

Allogeneic Stem Cell Transplant

Patient Education Guide 2021 Edition

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CHAPTER 1. GETTING STARTED

About This Book

If you are reading this book, either you or a loved one is being considered for an *allogeneic blood and marrow transplant,* or "BMT," at Cedars-Sinai.

"Bone marrow transplant" and "peripheral blood stem cell transplant" all refer to similar procedures that use cells collected in different ways. We will refer to both of these types of transplants using the term hematopoietic (blood-forming) stem cell transplant (SCT).

Your transplant doctor, **SCT nurse navigator ("navigator")** and nurses will teach you all about your transplant.

There is a lot of information that we need you to know about and understand. Please bring this book with you when you are admitted. The *inpatient* staff will be referring to it. Continue to bring it to the hospital even after you have been discharged.

We encourage your main caregiver (spouse, partner, etc.) to read this book as well.

Words that are written in **bold italics** are defined in the GLOSSARY at the end of the book.

History of Blood and Marrow Transplant

Doctors first began investigating **bone marrow transplantation** in the 1950s. They discovered that **stem cells** from the **bone marrow** given through an IV could regrow in damaged bone marrow and produce healthy new blood cells.

BMT is recognized as an effective treatment for certain types of malignant (cancer) and nonmalignant (non-cancer) diseases. Stem cells are collected from either the blood or the bone marrow.

At Cedars-Sinai, the BMT Program was founded in 1990. Since then, we have completed thousands of blood and marrow transplants.

During a blood and marrow transplant, high doses of chemotherapy are given to eliminate the disease or reduce the risk that it will come back. Sometimes radiation is also used. As a result of therapy, the bone marrow is destroyed and needs to be replaced with healthy *stem cells*.

Stem cells are collected from either the blood or the bone marrow. The transplant occurs when the collected stem cells are infused through an IV into the patient.

When a person's bone marrow is replaced with their *own* stem cells, this is called an *autologous stem cell transplant (SCT)*. If the bone marrow is replaced by *someone else's* stem cells, this is called an *allogeneic SCT*. This book discusses topics specific to allogeneic SCT. Autologous SCT is a different procedure and covered in a different book.

What Are Blood Stem Cells?

Imagine a family tree. The stem cell is the ancestor at the top. All of the descendants come from that ancestor. Like relatives, they look different and perform different functions. Blood stem cells originate inside bone marrow, the spongy tissue deep inside of bones. They also float around in circulating blood. We refer to those as *peripheral blood stem cells* or PBSCs.

Key fact:

Stem cells are the grandfathers of all blood-forming cells.

Stem cells can be collected from the bone marrow *or* the circulating blood. We will discuss this in more detail in Chapter 4.

Complete Blood Count (CBC): The Basics

Blood stem cells reproduce and divide into three main cell types:

- White blood cells (WBCs)
- Red blood cells
- Platelets

1. White Blood Cells (WBCs)

WBCs make up your immune system. They are warriors that fight infections caused by invaders like *bacteria*, *viruses* and *fungi*. White blood cells are also involved in *allergic reactions*.

One specific type of white blood cell is the *neutrophil*. When your neutrophil count is low (below one thousand), you are *neutropenic*. When you are neutropenic, you are at risk for infection because your immune system does not have enough warriors to fight back effectively.

You will hear your transplant team talk about your **ANC**, or **absolute neutrophil count**. This is the specific number of neutrophils you have that are capable of fighting infections.

Normal range for WBCs=4–11 (thousand) and normal range for ANC=1.8–8 (thousand).

2. Red Blood Cells

Red blood cells contain *hemoglobin* (Hgb). Hemoglobin is a vehicle that carries oxygen around round your body. It is what gives you rosy cheeks and pink nail beds.

When hemoglobin levels are low, it is called *anemia*. Symptoms of anemia include fatigue, shortness of breath and a fast heartbeat.

A transfusion of packed red blood cells (PRBCs) can raise the hemoglobin and temporarily improve anemia.

Typically, we transfuse PRBCs when the hemoglobin is less than 7 G/dL. The normal range for hemoglobin is 13-17 G/dL.

3. Platelets

Platelets help with blood clotting. When you cut yourself, platelets plug the injury and stop the bleeding.

When platelets are low, it is called *thrombocytopenia*. This condition carries a risk of spontaneous bleeding. The bleeding could occur on the outside (like a bruise or a nosebleed) or on the inside (in the intestines or brain).

Platelet transfusions can temporarily improve low platelet levels. Typically, we transfuse when the count is less than 10 (thousand). The normal range for platelets is 150-450 thousand.

White blood cells, red blood cells and platelets make up a complete blood count or CBC.

Chemotherapy and Total Body Irradiation

The National Cancer Institute defines *cancer* as abnormal *cells* that divide without control and invade other tissues.

Chemotherapy destroys rapidly dividing cells, making it an effective cancer treatment.

There are hundreds of types of cancer, and just as many different types of chemotherapy. A lot of research has been done to decide which chemotherapy drugs and doses work best for each type of cancer.

The chemotherapy drugs used in the SCT have a common feature: the higher the dose, the greater the number of cancer cells destroyed. If the cancer is in remission, the goal of giving high-dose chemotherapy and immune therapy is to prevent the cancer or bone marrow disorder (i.e., *aplastic anemia*) from coming back.

Chemotherapy cannot tell the difference between a rapidly dividing cancer cell and a rapidly dividing healthy cell. The destruction of healthy cells results in side effects from chemotherapy.

Radiation therapy is often also used in SCTs. It reduces the risk of cancer coming back but also helps with immune suppression.

Chemotherapy and radiation prior to BMT is called *conditioning.* Another term that may be used is *preparative regimens*, because these treatments prepare your body to accept the donor's stem cells.

Healthy cells that divide rapidly include:

- Hair. This is why many cancer patients lose their hair. Luckily, this is temporary, and the hair grows back when treatment is over. Regrowth of hair usually begins around three months after the SCT. In the meantime, we can provide you information on head/wig-covering resources.
- **Gastrointestinal (GI) tract.** These cells line your throat, stomach and intestines. Damage to these cells causes nausea, vomiting, diarrhea and mouth sores. Medications can help alleviate some of these symptoms.

• **Bone marrow/blood cells.** Destruction of these cells is called **myelosuppression**. To measure this, we check the complete blood count (CBC). When your CBC numbers are below the normal range, you are **myelosuppressed**. This results in neutropenia, anemia and thrombocytopenia, as described above.

High doses of certain chemotherapy drugs are very effective at treating cancer, but they cause severe myelosuppression, also called *myeloablation*. This means that the chemotherapy destroys the *bone marrow* beyond its ability to ever recover.

To safely recover from high-dose myeloablative chemotherapy, your bone marrow must be "rescued" with healthy stem cells. This is the purpose of the SCT. The healthy stem cells need to be donated from someone else. This person is your donor.

More about *conditioning* will be described later.

Finding the Right Donor: HLA (Human Leukocyte Antigen) Typing

HLA refers to proteins that live on the surface of **white blood cells**. The proteins help your immune system recognize which cells belong inside your body ("self") and which cells do not ("non-self").

Think of HLA typing like a fingerprint on the surface of cells inside your bone marrow. It has nothing to do with your blood type. The HLA system is very diverse, with over a quintillion different possible protein combinations! Your unique combination is inherited. Half of your typing comes from your mother and the other half from your father.

HLA testing is how we find you a donor for *allogeneic* SCT. The test requires a blood sample and sometimes a swab of your cheek. Potential donors also give a blood sample, and their results are compared to yours. A suitable donor has the same, or almost the same, HLA "fingerprint" (HLA typing) as you.

The HLA markers we look at are called HLA-A, B, C, DRB1 and DQ. These five pairs make a total of 10 markers to match. Although a "10 out of 10" match is ideal, there is the ability to transplant 'half-matched" (*haploidentical*) related donors.

Please see specific chapters to find further information about HLA testing on siblings, other relatives and unrelated donors.

Processing time: Once the HLA lab receives the blood, results take 7-10 business days to process. The search process can take a while, and sometimes it may feel as though nothing is happening. Rest assured, your SCT coordinator will be checking for results and notifying you immediately when they come back. If you would like an update on the status of the HLA results, please reach out to your SCT navigator for an update at any time.

