BLOOD & MARROW TRANSPLANT PROGRAM

ALLOGENEIC TRANSPLANT
PATIENT EDUCATION MANUAL
INTRODUCTION

Welcome to UC San Diego/Sharp BMT Program. Our goal is to provide you with an education manual that will be a resource and tool to help you and your family throughout the transplant experience. The content of this manual is designed to provide material on the transplant process, general information about medical procedures, supportive care and possible problems that might occur.

The Moores Cancer Center is a NCI-designated Cancer Center with a unique opportunity to provide specialized ‘bench-to-bedside’ personal care. A NCI or National Cancer Institute designation confirms that the Moores UCSD Cancer Center has established itself as a leader in cancer research and treatment. We are the only NCI-designated Cancer Center in San Diego. We are also one of 23 institutions that make up the National Comprehensive Cancer Network (NCCN) that represent the nation’s top cancer centers – coast to coast.

In addition, the Blood and Marrow Transplant Program is a joint venture between UC San Diego Health and Sharp HealthCare. These two healthcare organizations have joined together to provide you with the latest in technology in bone marrow, stem cell and cord blood transplant services. The UCSD/Sharp Blood and Marrow Transplant Program is truly unique in San Diego County and committed to providing you with the best care and service for you and your caregivers.

We suggest that you share this manual with the caregivers who are supporting you throughout your transplant. Taking time to discuss the protocols and sharing your understanding with each other helps to fully understand the treatments, their purpose and your expectations.

It is important to understand that if your health condition changes at any time, your eligibility for transplant may be affected. Not all patients who are referred to our program are accepted as candidates for transplant. Our program does have a process in place to review such cases on an individual basis.

Thanks again for putting your trust in our team.

Edward D. Ball, MD
Program Director
THE HEALTH CARE TEAM

The health care team caring for you during your transplant consists of a group of experienced care providers with various skills and abilities whose focus is on your care. The members of the team are described below.

INPATIENT
Physicians/Doctors
The **bone marrow/stem cell transplant/cord blood (BMT)** doctors providing care consists of attending physicians, fellows, and consultants.

Although your primary attending physician is in charge of your care, we have other attendings that may alternate during your inpatient stay. Due to this rotation, you may be under the direct care of one of the team’s attending doctors. However, your primary doctor will be in contact with the team and will visit you while you are in the hospital.

The fellow is a doctor who has completed specialized medical training and is focused on caring for patients with cancer (hematology/oncology patients). These doctors will see you in the hospital everyday and make decisions regarding your care with the assistance of the attending and your primary transplant doctor to provide you with consistent quality care.

Our bone marrow/stem cell transplant doctors often work together with other doctors within UC San Diego Health. You may meet the consulting doctors sometime during your treatment if needed. Often, these specialists are requested by the transplant doctors to make a consult and offer suggestions for your treatment. Some of these specialists include skin, heart, kidney, lung, liver and mental health doctors. Our doctors also network and consult with other national and world-wide medical centers and doctors.

Advanced Practitioners - Nurse Practitioner (NP) and/or Physician Assistant (PA)
The Advanced Practitioners on our team are specialized in bone marrow, stem cell, and cord blood transplantation. They follow your daily care and are trained to perform tests such as **skin biopsies**, **lumbar punctures** and **bone marrow biopsies**. They also work closely with the doctors and other members of the team to manage your care in both the inpatient and outpatient settings.

Inpatient Nurse
During your stay in the hospital, you will be cared for by specially trained BMT registered nurses who are also certified to administer chemotherapy. These nurses are responsible for meeting your daily needs which may include giving medications and teaching you on any of the necessary subjects for your treatment and discharge.
They work with the doctors and other members of the team to make sure you are receiving quality care, offer emotional support as needed, discuss treatment plans, and offer help with personal hygiene or meals and suggest a daily routine to best meet your needs.

**Clinical Care Partner**
The CCP is a trained nursing assistant who works closely with the nurse to make sure that all your basic needs are met each day. The CCP will help you with personal hygiene, changing your bed, assisting you with meals, and taking your vital signs. The CCP also plays an important role in providing you with personal quality care.

**Clinical Social Worker**
Your assigned social worker will help you before your transplant, during your hospitalization as well as after discharge. For further information, please refer to the section on Social Work Services.

**Dietitians**
A dietitian who specializes in transplant patients will closely monitor the amount of food you are eating. If you are having trouble eating or have special needs, the dietitian can provide helpful hints to improve your appetite. The dietitian is available to you throughout your hospital stay during daytime hours. Refer to Section 6 for further information on nutrition.

**Hospital Unit Services Coordinator (HUSC)**
You will meet the HUSC on your day of admission into the hospital. The HUSC is responsible for answering call lights, phones, and communicating your needs to the other staff members. He/she also assists in scheduling tests that you may receive while in the hospital and doctors’ visits you will have after discharge.

**Pharmacist**
Throughout your transplant, a pharmacist who is familiar with your treatment will manage the medications that you will be taking. The pharmacist works closely with your doctors and will monitor the use of medications during your transplant.

**Physical Therapist**
We feel that maintaining your strength helps you recover from your transplant and is an important part in the total healing process. Because, your white blood cells, red blood cells, and platelets will be low during your stay in the hospital, certain activities are limited. The physical therapist will help you in creating a daily exercise program that is safe for you. The physical therapist will monitor your strength to make sure you are staying as fit as possible and able to do things for yourself. The therapists are available during the day from Monday through Friday.
OUTPATIENT

Apheresis Team
The apheresis team includes a Medical Director, doctors, a Nurse Manager and specially trained registered nurses that collect your donor’s stem cells. They are available if you or your donor has questions regarding the apheresis schedule or procedure. Your cells may be collected at the Medical Center in Hillcrest or the Moores Cancer Center.

Advanced Practitioners – See description under Inpatient Team

BMT Coordinator
This is a specially trained transplant registered nurse whose role is to coordinate your care and tests after your attending doctor has evaluated you to be a transplant candidate. The coordinator is responsible for educating you and your caregivers regarding what is involved in transplantation, will stay in close contact with you throughout the entire transplantation process and is your link to the rest of the transplant team.

Case Manager (Clinic Nurse)
The case manager is a registered nurse who coordinates non-transplant related care including clinic visits, inpatient or outpatient chemotherapy, laboratory work and other tests or procedures. The case manager may also assist the team in providing post-transplant care.

Clinical Trials
The BMT Clinical Trials group includes a manager, Clinical Research Associates (CRAs), and an administrative assistant. Research studies involving people are called “Clinical Trials” and are one of the most important ways of finding out new information leading to better treatment and management of cancer. If you decide to participate in a clinical trial the CRAs will work very closely with you, the doctors and nurses to make sure that clinical trial treatment plan is followed.

Data Management
The BMT Data Management staff includes a data analyst supervisor and three data managers. Medical information is collected and sent to the Center for International Blood and Marrow Transplant Research (CIBMTR) and the National Marrow Donor Program (NMDP). The data is used to study important questions and concerns in transplant and cancer care treatment.

Dietician
A clinical dietitian who specializes in Oncology Nutrition is available at Moores Cancer Center after discharge. The clinical dietitian is available to provide nutrition counseling to help you achieve improved treatment tolerance, reduce weight loss, encourage overall improvement in quality of life.
Financial Manager
The UCSD/Sharp Blood & Marrow Transplant Program has a manager and staff whose purpose is to serve as a liaison and resource for the financial needs of our patients. We accept Medicare, Medi-Cal, Health Maintenance Organization (HMO’s), and Preferred Provider Organizations (PPO’s) and have contracts with most major insurance companies. The financial team verifies transplant benefit coverage and coordination of benefits on every new patient and obtains authorizations for all transplant related services. The team is available if you have concerns regarding your insurance coverage. Also, we encourage our patients to immediately notify the staff of any known changes to plan coverage or benefits.

Infusion Center Nurse
Before and/or after your transplant, you will need to come to the Infusion Center at the Moores Cancer Center as an outpatient for laboratory (lab) draws, intravenous (IV) fluids, blood products and medications. The specially trained registered nurses will carry out these tests for you and work closely with your doctor, coordinator, case manager and advanced practitioner to maintain quality care.

Stem Cell Processing Laboratory (SCPL)
The SCPL team includes a Medical Director, a supervisor and specially trained technicians that process and store the cells that are collected during apheresis or bone marrow harvest.
Directions to Jacobs Medical Center and Moores Cancer Center
at UC San Diego Health - La Jolla:

<table>
<thead>
<tr>
<th>Jacobs Medical Center</th>
<th>Moores Cancer Center</th>
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<tbody>
<tr>
<td>9300 Campus Point Drive</td>
<td>3855 Health Sciences Drive</td>
</tr>
<tr>
<td>La Jolla, CA 92037</td>
<td>La Jolla, CA 92037</td>
</tr>
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From I-5: Exit on Genesee Avenue and go east. Turn right on Campus Point Drive. When you reach the intersection with Medical Center Drive, Shiley Eye Institute will be located to the left; Perlman Medical Offices, Jacobs Medical Center (including Thornton Pavilion) and Sulpizio Cardiovascular Center will be to the right. To get to Moores Cancer Center, turn left on Medical Center Drive and follow it around Shiley Eye Institute to Health Sciences Drive.

From I-805: Exit on La Jolla Village Drive/Miramar Road, and go west. Turn right on Genesee Avenue, then turn left on Campus Point Drive. When you reach the intersection with Medical Center Drive, Shiley Eye Institute will be located to the left; Perlman Medical Offices, Jacobs Medical Center (including Thornton Pavilion) and Sulpizio Cardiovascular Center will be to the right. To get to Moores Cancer Center, turn left on Medical Center Drive and follow it around Shiley Eye Institute to Health Sciences Drive.
Parking at UC San Diego Health - La Jolla:

Closest Parking Options by Location
- Jacobs Medical Center (including Thornton Pavilion), Perlman Medical Offices, and Sulpizio Cardiovascular Center: Lot P751, Campus Point structure and Athena structure
- Moores Cancer Center: Athena structure, Lot P760
- Shiley Eye Institute: Lot P760, Lot P751 and Athena structure

Parking Costs for Lots and Structures
- $4 for first two hours and $1 for each additional hour ($8 daily maximum)
- With a handicapped placard, parking is free in any patient or visitor spot
- Park and then pay at pay stations in structure or lot before entering clinic or hospital
  - You do NOT need to display the ticket on your dashboard; in fact, you will need your ticket on hand if you need to add additional hours.
  - If you need to add hours to your ticket after you’ve parked, additional machines are available at Moores Cancer Center (first-floor lobby) and near at the entrance to Shiley Eye Institute. You will need to use the "add time" code that is on your receipt.
  - 24-hour tickets have return parking privileges in any visitor parking space, but you must display your ticket on your dashboard.

Valet
Valet parking is available between 8:30 a.m. and 4:30 p.m. weekdays at the circular driveways in front of Thornton Pavilion (Jacobs Medical Center) and Moores Cancer Center. Valet costs vary by location, but the total service and parking costs have a $10 daily maximum. With a handicapped placard, valet is free at Moores Cancer Center and a $5 flat fee at Thornton Pavilion / Jacobs Medical Center. Valet service is not available on nights or weekends.

Transportation: Public Transportation and Free Shuttles

For information on public transportation serving our Hillcrest and La Jolla hospital locations, please visit our website: www.transportation.ucsd.edu and click on commuting/alternative transportation.

UC San Diego Health — Free Shuttle Services

Hillcrest Campus to La Jolla Campus
Operates year-round, 6 a.m. to 9:55 p.m. weekdays, (excluding university holidays), between UC San Diego Medical Center in Hillcrest and Jacobs Medical Center in La Jolla.

