



Adult Stem Cell Transplant Program Patient and Family Education Handbook



At the U, we transform lives through teaching, research, and service.

Autologous





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INTRODUCTION

Welcome to Sylvester Comprehensive Cancer Center!

Welcome to Sylvester Comprehensive Cancer Center's Adult Stem Cell Transplant Program. Our team of professionals will help you through your transplant journey. Our goal is to provide you with high-quality care. You have the support of our multi-specialty and multi-disciplinary care team. Our care is guided by evidence-based research.

Sylvester Comprehensive Cancer Center, part of UHealth -- the University of Miami Health System, is the only university-based cancer center in South Florida. The cancer center's history dates back to 1973, and it has been recognized as a Cancer Center of Excellence by the state of Florida. It has more than 130 cancer specialists and 115 cancer researchers. Our staff collaborates with researchers from universities throughout Florida and around the world.

This stem cell transplant handbook is written to:

- Prepare you for your transplant and recovery
- Serve as a resource for you and your caregivers
- Help you understand this information
- Outline ways to reduce the risks associated with transplant-related complications

With this information you will be better prepared to make well-informed decisions together with your transplant team.

We would like to thank you for choosing Sylvester Comprehensive Cancer Center's Adult Stem Cell Transplant Program and for allowing us to be a part of your care.

**A glossary is provided on pages 77 through 88 for your reference on specific terminology used throughout this handbook.*

Telephone Numbers

Stem Cell Transplant Triage Nurse (305) 243-7000

**Available Monday through Friday 8 a.m. to 5 p.m., not on holidays or weekends*

On-call 24-hour pager service (after hours) (305) 243-1000

Available Sunday through Saturday, **including holidays, 5 p.m. to 8 a.m.*

Stem Cell Outpatient Clinic (305) 243-1738

Long-Term Care Follow-up Clinic (305) 243-7000

Graft versus Host Disease (GVHD) Clinic (305) 243-7000

Stem Cell Transplant Finance Dept. (305) 243-6414

Inpatient Stem Cell Transplant Unit (305) 243-9921

Transplant Licensed Clinical Social Worker (305) 243-4129

Chemotherapy Infusion Unit (CTU)

- Miami (305) 243-5234
- Deerfield (954) 571-0124
- Plantation (954) 210-1039

Patient Relations (305) 243-3820

Courtelis Center (305) 243-4129

Cancer Support Services (305)-243-5966 or (305) 243-2165

Pastoral Services (305) 243-1000

Walgreens In-house Pharmacy (305) 423-1757



Stem Cell Transplant Team

The Adult Stem Cell Transplant Team is made up of health care professionals. The following is a list of team members and their roles. You will meet each member at different times during your transition from the pre-transplant to the post-transplant phase.

- **Primary Hematologist**

Hematologists are physicians with special training in the treatment of blood diseases and blood cancers. The primary hematologist is the physician who has referred you to the transplant center. This physician is from within Sylvester or from the community, and has been treating and caring for you prior to coming to us.

- **Transplant Attending Physicians**

The attending physicians are faculty overseeing your treatment and care. These physicians have undergone an additional year of transplant training beyond their hematology/oncology training. Although you will have one specific physician who will be your primary physician, you will be cared for by different stem cell transplant physicians during your transplant. Be assured that these physicians will keep your primary physician updated on your plan of care and progress.

- **Hematology/Oncology Fellow**

The hematology/oncology fellow is a physician who has completed three years of internal medicine residency and is now training to specialize in the care of cancer patients. Periodically, the fellow will be collaborating with the transplant team in the management of patients.

- **Stem Cell Transplant and Cellular Therapy Fellow**

As an integral part of our healthcare team, the Stem Cell Transplant Fellow is a physician-in-training who has already completed internal medicine training as well as a fellowship in hematology/oncology. In pursuit of further specialization toward care of transplant patients, the fellow participates in one additional year of training at Sylvester Comprehensive Cancer Center.

- **Transplant Nurse Coordinators**

Your coordinator is a registered nurse who will be your primary contact for you, your family and primary physician during the pre-transplant phase. She/he will be present at all your pre-transplant clinic visits and is



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responsible for assuring that any procedures, testing and consultations required prior to your transplant admission are performed in a timely manner. She/he will also assure that necessary test results are sent to your insurer. Your coordinator will arrange the collection of your stem cells.

- **Advanced Practice Provider (APP)**

The advanced practice provider is either a nurse practitioner or physician assistant who will be responsible for your daily care when you are in the Stem Cell Transplant Unit, Ambulatory Treatment Center and Outpatient Clinic. The advanced practice provider will assess your condition, review your plan of care and collaborate with your primary transplant physician. These individuals have typically completed a master's or doctoral training. Many of our nurse practitioners have spent several years as hematology/oncology nurses or in an intensive care unit caring for critically ill patients. Some also hold certifications in the care of blood and bone marrow transplant patients.

- **Inpatient Unit and Outpatient Clinic Nurses**

These are licensed practical nurses or registered nurses who have been specially trained to care for transplant patients. They will be caring for you on a regular basis and will be able to contact an advanced practice provider or physician if needed. They also handle the phone calls once you have returned home and have questions or concerns.

- **Transplant Clinical Pharmacist**

The clinical pharmacist works in conjunction with the stem cell transplant team and is responsible for the management of medications for stem cell transplant patients. They will work with your doctor to come up with an appropriate dose for your chemotherapy prior to transplant, in addition to monitoring your medications throughout the transplant process. They have a pharmacy degree that is recognized by the Board of Pharmacy and are licensed to practice in the state of Florida. In addition, they have completed post-doctoral specialized training in hematology/oncology with exposure in or emphasis on stem cell transplant.

- **Licensed Clinical Social Worker**

There is a designated clinical social worker assigned to your care. You will meet him/her during your pre-transplant work-up. You can request a consult to see the social worker at any time. This person has completed a master's degree in social work and works with the team to support you and your



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family through the transplant process. The transplant social worker can provide supportive counseling, discharge planning, referrals to community resources, and assistance with financial concerns.

- **Transplant Financial Case Managers**

The stem cell transplant financial case managers advocate for you by contacting your insurance company to verify your transplant benefits. Transplant coverage may vary depending on the individual insurance company policy. The financial case managers are knowledgeable when it comes to common transplant insurance obstacles and familiar with transplant finance terminology. This allows them to obtain proper authorizations throughout all phases of the transplant process (i.e. stem cell transplant consultation, pre-transplant, transplant and post-transplant). The financial case manager will help you get information regarding your individual financial insurance components (i.e. co-pays, deductibles, co-insurance, out of pocket expenses, etc.).

- **Clinical Psychologists and Psychiatrists**

Sylvester Comprehensive Cancer Center has clinical psychologists and psychiatrists who are trained in the area of transplantation. They are available to meet with you before, during and/or after your treatment to address the emotional aspects associated with transplant. Your physician may request a referral for you to be seen to help with your emotional needs.

- **Dietician**

A clinical dietitian is a registered and licensed practitioner trained to assess the nutritional needs of individuals undergoing treatment. Dietitians complete at least an undergraduate education in food and nutrition science and must complete a supervised practice and a national examination. Most dietitians also hold advanced degrees and specializations. You will be evaluated by a dietitian during your stay. The dietitian can assist with meal planning, managing nutritional related side effects, and any other dietary questions you may have during your hospital stay and once you are home.

- **Physical Therapist**

Our physical therapist is a highly trained member of the transplant team who assists with reducing pain, improving or restoring mobility (in many cases without expensive surgery), and reducing the need for long-term use of prescription medications. Before working with you, the physical therapist will



review your medical history and your lab results and discuss your case with the transplant team. The physical therapist, when needed, will assess your physical condition and work closely with you to assure you remain as physically active as possible by developing fitness and wellness-oriented programs. The physical therapist can meet with you to review specific questions you might have related to your activity level. He/she can also provide tips on how to maintain physical function once you are home.



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My Care Team

Primary Hematologist

Name: _____

Phone: _____

Transplant Attending Physician

Name: _____

Phone: _____

Nurse Practitioner or Physician Assistant

Name: _____

Phone: _____

Transplant Nurse Coordinator

Name: _____

Phone: _____

Social Worker

Name: _____

Phone: _____

Transplant Financial Case Manager

Name: _____

Phone: _____



Notes



HELPFUL INFORMATION

Facility Services

Parking

There are many places to park on our campus. Each designated parking area has a fee. Valet parking is also available for a fee at UMHC/SCCC 14th Avenue entrance and on the north side of UMHC. Validation for valet parking is available during your hospitalization.

For outpatient visits, you will obtain validation for valet parking for the first 100 days following your hospital discharge.

Security

Sylvester Comprehensive Cancer Center has a 24-hour security program in place. Members of the security team may ask visitors to the cancer center to identify themselves and the purpose of their visit. They are responsible for enforcing the rules and policies of the campus for the protection and well-being of our employees, visitors and patients.

Electronic Equipment

During your stay, we will make every attempt to see that you are as comfortable as possible. All the rooms on the transplant unit are equipped with telephone, TV with cable and internet access. We encourage patients to bring any electronic equipment that may help make your stay more relaxed.

Guidelines for Visitors

Visitors

We encourage you to have visitors during your hospital stay. Meaningful social interaction can facilitate health and recovery. The unit does not have specific visiting hours, but we do have rules in place to protect you and the other patients on the stem cell transplant unit. It is important to remember you are at a high risk for infection following stem cell transplant.

Children under the age of 12 are not allowed on the unit. Special circumstances require further discussion by the stem cell transplant team. Any exceptions made will



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not place any patient on the unit at risk. **Individuals with signs and symptoms of illness are not allowed on the unit.**

All visitors and hospital personnel must abide by the safety precautions designated to you. These precautions are found on a sign that will be posted outside your door.

Flowers and Live Plants

Due to the high risk of transmitting infection, the stem cell transplant unit does not allow any flowers or live plants in the unit. If you receive a flower arrangement, the staff will accept it on your behalf. The accompanying card will be provided to you and the arrangement will be placed in the waiting area outside the unit.

Cancer Support Services

Cancer Resource Center

Monday- Thursday 9 a.m. to 2 p.m. (Closed for Lunch)
Friday 9 a.m. to noon



- In partnership with the American Cancer Society, the Cancer Resource Center is open to current patients, survivors, and caregivers.
- The Cancer Resource Center's specially trained volunteers offer guidance to cancer patients and their families on how to access supportive services and programs offered by Sylvester and the American Cancer Society.
- Navigating through the cancer center information and resources can be overwhelming; stop by during your next hospital visit and let us be your guide!
- Our Cancer Resource Center's specially trained volunteers can help patients, caregivers, and their families by offering the following services:
 - Computer access to information on cancer care through the American Cancer Society's website
 - Ability to access information on hospital and community support groups and events
 - Information on transportation and lodging support



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- Complimentary wigs, scarves, caps, and other types of head wraps
- Complimentary mastectomy bras and prostheses
- Complimentary books, newsletters, and informative pamphlets
- Sign-up for dynamic programs such as *“Look Good Feel Better.”*



For appointments, comments, or concerns please contact:
(305) 243-5966 or (305) 243-2165

Acupuncture

Addresses neurological, musculoskeletal, and digestive conditions as well as migraines, neuropathy, chronic pain, muscle cramps, anxiety, fatigue, and stress, among others.



Massage Therapy

Eases pain, improves energy level and overall feelings of well-being. Our massage therapist is oncology certified and considers all necessary safety precautions for transplant patients.

Music Therapy

Manages pain, stress, and anxiety while facilitating positive mood and mental outlook through music-based activities.

Arts in Medicine

Has the ability to raise spirits, minimize feelings of depression and boost morale through creative expression.



Chaplain Services

Pastoral care services include spiritual counseling and support, and pastoral resources including community clergy referrals and special holiday prayer services.

Exercise Physiology

Provides patients an opportunity to develop practical ways of adopting a healthier, active lifestyle both during and after treatment.



Nutrition Consultations

Help patients adopt healthy eating habits aimed at managing treatment side effects and preventing their recurrence.

Palliative Care

Treats complex pain and other symptoms, handles intensive patient/family communication, and assists with clarification regarding goals of care at any stage of care.

Social Work

Helps patients adjust to illness, provides supportive counseling and case management including referrals to community services and discharge planning.

Psychosocial Oncology

Provides individual and family psychotherapy and counseling, medication for mental health diagnoses, treatment for cancer-related issues, among others.

For more information or to schedule a consultation, please contact the Courtelis Center at (305) 243-4129.

Patient Experience

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The patient experience staff helps patients navigate through the treatment process by focusing on problem solving, addressing patient concerns, as well as explaining Sylvester processes and procedures. These individuals are committed to assisting you on your journey.

Patient representatives serve as advocates on behalf of our patients to offer the highest quality of care and satisfaction. They work diligently to ensure patients have seamless access to Sylvester services and provide assistance for the hearing impaired, as well as translation services for patients who do not speak English.

The patient experience number is (305) 243-3820.

Sites of Transplant Care

Apheresis Center

The apheresis center is where you will go for your stem cell collection. Our apheresis center is located at Sylvester Main Campus in Miami. The unit is staffed with highly trained nurses who manage your care during mobilization and stem cell collection. These nurses are skilled at preparing and encouraging you through the transplant process.

Inpatient Unit

The inpatient unit is where you will be receiving your stem cell transplant. It is located at Sylvester Main Campus in Miami. You will arrive a few days before your transplant in preparation for your stem cell infusion. During your stay in the inpatient unit, you will be cared for by your transplant health care team. They will be in charge of managing any issues or complications that may arise during your stay while collaborating with your primary transplant physician.

Ambulatory Treatment Center (ATC)

Once you have been discharged from the hospital, you will be transitioned to our Ambulatory Treatment Center for regular follow-up appointment with one of our highly trained advanced practice providers and stem cell transplant pharmacists. You will have typically two to three appointments weekly to have blood counts checked and to manage your recovery with treatments to be determined by your health care team. They will also address any urgent issues that may arise after you have been discharged.

Outpatient Clinics



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After your blood counts have stabilized and you begin to return to pre-transplant physical condition, you will be transitioned to the outpatient clinic. We have two locations, Sylvester Miami Main Campus and Sylvester Plantation. Your health care team will determine when you can be transitioned to one of our outpatient clinics.