More information about the donation and the SCT products are described in Chapter 4.

Allogeneic Blood and Marrow Transplant: An Overview

Allogeneic is defined as "taken from different individuals of the same species." In the setting of **Blood and Marrow Transplant**, allogeneic refers to a procedure in which a person receives **stem cells** from an HLA-matched donor. The donor may be a sibling, an unrelated person or a baby's umbilical cord blood.

Related donor stem cells are normally collected at Cedars-Sinai. This process is explained in more detail in Chapter 4.

Unrelated adult donor *stem cell* collections are organized through a registry called the National Marrow Donor Program/Be the Match. The stem cells are then delivered to Cedars-Sinai by courier.

Conditioning refers to the high-dose **chemotherapy** and sometimes **radiation** given before the transplant. This is also known as the **preparative regimen** because it prepares the body to receive the donor cells. This therapy is given over a number of days depending on the preparative regimen selected. Sometimes the conditioning chemotherapy is given before admission for the transplant.

Once conditioning therapy is complete, the transplant will occur. The donor's collected stem cells are infused into the patient through a vein. It occurs like a blood transfusion. Tylenol[®] and Benadryl[®] are typically given before the transplant to reduce the risk of a reaction. An experienced nurse performs the SCT infusion at the bedside.

Following the infusion of stem cells, or "transplant," is a hospital stay of three to six weeks. During this time, the patient is monitored very closely for side effects. The side effects from conditioning therapy include:

- Low blood counts
- Fever and Infection
- Fatigue
- Bleeding
- Nausea, vomiting and diarrhea
- Mouth sores
- Decreased appetite
- Skin rash

The healthcare team will be managing these side effects with medications, bloodtransfusions, IV fluids and interventions as appropriate.

Each day, the *complete blood count (CBC)* will be checked. After conditioning therapy, the CBC values will drop below normal. The *neutrophil* count will fall close to zero and can remain low for several weeks. During that time, the patient is at high risk for infections. That can be the time when you feel the sickest. When the WBCs start to recover, patients often start to feel better. This is called *engraftment*. After four to six weeks, you will be discharged home.

Discharge from the hospital is dependent on the following factors:

- 1. Blood counts have returned to a level the doctor feels is safe.
- 2. No fever or need for IV antibiotics.
- 3. Ability to drink fluids; nausea/vomiting/diarrhea controlled by oral medications.
- 4. Ability to walk and function safely at home.
- 5. Discharge medications are in hand and the medication schedule is understood.

The patient will be required to see their transplant doctor frequently in the first 100 days after transplant.

Chapter 6 will go into greater detail about conditioning therapy, transplant, short and long-term side effects, recovery and post-transplant instructions.

Timeline

The timeline varies depending on the availability of the donor. Once a donor is identified, the hospital admission lasts on average three to six weeks, but complications may extend this timeframe. Factors affecting length of stay include:

- Donor source (sibling, unrelated donor or cord blood)
- Intensity of *conditioning regimen* (myeloablative, reduced intensity or nonmyeloablative)
- Age and overall general health going into transplant
- Time to engraftment
- Individual response

Recovery after discharge may take several months to even a year or more. Individual cases vary. In some cases, it may be possible to have some or all of your *allogeneic* SCT done as an outpatient. Your doctor will let you know if this is a safe option for you. Typically, this is only offered to patients who can stay close to Cedars-Sinai

CHAPTER 2: PRE-TRANSPLANT TESTING

Work-Up Requirements and Results

Before you are admitted to the hospital for transplant, you must complete a "pre-transplant *work-up." There are two reasons why this is necessary:*

- 1. The transplant team must be certain that the organs are functioning normally before high-dose *chemotherapy.*
- 2. The insurance company requires these results to authorize payment for the transplant.

Pre-transplant testing may be completed at Cedars-Sinai or through a local doctor.

All patients must complete:

- *Echocardiogram*: This is an ultrasound of the heart to show how well it pumps blood to the body.
- Electrocardiogram (EKG): Measures the electrical activity of the heart.
- **Pulmonary function test:** Measures the lungs' ability to perform effective breathing and oxygen delivery. This test requires you to follow instructions to breathe in, hold your breath and exhale forcefully. Caffeine and smoking are not allowed on the day of testing as they will affect the results.
- Chest X-ray: Evaluates the heart, lungs and chest wall for abnormalities.
- **Blood and urine tests:** Evaluate kidney and liver function, complete blood count, and in some cases, help to measure disease status.
- Infectious disease panel: You are screened for a variety of previous virus infections. Please be aware that HIV testing is done on all SCT patients.
- Social work consult: A Cedars-Sinai SCT social worker will meet with you to assess psychological, social, emotional and practical needs. Please come prepared with your plan to have a caregiver 24 hours, 7 days a week for the first 100 days post-transplant, except when you are in the hospital. Your main caregiver should be present at this appointment. If your caregiver cannot attend, the social worker will need to speak with them by phone prior to moving forward with transplantation. Depending on your medical condition post-transplant, you may be required to arrange for local housing close to Cedars-Sinai. Please have a plan ready and discuss it with your social worker and medical team. The social worker can provide you with resources for housing, financial and other practical resources.

Some patients will also need:

- **Bone scan:** Uses a small amount of radioactive material to create images of bones on a computer screen. This test is useful in finding the spread of cancer to bones.
- **Bone marrow biopsy:** A sample of **bone marrow** is examined to confirm disease status and/or remission.

- **Computerized tomography (CT) scan**; A series of X-ray pictures taken of the body from different angles to search for abnormalities. This test is often done at the same time as a PET scan to confirm findings.
- **Dental evaluation**: It is highly recommended that you see your dentist prior to having a transplant. Any dental work should be completed BEFORE chemotherapy is given. Please speak to your transplant doctor about this.
- *Magnetic resonance imaging (MRI) scan*: Uses very high-powered magnets to form detailed pictures of the body's soft tissues and identify areas where tumors are present. You may not be able to have an MRI if you have any metal inside your body.
- *Multigated acquisition (MUGA) scan:* Creates video images of the lower chambers of the heart to check whether they are pumping the blood properly. A small amount of a tracer imaging dye is infused through a vein that helps the camera see the pumping of your heart.
- **Positron emission tomography (PET) scan:** You are injected with a small amount of radioactive sugar that **cancer** cells quickly consume. This causes them to light up on the scan so that the doctor can easily visualize their location in the body. You need to fast prior to the PET scan to make sure that your own body sugar is not too high.
- **Tissue-specific biopsies:** A small sample of tissue (e.g., a lymph node) is removed and examined in the lab. This confirms the presence of disease in a specific location.
- **Pregnancy testing and fertility planning:** If you are a female and of childbearing age, a pregnancy test will be required before admission. For both men and women, it is important that you discuss fertility concerns and contraception with your doctor prior to transplant.

Not every patient is a good candidate for an allogeneic blood and marrow transplant. There are many factors that must be considered before moving forward, such as:

- Response of the cancer or disorder to chemotherapy/radiation and other treatments
- Organ function (heart, lungs, liver, kidneys)
- Overall health and activity level
- Social support and the ability to follow important instructions related to medical care

Your transplant doctor will review your medical situation carefully before an approval for the SCT is given. This is to evaluate the safety of the transplant and its potential benefit.

The transplant team may decide that you do not qualify for a transplant because they believe the risks outweigh the benefits. If that occurs, then your doctor will discuss other treatment options and/or make additional recommendations for your care. It may still be possible to get to transplant later depending on your current situation and what needs to be done to get you there.

The following may be suggested:

- Other types of treatments/chemotherapy/radiation.
- A *clinical trial* at Cedars-Sinai if one is available, or at another hospital.
- Another opinion from a hospital that may have different standards than Cedars-Sinai.

Please feel free to discuss this with your SCT doctor.