East Campus Connector: La Jolla Campus to Executive Drive (Chancellor Park)
Operates year-round, 7 a.m. to 7:30 p.m. weekdays, (excluding university holidays), between UC San Diego Health – La Jolla campus, east campus parking areas, and UC San Diego Health – La Jolla: Executive Drive.
Please visit www.transportation.ucsd.edu and click on campus shuttles for schedules and stops.
Directions to UCSD Medical Center – Hillcrest and Medical Offices South:
UC San Diego Health – Hillcrest  Medical Offices South
200 W. Arbor Drive  4168 Front Street
San Diego, CA 92103  San Diego, CA 92103

From I-5: Exit on Washington Street and turn left (east). Turn left on First Avenue, and continue straight past E. Lewis Street. For the Montecito Parking Lot, select the left lane and turn left into the driveway past Montecito Way. For the Arbor Parking Structure, select the right lane and follow the curve left onto W. Arbor Drive. Drive past the Medical Center, directly into the parking garage at the end of W. Arbor Drive.

From SR-163: If you are coming southbound, exit on Washington Street West. If you are coming northbound, exit on Washington Street (which will take you eastward), and then make a U-turn so that you are headed west. Turn right on First Avenue, and continue straight past E. Lewis Street. For the Montecito Parking Lot, select the left lane and turn left into the driveway past Montecito Way. For the Arbor Parking Structure, select the right lane and follow the curve left onto W. Arbor Drive. Go past the Medical Center, directly into the parking garage at the end of W. Arbor Drive.
Bone Marrow and Stem Cells

Bone marrow is the soft, spongy tissue found inside the bone. Its goal is to form **blood cells**. All blood cells develop from immature cells called stem cells.

Stem cells develop into one of three following types of mature blood cells which enter into the blood stream:

- Red Blood Cells (RBCs)
- White Blood Cells (WBCs)
- Platelets

Some stem cells are also present in the blood stream; they are called **peripheral blood stem cells** (PBSCs).
The term **Bone Marrow Transplant** refers to those transplants in which stem cells are removed from the bone marrow. When taken from the bone, it looks just like blood. If the stem cells are collected from the blood (peripheral blood), the correct term is **Peripheral Blood Stem Cell Transplant or Peripheral Blood Progenitor Cell Transplant**. However, you may hear this shortened to stem cell transplant. You may also hear the term bone marrow transplant used for both types of transplants. Do not be confused by these differences.

**Clarification of terms:**
bone marrow transplant = peripheral blood cell transplant = hematopoietic cell transplant = stem cell transplant = blood cell transplant

The main source for most types of transplants due to improvements in collection and storage methods are PBSCs.

**Blood Cell Functions**

- **Stem Cells, also called Progenitor Cells**, as mentioned above, are located in the bone marrow and make most of our body’s blood cells. They divide to become new stem cells, RBCs, WBCs or platelets.

- **WBCs White Blood Cells** (also called leukocytes) are very important to our **immune system**. They help the body fight **infections**, viruses and other threats. There are many different parts of a WBC. Each one plays a specific role in destroying these “foreign” bodies. **Granulocytes** (also called neutrophils) are part of the WBCs that helps fight bacterial infections. **Lymphocytes** are another part of the WBCs that help in the immune response.

  For example, when you catch the flu, there is an increase in the WBCs to help fight the infection.

- **RBCs Red Blood Cells** (also called erythrocytes) are cells that contain a protein called **hemoglobin**. Hemoglobin carries oxygen from the lungs to the rest of the cells in your body. A low RBC count is a condition called **anemia**. Someone who is anemic may feel weak, dizzy, short of breath and tired.

- **Platelets** (also called **thrombocytes**) are cells that help prevent bleeding. When you cut yourself, it is the platelets that help form blood clots to stop the bleeding at the site of the injury. A low platelet count (thrombocytopenia) increases the risk of bleeding of the gums, nose and other tissues. Unexplained bruising and **petechiae** (tiny red spots) can also be caused by a decrease in platelets. Refer to Complications in section 5 for further detail.
**Reasons for a Blood Marrow, Stem Cell or Cord Blood Transplant**

The basic idea behind the transplant is to allow high doses of chemotherapy and/or radiation therapy to kill rapidly dividing cells in the body like cancer cells. However, though these treatments are among the most effective weapons against many forms of cancer, they cannot target only diseased cells. As a result, non-diseased cells that divide rapidly such as stem cells are also destroyed in the process.

Therefore “rescue” with transplanted bone marrow, stem cells or cord blood from a healthy donor enables the patient to produce new blood cells to replace those destroyed during treatment. It is a type of “transfusion” that replaces diseased or damaged bone marrow with new functioning stem cells. This is called an allogeneic transplant.

In addition in allogeneic transplant, the new immune system may help prevent relapse through a mechanism called “graft versus malignancy” effect.

There are two ways in which stem cells can be acquired from your donor; either by collection from the donor’s bloodstream or by collection directly from the donor’s bone marrow as described below. Your transplant physician will discuss with you which collection method is recommended for you and your donor.

**Donor Stem Cell Collection**

Before the time of transplant, medications will be given to your donor called growth factors to make the bone marrow produce more stem cells than it normally does. This is called mobilization. These cells are released into the blood stream, collected through a process called “apheresis” (refer to section 3 for details) then sent to the Stem Cell Processing Laboratory where they are either processed and prepared for infusion into you (called a fresh infusion) or frozen (cryopreserved) and stored until your scheduled transplant date.

**Bone Marrow Harvest**

Bone marrow harvest is a procedure that is done in the operating room. After your donor is given medication to make he/she sleep (general anesthesia). Special needles with syringes are then inserted into the back of the hip bones and marrow is collected. The cells are also sent to the processing laboratory and either frozen and stored or processed to be infused into you that day. See section 3 for further details.

**Engraftment**

After your transplant preparative regimen (chemotherapy or chemotherapy and radiation), the bone marrow or stem cells are infused and migrate back to their natural home (bone marrow). This is known as “engraftment” which means recovery of WBCs, RBCs, and platelets. Refer to section 5 for further details.
TYPES OF TRANSPLANTS

Autologous Transplantation
“Autologous” means from the self. In this type of transplant, the patient serves as their own donor.

Syngeneic Transplant
The donor is an identical twin.

Allogeneic Transplantation
Allogeneic means the donor is a person other than the patient, such as a family member, unrelated donor, or cord blood unit(s).
- Related donor transplant—using a family member such as a sibling, parent or child.
- Unrelated donor transplant — using someone other than a family member, either a donor from an international registry or a cord blood unit.

Donor selection is based on shared genetic tissue typing with the patient known as Human Leukocyte Antigen or HLA typing. HLA markers serve as a kind of genetic finger print which enables the body’s immune system to recognize its own cells. The genes occur in pairs, with one part of each pair being from each parent (mother and father). Therefore, the search for a matched donor begins with your immediate family. HLA typing is done using blood samples from you and your possible donor(s).

A full sibling (one who has the same mother and father as you) has a 25% chance of being HLA-identical to you and a 50% chance of being haplo-identical (half match) to you. It is rare to have a fully matched half-sibling, parent or child. If you do not have an HLA-identical sibling donor, an unrelated donor, haplo-identical related donor, or cord blood unit(s) can be considered. See descriptions below.

Once your donor is determined, he or she is asked to donate, and bone marrow or stem cells are collected. See “Related Donor Eligibility and Bone Marrow or Stem Cell Collection” in section 3 for further details. It is important to mention that the donor’s supply of cells will be replenished as bone marrow constantly makes new blood cells from stem cells. After your preparative regimen, the donor’s cells are given to your through your central venous catheter (refer to section 3) in a procedure similar to a blood transfusion.

You will also be placed on drugs that suppress your immune system called immunosuppressants which help to prevent your body’s rejection of the donor’s cells which can create a problem called Graft versus Host Disease (GVHD). This potentially common complication will be further discussed in section 5.
**Haploidentical Transplant**
A haploidentical (haplo) transplant is a treatment option for patients who do not have an HLA-identical sibling donor. This type of transplant is considered when the donor is half matched to the recipient and can be a sibling, parent or child.

**Matched Unrelated Transplants (MUDs)**
This is a type of allogeneic transplant that is done when a related donor cannot be found.

In this case, a HLA-matched donor is found using the National Marrow Donor Program (NMDP) data base. There are many donor centers in the United States, Europe and Asia who tissue type those who wish to become donors. These potential anonymous donors are typed, just as your relatives might be. The results are then placed in a data base with those of thousands of other possible donors.

Successful unrelated transplants occur frequently today as many people share similar genetic backgrounds. There are also an increased number of donors enrolled in the NMDP which increases the chance to find an unrelated donor with a similar genetic type.

**Cord Blood Transplants**
This refers to the blood stem cells from umbilical cords. Like bone marrow, umbilical cord blood is rich in stem cells. It is collected from the placenta and cord after a baby is born. A cord blood transplant is another form of allogeneic transplant and is sought if an unrelated donor cannot be found. There are several cord blood registries that may have matched units already frozen and stored.

**Nonmyeloablative, Reduced Intensity or Mini Transplants**
Although the number of transplant related deaths has drastically decreased since the first successful marrow transplant in 1968, complications from an allogeneic transplant still exist. Because of the possibility of side-effects such as Graft Vs. Host Disease, also called GVHD, infection, and organ damage from the high-dose chemotherapy and/or radiation patients receive, researchers are constantly looking for ways to make allogeneic transplant less toxic. Because of the significant side effects, allogeneic transplants have been traditionally used to treat younger patients, and those without pre-existing conditions whose bodies are able to withstand the rigorous treatment.

However, several transplant facilities, including UCSD Medical Center, are now treating patients with alternatives to the traditional allogeneic transplant. These are being called a number of names such as nonmyeloablative transplants, reduced intensity or mini-transplants. The preparative regimen of these transplants use lower, less toxic doses of chemotherapy and sometimes do not include radiation.

As previously mentioned, in an allogeneic transplant, it is the donor’s cells (the graft) that attack diseased cells that the patient (the host) has produced. This is called graft vs. disease
effect and is believed to be responsible for long-term survival. It is for this reason; physicians believe some patients can achieve long-term survival of their disease without the toxicity of the traditional transplant. Although many patients have achieved a remission following this type of transplant, follow-up has been short. It remains to be seen whether these patients will remain in long-term remission. This type of transplant is not appropriate for everyone. You can discuss this option with your physician. This alternative transplant, which relies on lower doses of chemotherapy and the power of the donor’s immune cells to eliminate the disease, may become a promising treatment option for older patients and for those with pre-existing conditions who would not tolerate a traditional transplant.
PREPARING FOR THE TRANSPLANT

Your Initial Visit (Consultation)
Your oncology doctor has referred you to one of our doctors to determine if you would benefit from an allogeneic stem cell / bone marrow transplant. During your first visit, your transplant doctor will obtain details of your present medical condition(s) and medical history. Reports of your scans, biopsies, and laboratory work; past and present treatments will also be reviewed at this time.

You will then meet with your transplant coordinator, an experienced bone marrow transplant nurse who will provide additional teaching regarding the transplant process and will continue to work with you through your transplant process and follow-up care. Your coordinator is your “link” to the transplant team.

If you are feeling anxious or distracted, it is common to forget things. It is a good idea to bring someone with you to all of your meetings at the transplant center as a lot of information will be discussed. Also, bring a note pad to write down questions that may come up before or after your meetings.

After your initial visit, your transplant physician will present your case to the other transplant attending physicians for their input. Your transplant coordinator and transplant physician will also continue to track your status with your referring physician until you are ready to proceed to transplant.

