

*NewYork-Presbyterian Hospital Weill Cornell Medical Center  
Allogeneic Stem Cell Transplant Patient Guide*

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Weill Cornell Medical Center**

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Patient Guide**

## **Introduction**

Dear Patient and Caregiver,

Welcome to NewYork-Presbyterian Hospital Weill Cornell Medical Center.

Stem Cell Transplantation is an important step in your recovery from illness. But transplant is a complex process that can be difficult and dangerous and that is followed by a period of recovery.

We have assembled a team of physicians, nurses and other healthcare professionals who are committed to providing you superior and compassionate care, ever mindful of your dignity and individuality. Our goal is to serve your health needs and assure your comfort and safety. Our second priority is to improve treatments through clinical research. Therefore, we may regularly ask your participation in clinical trials. Lastly, we are committed to training the next generation of caregivers and work closely with medical, pharmaceutical and nursing students and trainees. We also often have trainees in other areas of healthcare. We ask your cooperation in working with these professionals.

To complement the care you will receive, we have developed this booklet to help you prepare for your treatment at NewYork-Presbyterian Hospital Weill Cornell Medical Center. It explains the treatments and precautions that will be taken to ensure your rapid and complete recovery before, during and after transplant.

This booklet contains a great deal of information. Publications from patient support groups and professional organizations are also available. In our booklet, we have focused on issues that pertain particularly to patients. Many times, we refer patients to other publications as well. In the course of your readings, take notes and write down any questions you may have. We encourage you to direct your questions to our staff, ask as many questions as you want and as many times as you need to get your answers. We understand this is a new experience for you and we want to make you as comfortable as possible.

The NewYork – Presbyterian Hospital Stem Cell  
Transplant Team

## **Mission Statement**

The mission of our transplant program is to provide optimal clinical care, to contribute to improvement in healthcare through research and to educate the next generation of caregivers. For this purpose we have assembled a team of experienced physicians, nurses and other health care professionals. Physicians involved in the transplant program work closely together with the disease-specific programs at NewYork – Presbyterian Hospital Weill Cornell Medical Center.

## Phone Book for the Stem Cell Program

Staff	Phone Number
<p><b>Research Nurse: June Greenberg</b></p>	<p><b>212-746-2651</b></p>
<p><b>Inpatient Physician Assistants:</b></p>	<p><b>212-746-0573</b></p>
<p><b>Outpatient Nurse Practitioners and Physician Assistants:</b></p> <p><b>Jessy Ryan, NP Edwidge Culvilly, NP Maria Baldo, PA Grace Suhu, NP Adomah Opong, NP</b></p>	<p><b>212-746-5266 212-746-2433 212-746-3114 212-746-4504 212-746-2629</b></p>
<p><b>Social Workers: Meredith Shufeld, LCSW Jillian Redner, LCSW</b></p>	<p><b>212-746-3114 212-746-3798</b></p>
<p><b>10W Case Manager: Ellen Kaplan</b></p>	<p><b>212-746-0330</b></p>
<p><b>Financial Coordinator: Adelixa Rodriguez</b></p>	<p><b>212-746-5415</b></p>
<p><b>BMT Coordinators: Kevin McNamara, RN Jennifer Bourke, RN Janel Joaquin, RN Edgar Rey, RN Angela Parilla Rosanna Ferrante, CHTC</b></p>	<p><b>212-746-2130 212-746-1129 212-746-7813 212-746-4725 212-746-6375 212-746-9115</b></p>

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<b>Physicians:</b> <b>Koen van Besien, MD, PhD</b> <b>Tsiporah Shore, MD</b> <b>Usama Gergis, MD</b> <b>Sebastian Mayer, MD</b> <b>Tomer Mark, MD</b> <b>Adrienne Phillips, MD, MPH</b>	<b>212-746-2048</b> <b>212-746-2646</b> <b>212-746-2119</b> <b>212-746-2119</b> <b>212-746-3964</b> <b>212-746-2048</b>
<b>Infusion Treatment Area:</b>	<b>212-746-2086</b>
<b>BMT Inpatient Unit 10 West:</b>	<b>212-746-0573</b>
<b>10W Patient Care Director:</b>	<b>212-746-3247</b>
<b>Apheresis Unit:</b>	<b>212-746-9071</b>
<b>BMT Office:</b>	<b>212-746-2646 or 212- 746-2119 or 212- 746-2048</b>
<b>BMT Administrator:</b> <b>Tracey Schonfeld, RN</b>	<b>212-746-9420</b>

## Other Sources of Information and Websites of Interest:

### Publications:

#### Web Sites for Patients

[www.themarrowfoundation.org](http://www.themarrowfoundation.org) (Be the Match)

*This site is sponsored by the national marrow donor program and contains extremely useful information for all patients undergoing allogeneic stem cell or bone marrow transplantation. It also contains useful information for your primary oncologist or primary care physician. (Some recommendations in our guide have been adopted from this website.)*

**Bone marrow foundation:** <http://www.bonemarrow.org/>

Information for patients

**BMT infonet:** <http://www.bmtinfonet.org/>

Information for patients on transplant centers and outcome data

# **General Information**

## ***What is meant by Stem Cell Transplantation?***

Blood cells (red cells, white cells and platelets) and immune cells (lymphocytes) arise from the blood stem cells, which normally reside in the marrow but can also be found in small numbers in the blood stream or in umbilical cord blood. In a stem cell transplant such stem cells are given to restore blood production after heavy chemo- and/or radiation therapy has irreparably damaged the bone marrow stem cells or after illness has damaged them. Previously, stem cells were always collected from the bone marrow. Currently blood is an increasingly

frequent source of stem cells for transplant. Stem cells circulate in the blood in very small numbers. Drugs are used to increase the number of stem cells in the blood by drawing them out of the marrow. Sufficient quantities of stem cells for transplant are recovered by circulating large volumes of blood through an apheresis machine and skimming off a portion that contain stem cells. When these stem cells are used for transplant the procedure is sometimes still referred to as "bone marrow transplantation" (BMT), but the term "stem cell transplantation" (SCT) or peripheral blood stem cell transplantation (PBSCT) is now often used.

The third source of stem cells is the cord blood from newborns. The cord is normally thrown away after birth, but contains a small number of stem cells that can be stored and used for transplant.



## ***What are the different types of transplants?***

**Autologous:** Stem cells are obtained from the patient, usually by a process called a stem cell harvest or stem cell apheresis. These cells are then usually frozen down (cryopreserved). They will be thawed and infused into the patient's blood stream after completion of intensive chemotherapy. These cells then allow rapid recovery from the effects of chemotherapy. Since the patient's own cells are used, the term hematopoietic rescue rather than the term transplant, is sometimes utilized.

**Syngeneic-** Patients receive stem cells from their identical twin.

**Allogeneic-**Stem cells are obtained from another individual who is genetically as close to the patient as possible. This is usually a brother or sister, but may be an unrelated volunteer donor. The stem cells are usually collected from the blood, but may be collected from the bone marrow. Occasionally cord blood cells from a newborn are used.

The allogeneic donor can be **related** (i.e. a relative) or **unrelated** (i.e a volunteer who has agreed to donate)

The related donor is usually a brother or sister, but occasionally a parent or child are used. Donors can be **completely matched (or HLA-identical)**. Siblings have a one in four chance of being HLA-identical to one another. Donors can also be **partially matched (or haplo-identical)**. Parents are usually **haplo-identical** to their children. Siblings have a one in two chance of being haplo-identical to one another.

The allogeneic cells are usually obtained from the blood stream of the donor after the donor receives a medication to stimulate production of stem cells. In that case we talk about **mobilized peripheral blood stem cells**. Occasionally cells are collected from the bone marrow of the donor, called **bone marrow stem cells**. Cord Blood is rich in stem cells- Umbilical cord blood is collected from the umbilical cord and placenta after a baby is born. The donated cord blood is tested, frozen and stored at a cord blood bank for future use. Most of the **cord blood transplants** are from newborns that are unrelated to the donor, but occasionally a related cord blood donor is utilized.

## ***What is HLA typing?***

HLA antigens are proteins — or markers — found on the surface of most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not. Human leukocyte antigen (HLA) typing is used to match patients and donors for bone marrow, stem cell or cord blood transplants.

A close match between your HLA markers and your donor's can reduce the risk that your immune cells will attack your donor's cells or that your donor's immune cells will attack your body after the transplant. If you need an allogeneic transplant (which uses cells from a family member, unrelated donor or cord blood unit), your doctor will take a blood sample to test for your HLA type.



A well matched donor is important for the transplant to be successful; if you have siblings they will be the first to be HLA typed to find out if there are matches to you. We all inherit 50 % of the HLA-type from the father and 50% from the mother, so each brother or sister have a 25 % chance to be **HLA-Identical** to each other. HLA-identical donors are considered the best donors. Sometimes we also find an HLA-identical donor who is not related (through the registry). Those are **Matched Unrelated Donors**. Parents are only half-matched with their children, and so are many siblings. These are called **Haplo-Identical** donors.

## ***What are the HLA matching requirements?***

If you don't have a sibling who is HLA-identical, we will look for a donor or cord blood unit that matches you at the best level possible. Research has found that matching patients and donors at a detailed level can improve the patient's chances of having a successful transplant. There are many HLA markers. They are called HLA-A, HLA-B, HLA-C, HLA-DR, HLA-DQ and HLA-DP. The NewYork-Presbyterian Hospital Weill Cornell Medical Center Stem Cell/Bone Marrow Transplant program requires matching at a minimum of 8 HLA markers, two HLA-A, two HLA-B, two HLA-C and two HLA-DR for adult unrelated donors. For cord blood the matching requirements are less stringent. Only 4 of 6 HLA markers (2 HLA-A, 2 HLA-B or 2 HLA-DR) need to match. It is therefore easier to find a suitable cord blood donor than a matching adult unrelated donor.

## ***Are there other factors that determine successful transplant?***

The level of HLA matching is only one of the things that can affect your chances of having a successful transplant. Other important predictors are your overall health, whether or not you have other illnesses such as diabetes, hypertension or heart disease and of course the illness for which you undergo transplant.

## ***What is a clinical trial?***

Clinical trials are structured research studies which are conducted to answer questions about new therapies or about improving known treatments. Each study tries to answer scientific questions and to find better ways to prevent, diagnose, or treat cancer. Many standard treatments used today are the result of past clinical trials.

A protocol is a written document that enables communication among those who are working on the clinical trial. It provides direction and specific guidelines for the trial. It includes the treatment plan and is like a recipe for conducting the clinical trial. Your rights and safety are protected through careful review and approval of the clinical trial protocol by an institutional review board (IRB) and ongoing monitoring by the IRB and your research team.