Getting Ready Physically and Emotionally

As you prepare for your SCT, talk to your doctor about ways you can help yourself prepare for this treatment. Your doctor may recommend activities and perhaps specific exercises to help get you physically stronger. We realize that the time prior to SCT may create feelings of anxiety as you are going through the medical evaluations. Exercise, as guided by your doctor, can be a very useful way to reduce anxiety and stress while optimizing your fitness level going into theSCT.

Nutrition is important to help you maintain your weight and strength during the transplant process. The chemotherapy you will receive during your stem cell transplant will affect your nutrition in many ways. You may find that you are not eating the way you normally do because of nausea, mouth and throat soreness, lack of appetite or changes in the way foodstaste. You will meet with a registered dietitian to help guide you on the best food choices before, during and after transplant.

Emotional readiness is important as well. Speak to the medical social worker or other team members of our support services as needed.

Smoking Cessation

Cedars-Sinai is a completely smoke-free campus. All patients and visitors coming to Cedars-Sinai must be aware that smoking or vaping is not permitted anywhere on campus. There is no smoking on sidewalks, in parking structures or inside vehicles (whether parked or driving through campus).

Certain insurance companies will not pay for the *SCT* if you are a smoker. They may require the signing of a no-smoking contract and periodically request blood or urine tests to ensure compliance.

Feel free to discuss options for quitting with the **SCT nurse navigator**, clinical social worker or your doctor.

Alcohol and Drug Addiction

Like smoking, some insurance companies will not authorize the SCT if you have an alcohol or other drug addiction. They may require a contract be signed and blood tests to periodically screen for these substances.

Being honest with your transplant team about these issues is very important. Our goal is to get you through the SCT safely. In order to do that, we need to know if you have any alcohol or drug-related problem or concern. We will then direct you to the right professional and resources for help.

The transplant team can help you meet the requirements by making appropriate referrals based on your addiction and your commitment to overcome it.

CHAPTER 3. DONOR TESTING AND COLLECTION

Sibling/Related Matched Donor (MRD) and Half-Matched (Haploidentical) Related Donor

If your sibling is an HLA match to you, they are a "Matched Related Donor" and may donate *stem cells* for your SCT. Another option is a "Half-Matched" (*Haplo*) related donor who may donate stem cells for your SCT.

It can be an exciting, heartwarming experience to receive stem cells from your relative. It can also be very stressful.

Many patients are concerned about what their relative must go through in order to donate. This chapter discusses the details.

You have a 25% (1 in 4) chance of matching a sibling that has the same mother AND father as you do. This does not mean that if you have four siblings you have a 100% chance at finding a match. You have a 50% (1 in 2) chance of half-matching with a parent or your child.

Imagine rolling the dice and one of the chances is an HLA match. If you have four siblings, you get to roll that dice four times. If you have three siblings, you get to roll three times, etc. With each roll you have a 25% (1 in 4) chance of finding a 100% match. With each roll you have a 50% (1 in 2) chance of finding a 50% match.

Friends and family that wish to be tested may contact the National Marrow Donor Program at <u>bethematch.org</u> or by calling 1-800-MARROW2 (1-800-627-7692). Insurance authorization is requested prior to HLA testing. If there are copays or limits to your policy's donor search benefits, you will be notified up front. If you or your sibling(s) receive a bill for HLA testing or if you have questions, please contact our financial coordinator.

There are **two options** for HLA typing your relatives:

1. They may come to Cedars-Sinai

Your *navigator* will give them a doctor's order to have blood drawn at a Cedars-Sinai outpatient laboratory. There is no charge for this service. *OR*

2. They may have their blood drawn at a local lab or doctor's office

Your *navigator* will FedEx[®] empty blood tubes, a doctor's order, and instructions to the address you provide. A prepaid FedEx[®] envelope is included to return the blood to Cedars-Sinai for testing.

There may be a fee charged by local labs/offices for drawing the blood. We recommend your sibling ask about fees prior to having their blood drawn, as insurance never covers these costs.

It is very important that you provide the legal full name as it appears on their identification, date of birth, address and phone number of all of your relatives. Samples returned by mail must have the full name, date of birth and date the blood was drawn labeled on the blood tube.

Missing or inaccurate information may result in the blood sample being thrown away and will delay identifying your donor!

Once a match is identified and your pre-transplant testing is complete (see Chapter 2), insurance authorization for the transplant will be requested.

The transplant authorization covers the required testing and procedures for your donor. Your donor does not have to have their own medical insurance in order to donate for you.

Related Donor Pretesting

Related donor testing will be done at Cedars-Sinai. It takes about four hours to complete and includes:

History and physical with the SCT doctor.
 The SCT doctor they see will not be the same as the one

The SCT doctor they see will not be the same as the one you see. This is to ensure that they have a doctor acting on their behalf, not one that already has a relationship with you. Questions about their health, travel and lifestyle will be asked. This is part of screening for infectious diseases.

- **Informed consent.** You are not permitted to attend this appointment. It is a private discussion between your relative and their SCT doctor. The risks and benefits of donating will be explained to them and they will have an opportunity to ask questions. Donating **stem cells** for you is their choice. The doctor will move forward if your relative is voluntarily agreeing to the procedure, meets medical clearance and signs the consent forms.
- Chest X-ray. Standard procedure to look for abnormalities in the heart, lungs and chest.
- EKG (electrocardiogram). To measure electrical activity inside the heart.
- **Blood and urine testing.** Testing for a variety of infectious diseases such as HIV, hepatitis and other *viruses* will be done in the Rita and Taft Schreiber Blood Donor Facility. A complete blood count and chemistry panel will also be drawn to evaluate basic organ function.
- **Donor education.** Your navigator will ensure your relative understands the process and schedule for donating stem cells. They may contact the navigator anytime if they have further questions.
- Sometimes relatives have a medical condition that would normally exclude them from donating. Your SCT doctor will decide whether medical necessity outweighs the risks involved in using them as your donor. In this case, you will be notified, and the risks will be explained to you.
- When all the results are reviewed and your relative has signed the consent to donate, your admission to the hospital will be scheduled. Usually, *conditioning chemotherapy* begins before your relative's stem cell *mobilization* and harvesting (or collection).

Mobilization

Mobilization is the process of using medications called *growth factors* to move stem cells from the *bone marrow* and into the circulating blood.

The growth factor medication used to move the stem cell from the bone marrow to the blood is called Filgrastim. It is given as a small injection under the skin (*subcutaneous*). This is called "*Mobilization.*" This medication is given for four days in a row in the Cancer Center. On the fifth day, stem cell collection takes place. The main side effect from Neupogen[®] is bone pain. The donor can take Claritin[®] or Allegra[®] on days the donor is getting growth factors, as they may reduce bone pain.

Other side effects include:

- Low-grade fever
- Left-side abdominal pain. This is a very rare complication that needs to be reported right away to your nurse or doctor as it could indicate a problem with the spleen.

Your donor should let the nurse know if they are experiencing side effects so an appropriate medication may be suggested.

After mobilization, it is time to collect or harvest these stem cells. There are two ways to harvest the stem cells: through peripheral blood or directly from the bone marrow.

Harvesting of Peripheral Stem Cells

Stem cells are collected from your donor's circulating blood. These are called *peripheral blood stem cells* or PBSCs. On collection day, your donor will come to the Cancer Center first for Neupogen[®]. Then, a special IV line must be placed. There are two possible ways to collect PBSCs:

1. Two needles (one in each arm) are placed into the vein right below where the arms bend at the elbow. This is the same vein that is used for a whole blood or platelet donation. This method may only be used for donors that have very good veins and can sit for four hours without bending their arms.

2. A special IV line called an apheresis catheter or internal jugular (IJ) is placed into the large vein (internal jugular vein) inside the donor's neck. One type is called "Mahurkar." The line is held in place by a suture and a sterile dressing. This may feel uncomfortable due to its location on the neck. This will only be required until stem cell collection is complete.

Things to know:

- This IJ catheter allows us to harvest cells from the circulating blood. It is placed in the Cedars-Sinai Procedure Center by a specially trained doctor with the assistance of specialty trained nurses.
- The area is numbed prior to insertion. Your donor will feel pressure but usually not pain when it goes in.
- Once it is in place, your donor is able to eat, sleep, read or do other quiet activities while their stem cells are being collected.
- The IJ will be removed as soon as the collection is complete, one to two days.