Long-Term Care Follow-up (LTCFU) Clinic

Once you have reached six months post-transplant, you will be scheduled to be seen in our LTCFU clinic by one of our advanced practice providers who specialize in management of patients who have undergone a stem cell transplant. The advanced practice providers will work closely with your transplant physician. This is to ensure your health is promoted and maintained, by coordinating, screening, and assessing you to detect late effects related to transplant and/or recurrence of cancer. Should a recurrence occur they will coordinate care with your primary hematologist. You will be provided a treatment summary and follow-up care plan that will detail health promotion recommendations.

Comprehensive Treatment Unit (CTU)

If outpatient infusions (blood, hydration, medication, etc.) are required, you may be scheduled at Sylvester's Miami CTU. Our Comprehensive Treatment Unit is a 12,000-square-foot, state-of-the-art facility. The unit includes 33 comfortable recliners and 11 private rooms, all designed for patient comfort and convenience. Each chair and private room includes a television and DVD player.

Satellite Centers

Infusion treatments also are available at certain satellite locations, which have a dedicated laboratory and pharmacy program for patients receiving infusions, as well as recently renovated areas featuring state-of-the-art equipment and amenities. You may be scheduled for treatments at one of our satellite locations at the discretion of your health care provider. We also offer follow-up visits in our Plantation office three times per week. You will be scheduled to be seen by one of the advanced practice providers.

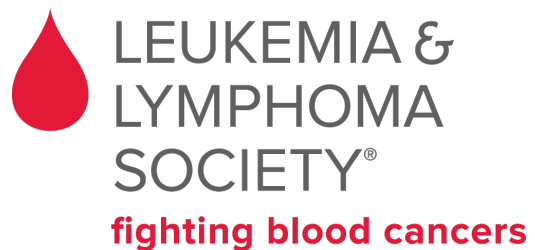


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Websites

These are selected websites determined to be of help for transplant patients. For more information, please visit the following websites:

Cancer.net	www.cancer.net
BMT Infonet	www.BMTinfonet.org
Be The Match	www.bethematch.org
American Cancer Society	www.cancer.org
NIH National Cancer Institute	www.cancer.gov
Leukemia and Lymphoma Society	www.lls.org
International Myeloma Foundation	www.myeloma.org
Multiple Myeloma Research Foundation	www.themmrff.org
Medline Plus	www.medlineplus.gov
American Society of Hematology	www.hematology.org/Patients





Notes

STEM CELL TRANSPLANT BASICS

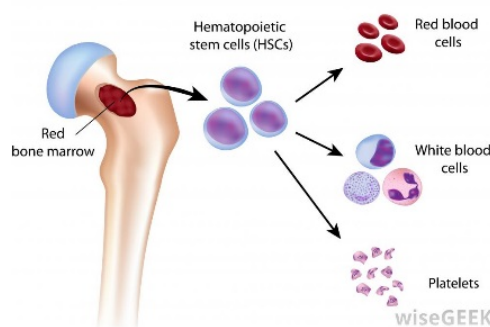
History of Stem Cell Transplantation

The concept of stem cell transplantation (SCT) began during the 1940s post World War II. Scientists experimented on recovering bone marrow after exposure to nuclear radiation, as was seen with soldiers in WWII. Studies were conducted in mice to gain better understanding of side effects and complications. It was not until 1957 that the first human donor was able to derive stem cells for transplant; this procedure was completed by Dr. E. Donnall Thomas. Over the last 60 years, studies have aimed at improving patient outcomes related to autologous (you receive your own cells) and allogeneic (donor based) transplants for the management of hematological malignancies. The evolution of SCT with improved donor identification and supportive care has led to better tolerated treatments. Older individuals, who previously were not candidates due to high treatment toxicities, are now frequently considered for transplant. These advancements have led to improved morbidity and mortality among SCT recipients.

Initial SCT was done with stem cells collected from bone marrow via a surgical procedure. Later it was discovered how to mobilize stem cells from a central catheter in the vein.

What is Bone Marrow?

Bone marrow is the soft tissue inside bones (hip, breastbone, and pelvis) that produces blood-forming cells. Bone marrow contains a large number of stem cells. Stem cells are immature cells that can grow into red blood cells, white blood cells or platelets. Red blood cells carry oxygen throughout the body. White blood cells help fight infections. Platelets assist with coagulation and prevent us from bleeding.



What are Stem Cells?

Stem cells are undeveloped blood cells that will give rise to different types of blood cells. They are constantly dividing in your body, replacing older blood cells. Some stem cells also circulate in your bloodstream.

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The terms “bone marrow transplant” and “hematopoietic stem cell transplant” are used interchangeably.

Stem Cell Collection

What are progenitor cells?

Progenitor cells are also referred to as *hematopoietic stem cells*. They are immature cells that grow and divide into mature red blood cells, white blood cells, or platelets.

- *Red blood cells* are the most common type of blood cell and are responsible for the delivery of oxygen to organs and tissues of the body.
- *White blood cells* are responsible for our immunity -- defense against foreign organisms such as bacteria or viruses.
- *Platelets* are tiny blood cells that help your body form clots to stop bleeding.

What is a peripheral blood stem cell (PBSC) collection?

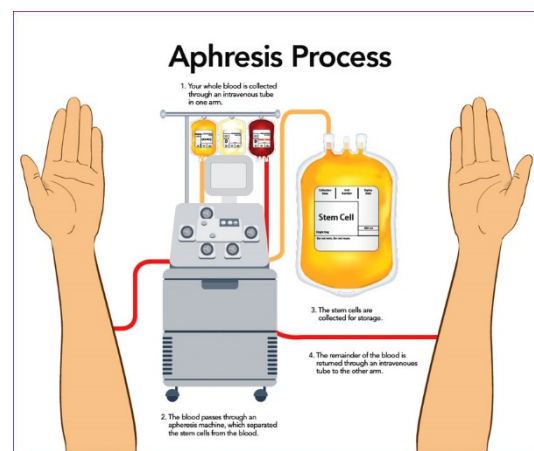
It is a non-surgical procedure involving the separation and collection of stem cells from the circulating blood. This is also referred to as *apheresis*.

Why is a PBSC collection necessary?

When patients are being treated with high doses of chemotherapy, it may suppress the ability of the bone marrow to make blood cells. Peripheral blood stem cells are needed to restore bone marrow function. The doctor will decide based on your disease and other factors which transplant is best for you. Depending on this decision, and prior to the administration of high dose chemotherapy, stem cells will be collected from your own bloodstream. A transplant using your own stem cells is called an autologous transplant.

What is mobilization or harvesting?

Before the collection of stem cells, the patient or donor may receive a series of injections called growth factors. These drugs will generally cause the release of a large number of stem cells into the bloodstream. This is referred to as “mobilization.” When your doctor determines you have reached a sufficient cell count level, the collection will begin.





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What happens during stem cell collection?

The collection is performed by a medical device called a blood cell separator or an apheresis system. It uses a machine with a fast spinning container to separate stem cells from other blood parts and plasma. The sterile tubing set and needles are used one time only and then discarded. Highly trained nurses will operate this machine and monitor your condition at all times.

In order for this procedure to be successful, a catheter will be placed into a large vein in your neck, groin or chest prior to the collection. This will allow for an easier collection process. An anticoagulant is added to the blood to keep it from clotting. The blood and anticoagulant will enter the collection machine where the different blood components are separated and the stems cells are transferred to a collection bag. The other cellular components and plasma are then returned to you through the central catheter. You will be monitored closely throughout the procedure.

What are the potential risks and side effects?

Although the apheresis machine moves less than 237ml (8oz) of blood at one time, you may feel dizzy and lightheaded. The medication used to keep your blood from clotting in the machine may cause a sour taste in your mouth, tingling around lips and fingers, cramping of your fingers, feet or legs, or chest vibrations. These symptoms do not occur in every patient. You should tell the medical staff immediately if you begin to feel uncomfortable. They may give you calcium tablets, slow down, or stop the procedure for a short time to make you more comfortable.

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A Glance at the Transplant Process

Before

In order to prepare you for your stem cell transplant, you will receive medications that stimulate your body to make more stem cells than normal and encourage those stem cells to circulate in your bloodstream. You will have a triple lumen catheter (trifusion catheter) placed prior to transplant. It will be used to collect your cells. Once your stem cells are harvested from your bloodstream they will be stored until they are transplanted. This process is called *apheresis*.

During

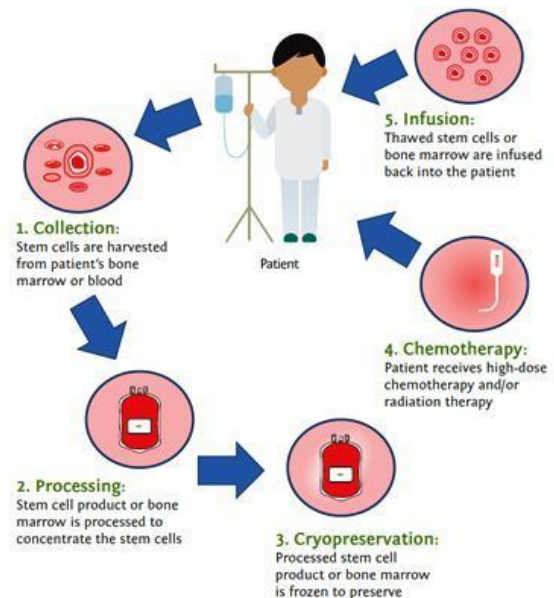
Your transplant doctor decides which “conditioning regimen” is best for you based on your disease process, age, and health status. The “conditioning regimen” is the type of chemotherapy or radiation you will receive in order to prepare your body for the transplant. You will receive chemotherapy to kill any cancer cells that remain in your body prior to receiving your harvested stem cells. The stem cells remaining in your body and other blood cells will also be removed. This process will cause your immune system to become severely compromised during this period.

Next your stem cells will be taken from storage, thawed and infused into your body through your trifusion catheter. This is your stem cell transplant, which is given to you on what is termed “Day 0.”

After

The infused stem cells will find their way through your bloodstream to your bone marrow. They will begin to divide and create healthy new blood cells. This process is called *engraftment*. Your immune and body systems will begin to return to normal. This process takes time and varies from patient to patient.

What is engraftment?





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Engraftment is when your white blood count begins to recover. Soon after your stem cell infusion your stem cells begin to travel to your bone marrow, where they begin the process of engraftment. The entire process may take up to 10 to 14 days to see your white counts begin to increase, but this may vary depending on your disease and treatment. During this time, your red blood cells and platelets may still be recovering and you could require transfusions. Your health care team will be monitoring your white blood count by checking labs using a complete blood count (CBC).

Autologous Stem Cell Transplant

Your doctors have determined that at this time the best course of treatment for your condition is to undergo an autologous stem cell transplant.

Autologous (from yourself) means your stem cells are harvested from your body, then frozen for a period while you receive a high dose of chemotherapy. Most of the cells in your body and bone marrow will be destroyed.

Harvesting will take place prior to your admission to the hospital. This non-invasive procedure will take place in our apheresis department with specialized nurses. After your stem cells have been collected, staff will protect and preserve the harvested cells by storing them in our lab. Your stem cells will be kept frozen until you are ready for the stem cell infusion.



The Transplant Process



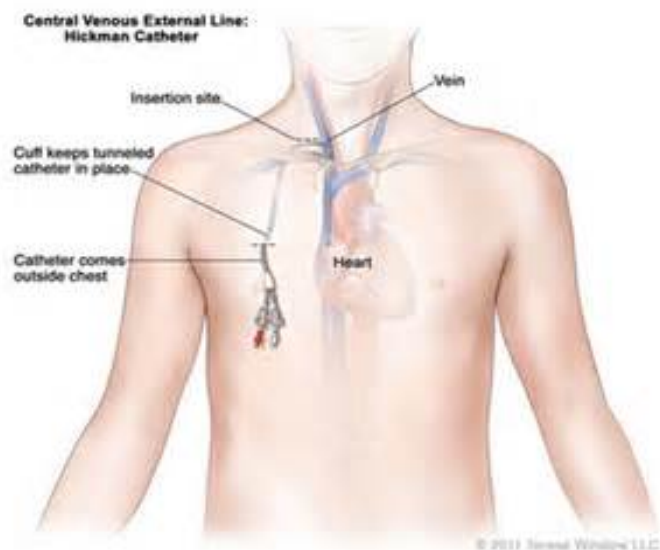
PREPARING FOR TRANSPLANT

Meet and Greet

You will be scheduled to attend an informational session hosted by our licensed clinical social worker in collaboration with our Adult Stem Cell Program staff members. Here you will receive useful information that will prepare you for your journey through transplant. You will have the opportunity to meet members of your stem cell team and Sylvester transplant survivors will also be available to share their experiences and answer any questions you may have. We request that you bring a caregiver and/or family member who will be working closely with our transplant team and assisting you throughout the transplant process. We look forward to building a lasting relationship that will prepare you for life during and after transplant.

Having Your Trifusion Catheter Inserted

In preparation for your chemotherapy treatment, you will come to the Interventional Radiology Department at Sylvester Comprehensive Cancer Center to have your trifusion catheter inserted into a large vein in your chest. A trifusion is a small, flexible tube that is inserted into a large vein near your collarbone, also referred to as a central venous catheter. On the outside of your body, the catheter divides into two or three smaller tubes called lumens.



This trifusion catheter serves as a route to give you fluids, electrolytes, blood transfusions, chemotherapy and other medications without having to stick you with a needle each time. It also allows for blood draws for lab tests. Having a trifusion catheter will ensure you have the most comfortable transplant experience possible.



The trifusion catheter will be put in place a couple of weeks prior to your stem cell transplant and it will be used during the collection of your stem cells. The trifusion catheter will stay in your body throughout your treatment. It will be removed two to three weeks after you receive your stem cell transplant. This can be either prior to being discharged from the hospital or in the week following your discharge.

Before your Trifusion Catheter Procedure

Your clinical coordinator will work with you to schedule the procedure for placement and any necessary blood tests required.

Day of Procedure

About two business days before your procedure, you will receive a call from a staff member of Interventional Radiology. He/she will tell you the time of your procedure. You MUST have a driver with you.

The placement of your trifusion catheter should take about 30-60 minutes. First, an IV line will be inserted and you will be given medication that will make you sleepy. A small area near your collarbone will be numbed with a local anesthetic. A small incision (cut) is made on the neck or upper chest and then a smaller incision is made lower on the chest. The trifusion catheter will be inserted through the incisions and threaded into the vein until it reaches the entrance to the right-upper chamber of the heart. Your trifusion catheter will be stitched to your skin at the point where it exits your body so that it will stay in position. Your trifusion catheter should not interfere with your daily activities, but you should avoid strenuous activities and contact sports.