Identification of a Caregiver
While you are preparing for transplant, you will be asked to identify someone as your primary caregiver. This person will play an important role in your post-transplant care and recovery. Often times this person is a spouse, family member or close friend. Sometimes one person cannot be available for the extended period of time required, so other caregivers may also step in to be your primary caregiver. Your transplant coordinator and social worker will help you navigate this requirement so that you can formulate a plan. Your primary caregiver(s) will need to meet with the transplant team as part of your transplant evaluation and will need to attend an Allogeneic Transplant Patient and Caregiver Class prior to your transplant.

Upon discharge from your transplant hospitalization, your caregiver will need to be with you at all times for a set period of time. For an allogeneic transplant this can be 3-4 months or sometimes longer depending on your recovery. Having someone with you at all times is important in case a sudden complication arises or a change in your condition occurs.
Your caregiver will help you with your daily needs at home including:
- Preparing meals and encouraging you to eat and drink
- Keeping your environment clean
- Assisting with your medications
- Transporting you to your medical appointments, sometimes on short notice
- Reporting your symptoms and condition to your medical team

**Housing**

Most patients who are having transplants live in San Diego County; however, some patients do not. The transplant doctors have carefully analyzed the travel distances and time to Moores Cancer Center and Jacobs Medical Center to make sure that patients have access to specialized medical care. Therefore, patients who live in San Diego County are allowed to remain in their own homes. If a patient lives outside of San Diego County, the patient and their caregiver will need to make different arrangements. You may have a family member or friend who lives in San Diego County and would be willing to allow you to live with them during the transplant process or other arrangements such as a hotel, an apartment, the UC San Diego Bannister Family House or Mesa Housing on campus (if available). Resources are available on the following website: [www.joeshouse.org](http://www.joeshouse.org)

**Pre-transplant Evaluation**

Once authorization for your transplant evaluation has been obtained through your insurance carrier, and before the actual transplant process begins, you will need to have several tests taken. These tests will help to decide if you are eligible for transplant and are used to obtain insurance authorization for transplant. The results will also be used as a baseline to measure your progress through your hospitalization. Any tests that are not normal may need further discussion and investigation.

The tests, along with a reassessment of your disease, are usually done after you have completed a set amount of treatment as determined by your referring physician and transplant physician. You will need to identify someone to help you as you may need someone to drive you to some of the appointments such as your catheter placement appointment. Your coordinator will assist in scheduling and explaining the tests with you including:

- **Blood tests** which assess how your organs are functioning and for certain infectious diseases
- **Urine tests** that measure kidney function
- Test for the **heart** may include:
  1) Electrocardiogram (EKG) which measures the heart’s rhythm and function.
  2) Echocardiogram is an ultrasound of the heart. It measures the heart’s muscle strength and is used to look at parts such as valves and chambers.
- Tests for the **lungs** (pulmonary) include:
  1) Chest x-ray
  2) Pulmonary function test (PFT) which involves inhaling and exhaling into a machine to measure lung function.
• A **skeletal survey** is a series of x-rays of the long bones in the body (arms, legs, spine and skull) to see if lesions are present. *This test is only done on patients with multiple myeloma.*

• A **bone marrow biopsy** is an outpatient procedure to obtain samples for testing the bone marrow function. After medication is given to numb the site, a needle is inserted into the back of the hipbone and a small amount of bone marrow is removed.

• A **Computerized Tomography (CT Scan)** is a special x-ray technique that produces images of cross-sections (slices) through your body. This enables your doctor to view the inside of your body at different angles.

• **Magnetic Resonance Imaging (MRI)** uses a magnetic field and radio-waves to take multiple cross-section images of your body. These slices are then put together into a three dimensional image. This shows the contrast between different types of body tissue in great detail.

• **Positron Emission Tomography (PET scan)** is a procedure in which a small amount of radio-active sugar is injected into your veins. A scanner then is used to make detailed pictures of the areas inside the body where the sugar is used. Because cancer cells often use more sugar than normal cells, these pictures can be used to find active cancer cells in the body.

• Decayed teeth and gum disease can cause serious infections in transplant patients. If possible, it is important to have a complete **dental exam** before your transplant. All dental work should be completed at least 14 days before the beginning of your preparative regimen.

• You will also meet with your clinical social worker, along with your caregiver(s), to discuss non-medical aspects of the transplant.

• **Attend the Allogeneic Patient & Caregiver class that is offered once a month**

**Alternative and Complementary Therapies**

With growing public interest in alternative and complementary therapies comes an increased need for accurate information to be made available for patients and families to help in making informed choices for safe, effective treatment options. If you have questions on the different therapies, please discuss with your physician.

**The Consent Process**

Once all of your exams have been completed and reviewed by your transplant doctor, you will meet with your coordinator who will provide you with a **treatment calendar**. This is a useful tool to use to remember the appointments that have been scheduled for you. The coordinator will also discuss the transplant process in detail.

It is a good idea to review any written materials you received at your initial visit and to ask a family member and or friend to come with you to this visit. Explanations of various tests will be provided before you are asked to sign a consent form. You will also have an appointment with your transplant doctor to discuss the consents and answer any questions you might have.
Central Venous Catheters
All patients receiving a bone marrow, stem cell, or cord blood transplant will need a central venous catheter placed prior to transplant. The type of catheter placed depends upon the type of transplant you will receive. Below are two of the most common types of catheters that are used to give IV medications, IV fluids, blood and platelet transfusions, chemotherapy, and the bone marrow, stem cells or cord blood transplant. The catheter is also used to take blood samples. It will remain in place throughout the entire transplantation process.

If you are having a Hickman Catheter placed, it will be performed by our Interventional Radiology (IR) Team at Jacobs Medical Center. After the doctor discusses the procedure you will be asked to sign a consent. You will then be given medication to put you to sleep (sedation). After the catheter is inserted, you will have a chest x-ray in the recovery area to make sure the catheter has been placed properly. Due to the sedation, you will need a driver to take you home. You will not be allowed to take a bus or taxi.
PICC lines are also placed in the outpatient setting in IR. If you are a patient in the hospital, a specially trained nurse may insert the catheter at the bedside, or you may have it placed by IR. PICC placement does not require sedation. A chest x-ray will also be needed verify proper placement.

**Hickman Catheter Care**
The nursing team in Interventional Radiology will instruct you not to bathe or shower for four days after your catheter is placed as the site must be kept clean and dry. However, you may take sponge baths during this time. After the four days, you may resume your bathing or showering schedule. To prevent moisture from collecting under the dressing, you will be taught how cover the entire catheter site with a plastic bag and tape.

You will need to have the dressing on your catheter changed within one or two days initially and then weekly. Dressing changes will be done in the Infusion Center by the nursing staff. Your coordinator will schedule the appointments for you. If your dressing becomes wet or soiled, please notify the Infusion Center or your coordinator.

**PICC Line Catheter Care**
The dressing applied after your PICC line is placed will have gauze under the clear dressing. This will be changed within 24 hours after insertion either by your nurse in the inpatient setting or by an infusion center nurse in the outpatient setting. After that, the dressing is normally changed weekly by the inpatient or outpatient nursing staff.

**Exit site care**
Your catheter will have two or three separate tubes (lumens) that extend from the exit site. The tubes will have a clamp on them that should remain closed when not in use. The tubes are flushed with a medication to prevent clots. The type of medication and the frequency they are flushed is determined by the type of catheter.

**Monitoring the site**
You will be asked to inspect your catheter site every day and to monitor your temperature twice a day for signs of infection. *If you experience any of the following symptoms, please contact a member of the health care team immediately.*

**Signs of infection include:**
- pain
- redness
- tenderness
- pus around the site
- fever (100.5 or higher)

It is also important to report shortness of breath and/or swelling in your arms, hands or chest or any changes in the color of your skin on your arm.
Related Donor Eligibility and Bone Marrow or Stem Cell Collection

Eligibility
Once your donor has been selected, he or she will be asked to come here to meet with one of our transplant physicians to have a physical exam, complete a health history form, take screening tests such as blood and urine tests, a chest x-ray and an EKG to make sure the donation process is safe for the donor and for yourself. Based on the results, the transplant doctor will determine if your donor is eligible.

If the donor is found ineligible but accepted, the doctor will discuss the abnormal findings with the donor and he or she will be asked to sign a form stating that they are aware of the abnormalities and consent to the results be released to you. Your transplant doctor will then discuss the findings with you and you will be asked to sign a form that states you are aware of the abnormal findings. The doctor will also sign the form stating that the donor is an acceptable candidate and that it is safe for you to receive the cells.

Related Donor Stem Cell or Bone Marrow Collection
One method to collect stem cells from a donor is called apheresis. Apheresis is derived from a Greek word meaning to take away. Your donor will receive daily growth factor injections for several days to stimulate stem cell production. This is called mobilization. While receiving growth factors, your donor will begin apheresis. The process takes between 1-3 days for approximately 4-6 hours each morning and is usually performed on an outpatient basis. Rarely, some cases are done in the hospital. It is recommended that someone drive your donor to these scheduled appointments.

The procedure will be explained by a doctor and the donor will be asked to sign a consent. The apheresis RN will place an intravenous catheter into both arms and each catheter will be connected to the apheresis machine. The machine is a blood separator and a small amount of blood (no more than a cup) is removed through one iv catheter. It goes through the cell separator called a centrifuge which separates platelets, RBCs and WBCs. The stem cells are located in the bag containing the WBCs. The remainder of the blood is returned through the catheter in the other arm.

Keep in mind, this is a painless procedure and the donor may relax in the chair or bed while watching television, movies, or may wish to read. A specially trained nurse will be there throughout the procedure.

During the time the donor is undergoing apheresis, daily lab tests are done to count the number of stem cells collected. Each patient has a targeted number of cells to be collected for transplant. The apheresis staff will be in contact with your donor daily and will notify them when the goal has been met.
After the stem cells are collected, they are transported to the Stem Cell Processing Laboratory. The cells are processed under germ-free (sterile) conditions. During the process, the amount is reduced by removing the liquid that does not contain cells. Cells are either prepared for infusion right away (called fresh infusion), or a small amount of preservative is added and the stem cells are frozen (cryopreserved) and stored.

Another method used to collect stem cells from a donor is called a bone marrow harvest. If your donor will undergo a harvest, the evaluation and eligibility process is the same as above. A bone marrow harvest is a surgical procedure performed in the operating room under anesthesia, usually general. The transplant physician along with another practitioner, such as a transplant physician or one of our advanced practitioners, performs the procedure. One or two cuts are made into the skin at the back of each hip bone. Special needles with syringes are then inserted into the bone and marrow is collected. This procedure generally takes about 1 ½ hours. The cells are sent to the processing laboratory and either frozen and stored or processed to be infused into you that day. Following a bone marrow harvest, your donor will be scheduled the next day for a visit to have the dressing removed and the small incisions cleaned and band-aids applied and will have special instructions for keeping the surgical site clean and dry.

Regardless of the method of donation, your donor will have a small recovery period. The recovery time varies depending on the person and type of donation. Most donors are able to return to their normal activities within a day or two for apheresis or within a few days to a week for a harvest.

**Matched Unrelated Donors (MUD)**

With unrelated donors, eligibility screening as was described above in the related donor section is conducted by a donor center. Once a donor has been cleared to donate, bone marrow or stem cells are collected at the donor center and sent by a courier to our Stem Cell Processing Laboratory for processing. The cells may come at any time of the day or night depending on where the donor is collected. Once processed, the cells are not frozen. They are brought directly to the inpatient floor for infusion.