If your donor is claustrophobic or anxious about the IJ, their transplant doctor may prescribe medication to help them relax. Once the IJ is placed, an X-ray will be done to make sure it is positioned correctly. The stem cell collection nurses will assess your donor's veins. In some cases, your donor will get to decide which collection method they would prefer to have.

The process of harvesting stem cells is called *apheresis* and takes place in the Rita andTaft Schreiber *Blood Donor Facility*.

Each session on the apheresis machine is four to five hours long. During that time your donor is resting in bed and the nurse will be monitoring them. The donor may sleep, eat, watch TV or do other quiet activities.

The apheresis machine looks like a cross between a kidney dialysis machine and a washing machine on spin cycle.

Apheresis works like this:

- 1. Blood exits the body through one side of the IJ line.
- 2. It travels through a machine that spins the blood so fast that it separates into different parts.
- 3. The stem cells are removed and collected into a bag hanging above the machine.
- 4. The rest of the blood is returned to your donor through the other side of the line.

All of this happens simultaneously: blood comes out, stem cells removed, blood is returned. Things to know:

- The bags and tubing are sterile and discarded after each donor. Blood never comes into direct contact with any part of the *apheresis* machine.
- There is no risk of contracting any bloodborne illness from apheresis.
- Every drop of blood in the body travels through the tubing in the apheresis machine three to four times. This maximizes the number of stem cells collected.
- Your donor cannot be disconnected from the machine to use the restroom. A urinal, bedpan and commode are available.
- For most donors, the main side effect of apheresis is boredom. However, quiet activities are allowed. The following side effects are also possible:
- **Tingling around the lips and fingers.** This may occur because the anticoagulant being used combines with the calcium in your donor's body. To prevent these symptoms, a calcium IV drip will be running continuously during the stem cell collection.
- **Discomfort.** Sometimes donors find it uncomfortable to lay in bed for four to five hours. *Growth factors* can cause bone pain, which adds to this discomfort. Tylenol[®] can help alleviate this.

If your donor experiences any of the side effects listed above, or feels anything different, they should make sure to let the apheresis nurse know right away.

At the end of each collection day, the SCT navigator will receive the stem cell count. Once enough cells are collected, your donor's IJ line will be removed. At that point the stem cell collection is complete. The donor may resume normal work and activities the following day.

Harvesting From the Bone Marrow

Bone marrow harvesting is a surgical procedure that takes place in the Cedars-Sinai operating room. Sometimes, the bone marrow is harvested in a hospital closer to the donor's home. It does not require "*Mobilization*."

Harvesting in the operating room works like this:

- 1. The donor is put under *anesthesia* during the procedure.
- 2. Bone marrow is pulled out by a needle and syringe placed into the back of the pelvic bone, near the hip.
- 3. To get enough stem cells, multiple aspirations must be taken, until 1-2 quarts have been collected. It sounds like a lot, but actually it is only 2-5% of a person's bone marrow. The donor will regenerate those cells within one month. When the donor wakes up, they may have some discomfort in their lower back. The pain is generally mild and can usually be relieved with Tylenol[®].
- 4. There will be several puncture wounds from where the needle was inserted, but no stitches or surgical incisions. Donors may resume normal activity within a couple of days.
- 5. The donor is usually discharged after recovering in the post-anesthesia care area. The back of the pelvic bone will have a large dressing on both sides. If needed, the donor will be admitted to the hospital for overnight observation.

Common side effects of marrow donation usually last only a few days. They include back or hip pain, fatigue, throat pain and/or muscle pain. Less frequently, donors report insomnia, headache, dizziness, and loss of appetite. (Source <u>bethematch.org/support-the-cause/donate-</u><u>bone-marrow/donation-process/donating-bone-marrow/</u>)</u>

There are advantages and disadvantages to receiving a marrow product or a PBSC product. Your SCT doctor will decide which type of stem cell is preferred for your transplant. The donor, with the advice of their doctor, will decide if they are willing togive what is asked. In most cases, we will accept either product.

RELATED DONORS—Frequently Asked Questions

Is my donor too old to donate?

Age may be a factor in determining whether a donor may donate. Donor testing results and overall health will determine if your relative is eligible.

What if my related donor has a preexisting medical condition?

All preexisting medical conditions will be considered on a case-by-case basis. The SCT doctor will determine whether or not they are healthy enough to safely donate *stem cells* for you. Some medical conditions do not increase the risk of donating at all (e.g., diabetes, high blood pressure), while others would make them ineligible to donate (e.g., HIV, cancer).

Will donating stem cells hurt my donor?

The procedures to collect stem cells are generally well-tolerated and painless. There are minimal risks when donating *peripheral blood stem cells*. Bone pain is the most common complaint. Their BMT doctor may recommend medications to relieve such pain. Mild discomfort may also be experienced from the special IV lines used during peripheral stem cell collection. Donating bone marrow in the operating room also has risks associated with general anesthesia.

Most donors resume normal activities the day after donation.

Can my donor do anything to make their stem cells stronger and improve my transplant?

Unfortunately, no. Relative donors cannot do anything to improve the outcome of your transplant. There are many factors that contribute to the success of a transplant: your diagnosis, the stage of your disease, your age and overall health.

What if my donor does not have medical insurance?

Once we receive authorization for your transplant, your insurance covers your donor's medical costs related to your transplant. This includes their HLA typing, donor testing, stemcell *mobilization* and stem cell collection. Your relative donor will not need medical insurance to donate for you.

What if my donor lives in another state/country?

Your navigator can coordinate with the National Marrow Donor Program[®] related donor services, such as donor evaluation and stem cell collection to be done in their state or country. Application fees and travel costs (including flights) for the donor are usually not covered by your insurance.

Are there other costs that insurance does not pay for?

Costs that are not covered include but are not limited to: loss of salary due to missed work, hotel and transportation costs, personal expenses, fees charged by outside labs for drawing the sample for initial HLA testing.

What if my donor is unavailable during the time I need the transplant?

If your donor cannot be in Los Angeles for the preferred date for your transplant, we may collect their stem cells early and freeze (*cryopreserve*) them. They are placed into a freezer in the Stem Cell Lab until you need them for transplant.

What if my donor is pregnant?

We cannot mobilize stem cells or harvest them if the donor is pregnant. If your transplant cannot wait until after the baby is born, we will look for an unrelated donor for you.

What if my donor and I do not get along?

It is up to you to let your transplant team know if you do not wish to HLA type certain relatives. Because stem cell donation is voluntary, your donor must decide if they are willing to participate. If they are willing to donate and you do not want to accept their *stem cells*, you may opt out of having them as your donor. There are many emotions involved in stem cell donation between relatives. It can bring people closer together, but it also has potential to pull people further apart. It is up to you and your donor to decide what to do. The SCT medical social worker is available to assist with issues related to patient/donor relationships. Please speak with your SCT navigator and/or doctor about any concerns you have about your potential donors.

Will I become more like my donor after transplant?

Yes and no. Your personality will not become more like your donor after SCT. However, you will have their DNA inside your **bone marrow** and will likely convert to their blood type.

What if my sibling is in prison?

We are not able to HLA test incarcerated relatives, so they cannot be donors.

Matched Unrelated Donor (MUD) BMT

About **70%** percent of patients do not have an HLA-matched family member. Depending on the patient's size of family and number of relatives, a half-matched relative may not be available either. For this big group of patients, a half-matched relative or an unrelated donor search is needed.

The National Marrow Donor Program

The National Marrow Donor Program[®], or NMDP, is a nonprofit organization that operates the world's largest **bone marrow** donor registry called Be the Match[®]. Through relationships with international donor and **umbilical cord blood** registries, a single search provides access to millions of volunteer donors worldwide. Your SCT coordinator will work closely with the NMDP to find you a suitable donor for transplant.

Often, friends and family members wish to be tested to see if they are a match for you. They may even want to organize a donor drive. The best way for them to help is by joining the unrelated donor registry. Even if they are not a match for you, they may help another patient in need of a donor. Contact Be the Match at BeTheMatch.org or by calling 1-800-MARROW2 (1-800-627-7692).