Caring for your Trifusion Catheter

Taking good care of your trifusion catheter is important in order to prevent infection. Clamp the lumens when your trifusion catheter is not in use. Keep your trifusion catheter secure at all times to avoid pulling it. Your trifusion catheter MUST be flushed at minimum every seven days. This will be done during your office visit by a specially trained nurse. It is flushed with normal saline.



Guidelines for Showering

- You may shower daily with your trifusion catheter but the line and the exit site *must* be kept dry. Staff will help you cover the line and the exit site, while you are admitted.
- You may cover your catheter site with a clear plastic wrap to keep it dry.
- If the dressing becomes wet, it needs to be changed immediately as this can place you at risk for infection.
- We recommend that you bathe with antibacterial soap every day while your trifusion catheter is in place.
- Do not soak your trifusion catheter in water, such as in a bathtub or swimming pool.
- A sterile dressing will be placed over your central line and will be changed every seven days.
- This dressing may be changed sooner than seven days if it is loose, wet or dirty.
- The nurse will look at the site to examine the skin around the line for any signs or symptoms of infection such as soreness, redness, swelling or discharge.

Problems with your Trifusion Catheter

You and your caregiver should be on the lookout for any problems with your trifusion catheter. Infection is the most serious complication to watch out for. Look at your trifusion catheter site daily. Notify your health care provider if you experience any of the following:

- Redness, swelling, or drainage at your exit site.
- Pain or tenderness at your exit site.
- A temperature of 100.4°F (38°C) or higher.
- Flu-like symptoms or chills.

Other complications may be related to the trifusion catheter itself such as:

- A hole, break or leak in the trifusion catheter.



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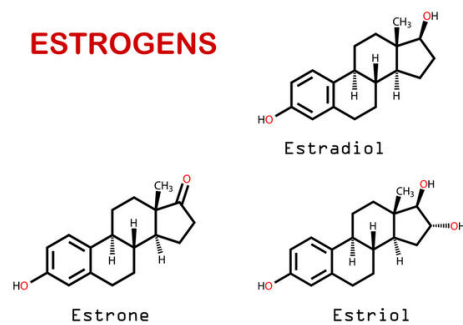
- Swelling in your face, neck or arm on the same side of your body as your trifusion catheter may be a sign of a blood clot.

Fertility Issues and Reproductive Options

Information for Women

Women who are pre-menopausal prior to transplant usually become menopausal. After your transplant, you may have:

- Fewer menstrual periods
- No menstrual periods
- Vaginal dryness and discomfort



Depending on your treatment, the function of your ovaries may change. This can result in decreased estrogen levels. Your doctor may recommend that you take estrogen supplements after your transplant.

Information for Men

Men's testosterone levels are reduced during transplant and recovery, although they usually return to normal one year after transplant. A reduction in testosterone may result in a decreased interest in sex.

Some men also experience erectile dysfunction (ED) after their transplant. ED can be treated with medication, including sildenafil citrate (Viagra®) or tadalafil (Cialis®). There are many other ways to treat ED. Your doctor can refer you to a specialist in Male Sexual and Reproductive Medicine.

Fertility



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Prior to your transplant, it is important to speak to your doctor about the possibility of infertility. The chemotherapy or radiation therapy you receive with transplant will likely lead to infertility or sterility. Sperm banking is a consideration for some men, although previous treatment may have already caused sterility. Some options are also available for female patients. The following services are offered at UM; please discuss your options with your transplant doctor.

In-Vitro Fertilization (IVF) and Embryo Banking, Egg and Sperm Banking

UHealth Fertility Center, Miami
1400 NW 12th Avenue, Suite 5
Miami, FL 33136
Phone: (305) 243-8642

UHealth Family Center, Plantation
8100 SW 10th Street, Suite 3340
Plantation, FL 33324
Phone: (954) 210-1078

Caregiver

What is a Caregiver?

A caregiver is someone who helps provide care and support to you before, during and after your transplant. It is usually a family member or close friend. This person is very important to your treatment and will help to ensure the success of your transplant. You **MUST** have an identified caregiver in order to be transplanted at Sylvester. Please note that insurance will **NOT** provide this service to you. Though one person will likely be your primary caregiver, it is not always possible to have only one person meet all your needs. Therefore, you may need/want to find other people to help. If you have more than one caregiver, these people should stay in contact with each other to provide current updates about your care and needs.

Choosing a Caregiver

Being a caregiver is a full-time commitment to the patient and is often stressful and tiring. You may want to consider someone who is able to remain calm and keep a positive attitude even in the face of challenges. Due to the important role the caregiver plays, he/she must be 18 years old and available to you 24/7. Your physician will tell you what length of time this person must remain present. As this role is both difficult and crucial, you should think carefully about who will act as your caregiver and consider the following:

- Is your caregiver in good health and in reasonable shape to fulfill the caregiver role (see below)?
- Does your caregiver drive? If not, how will you get to/from clinic?
- Can he/she be available 24/7 following transplant; does he/she have the ability to take time off work?
- Is he/she comfortable in the hospital setting?
- Can your caregiver help with chores around the home including cleaning, cooking, bathing and dressing assistance, if needed?
- Do you and your caregiver get along well? Are you able to spend long periods of time together?



The Roles of the Caregiver

Your caregiver will be expected to be an active part of your transplant. He/she will provide medical, practical and emotional support. Some of the duties of your caregiver may include:

- Providing transportation to/from appointments after transplant (between two to five times per week, determined by your health care provider).
- Responding to an emergency for the patient immediately and bringing him/her to Sylvester at any time if instructed by the care team.
- Gathering and organizing medical information and instructions from the transplant team.
- Keeping track of the patient's symptoms or any changes in condition.
- Cleaning the home and preparing meals in accordance with safe food handling recommendations (see page 32).
- Managing visitors and ensuring that large crowds and sick people are avoided.
- Paying attention to the patient's mood, understanding needs and communicating effectively with both the patient and the medical team.
- Engaging in self-care to avoid caregiver strain or burnout.

Tips and Resources for Caregivers

It is very common and normal for caregivers to become overwhelmed or exhausted because of their roles and responsibilities. To prevent this kind of strain, we suggest you practice regular self-care. Caregivers are encouraged to find time for themselves and to practice a healthy lifestyle, including eating well, exercising and getting enough sleep. You may benefit from finding additional people to help with the patient or chores so that you may take a much-needed break from time to time.

If at any point you are feeling emotionally, physically or financially overwhelmed, you can contact the social worker for supportive counseling or referrals. You may also use the Courtelis Center for Psychosocial Oncology (305-243-4129) where you can access psychiatrist, psychologist, massage therapy, acupuncture, integrative medicine and chaplain services.



Advance Directives

What are Advance Directives?

Advance directives are written statements that allow you to make your health care wishes and preferences known in case you are not able to voice them in the future. These directives may include the type of care you would or would not want and who you would want to make decisions for you if you unable to do so. These documents are available at Sylvester and are strongly recommended as part of your pre-transplant preparation. These documents can be changed or canceled at any time.

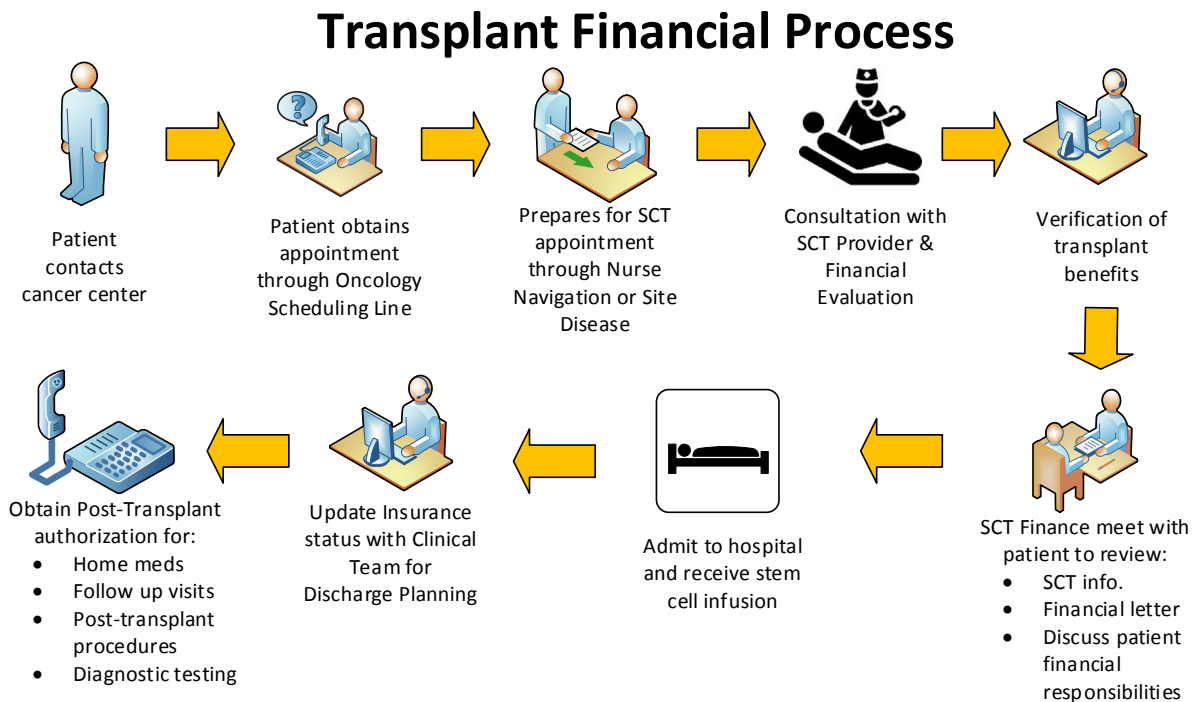
Types of advance directives available at Sylvester:

- **Health Care Surrogate Designation:** This form allows you to identify someone to make your health care decisions, a health care surrogate, in the event you are unable to do so. You may also choose a backup surrogate in the event your primary designee is not available or is unwilling to make decisions.
- **Living Will Declaration:** This document gives you the chance to indicate the kind of life sustaining or life prolonging care you would or would not want in the event you are in a terminal or vegetative state with no hope of recovery, as determined by your doctor.

How to complete advance directives:

Your transplant social worker can assist you in answering any related questions or completing these documents. They require two witnesses to your signature and these witnesses may not be the health care surrogate or a family member. The original document will be provided to you to keep and a copy will be scanned into your Sylvester medical record. Another type of advance directive, called a power of attorney, may be helpful to you as it can relate to transferring legal or financial decision-making power in the event you become incapacitated. These cannot be completed at Sylvester and you may wish to consult an attorney for help with completing one.

Financial Considerations of Transplant



Pre-Transplant Finance Process

The financial evaluation process begins on the date that the patient is determined to be a candidate by the transplant physician. The transplant physician also determines the type of transplant the patient will have according to their diagnosis. This process includes evaluating patients for outpatient services, possible psychosocial visits and testing. This is done to comply with insurance requirements as well as making sure each candidate is medically fit to go through the transplant process. The SCT Finance team “*flags*” the patient and donor, if applicable, as a SCT patient throughout the medical record. This establishes that all pre-transplant related services performed throughout the continuum of clinics, including satellites, are financially cleared and authorized as per the designated insurance transplant case manager.

The SCT Finance Case Manager verifies transplant-related benefits and works closely with the SCT Nurse Coordinator to advise you of what may or may not be covered based on the individual insurance coverage the patient has. If the insurance has an associated transplant network and/or the SCT Finance team has determined that the transplant request meets the required guidelines, the SCT Finance Case Manager will



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approve the transplant. The SCT Finance Case Manager will meet with the patient to review the SCT information and financial letter to inform the patient of any financial responsibility including deductibles, copays, coinsurance, post-transplant medication copays, etc. Each patient is given an orange UHealth folder with our business card and limited, personalized financial information (i.e. any pertinent correspondence we may have received from the insurance company, financial information letter and possible post-transplant medication list).

The SCT Finance team accepts responsibility for being patient advocates and strives to assist with answering any questions. If the answer is not known, which mostly occurs in clinical matters, the designated SCT Nurse Coordinator will facilitate obtaining an answer.

Post-Transplant Finance Process

A weekly SCT discharge meeting is held to discuss patients' tentative plans for discharge from the hospital and continuous success after being transitioned back home. Various members of the transplant team meet to discuss each patient's case. In this meeting, both the clinical and financial status of the patient is updated. We discuss what post-transplant medications will be required, if they have been ordered and identify the specific pharmacy that will be delivering the medications.

After the transplant admission, the SCT Finance Case Manager will contact the assigned transplant case manager at the insurance company to obtain a post-transplant authorization starting the day after the inpatient discharge. The post-transplant authorization will cover all transplant-related services including transplant physician office visits, catheter removal, labs, diagnostic testing, etc. The post-transplant authorization is usually valid for 90 days after transplant. The SCT Finance team will continue to financially clear all SCT-related visits via your electronic health record (i.e. UChart), as the patient will have visits scheduled throughout the continuum of clinics, including satellites. The patient is welcome to contact the SCT Finance team if they have any questions, receive any bills or need any assistance as we continue to advocate for the patient.

Transplant can result in a lot of unexpected costs. If you have a long commute to and from pre- and post-transplant follow-up, you may find that gas, tolls, and parking become a challenge for you and your family. Depending on your insurance coverage, you may have deductibles or co-pays to cover these expenses. After transplant, you will also be on new prescription medications, which can cause additional financial stress. It is important to be aware of these costs and prepare accordingly. To prepare for these

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costs, you may want to participate in fundraising for your care in advance of transplant. There are various organizations that can help you and your family set up a fundraising campaign. While some monies exist, please note that grants/money through non-profit organizations can be limited and difficult to obtain. There are also assistance programs for medications but these, too, are based on insurance coverage and household income. Your transplant social worker can assist you with determining resources that are available for you.

Coping with Separation from Children

Many of our patients have children of all ages at home. It is often very difficult for people to leave their families behind during the transplant admission. Given that children under the age of 12 CANNOT visit on the unit, the difficulty of separation is frequently intensified. You, as the patient, may miss and feel worried about your children. In turn, your children may feel the same toward you. Though we recognize there is no substitute for in-person time with your kids, we want to provide a few suggestions.