The only information about the donor that can be released to the patient is age, gender, blood type and if the donor has a virus that can be detected in the blood called Cytomegalovirus (CMV). The patient may communicate with the donor anonymously through the transplant coordinator; but, any identifying information about the donor or patient such as names, addresses, location information or family details must be excluded. One year after the transplant, the patient and donor may agree to release personal information to one another. Note some countries where a donor may reside require a two year waiting period.

Cord Blood Units arrive from the Cord Registry Center frozen. Once thawed and processed by our laboratory, the cells are brought to the inpatient unit for immediate infusion.
PREPARATIVE REGIMEN

The preparative (conditioning) regimen is the high dose chemotherapy and/or total body irradiation (TBI) that patients receive prior to their transplant. The primary goal of this treatment is to destroy any cancerous cells throughout the body more effectively than may be possible through other types of treatment. The regimen may take place over 3-7 days.

Your doctor and coordinator will discuss which regimen is best for you. You will receive a copy of the administration schedule along with chemotherapy educational handouts. The material can be placed in this section to refer to as needed. The inpatient team will also review the regimen with you after you are admitted to the hospital for your transplant.

Preparative regimens are usually given in the hospital when you are admitted for your transplant. However, some are given in the outpatient setting. Your transplant physician and transplant coordinator will discuss with you where your preparative regimen will be given and requirements for transportation to and from the Infusion Center at Moores Cancer Center.

TOTAL BODY IRRADIATION

Total body irradiation (TBI) is part of a complex treatment program for aplastic anemia, leukemias, and lymphomas and certain other cancers that include chemotherapy and bone marrow transplantation, stem cell, or cord blood transplantation. TBI helps to destroy cancer cells within the body and to create space within the bone marrow for the grafted marrow. For bone marrow transplants to a person (the "recipient") from another person (a "donor"), TBI also helps to produce immunosuppression that is necessary to keep the recipient’s immune system from rejecting the transplant.

In preparation for TBI, you will have a consultation in Radiation Oncology department with a radiation oncologist and a nurse case manager. You will have a planning CT scan at which time radiation therapists will talk with you about the position you will be in for your treatment. This scan will be used to plan your radiation treatment. This part of your planning is called simulation.

When the actual treatments begin, TBI is usually given in two treatments per day about six hours apart during each of three consecutive days for a total of six treatments. You will be asked to remove all clothing and change into a hospital gown. You will be escorted to the treatment room and you will lie on a stretcher in the same position as your planning scan. The stretcher will be placed up against the wall, and a part of the radiation machine will be tilted and aimed across the room.

In the treatment room, the therapists will turn down the lights, shine a light from the radiation machine onto you, and use shadows and laser lights to align your body. They will
also take physical measurements with a tape measure, to ensure precise placement, protective blocking of your lungs, and even distribution of radiation to your body. This entire set up procedure takes approximately 15 minutes each treatment.

The therapists will have you lie flat on the stretcher. A lead block will be tucked under your left arm to shield your lung from radiation. Many IV bags of saline will be placed between your legs to fill the gap between your legs and create a more solid, consistent field.

Each treatment will require a visit of about 30 to 60 minutes in the Radiation Oncology Department. The six treatments complete the TBI process. Side effects are not generally expected from TBI radiation as the treatments occur over such a short period of time. However, you may experience some nausea and fatigue. The radiation oncology nurse and therapists will make sure you are comfortable and receive any medication needed for nausea.

The expected effects or “goals” of TBI are the killing off of any cancerous cells to prepare the bone marrow space to engraft the infused transplanted cells and to eliminate any white blood cells in your body that could mount an immune response and fight off the newly infused transplant cells.

**HOSPITAL ADMISSION**

**What to Bring to the Hospital**
Preparing for your hospital admission can make your stay much more comfortable. You will be staying in a private room that is spacious and has good storage space. Your friends and family can bring additional supplies during your stay if needed. Remember that your immune system will be compromised (immunosuppressed) while in the hospital, so keeping your room clean is important.

Here are some helpful tips to remember while you are packing:

**Clothes**
We do provide hospital gowns and pants. However, you may wish to bring your own clothing. Please bring clothing that is comfortable and opens in the front, so that your central catheter can be easily accessed (i.e. button down top). Please wear clothing that does not require your line to be unhooked. We discourage unhooking your central line from the IV tubing in order to prevent infection, even while you are showering. We want you to have a clean change of clothes after you shower each day. We recommend packing at least a week’s worth of clothing. You will need to make arrangements for your caregiver to wash your clothes or bring in additional clothes/take home soiled clothes because we do not provide laundry service. We also want you to wear something on your feet while walking on the
floors in your room. We provide booties. You are also welcome to bring your own slippers. Having a hat, scarf or wig will provide you with warmth as well.

**Bedding**

We change your bedding everyday usually while you take a shower. You may want to bring your own pillow (not feathered), several clean, colored pillow cases and a freshly laundered quilt or spread. Keep in mind that pillowcases and spreads will need to be laundered by your caregiver.

**Toiletries**

Again, we do provide you with items for you for your personal hygiene. Keep in mind that your skin will be sensitive due to the treatment and perfumed products should be avoided. Do not bring a toothbrush or toothpaste because a special mouth-care regimen will be started on admission. Your nurse will teach you about how to specially care for your mouth on your admission day. Be sure to trim your fingernails and toenails prior to admission.

**Items to Bring**

* pictures of loved ones and special places
* eyeglasses
* electric razor
* portable radio/DVD/CD player
* music
* new makeup
* new nail file
* slippers
* scarves/hats/wigs
* extra pillow (not feathered)
* favorite blanket or quilt (washed)
* notepad/journal/magazines/books
* books on tape
* crossword puzzles, Sudoku, word search
* hard candy for your transplant day
* a large calendar to track your progress
* lap-top computer

**Things Not to Bring**

* money / wallet
* toothbrushes or dental floss
* mechanical razors
* nail clippers
* scissors
* contact lenses
* pets
* jewelry
* fresh flowers
* dried flowers
* live plants
* no moss around the base of silk flowers
* medications as medicine will be provided

Please note: Jewelry is discouraged as IV fluids may cause fingers to swell, so your rings may be tight and hard to remove.

**Electronic Equipment**

PH1156 (2-18)
During your stay at UC San Diego, we will make every attempt to see that you are as comfortable as possible. All of the rooms on the BMT unit have a television and cable and are supplied with an iPad for patient use.

*Note on lap-top computers: Jacobs Medical Center and the Cancer Center both have free WIFI access.

**Mail**
If mail is sent to you, please make sure that your **full name and room number** is on the letter or package. Mail can be sent to:

**UC San Diego Health**  
**Jacobs Medical Center**  
(Your name)  
6th Floor Room ____  
9300 Campus Point Drive  
La Jolla, Ca 92037

**Daily Hospital Routine**
The mornings are usually the busiest part of the day. This is the time when doctors and other members of the team including nurse practitioners, pharmacists, the charge nurse and the social workers visit each patient and discuss their progress. We call this "rounds". Also, tests are done and treatments are given. Throughout the day, you may see other members of the staff including housekeepers, dietitians, and physical therapists.

A nurse and CCP will be assigned to you on a daily/nightly basis. Remember, the attending physicians do rotate. Whoever is “on-service” at the time you are in the hospital is in charge of your daily care. The team does communicate your plan of care and needs as they arise with your primary transplant doctor on a regular basis.

You probably will have expectations of the transplant team; and, we have expectations of you. Expectations are part of your plan-of-care and were created to help you maintain your strength and prevent infections and problems from occurring. Your care plan will be discussed with you daily; and, we encourage you to ask questions as needed.

**Meals**
Upon admission to the hospital, you will have the ability to order meals via room service. A Room Service Attendant (RSA) will be meeting with you to explain the menu and ordering process, your diet restrictions (if any), and address any questions and/or concerns you may have. If you would like to order something prior to the arrival of your RSA, you will have the ability to call him/her directly using your hospital phone. Your RSA’s phone number will be written on the white board in your room.
Breakfast is served all day, starting at 6:30 a.m. Lunch and dinner are served beginning at 11 a.m. Service will stop at 8 p.m. each evening. Snacks are also provided throughout the day per your request any time during meal service by dialing your RSA’s extension. On the day of your admission, your nurse will notify your RSA and assist you with ordering your first meal. A dietary consult order can be placed for you and the dietician can meet with you to discuss your dietary options. The dietician will also discuss with you the importance of obtaining enough nutrition and calories during your transplant.

When you are neutropenic (ANC <500), you will be placed on a special diet that is intended to lower the risk for getting food related infections. Please see the attached Low Microbial Diet Guidelines found in Section 9.

No food from home is allowed without an MD order. If an MD order is received, the person cooking the food must first consult with the dietitian for safe food handling education. Food from home that is allowed without an order is prepackaged one time use food.

**Fluid Balance**

It is very important that we monitor your **intake and output (I&O)** as well as complete physical assessments daily. Fluid balance is important in preventing dehydration, fluid overload and maintaining electrolyte balance (high or low sodium, magnesium, potassium, calcium and phosphorous).

We will place collection containers in the toilet so that your output can be measured. Please use these containers as it will help the staff in determining your care needs. We will also weigh you daily to monitor your fluid balance and nutritional status. Because a large amount of intravenous fluid is given to you during your conditioning chemotherapy, you will be weighed between 10am and 12pm daily.

To maintain electrolyte balances, you may receive oral or IV replacements based on your morning laboratory values.

**Medications**

When you are admitted to the hospital, we ask that you bring a list of your medications and the dosages with you. It is helpful for the admitting practitioner to have an accurate account in order for you to continue those medications while you are in the hospital. Please do not bring any medications with you. At times, certain medication swill be stopped or held until you leave the hospital.

After your transplant, you will be put on new medications that will help prevent different types of infections (bacterial, viral and fungal). In addition, other medications will be ordered that help support the transplant process. All the medications are important for you to take. They will be discussed with you and your caregiver regularly during your hospital stay and after you go home.
Once you are discharged, you will receive a new medication list called a Med Action Plan. This list and will include new medications along with any that you were taking before your admit. Keep in mind; these may have been changed during your hospital stay.

All medications must be picked up at a UC San Diego Health System pharmacy before you are discharged and for the next 2-3 months. This is done to prevent any interruptions with your medication care.

It is important to remember that if you have any questions or concerns regarding your medications that you speak to your transplant coordinator, advanced practitioner, case manager or doctor as soon as possible. It is not unusual for you to be on some of the medications for 6-12 months.

Vital Signs, Nursing Assessment, and Blood Work

Vital signs (heart rate, blood pressure, temperature, respiration rate, and oxygen and pain levels) are taken at least every four hours around-the-clock or more often as necessary. The doctors will perform a head-to-toe assessment on you in the morning before or during “rounds”. The RN’s also perform an assessment in the morning and evening and communicate any changes to the team of physicians. The nurses will draw your blood at least once a day, usually between 8:00 PM to 10:00 PM and the results will be posted to the iPad in your room.

Hygiene

We will instruct you on how to perform oral hygiene with a soft toothbrush (provided by the unit) and toothpaste. Use salt water to rinse your mouth four times a day prior to brushing your teeth. Good hygiene, such as frequent hand washing and daily skin cleaning promotes good health. Cleaning your skin every day helps to remove bad bacteria that may cause diseases (especially while your immune system is depressed). Hibiclens is an antiseptic, antimicrobial skin cleanser that helps to prevent infections. The inpatient team will provide you with instructions for handwashing, bathing and showering when you are admitted. As mentioned above, you will be expected to shower daily and you will be expected to put on a new gown or clothes each day. See proper handwashing technique in visitor section below. This handwashing technique applies to you too.