The known risks associated with a particular clinical trial will be discussed during the informed consent process and are explained in detail in the informed consent document that you will receive from the research staff. In a clinical trial some of the risks and benefits may not be known or may be observed during the course of the study. Participation in clinical research is voluntary. After information has been provided to you and your questions have been answered, you will be asked to give

your voluntary consent to participate by signing a form that has been approved by the IRB.

Registry studies follow patterns in disease diagnosis, treatment and/or survival over time. They are different from clinical trials in that they do not involve the study of new treatments for diseases. Rather a large group of patients undergoing a particular treatment such as stem cell transplant or with a particular disease such as lymphoma or leukemia are followed. The purpose is to follow patterns of medical history, diagnostics and/or treatment in real practice settings in a large number of patients and to observe outcome and/or survival. You will be asked to participate in a disease specific registry.

Clinical trials and registry studies are essential for the progress of medicine. Many advances in medicine have been made thanks to knowledge gained from these studies. Without the voluntary participation of countless previous patients in many studies, we would not be able to offer you your current treatment. Future generations of patients will be grateful for your participation.

## ***What is informed consent?***

Informed consent is the communication process by which you learn important information about a clinical trial or procedure and which helps you decide whether to participate. This information includes details about the purpose of the study, the tests and other procedures used in the study, and the possible risks and benefits.

In addition to talking with your doctor or nurse, you will receive a written consent form explaining the study. If you agree to take part in the study you will be asked to sign the informed consent form. However, signing the form does not mean you must stay in the study. You can choose to withdraw from the study at any time - either before the study starts or at any time during the study or the follow-up period. If you decide to leave the study, your doctor will discuss other treatment options with you.

You are encouraged to ask questions and take enough time to critically review your options. Please take time to discuss the treatment plan, including the expected risks and benefits with the transplant team and your family members prior to committing to the study.

The informed consent process continues throughout the study. If new findings are observed during the study, the researchers must inform you. If you are still engaged in therapy on the study or could be affected by the new findings, you might be asked to sign an amended consent.



## ***Will you communicate with my referring physician?***

We would like to keep your oncologist and primary care physician informed of your progress. Frequent written communication is essential and occurs when you are first evaluated, prior to your transplant admission and at discharge.

Please check with your nurse to be sure we have the most current information regarding your referring oncologist or primary care physician

# **Pre -Transplant Phase**

## ***What will I need to do before the transplant?***

There are many steps involved in the preparation of your transplant. Use this checklist to help you keep track of what you need to complete.

- Read the NewYork-Presbyterian Hospital Weill Cornell Medical Center Allogeneic Stem Cell Transplant Patient Guide.
- Review other information from the internet or other sources with your physician and nurse.
- Meet with your Transplant Coordinator to review your schedule and receive a calendar
- Meet with a social worker regarding housing, disability, extra financial support, and medication issues (if applicable)
- Meet with the financial coordinator to review insurance issues and other financial concerns
- Complete consent forms. You will be scheduled to meet with your transplant coordinator to review your treatment plan and sign consent forms. To prepare for this meeting please review the consent forms that were given to you and prepare a list of questions you have.
- Have a dental exam with your dentist. Any cavities should be filled. Dental work should be completed at least 14 days prior to the transplant
- Change the air filter on your home air conditioner or furnace.
- Check your outpatient prescription coverage and location for filling prescriptions.
- Identify a caregiver(s). You will need to have a friend or family member act as your caregiver during the entire transplant process.
- Make arrangements for child care.
- Make arrangement for household maintenance while you are in the hospital.
- Make arrangements for care of your pet(s).
- Make arrangements for your transportation needs to and from the hospital and for frequent post transplant visits to the clinic. Most of our patients are seen once a week in the clinic after discharge, but more frequent visits may be needed.

## ***What is the insurance approval process?***

You and your family can cope more easily with the transplant process by understanding your insurance benefits before the process begins. Please review your policy so that you know what portion of your treatment costs will be your responsibility. You should confirm the amount of your policy deductible (s), co-payments, out-of-pocket maximum and policy maximum (s).

When a transplant is being planned a transplant financial coordinator will contact your insurance company to request authorization for the transplant. The authorization process is complex, and most insurance companies require that all pre-transplant diagnostic studies be completed and submitted to them before the medial review can begin. Because of this, authorization is usually issued shortly before the actual transplant, not months in advance.

Please be sure to notify your nurse coordinator immediately if your insurance coverage changes.

## ***Will I need tests before the transplant?***

Prior to being considered for an allogeneic transplant you will undergo many tests. Your insurance company will likely require this information before giving approval for the transplant and your doctor will also require this information to make clinical decisions throughout your treatment. Some of these tests will be performed less than 30 days prior to starting conditioning. If you are enrolled in a clinical trial you may need additional labs.



## ***What are the tests?***

- A complete history and physical exam with blood work
- A consultation with one of our social workers. This will be helpful in identifying social or emotional concerns as well as physical support during the months ahead.
- Dental evaluation by a dentist or your physician will identify problems and develop a plan to solve them during your treatment.
- MUGA/ Echo which is a special test to evaluate your heart function
- Chest X-Ray
- Sinus X-Ray
- Pulmonary function test that evaluates how well your lungs work
- A bone marrow biopsy and aspirate to assess the status of your disease. A bone marrow aspirate is a procedure in which an area on your hip is numbed and a small amount of bone marrow is withdrawn through a needle. A bone marrow biopsy is similar to a bone marrow aspirate except a small core sample of bone marrow is removed through the needle.

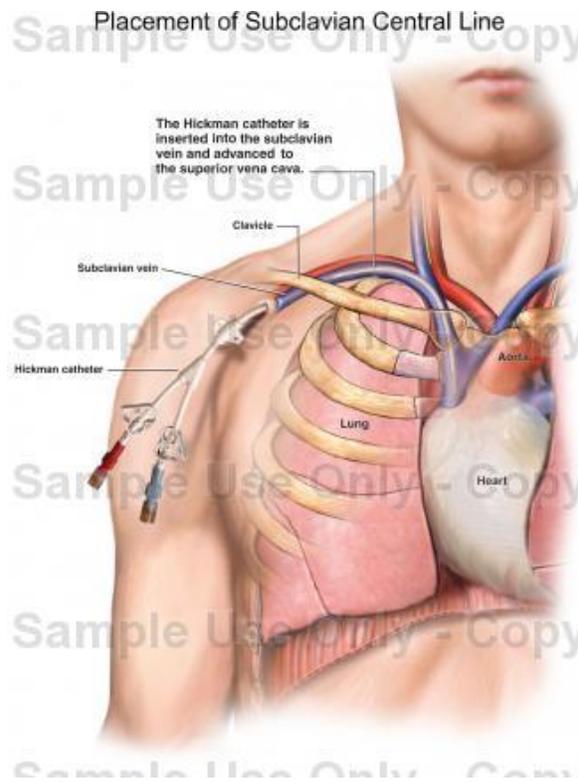
- CT scans (similar to a chest x-ray except more detailed) of your chest, possibly abdomen, pelvis and sinus.
- Females and patients over 50 will receive a bone density test.
- Blood will be taken to assess certain infectious disease markers, including HIV and hepatitis will be checked. You will be asked to consent for the HIV test. Other blood tests will also be collected looking at your blood counts and chemistries.
- Pregnancy test for premenopausal females.

### ***Will I need a central catheter?***

Yes, all patients admitted for transplant will have central line access. A central line is a large tube that runs under the skin and ends into the large veins leading to the heart (see figure). This line will remain in place for weeks, to months.

### ***What kind of catheter will I need?***

Allogeneic transplant patients usually require a triple lumen Hickman catheter. This catheter is inserted by our interventional radiologists under local anesthesia. It is tunneled in under your collar bone and comes out from the skin.



## ***How will I care for my catheter when I am at home?***

You or your caregiver will be taught how to care for your catheter while you are in the hospital. The catheter will require a flushing daily and dressing change weekly (some type of dressings may need to be changed every other day).

## ***Do I need to have a caregiver in place?***

Prior to admission, you will be required to identify a caregiver. The caregiver plays a vital role during the patient's transplant process and recovery. Some patients may require a 24 hour caregiver. This may require hiring a caregiver which is not covered by insurance.

The caregiver responsibilities include:

- Be present to learn discharge instructions on day of discharge
- Ensure safe transportation to and from medical appointments
- Assist with activities of daily living (e.g. grocery shopping, meal preparation, laundry, housekeeping, etc)
- Assist with medication
- Manage central venous catheter or PICC line care if applicable
- Monitor, assess, and report physical symptoms
- Facilitate communication with medical team
- Provide emotional support

## ***What is the Outpatient Bone Marrow Transplant Day Hospital Program?***

- The program was designed to provide comfortable and safe care in the outpatient setting to selected patients.
- You will be asked to be part of the program if:
  - You've received an allogeneic transplant
  - You've received a stem cell transplant and require frequent monitoring, medication administration, and/or transfusions more than two times a week.

## ***What are some benefits in completing the transplant process as an outpatient?***

- It allows you and your caregiver to be in the comforts of your home or home-like setting.

## ***What do I do if I don't feel well?***

- If you are experiencing a life-threatening emergency, we ask you to call 911 or go to the nearest Emergency room.
- For all other concerns, we ask you to call the day hospital between 9am-5pm. You will be triaged over the phone and instructed what to do. You may be asked to come to the day hospital to be assessed. During after hours, there is a covering physician on call who will also instruct you on what to do. Depending on the severity of your symptoms, you may be readmitted to the hospital.

# **Inpatient Phase**

## ***What unit will I be on when I am admitted to the hospital?***

You will be admitted to the Bone Marrow Transplant Unit (10 West). It is a 16-bed, all private room specialty unit on the 10<sup>th</sup> floor of the Greenberg Pavilion. The address is 525 East 68<sup>th</sup> Street. The phone number to the unit is 212-746 - 0573. The unit has a special HEPA air filtration system to minimize the risk of infection. Doors to patient rooms are to be kept closed at all times to allow the air filtration system to function properly. Fans, humidifiers or air filters are NOT allowed as it may compromise the HEPA system already in place. NO fresh flowers/plants are allowed on the unit.

Some patients who are admitted or diagnosed with upper respiratory tract infections (colds) or pneumonias are admitted to other areas of the hospital. This is done to avoid spread of infection to other patients.

## ***What is the process for being admitted?***



Your transplant coordinator will discuss an admission date with you. She/He will put in a request to the admitting office. On the day of your scheduled admission your bone marrow transplant coordinator will call you when your bed is available. If there is no bed available on the day of your planned admission your transplant coordinator will contact you and arrange another date for your admission.

## ***Where do I go when I get the call to come in?***

You need to come to the admitting office on the first floor of the NewYork -Presbyterian Hospital Weill Cornell Medical Center.