There is an excellent book called *Helping Children Through a Parent's Serious Illness*, by Kathleen McCue. The author is a child life specialist and provides information and ideas for how to communicate with and approach your children of all ages regarding your illness and hospitalization. She also gives ideas of how to help your children feel connected and how your children can help you during this time. Keeping children uninformed may lead to anxiety, especially if you are out of the home for a long period of time. However, we understand that you are the expert in understanding your own children and their needs.

Once you have decided what and how you want to communicate with your children, you can begin to plan how to maintain contact with them during your stay. Many families opt to use Skype, FaceTime, and other forms of video communication during their stay. We often see that patients will decorate their rooms with photos of and artwork from their children to make the space feel more welcoming and personal. Your children can be encouraged to write letters or create additional artwork for your hospital room. Our Arts in Medicine program can also give you the opportunity to create your own art projects to send home to your children, which many families appreciate.

If you have any questions or concerns in this area, prior to or during your hospital stay, you can contact your transplant social worker at any time. She/he may also have other



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community resources, information, or referrals that will be helpful in supporting you and your children.

Preparing Your Home

Cleaning

Your home should be well cleaned prior to discharge. It is not necessary to have air ducts cleaned or carpets shampooed. However, your home should be free of dust. Kitchens and bathrooms should be disinfected. It is okay to share bathrooms and bedrooms with healthy family members.

On a regular basis, you should continue to maintain a clean environment at home to avoid greater risk of infection. Below are suggested routines to adhere to:

- Wash your eating utensils with soap and water after use or use your dishwasher
- Keep the shelves and tables free from dust and debris
- Have a family member or friend vacuum for you at least a couple of times a week
- Clean your kitchen and bathroom regularly to prevent the growth of mold and bacteria
- Wash bed linens and towels/washcloth twice a week

Plants

Household plants are allowed in your home after transplant. You may water and care for your plants with some precautions:

- Avoid handling soil (i.e. repotting plants or churning the soil)
- Avoid trimming plants with thorns

Pets

In most cases your pet(s) can remain in your home after transplant. It is important to discuss the species of pet you have with your transplant physician. There are some pets that will need to stay with friends or family while you recover (i.e. lizards, snakes, rodents). Below you will find precautions to help protect you from infection:



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- Do not expose yourself to your pets' waste. Even if you use a plastic bag or gloves, material can become airborne and cause infection. This is especially important for cleaning the litterbox of cats.
- Pets should be seen by your veterinarian and vaccinated prior to your return home if vaccines are not current. Cats should be screened for toxoplasmosis.
- All pets should be tested for parasites.
- Do not adopt, purchase or care for new pets until cleared by your physician.
- Avoid rambunctious animals to minimize the chance of scratches or bites.
- Animals carry bacteria, viruses and fungus in their mouths and claws.
- Wash your hands after playing with or touching your pet.





Notes



LIFE INPATIENT

Preparing for Hospital Admission

Items to bring to the hospital

Here you will find a list of items you may want to consider bringing to the hospital to use for the duration of your stay.

- ✓ Slippers
- ✓ Prescription eyeglasses
- ✓ Pictures of your family and friends
- ✓ Socks
- ✓ Bathrobe
- ✓ New soft toothbrush, tube of toothpaste and toiletries
- ✓ Videos or DVD's with player
- ✓ Books, magazines and cards
- ✓ iPod®, small radio or CD player
- ✓ Laptop or tablet
- ✓ Front button pajamas or nightgown (a hospital gown will be provided if you prefer)
- ✓ Sneakers or sturdy shoes for walking
- ✓ Comfortable lounging clothes
- ✓ Electric razor
- ✓ Make-up
- ✓ Extra pillow (if you wish)
- ✓ Walker or cane if needed



Items NOT to bring to the hospital

- ⊗ Mechanical razors
- ⊗ Scissors
- ⊗ Contact lenses
- ⊗ Jewelry
- ⊗ Portable refrigerators

Please note: Patients are responsible for the safekeeping of their belongings. Do not bring valuables to the hospital.

Hospital Admission



Chemotherapy

During your hospitalization you will receive chemotherapy and/or radiation also called the “conditioning regimen” or “preparative regimen” before your transplant. This regimen is usually a combination of various chemotherapy agents with or without total body irradiation (TBI). This therapy can be high-dose (ablative chemotherapy), reduced-dose (reduced intensity chemotherapy) or low-dose (non-myeloablative chemotherapy). This will be used to prepare your body to receive and accept stem cells for an autologous transplant. Your physician will decide which conditioning regimen is right for you.

- **Ablative (myeloablative) chemotherapy:** This is high-dose chemotherapy, radiation or both that kills cancer cells as well as healthy cells.
- **Reduced intensity (non-myeloablative) chemotherapy:** This is lower dose chemotherapy in combination with radiation before transplant.

You will be given information on the specific chemotherapy regimen that is planned for you to receive. The information you receive will review some of the short- and long-term side effects of each chemotherapy agent and/or radiation. Once admitted, the typical length of stay for transplant patients is two to four weeks in the hospital. You will be monitored closely by our team of transplant experts on a daily basis. Our team will determine when it is safe for you to return home after engraftment has occurred. Rate or speed of recovery post-transplant varies between individuals.



Transplant Day

Your special day has finally arrived! The day you receive your stem cell infusion is referred to as “transplant day” or “day 0.”

This section will explain what to expect on this special day. The process of infusing the stem cells is very similar to that of a blood transfusion. Your nurse, along with the stem cell technologist, will coordinate the timing of your infusion. Your nurse will inform you of the estimated time of arrival of your stem cell product on the day of infusion. Autologous stem cells may be infused in one to two days depending on the volume.

When the product has arrived, your nurse will ask you to lie down in bed during the procedure. Your nurse will connect you to a monitor that will read your vital signs (heart rate, blood pressure, respirations and oxygen saturation). These are all important readings to inform your nurse how well you are tolerating the procedure.

You will receive medications prior to the infusion to help minimize a transfusion-related reaction and/or effects of DMSO. DMSO, dimethyl sulfoxide, is added to cryopreserved stem cells to protect them from injury. Not all stem cells are cryopreserved.

If you are receiving cryopreserved stem cells, a stem cell laboratory technician will be present with a water bath. This is needed to thaw your stem cells without injury. Once thawed, your nurse will infuse the stem cells through your central venous device. During the infusion, your vital signs will be monitored closely.

Possible side effects from the infusion and DMSO are:

- Fever, chills, or facial flushing
- Rash or hives
- Changes in heart rate and/or blood pressure
- Chest pain or tightness
- Shortness of breath
- Nausea and/or vomiting
- Diarrhea and/or abdominal cramping

If any of these side effects occur, your nurse will intervene appropriately to treat and minimize these effects. The advanced practice provider and/or physician will be available during your infusion.



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Following your transplant, you may experience red-tinged discoloration to your urine. This may occur when red blood cells are present with your stem cells. Notify your nurse if this occurs. This usually resolves with hydration over the next few days.

If you received cryopreserved stem cells, you may experience a garlic-like taste and smell for up to two days following your transplant. This is due to the DMSO and will resolve. If the unusual taste is bothersome during the infusion, you may have hard candy or flavored ice pops as this sometimes helps to alleviate this effect.

Once your infusion is complete, we encourage you to continue with your daily routine. This includes walking in the hallway, sitting in the bedside chair and using your incentive spirometer. An incentive spirometer is a device used to assist in opening the lungs. It can prevent pneumonia.

Timing of Engraftment

It is important to consider that timing of engraftment varies based on donor graft (i.e. bone marrow, peripheral blood, or cord blood), cell dose count and marrow function. Depending on the type of graft you are to receive, this will influence the speed of recovery.

Type of Graft	Time to Neutrophil Engraftment
Bone Marrow	~14-20 days
Peripheral Blood	~10-14 days
Umbilical Cord	~25-42 days

Side Effects and Supportive Care

There are secondary effects that occur following your stem cell transplant. The most common are a result of the chemotherapy and/or radiation you received prior to receiving your stem cell infusion. This chapter will review those side effects in more detail. There are also some changes you can make to help lessen certain side effects.

Your bone marrow produces your blood cells (white blood cells, red blood cells, and platelets). Until the graft marrow begins to work your blood counts will remain very low. This may result in low white blood cells, specifically a decrease in your neutrophils called neutropenia, low red blood cells called anemia, and low platelets called thrombocytopenia.



Neutropenia (low white blood cell count)

Neutropenia is a decrease in the number of neutrophils. Neutrophils are a type of white blood cell that protects you against infections. A normal neutrophil count is 2,500 to 6,000. Neutropenia is the term used to describe a neutrophil count below normal and is expected after chemotherapy and/or radiation for your stem cell transplant.

Neutropenia is the time when you are at greatest risk for infection. The duration varies with the type of stem cell transplant you receive. It may be as short as a few days and as long as a few weeks. To help decrease this time span, you will receive daily white blood cell growth factor injections. In addition, you will be placed on medications to minimize your risk or prevent infections from bacteria (antibiotic), viruses (antiviral), and fungus (antifungal). If you have a fever, intravenous antibiotics will be started right away as treatment.

During this time, you will also be placed on what is known as “stem cell precautions.” This alerts visitors and hospital staff on the proper steps to be taken prior to coming in contact with you, proper hand hygiene and use of gloves. When exiting your room, you will need to practice precautionary measures as well. This includes wearing gloves and a face mask. Other important measures you can take are:

- Shower daily with chlorhexidine body wash
- Practice proper hand hygiene regularly (before eating, after using the toilet, blowing your nose, coughing or sneezing)
- Good oral hygiene (discussed in this section)
- Good perianal care (discussed in this section)

Anemia (low red blood cell counts)

Anemia is a decrease in red blood cells or hemoglobin level that results in a decrease of the oxygen-carrying capacity of the blood. After chemotherapy and/or radiation, there is a decrease in red blood cell production from the bone marrow along with an increase in red blood cell destruction. During your hospitalization, you may require a red blood cell transfusion. Every day the stem cell transplant team will review your labs and perform a physical exam on you to determine if you require a transfusion. Signs and symptoms to report that may indicate the need for a red blood cell transfusion include:



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- Active bleeding
- Changes in heart rate
- Changes in the rate of your breathing
- Changes in blood pressure
- Difficulty breathing
- Feeling tired

Thrombocytopenia (low platelet counts)

Platelets play an important role in blood clot formation. When a blood vessel is injured and bleeding occurs, platelets stick together and attach to the site of injury to form a plug and stop bleeding. *Thrombocytopenia* is a decrease in the number of platelets in the blood. A normal platelet count is between 140,000 and 400,000. During your hospitalization, you may require a platelet transfusion. Every day the stem cell transplant team will review your labs and perform a physical exam on you to determine if you require a transfusion. Signs and symptoms to report that may indicate the need for a platelet transfusion include:

- Bleeding from mucous membranes (nose or mouth)
- Blood in emesis, urine and/or stool
- Heavy menstruation (female patients)
- Changes in mental status
- Headaches

Due to the increased risk for bleeding it is important to practice “bleeding precautions.” These include:

- Avoid injury/falls
- Only use electrical razor for shaving needs
- Use of soft bristled tooth brush
- Avoid flossing

Blood or Platelet Transfusion

After reviewing your labs and examining you, the stem cell transplant team may decide you require a transfusion. If so, the nurse will obtain a blood specimen (if not already done) to determine and confirm your blood type. The nurse will receive notification when your blood product has arrived at the hospital and is ready to be transfused. At this time, you may receive pre-medications prior to the transfusion.



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When the product has arrived in the unit, your nurse will ask you to lie down in bed or sit in a chair during the transfusion. Your nurse will connect you to a monitor that will read your vital signs (heart rate, blood pressure, respirations and oxygen saturation). These are all important readings to inform your nurse how well you are tolerating the transfusion.

The transfusion will infuse through your trifusion catheter or CVC. Red blood cell transfusion is commonly given over two to four hours and platelet transfusions are given over 30 minutes to one hour. During the infusion, your vital signs will be monitored closely.

Possible side effects of a blood transfusion are:

- Fever, chills, or facial flushing
- Rash or hives
- Changes in heart rate and/or blood pressure
- Chest pain or tightness
- Shortness of breath
- Nausea

If any of these side effects occur, your nurse will intervene appropriately to treat and minimize these effects. The transfusion may be stopped and the APP and/or physician will assess you.

Once your transfusion is complete, we encourage you to continue with your daily routine. This includes walking in the hallway, sitting in the bedside chair and using your incentive spirometer.

Nausea/Vomiting

Nausea and vomiting are common side effects following chemotherapy and/or radiation. Prior to receiving chemotherapy and/or radiation you will receive medications to prevent nausea and vomiting. Certain chemotherapy agents have a higher risk and may require several medications to prevent or manage nausea and vomiting. You will always have additional medications available that you can request from the nurse if you develop nausea or vomiting. However, these symptoms may persist after receiving chemotherapy. If you experience nausea or vomiting, notify the stem cell transplant team right away. It is important to prevent or control nausea and vomiting quickly, because it can result in weight loss and electrolyte imbalances in your blood. Your nurse or certified nursing assistant will provide you with a bag/basin if you are nauseous or

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vomiting. It is important to monitor how much emesis you are having to prevent complications such as dehydration and electrolyte imbalances. This also helps the nurse visually inspect the emesis for medications, should you have an episode following intake of medications.

There are many ways to help minimize these symptoms. The APP and/or physician may prescribe anti-nausea medications. There are certain things you can do to help as well. These include:

- Eat small, frequent meals
- Avoid overeating
- Request anti-nausea medication before meals
- Avoid fatty, spicy and highly salted foods
- Avoid foods with strong odors
- Eat cold or room-temperature foods
- Elevate the head of the bed or sit up in a chair 30-45 minutes after eating

Diarrhea

Diarrhea is described as loose or watery stools. This may occur following chemotherapy and/or an infection including the antibiotics used to treat an infection. It is important to notify the stem cell transplant team if you begin to experience loose stools. Your nurse will provide you with a collection device that should always stay under the toilet seat. This will allow your nurse to measure your stool output and collect a specimen if needed to rule out infection. It is important to monitor how much stool you are having to help prevent complications such as dehydration and electrolyte imbalances. This may be unpleasant for you as the patient and we ask you to notify your nurse or certified nursing assistant after having a bowel movement to help facilitate prompt disposal of your stool.