Exercise

During your hospital stay it is important that you exercise daily. Your doctor might order a consultation from a physical therapist. Physical therapy can provide safe exercises that are specific to your needs. There is a patient gym located in G pod that can be used once you have had a PT consult and approval. There are different strength exercise bands that can be provided to help you stretch and strengthen your muscles. Staff will let you know when it is okay for you to walk in the hallways with or without a mask.
It is also important to keep your lungs in good shape. We will provide you with an **incentive spirometer** which is a plastic device that you will use every three hours during the day to help expand your lungs to **prevent problems** such as **pneumonia**. The nurse will teach you how to use it as well as other types of deep breathing exercises.

**Risk of Falls**
Treatment with chemotherapy is associated with a high risk for falls. You may experience significant changes as a result of your treatment. This includes changes in your balance and how you walk. The inpatient team will be evaluating you and educating you on ways to keep you safe throughout your hospital stay and beyond.

**Chaplain Services and Spiritual Care**
Spiritual care is an integral part of the healing process. It provides an important source of comfort and strength to patients and families faced with serious illnesses or difficult decisions to make. Our volunteer clergy is made up of leaders from many different faiths and provides compassionate and caring spiritual support to patients and their family members with respect for their beliefs, culture and values. Chaplain services are free and include:

- Crisis intervention
- Comfort and emotional support
- Spiritual consultations and guidance
- Support in decision making and ethical dilemmas
- Prayers, blessings, rituals and sacraments
- Making arrangements with patients’ clergy or spiritual leaders
- End-of-life support

If you are interested in chaplain services, please tell your nurse. You may also contact the Chaplain Office by calling **619-543-2103**.

**Visitor Guidelines**
We know that your friends and family are important to you; and, we encourage visitors. However, we also want to protect you from **microorganisms** (bacteria, fungus, and viruses) that can cause infection. So, we have created the following visitor guidelines.

Jacobs Medical Center does not have formal visiting hours. If your visitor arrives after 8:00 PM, please instruct him/her to enter the hospital through the Emergency Department. One visitor over the age of 18 years old can stay with you overnight; a sleeper sofa is available in each patient room. Visitors are not allowed to sleep in the hospital lobby or the hospital atrium.
All visitors must stop at the nurse’s station before entering your room. The staff will briefly screen your visitors for infection. We will not allow someone to visit if he/she has a cold or contagious infection. Visitor guidelines will be posted in your room and it is important that you and the staff discuss them with your visitor(s). This is especially important if you have been placed on special precautions such as isolation precautions. All visitors must abide by precaution instructions as they help prevent the spread of highly transmissible infections.

The unit has beautiful family rooms with scenic views located in each pod that provide another area that may be used for visitation aside from your patient room.

Proper Hand-washing
Turn on the water and wet hands, dispense soap and lather hands, and scrub around the wrists and between fingers and fingernails for at least 15 seconds, rinse and dry with paper towels, discard paper towels in the trash. Each and every patient’s room has its own antibacterial hand gel just outside the door, and sinks for handwashing just inside each patient room.

Children are allowed to visit; however, they must be supervised at all times and are not allowed to play in the hallways. They must not show any signs of infection. Infants and children who have recently received the oral polio vaccine (OPV) which is a live attenuated vaccine should not visit the transplant floor for 4-6 weeks. Household members of transplant patients should receive the inactivated polio vaccine (IPV).

While in the room, visitors are not allowed to use the patient’s bathroom, phone, sit on the bed or eat in the patient’s room. There are bathrooms located in the hospital that are available for their use.

Visitors may bring food from home with a written order from the doctor and after the dietitian has met with them and discussed proper food preparation and handling. The food must be well-washed, cooked, and then immediately wrapped and refrigerated. It should be in a single serving container and may be microwaved only ONCE prior to eating.

It is important for visitors to understand that you may be tired or not be feeling well. Therefore, they may need to limit their visits accordingly.

Jacobs Medical Center provides a tobacco-free environment. Smoking is only allowed in posted smoking areas.
THE TRANSPLANT

Day Zero – Your New Birthday
Day zero is the day you will receive your donor’s cells. The days leading up to day zero are referred to as “minus days” and the days after your transplant are “plus days”. Each day, staff will write the day (minus or plus) of your transplant on the board in your room.

On day zero, your assigned nurse will infuse your donor’s marrow, stem cells or cord blood. This procedure takes place in your room and it is similar to a blood transfusion. You will be given medications to prevent a possible reaction(s) that may occur from the infusion of the cells. These medications may make you sleepy during the procedure. Your vital signs will be checked often and you will be closely observed by your nurse.

If your cells arrive frozen, the nurse will thaw them in a heated water bath at your bedside and infuse them through your central line into your blood stream. The cells are preserved with a chemical called dimethylsulfoxide (DMSO) that protects the cells during the freezing and thawing process. This preservative will cause your room to have an odor for a day or two. The odor has been described as a garlicky or canned corn smell. You may also have a bad taste in your mouth, or feel a tickle in your throat or experience coughing during the infusion. Sucking on candy or mints may help lessen the taste.

Following the transplant, your blood counts will be monitored daily. You will be informed of your results and transfusions of blood and platelets will be given as needed. The nurse will tell you about special precautions to take when your blood counts are low.

Engraftment
The time for your bone marrow to engraft and start to work and make new white cells, red cells and platelets differs depending on the type of transplant you receive. The nurses and doctors will tell you when to expect your new cells to grow on their own. Please remember that every patient is different and the time of engraftment varies for each person.

Complications
The success of the transplant depends on your type of disease, its stage, your age and general state of health. There are several possible complications that can happen during or after an allogeneic transplant. No one gets all of them, but most people get some of them.

Depending on the complications you may experience, you may be transferred to a unit that has specially trained staff that can provide a higher level of care such as heart monitoring and/or specialized medicines. However, you will still be seen daily by the physician or advanced practitioner on the BMT team.

The first few complications discussed here will be early side effects that can be caused by the preparative regimen. Some common side affects that people have within the first few days
of treatment may be nausea, vomiting, diarrhea, or mouth sores. Bleeding, infection and/or hair loss may occur during the first 1-2 weeks after treatment. Damage to the reproductive organs often results in long term infertility. Severe or long term damage to organs such as kidneys, liver, or lungs occurs much less often.

The transplant team will see that the correct measures are taken to prevent or decrease any discomfort.

**Nausea and Vomiting**
Drugs called antiemetics are used to prevent and treat nausea and vomiting. These medications have improved recently; however, not all people respond to medicines the same way. Be sure to let the team know if you are having any nausea or vomiting so changes to your medications can be made.

**Diarrhea**
Diarrhea can also be common in people receiving chemotherapy. Antidiarrheals can also be used to slow down diarrhea or cramping. A stool culture will need to be performed prior to starting antidiarrheal medications. This is because a certain type of bacterial overgrowth called C. diff can also cause diarrhea, and if the culture is positive for C. diff it will need to be treated. Be sure to cleanse your anal area after each bowel movement. This will help prevent any skin breakdown or infection.

**Mouth Sores**
Mouth and throat discomfort, or mucositis, can occur 4-8 days following some preparative regimens. Good oral hygiene is very important during your transplant and will help limit the amount of discomfort and prevent mouth infections. Medications can be applied to numb the area (topical anesthetics) or intravenous narcotics can be given to relieve any mouth or throat pain. Mucositis normally improves when the white blood cells start to engraft.

**Bleeding**
Chemotherapy causes a decrease in the platelet count. These are the blood cells responsible for helping the blood to clot. A low number of platelets, or thrombocytopenia, may cause a patient to bleed or bruise more easily than usual. Platelet transfusions may be given if the platelet counts drops too low. During this time there are a few precautions that can be taken to help prevent bleeding. These include:
- keeping your skin and lips moisturized as dryness may lead to cracks and bleeding
- sexual intercourse is not advisable if a platelet count is less than 50,000
- only use an electric razor
- do not go barefoot; wear slippers or shoes at all times
- do not use nail clippers
- drink plenty of fluids to avoid constipation and avoid straining during bowel movements
• do not use rectal thermometers, suppositories, or enemas
• do not use aspirin or products containing aspirin
• use only a soft toothbrush, do not scrub gums too hard or use floss
• no contact sports

**Infection & Neutropenia**

Infection is the most common side effect of transplantation. This is due to the destruction of white blood cells (that help fight infection) by chemotherapy. Infections can come from the environment but the most common source of infection is bacteria originating from the patient’s own body. Medications will be used to prevent and treat infection and special precautions will be taken to help avoid infection.

Neutrophils are a type of white blood cell and are an important part of how your defense system fights infection. An absence or low count of neutrophils (neutropenia) makes a person more likely to get an infection. The degree of neutropenia is based on the absolute neutrophil count (ANC) which is a measure of the number of neutrophils present in the blood. A normal ANC is about 1,500. An ANC of less than 500 is defined as neutropenia and significantly increases the risk of infection. **Nadir** is the word used when your WBC count is at its lowest.

The ANC is calculated using the number of neutrophils (“segs” or segmented cells) plus the bands (young neutrophils) which represents a percentage of the total number of white blood cells (WBC). The following is the formula for calculating the ANC:

\[
\text{ANC} = (\text{Segs\%} + \text{Bands \%}) \times \text{WBC}
\]

For example, a CBC lists the:

- WBCs as 4.6K (“K” stands for 1000) = 4,600
- Segs = 40
- Bands = 5

\[
40\% + 5\% = 45\% \text{ or } .45
\]

\[
\text{ANC} = .45 \times 4600 = 2070
\]

It is recommended that allogeneic transplant patients follow the guidelines listed below to prevent infection:

- follow a low microbial diet (refer to Section 9 – Low Microbial Diet Guidelines)
- bathe or shower daily with antibacterial soap
- good oral hygiene with mouth care to be done as prescribed
- cleanse rectal area after each bowel movement
- have an incentive spirometer in your room and use it every 3 hours while awake
- avoid contact with people who have colds, flu, chicken pox, or any other contagious disease
- keep your door closed as much as possible as your room has special air handling to aid in infection prevention (positive air flow)
- you may wear a mask and go for a walk on the BMT unit as it has special air handling. If you are on isolation precautions, however, you will not be able to go for walks on the unit.
• if you do have to leave your room for tests or procedures, you must to wear a mask
• avoid plants, fresh flowers
• take antibiotics/antivirals/antifungals as prescribed
• take granulocyte colony stimulating factors (G-CSF) as prescribed

At any time when a blood marrow or stem cell transplant patient develops a fever over 100.5F, the “fever” protocol will be started by the inpatient RN including:
  • Drawing blood for cultures from your central line and arm
  • Collecting urine, sputum and central line area samples
  • Ordering a chest x-ray
  • Starting intravenous antibiotics
  • Notifying the practitioner
  • Provide comfort measures if needed (i.e. a fan, cool or lukewarm bed bath, Tylenol)

It usually takes 2-3 weeks for the white blood cell count to be high enough for a patient to be discharged from the hospital following an allogeneic bone marrow or stem cell transplant. Cord blood transplants take a longer time to engraftment. Discharge date will be determined by the attending physician. Refer to the time-line in Section 4.

**Hair Loss**
Most preparative regimens will lead to temporary scalp and body hair loss (alopecia) one to two weeks after the start of treatment. Some patients cut their hair short or shave their heads before hair loss begins. Scarves, hats, or wigs can be used until hair grows back. Hair normally grows back within 3-4 months after the transplant.