## ***Can I have visitors when I am in the hospital?***

Yes, the hospital is very open to having visitors for patients. One visitor/family member may stay overnight. If you will be having someone spend the night please notify your nurse so she can check the availability of a cot. Visitors with colds/flu symptoms cannot visit. We also discourage family members of other patients to visit your room. This is to avoid transmission of hospital acquired infections Children are not allowed to stay overnight except in rare circumstances.

## ***What precautions should my visitors take?***

***Handwashing*** : Transplant Patients are extremely immunocompromised and hospital acquired infections are an important source of infections.

Prior to entering a patient room, caregivers, visitors and family should clean their hands with antiseptic solution (Purell).

Upon entering and leaving the room of a patient with C. Difficile infection, handwashing with water and antibacterial soap is recommended.

***Isolation Policies:*** Guidelines for isolation of individual patients are posted at the doors. Your visitors should respect them.

## ***Can my family call and get updates on my condition while I am in the hospital?***

Yes, your family and friends can call and request information regarding your care but they must provide a “password” when calling. This password, to protect your privacy, will be assigned to you upon admission in the admitting department.

## ***What amenities are available to me on the unit?***

There is a nourishment room with an ice machine, refrigerator/freezer and microwave. There is a bike program through Physical Therapy and a computer with internet access. DVD players are in every patient room and a movie library is available. Every patient room has a safe located in the closet. **Please** use this safe to lock up any valuables you may have brought with you. Instructions for use are posted inside the closet. However, we do recommend that all valuables be sent home with your family members, as we are not responsible for the loss of any personal property, including computers.

All local calls made from your room are free. You will need a calling card or operator assistance to make long distance calls.

## ***Can I bring electronic appliances to keep in my room?***

Personal electronic appliances are NOT allowed to be used in your room. This includes things such as coffee makers, refrigerators, lamps etc. These items are potential fire hazards and should not be brought to the unit.

## ***Can I bring my laptop?***

Yes, you can bring your personal laptop computer. The Greenberg Hospital does have wireless capabilities and you can login to the hospital network.

## ***What others things should I think to bring with me when I am admitted to the hospital?***

You can bring in hobbies, simple reading materials and other projects. If you bring your own pillow, put a colored case on it to avoid losing it in laundry. (No feathered pillows are allowed). Bring loose fitting clothes preferably tops/shirts with buttons and a pair of slippers and/or shoes that fit well. We encourage you to decorate your room with pictures, posters, cards, etc. It is helpful to bring a calendar and note pad so you can write things down.

## ***Can someone stay with me in my room?***

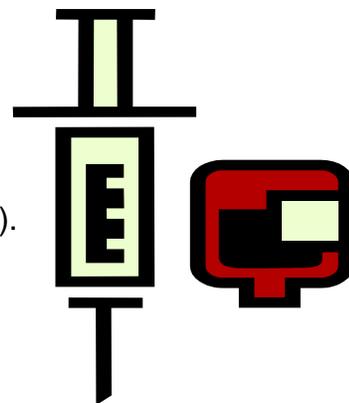
Yes, a cot may be placed in your room for overnight visitors.

## ***Can people send me flowers when I am in the hospital?***

No fresh flowers/plants are allowed on the unit. You can receive silk flowers as long as they do not contain Spanish moss.

## ***What is the daily routine like on the unit?***

On 10 West, the nursing staff works 12 hour shifts, either 7:30 pm - 8:00 am or 7:30am – 8:00 pm. Your nurse on the floor is responsible for approximately 3 patients at a time. She/he begins the shift by seeing you and bringing any medications due and performing an initial assessment (ex. listening to your heart and lungs). After seeing you, the nurse coordinates with physicians, nursing support assistants, and other members of the healthcare team to develop



a plan for the day. The plan may include new medications, blood transfusions, tests such as an X-ray or MRI, or chemotherapy. Throughout the day, your nurse will frequently round on all his/her patients as well as bring any medication scheduled.

A very important part of the nursing team is the NA, or nursing assistant. NA's are responsible for 9-10 patients at a time. They assist you and your nurse by taking vital signs, helping keep track of your intake and output, assisting you in personal hygiene needs and pass out water. Throughout the day, NA's will also round on all patients to ensure that they are as comfortable as possible.

You will be weighed daily at 6 am. While this is an early hour, it is imperative to have your weight before physician rounds. It is important for the doctors to monitor your daily weight because it assists them in properly dosing your medications as well as ensures that your body is maintaining a healthy weight throughout your hospital stay.

The staff will also be keeping track of how much fluid you are taking in each day. This includes what you drink as well as any IV fluids you are given. We also keep track of your output. You will need to urinate in a urinal or container provided so that we can get an accurate count of your daily output. We monitor daily intake and output to ensure our patients are properly getting rid of the fluids they have taken in throughout the day. You are on complex combinations of medications that can have various side effects, including causing the body to hold on to fluids rather than eliminating them.

### ***Will you wake me in the middle of the night?***

Yes, we monitor your vital signs every four hours at 8am, 12pm, 4pm, 8pm, 12am, and 4am. Vital signs include checking your temperature, blood pressure, heart rate, and respiratory rate. Because you are on complex combinations of medications that have many different side effects it is important that we monitor your vital signs, even in the middle of the night. A temperature over 38 C or 100.4 F is considered a fever and will be reported to a doctor.

### ***When will I see my doctors in the hospital?***

The inpatient attending physician and fellow rotate every 2 – 4 weeks. Rounding by the medical team will vary. Often, the fellow and physician assistant may see you in the morning first between 8 and 10 am, particularly if there are new problems. The Attending Physician will see you every day, often between 10 and noon but this will vary depending on their schedule. Overnight a covering physician is in-house for medical problems that arise.

## ***Who is my medical team when I am in the hospital?***

The members of the inpatient stem cell transplant team include an attending physician, fellow, physician assistants and nurses. Attending physicians have completed their medical training and are the primary medical decision makers. Fellows are trained internists who are continuing their medical education to specialize in the care of patients with cancer. A physician assistant has earned an advanced science degree which qualifies them to perform physical examinations, order tests and procedures, and manage patient symptoms. Other members of your team may include a chemotherapy pharmacist, social worker, dietician, and discharge planner. Chaplain services, physical therapy, and recreational therapy are available if requested. Since our transplant physicians take turns caring for the inpatients, your primary transplant physician whom you got to know during the pre-transplant phase, may not be the one you see from day to day on the inpatient service. Still, we will keep your primary transplant physician informed. All patient problems are also discussed at our weekly Tuesday meeting.



## ***How can I receive mail when I am in the hospital?***

Your family and friends may write to you at the following address:



NewYork – Presbyterian Hospital Weill Cornell Medical Center  
Greenberg Pavilion 10 West -Your name  
525 East 68<sup>th</sup> Street  
New York, NY 10021

## ***How do I order my meals when I am on the unit?***

Once you have been admitted to 10 West, your doctor will order the diet you will be on while in the hospital.

## ***Will I have my blood drawn daily when I am in the hospital?***

You will have your blood drawn every day. The most common daily blood draw times are 5 am. We are drawing your blood to monitor your blood counts (white blood cells, hemoglobin, and platelets) as well as your electrolyte levels, such as potassium, magnesium, sodium, calcium, and phosphorus. If you have a central line we can draw your samples from your line. However, there are some tests that cannot be drawn from your central lines. If your doctors need to check to see that your blood is clotting you will have to be drawn by a needle stick in the arm. Other tests that may require a needle stick include tests that monitor the blood levels of certain medications you are on. Because these medications are often infused through your central line, the blood must be drawn by needle stick so as to avoid errors in test results. If you would like to see a copy of any of your test results, just let your nurse know and he or she will be happy to print you a copy.

## ***What is available in the nutrition room on the unit?***

The nutrition room consists of a water/ice machine, refrigerator, freezer, microwave and a locked cabinet with extra crackers, cookies, nutrition supplements and a few carbonated beverages.

## ***Can I go into the nutrition room and store food?***

If you wish to place food in the refrigerator it must be brought to the nursing station and the staff will put it in the nutrition room. Food/beverages can be stored in the refrigerator/freezer as long as it is labeled with your name and room number.

## ***Can I leave the unit and walk around the hospital?***

You are allowed and encouraged to walk in the unit corridor. We recommend you do **NOT** walk beyond the double doors or leave 10 West until unless going for a test or procedure. 10 West is a closed unit and is considered clean. In other areas of the hospital, many patients with contagious illnesses are admitted. Therefore it is strongly recommended that you avoid other areas of the hospital particularly common areas (cafeteria, lounges etc.)

## ***Are there Social Workers involved in my care?***

Yes, social workers are here to assist you from diagnosis through recovery.

## ***What can the Social Workers help me with?***

The social workers can assist in providing you with support in adjusting to your diagnosis, treatment and recovery. They can help with coping strategies in dealing with lengthy hospitalizations. Resources can be given to you on how to communicate with children regarding your illness and treatment. The social workers can provide financial resource information including applying for social security and disability. They can also assist you in transportation, discharge planning, family meetings and interpreting insurance benefits.

## ***Are there chaplain services available to me at the hospital?***

Yes, the chaplains are available to assist you and your family to understand more fully life's events as they relate to your spiritual and emotional well-being. They also offer pastoral counseling, prayer or reflection, attend to your theological/religious needs as well as other areas upon request. A chaplain is assigned to each unit of the hospital. If you would like to speak to a chaplain you can notify your nurse or doctor and a visit can be arranged.

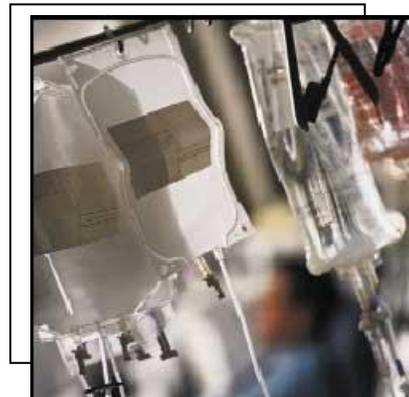
## ***What other services are available to me when I am in the hospital?***

Some specific activities available on 10 West are:

- Exercise Sessions: Guided stretching, walking, and resistance exercises keep you strong and flexible by a physical therapist if clinically necessary.
- Art/Crafts: Knitting, crocheting, jewelry making, painting, sewing and more help you get in touch with your creative side.
- Games: card games, word search/crossword puzzles, board games to challenge you, your family and friends

## ***When will I have high dose chemotherapy?***

Prior to receiving your transplant, you will be given chemotherapy through your central line. You will also receive medications and IV fluids to help prevent side effects.



