> <li>Cooked gravy and sauces</li> </ul>	<ul style="list-style-type: none"> <li>Fresh salad dressings found in the grocery store refrigerator case</li> <li>Dressings with raw eggs or cheeses listed under the dairy section of this table (for example, homemade blue cheese dressing or Caesar dressing)</li> </ul>
Other	<ul style="list-style-type: none"> <li>Grade A honey</li> <li>Salt, granulated sugar, brown sugar</li> <li>Jam, jelly, syrups – <i>refrigerate after opening</i></li> </ul>	<ul style="list-style-type: none"> <li>Raw honey; honey in the comb</li> <li>Herbal, dietary, probiotic and multivitamin/mineral supplements – unless recommended by your physician</li> </ul>

	<ul style="list-style-type: none"> <li>• Ketchup, mustard, BBQ sauce, soy sauce and other condiments – <i>refrigerate after opening</i></li> <li>• Pickles, pickle relish, olives – <i>refrigerate after opening</i></li> <li>• Vinegar</li> </ul> <p>**Honey products are not allowed for any child less than one year old and not allowed for children with SCIDS until nine months post-transplant</p>	<ul style="list-style-type: none"> <li>• Uncooked Brewer’s yeast</li> <li>• Uncooked freshly ground pepper or imported spices<sup>8</sup></li> <li>• Foods in bulk bins</li> </ul>
Beverages	<ul style="list-style-type: none"> <li>• Tap (city) water and ice made from tap water</li> <li>• All canned, bottled and powdered beverages – <i>Rinse cans and pour liquid into a cup before drinking.</i></li> <li>• See Safe water section below on well water and bottled water</li> <li>• Instant and brewed coffee or tea</li> <li>• Herbal teas brewed from packaged tea bags</li> <li>• Nutritional supplements, both liquid and powdered: <ul style="list-style-type: none"> <li>○ Carnation Instant Breakfast<sup>®</sup>, Ensure<sup>®</sup>, Pediasure<sup>®</sup>, or similar</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Well water – unless boiled (see water section below)</li> <li>• Cold-brewed tea or coffee made with warm or cold water</li> <li>• Unpasteurized beverages: <ul style="list-style-type: none"> <li>○ Kombucha tea</li> <li>○ Fruit and vegetable juices</li> </ul> </li> <li>• Slushies or milkshakes from a public machine</li> <li>• Alcohol – speak with your doctor about alcohol</li> <li>• Grapefruit juice</li> <li>• Pomegranate juice</li> </ul>

### Resistant Starch

*This type of carbohydrate, or starch, resists digestion in the intestine. This helps promote a healthier digestive system. Include at least (1) one cup of one of the following sources per day:*

- Plantains and green bananas
- Beans, peas, seeds and lentils
- Cooked and cooled rice, potatoes, pasta, cereal and whole grains (for example, oats, barley, millet, buckwheat, etc.)
- Green banana flour, plantain flour, cassava flour, or potato starch
  - Resistant starch will be lost when baking or cooking with these foods. Consider sprinkling a small amount of the flours (1-2 teaspoons) on your food after cooking or mix into smoothies.
  - Choose Bob’s Red Mill<sup>®</sup> or other precooked brands for food safety

### Water

- Municipal (city) tap water is safe but be aware of public warnings for “boil-water advisories.”
- If you have well water, have it tested by your local health department.
- Well water can be made safe to drink by boiling it rapidly for 15-20 minutes. Store boiled water in the refrigerator. Throw away water not used within 48 hours (2 days).
- Bottled water is safe if it meets FDA standards. Check your brand at [www.bottledwater.org](http://www.bottledwater.org).
- Avoid fountain drinks and ice at restaurants, bars and theaters, gas stations, etc.

## Eating Out

*In general, we do not recommend eating foods from restaurants or other establishments that serve food. This is because you cannot know if the food was prepared or stored safely.*

- Use your best judgement when choosing a restaurant. Continue to follow diet guidelines.
- Avoid buffets, smorgasbords, deli counters, potlucks, salad bars, food trucks and sidewalk vendors.
- Order cooked foods only. Avoid garnishes and raw sandwich or burger toppings such as lettuce, tomato and onion.
- Ask for food to be made fresh and without condiments. Request single serving packets.
- Consider bringing your own bottled beverages. Avoid ice from restaurants.
- Transfer your own leftovers into a box at the table.
- Avoid sharing food and drinks with friends and family.