If the stool becomes watery, the nurse will send a specimen to rule out infection. While we wait for the results of this test, you will be placed on “special contact precautions.” These precautions require visitors and hospital staff to wear a yellow gown and gloves when entering your room. It will also require you to wear a yellow gown, gloves and mask when exiting your room. It is important to wash your hands with soap and water when under these precautions.

There are medications available to help minimize the amount of diarrhea you may be experiencing. The stem cell transplant team will prescribe the appropriate medications



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for you. Diet modifications can help minimize the frequency of bowel movements. These include decreasing the following in your diet:

- dairy
- caffeine
- greasy or fried foods

It is important for you to practice thorough hygiene to decrease your risk for infection and prevent skin breakdown. Clean the rectal area with mild soap and water after each bowel movement, rinsing well and patting dry with a soft towel. You will be provided protective barrier creams for use with perianal care.

Anorexia

Anorexia is defined as loss of appetite. This is expected to varying degrees with most patients during your transplant process. This occurs because of the chemotherapy and radiation secondary effects. You will receive treatment to help alleviate the anorexia and improve your appetite. A dietitian is available for nutritional counseling. We encourage you to eat small, frequent meals throughout the day. Meal supplements, such as Ensure, are available.

Mucositis

Mucositis is a general term used to describe inflammation of the mucous membranes that can result in painful sores. There are many different areas in your body that have a protective layer, a mucous membrane. These areas include your mouth, throat, stomach, intestines and rectum. Mucositis occurs when the chemotherapy and/or radiation have caused injury to the fast-growing cells of the mucous membrane. Damage to these cells causes ulcerations, resulting in a varying degree of discomfort and risk for infection for patients.

Signs and symptoms of mucositis vary depending on the location. Signs and symptoms of oral mucositis include:

- changes in taste and ability to swallow
- hoarseness or decrease in voice strength
- pain with swallowing or talking
- changes in the amount and/or consistency of saliva
- inflammation of the tongue and ulcers
- abdominal pain or cramping

- diarrhea

There are certain strategies that can be used to keep the mouth clean (or oral hygiene). Good oral hygiene may provide comfort and decrease your risk of infection. During your stay, you will be provided with a soft-bristled toothbrush and two oral rinsing solutions. One is an antimicrobial rinse known as chlorhexidine. It is important for you to rinse your mouth with chlorhexidine twice a day after brushing as tolerated. The other is a sodium-based rinse that you will use every two hours while awake for cleansing and moisturizing. It is important to note that flossing is discouraged as this could increase the risk of bleeding and infection.

Always notify the team if you are having any pain, as this is an expected and recognized symptom of mucositis. Medications are available to help alleviate mucositis pain, including numbing mouth rinses and pain medications. Things you may do to help minimize your discomfort include avoiding hot or spicy foods, rough foods, and commercial alcohol-based mouthwashes. If needed, most of your medications can be given by infusion temporarily until your mouth sores heal and you are able to swallow pills again.

Alopecia

Alopecia or hair loss is a common and distressing side effect of chemotherapy treatment in the transplant process. You may begin to lose all or some of your hair approximately two to three weeks after transplant. You may also experience scalp itching, dryness or discomfort. Hair loss may cause you to feel cold, so covering your head becomes important to retain body heat. Feel free to bring your own head pieces as you desire. Head coverings are available upon request. Hair will start to grow back a few months after treatment and may become a different color or texture.

Post-Transplant Complications

Infections

While waiting for your new cells to engraft, you are at a higher risk for developing infections. You are at risk of developing fungal and bacterial infections, as well as reactivation of certain viruses, such as the herpes virus. Any infection can become life threatening and lead to sepsis. Sepsis is the body's response to widespread infection. You will be placed on prophylactic (preventative) antibiotics while waiting for immune system recovery. If you experience a fever or signs and symptoms of infection your health care team may order specific tests (i.e. blood cultures, x-ray, urinalysis, etc.). You



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will also be placed on intravenous antibiotics and seen by one of our infectious disease doctors who specializes in the care of post-transplanted patients.

Your immune system may take as long as one year to recover following your transplant. Although you will be able to do many of the activities you did before, it is important to remain cautious and report any new onset of infection to your transplant team immediately.

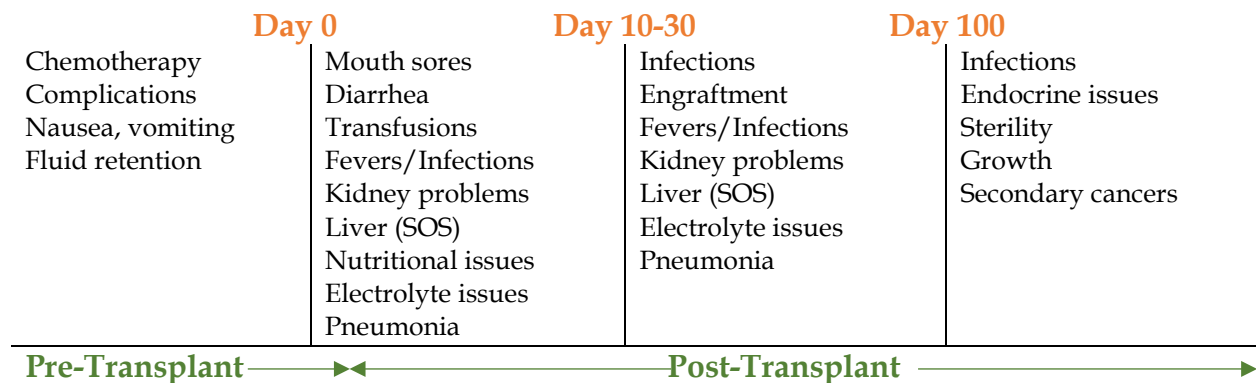
Graft Failure

There is a possibility that the new stem cells will fail to develop or mature after the transplant. If this occurs, it is called a rejection or graft failure. The risk of rejecting the new bone marrow or stem cells is rare. If your blood counts fail to recover following a transplant, your doctors will talk with you about the potential need to perform a second transplant or supply additional stem cells.

Relapse

Unfortunately, transplant does not guarantee that you will be cured of your cancer or underlying disease. Even with transplant, your disease could still return or relapse. In a small number of patients, a different type of cancer can occur after transplant. Such secondary cancers may be caused from the chemotherapy or radiation given prior to transplant. The risk of secondary cancers is low. If this occurs, you and your doctor will discuss available treatment options (i.e. second transplant, more chemotherapy, etc.).

Phases of Transplant Complications



Courtesy of Cancer Center Patient & Family Guide to BMT, 2013.





Transplant Specialty Care

Intensive Care Unit (ICU)

There may be a time during the transplant process when your condition becomes more serious and you may require closer monitoring in an ICU setting. This is a specialized unit where the doctors and nurses are trained in caring for patients requiring intensive or specialized treatment. The bone marrow transplant team works very closely with the ICU team to care for you while you are in the ICU. There may be different visiting hours and family guidelines in the ICU than those on the transplant unit.

Medications

There may be several medications that your transplant physician and team determine are important to continue taking after the transplant. It is common to be discharged with electrolyte supplements (magnesium and/or potassium), anti-infective medications, medications for acid reflux prevention and medications for any acute or ongoing symptoms you may have. Some autologous transplant patients will require a medication to protect their liver (ursodiol) depending on which chemotherapy regimen they receive or their risk of liver complications. The pharmacist or nurse will go through your medications with you before you leave the hospital.

You will be given some medications during your hospital stay that you will keep taking when you go home. The most common medicines you may be given are listed below. An allergic reaction (itching or hives, swelling in face or hands, swelling or tingling in mouth or throat, chest tightness, trouble breathing) can occur with any new medication.

If you have any questions about the medicines, ask your nurse to speak with the pharmacist.

Medications to PREVENT infection:

Option(s) to prevent viral infections (e.g., shingles)

Generic name (brand name)	Acyclovir (Zovirax)
How to take this medicine	<ul style="list-style-type: none"> ○ Take 2 times a day ○ Take with or without food ○ Keep taking this medicine until your doctor tells you to stop
Possible side effects	<ul style="list-style-type: none"> ○ Red skin rash ○ Yellowing of skin or whites of your eyes



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Generic name (brand name)	Acyclovir (Zovirax)
	<ul style="list-style-type: none"> ○ Decrease in how much or how often you urinate ○ Uneven heartbeat or weakness ○ Headache or muscle pain ○ Nausea, vomiting, diarrhea or stomach pain ○ Nervousness or tired feeling ○ Problems with vision

Generic name (brand name)	Valacyclovir (Valtrex)
How to take this medicine	<p>Take 2 times a day Take with or without food Keep taking this medicine until your doctor tells you to stop</p>
Possible side effects	<p>Red skin rash Yellowing of skin or whites of your eyes Seizures or tremors Uneven heartbeat or weakness Decrease in how much or how often you urinate Headache or dizziness Nausea, vomiting, diarrhea or stomach pain</p>

Option(s) to prevent viral hepatitis infections

Generic name (brand name)	Lamivudine (Epivir)
How to take this medicine	<p>Take 1 time a day Take with or without food Keep taking this medicine until your doctor tells you to stop</p>
Possible side effects	<p>Yellowing of skin or whites of your eyes Lightheadedness, severe weakness, tiredness, or confusion Uneven heartbeat or weakness Headache or dizziness Nausea, vomiting, diarrhea or stomach pain</p>



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	Numbness, tingling, or burning pain in hands, arms, legs or feet
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Option(s) to prevent bacterial infections (e.g., urine infections)

Generic name (brand name)	Levofloxacin (Levaquin)
How to take this medicine	Take 1 time a day Take with or without food Avoid antacids, calcium, magnesium, and dairy products 2 hours before and 2 hours after taking this medicine
Possible side effects	Red skin rash Uneven heartbeat, chest pain Tingling or numbness in hands or feet Seizures, headaches, anxiety Unusual bleeding, bruising or weakness Diarrhea Muscle or joint pain Yellowing of skin or whites of your eyes

Option(s) to prevent fungal infections (e.g., yeast infections)

Generic name (Brand name)	Fluconazole (Diflucan)
How to take this medicine	Take 1 time a day Take with or without food Keep using this medicine until your doctor tells you to stop
Possible side effects	Red skin rash Yellowing of your skin or whites of your eyes Fast or uneven heartbeat Unusual bleeding, bruising or weakness Headache

Generic name (brand name)	Voriconazole (VFend)
How to take this medicine	Take 2 times a day Take 1 hour before or 1 hour after a meal Keep taking this medicine until your doctor tells you to stop
Possible side effects	Red skin rash



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Generic name (brand name)	Voriconazole (VFend)
	<p>Bone pain</p> <p>Yellowing of your skin or whites of your eyes</p> <p>Change in how much or how often you urinate, painful, or cloudy urine</p> <p>Vision changes, light sensitivity</p> <p>Decreased appetite</p> <p>Headache</p> <p>Fast or uneven heartbeat</p> <p>Sudden or severe stomach pain</p>

Generic name (brand name)	Posaconazole (Noxafil)
How to take this medicine	<p>Take 1 time a day</p> <p>Take with food</p> <p>Keep taking this medicine until your doctor tells you to stop</p>
Possible side effects	<p>Diarrhea or vomiting</p> <p>Fast or uneven heartbeat</p> <p>Unusual bleeding, bruising or weakness</p> <p>Yellowing of your skin or whites of your eyes</p>

Option(s) to prevent a rare type of pneumonia (e.g., PCP/PJP pneumonia)

Generic name (brand name)	Trimethoprim/Sulfamethoxazole (SMZ-TMP; Bactrim)
How to take this medicine	<p>Take 1 time a day on Monday, Wednesday, Friday</p> <p>Take with or without food, should be taken with 8 ounces of water</p> <p>Do not start taking this medication until you are told to during a clinic visit</p>
Possible side effects	<p>Rash</p> <p>Chest pain, cough or trouble breathing</p> <p>Confusion or weakness</p> <p>Muscle twitching or pain</p> <p>Diarrhea, stomach pain, or bloating</p> <p>Nausea, vomiting or loss of appetite</p> <p>Unusual bleeding, bruising, or weakness</p>



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	Uneven heartbeat, numbness or tingling in your hands, feet, or lips Yellowing of your skin or whites of your eyes
--	--

Generic name (brand name)	Atovaquone (Mepron)
How to take this medicine	Take 1 time a day Take with food; shake suspension gently before taking Do not start taking this medication until you are told to during a clinic visit
Possible side effects	Rash Yellowing of your skin or whites of your eyes Diarrhea Headache

Generic name (brand name)	Pentamidine (Pentam)
How to take this medicine	Take 1 time a month (infusion in the vein) Do not start taking this medication until you are told to during a clinic visit
Possible side effects	Rash Feeling hungry or thirsty Nervous, sweating or confusion Unusual bleeding or bruising Sore mouth or throat Pain, itching, swelling or burning where the IV is given Nausea, vomiting, or loss of appetite Change in taste or a metallic taste in your mouth

Medication(s) to PREVENT liver complications:

Generic name (brand name)	Ursodiol (Actigall)
How to take this medicine	Take two times a day Take with food
If a dose is missed	Take your dose as soon as you remember If it is less than 6 hours until your next dose, skip the missed dose



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Generic name (brand name)	Ursodiol (Actigall)
	Do not take extra medicine to make up for a missed dose
Possible side effects	Chest pain Nausea or vomiting Stomach pain Swelling in your hands or ankles Headache Diarrhea or constipation Unusual bleeding or bruising Itching, dry skin, rash or hair thinning Bitter taste in your mouth

Common medications to PREVENT or TREAT nausea or vomiting:

Generic name (brand name)	Ondansetron (Zofran)
How to take this medicine	Take up to 3 times a day as needed
Possible side effects	Headache Constipation Tiredness Fainting, dizziness or lightheadedness Uneven heartbeat or slow

Generic name (brand name)	Prochlorperazine (Compazine)
How to take this medicine	Take up to 4 times a day as needed
Possible side effects	Constipation Drowsiness or blurred vision Dry mouth Fainting, dizziness or lightheadedness Uneven heartbeat or slow Jerky muscle movement you cannot control (face, tongue) Unusual bleeding, bruising, or weakness Yellow skin or eyes

Other medications you may be given during stem cell transplant:



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Generic name (brand name)	Filgrastim or filgrastim-sandz (Neupogen or Zarxio)
Reason for use	Helps the body make white blood cells
How to take this medicine	Injection 1-2 times a day
Possible side effects	Bone, joint or muscle pain Headache Nausea Skin changes or redness Fainting, dizziness or lightheadedness Pain in the left side or shoulder, or feeling unusually full Unusual bleeding, bruising, or weakness

Generic name (brand name)	Furosemide (Lasix)
Reason for use	Helps the body get rid of extra fluid
How to take this medicine	Take as directed
Possible side effects	Increased urinary frequency Dizziness Skin rash Confusion, weakness or muscle twitching Dry mouth Hearing loss, ringing in the ears Stomach pain or diarrhea Yellow skin or eyes

Generic name	Magnesium supplements (Mag-Ox, mag plus protein)
Reason for use	To increase the amount of magnesium in your body
How to take this medicine	Take as directed Take with meals or milk to decrease stomach upset
Possible side effects	Diarrhea

Generic name	Loperamide (Imodium)
Brand name	Imodium
Reason for use	To stop diarrhea
How to take this medicine	Take 1 tablet by mouth after every loose stool until no diarrhea for 24 hours
Possible side effects	Constipation, nausea or vomiting Stomach pain, cramps or bloating Dry mouth Changes in vision



	Drowsiness or dizziness
--	-------------------------

Discharge from the Hospital

Follow-up Appointments

Prior to your discharge, follow-up appointments will be arranged and scheduled. You will be given a “Priority Access Card” that is valid for three months after transplant. This card will allow you to move quickly through the registration process for follow-up appointments. The card will also have important numbers listed on the back if you need to contact a stem cell transplant team member.