## ***Will I have side effects from my chemotherapy?***

Yes, unfortunately there are many possible side effects to high dose chemotherapy. They will be explained to you by your physicians and nurses and also documented in the consent forms. We describe here some of the side effect that can occur during your hospital stay.

Side effects that occur after discharge are described elsewhere.

- **Nausea and Vomiting**

This usually begins after chemotherapy, but you can experience nausea and vomiting during the infusion. During the days of chemotherapy an anti-nausea medication is used to help control nausea and vomiting. You will have “as needed” anti nausea medications available for break through nausea. It is important to inform your nurse if you are feeling nauseated so that medications can be given.

- **Mucositis**

Chemotherapy causes thinning and inflammation of the mouth lining; As a result you may experience a sore throat. In some cases, mouth ulcers can develop and patients may not be able to eat.

In some cases, we use medications to prevent mouth sores. For other patients, we recommend they keep ice chips in their mouth during chemotherapy. This has been shown to reduces sores, particularly after administration of the drug melphalan.

It is important to practice good oral hygiene to minimize sores and infection. It is good practice to rinse your mouth after each meal and before bed with saline; saline is salt water. Everybody has bacteria and fungus in their mouth, throat, bowels and skin. The immune system and mucous membranes are temporarily compromised after your high dose chemotherapy. The rinse can help prevent infections.

When your WBC count is low (below 1,000) your mouth lining becomes thinner. A toothbrush can cause gums to bleed (from low platelets) and lead to an infection. Until your WBC count rises, you will be given a special "sponge" called a toothette to clean your teeth.

- **Diarrhea**

The chemotherapy may cause your bowel movements to be loose, watery and frequent. You will be asked to save all stool and urine so it can to be measured and tested. Once certain testing is completed on stool samples, medication can be given to help control the diarrhea.

- **Hair loss**

Approximately 10 days after receiving high dose chemotherapy you will experience temporary hair loss. Unfortunately medicine cannot prevent hair loss. Your hair will grow back in two to three months after your treatment. You may consider finding a wig, scarf or hat that you are comfortable wearing before you lose your hair; it will be less of an adjustment.

- New York-Presbyterian Hospital Weill Cornell Medical Center has a barber that is available to you. The number where the barber can be reached is: 212-535-2385

- **Damage to Heart, Lungs, Liver and Kidneys**

Damage to the heart, lungs, liver and kidneys can occur, though rarely, after transplant. Such damage can be life-threatening.

- **Infections**

## ***Will I receive Total Body Irradiation (TBI)?***

Most patients at NewYork-Presbyterian Hospital Weill Cornell Medical Center do not receive any radiation as part of their transplant. For some patients total body radiation is required. This is a form of radiation that it is administered to the entire body under carefully controlled conditions. Typically patients receive 2 doses of TBI per day for three consecutive days. TBI is administered in the radiation department and patients therefore leave the floor for every session. The side effects of TBI are very similar to those of chemotherapy.



## ***What is it like when I receive my stem cell transplant?***

The day you receive your stem cell transplant is an exciting day. The cells will be taken from the lab and brought to your hospital room. You will be given medications prior to receiving your cells to prevent a reaction. Your transplant team and inpatient nurse will be present during your infusion. The stem cells will be given through your central line and will flow by gravity in the



same way as a blood or platelet transfusion.

You may experience flushing of the skin or chest tightness. All of these are easily managed and should be reported to your nurse. The number of bags you receive will be determined by the number of days your donor was collected. Each bag should infuse over ten to fifteen minutes. You may also notice that your urine is pink tinged after you receive your cells. This is perfectly normal and a result of the red blood cells in the stem cell product leaving your body. If the cells you are receiving were frozen you will receive additional medication to prevent an allergic reaction to the preservative (DMSO) that is used to freeze the cells. A member of the stem cell laboratory will thaw your cells outside your room and give them to the nurse to administer at your bedside. Potential side effects include scratchy throat, flushed skin, or chest tightness. After you have received your cells, friends or family may visit you. They may notice a funny smell in your room. Some people say they smell garlic, creamed corn or tomato juice. This is from the preservative, DMSO, which leaves your body through the pores in your skin and breath. You may not be able to smell the DMSO and the odor should clear in about 24 hours.

### ***What happens after I receive my stem cells?***

After transplant, your blood counts will begin to drop if they have not already. The day of your transplant is day 0 and each day following is Day +1, +2, +3, etc. It is important that you stay active during this time to prevent infections and remain strong. Walking in the transplant unit is encouraged. If you are unable to leave your hospital room for any reason, it is recommended that you spend as much time as possible out of bed and use an incentive spirometer to help promote good lung function and prevent pneumonia.

### ***When will my counts recover?***

Recovery of your blood cells usually occurs between 10 and 16 days after transplant sometimes later. Your white blood cells (WBC) will recover first, followed by your red blood cells (RBC) and platelets. When all counts have recovered the stem cells are considered to have engrafted.

### ***Will I develop an infection when my counts are low?***

White blood cells (WBC) protect you from infection. When your WBC count is low you will be neutropenic and at risk for infection. Over 50% of transplant patients will develop a fever when their counts are low. If you develop a fever, your antibiotics will be changed from oral to IV. You will have cultures drawn from both your central line and your arm to look for blood infections. You will also be asked for a urine sample to look for urinary tract infections, and a chest x-ray will be done to rule out pneumonia. If you continue to have fevers you may be required to give a sputum sample or have a

CAT scan of your chest and sinuses to look more closely for infection. The GI tract (stomach and intestines) is another potential source of infection. If you develop diarrhea, you will be asked to save your stool so that infection can be ruled out. If you do have an infection in your GI tract, you will be started on the appropriate antibiotics. It is important that this infection is allowed to clear your system so you will not be given medications to stop the diarrhea. You may also be visited by physicians from other specialties including infectious diseases, pulmonary medicine, cardiology, and dermatology. These physicians may give recommendations for additional testing. However, no tests will be ordered without the approval of your transplant team.

### ***Can I still have visitors when my counts are low?***

Yes, but all visitors must be well and not ill – appearing and/or must not have been with anyone that was sick. All visitors and staff entering your room must wash their hands. All your visitors should be feeling well. Anyone who has a cold, flu or infection cannot visit until they are fully recovered. Well children are able to visit.

### ***Can I eat ALL foods when I am neutropenic?***

No, you will receive a low microbial diet. This means that the food you order will need to be well-cooked, well-washed and/or pasteurized.

### ***Will I require blood or platelet transfusions?***

Yes, another potential complication of the transplant is low blood counts that include anemia when the RBC or hemoglobin is low and bleeding when platelets are low. You will likely require a blood product transfusion while in the hospital. This is very common and safe. A general rule for blood transfusions is when your hemoglobin is less than 8 and your platelets are less than 10,000. However, this is a guideline and transfusion decisions will be made based on symptoms and clinical presentation. All blood products are obtained from the blood bank, screened for infectious diseases, and comply with federal guidelines. You will be asked to sign a consent form to receive blood or platelet transfusions.

### ***How will I feel when I need a blood transfusion?***

You may feel weak and short of breath when you move. Your skin and fingernails may look pale and your skin and hair may feel dry.

## ***What medicines will I get before my blood or platelets?***

We do not give pre-medications prior to blood or platelet transfusions unless you have a history of transfusion reactions.

## ***Can a family member donate blood or platelets for me?***

After your doctor has approved the use of Directed Donors, Transfusion Medicine will contact the New York Blood Center (NYBC) to arrange with them for your donors to be accepted by their service. NYBC will open a special file for each patient. Each patient will have a unique associated “File number” and “Patient number”.

## ***How can my family members schedule a donation?***

When a donor is prepared to donate, that donor or someone who has agreed to be the coordinator for the patient, will call NYBC to schedule an appointment to donate. The “File number” and “Patient number” assigned to the patient must be given when the appointment is made in order for the donated unit to be sent to the correct hospital and given to the correct patient. The same two numbers will be used for any donor who will donate for that patient.”

## ***What is graft versus host disease (GVHD)?***

Graft versus Host Disease (GVHD) is a common and serious complication following allogeneic transplant. It is an immune reaction (or attack) of the donor’s cells against your body. It is triggered by a type of white cell, called T cells. The donor T cells are trained to recognize which cells belong in the donor body and which cells do not. Once transplanted into you, the T cells may see your body as foreign and start an immune reaction.

There are two types of GVHD-acute and chronic. Acute usually occurs during the first three months following transplant. Chronic GVHD can occur anytime after that. You may experience either types, or neither.

## ***Who gets graft versus host disease (GVHD)?***

Roughly 20 to 50 % of individuals who receive a transplant from a matched related donor develop GVHD. The risk of GVHD is higher in older individuals and those who have an unrelated or mismatched donor.

## ***Can you tell me more about acute GVHD?***

Yes, acute GVHD usually affects three systems of the body: skin, liver and the gastrointestinal tract (your stomach or bowel). Acute GVHD can be a mild problem, or it can be very serious and sometimes fatal. The onset can be fast requiring quick detection and aggressive treatment. We will monitor you closely the first three months after your transplant. You will be required to make frequent trips to the NewYork-Presbyterian Hospital Weill Cornell Medical Center for monitoring.

## ***Can you tell me more about chronic GVHD?***

Chronic GVHD occurs after the first 100 days following the transplant. The onset is usually more gradual than acute. It mainly affects the skin, eyes, mouth and liver. It can also affect the lining of the lungs, heart, gastrointestinal tract (your stomach or bowel), vaginal lining, muscles, connective tissue and the immune system. Chronic can be a mild problem or it can cause significant illness. It is rarely fatal but can lead to life threatening infection. Chronic GVHD can worsen when there is an infection. It is important to treat any infection promptly.

## ***Are there things I can do to prevent GVHD?***

You can take your immunosuppressive medications as ordered, prevent infections and protect yourself from sunlight exposure.

For more information on GVHD see the Post Transplant Complications section of this book.

## ***What happens if the transplant does not go well?***

Sometimes serious complications occur, that require transfer to the Intensive Care Unit (ICU). Your care is taken over by a specialized team of physicians and nurses. Your transplant team will however remain very involved in your care and will come by every day. They will serve as consultants to the ICU team.

Visiting hours in the ICU may be different from those on the regular floor. Please have your family members talk with the nurses in the ICU.

Some patients become so ill that they lose consciousness or they may require a ventilator to help them breathe. Most of the patients on ventilators are also asleep. In all these cases, you won't be able to make your own decisions on health care anymore. In such situations your next of kin may have to make decisions for you and it is important that you consider delegating power of attorney to a person of your choice. If you have a living will, its content will also be respected by the health care team.