**Relapse and Secondary Malignancy**
Some patients will experience a relapse of their disease even after a transplant. The risk of forming another type of cancer, caused by the chemotherapy and/or radiation has been documented in a small number of patients. If either of these situations occurs, you and your transplant doctor will discuss available treatment options.

**Organ Toxicity**
There is a possibility that high dose chemotherapy as well as a number of other medications required during transplant can cause a decrease in the ability of your lungs, heart, kidney, or liver to function. These organ toxicities are usually mild as well as temporary and reversible.

**Graft Versus Host Disease (GVHD)**
Graft versus host disease can develop in patients who receive a transplant from a relative or unrelated donor. It occurs when the donor’s cells do not recognize the transplanted recipient’s cells and begin attacking the tissues of the liver, skin and/or gastrointestinal (GI) tract. The chances of getting GVHD are dependent on several factors including age, HLA matching, gender of the donor and recipient.
GVHD can be acute and/or chronic. The severity can range from mild to severe. Medications will be given to you before, during, and after transplant in order to minimize the degree of GVHD, although, it may still occur. Some of these medications include: Cyclosporine, Steroids, Methotrexate, FK506, Cellcept, and ATGAM.

**Acute GVHD**
This can occur from day 25 – 100 post transplant. Some of the signs of GVHD are diarrhea that is not caused by infection, persistent nausea, changes in skin appearance, and signs and symptoms of liver disease including weight gain around the abdomen and yellow colored eyes or skin. Again, these symptoms may be mild, such as a skin rash, to severe, such as to large volumes of diarrhea. If severe, GVHD can be life threatening. The transplant team will monitor you closely for these signs and symptoms and procedures may be conducted to confirm the presence of GVHD, such as biopsies from the skin and/or gut. If GVHD is suspected or confirmed, you will receive medications in an attempt to control it. Dietary guidelines may also be set up to help control aggravation to your gut during this time. Lotions may also be applied to skin frequently to prevent breakdown and infection.

**Chronic GVHD**
This may occur from day 100 up to two years after your transplant. The disease primarily affects the skin, mouth, gut, joints, and eyes. Because your mucus membrane may become dry, it is important to keep fluid intake high and your skin well lubricated with non-irritating lotions and use sunscreen. We also recommended using gentle soaps and detergents. Women may experience vaginal dryness. Water-soluble lubricants are recommended. Please consult your doctor to see if it is safe for you to engage in sexual activities. Also, because of the drying effect in your mouth, your taste sensation will be altered and you may experience pain when eating hot and spicy foods. Your eyes may be light-sensitive (photophobia) and it is important to protect them from the sun by wearing sunglasses and using artificial tears to prevent dryness. Exercise can also help if your joints become stiff.

Again, if the chronic GVHD is severe, it can be life threatening. The physicians will monitor your progress throughout this time and attempt to control the GVHD with medications and other interventions.

It is important to notify your physician if one or more of the following occurs:
1. Persistent diarrhea not associated with infection
2. Persistent nausea
3. Distended abdomen
4. Difficulty in breathing
5. Skin changes
6. Changes you notice in your mouth and eyes
7. Difficulty moving your joints
**Graft Failure**
It is considered graft failure if the transplanted cells do not engraft. The risk for this varies with different underlying diseases and the type of transplant the patient is having. In general, graft failure is rare. Unsuccessful engraftment can result from two different cases.

**Graft Rejection**
The patient’s body rejects the donated cells. Graft rejection is a problem exclusive to allogeneic transplants, and is typically due to the survival of a sufficient number of T-cells in the patient. If enough of these T-cells survive the conditioning regimen, they may be capable of rejecting the donor’s cells (the graft). Graft rejection is more common for mismatched transplants and transplants that have been manipulated to reduce T-cells in an effort to prevent GVHD.

**The Transplanted Cells Fail to Grow & Produce New Cells**
This can occur in patients receiving any type of transplant, but once again, this is rare. In allogeneic transplant recipients, this can be due to a viral illness or due to the use of certain medications.

**Infertility**
Sterility is a potential complication of high dose chemotherapy and TBI. The likelihood of infertility depends on the patient’s age, gender, type and amount of chemotherapy received. Although most patients who undergo a transplant will be infertile afterwards, those who do not wish to become pregnant should not assume they cannot. The normal options of avoiding unwanted pregnancies need to be practiced.

Fortunately, there are options available to couples who wish to have children after a transplant. Adoption or medically-assisted reproduction technologies can be explored if this applies to you.

Feel free to discuss options with your doctor, coordinator or social worker. Refer to the Resource Guide for further resources.
SOCIAL WORK SERVICES

If your doctor has recommended a bone marrow, stem cell, or cord blood transplant, you may be feeling overwhelmed and somewhat frightened by what may lie ahead. You may have concerns about your job, finances, family, friends, and your own survival. You may also feel a great sense of hope about the future. There is support available to help you and your family.

Clinical Social Worker
You and your caregiver will meet with your BMT clinical social worker during one of your initial visits with our team. Our social workers have a Masters degree in Social Work and are licensed counselors. During your initial interview (or psychosocial assessment), your social worker will get to know more about you and your situation. Your social worker may also answer non-medical question, and you may be given information on hospital services and community resources. Many insurance companies require that a social worker meet you, and they may ask for information from your social worker.

During your treatment, your social worker will monitor the effects that this treatment is having on your emotional and social well-being. She/he will be available to give you and your loved ones the support you may need. This might include counseling or community resource referrals. To best help you, and to help prepare for your return home, your social worker will often talk with your doctor, nurses, and other members of your health care team. All communications are confidential. If you or your loved one would like psychotherapy, check your insurance plan’s mental health benefits. Out-patient psychological or psychiatric services may be available at Moores Cancer Center.

Your BMT social worker will be available to help you for about six months after your stem cell transplant. After six months, an oncology clinical social worker is available by request.

How should I prepare for my transplant?
We encourage you to bring family members and/or friends to your appointments and tests as they will have a large part in your care. Before the transplant and during the in-patient hospitalization it is not required to have a family member with you at all times. After you are discharged from the hospital, you are required to have someone with you full-time to assist you with your daily care and transportation needs and we encourage you to have a help from other caregivers for respite for your primary caregiver. Plan for a primary caregiver to be available for a minimum of three to four months. This requirement may be longer depending on your health status and the type of transplant you have. Transplantation requires a serious commitment from you and your caregivers.

Advance Health Care Directives (Durable Power of Attorney for Health Care, Living Wills) are written documents where you state the kind of medical care you would want in the future. This is based on your values and personal beliefs. There are two primary parts to an
Advance Health Care Directive. One is to pick a person with whom you can discuss your wishes, and who will carry out your wishes if you cannot speak for yourself. The second part is to write down under what conditions you would no longer want certain medical treatments. When making this decision it is important to consider quality of life.

At UC San Diego, we recommend that all patients have Advance Health Care Directives. You will be asked at the time of your hospital admission for a copy of your completed Advance Health Care Directive for your medical record. If you do not have a completed directive, you may obtain a form from your social worker.

**What about relationships?**
This experience, most likely, has changed your perspective on life. Your priorities may have changed as well as what you value. Your illness may also have affected the feelings and perspectives of the people around you. Sometimes people may treat you differently, like you are fragile or delicate. Talking about your feelings will help other people understand. Help them understand that although you may need assistance, it is important for you to participate in life as much as possible.

The transplant experience may be stressful for your family members. Roles often change within the family. The well spouse or support person may need to take on added responsibilities or learn new tasks. There may be financial concerns (ask your clinical social worker if any resources are available for you and your family). Family members and caregivers are encouraged to ask for help from others. We find that people are eager to help and may not be able to anticipate your family’s needs. They may be waiting for you to ask!

**What about my children?**
It is very important to be honest with your children and encourage them to ask questions and talk with you. While some parents may feel that keeping their cancer diagnosis a secret is protective, children may actually feel excluded and confused by the secrecy. Let your children know that they are allowed to ask questions and that you will answer them as honestly as you can. This should begin before your transplant and continue throughout the transplant process.

When you discuss your medical condition with your children, it is important to be age appropriate. You may give simple information to a small child and more complex information to a teenager. Since you know your children the best, gauge your answers accordingly. Take the time to listen to their successes, problems, and fears. Encourage them to draw, talk, or act out their feelings. Children have vivid imaginations, and what they imagine may be more frightening to them than reality. Books are available to help you discuss issues with your child. Professional help is also available.
**Tips for Coping:**
Everyone experiences some emotional reaction to their illness and transplantation, although individuals may experience them at different times and in different ways. There are many ways to cope with emotional and practical changes.

Suggestions for patients include:
- Write down your questions and ask them as frequently as needed. You may also want to write down your feelings.
- Sometimes your memory can be short and unpredictable. Write down information during your transplant.
- Request contact from a former transplant patient with whom you can talk and receive support.
- Do the best you can to make each day count.
- Take one day (or one moment) at a time.
- Read inspirational books by survivors.
- Manage stress through deep breathing, visualization, meditation, or other relaxation techniques.
- Focus on something that puts you in control, such as your attitude or communicating with your health care team.
- Before you are discharged home, be sure that you and your support person clearly understand what follow-up care is necessary.
- If you have a chaplain, rabbi, or minister, they are welcome to visit you in the hospital. Hospital chaplains are available if requested.

Suggestions for caregivers:
- Ask other family members and friends for help caring for the patient, your family, and you during the transplant process.
- Be realistic about your limitations. Get enough sleep, eat properly, and take time off for yourself. You will be a bigger help to the patient if you are healthy and calm rather than sick and overwhelmed.
- Be prepared for possible changes in the patient’s behavior. The medications and stress may cause the patient to become depressed, anxious, or angry. Speak with the doctor if you have concerns. At the same time, understand that your loved one needs you more now than ever before. Your help is not only welcomed, it is absolutely essential.
- Don’t be shy about tracking down the medical staff to get help or have your questions answered. You’ll feel better knowing that staff is aware of issues that you’ve noted.
- Finally, if you are feeling helpless, remember that the moral support you provide is often the “best medicine” the patient can receive.
Discharge Home from the Hospital:
It is an exciting time when the patient goes home from the hospital. However, it is normal if the patient and/or caregivers have some fears or concerns. There may be worries about being away from the security of the hospital setting or close contact with the hospital staff. Be patient with yourself and others as these are valid feelings.

Going home has been your main goal during your hospital stay. Now your goal is to continue to take care of yourself and regain strength.

Suggestions for Patients:
- Do not try to resume all of your previous responsibilities immediately. When family and friends offer to help, let them!
- Keep stress factors to a minimum. Let a member of your medical team know if any specific things are bothering you.
- If children have behavioral changes when you go home, allow time for routines to stabilize. Let teachers and friends know what is happening so that they can provide help if needed.
- Friends and relatives may be unsure of what to say or do, especially if they have not seen you since your transplant. Bring them up to date on your condition, feelings, and hopes for the future to the degree that you are comfortable. Help them know how to be supportive to you.

Returning to Work or School:
You should inform your employer or school staff that the usual recovery time after a transplant is six months. This may be longer depending on how quickly you recover and what type of transplant you’ve had. It may be possible for you to work at home or your office for short periods of time during off-hours. If you are in school, you might hire a tutor or take classes online. Since there are important medical considerations, any decision to return to work or school should be discussed with your doctor. If you have concerns about returning to work or school, you can discuss them with your social worker.
GOING HOME

Discharge Planning
Planning for your discharge from the hospital begins on your day of admission. Due to the advancements made in the bone marrow, stem cell and cord blood transplants, patients are being discharged from the hospital earlier. The discharge process can be overwhelming due to the amount of information, anxiety and other emotions. Therefore, it is important for you, your caregivers and the transplant team to address your needs early in the course of your hospitalization.