PRIORITY: SCTP

SAMPLE

****This card is for 3 months or Autologous patients and 6 months for Allogeneic patients from date of transplant****

For Clinical concerns please contact:

- Dr. Komanduri, Dr. Pereira, & Dr. Lekakis:
305-243-9127
- Dr. Goodman: 305-243-6520
- Dr. Byrnes: 305-243-6611
- Dr. Beitinjaneh & Dr. Jimenez- Jimenez:
305-243-6626
- SCT Triage Nurse: 305-243-7000

Important Numbers:

- Page Operator at 305-243-1000
- Bone Marrow Transplant Prog. 305-243-4141
- Patient Relations at 305-243-3820

Please return this card to your physician





Notes



POST-TRANSPLANT LIFE

Signs and Symptoms to Report

In addition to any other concerns you may have, make sure to report if you experience any of the following signs and symptoms after discharge from the facility:

- Temperature of 100.5°F or greater
- Chills or sweating
- Persistent cough (note any sputum production and color)
- Cold or flu symptoms
 - The above-mentioned signs and symptoms may be apparent when an infection is present. Some ways to protect yourself against infections include:
 - Avoiding large crowds such as movie theaters and public transportation
 - Wearing a mask when coming to the clinic or hospital, or when you are out in public when it is not possible to avoid large crowds
- Rash/redness
 - Skin changes are common after transplant due to chemotherapy and radiation and they may include increased dryness, flaking, discoloration and darkening. Although these are common, you should report the appearance of a new rash or increased redness, pain, itching or changes in skin texture, such as thickening.
 - Your skin will be very sensitive to sun exposure and sunburn very easily. Avoid bright sunlight after transplant and wear sun block when outdoors or protective clothing such as long-sleeved shirts, long pants and a hat with a brim.
- Nausea or vomiting not relieved by anti-nausea medications
- Diarrhea, constipation or abdominal pain
 - Persistent gastrointestinal symptoms after stem cell transplant may be related to things such as infection, medications, damage to GI mucosa, etc.
- Shortness of breath and/or excessive fatigue
 - This can be related to infection.
- Blood in urine, stool or sputum, bleeding from gums or nose, appearance of bruises or pin-point red dots (petechiae and/or purpura) anywhere on the skin, etc.
 - The most common cause of bleeding in post-transplant patients is due to low platelet counts. If you experience any signs and symptoms of bleeding, report it immediately to your transplant team.





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- Difficulty emptying bladder, burning on urination, increased frequency of urination
- Feeling dizzy or light-headed
- Changes in your venous access device or the area around it
- Mucositis
 - Chemotherapy affects the rapidly dividing cells that line the mouth and digestive tract. This is known as mucositis which may cause tenderness, soreness, dryness, occasional white patches, ulcerations, bleeding gums, sore throat, and/or difficulty or inability to eat, drink, or swallow.

Exercise

It is important to continue to remain as active as possible throughout the transplant process both during and after your hospital admission. There will be days that you will feel too weak to participate in any physical activity, but even light physical activity will be beneficial on those days. Prolonged inactivity can lead to muscle weakening and may delay your recovery. It can also lead to the development of pneumonia. Pneumonia is when fluids accumulate in your lungs. An incentive spirometer will be given to you at admission. You are encouraged to use it frequently when you are awake to help maintain lung expansion. You will have a physical therapist to assist you in the event you require support. The physical therapist will also monitor your activity and make recommendations as needed to ensure your safe transition back home.



You are encouraged to walk the halls three to four times daily for a minimum of 10-15 minutes each time while admitted. You must wear sneakers for walks to keep you safe and your body well supported. If you are having difficulty meeting this goal you can request assistance from our physical therapist.

Once you return home, continue to take brisk walks either indoors or outdoors. If you are planning to walk outdoors once you return home, be sure to use minimum SPF 30



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and a wide brim hat for protection. It is recommended that you walk during early morning and late afternoon hours to minimize sun exposure.

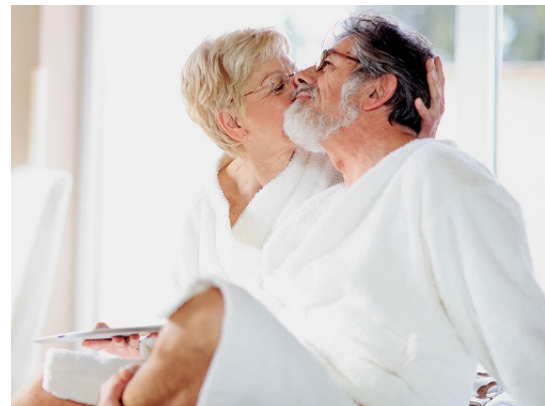
Maintaining an active lifestyle will help you return to your normal daily activities and prevent infections.

Driving

You will be unable to drive for the first three months following your transplant. While you are recovering it is unsafe to drive. This is due to the side effects of medications and your physical condition. It is important that you consider this when arranging your follow-up care. Have someone available to drive you to your appointments or for evaluation requiring urgent medical attention. Any delays in initiating treatments can be life-threatening.

Sexual Activity

Many transplant survivors experience sexual problems such as a lack of interest in sex, inability to perform and pain. Factors that can have an impact on sexual desire include hormonal changes due to chemotherapy or total body irradiation, excessive fatigue, cancer pain or treatment, or changes in your self-image.



Some people experience more sexual problems after transplant than others. These include older patients, women, those who had sexual difficulties or lower relationship satisfaction before transplant and those who do not resume sexual activity within a year after transplant.

When can sexual activity resume after my transplant?

We recommend having a platelet count of at least 50,000 before engaging in sexual intercourse. Until then, avoid sex that involves penetration or contact with



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mucous membranes while your blood counts are low. This includes vaginal, oral and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus.

To reduce your risk of exposure to sexually-transmitted infections such as CMV, HIV, hepatitis and herpes, and because some medications can be passed to your partner during sexual activity, we recommend the use of latex condoms. Use a barrier device (condoms or dental dams) anytime your partner's vaginal secretions or semen could enter your mouth.

What can I do to treat vaginal dryness?

Some women might experience vaginal dryness after transplant because of the changes in hormone levels. Water-soluble lubricants such as KY® Jelly or Astroglide® can be useful during intercourse to decrease the discomfort of vaginal dryness.



The American Cancer Society provides excellent resources on sexuality following cancer treatment. They are available free from your local American Cancer Society or on the ACS website at the links below:

- [Sexuality for the Man With Cancer](http://www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf)
www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf
- [Sexuality for the Woman With Cancer](http://www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf)
www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf

Psychosocial Considerations of Transplant

Along with other changes, you may experience emotional, social, and spiritual changes throughout your transplant process. You may find that you experience feelings of anxiety, fear and sadness but also feelings of hopefulness, courage and joy. These changes in thoughts, feelings and relationships are normal but it is helpful if you are aware. Seek help for these changes if they become uncomfortable or ongoing. Changes in sexuality and intimacy are also possible and discussed in greater depth within this



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guide (page 39). The Courtelis Center for Psychosocial Oncology has social work, psychiatry, psychology, music therapy and pastoral care available to you for ongoing support. Below are some common psychosocial concerns during each phase of the transplant process:

- Pre-transplant you may experience a combination of fear, nervousness and hopefulness. Traveling back and forth to the hospital for pre-transplant appointments and work-up may require a lot of time and result in expenses for gas, parking, tolls, etc. It is common for patients to feel overwhelmed or confused and for the patient/family to worry about how they will manage the transplant process. We encourage you to contact the transplant team at any time for help.
- During your transplant hospitalization, you may become nervous about the transplant process and how you will feel throughout. Our team will make every effort to manage your symptoms and keep you comfortable. Separation from family, children and home is often difficult. It is normal for our patients to experience feelings of isolation, sadness and frustration. It is also common, however, for people to feel excited and hopeful about their transplant. Many support services, as suggested above, are available to you throughout your hospital stay. We encourage friends and family to visit with you if they are over the age of 12 and not feeling sick.
- Post-transplant, patients can feel nervous about returning home after being hospitalized for a duration of time. We will work with you and your family to ensure that you understand how to provide appropriate care in the home. Our transplant team is available to you for questions and concerns after discharge. Common reasons for anxiety once returning home are:
 - Lack of energy or fatigue: It may take some time for you to feel as energetic or independent as you did prior to treatment. This may cause frustration. We encourage you to be patient with yourself and to listen to the limitations and needs of your body.
 - Financial toxicity: Expenses for post-transplant follow-up can cause added stress. This is associated to co-pays related to medications, and loss of income while receiving treatment and during the recovery period. The



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financial implications of transplant are discussed in more detail in *“Financial Considerations of Transplant, page 31.”*

- Relapse or effectiveness of transplant: It is common to become preoccupied with focusing on whether or not the transplant was effective in achieving remission. The transplant team will be frequently assessing your disease status post-transplant and discussing results with you during follow-up visits.

Nutrition

Food Handling



“Food-borne illness” is caused by consuming contaminated foods and/or beverages. An estimated one in six Americans will likely develop a food-borne illness every year. Patients undergoing cancer treatment are at increased risk for developing a foodborne illness if they become neutropenic. Being *neutropenic* means that the immune

system is low, and not as strong to fight off infections. The most important thing we can do to prevent foodborne illness is to practice safe food handling. Please refer to the USDA/FDA “Food Safety Guide for Transplant Recipients” for specific information and guidelines in regard to food safety.

Grocery Shopping

While shopping, follow these tips for safe food-handling:

- Check the integrity of products before purchasing. Never buy foods that do not appear to be safe or kept in a clean environment. Check packaging well. Leave behind food items in broken or dented packaging.
- Check expiration dates. Do not buy products after the “use by” date.
- Place fresh produce and meats/poultry/seafood in separate plastic bags prior to placing them in your shopping cart.
- Avoid free tastings.



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- Leave refrigerated/frozen items and meats for last.

FOOD SAFETY FOR PEOPLE WITH CANCER

1 IN 6 Americans get sick from foodborne illness each year

WHY Food safety is important for people with cancer because treatment can weaken the immune system. Chemotherapy and radiation therapy may cause **neutropenia**—a decrease in white blood cells that fight off infection.

Ask Your Doctor:

- Am I at increased risk for foodborne illness? How long will this risk last?
- What steps should I take to prevent foodborne illness?
- Which foods require special preparation to prevent foodborne illness?
- Whom should I contact if I think I have a foodborne illness?
- What treatment do you recommend for my foodborne illness?
- How can I prevent dehydration?
- Is there anything else I should be asking?

What are the SYMPTOMS of foodborne illness?

SAFE MINIMUM INTERNAL TEMPERATURES

145°F Beef, Pork, Lamb, & Veal (w/ 2 inch roast level)	160°F Ground Meat	165°F All Poultry
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Foods to AVOID

- Raw or undercooked meat, poultry, or seafood
- Unpasteurized or raw milk
- Raw or undercooked eggs
- Unwashed fresh produce
- Soft cheeses made from unpasteurized (raw) milk
- Cold hot dogs & deli meats
- Raw sprouts (alfalfa, bean, etc)

Foods to EAT

- Meat, poultry, & seafood cooked to a safe internal temperature
- Pasteurized milk
- Cooked eggs with a firm yolk
- Washed fresh or cooked produce
- Hard cheeses or soft cheese made from pasteurized milk
- Reheat hot dogs & deli meat to steaming hot or 165 °F
- Cooked sprouts

CLEAN:
Wash hands & surfaces often.

SEPARATE:
Keep raw meat & poultry separate from ready-to-eat foods.

COOK:
Cook foods to a safe internal temperature.

CHILL:
Chill perishable foods within 2 hours.

For more food safety tips, go to
—FoodSafety.gov—

USDA IS AN EQUAL OPPORTUNITY PROVIDER AND EMPLOYER. Cancer.Net® Patient Information Files, ASCO®

Preparing your meals

There are four basic steps to food safety.

1. CLEAN

Wash hands and surfaces often. Bacteria can spread throughout the kitchen and get onto cutting boards, utensils, counter tops and food.



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- Wash your hands in warm soapy water for at least 20 seconds before and after handling food and after using the bathroom, changing diapers or handling pets. (Washing your hands properly takes about as long as singing “Happy Birthday” twice.)
- Wash cutting boards, dishes, utensils and counter tops with hot soapy water between preparation of raw meats and any other food that will not be cooked.
- Use paper towels to clean surfaces. If you use cloth towels, wash them often.
- Wash produce. Rinse fruits and vegetables, and rub firm-skin fruits and vegetables with $\frac{1}{2}$ water and $\frac{1}{2}$ white vinegar. Then rinse under running water.
- Clean lids before opening canned goods.

2. SEPARATE

Don't cross-contaminate. This can occur when bacteria are spread from one food product to another. It's especially common when handling raw meat, poultry, seafood and eggs. The key is to keep these foods, and their juices, away from ready-to-eat foods.