## For More Information:

- General Food Safety: [www.foodsafety.gov](http://www.foodsafety.gov)
- Food & Drug Administration: [www.FDA.gov](http://www.FDA.gov)
- Eat Right Home Food Safety: [www.homefoodsafety.org](http://www.homefoodsafety.org)
- Fight BAC! Food Safety Education: [www.fightbac.org](http://www.fightbac.org)
- Centers for Disease Control and Prevention: [www.cdc.gov/foodsafety/](http://www.cdc.gov/foodsafety/)
- Restaurant Grade: [www1.nyc.gov/site/doh/services/restaurant-grades.page](http://www1.nyc.gov/site/doh/services/restaurant-grades.page)

Tomblyn M, et al. (2009). *Biology of Blood and Bone Marrow Transplant*, 15(10), 1143-1238.

C. Taggart, et al. (2019). *Biology of Blood and Bone Marrow Transplant* 25(7), 1382-1386.

1 <https://www.fda.gov/food/buy-store-serve-safe-food/safe-food-handling>

2 [https://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/get-answers/food-safety-fact-sheets/safe-food-handling/cutting-boards-and-food-safety/ct\\_index](https://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/get-answers/food-safety-fact-sheets/safe-food-handling/cutting-boards-and-food-safety/ct_index)

3 <https://www.ars.usda.gov/news-events/news/research-news/2007/best-ways-to-clean-kitchen-sponges/>

4 <https://www.fda.gov/food/buy-store-serve-safe-food/selecting-and-serving-produce-safely>

5 [https://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/get-answers/food-safety-fact-sheets/safe-food-handling/shelf-stable-food-safety/ct\\_index](https://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/get-answers/food-safety-fact-sheets/safe-food-handling/shelf-stable-food-safety/ct_index)

6 <https://www.cancer.org/content/cancer/en/treatment/survivorship-during-and-after-treatment/staying-active/nutrition/weak-immune-system.html>

7 <https://www.foodsafety.gov/food-safety-charts/cold-food-storage-charts>

8 <https://www.fda.gov/media/108126/download>

9 Taggart, Cynthia, et al. "Comparing a Neutropenic Diet to a Food Safety-Based Diet in Pediatric Patients Undergoing Hematopoietic Stem Cell Transplantation." *Biology of Blood and Marrow Transplantation: Journal of the American Society for Blood and Marrow Transplantation*, U.S. National Library of Medicine, July 2019,

<https://www.ncbi.nlm.nih.gov/pubmed/30910605>.

## Risks of Transplant

Many side effects and complications from transplant can be treated. Everyone is different. The side effects and possible complications they experience after transplant will vary. Talk to your Transplant Team about the side effects you have throughout your transplant course. Often, there are medications, helpful support measures or suggestions that we can offer to help you manage your side effects.

Possible, common side effects may include but are not limited to:

- Low blood counts and an increased risk of infection:
  - Until you engraft, your blood counts will be low. This means it may be hard for you to get rid of any infections. We will take extra care while you are in the hospital and at the clinic to limit your exposure to germs that can cause infection. We will also teach you how to be careful at home. These germs can cause serious infections and sometimes death in people with low white blood cell counts.
  - You will be given medications to both prevent and treat infections that may develop. You may need to stay on these medications after you go home. Once you get home after the transplant, you may need to be readmitted (come back) to the hospital to treat these infections.
- Low blood counts. After the transplant, your bone marrow may not make enough red blood cells (RBCs) and/or platelets:
  - If your RBC count is low, you may have fatigue (a very tired feeling) or shortness of breath.
  - If your platelet count is low, you will have an increased chance of bleeding. Therefore, you may need RBC and platelet transfusions.
  - As your RBC and platelet counts return to normal, you will not need transfusions as often.
- Fatigue or tiredness. Everyone's recovery is different. You should expect this to continue for a couple months at least.
- Hair loss
  - Your hair will most likely grow back in two (2) to three (3) months after transplant. Your hair may grow back in a different color, shade and/or texture.
- Mouth sores (mucositis). Good mouth care is important for your comfort and to prevent infections.
- Nausea and/or vomiting. You will be given medications to help prevent nausea and vomiting during your conditioning regimen. There are other medications we can give you to help with your symptoms throughout the transplant course.