Transplant team members will provide you with the information about your post-transplant care. It is important to ask questions and take notes. **We recommend bringing this manual with you into the hospital so we can refer to it during your stay.**

Some common guidelines regarding discharge planning and home care are listed below:

- **A clean home!**
  Your home should be thoroughly cleaned at least a few days before you are discharged due to your risk for infection. Special attention should be given to the floors, carpets, bathtubs, sinks and toilets. Have the filter on your ventilation system changed to decrease dust and dirt.

- **You are not allowed to clean!**
  Let your family and friends clean for you and please stay out of the room they are cleaning. Cleaning should be done on a regular basis.

- **Do not share!**
  Use your own utensils, towels and toothbrush. Clean bath towels and linens regularly in HOT water.

- **Plants and Flowers!**
  Limit the number of plants and flowers in your house. DO NOT take care of them. Allow your caregiver to water and re-pot them. You should avoid caring for plants and gardening for six months and during periods of substantial immunosuppression. Once you are able to garden, you must use garden gloves and we recommend wearing a mask.

- **Pets!**
  You can keep your pets in your home and you CAN pet them. Remember to wash your hands afterwards. DO NOT clean litter boxes, bird cages, fish bowls, etc. DO NOT handle animal excretions for at least 1-year post-transplant.
**Mouth or Oral care**

Thorough mouth care is important to maintain healthy gums and teeth. You will need to rinse your mouth with Normal Saline for a full minute four times a day then gently brush your teeth, gums and tongue with fluoride toothpaste. If bleeding occurs or if the toothbrush causes pain, use a foam toothette instead.

If you are regularly flossing your teeth, you may continue to do so but only do it once a day. Do not floss if it causes bleeding or increased pain, if your platelets drop below 50,000 and/or ANC is less than 1,000.

Keep your lips moist using a lip balm or Vaseline. Avoid mouth rinses containing alcohol or hydrogen peroxide. Acidic, salty, spicy, hot and coarsely texture foods should be kept at a minimum.

Continue to see your dentist twice a year. Notify the transplant team before your first dental visit after transplant.

If your mouth feels dry, rinse your mouth with Normal Saline before and after meals as needed, chew sugar-free gum, avoid tobacco and alcohol or ask your doctor about artificial saliva.

**Nutrition**

Nutrition is very important during this time. It is important that you have an adequate intake of calories, protein, vitamins and minerals to support your growing immune system. As mentioned above, you will remain on the Low-Microbial Diet until you are off all immunosuppressive therapy such as cyclosporine, prednisone, FK-506 (Tacrolimus®) or MMF (CellCept®) or as decided in a conversation with your doctor.

Changes in taste, dry mouth and possibly some nausea may decrease your interest in eating. During this time, small frequent meals with snacks and the use of nutritional supplements (Carnation instant drinks, Ensure, Sustacal, and Slim Fast) may be helpful in supplying enough calories and nutritional intake.

A clinical dietitian who specializes in Oncology Nutrition is available at Moores Cancer Center to assist you with maximizing your nutrition intake after discharge. The clinical dietitian will provide you with nutrition counseling to help you achieve improved treatment tolerance, reduce weight loss, and encourage overall improvement in quality of life.
SKIN CARE

Sun Exposure
You should avoid direct sun exposure. Your skin will be sensitive to the sun because of the high-dose chemotherapy and/or radiation.

Wear sunglasses to protect your eyes, always wear a sunscreen of at least 30SPF and wear a hat and long sleeves as well as long pants. Cover as much skin as possible. Light colored clothing is the best. If you plan to be outside, such as for a walk, it is best to do that early in the morning or late in the day (near dusk) to avoid sun exposure.

Examine your skin daily for signs of:
- Bruising, rash, swelling or redness.
- Shower daily and use a moisturizer. Use a mild shampoo and conditioner on your hair and scalp. After bathing, pat skin dry – DO NOT RUB. Pay special attention to drying skin folds, including genital and rectal areas. Use a rubber mat in the tub to avoid slipping. Use mild soaps without perfumes and deodorants.
- Cover your central venous site when showering.
- Wear comfortable loose clothing.

More on Infection Prevention
Even though your white blood cell count may be in the normal range when you are discharged from the hospital, your immune system may not function normally for as long as one year.

Here are some guidelines to help you stay free from infections:
- **Wash hands frequently.** This includes you, your family and friends. Please refer to “Visitor Guidelines,” section for hand-washing guidelines. Make sure hands are washed after touching an animal, before and after meals, before preparing food, after using the toilet and before taking medications. Have paper towels handy to dry your hands.
- **Avoid large crowds and people with infections or colds for at least 1 month.**
- Take your temperature at the same time once or twice a day, more often if you are not feeling well.
- **Avoid** swimming in oceans, lakes, public pools, rivers, or hot tubs for three months. If you have a central venous catheter, this is also prohibited.
- If you MUST change a diaper on a baby, please wear disposable gloves and wash your hands immediately after changing the diaper.

Immunizations
Talk to your doctor before receiving any immunizations. Avoid infants and children who have been recently vaccinated with oral polio. Tell your doctor if you have been exposed to such child. If you have children, talk to your child’s pediatrician about your child’s immunization schedule and inform him/her that you are a transplant patient.
Exercise
Be aware that you will tire easily after the transplant process. Be patient with your body. You will need to rebuild your strength and endurance slowly. As your body adjusts to an increase in activity, you will find that you have more energy.

Prioritize your tasks and activities. Plan your day and include time for exercise and rest. Regular exercise is important to improve muscle tone and strength. Walking or riding a bike is good ways to exercise.

Preventing Bleeding
After your discharge from the hospital, you may still be at risk for bleeding. Please ask your nurse or doctor if this is a risk for you. A platelet count of less than 50,000 and the need for frequent platelet transfusions will put you at risk for bleeding.

Use these following precautions:
- Use an electric razor.
- Avoid contact sports.
- Avoid heavy lifting.
- Do not go barefoot. Always wear slippers or shoes.
- Drink plenty of fluids to avoid constipation.
- Avoid sharp kitchen utensils or tools.
- **Do not use rectal thermometers, suppositories or enemas.**
- Do not have sexual intercourse if your platelet count is less than 50,000. See the following section on sexual activity for more recommendations.
- **Do not use aspirin or products containing aspirin (it causes bleeding) such as:** Alka-Seltzer, Anacin, Bufferin, Ascriptin, Aspergum, Bayer and Bayer Decongestants, BromoSeltzer, Congesprin, Dristan, Ecotrin, Excedrin, Fiorinal, Midol, Nuprin, Percodan, Sine Off, St. Joseph’s Aspirin, Four Way Cold Tablets.

Sexual Activity
Your sexual desire may be decreased following your transplant. In most cases this is only temporary and normal desire will return. Try to keep an open mind about the different ways to feel sexual pleasure. Many couples have different ideas of what is "normal" sex. There may be times when intercourse is not possible. Those times can provide you the opportunity to learn new ways to give and receive sexual pleasure. You and your partner can help each other reach orgasm through mutual caressing and stimulation. At times, just cuddling can be enough. Do not deny yourself different ways of expressing, caring, and feeling alive, just because your usual routine has been disrupted. Open communication between you and your partner is an important part of resuming sexual activity.

If you are having a hard time coping with issues such as body image, desire, response and your identity as a man or woman, please let your nurse, doctor or social worker know.
Here are some guidelines to follow:
If your platelet count is below 50,000, be gentle to avoid bleeding and infections. Sexual intercourse is not advisable if your platelet count is less than 50,000. Practice cleanliness and safe sex. Also, remember you will become tired more easily, so do not over-exert yourself. You and your partner should use a condom for three months following your transplant. It is advisable to avoid oral sex until your mouth is completely healed. It is also advised to refrain from anal intercourse for six months following transplant.

Kissing is fine after transplant. Good oral hygiene is important. If you or your partner has a cold, fever, open sore on the mouth-DO NOT KISS each other.

Masturbation is okay, just remember to maintain good hygiene and to BE GENTLE. To prevent trauma to this area, use a water-soluble lubricating jelly, such a KY Jelly, Replens, or Lubrin. You can purchase these items at your local drugstore. Never use Vaseline, as it can cause infections and decreases the effectiveness of condoms. Condoms are also recommended to prevent infection.

**Women**

Although infertility is possible, birth control should be used. Six months after transplant, you should visit your gynecologist. Keep track of any menstrual cycles you have and any signs of menopause. These signs include hot flashes, mood swings, flushing and difficulty sleeping. When you visit the gynecologist, discuss the pros and cons of hormone replacement therapy. If hormonal therapy is not an option for you, an endocrinologist may be able to relieve these symptoms using non-hormonal therapy.

Chemotherapy can cause your vagina to be dry. Douching with chemical products is not recommended. These products can destroy the natural bacteria in the vagina and cause infection to occur. Douching with water is okay. Sexual aids such as vibrators are fine to use. Just remember to be gentle. Clean the vibrator after every use.

**Men**

Although infertility is possible, birth control should be practiced. You can have a sperm count done to determine if you are sterile. Chemotherapy can cause your semen to appear brown or burnt orange with the first few ejaculations. If you continue to have brown discharge, pain, or inability to attain or sustain an erection consult your physician. Also, if you are unable to sustain or obtain an erection and you feel that your interest in sexual activity has not returned, consult your doctor. Your testosterone levels may be low due to chemotherapy. Your testosterone may need to be replaced.

**Infertility (Men & Women)**

Infertility generally follows high-dose chemotherapy or radiation treatment. Sperm or egg banking should be done well before admission for transplantation if this is a concern. An interruption in the menstrual cycle is common in women, and, long-term estrogen
replacement may be recommended. However, fertility may recover in a small percentage of both men and women. Birth control measures are recommended while you are taking medications related to transplantation.

**Calling the Transplant Team**
If you do get an infection, your doctor should be notified immediately. The following is a list of signs and symptoms that should be reported:

- A temperature greater than 100.5 degrees F.
- A persistent cough.
- Shaking chills with or without fever.
- Persistent nausea and vomiting.
- Persistent pain.
- Diarrhea, constipation or pain with bowel movements.
- Shortness of breath.
- Excessive fatigues, irritability, or lethargy.
- Chills that occur after your central line is flushed.
- Redness, swelling, drainage, or tenderness at your catheter site.
- Pain, burning, or increased frequency with urination.
- Sores in the mouth or throat.
- Any sore or wound that does not heal.
- Swelling in any area after injury.
- Unusual vaginal discharge or itching.
- Development of a rash on your skin.
- Presence of blood when vomiting.
- Blood in your urine or stools (red or black).
- Persistent nausea, vomiting, constipation, or diarrhea.
- Exposure to chicken pox.
- Sudden bruises or hives.
- Headache that persists or any severe headache.
- Blurry vision.
- Persistent dizziness.

**Call 911 in an emergency situation.**
The Bone Marrow Transplant doctor can be reached by calling the page operator at (858)657-7000.
CLOSING REMARKS

We hope you have found the information in this manual a valuable resource. Please refer to it as needed, bring it to the hospital when you are admitted and to your clinic and infusion center appointments. Keep in mind we are available to answer questions that you may have about your plan of care and the transplant process.

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We welcome your comments about this manual and its contents. Please write to:

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Additional copies of this manual can be located on-line at

RESOURCE GUIDE

American Cancer Society
800-227-2345
www.cancer.org
Brochures on cancer and treatment options; support groups.

Blood & Marrow Transplant Information Network (BMT InfoNet)
888-597-7674
www.bmtinfonet.org
Books, recommended reading, monthly newsletter, and on-line support network.