- Separate raw meats from other foods in your shopping cart, grocery bags and refrigerator.
- Never place cooked food on a plate that previously held raw meat, without first washing the plate.
- Don't reuse marinades used on raw foods unless you bring them to a boil first.
- Consider using one cutting board for only raw foods and another one only for ready-to-eat foods like bread, fresh fruits and vegetables and cooked meat. You can find colorful cutting boards to designate for different food items.
- Avoid cutting boards that are made from porous materials that are hard to clean. Ceramic chopping boards are preferable to wooden ones.



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3. COOK

Cook to safe temperatures.

- Use a food thermometer to measure the internal temperature of cooked foods.
- Below are the recommendations for appropriate cooking temperatures and rest times, according to the CDC.

Category	Food	Temperature (°F)	Rest Time
Ground Meat & Meat Mixtures	Beef, Pork, Veal, Lamb	160	None
	Turkey, Chicken	165	None
Fresh Beef, Veal, Lamb	Steaks, roasts, chops	145	3 minutes
Poultry	Chicken & Turkey, whole	165	None
	Poultry breasts, roasts	165	None
	Poultry thighs, legs, wings	165	None
	Duck & Goose	165	None
	Stuffing (cooked alone or in bird)	165	None
Pork and Ham	Fresh pork	145	3 minutes
	Fresh ham (raw)	145	3 minutes
	Precooked ham (to reheat)	140	None
Eggs & Egg Dishes	Eggs	Cook until yolk and white are firm	None
	Egg dishes	160	None
Leftovers & Casseroles	Leftovers	165	None
	Casseroles	165	None
Seafood	Fin Fish	145 or cook until flesh is opaque and separates easily with a fork.	None
	Shrimp, lobster, and crabs	Cook until flesh is pearly and opaque.	None
	Clams, oysters, and mussels	Cook until shells open during cooking.	None
	Scallops	Cook until flesh is milky white or opaque and firm.	None

4. CHILL

Cold temperatures slow the growth of harmful bacteria. Keeping a constant refrigerator temperature of 40 °F or below is one of the most effective ways to reduce risk of foodborne illness.



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- Refrigerate or freeze meats and other perishables within two hours of cooking or purchasing.
- Never thaw food at room temperature. Thaw in the refrigerator, in cold water or in the microwave.
- Divide large amounts of food into shallow containers for quicker cooling in the refrigerator.

WHEN IN DOUBT, THROW IT OUT!



KEEP YOUR FAMILY SAFER FROM FOOD POISONING
Check your steps at FoodSafety.gov

Eating Out

Because it is hard to guarantee that third parties will observe safe food handling, it may be safest to avoid eating out altogether. If you decide to eat out, go to places that are

known for their safe food handling. It might be safest to avoid food carts and street vendors. Your provider will be able to tell you when it is safe to start eating out again.

Alcohol Consumption

After your transplant, you will be on medications that can interact with alcohol. Alcohol can be harmful to your liver and recovering bone marrow. Alcohol consumption is not recommended after transplant. You should first consult your transplant physician and discuss safe use of alcohol. Your transplant pharmacist can assist with specific information related to your medications and any drug interactions.

Electrolytes

Based on your medications and your lab results, your physician may ask you to avoid or increase the consumption of foods that are high in specific minerals. Below is a list of foods that are high in sodium, potassium and phosphorus, according to the FDA Medical Nutrition Manual. This list does not include all food sources. For a more extensive list, please ask your doctor or dietitian or consult our food and nutrition manual.

- **Sodium**
Good sources of sodium include table salt, certain seasonings and condiments, canned foods, frozen meals, processed/luncheon meats, cured foods, and chips/crackers/pretzels. For packaged meals and food items, be sure to check the nutritional label to determine the sodium content of that food. Usually foods considered low in sodium have less than 140mg of sodium per serving.
- **Phosphorus**
Good sources of phosphorus include foods that are high in protein (organ meats/sardines/oysters), dairy (cheese/milk/yogurt/ice cream/puddings), dried beans, peas and whole grain products. Processed beverages such as colas, iced teas, and ale may also be high in phosphorus.
- **Potassium**
Good sources of potassium include some fruits (apricots, bananas, oranges, cantaloupes, mangos, kiwi, avocado, prunes), dried fruits, some vegetables (squash, potatoes, pumpkin, tomatoes, spinach) and dried peas/dried beans and



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lentils. Other foods include milk, peanut butter, yogurt and nutritional supplements. Canned foods that are lower in sodium or salt substitutes can also provide potassium. Foods that provide more than 200mg of potassium per portion are considered high in potassium.

These are nutritional resources you may find useful:

- Cancer.net: <http://www.cancer.net/survivorship/healthy-living/food-safety-during-and-after-cancer-treatment>
 - CDC Food Safety: <https://www.cdc.gov/foodsafety/>
 - Food Safety.gov: <https://www.foodsafety.gov/risk/cancer/index.html>
 - Food Safety for Transplant Recipients link:
<http://www.fda.gov/downloads/Food/FoodborneIllnessContaminants/UCM312793.pdf>
 - Foodborne Outbreaks: <https://www.cdc.gov/foodsafety/outbreaks/index.html>
- Food Recalls and Alerts: <https://www.foodsafety.gov/recalls/index.html>

Returning to Work or School

Returning to work or school will depend on your speed of recovery. Typically, you are unable to return to work or school until three months after transplant. Most individuals will return on a part-time basis and slowly progress to full-time employment based on how you feel. These are estimates and may vary. You and your transplant team can work together to determine when is the optimal time for you.

LONG-TERM CARE FOLLOW-UP

Survivorship

It is important that after your transplant you continue to have regular health maintenance checkups. At six months post-transplant you will be required to visit our Long-Term Care Follow-up (LTCFU) clinic for your survivorship care plan. You and your survivorship team will review and complete specific information related to your cancer and treatment. We want to empower you with resources and healthy living tips to help you move forward with your life post-treatment.

Our team and highly experienced medical professionals look forward to working with you and your family to give you all the information and resources to achieve the best possible quality of life following transplant.

Your LTCFU team will help you determine when it is appropriate to schedule routine exams. Health maintenance exams include:

- Breast self-examination for women
- Testicular self-examination for men
- Skin self-examination
- Annual eye-examination
- Pap smears for women
- Mammograms (women over 40 years old)
- Prostate exam for men
- Colonoscopy (patients over 50 years old)
- Annual physical examination by your primary care provider
- Yearly flu shot

Immunizations

Once you have undergone a stem cell transplant, your immune system is altered and may no longer remember previous exposures to vaccinations received during childhood. You will need to be re-immunized over a period of two years as instructed by your provider. Arrangements can also be made to have them completed by your primary oncologist or primary care provider with the guidance of your physician or nurse practitioner.



It is important to avoid receiving live vaccines post-transplant or be exposed without the guidance of your physician. After your transplant, you will not be able to receive the flu vaccine for at least six months. If there is an influenza outbreak your transplant provider may consider vaccination earlier.

You will be provided a vaccination card once you begin receiving your vaccines. Please remember to bring your card to each visit. Your primary hematologist will keep track of all immunizations completed following transplant.

Second Primary Malignancy

After stem cell transplant, there is a risk for a second primary cancer resulting from the irradiation and/or chemotherapy you received through the duration of your treatment both before and after transplantation. As part of our long-term care management of post-transplant survivors, we recommend preventative screenings to be completed. If you have any questions or concerns it is important that you speak with your provider.



MORE INFORMATION

Maps



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*Shuttle service to University of Miami Hospital, Sylvester Comprehensive Cancer Center, and University of Miami Hospital & Clinics.



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Pastoral Services and Places of Worship

Spiritual (and religious) well-being is associated with improved quality of life. Research shows that spiritual or religious beliefs and practices promote a positive mental attitude. This may help a patient feel better and recover more quickly and easily.

Pastoral care services offered at Sylvester provide spiritual counseling and support. Pastoral resources include community clergy referrals and special holiday prayer services.

The onsite, nondenominational Jill Selevan Chapel offers an inviting place for prayer, reflection and services. The chapel is located adjacent to the lobby of the University of Miami Hospital and Clinics (UMHC) and is open to the community 24 hours a day.

For more information about pastoral services at Sylvester, call 305-243-1000 or 800-545-2292.

See below for local churches and places of worship:

Local Churches/Places of Worship			
Lebanon Seventh Day Adventist	1491 NW 26 th St, Miami, FL 33142	(305) 635-7188	http://lebanonfl.adventistchurch.org/
Miami Central Spanish Seventh Day Adventist Church	862 SW 4 th St, Miami, FL 33130	(305) 545-0300	http://www.miamicentralsda.com/
Greater Historic Bethel AME Church	245 NW 8 th St, Miami, FL 33136	(305) 371-9102	http://www.proimagen.com/clients/church/
Apostolic Mission of Christ	261 NE 23 rd St, Miami, FL 33137	(305) 573-2590	
Miami Central Brazilian Seventh Day Adventist	511 NW 4 th St, Miami, FL 33128	(954) 849-1571	http://www.miamisda.com/



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Local Churches/Places of Worship

Mt Zion Baptist Church	301 NW 9 th St, Miami, FL 33136	(305) 379-4147	
St. Agnes Episcopal Church	1750 NW 3 rd Ave, Miami, FL 33136	(305) 573-5330	http://www.stagneseiscopalchurch.org/
Corpus Christi Catholic Church	3220 NW 7 th Ave, Miami, FL 33127	(305) 635-1331	http://corpuschristimiami.com/
Mt Olivette Baptist Church	1450 NW 1 st Ct, Miami, FL 33136	(305) 573-4825	
St. John Institutional Missionary Baptist Church	1328 NW 3 rd Ave, Miami, FL 33136	(305) 372-3877	
Miami Beach Community Church	1620 Drexel Ave, Miami, FL 33139	(305) 538-4511	http://www.miamibeachcommunitychurch.com/
Temple Baptist Church	1723 NW 3 rd Ave, Miami, FL 33136	(305) 573-3714	
Celestial Church of Christ - Miami Miracle Parish	3421 NW 7 th Ave, Miami, FL 33127	(305) 637-3668	http://www.ccc-miami.org/
Vous Church	3100 NW 5 th Ave, Miami, FL 33127	(786) 671-0913	http://vouschurch.com/
Unity On The Bay	411 NE 21 st St, Miami, FL 33137	(305) 573-9191	https://www.unityonthebay.org/



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Local Churches/Places of Worship

Christ Fellowship	500 NE 1 st Ave, Miami, FL 33132	(305) 238-1818	https://downtown.cfmiami.org/
Trinity Cathedral	464 NE 16 th St, Miami, FL 33132	(305) 374-3372	http://www.trinitymiami.org/
Diocese of Southeast Florida Episcopal	525 NE 15 th St, Miami, FL 33132	(305) 373-0881	http://www.diosef.org/
First United Methodist Church of Miami	400 Biscayne Blvd, Miami, FL 33132	(305) 371-4706	http://firstchurchmiami.org/
Gesu Catholic Church	118 NE 2 nd St, Miami, FL 33132	(305) 379-1424	http://gesuchurch.org/
Holy Comforter Episcopal Church	150 SW 13 th Ave, Miami, FL 33135	(305) 643-2711	http://www.espiritusantos.org/
St. John Bosco Catholic Church	1349 W Flagler St, Miami, FL 33135	(305) 649-5464	http://sjboscomiami.org/
Trinity CME Church	511 NW 4 th St, Miami, FL 33128	(305) 373-7162	
First Church of Christ	15 W Flagler St, Miami, FL 33130	(305) 373-1645	http://christianscienceflorida.org/
First Miami Presbyterian Church	609 Brickell Ave, Miami, FL 33131	(305) 371-3439	http://firstmiami.org/



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Local Churches/Places of Worship

Greater Mercy Missionary Baptist Church	1135 NW 3 rd Ave, Miami, FL 33136		
St. Peters Antiochian Orthodox	1811 NW 4 th Ct, Miami, FL 33136	(305) 573-8941	
Temple Israel of Greater Miami	137 NE 19 th St, Miami, FL 33132	(305) 573-5900	http://www.templeisrael.net/
Temple Beth Shumel	1700 N Michigan Ave, Miami Beach, FL 33139	(305) 534-7213	
Temple Emanu-El Synagogue	1701 Washington Ave, Miami Beach, FL 33139	(305) 538-2503	http://www.tesobe.org/
Masjid Al-Ansar	5245 NW 7 th Ave, Miami, FL 33127	(305) 757-8741	http://www.masjidalansar.org/

Hotels and Accommodations

Many hotels, car rental companies and airlines offer discounted rates to Sylvester’s patients and guests. There are resources that may help with lodging issues as the American Cancer Society or Joe’s House. Contact your social worker if you need help arranging these or other services. The social worker can help coordinate these services and provide other resources that might be helpful through your treatment.

American Cancer Society
www.acs.org



1-800-227-2345

Joe's House
www.joeshouse.org
877-563-7468



Notes

GLOSSARY OF TERMS

Afebrile: Having no fever; normal temperature.

Allogeneic Transplant (allograft): A transplant in which bone marrow, peripheral blood stem cells, or cord blood stem cells come from a donor, such as a family member or unrelated person.

Alopecia: Hair loss associated with chemotherapy and other cancer treatments.

Ambulatory: The ability to walk; not confined to bed.

Analgesic: A medication used to reduce pain.

Anaphylaxis: A serious, potentially life-threatening allergic reaction that can cause you to go into shock.

ANC (Absolute Neutrophil Count): The number of neutrophils (a type of white blood cell responsible for fighting bacteria) in a blood sample.

Anemia: Low red blood cell count, which can cause you to feel fatigued and have shortness of breath. Anemia can be caused by a variety of conditions and diseases.

Antibiotic: Medication used to kill microbial organisms that cause disease. Since some cancer treatments can reduce your body's ability to fight infection, antibiotics may be used to treat or prevent these infections.

Antibody: A protein produced by immune system cells and released into your blood. Antibodies defend against foreign substances such as bacteria. For example, if you get a tetanus vaccine, you will make a protein (antibody) which protects against tetanus, called a tetanus antibody. Each antibody works against a specific substance called an antigen.

Anticoagulant: Medication that reduces your blood's ability to clot. Also known as "blood thinners."

Antiemetic: A medication that prevents or relieves nausea and vomiting.



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Antifungal: A medication that kills fungi (organisms that cause fungal infections). Patients undergoing treatment for cancer are especially vulnerable to fungal infections.