Living Wills and a Durable Power of Attorney's for Health Care can be explained and completed by our Social Work staff and our Spiritual Care staff. A Living Will is a document that tells your physician not to use medical interventions that would delay the dying process if you are close to death, and are unable to communicate your wishes. A Durable Power of Attorney for Health Care is a document where you name someone as an "agent" to make decisions about medical treatment, if you are unable to make decisions for yourself. Power of Attorney for Health Care differs from the Living Will in that it is good for any kind of medical decision, not just end of life concerns. If a patient has both a Living Will and Power of Attorney, the Power of Attorney takes precedence. These documents pertain to health care decisions only and do not pertain to financial concerns.

# **Preparing for Discharge**

## ***How do you know when I am ready to go home?***

Prior to transplant you were told that your admission would be approximately 4 weeks. We determine your ability to go home on the following points:

- **Engraftment**  
When the new blood cells begin to grow in your bone marrow and reach a healthy level in your blood engraftment has taken place. Your white blood cell count must be adequate to prevent severe bacterial infections. Your neutrophil count (neutrophils are part of the white blood cells) must be greater than 500/uL for 3 days. Your platelet count must be high enough to prevent spontaneous bleeding and you will not require a platelet transfusion more than every 2 -3 days. Your hematocrit, which is your percentage of red blood cells, must be 25-30% and you will not need a blood transfusion more than every 2-3 days.
- **Intake**  
You must be able to take your medications by mouth for 48 hours prior to discharge and be able to tolerate both liquids and solid food.
- **Diarrhea**  
You must have minimal and controlled diarrhea. No more than 200cc or 6 oz per day.
- **Free of Infection**  
You must be without fever and off IV antibiotics for 48 hours prior to discharge and without signs of infection.
- **Other issues that need to be considered include:**  
Home care needs to be arranged for your line care and labs as needed. You need to have local lodging or be able to return to the hospital when needed.  
You and your caregiver will need to demonstrate an understanding of your discharge instructions.

## ***What do I have to have done in my home to prepare me for discharge?***

Your house or apartment should be thoroughly cleaned before you return home from the transplant center.

If possible you should consider the following:

- Shampoo carpets and wash the floors
- Clean drapes, blinds and furniture

- Change air conditioning and furnace filters
- Turn off humidifiers
- Remove plants, fresh and dried flowers etc. from your bed room or other rooms you spend most of the time.

## ***Do I need a transplant caregiver?***

Prior to admission, you will be required to identify a caregiver. The caregiver plays a vital role during the patient's transplant process and recovery. Some patients may require a 24 hour caregiver. This may require hiring a caregiver which is not covered by insurance.

The caregiver responsibilities include:

- Be present to learn discharge instructions on day of discharge
- Ensure safe transportation to and from medical appointments
- Assist with activities of daily living (e.g. grocery shopping, meal preparation, laundry, housekeeping, etc)
- Assist with medication
- Manage central venous catheter or PICC line care if applicable
- Monitor, assess, and report physical symptoms
- Facilitate communication with medical team
- Provide emotional support

## ***What would my caregiver need to do?***

- Grocery shop and prepare meals
- Assist with medication management
- Housecleaning and laundry
- Assist with line care needs
- Transport to and from appointments (This can be up to 3 times a week)
- Communicate symptoms
- Provide emotional and spiritual support

## ***Will I need to take prescription medications after the transplant?***

After allogeneic stem cell transplantation patients take many medications. These fall into three categories:



### **Immunosuppressants**

These include the drugs tacrolimus (Prograf®), Cyclosporin (Neoral®), mycophenolate (Cellcept®) and a variety of steroids. These drugs are usually given for three to six months after transplant, but some patients, particularly those with GVHD may need to take them much longer.

### **Antivirals**

These include the drugs acyclovir, valacyclovir, valganciclovir. They suppress viral infections, many of which lay dormant in our body and can flare up after transplant. They are typically given for up to a year after transplant.

### **Antifungals**

To prevent fungal infection. Typically given for up to six months after transplant.

### **Anti PCP**

Pneumocystis carinii pneumonia or PCP can occur after transplant. Patient are asked to take weekly Bactrim® for up to a year after transplant. For those who cannot take Bactrim®, other medications are available.

It will be useful for you to understand your prescription drug insurance benefits and know where you can get medications filled. Your prescription drug insurance can provide you with the names and locations of participating pharmacies. Remember that your insurance may only cover medications at specific pharmacies. Be sure to let your nurse know if you have a plan that requires mail-in prescriptions as that can take some time to organize.

Most prescription insurance plans have co-payments that are the patient's responsibility. Since transplant patients require dozens of prescriptions, many of them brand name medications, total co-payments may be significant and it will helpful for you to budget accordingly. The next question lists most common medications that you might be required to take after your transplant and their approximate prices.

Below are the medication costs of the most common oral medications according to their **Average Retail Price**. This is an estimate if you paid for these medications in cash. When possible, we have listed the generic drug costs too. Actual prices may vary, depending on your insurance coverage and preferred pharmacy. **Keep in mind that you might not need all the medications listed.**

<b>Drug Name</b>	<b>Purpose</b>	<b>Typical Dose</b>	<b>Approximate Duration</b>	<b>Approximate cost per 30 day supply</b>
Acyclovir	Prevents viral infections. Dose depends on type of infection we are trying	800 mg orally four times a day	Up to a year	\$50
		800 mg orally twice a day	Up to a year	\$27

	to prevent.	400 mg orally three times a day	Up to a year	\$24
Valacyclovir (also called Valtrex)	Prevents viral infections	2000 mg orally four times a day	Up to 7 months	\$1,355
Valganciclovir (also called Valcyte)	Treats CMV infection	900 mg twice a day	Up to 1 month	\$ 6,519
Fluconazole	Prevents fungal infections	200 mg orally once a day	Up to a year	\$35
Voriconazole (also called VFEND)	Prevents fungal infections	200 mg orally twice a day	Up to a year	\$2,537
Posaconazole (also called Noxafil)	Prevents fungal infections	200mg orally four times a day	Up to a year	\$5,294
Bactrim DS (also called cotrimoxazole)	Prevents bacterial infections	1 tablet orally twice daily every Saturday and Sunday	Up to a year	\$12
Moxifloxacin (also called Avelox)	Prevents bacterial infections	400 mg orally once a day	Up to 1 month	\$555 (30 tablets)
Tacrolimus (also called Prograf)	Immunosuppression or Anti-rejection	Dose varies per person; dose is based on blood levels. Typical dose is 2 mg orally twice a day	3 to 9 months	\$485
Mycophenolate (also called Cellcept)	Immunosuppression or Anti-rejection	1000 mg orally three times a day	Two months	\$96
Esomeprazole (also called Nexium)	Proton pump inhibitor, used to decrease stomach acids	40 mg orally once a day	Up to a year	\$209
Ondansetron	Prevents nausea and vomiting	8 mg orally three times a day as needed	One month	\$120 (30 tablets)
Cyclosporin	Immunosuppression or Anti-rejection	Dose varies per person; dose is based on blood levels	3 to 9 months	\$ 500
Prochlorperazine	Prevents nausea and vomiting	10 mg orally four times a day as needed	One month	\$35 (30 tablets)
Loperamide	Helps manage diarrhea	4 mg orally four times a day as needed	Up to a month	\$17 (30 tablets)
Lorazepam	Helps manage nausea, vomiting, helps control anxiety and also can be used a sleeping aid	1 mg orally every six hours as needed	Up to a month	\$15 (30 tablets)

### ***Can I have visitors when I go home?***

Yes, but be aware that even though your granulocyte count is recovering, your body's defense system against infections (called the immune system) is still compromised,

and will be for about 12 months. During this period, you are more susceptible to some bacterial and viral infections. Bacterial and viral agents found in the environment and on other individuals can cause infections. Below are recommendations regarding visitor contact:

- Family Contact- By the time you go home, contact with other family members is fine as long as no one is sick
- Visitor Contact- Limit the total number of visitors who come to your home. Instruct your friends or family to **stay away if they are sick** or if they have been in contact with anyone else who was sick in the past few days.
- Children Contact- If you have children at home, talk with your doctor about ways to limit your risk of infection, since children (especially preschool and early school age) tend to get colds and other common illnesses. These infections can be life-threatening as your immune system recovers.

### ***Do I have to wear a face mask when I leave the hospital?***

After you leave the hospital a mask is not necessary. You should not allow anyone with a potentially infectious illness (flu, cold, etc.) to visit you. Avoid crowds of people. For example, plan to go to the grocery store at a time when the number of shoppers is light. Avoid theaters and crowded shopping centers. If you go to a restaurant, go at a time when it is not crowded. This should be continued for 30 days after your transplant.

### **Can I have sexual intercourse after transplant?**

Sexuality is an important part of life and you and your partner should discuss this as part of your recovery, both with each other and with the transplant team. Following the transplant you need not abstain from kissing or having sexual intercourse with a healthy partner.

The following guidelines are recommended:

- Single partner
- Your partner should not be ill including having a cold, flu or cold sores
- Your platelet count should be at least 25 thousand
- Condoms should be used for at least 3 months after transplant
- You may receive oral sex but should not offer it to your partner for 3 months or if you are on immunosuppressive agents.
- Vaginal dryness or loss of elasticity may occur after transplant or be a sign of GVHD. Water soluble lubricants (Lubrin, K-Y jelly, Surgilube,

Replens, Personal Lubricant, Ortho Personal Lubricant) may improve the symptoms of vaginal dryness

- Testosterone levels may remain low after chemotherapy/radiation therapy. If interest in sexual activity has not returned in 4-6 months, Viagra may be a useful adjunct in males with erectile dysfunction

### ***Can I resume my normal activity?***

Yes, activity is **IMPORTANT**. Staying active helps your recovery. If you feel tired rest or take a nap. Do not stay in bed! Avoid strenuous activity: avoid lifting weights and contact sports (football, etc.) until your platelet count is normal. Keep busy; engage in a favorite hobby, walking, etc.

### ***Can I resume my normal eating?***

Yes, we recommend that you EAT! Many transplant recipients experience a decrease in appetite or a change in their taste buds. These are temporary side effects of treatment. Work with your dietitian to plan meals that are both satisfying and nutritious.

### ***Why is it important to eat healthy food?***

After a bone marrow or cord blood transplant, eating a nutritious diet is important to help your immune system and body get stronger. You may need more protein or more calories than usual. You may also need to avoid certain foods to protect yourself from the risk of infection. If you have mouth sores or other eating problems after your transplant, you can choose foods that are easier to swallow.