Insurance authorization for an unrelated donor search will be requested. Depending on your policy, this process may or may not be covered. You will be notified if we cannot get authorization to perform an unrelated search. The NMDP has some funding available to help patients whose search is not covered by their policy. Your navigator will connect you with these resources if necessary.

Unrelated Donor HLA Testing

Potential donors will be asked to have their blood drawn and sent to Cedars-Sinai for HLA testing. This process may take four to eight weeks to complete. Donors may work or have other commitments, so we must wait until they can schedule their blood draw. Sometimes donors listed have moved or are otherwise unavailable for testing.

Your navigator will monitor the status of each of the requested donors, and let you know when results are available. There is no way to get personal information like the name or address of any potential donor.

Unrelated donors must be at least an 9/10 HLA match to you in order to proceed with transplant.

Before Your Admission

Once the best donor is identified you will be scheduled for pre-transplant testing (refer back to Chapter 2 for more information). The pretesting results will be used to get insurance authorization for the transplant.

Once insurance authorization is received, your navigator will officially request your donor. A backup donor will be requested to remain on hold. If the donor agrees, they will move forward with donor testing.

Unrelated Donor Testing

An unrelated donor will be testing in the city/country where they live. This will happen after you have competed your pre-transplant testing and insurance authorization for the transplant has been received.

Your navigator will know the date testing will take place and receive notice of donor "clearance" if everything goes well. You will not be admitted to the hospital until after donor clearance has been received.

You will be told your donor's gender, age, and what HLA match they are to you (9/10, 10/10,etc.).

Sometimes donors have a medical condition or live in a country that would normally exclude them from donating. Your SCT doctor will decide whether a donor is suitable for you. If there are any potential risks involved with using a particular donor you will be notified, and the risks explained.

Donors are educated about the entire process and asked to sign a consent form. Once they have signed consent and their stem cell collection has been confirmed, your SCT navigator will schedule your admission to the hospital.

Stem cells for SCT can be collected directly from either the donor's bone marrow or their circulating blood (peripheral blood stem cells or PBSCs). There are advantages and disadvantages to receiving a marrow product or a PBSC product. Your SCT doctor will decide which type of stem cell is preferred for your transplant. The donor, with the advice of their doctor, will decide if they are willing to give what is asked. In most cases, we will accept either product.

Unrelated Patient/Donor Confidentiality

SCT patients and unrelated donors are ALWAYS anonymous to one another for a minimum of one year after transplant. In some cases, you are allowed to send anonymous correspondence before one year. Rules about contact vary by country. Please speak with your navigator for more information about donor contact.

UNRELATED DONORS—Frequently Asked Questions

1. Why does it take so long to coordinate an unrelated donor BMT?

In order to maintain strict patient/donor confidentiality, the transplant center and the donor center do not have direct contact with one another. The NMDP serves as a liaison, and they do their best to quickly move requests back and forth between the two. Many attempts are made to contact the top donors on your search, who must then go to have blood drawn. Usually we request 5-10 donors be tested and hope that samples start coming soon. Once samples are received, they take up to 10 days to process. Once a donor is identified, pretesting and authorization take another couple of weeks to complete. Then the donor needs to complete testing, and you must complete your **conditioning regimen**. If you are feeling like nothing is happening during your SCT search process, contact your navigator for an update. We do everything we can to move things forward for you as quickly as possible.

2. What if my donor has a preexisting medical condition?

These will be considered on a case-by-case basis. The SCT doctor will determine whether or not they are healthy enough to safely donate *stem cells* for you. Some medical conditions do not increase the risk of donating at all (e.g., diabetes, high blood pressure), while others would make them not eligible to donate (e.g., HIV, *cancer*).

3. When can I find out who my donor is? Can I send my donor a thank-you gift?

After a year, in most cases, if both you and the donor sign a consent form authorizing personal contact, you can have contact with your donor. Sometimes anonymous contact such as a thank-you card or small gift that does not contain your name or any personally identifying information is allowed before one year.

4. What is the difference between marrow and PBSC (peripheral blood stem cell) product?

The difference is the location from where they are collected. Marrow product is collected from the back of the pelvic bone, near the hip. PBSCs are collected from the circulating blood via a special IV line. In some diseases, marrow product is preferred over PBSCs. In most cases, we will accept either product and are most concerned about the degree of HLA matching (9/10, 10/10, etc.).

5. How do the cells get here?

The cells are hand-carried by a courier, assigned by the donor center. You will not meet the individual carrying the cells. They will be given directly to the stem cell laboratory at Cedars-Sinai for processing. Your transplant date is based on the arrival time of the cells to Cedars-Sinai.

6. Will I become more like my donor after transplant?

Yes and no. Your personality will not become more like your donor. Some people claim that their tastes change or that they are interested in new hobbies after their transplant. This cannot be scientifically verified. However, you will have their DNA inside your bone marrow and will likely convert to their blood type.

7. Will donating hurt my donor?

The procedures are generally well-tolerated with minimal risk to the donor. Mild discomfort for a short period of time may be experienced. Most donors may resume normal activities the day after a PBSC donation, and within a couple of days after a marrow donation.

8. Is there financial assistance available through the NMDP?

Yes. The NMDP has two financial assistance programs available:

- 1. Search Assistance Funds to help if your insurance plan does not cover the costs of finding an unrelated donor.
- 2. Transplant Support Assistance Funds help pay for some costs during the first six months after transplant that are not covered by insurance (such as food, transportation, temporary housing near the hospital, etc.).

Admission and Transplant

In most cases, you will be admitted to the hospital to begin the *conditioning regimen* about a week before your donor's stem cell collection, whether it is a relative or not. You will be receiving your *chemotherapy* while they are preparing for donation. See Chapter 6 for more information about *conditioning regimens*.

There are some cases in which the stem cell collection takes place before your admission. In this case, the stem cells would be frozen (cryopreserved) until your transplant date.

CHAPTER 4: PREPARING FOR ADMISSION

Informed Consent

Before admission, the doctor will explain in detail the treatment plan, risks, benefits and expected side effects. This is called *informed consent.*

At the end of this discussion, you must sign consent forms for:

- Chemotherapy/radiation and allogeneic blood and marrow transplant
- Research participation*
- Transfusion of blood products

* Not all patients qualify for research. This is discussed in the next section.

Participating in Research

Thank you for being our partners in health. Please help us help other transplant patients like you. The Stem Cell Therapeutic and Research Act of 2005 requires us to anonymously collect data about your transplant throughout the first post-transplant year and then annually. This data is analyzed so that outcomes for future transplant patients can be improved worldwide.

Important tip: The informed consent discussion may be the last time you see the doctor before being admitted to the hospital. This is a good time to ask any remaining questions you have about the SCT.

Your transplant doctor will eventually discharge you back to your local oncologist. Please let us know which doctor you are seeing so we may contact them for updates on your condition.

Please contact us on each anniversary of your transplant to let us know how you are doing and anytime your address or contact information changes.

Cedars-Sinai Blood and Marrow Transplant Program 8700 Beverly Blvd., Suite AC1060 Los Angeles, CA 90048 Phone: 800-265-4186

The Importance of a Caregiver

A caregiver is someone who provides emotional support, physical care and practical assistance for you before, during and after SCT. In order to have a transplant at Cedars-Sinai, you must identify a caregiver to assist you 24 hours a day, 7 days a week for the first 100 days post-transplant.

This person must be available to drive you to the hospital at any time of day or night for at least 100 days after your SCT.

Caregivers are usually friends or family members but can be anyone you decide. Some things to consider before choosing your caregiver:

• Do you get along well with this person?

- Can this person take you to medical appointments when needed?
- Can they take a leave of absence from work (Family Medical Leave Act—FMLA) and financially support themselves during this extended absence?
- Does this person handle stressful situations well?
- Will this person support your healthcare decisions and be an advocate for you?

Some important roles of the caregiver are:

- Remembering and following medical instructions
- Attending medical appointments and assisting with transportation
- Staying with you in the hospital
- Organizing health information
- Reporting changes in your health condition to the medical team
- Advocating for you
- Communicating with friends and family

A blood and marrow transplant is a long, emotionally and physically challenging process for you and your loved ones. Feel free to discuss any concerns you have with your navigator, nurse, doctor or social worker.