Antigen: A substance that causes your body's immune system to react. This reaction often involves the production of antibodies. Cancer cells have certain antigens that can be found by laboratory tests. They are important in cancer diagnosis and in watching response to treatment.

Antihistamine: A medication used to relieve the symptoms of allergies, such as hives, stuffy nose, etc.

Antimicrobial: A substance that kills microorganisms such as bacteria or mold, or stops them from growing and causing disease.

Antinausea: Medications used to prevent or treat nausea and/or vomiting.

Apheresis: A procedure used to collect certain types of blood cells. Blood from a donor is passed through a continuous-flow blood processor; the type of cell being collected is removed from the blood and the remaining blood components are returned to the donor.

Autologous Transplant (autograft): A transplant in which the bone marrow or peripheral blood stem cells are taken from the patient, frozen, and later returned to the patient.

Bacteria (singular bacterium): Small germs that can cause infection.

Benign: Not malignant or cancerous.

Biopsy (buy-op-see): The removal of a sample of tissue to see whether cancer cells are present and to determine an exact diagnosis. There are several kinds of biopsies.

Blast cells: Immature blood cells: a usually large blood cell precursor that is in the earliest stage of development in which it is recognizably committed to development along a particular cell lineage.

Blood culture: A blood sample taken to find infection in the blood.

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Blood typing and cross matching: Making sure that the blood from a donor is compatible with the recipient before a blood transfusion. Blood cells contain factors that are not the same in all people. Before a transfusion can be given, blood samples from the recipient

and the donor are typed, or classified, according to which of these factors are present. The four principal red blood cell types or groups are A, B, AB, or O. Other factors such as Rh factor must also be checked for compatibility.

Bone Marrow Aspiration: Obtaining a sample of bone marrow using a needle and syringe. This is done for laboratory study.

Bone Marrow Harvest: Collecting marrow from the hip bones with a needle and syringe for use in transplant. Marrow is harvested in the operating room.

Stem Cell Transplant: The process of treating disease with chemotherapy, radiation therapy, or both and then giving stem cells (directly from bone marrow, peripheral blood, or cord blood) to restore the production of blood cells.

Cancer: A general term used for over a hundred different diseases characterized by abnormal, uncontrolled cell growth.

Caregiver: A responsible family member or friend who is able to provide physical care, observational care and emotional support for a patient during all phases of treatment.

CD 34+ cells: Lymphocytes (white blood cells) which have a specific antigen marker which allows them to be detected in a sample of cells. The number of CD 34+ cells is counted after stem cell collection to determine if adequate numbers of stem cells are present.

Central Venous Catheter/Line: A small flexible tube inserted into a large vein near the heart. This serves as a route for medications, fluids, and to obtain blood samples.

Central Line Placement: The process of inserting a catheter into a large vein. This is a minor surgical procedure performed in the operating room under either local or general anesthesia.

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Chemotherapy: Medications used to destroy or slow growth of abnormal cells, usually cancer cells.

Clinical Trials: Human research studies that test new drugs or treatments and compare them to current, standard treatments. Before a new treatment is used on people, it is studied in the lab. If the lab studies suggest the treatment works, it is tested with people. These human studies are called clinical trials. Your doctor may suggest a clinical trial. Participation is voluntary.

Clot: To change from a liquid form into a solid or semi-solid; for example, when blood clots, it changes from a liquid to a semi-solid, helping bleeding to stop. Clots can be life-threatening or helpful depending on where they are in the body (i.e. clot in the lungs vs. a small cut on the skin).

Collection: The process of accumulating or keeping together, such as collecting stem cells.

Colony stimulating factors (CSF): Types of growth factors that promote growth and division of blood-producing cells in bone marrow. CSFs are naturally produced in the body. Extra amounts may be given to reduce or prevent side effects of chemotherapy. See growth factors.

Complete Blood Count (CBC): A laboratory procedure that determines the number of red blood cells, white blood cells, and platelets in a sample of blood.

Complication: An undesired symptom or medical problem that is a consequence of therapy, or another disease.

Conditioning regimen: The treatment given to the patient before transplant, intended to kill cancer cells and prepare bone marrow to receive stem cells. This consists of chemotherapy and/or radiation therapy.

Constipation: Difficulty having a bowel movement.

Contagious: An illness that can be spread from one person to another. Cancer is not contagious.

Cord blood: Stem cells collected from the umbilical cord and placenta when a baby is born and then frozen for future use.

Counts: Refers to monitoring the ANC (absolute neutrophil count) when watching for engraftment.



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Cytomegalovirus (CMV): A virus that can cause serious illness in people who have weak immune systems.

Decongestant: A medication that helps shrink mucous membranes and decrease the production of mucus.

Dehydration: Excessive loss of fluids from your body.

Diuretic: Substance that increases the elimination of water and salts (urine) from your body.

Dizziness: A sensation of instability and sometimes a feeling that you are about to fall.

Donor: A person who gives stem cells to be infused into the patient following chemotherapy and/or radiation. A donor may be the patient, family member, or unrelated person.

Donor leukocyte infusion: A transfusion of whole blood or isolated lymphocytes that contain a calculated dose of T lymphocytes. This is sometimes given to treat a recurrence of a patient's original disease or for the treatment of certain viral infections.

Dysphagia: Difficulty swallowing.

Dyspnea: Difficulty or labored respiration.

Echocardiogram (ultrasound cardiography): A method of obtaining a graphic picture of the internal structure, position, and motion of your heart. It is done by using sound waves directed through your chest.

Edema: Build-up of fluid within the tissues; swelling.

Electrocardiogram (EKG): A method of evaluating your heart's rhythm and muscle function by measuring electrical impulses.

Electrolytes: A general term for the many minerals needed to provide the proper setting for the cells of your body. Common electrolytes include calcium, sodium, potassium, and chloride.

Emesis: To vomit.

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Engraftment: The process by which the normal growth and production of blood cells and the marrow resumes functioning.

Febrile: Fever; elevated body temperature.

GCSF (granulocyte colony-stimulating factor): Medications that stimulate the production of neutrophils (a type of white blood cell). These include filgrastim (Neupogen®), filgrastim-sndz (Zarxio®), pegfilgrastim (Neulasta®), and plerixafor (Mozobil®).

Graft-versus-Host Disease (GVHD): A process whereby the transplanted cells (the graft) attack certain organs in the recipient (the patient/host); can be short-term (acute) or long-term (chronic).

Growth Factors: Substances naturally occurring in the body that control the productions and function of blood cells. These may be given after transplant to speed up engraftment, or given to donors to increase the number of stem cells in the blood stream that will be collected for transplant.

Hair loss: This often occurs as a result of chemotherapy or from radiation therapy to the head. In most cases, the hair grows back after treatment ends.

Haplo-identical donor: This is a donor who is 50% match to you. This donor may be a parent, child, or sibling (brother or sister).

Harvest: The removal of bone marrow or peripheral blood stem cells to be used for a hematopoietic blood stem cell transplant (HCT).

Hematocrit: The percentage of the volume of whole blood that is made up of red blood cells.

Hemoglobin: The substance in red blood cells that carries oxygen.

Hemorrhagic cystitis: Bleeding into the bladder that causes bloody urine. It can be caused by certain viruses, as well as certain chemotherapy medications such as ifosfamide or cyclophosphamide.

HLA (human leukocyte antigens): Proteins (antigens) that appear on white blood cells, as well as cells of almost all other tissues. By typing for HL-A antigens, donors and recipients of white blood cells, platelets, and organs can be “matched.” This helps to make sure the transfused and transplanted cells will survive.

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Host: The person into whom stem cells have been infused.

Hydration: A reference to the amount of water in the body. You may be dehydrated, well hydrated, or excessively hydrated (edematous).

Hyperglycemia: High blood sugar.

Hypertension: High blood pressure.

Hypocalcemia: Low calcium in the blood.

Hypoglycemia: Low blood sugar.

Hypokalemia: Low potassium in the blood.

Hypotension: Low blood pressure.

Ileus: Severe constipation; obstruction of the intestines.

Iliac crest: The top edge of your hip bone. Marrow is usually taken from it for a diagnosis of blood cell diseases.

Immune System: A complex network of organs, cells, and specialized substances distributed throughout the body which defend it from foreign invaders that cause infection or disease.

Immunity: The state of your body's defenses against an infection or possibly against a certain cancer.

Immunizations: Vaccines given to help your body resist disease.

Immunosuppression: A decrease in the immune system which fights infection that can be caused by chemotherapy, radiation.

Immunotherapy: Treatments that promote or support your immune system's response to a disease such as cancer.

Infection: Invasion of the body by disease-producing organisms.

Infectious disease: A disease caused by germs; one that can be passed from one person to another. Cancer is not an infectious disease.



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Informed Consent: A legal document that explains a course of treatment and the risks, benefits, and possible alternatives. A patient's signature on this document indicates the patient has been informed and further agrees to consent to the described treatment. If you are under 18 years of age, your parents or legal guardian must also sign this form.

Infusion: Administration of medications or fluids into a vein over a period of time.

Intravenous (IV): A route of administration for fluids or medications that are given into a vein.

Leukapheresis: The process of filtering white cells, leukocytes, or "polys" from the blood of the patient or a healthy donor. These cells may be given to you if you have a severe infection and a shortage of "polys".

Leukocytes: White blood cells that play a major role in the body's immune system.

Low microbial diet: A diet designed to minimize bacteria, viruses, yeast, and molds in food and beverages.

Lumbar puncture (LP)/spinal tap: A procedure in which a thin needle is placed in your spinal canal. It is done to remove a small amount of spinal fluid or to give medication through the central nervous system.

Lymph nodes/glands: An important part of your body in the defense against infections.

Lymphocytes: A type of white blood cell that helps your body fight infection. There are 3 main types of lymphocytes: (1) T cells that help fight infections such as viruses and fungi; (2) B cells that make proteins called antibodies that help fight infection. For example, if you receive a vaccination against tetanus, you make a protein (antibody) against tetanus; (3) natural killer cells that help fight viruses and other germs. They are sometimes given to help fight cancer.

Malignant tumor: A mass of cancer cells that may invade surrounding tissues or spread to distant areas of the body.

Metabolism: A general term for the many chemical processes needed for your body to live.

Metastasis: The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

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Mobilization: Stimulating release of large numbers of stem cells into the bloodstream.

Mucositis: Reddening and soreness of the tongue, lips, mouth, throat, and gastrointestinal tract as a result of chemotherapy or radiation therapy.

Myeloablative: This means that the preparative regimen will completely eliminate your ability to make cells.

Neutropenia: A condition in which there is a lower than normal number of neutrophils (a type of white blood cell) in the body. While you are neutropenic, you will need to take precautions to prevent infection.

Neutrophil: A type of white blood cell that provides defense against infection.

Non-Myeloablative Transplant: A transplant in which stem cells are received from a family or unrelated donor and conditioning is done with moderate dose chemotherapy and/or radiation.

NPO: Abbreviation for “nothing by mouth.”

Oncology: An area of medical science that studies tumors and cancers.

Pancytopenia: The decrease of all blood cells (red, white, and platelets).

Peripheral Blood Stem Cell (PBSC's): Cells made in the bone marrow that are circulating in the blood stream and that have the ability to develop into white blood cells, red blood cells, or platelets.

Peripheral Blood Stem Cell Transplant: Stem cells circulating in the bloodstream are collected and later given back to a patient after chemotherapy or radiation therapy is given.

Phlebitis: Inflammation of a vein. Signs include pain, swelling, and tenderness in an area. If a superficial vein is involved, the phlebitis can be felt as a cord-like thickening along the vein.

Platelets: A part of the blood that helps repair (plug) holes in blood vessels after an injury. If you have a low platelet count, you are at risk for bleeding. Chemotherapy can cause a drop in the platelet count. This is called thrombocytopenia.



Pneumonia: A disease in which the lungs are inflamed or infected.

Preparative regimen: A combination of chemotherapy and/or radiation therapy given prior to the transplant. The purpose of the preparative regimen is to eliminate the malignancy. In an allogeneic transplant, the preparative regimen is also given to weaken the immune system so the donor's cells can grow and function.

Protocol: The plan for a specific treatment; may be a scientific study such as a research protocol.

Radiation Therapy: A cancer treatment that uses radiant energy waves to damage/kill cancer cells.

Red blood cell (RBC): A type of blood cell (also called erythrocyte) that carries oxygen in the body.

Rejection: A process by which transplanted cells are attacked by the patient's immune system.

Septicemia/sepsis: A very serious bacterial or fungal blood infection. It usually spreads from another site of infection such as skin, bowel, or urinary tract. It can cause high fever, shaking chills, and heavy sweating. It is more likely to occur in patients with a very low white blood cell count.

Side Effect: An additional and usually undesirable effect from a drug or other treatment.

Sinusoidal Obstruction Syndrome (SOS): A disease caused by obstruction of blood flow through the small blood vessels in the liver, resulting in damage to the liver.

Stem Cells: An immature cell which is the "parent" cell of the blood cell and has the capacity to mature into a red blood cell, white blood cell, or platelet.

Syngeneic Transplant: An identical twin donates stem cells to the other twin for transplant.

T cell-depleted blood stem cell transplant: A type of transplant in which T cells



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are removed in a laboratory after donor stem cells are obtained. This process reduces the likelihood of graft versus host disease that is caused by the donor's T cells.

T cell or T lymphocyte: A type of white blood cell or lymphocyte that plays a major role in the body's defense against viral and fungal infections.

Tissue Typing: Tests that determine how closely the tissues of a donor and the patient match.

Total Body Irradiation: Radiation treatment of the entire body, used to destroy malignant cells and bone marrow cells in preparation for transplant.

TPN (total parenteral nutrition): Nutritional support given intravenously. Also called hyperalimentation.

White Blood Cells (WBC): A group of blood cells, the leukocytes, that helps fight infection



Notes



DISCHARGE SKILLS ASSESSMENT

1. Are you able to read a Thermometer? Yes No
2. When would you call to report a fever?
3. What phone numbers can you call for medical attention?
4. Do you have a clear understanding of all the medications you will be taking?
 Yes No
5. Do you know what your medications are for? Yes No
If no.....nurse to explain.
6. List what type of foods you should avoid?
7. List three signs and symptoms of infection.
8. List three signs and symptoms of low platelets.
9. How often does your central line catheter need to be flushed?
10. What can you do to avoid infections when leaving the home environment?

I have read the SCT Patient and Family Education Handbook and understand how to care for myself at home.

Patient Signature

Date