### ***What are the foods which I can eat, and which I should avoid eating?***

Following table lists foods that you may eat or should avoid eating:



May Eat	Do Not Eat
<p>commercially-packaged salami, bologna, hot dogs, ham and other luncheon meats, heated until steaming</p> <ul style="list-style-type: none"> <li>• Pasteurized or cooked tofu</li> </ul> <p><b>Fruit and Nuts</b></p> <ul style="list-style-type: none"> <li>• Well washed raw and frozen fruit and foods containing them.</li> <li>• Cooked, canned and frozen fruit, dried fruits.</li> <li>• Pasteurized juices and frozen juice concentrates</li> <li>• Canned or bottled roasted nuts, shelled roasted nuts and nuts in baked products.</li> </ul> <p>Commercially-packaged nut butters (such as peanut butter, almond butter, soybean butter)</p> <p><b>Entrees, soups</b></p> <ul style="list-style-type: none"> <li>• All cooked entrees and soups</li> </ul> <p><b>Vegetables</b></p> <ul style="list-style-type: none"> <li>• Well washed raw and frozen vegetables</li> <li>• All cooked frozen or canned vegetables, including potatoes (refrigerate canned foods after opening)</li> <li>• Cooked vegetable sprouts such as mung bean sprouts</li> <li>• Fresh well washed herbs, dried herbs and spices</li> </ul>	<ul style="list-style-type: none"> <li>• Pickled fish</li> <li>• Tempe (tempeh) products</li> </ul> <ul style="list-style-type: none"> <li>• Unwashed raw fruits</li> <li>• Fresh or frozen berries</li> <li>• Unroasted raw nuts, roasted nuts in shell</li> <li>• Non-pasteurized fruit and vegetable juices</li> </ul> <p>Non-pasteurized items containing raw fresh fruits. such as salsa, found in the grocery refrigerator case.</p> <ul style="list-style-type: none"> <li>• All miso products (such as miso soup)</li> </ul> <ul style="list-style-type: none"> <li>• Unwashed raw vegetables or herbs</li> <li>• Fresh, non-pasteurized vegetable salsa found in the grocery refrigerator case</li> <li>• Non-pasteurized items containing raw fresh vegetables such as salsa, found in the grocery refrigerator case.</li> <li>• All raw vegetable sprouts (alfalfa sprouts, clover sprouts, mung bean sprouts, all others)</li> <li>• Salads from salad bar and delicatessens.</li> </ul>





## **Centers for Disease Control and Prevention “Check Your Steps” to Keep Food Safe**

### **Step 1: Clean**

#### **Wash fruits and veggies—but not meat, poultry, or eggs!**

Did you know that—even if you plan to peel fruits and veggies—it’s important to wash them first because bacteria can spread from the outside to the inside as you cut or peel them?

Here’s how to wash all your produce effectively...

1. Cut away any damaged or bruised areas.
2. Rinse produce under running water. Don’t use soap, detergent, bleach, or commercial produce washes.
3. Scrub firm produce—like melons or cucumbers—with a clean produce brush.
4. Dry produce with a paper towel or clean cloth towel... and you’re done.
5. The good news? Bagged produce marked “pre-washed” is safe to use without further washing.

#### **Why not wash meat, poultry, and eggs?**

Washing raw meat and poultry can actually help bacteria spread, because their juices may splash onto (and contaminate) your sink and countertops.

All commercial eggs are washed before sale. Any extra handling of the eggs, such as washing, may actually increase the risk of cross-contamination, especially if the shell becomes cracked.

#### **Wash surfaces and utensils after each use.**

Bacteria can be spread throughout the kitchen and get onto cutting boards, utensils, and counter tops. To prevent this:

- Use paper towels or a clean cloth to wipe up kitchen surfaces or spills. Wash cloths often in the hot cycle of your washing machine.

- Wash cutting boards, dishes, utensils, and counter tops with hot, soapy water after preparing each food item and before you go on to the next item.
- As an extra precaution, you can use a solution of 1 tablespoon of unscented, liquid chlorine bleach in 1 gallon of water to sanitize washed surfaces and utensils.

**Wash hands the right way—for 20 seconds with soap and running water.**

Washing your hands the right way can stop the spread of illness-causing bacteria.

Here's how to do it:

- Wet your hands with warm or cold running water and apply soap.
- Rub your hands together to make a lather and scrub them well. Be sure to scrub the backs of your hands, between your fingers, and under your nails. Bacteria can hide out here too!
- Continue rubbing hands for at least 20 seconds. Need a timer? Hum “Happy Birthday” from beginning to end twice.
- Rinse your hands well under running water.
- Dry your hands using a clean towel or air dry

**Step 2: Separate**

**Use separate cutting boards and plates for produce and for meat, poultry, seafood, and eggs.**

Placing ready-to-eat food on a surface that held raw meat, poultry, seafood, or eggs can spread bacteria and make you sick. But stopping cross-contamination is simple.

- Use one cutting board for fresh produce, and one for raw meat, poultry, or seafood.
- Use separate plates and utensils for cooked and raw foods.
- Before using them again, thoroughly wash plates, utensils, and cutting boards that held raw meat, poultry, seafood, or eggs.
- Once a cutting board gets excessively worn or develops hard-to-clean grooves, consider replacing it.

**Keep meat, poultry, seafood, and eggs separate from all other foods at the grocery.**

Make sure you aren't contaminating foods in your grocery bag by:

- Separating raw meat, poultry, seafood, and eggs from other foods in your shopping cart.
- At the checkout, place raw meat, poultry, and seafood in plastic bags to keep their juices from dripping on other foods.

**Keep meat, poultry, seafood, and eggs separate from all other foods in the fridge.**

Bacteria can spread inside your fridge if the juices of raw meat, poultry, seafood, and eggs drip onto ready-to-eat foods. But stopping this contamination is simple.

- Place raw meat, poultry, and seafood in containers or sealed plastic bags to prevent their juices from dripping or leaking onto other foods. If you're not planning to use these foods within a few days, freeze them instead.
- Keep eggs in their original carton and store them in the main compartment of the refrigerator—not in the door.

**Step 3: Cook**

**Use a food thermometer.**

Cooked food is safe only after it's been heated to a high enough temperature to kill harmful bacteria. Color and texture alone won't tell you whether your food is done. Instead, use a food thermometer to be sure.

- If you don't already have one, consider buying a food thermometer. Learn more about the different types of food thermometers available.
- When you think your food is done, place the food thermometer in the thickest part of the food, making sure not to touch bone, fat, or gristle.
- Wait the amount of time recommended for your type of thermometer.
- Clean your food thermometer with hot, soapy water after each use.

<b>Food Item</b>	<b>Safe Minimum Temperatures</b>
Eggs	Cook until yolk and white are firm
Egg Dishes & Egg Sauces	160 °F
Turkey and Chicken	165 °F
Ground meats including: Beef, Hamburgers, Veal, Lamb, Pork	160 °F
Fresh Beef, Veal, Lamb, Pork (including cured ham)	160 °F
Seafood/Fish	145 °F

**Keep food hot after cooking (at 140 °F or above).**

The possibility of bacterial growth actually increases as food cools after cooking because the drop in temperature allows bacteria to thrive. But you can keep your food above the safe temperature of 140°F by using a heat source like a chafing dish, warming tray, or slow cooker.

**Microwave food thoroughly (to 165 °F).**

To make sure harmful bacteria have been killed in your foods, it's important to microwave them to 165° or higher. Here's how:

- When you microwave, stir your food in the middle of heating.
- If the food label says, "Let stand for x minutes after cooking," don't skimp on the standing time. Letting your microwaved food sit for a few minutes actually helps your food cook more completely by allowing colder areas of food time to absorb heat from hotter areas of food. That extra minute or two could mean the difference between a delicious meal and food poisoning.
- After waiting a few minutes, check the food with a food thermometer to make sure it is 165°F or above.

## **Step 4: Chill**

### **Refrigerate perishable foods within two hours.**

Cold temperatures slow the growth of illness causing bacteria. So it's important to chill food promptly and properly. Here's how:

- Make sure your fridge and freezer are cooled to the right temperature. Your fridge should be between 40 °F and 32 °F, and your freezer should be 0 °F or below.
- Pack your refrigerator with care. To properly chill food (and slow bacteria growth), cold air must be allowed to circulate in your fridge. For this reason, it's important not to over-stuff your fridge.
- Get perishable foods into the fridge or freezer within two hours. In the summer months, cut this time down to one hour.
- Remember to store leftovers within two hours as well. By dividing leftovers into several clean, shallow containers, you'll allow them to chill faster.

### **Never thaw or marinate foods on the counter.**

Many people are surprised at this tip. But since bacteria can multiply rapidly at room temperature, thawing or marinating foods on the counter is one of the riskiest things you can do when preparing food for your family.

To thaw food safely, choose one of these options:

- **Thaw in the refrigerator.** This is the safest way to thaw meat, poultry, and seafood. Simply take the food out of the freezer and place it on a plate or pan that can catch any juices that may leak. Normally, it should be ready to use the next day.
- **Thaw in cold water.** For faster thawing, you can put the frozen package in a watertight plastic bag and submerge it in cold water. Be sure to change the water every 30 minutes. Note: If you thaw this way, be sure to cook the food immediately.
- **Thaw in the microwave.** Faster thawing can also be accomplished in the microwave. Simply follow instructions in your owner's manual for thawing. As

with thawing in cold water, food thawed in the microwave should be cooked immediately.

- **Cook without thawing.** If you don't have enough time to thaw food, just remember, it is safe to cook foods from a frozen state—but your cooking time will be approximately 50% longer than fully thawed meat or poultry.

To marinate food safely, always marinate it in the refrigerator.

### **Tips for when Eating at Restaurants**

Choose restaurants carefully. Local health departments inspect restaurants to make sure that they are clean, and that they follow safe food practices. You can find out how your local restaurant of choice did on recent health inspection by going to your local Department of Health (DOH) website; for example:

[www.nyc.gov/html/doh/html/rii/index.shtml](http://www.nyc.gov/html/doh/html/rii/index.shtml)

You can also ask your local restaurant about their food safety training rules. This is good to know what you are planning to eat out.

- Order all foods to be well done.
- Do not order foods that may have raw meat and fish or raw eggs, such as Caesar salad dressing, Hollandaise Sauce, sushi and sashimi, tartare and some homemade ice creams or custards.
- Ask the wait-staff if you are not sure of the ingredients in your meal.
- Do not eat foods from buffets and salad bars.
- Request that foods are cooked fresh and not served from steam tables or kept warm by heat lamps.
- Request single serving condiments. Multiple customers may use open containers.
- Do not eat soft-serve ice cream and soft serve frozen yogurt. The dispensers may not be cleaned on a regular basis.
- Always order a whole or personal pizza. Do not order single slices since they are often kept warm under heat lamps.

### **Herbal Supplements**

Do not take homeopathic remedies or herbal products including Traditional Chinese Medicines.

- There are no federal standards for these products in the United States. They may be contaminated during production or storage.
- Contaminated products may be a health risk and may cause infection.
- Herbal products may interfere with or change the activity of a prescription medicine.