- Electrolyte level imbalance. If this happens, you would need electrolyte replacement. You can take these replacements as a pill by mouth or through your IV. Your lab results and replacement needs will be discussed with you.
- Graft versus host disease (GvHD): GvHD is a condition that happens when your new immune cells (from the donor) see your body as "foreign" and react against you. There are 2 types of GvHD:
  1. Acute: This usually happens within the first 100 days after the transplant. It can affect the skin, gut, and/or liver. The most common reported symptoms are skin rash, nausea and vomiting, belly (abdominal) pain/cramping, diarrhea, high liver-function tests (shown by lab test).
  2. Chronic: This usually happens after Day +100. It can affect the hair, mouth, eyes, lungs, liver, gut, skin, muscles/joints. Symptoms include nausea, skin changes (including tightness and ulcerations), mouth sores, dry eyes, shortness of breath, high liver function tests, and changes in the muscles/joints.

You must tell the Transplant Team if you notice any of the symptoms above or any new symptoms. GvHD may be diagnosed by biopsy. How severe the symptoms of GVHD are and how it is treated vary. Nevertheless, most often, GVHD can be treated.

Possible, less common side effects include but are not limited to:

- Sinusoidal obstruction syndrome (SOS) of the liver:
  - SOS is a condition that happens when the veins in your liver become blocked.
  - To try to help prevent SOS, we will give you a medication called ursodiol (Actigall).
  - Side effects that happen most often are fluid retention/weight gain, jaundice, enlargement/tenderness of the liver.
  - SOS can be life threatening. You will be watched for signs and symptoms of SOS.
- Graft failure:
  - This is when the cells that were transplanted fail to grow or are lost over time.
  - Treatment may include: receiving medications to stimulate the failing cells, stopping certain medications to allow cells to recover, transplanting additional donor cells, or transplanting cells from a second donor.
- Risk to an unborn child:
  - This treatment has not been proven safe during pregnancy. You cannot have this treatment if you are pregnant or nursing. Because of the risk to an unborn child, there will be times throughout the transplant process when you will be instructed not to have sexual intercourse that could lead to pregnancy. Please check with your Transplant Team about when it is safe.

Long term side effects after transplant include, but are not limited to:

- This cancer coming back (recurrence):
  - After the transplant, there is a chance that your cancer may return. You will be monitored closely after the transplant for signs of disease.
- Cancer later in life:
  - The medicines that you get for treatment and transplant rarely cause cancers later in life.
  - It is very important that you have regular exams with your primary care doctor.
    - You should have regular cancer screenings (for breast, testicular, skin, colon, etc.).
    - You should make good health choices such as wearing sunscreen, eating a well-balanced diet, exercise, and not using alcohol or tobacco products.
- Other Risks:
  - There may be some unexpected discomforts or other risks from this treatment in addition to those discussed above.
- Reproduction (the ability to have children):
  - Conditioning regimens use high-doses of chemotherapy and (sometimes) radiation to destroy cancer cells and suppress or eliminate the bone marrow. Side effects of this treatment therapy occur when normal cells in the body are also destroyed by the treatment. Cells of the male and female reproductive systems fall into this category. Transplant patients may suffer from temporary or permanent damage that can affect reproduction or fertility.
  - There are options that can be discussed prior to transplant to preserve fertility.
    - For men, this may include having sperm frozen or “banked” prior to receiving the conditioning regimen, to be used later in artificial insemination or in vitro fertilization.
    - For women, this may include freezing an embryo or egg prior to the conditioning regimen.
    - This requires a consult with a specialist who would be able to provide more detail on the process, along with benefits and risks of the procedure. These procedures are performed at an additional cost, some of which may or may not be covered with by your insurance. If you are interested in discussing your options with a specialist, discuss this with your Transplant Team and they will help you with a consult prior to transplant.

Many factors can affect your post-transplant recovery. These include pre-transplant treatment, conditioning regimen, transplant type, donor source, infections and medications. Other systems of your body may be affected; this may include but are not limited to:

- Changes to the eyes
  - Vision may get worse, cataracts
- Changes to the heart
  - High blood pressure
  - Irregular heartbeat

- Congestive heart failure
- Changes to the lungs
  - Idiopathic pneumonia syndrome (IPS)
- Changes in how your blood clots
  - Stroke
  - Blood clots

## **Going Back to Your Normal Life**

It is natural for you to have many questions about how and when you will be able to go back to your normal life. Most people wonder when they will be able to return to work or school, or travel overseas. Your social worker on the Transplant Team can help you by making any arrangements with your employer, school, or insurance company. Your physical therapist can help outline an activity program. Your dietitian can plan a diet that has enough protein and calories to help you regain your energy.

You will most likely have questions also about your long-term medical and physical health. The answers to each of these questions will be different for each person. The NYU Langone Health Transplant Team is always available to answer any questions you and your family may have, address concerns, and provide suggestions and support.











# Blood Counts

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