The National Marrow Donor Program also has many excellent resources for patients and caregivers. Please contact the NMDP's Be the Match Patient Services at 1-888-999-6743 or marrow.org/patient/caregiving for more information.

What to Pack for the Hospital

- This book.
- A copy of your Advance Directive for Healthcare.
- Comfortable and clean pajamas, loose "sweat" outfits, T-shirts, socks, underwear, slippers, bathrobe, athletic shoes. (Note: There is no laundry service for patient belongings. Clean clothes must be worn daily after the daily shower. Hospital gowns are always available.)
- Soft head cover, such as a scarf, hat or baseball cap.
- A brand-new soft toothbrush and dental floss.
- Personal assistive devices, such as eyeglasses, hearing aids, walker, cane.
- Stuff to do: books, crossword puzzles, laptop computer or tablet, etc.*
- Pictures, calendar, posters to decorate your room.
- A special project scrapbook, knitting, etc.
- Newly purchased magazines.
- Cellphone* and charger.

*Note: Bringing expensive items to the medical center is done at your own risk.

What NOT to Pack:

- Crafts that require the use of sharp needles (no needlepoint).
- Razor blades, cuticle scissors, nail clippers (consider clipping nails short and manicuring them prior to admission).
- Jewelry
- Makeup (brand-new makeup may be brought and lightly applied).
- Perfumed lotions, creams.
- Food (as well as vitamins, minerals, herbs and probiotics).
- Fresh flowers, dried flowers, plants.
- Any medications, unless you are specifically told to bring them with you.

CHAPTER 5. ADMISSION DAY

Here's What to Expect on Admission Day:

- 1. Arrival. Your SCT navigator will instruct you where to arrive for registration.
- 2. IV placement. You need to have a three-lumen peripherally inserted central
- catheter (3L PICC) line placed. This is a long-term IV line placed into the upper arm that is used for the transplant admission. Your SCT navigator will communicate the time for this appointment.
 - If you already have a functioning three-lumen PICC line, it will be used for transplant.
 - A single- or two-lumen PICC line will be replaced with a three-lumen PICC.
 - *Implanted Ports* (i.e., PAS Ports and Portacaths) will not be used for transplant. Patients with these lines will have a-three lumen PICC placed.
- 4. **Chemotherapy.** Some patients may receive part of their treatment in the Samuel Oschin Cancer Center before admission. (E.g., Melphalan, Rituxan or Carmustine.) Your SCT navigator will let you know if this applies to you.
- 5. **Registration and admission to 4th Floor Southwest (4SW).** Once you have been assigned a bed and it is available, you will be phoned and given instructions.
- 6. Sometimes the bed is not available until the evening. If *chemotherapy* is scheduled to begin on admission day it will be given, even if it is late at night.

Welcome to 4 Southwest (4SW)

Our team of professionals is committed to providing you with excellent service every step of the way through your transplant. We are very proud of our inpatient SCT patient care team on 4SW. If at any time we do not meet your expectations, please let us know right away.

Our team includes:

Attending doctors. Your transplant doctor works as part of a team. They rotate coverage of patients admitted for transplant. You will be seen by a member of this team every day that you are in the hospital. They will be in constant communication with your transplant doctor about your progress.

Fellows and residents. Cedars-Sinai is a teaching hospital, so you will have several different doctors involved in your daily care. Fellows have completed their residency and are now specializing in oncology and SCT. Both fellows and residents are supervised by the attending doctors.

Nurse practitioners. Nurse practitioners have an advanced degree (master's) in nursing and special training in SCT. They may be involved in your daily care and are supervised by the attending doctors.

Registered nurses. All of your nurses are highly trained professionals with experience in caring for patients undergoing SCT. They have met set requirements in education and competency.

Clinical partners. Nurses' aides are called clinical partners at Cedars-Sinai. They are also specially trained in the care of patients undergoing the SCT.

Clinical dietitian. A dietitian will meet with you at least once and then as needed during your hospitalization to assess your nutritional status.

Medical social worker. The medical social worker can assist you and your family with needs such as:

- Housing and transportation
- Financial concerns and discharge planning
- Emotional support services

If needed, the psychiatric care team is available to help with issues of anxiety, depression or mental health.

Clinical nurse specialist. This nurse has an advanced degree (master's) in nursing and is an expert in SCT. The clinical nurse specialist trains the nurses and is available to answer any additional questions about your transplant.

Clinical pharmacists. The clinical pharmacy works closely with the team and is available to answer any additional questions regarding your medications.

Rehabilitation medicine specialists. Physical therapy is an important part of the recovery process. You will have an exercise program to follow during your *transplant* admission.

Other services and resources available:

- Volunteers
- Patient relations
- Psychiatry
- Supportive care medicine
- Chaplain

Visitor Guidelines for 4SW

Have all visitors check with you or your nurse to see if you may have visitors. No children under 18 may visit 4SW.

Visitors should DO the following:

- Wash hands thoroughly; it is the key to infection prevention. They should use soap and water, then dry their hands or use Purell[®] before entering the room. Repeat when leaving the room. They should rewash hands in the room sink or use Purell[®] prior to touching you (the patient) if they have been in the room for longer than five minutes.
- Assist you with care only after they have checked with your nurse.

- Visit during visiting hours. (Visiting hours are generally 10 a.m.-9 p.m.)
- They will need to have a visitor's badge. The visitor can get one in the lobby of the South Tower, Street Level.

Visitors should NOT do the following:

- Visit if they have any type of illness or have been recently exposed to infections or immunizations.
- Sit on the bed or put their shoes on the bed.
- Eat in your room.
- Bring fresh or silk flowers, plants or fruit baskets.
- Use the toilet or shower in your bathroom.
- Turn off or silence the IV pump or any other alarm in your room.

Phones

The phone number of the 4SW nurses' station is 310-423-4415.

You can only receive incoming calls on the room phone between the hours of 8 a.m.- 9p.m.

If you are not feeling well, the phone can be turned off for four hours minimum and phone calls will be directed to the nurses' station.

If you bring your personal cellphone, please note that the staff cannot be responsible for it. Never leave your cellphone on the bed or meal tray.

Please identify one family member to the nursing staff as a "caller" if your family wants to receive information over the phone. We ask that you limit this call to once a day so that the nurses are not taken away from your direct care.

Daily Routines

Temperature, pulse, respirations and blood pressure are taken every four hours or more frequently if necessary.

You will be awakened at night for *vital signs* and other procedures; this is part of keeping you safe. Blood will be drawn daily between 4 a.m.-7 a.m. Sometimes blood will have to be drawn directly from a vein and not from your *PICC* line.

The team will be keeping a careful record of your fluid balance. This includes all **intake**: IV fluids and liquids by mouth and all **output**: urine, stool and vomit. Do not dispose of any specimen before the nurse or clinical partner sees it.

You will be weighed daily early in the morning. This is also to help measure your fluid balance.

Hygiene: You will be required to take a shower every day using an antibacterial soap. The nurses will cover your PICC line before you shower.

Mouth care should be done at least four times a day. Personal hygiene is important in preventing infection.

PICC dressing changes are done once a week and more often if needed. If it becomes loose or wet, let the nurse know right away.

You will be in a private room. It will have a sign: "*Neutropenic Precautions*." This is to let everyone know that they **must wash their hands** (or use Purell[®]) before entering the room and that the door must remain closed at all times.

While you are *neutropenic,* you may leave your room only with the permission of your doctor or nurse. You **must** wear a mask and only walk in the 4 South Unit Area.

Sometimes these routines can be irritating. Please remember that they are designed to maximize your safety and enhance your recovery.

CHAPTER 6. CONDITIONING REGIMENS

Conditioning regimens (also known as "preparative regimens") refers to *chemotherapy* and *radiation* given prior to transplant day.