- Always talk to your physician before taking any homeopathic remedy or herbal product that is not prescribed.

### ***What areas of personal cleanliness should I remember?***

- **Wash your hands!** Thorough, frequent hand washing with soap and water is important to guard against bacteria and viruses transmitted by hand-to-mouth and hand-to-nose contact. Examples of when to wash your hands: after using the toilet, after you come in contact with anyone who is sick, and before eating.
- Wash daily. Use a mild soap. Rinse with lukewarm water and gently pat your skin dry with a soft towel. Apply a non-alcohol lotion generously to skin. (Keri or Lubriderm)
- Brush your teeth after each meal with a soft bristle toothbrush. You may floss as long as your platelet count is greater than 50,000.
- Keep your nails clean. File your nails only after bathing. Do not clip your nails unless your platelet count is greater than 50,000.
- **DO NOT GO BAREFOOT!!!**
- Your skin will be sensitive to sunlight. A good sunscreen and sensible precaution will protect your skin from burning.
- You can begin using lotions and makeup, but this should be done gradually and with care.

### ***Are there any household chores I should avoid?***

You should avoid household chores while you are at risk for infection. Some chores that may expose you to viruses and fungus are:

- Yard work including gardening, mowing the lawn, raking leaves
- Caring for plants – any task that includes contact with indoor plants or potting soil
- Dusting or vacuuming. This includes being in the room while this is done
- Carpentry or home repair project
- Errands that expose you to crowds – grocery shopping

### ***Can I go to my dentist?***

Yes, we suggest you see your dentist every six months. You should not have any major dental work (drilling, removing, etc) performed until your platelet count is stable and greater than 100,000, and granulocyte count is greater than 1500. Please contact your doctor first before any dental work is scheduled. Many times we recommend you take antibiotics before dental work.

## ***Will I go home with my central catheter in?***

Yes, you will go home with your catheter in. It will remain in place for 1-3 months. You will be required to flush your catheter daily. You will need to change the dressing weekly (some type of dressings may need to be changed every other day). You will also need to change the dressing if it gets wet or soiled.

## ***How will I be able to shower or bath with the catheter in place?***

Use a protective covering over your catheter when showering or bathing. For example, place a plastic bag over the insertion site and tape along the edges.

## ***How do I care for my central line?***

Your catheter, either a central venous tunneled catheter or PICC line, may be left in place for several weeks following discharge from the hospital. With the assistance of a home infusion/care company, you will be asked to have the catheter flushed and the dressing changed once a week. A central venous tunneled catheter is flushed 3 times a week, and a PICC line is flushed daily.

Social worker will assist in arranging home care services through an infusion agency. This infusion agency will provide you with all the necessary supplies to care for your line. A nurse will come to your home to teach you and/or your caregiver how to flush the line. You will be required to flush the line on your own. A nurse will come back once per week to change the dressing on your line

## ***What types of things should I watch for when I go home?***

- Changes in the appearance of your Hickman catheter site. (Redness, swelling, pus-like drainage, tenderness to touch, etc.)
- Changes in the number, color, or consistency of your bowel movements.
- Changes in the color of your urine.
- Appearance of a rash anywhere on your skin.
- Temperature increases of one degree or more over your usual temperature. (100.5 or greater)
- Persistent cough
- Difficulty catching your breath.

- Nausea or vomiting.
- Inability to take the medication prescribed for you.
- Pain.

### ***What should I do if any of the above occurs?***

You should contact your physician immediately and follow his/her instructions.

### ***Can I have my pets in my home?***

Yes, but we recommend that you take precautions with your pets for 3-6 months after your transplant. Indoor pets can remain in your home. It is best to find new homes for reptiles and birds. Do not clean up pet waste such as cleaning the litter box or picking up dog waste. Do not sleep with, kiss, or be licked by your pet.

### ***Is it OK to have plants in my home?***

Yes, but the main concern is being exposed to bacteria and other organisms that grow on plants and are found in plant water. We suggest that you do not keep plants or flowers in your bedroom or other rooms where you spend most of your time.

### ***Can I go swimming after my transplant?***

There are a number of nonbacterial infections that can be acquired in any swimming pool (private or public), hot tub, lake or ocean. We do not recommend swimming for 6 months after transplant. If you have a central line you should **NOT** go swimming!

### ***How will I feel emotionally when I go home?***

After a long stay in the hospital with numerous physicians caring for you, many patients find it difficult to adjust to home life. Concerns about your disease returning and lack of constant medical care can lead to symptoms of anxiety and depressed mood. Further, concerns over infections from visitors can lead to social isolation. Do not panic, while anxiety and a depressed mood are common among patients, there are professionals who can help you adjust to being home. Monitor yourself for the following symptoms: changes (increases or decreases) in your appetite, weight, sleep, and activity level, or feelings of loneliness, sadness, and depression. If any number of these symptoms persist for more than a few days, please notify your physician so we can help you directly or refer you to someone who can.

## ***When will I have follow-up visits?***

You will be seen at least weekly until day 100, monthly day 100-180, every two months day 180-365, every six months until year 2 and finally yearly thereafter.



## ***Will I have blood tests at these visits?***

Yes, you will have blood work looking at your counts, kidney and liver function. Also, we will be checking for some viruses that can occur in the post transplant phase. If you are on prograf we will be monitoring your levels.

## ***Will I have other testing besides blood work?***

Yes, on day 30 after your transplant you will have a bone marrow aspirate and biopsy and pulmonary function tests (to assess your lung function). Day 100, 180, 1 year and then yearly you will have a bone marrow aspirate and biopsy, pulmonary function tests, an assessment for GVHD, and an eye test. You may also require other tests such as CT scans, MRIs or PET scans.

## ***Will I receive immunizations after my transplant?***

Yes, you will require immunizations after transplant since your previous immunizations will no longer be effective. These immunizations may be given at NewYork-Presbyterian Hospital Weill Cornell Medical Center Medical Center during your oncology physician clinic appointment or they may be given locally at your oncologist's or primary physician's office. If you prefer, the schedule of required immunizations may be sent to your local physician.

## ***When will I receive the immunizations?***

We recommend vaccinations according to following schedule;

Vaccine name	Months post transplant
Pneumococcal vaccine **	3-6 months post transplant, every 2 months
Hepatitis B	6-12 months post transplant
Inactivated polio	6-12 months post transplant, every 2 months
Haemophilus influenzae B conjugate	6-12 months post transplant , every 2 months
Tetanus-Diphtheria-Pertussis	6-12 months post transplant , every 2 months
MMR (if not contraindicated)	2 years post transplant
Influenza	Annually every fall commencing 6 months after transplant
Meninogococcus	6-12 months post transplant- only for college students or people at summer camps

\*\* There are two types of pneumococcal vaccines; we usually administer PCV vaccine for the first three doses and Pneumovax for the fourth dose.

## ***Are there any vaccination recommendations for live-in household members?***

If you have children who need vaccination please follow the following recommendations;

- Hepatitis A : Routine vaccination recommended for children more than 12 months old
- Influenza : Trivalent inactivated vaccine is strongly recommended annually during each flu season and require two doses if receiving for the first time (do not use intranasal influenza vaccine)
- Polio: Inactivated polio vaccine should be administered when indicated. Live vaccine should be avoided.
- Measles-mumps-rubella(MMR)(live): Routine vaccination recommended for children more than 12 months old.
- Pertusis: Vaccination with DTaP is recommended for children <7 years
- Varicella: Two doses of vaccination, 3 months apart should be administered to children >12months old. The vaccination should be given at least 4 weeks before or 6 weeks after the transplant.

For adults and family visitors;

- Zoster vaccination is recommended for all family members and close contacts. The vaccination should be given at least 4 weeks before or 6 weeks after the transplant. Adolescents and adults should receive 2 doses 4 weeks apart.

### ***Will I have to be readmitted again?***

Occasionally, patients need to be readmitted for transplant complications such as infections or GVHD. If that happens, you will be under the care of the transplant team again. If possible we will admit you to 10 W. Some patients with infections need to be admitted to other floors.

### ***Who do I contact in case of emergency?***

You will be given a patient card at the time of discharge. You should carry this card in your valet. Please refer to the card for contact information.

### ***What if I live far away?***

A limited number of hotel suites are available at the Helmsley towers for patients receiving treatment at NYP Cornell Medical Center. If your healthcare provider feels that you have sufficiently recovered to leave the hospital but you live too far away to safely commute for visits then you may be a candidate for the program.

You must have a designated 24 hour- 7 day a week caregiver to stay with you during the duration of your stay. Each room has either a bed with pullout sofa bed or 2 beds with full amenities including fully equipped kitchen with refrigerator, stove, microwave, dishwasher and kitchen supplies. There is daily maid service and cable television. There is free WiFi in the room and computer/printer available in the lobby. The room is provided for free. The only expense you would incur is for phone calls and parking (there is \$5 discount for parking).

You and your family member can stay as long as their healthcare provider feels it is necessary. But in the event that you get readmitted to the hospital, the caregiver or any family member has 24 hours to check out of the room, otherwise they will be charged for the room.

Ask your healthcare provider or social worker to see if this option might be available or right for you. Arrangements will be made through a representative of the hospital. The Helmsley Hotel is located at 1320 York Avenue between 70<sup>th</sup> and 71<sup>st</sup>. Phone is 212-472-8400.

# **Dealing with Finances**

## ***What Do I Do about Financial Concerns and Issues Relating to My Transplant?***

Stem Cell Transplantation is a costly and complex medical procedure. In order to minimize expenses for yourself and your family we make sure that as much of the expenses as possible are covered by your insurance carrier.

Our financial coordinators are responsible for organizing this aspect of your care.

An allogeneic transplant requires identification of a donor (a sibling, another relative, an adult unrelated donor and/or a cord blood donor). This process can be lengthy and costly.

Sometimes your own stem cells have to be collected as well.

The national marrow donor program or similar organizations charge us for identification of unrelated stem cell or bone marrow donors. The clearance of the donor, the collection of stem cells and their shipping all generate considerable expense.

If cells are collected from a related donor, this incurs considerable expense. These expenses are usually covered by your (the recipient's) insurance. If insurance issues occur please contact the financial coordinator.

The transplant itself requires admission for dose chemotherapy and stem cell infusion. You usually spend several weeks in the hospital.

After discharge you will still have frequent outpatient visits and will need to take many medications.

Each of these treatments and procedures results in charges from NYP hospital. In addition you will receive bills from the specialty group with which your hematologist/oncologist is affiliated. You may also receive bills from other doctors involved in your care.

Your financial coordinator makes sure that as much of the charges as possible are covered by insurance. This usually requires an approval in writing from the insurance company which may take several weeks.