Cancer Care, Inc.
800-813-4673
www.cancercare.org
Publications, counseling services, and financial aid.

Cancer Legal Resource Center
866-843-2572
www/disabilityrightslegalcenter.org
Information and resources on cancer-related legal issues, including insurance, health care, employment, family, finances, and government benefits.

fertile HOPE, Fertility Resources for Cancer Patients
855-220-7777
www.fertilehope.org
Education and support for cancer patients dealing with fertility issues.

International Myeloma Foundation
800-452-2873
www.myeloma.org
Education, support, and research updates.

Kids Konnected
800-899-2866
www.kidskonncected.org
Free programs for children who have a parent with cancer.

Leukemia and Lymphoma Society of America
800-955-4572 or 858-277-1800 (San Diego/Hawaii Chapter)
www.lls.org
Publications, support services, and financial aid.
National Bone Marrow Transplant Link (BMT Link)
800-546-5268
www.nbmtlink.org
BMT information, publications, and links patients with BMT survivors. “Survivor’s Guide for Stem Cell Transplant” can be ordered or downloaded.

National Marrow Donor Program (NMDP)
800-627-7692
www.bethematch.org
The NMDP has a data bank of volunteer marrow donors.

OncoLink
www.oncolink.com
Information on cancer types, treatment, coping, resources, and reading lists.

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org
Help with insurance and healthcare access problems, attorney referrals.

Planet Cancer
www.planetcancer.org
An international community of young adults with cancer (ages 18-40). The site offers information, entertainment, and support.

The Bone Marrow Foundation
800-365-1336
www.bonemarrow.org
Financial aid, education, resources, and emotional support.

Personalized Websites:
Caring Bridge
651-452-7940/651-789-2300 (Customer Service)
www.caringbridge.org
Free, private, personalized websites for easier communication with family and friends.

Care Pages
888-852-5521
www.carepages.com
Free personal, private web pages that help family and friends communicate when someone is facing illness, both in English and Spanish.

For additional resources, please contact your BMT social worker.
GLOSSARY OF TERMS

Advanced Healthcare Directive
An advance directive identifies a person whom you have chosen to make health decisions for you if you are unable. It assigns someone you trust to make choices in whatever situation arises-based on the stated preferences in your living will.

Allogeneic Transplant
The use of a donor's hematopoietic cells to restore bone marrow function and blood cells after receiving high dose chemotherapy. Hematopoietic cells are obtained from a genetically matched individual who is usually a brother or sister, but may be an unrelated volunteer donor.

Alopecia
Hair loss.

Anemia
A low number of red blood cells. Symptoms may include fatigue, weakness, pale skin color, dizziness and headaches.

Antibiotic
A drug used to prevent or fight infection from bacteria.

Antidiarrheal
A drug that helps relieve diarrhea.

Antiemetic
A drug used to relieve nausea and vomiting.

Antifungal
A drug used to prevent or fight infections from fungi.

Antineoplastics
Drugs used to treat cancer, refer to Chemotherapy.

Antiviral
Drugs to prevent or fight viral infections.

Apheresis
The collection of immature hematopoietic cells from the blood. This is accomplished using a blood separating machine that sorts the blood cells.

Aspiration
The removal of fluids from the body by suction.
**Autologous transplant**
A transplant in which the patient’s own bone marrow or stem cells are used.

**Bacteria**
Living organisms that can be seen only under a microscope and that can cause infection.

**Biopsy**
The removal of a small amount of tissue from the body to be studied under a microscope in order to determine the presence or absence of disease.

**Blood cells**
Cells that make up the blood, including red blood cells, white blood cells, and platelets.

**Blood count**
A lab test to determine the number of cells in blood.

**Blood transfusion**
To replace blood cells in the blood stream when there is a deficiency of a particular type (e.g., platelets, red blood cells).

**Bone marrow**
A spongy substance, which fills the hollow spaces in bones. This is where blood cells (red, white and platelets) are produced.

**Bone Marrow Biopsy**
A procedure used to obtain a sample of bone marrow from the hip bone for microscopic examination.

**Bone Marrow Harvest**
The collection of immature hematopoietic cells from the hip bones. This procedure is performed in the operating room.

**Catheter**
A hollow tube inserted into a body cavity (i.e. vein, bladder, etc.) to drain fluid or instill medications, fluids, etc.

**Central venous catheter**
A small, soft plastic tube inserted into the large vein above the heart through which medication can be given and blood drawn.

**Chemotherapy**
A drug or combination of drugs used to kill cancer.

**Conditioning regimen**
The combination of chemotherapy drugs and/or radiation used to prepare your body for bone marrow transplantation.
Cryopreserve
A process by which something (such as cells, sperm or embryos) is frozen to preserve it for later use.

Cytomegalovirus (CMV)
Transmission of CMV occurs from contact with another person’s saliva, urine, or other bodily fluids. CMV can be sexually transmitted or transmitted through breast milk, transplanted organs and rarely from blood transfusions.

Day zero
Day zero is the day of your bone marrow, stem cell or cord blood transplant.

Dehydration
Abnormally low body fluids. Symptoms include flushed, dry skin, decreased urine output, thirst, weight loss, dark urine.

Diuretic
A drug which increases the elimination of water and salts (urine) from the body.

DMSO - Dimethylsulfoxide
A chemical preservative used when stem cells are frozen.

Donor
An individual who will donate hematopoietic cells for another individual. Types of donors include siblings (brothers/sisters) and unrelated volunteers. The donor and recipient may be fully matched and partially matched. One type of donor is a haploidentical donor. A haploidentical donor is an approximately 50% match.

Durable Power of Attorney
Refer to Advanced Healthcare Directive.

Edema
The accumulation of fluid in parts of the body causing swelling.

Eligibility
A series of tests of organ function (heart, liver, kidney and lungs) that determine if you are healthy enough to undergo a transplant.

Engraftment
The time when the transplanted cells begin to manufacture new cells in the bone marrow (white blood cells, red blood cells and platelets).

Gastrointestinal tract
The digestive system, including the mouth, esophagus, stomach and intestines.

Genes
Structures that transfer hereditary information from cell to cell.
Graft-vs.-host disease (GVHD)
A common complication of allogeneic transplants. It occurs when the new marrow (the graft) recognizes the recipient (the host) as foreign and sends out lymphocytes to attack it. It can involve the skin, liver, gastrointestinal tract and other organs.

Granulocytes
A category of white blood cells that contain granules in their cell body.

Granulocyte-colony stimulating factor (G-CSF, Neupogen)
A medication that makes the bone marrow produce more stem cells.

Growth factor
An agent that stimulates growth of cells.

Haploidentical donor
Transplant used for patients that do not have a HLA identical sibling donor, only half-matched. Can be a sibling, parent or child.

Hematopoietic stem cells
Hematopoietic means blood. Hematopoietic cells are blood cells. Immature hematopoietic cells, often called stem cells, can divide and mature into white and red blood cells or platelets.

Human Leukocyte Antigen (HLA)
The human leukocyte antigen system is a group of markers on the surface of your immune cells. The human leukocyte antigens are inherited. These markers are used to find a donor within your family or from the registry of volunteer donors.

Hemoglobin
That part of the red blood cell that carries oxygen around the body. A low hemoglobin may indicate a low number of red blood cells, or anemia.

High-dose chemotherapy
The treatment of disease through very high doses of anticancer drugs, also referred to as the preparative regimen.

Hydration therapy
Intravenous fluids given to make sure the kidneys are functioning properly.

Immune
A state of adequate protection against certain infections or foreign substances.

Immune system
A group of organs, cells and other substances in the body that fights disease.

Immunosuppressants
Medications given to weaken the immune system to prevent graft versus host disease.
**Immunosuppressed**
When the body's immune system is weakened and less able to fight infection and disease.

**Incentive Spirometer**
A small breathing device that is used to help prevent infections in the lungs.

**Infection**
The increase and invasion of disease producing organisms within the body.

**Inflammation**
Swelling, sometimes due to infection.

**Infertility**
The inability of a couple to achieve a pregnancy.

**Informed consent**
Your formal authorization to the hospital to perform transplant procedures. They are written in medical terms with detailed descriptions of the risks and side effects associated with BMT including potential long-term complications.

**Intake and Output (I&O)**
A measure of the amount of fluids you take in and the amount of all body fluids put out.

**Intravenous (IV) infusion**
Delivering fluids or medicine directly into the bloodstream through a vein.

**Living Will**
Refer to Advanced Health Care Directive.

**Low microbial (bacterial) diet**
A diet to decrease the risk of getting a food related infection.

**Lumbar puncture (LP)**
Technique used for removing small amounts of the fluid that bathes the brain and spinal cord. This fluid is tested for the possible presence of cancer cells as well as bacteria and other substances.

**Lumens**
Lines or tubes attached to a surgically placed catheter.

**Lymphocytes**
The white blood cells which form antibodies necessary for immunity to specific diseases.

**Matched unrelated donor (MUD)**
A type of allogeneic transplant using a donor from the general population who is not related to the patient but who is a very close HLA match.
**Microorganisms**
A microorganism can be a bacteria, virus, protozoa or fungus. Microorganisms cause infections in individuals with low white blood cell count or who are taking immunosuppressants (medications that weaken the immune system).

**Mobilization**
A process to increase the number of immature hematopoietic cells in the blood. By mobilizing (moving) the immature hematopoietic cells from the bone marrow into the blood, these cells can then be collected from the blood. Mobilization can be accomplished using high dose chemotherapy and/or a hormone that stimulates the bone marrow to make more hematopoietic cells.

**Nadir**
When the WBC is at its lowest, usually 7-10 days after chemotherapy.

**Neupogen**
Trademark name of the drug that makes the bone marrow produce more stem cells.

**Neutropenia**
Lack of white blood cells.

**Pasteurized**
Exposed to an increased temperature for a time long enough to destroy certain microorganisms that can produce disease or spoilage.

**Peripheral blood stem cells (PBSCs) or Peripheral blood progenitor cells (PBPCs)**
Stem cells that circulate in the blood stream.

**Petechiae**
Tiny pinpoint red spots on the skin or in the mouth, which indicate a low level of platelets.

**Physical therapy**
Provides intervention to restore or maximize the physical abilities of patients of all ages. The focus is to provide patients with the means to maximize functional independence.

**Platelet**
One of the main components of blood that produces clots to seal up injuries and prevent excessive bleeding. Also called thrombocyte.

**Preparative regimen**
The chemotherapy or radiation therapy given before transplant.

**Progenitor Cells**
Another name for stem cells; young blood cells found in the bone marrow, from which all other types of blood cells develop.

**Red blood cells (RBCs)**
Cells that carry oxygen to all parts of the body. Also called erythrocytes.
**Side effects**
Reactions to drugs that are usually temporary and reversible. They do not relate to drug effectiveness.

**Sitz Bath**
A device that is used to clean around the rectal area.

**Stem cells**
Young blood cells found in the bone marrow, from which all other types of blood cells develop.

**Syngeneic Transplant**
A transplant from an identical twin.

**Thrombocytopenia**
A low platelet count. A low platelet count increases the risk of bleeding.

**Topical**
Applied to the skin.

**Total Body Irradiation**
Treatment using high-energy radiation.

**Transfusion**
Administering blood cells to minimize the symptoms of anemia or platelets to reduce the risk of bleeding.

**Umbilical Cord Transplant (Cord Blood)**
Transplant using cells from a newborn’s umbilical cord.

**Vascular access device (VAD)**
A long, narrow tube that is surgically placed into a large vein leading directly to your heart.

**White blood cells (WBCs)**
A variety of blood cells that help fight infections. Also called leukocytes.