CHEMOTHERAPY

Conditioning chemotherapy is given in either high doses (myeloablative) or reduced-intensity doses to kill remaining **cancer** cells and chemically destroy your **bone marrow** to prepare it for the new donor cells. The drugs given are specific to the disease being treated. Your donor's **stem cells** will be given back to you after the conditioning chemotherapy so that your bone marrow will function again.

Conditioning chemotherapy will be given as an intravenous infusion. Each chemotherapy drug has its own side effects. Your doctors and nurses will make every effort to minimize the side effects you're experiencing. Medications to prevent and treat side effects will be given to you on a regular basis.

Conditioning regimens are an important part of the SCT process and are carefully chosen based on their intensity. Your doctor will consider factors such as your age, overall health, organ function and disease status to determine what type of conditioning regimen you will receive.

Goals for conditioning:

- 1. Make room inside your *bone marrow* for the new donor *cells* to grow.
- 2. Minimize the risk of complications during and after transplant.
- 3. Maximize disease response, prevent the disease from coming back and transplant success.

Maintaining your safety is always our top priority. *Myeloablative*, *reduced intensity* and *nonmyeloablative* are words used to describe different methods of preparing your body for *allogeneic* SCT. Their names come from the effect they have on your bone marrow.

Recall that *myeloablative* chemotherapy destroys the bone marrow beyond its ability to ever recover function. *Reduced intensity* involves using less-toxic doses of chemotherapy. *Nonmyeloablative* regimens utilize the transplanted donor immune system to achieve disease response.

The table on the next page shows you the three possible methods of conditioning used in allogeneic SCT.

Once the method of conditioning is determined, the actual regimen will be selected. Regimens usually have strange names like FluMel or TBI+Cy+VP16. These names come from the combination of drugs and radiation that are included in the regimens.

Three Methods of Conditioning Used in SCT

	Myeloablative	Reduced Intensity	Nonmyeloablative
Intensity	Strong	Medium	Mild
Recommended age of patient	50 or younger	51-64	65 or older
Main benefit	Highest possible dose of chemo/ <i>radiation</i> therapy to destroy the disease	Less potential for toxicity to other organs,faster recovery post- transplant	Very survivable, low risk for infection, can be done outpatient
Main risk	Infection, organ toxicity	Relapse from disease, infection post-transplant	Relapse from disease post-transplant
Chemotherapy Included?	Yes	Yes	Sometimes
Radiation included?	Sometimes	Sometimes	Yes
Mechanism of action in achieving disease remission	 High-dose chemo +/- radiation Donor immune response 	 Medium-dose chemo +/- radiation Donor immune response 	• Donor immune response only
Examples of common regimens	 Busulfan + Cytoxan TBI + Cytoxan +VP16 Fludarabine +Cytoxan + TBI Fludarabine +high- dose TBI Fludarabine + Busulfan <u>+</u> Cytoxan 	 Fludarabine +Melphalan Fludarabine +moderate- dose TBI Fludarabine + lower- dose Busulfan + Cytoxan 	 TLI + ATG Fludarabine + low-dose TBI Fludarabine + Cytoxan + low-dose TBI

Almost all of the chemotherapy used in conditioning regimens cause severely low blood counts. When blood counts are low, you will be at risk for fevers, bleeding, mouth sores and diarrhea. Nausea and vomiting can occur with chemotherapy. Medications will be given to reduce nausea and vomiting, and you can request additional medications if your symptoms are not wellcontrolled. Additional side effects can happen that are specific to each drug, as listed below. Hair loss is expected with each chemotherapy, but it will begin to regrow approximately three months after transplant. Infertility can occur with each chemotherapy regimen.

There may be chemotherapy drugs the transplant doctor decides to use that are not listed here. Your SCT navigator can provide you with information about those drugs.

Generic Drug Name	Brand Name	Potential Side Effects	Long-Term Potential Side Effects
Busulfan	Busulfex®	Seizures	Lung toxicity Liver toxicity
Cyclophosphamide	Cytoxan [®]	Bladder bleeding	Heart toxicity
Etoposide	VP16 [®]	Low blood pressure Allergic reaction	
Melphalan	Alkeran®	Mouth sores	
Rituximab	Rituxan [®]	Fever/chills Allergic reaction Body aches	
Fludarabine	Fludara®	Fever/chills Fatigue, dizziness, confusion Cough Skin rash	

Drug Information table—Chemotherapy

Radiation Therapy

Not all patients will need *radiation*. If radiation is part of your treatment plan, the transplant doctor will refer you to a radiation oncologist for consult one to two weeks before admission to the hospital.

After the consult, you will have measurements taken. A CT scan may be used to determine exactly where the radiation will be directed.

1. Cranial Boosts

Cranial boosts describe radiation that is focused on the head, specifically the brain and the fluid surrounding the brain. This fluid is called cerebrospinal fluid or "CSF," and *leukemia/ lymphoma* cells can hide there. Cranial boosts occur over six days prior to admission for transplant.

2. Total Body Irradiation (TBI)

TBI means radiation delivered across the entire body. The purpose of TBI in *allogeneic SCT* is to kill residual *cancer cells* that are not visible on imaging scans. It also may be used as immunosuppression.

TBI will occur once you are admitted for transplant and is part of the *conditioning regimen. Radiation* oncology staff members will help you get comfortable prior to starting the treatment. Once it starts, you need to lie very still. You will be alone in the room lying on a gurney while the treatments are given. However, the radiation therapist will be monitoring you on a screen just outside the room. You will be able to talk to each other through a speaker.

Treatments may be given as a single dose or may require up to three times per day for several days in a row. Each treatment lasts 15-30 minutes.

On the first treatment, small clips will be taped to your skin at different levels; they are there to measure exact doses to different parts of the body.

TBI is painless and the radiation cannot be seen. You will not be "radioactive" after you leave the room. However, there are often side effects from radiation which are similar to chemotherapy. Pre-medications will be given prior to therapy to help prevent side effects.

All *conditioning regimens* also include a class of drugs called *"immunosuppressants"* with *chemotherapy* and/or *radiation* therapy. They are used to do two things:

- 1. To prevent your immune system from attacking the new donor cells.
- 2. To suppress the new donor immune system from attacking your body (we call this *graft-versus-host disease.*

Immunosuppression

All *allogeneic* SCT patients will receive *immunosuppression*. Immunosuppression is critical to the success of the transplant and may continue for a minimum of six months after transplant.

Allogeneic SCT patients must strictly adhere to a medication regimen that often includes daily immunosuppression. For most of these drugs, the level of the immunosuppressant drug in your blood must be carefully monitored to ensure that the dose is correct. This will happen while you are in the hospital. Discharge teaching will include important information about taking your immunosuppressants at home.
Drug Information table—Immunosuppressants

Generic Name	Brand Name	Route	Potential Side Effects	Long-Term Potential Side Effects
ATG (Anti-Thymocyte Globulin)	Atgam [®]	IV infusion	 Allergic reaction Flu-like symptoms Swelling/flushing Nausea/vomiting/diarrhea 	 Infection Secondary cancer
Cyclophosphamide	Cytoxan [®]	IV infusion	 Nausea/vomiting Bladder toxicity Hair loss Mouth sores 	 Heart toxicity Infertility Secondaryleukemia
Cyclosporine	Neoral [®] Sandimmune [®]	IV infusion, oral capsules or liquid	 Nausea/vomiting High blood pressure Tremors/shaking/flushing Swelling of the gums Abnormal body hair growth 	 Kidney and liver toxicity Infection Secondary cancers
Mycophenolate	Cellcept [®]	IV infusion, oral capsules or liquid	 Diarrhea, vomiting Leg swelling Low blood counts and infections Birth defects (talk to MD about contraception) 	Secondary cancers Infection
Tacrolimus FK506	Prograf [®]	IV infusion, oral capsulesor liquid	 Headache/dizziness Shaking/seizures Tingling/numbness Nausea/vomiting/diarrhea High blood pressure Hair Loss 	 Secondary cancers Infection Kidney toxicity Liver toxicity
Sirolimus	Rapamune®	Oral- tablet or liquid	 Infection Nausea, vomiting, diarrhea Stomach or joint pain 	Secondary cancer Infection

Drug Information Table—Supportive Medications

The following medications may be used to reduce the side effects of high-dose chemotherapy and radiation therapy.