We will inform you of costs that may not be covered. For example, some insurance policies cover transplant, but not the donor search process.

We will provide you with contact information for organizations that may be able to provide help or information. The hospital will help provide as much assistance as possible. Sometimes your social worker can help identify additional aid and resources.

**The financial coordinator can be contacted at (212) 746-5415.**

Other numbers of interest:

Financial assistance for hospital billing please contact:

**Network Recovery Services at 866-252-0101**

Physician assistance with billing please contact:

**Physician Organization at (212)-590-5710**

# **Patient Resources**

## Web Sites for Patients

**Marrow Foundation:** [www.themarrowfoundation.org/](http://www.themarrowfoundation.org/)

The Marrow Foundation was created by the late Admiral E.R. Zumwalt Jr., in 1991 to fund National Marrow Donor Program initiatives that will increase the size and diversity of its National Registry of potential volunteer marrow or blood cell donors. The Foundation also assists patients with financial need in the process of searching for a donor match and sponsors research.

**Bone marrow foundation:** [www.bonemarrow.org/](http://www.bonemarrow.org/)

The Bone Marrow Foundation is a national non profit organization that offers financial assistance and free support services to bone marrow/stem cell transplant patients and their families and relies 100% on private donations to provide these vital services.

**BMT infonet:** [www.bmtinfonet.org/](http://www.bmtinfonet.org/)

BMT infonet is a not-for-profit organization that provides publications and support services to bone marrow, peripheral blood stem cell, and cord blood transplant patients.

**Multiple Myeloma Research Foundation:** [www.multiplemyeloma.org/](http://www.multiplemyeloma.org/)

The Multiple Myeloma Research Foundation is a non-profit aims include fostering a cure by funding research. The foundation addresses the organization, the disease, treatment options and clinical trials.

**Multiple Myeloma Research Consortium:** [www.themmrc.org/](http://www.themmrc.org/)

The Multiple Myeloma Research Consortium works to accelerate the development of novel and combination treatments for patients with multiple myeloma by promoting and facilitating collaborative research between industry and academia. This bench to bedside research is solely directed to provide new and more effective treatments for our patients and fast forward progress toward the ultimate cure of myeloma.

**Leukemia Lymphoma Society:** [www.leukemia-lymphoma.org/](http://www.leukemia-lymphoma.org/)

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to funding blood cancer research, education, advocacy, and patient services.

**Sickle Cell Disease Association of America:** [www.sicklecelldisease.org/](http://www.sicklecelldisease.org/)

The Sickle Cell Disease Association of America provides education, advocacy and other initiatives which promote awareness and support for sickle cell programs and patients

**Leukemia Research Foundation:** [www.leukemia-research.org/](http://www.leukemia-research.org/)

The Leukemia Research Foundation mission is to conquer leukemia, lymphoma and myelodysplastic syndrome by funding research into their causes and cures and to enrich the quality of life of those touched by these diseases.

**Lymphoma Research Foundation:** [www.lymphoma.org/](http://www.lymphoma.org/)

The Lymphoma Research Foundation promotes and supports research aimed at more effective and safe treatment.

**The National Marrow Donor Program:** [www.marrow.org/](http://www.marrow.org/)

The National Marrow Donor Program provides Information and resources for donors, patients and physicians about bone marrow and cord blood transplant

**The following sites are available to transplant patients to allow the ability to speak with other transplant patients for support.**

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

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

[www. MyHopeSpace.com](http://www.MyHopeSpace.com)

[www.CarePages.com](http://www.CarePages.com)

## Parking Information

As a courtesy to our patients, the Bone Marrow and Stem Cell Transplant Program offers parking passes to our patients who are admitted here for transplant. These passes allow our patient's caregiver/visitor to park free of charge at the New York Presbyterian Hospital Valet Parking Garage located at the 68<sup>th</sup> street entrance.

Passes are available to those patients who are admitted to the hospital for their transplant. Patients can receive one pass per day, if needed, for their caregiver/visitor.

Patients who are readmitted to the hospital within one month of discharge after transplant are also entitled to one pass per day, if needed. If a patient is readmitted after this time frame, they are no longer entitled to these passes as the passes are dedicated to patients who are currently going through their transplant.

\*Please note, these prices have been gathered for informational purposes only and are subject to change at the discretion of the vendor. We recommend you check with Parking Garage for updated prices and specials.\*

Location	Notes
Alliance Parking 301 East 69 <sup>th</sup> Street Between 1 <sup>st</sup> and 2 <sup>nd</sup> Avenue <a href="http://www.allianceny.com">www.allianceny.com</a> Phone: 212-988-7275	Weekday special \$22, any 12 hours after 9am  Online special \$17, any 10 hours
Alliance Parking 401 East 74 <sup>th</sup> Street Between York and 1 <sup>st</sup> Avenue <a href="http://www.allianceny.com">www.allianceny.com</a>	Weekday special \$14, enter after 9am, max to 5pm  Online special \$15, any 10 hours
Alliance Parking 404 East 76 <sup>th</sup> Street Between York and 1 <sup>st</sup> <a href="http://www.allianceny.com">www.allianceny.com</a>	All day special \$15, enter after 10am, max to 5pm  Online special \$12, any 10 hours
496 East 73 <sup>rd</sup> Street at York avenue	Early Bird (by 9am) special \$14.36
1385 York Avenue Between York and First Avenue	Enter before 10am, max to 7pm \$16.50 (includes tax)
Champion Parking 341 East 75 <sup>th</sup> Street	All day special \$14 Enter 4am to 3pm, max to 8pm

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Between 1 <sup>st</sup> and 2 <sup>nd</sup> Avenue <a href="http://www.championparking.com">www.championparking.com</a>	
Heights Management 63 LLC 405 East 63 <sup>rd</sup> Street Between York Avenue and First Avenue Phone: 212-486-8613	Early bird special \$14, enter before 10am, max to 8pm
Prime Parking 333 East 75 <sup>th</sup> Street Between 1 <sup>st</sup> and 2 <sup>nd</sup> Avenue Phone: 212-249-4794	Early bird special \$13, enter before 12 noon, max to 8pm
Memorial Sloan Kettering 495 East 66 <sup>th</sup> Street Between York Avenue and First Avenue Phone: 212-639-2338	3 hours - \$14 8 hours - \$19 After 12 hours - \$24

# **Glossary**

**Absolute Granulocyte/Neutrophil Count (ANC):** is a measure of the number of neutrophil granulocytes (also known as segmented neutrophils or segs) present in the blood. Neutrophils are a type of white blood cell that fights against infection.

$ANC = (\% \text{neutrophils} + \% \text{bands}) \times \text{WBC}$

**Afebrile:** Without fever.

**Allogeneic Stem Cell Transplant:** Stem cells are obtained from a genetically matched individual. This is usually a brother or sister, but may be an unrelated volunteer donor. The stem cells are usually collected from the blood, but may be collected from the bone marrow.

**Anemia:** A reduced number of red blood cells that can cause you to be pale, weak, tired and feel breathless.

**Apheresis:** The collection of immature hematopoietic cells from the blood.

**Apheresis Catheter:** An intravenous catheter that is placed in a large vein under the collarbone. This catheter is used to collection stem cells during the apheresis process.

**Autologous Stem Cell Transplant:** You serve as your own donor. The stem cells are usually collected from the blood, but may be collected from the bone marrow. The cells are collected while the patient is in remission

**Bone Marrow:** A liquid found within the soft sponge like cavities of large bones.

**Bone Marrow Transplantation:** The process of treating disease with high doses of chemotherapy, radiation therapy or both. This treatment destroys the bone marrow preventing the ability to produce blood cells. Bone Marrow or peripheral blood stem cells are given following treatment to restore the production of blood cells.

**Chemotherapy:** Medication used to destroy or slow the growth of abnormal cells, usually cancer cells.

**Central Venous Catheter:** A small flexible tube that is inserted into a large vein near the heart. This is used as a route for medications, nutritional supplements, administration of blood products, and to obtain blood samples.

**Cord Blood:** Umbilical cord blood is collected from the umbilical cord and placenta after a baby is born. This blood is rich in blood-forming cells. The donated cord blood is tested, frozen and stored at a cord blood bank for future use.

**Engraftment:** The process in which the normal growth and production of blood cells in the bone marrow resume after transplant.

**Febrile:** Having a fever.

**Graft Versus Host Disease (GVHD):** A process whereby the transplanted cells (graft) attack certain organs in the recipient (patient).

**Growth Factors:** Naturally occurring substances in the body that control the production and function of blood cells. These substances may be given after transplant to speed up engraftment.

**Haplo-identical-** Stem cells are obtained from an individual that is not fully matched genetically. This is usually a brother or sister, but may be a child or parent.

**Hemoglobin:** The part of a red blood cell that contains iron. Iron binds to oxygen and is transported throughout the body.

**Hickman Catheter:** This is an intravenous catheter that is placed in a large vein under the collarbone. This catheter is used to give fluids, medications and blood products.

**HLA Typing:** A series of tests done to determine how closely the stem cells of a donor match with the recipient (patient).

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

**Immunosuppression:** A decrease in the immune system's ability to fight infection, which can be caused by chemotherapy and radiation therapy.

**Mucositis:** Reddening and soreness of the tongue, lips, mouth, throat and gastrointestinal tract from chemotherapy or radiation therapy.

**Myeloablative:** Doses of chemotherapy and/or radiation completely eliminate one's bone marrow.

**Neutropenia:** Low neutrophil count. A person with neutropenia is at high risk for developing an infection.

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

**Non-Myeloablative:** Doses of chemotherapy and/or radiation only suppress and weaken one's immune system.

**Peripheral Blood Stem Cell:** Blood cells that are circulating in the blood stream and which have the ability to develop into white cells, red cells, and platelets.

**Peripheral Blood Stem Cell Transplant:** A type of transplant in which stem cells that circulate in the bloodstream are collected and later given back to a patient after high doses of chemotherapy or radiation are given.

**Platelets:** Tiny disc-shaped blood cells that help prevent bleeding and help the blood to clot.

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

**Protocol:** The outline or specific plan for a treatment usually an experimental procedure or treatment.

**Radiation Therapy:** A type of treatment for cancer that uses radiant energy waves to damage or kill cancer cells.

**Red Blood Cell:** A type of blood cell, an erythrocyte, which carries oxygen in the body.

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

**Syngeneic Transplant:** Patients receive stem cells from their identical twin.

**Thrombocytopenia:** A decreased number of platelets in the blood.

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

**Veno-Occlusive Disease:** A disease caused by obstruction of blood flow through the small blood vessels in the liver, resulting in damage to the liver.

**White Blood Cells:** A type of blood cell, the leukocyte, that helps fight infection.



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