Generic Name	Brand Name	Purpose	How It Is Given	
Acyclovir	Zovirax®	To prevent virus infections	Oral pill or intravenous	
Dexamethasone	Decadron [®]	To prevent nausea	Oral pill or intravenous	
Filgrastim-sndz	Zarxio®	To help recover white blood cells	Intravenous or <i>subcutaneous</i>	
Fluconazole	Diflucan®	To prevent fungal infections	Oral pill or intravenous	
Fosaprepitant	Emend®	To prevent nausea	Intravenous	
Lorazepam	Ativan®	To prevent or reduce nausea and anxiety	Oral pill or intravenous	
Metoclopramide	Reglan®	To prevent nausea	Oral pill or intravenous	
Ondansetron	Zofran [®]	To prevent or reduce nausea	Oral pill or intravenous	
Pantoprazole	Protonix®	To reduce acid in the stomach	Oral pill or intravenous	
Prochlorperazine	Compazine®	To prevent or reduce nausea	Oral pill or intravenous	
Ursodiol	Actigall [®]	To prevent liver problems	Oral pill	

CHAPTER 7. TRANSPLANT DAY

Congratulations, your big day has arrived! Your *conditioning* regimen has been completed, and it is time to receive your donor's *stem cells*.

Here is what you can expect on *transplant* day, also called "day zero."

The Infusion

- The cells will be delivered to your room just after they have been received, inspected, washed (if the donor's **blood type** is not compatible with yours), counted and tested. The color inside the bag may range from light candy red to dark red, like blood. If the cells were frozen, they will be thawed in the Stem Cell Lab.
- Your nurse will give you medications such as Benadryl[®] and Tylenol[®] before the infusion. Steroids may also be used.
- Your nurse will be present throughout the transplant infusion.
- A transplant doctor and/or nurse practitioner will be immediately available throughout the infusion.
- The stem cells are infused into your *PICC* line much like a blood transfusion. The infusion will not hurt.
- Your nurse will take frequent *vital signs* and watch for potential side effects. This will include measuring the amount of oxygen in your blood with a pulse oximeter.
- The number and volume of bags vary for each patient.
- Each bag is infused one at a time over 20 minutes to several hours.
- If the product was frozen, the stem cell preservative *dimethyl sulfoxide (DMSO)* has an odor that will be present in the room for 24 hours after the infusion. You will stop noticing the odor shortly after the cells are infused. Any visitor within that 24-hour period will notice the odor when they first arrive to your room.

Most patients do not experience discomfort during their stem cell infusion. You will most likely feel tired from the pre-medications and sleep through much of your transplant day. The table on the next page describes potential side effects in more detail.

Side Effects From the Stem Cell Infusion

Potential Side Effect	Response
Allergic reaction: hives, itching, <i>fever,</i> sweating, rapid pulse, shortness of breath, anxiety, stomach cramping, dizziness, general swelling	The nurse will slow down or briefly stop the infusion to administer medications that will help relieve these symptoms. The doctor will let the nurse know when the infusion can be restarted.
Red urine	This will go away on its own within 24 hoursof the infusion. It is from broken red blood cells present in the stem cell product (red blood cells do not survive the freezing process).
Nausea or taste changes from the smell and taste of the stem cell preservative (if it was frozen)	This is also temporary as the preservative <i>dimethyl sulfoxide (DMSO)</i> will be out of the body within 24 hours. Medications can alleviate this side effect. Sucking on hard candies may also help.

After the Infusion

The donor cells will find their way from your bloodstream and into your **bone marrow**. Once they get there, they are like seeds planted in the earth; they just need time to grow. When they do, they will begin the process of making new blood cells and slowly rebuilding your immune system. This is called **engraftment** and is discussed further in Chapter 15.

Your blood counts will be checked every day. You can expect your blood cell counts will drop. Even after they recover it is VERY important to follow the post-transplant instructions.

The transplant team keeps track of how many days it has been since the infusion. The day after transplant is "Day +1," a week after the transplant is "Day +7," etc. You will be closely monitored for a minimum of six months to one year after transplant depending on how your recovery goes.

Cytokine Release Syndrome

If you receive a half-matched transplant from a relative, you may have *cytokine release syndrome* starting the day after transplant. This is because parts of the donor immune system in the stem cell product (messenger proteins called *cytokines*) have been activated. Signs and symptoms of cytokine release syndrome include fever, nausea, headache, rash, rapid heartbeat, low blood pressure, and trouble breathing. Most patients have a mild reaction, but sometimes, the reaction may be severe or life threatening.

Post-transplant cyclophosphamide (used as an immune suppressant) or other medications can be used to reduce these symptoms. These medications will not affect the donor stem cells. The nurses will watch you closely. They will work with the doctors to make sure you are safe. You may also be started on antibiotics as a precaution in case of infection.

CHAPTER 8. POST-TRANSPLANT

The reason you are kept in the hospital for recovery after your *transplant* is so the transplant team can prevent and manage side effects. Remember, your safety and comfort are our top priorities. The risks and complications of an *allogeneic* transplant are caused by:

- Side effects of high-dose *chemotherapy* and/or *radiation therapy*
- The period of lowered blood cell counts (*neutropenia*, *anemia* and *thrombocytopenia*)
- Organ toxicities
- Graft-versus-host disease (explained later in Chapter 12)

Review: The Complete Blood Count (CBC)

Recall from earlier: *white blood cells, red blood cells* and *platelets* make up a *complete blood cells* or *CBC.* It is very important that you understand what your CBC is and why we check it all the time.

White Blood Cell Count (WBC)

- Number of all of the white blood cells that fight and prevent infection
- Normal values are 4-11 (thousand)

Absolute Neutrophil Count (ANC)

- Number of specific type of white cell, the *neutrophil*, that is most important in fighting bacterial infection
- Normal values are 1.8-8.0 (thousand)
- *Neutropenic precautions* implemented when *ANC* is less than one (thousand)

Hemoglobin (Hgb)

- Measure of red blood cell's ability to carry oxygen, which helps give you energy
- Normal values are 13-17 G/dL
- When your hemoglobin is low, it is called anemia
- Packed red blood cells are generally transfused when hemoglobin is less than 7 G/dL

Platelets

- Platelets help prevent bleeding
- Normal values are 150-450 (thousand)
- Platelets are generally transfused when the platelet count falls below 10 (thousand)
- When platelets are low, it is called *thrombocytopenia*

We know that after receiving *conditioning*, your CBC numbers will all drop below normal. For each type of blood cell, there are specific risks and safety measures to be aware of.

Neutropenia and Neutropenic Precautions

Neutropenia: White Blood Cell Count Below One (Thousand)

Neutropenia is a condition that requires extreme caution. Imagine that your immune system is an army that protects your body from invaders like bacteria. Neutropenia is like the whole army taking a vacation at the same time!

In order to remain safe until you recover from neutropenia:

- **Clean your hands** frequently with either Purell[®] or soap and water. This means after going to the bathroom, before and after meals, after walking in the hallway or handling magazines and other items that may have been touched by several people. Make sure others clean their hands before touching or assisting you!
- Do your mouth care at least four times a day. If you have dentures, these need to be removed and cleaned too.
- Cleanse and dry rectal area after each bowel movement. If you have diarrhea, let your nurse know because it can cause skin irritation. Do not use suppositories or tampons.
- Shower and look at your skin daily. Any rashes, sores, redness or cuts you see or feel, tell your nurse or doctor. Use the **chlorhexidine soap** provided and apply antifungal powder to skin folds after towel drying. Please do not use soap from home unless it is approved by your nurse.
- Keep your room free from clutter so that the housekeeping staff can clean well.
- Do not save leftover food at the bedside (see Chapter 10).

Your CBC will be checked daily. Following *transplant*, your *white blood cell* count will continue to drop, and may reach zero for several days.

If you get a *fever* (temperature 100.4 degrees orally/101.2 degrees temporal or higher), your nurse will obtain blood and urine cultures right away. IV antibiotics will be started.

Sometimes when a patient has neutropenia, the temperature may not be high, but other symptoms of infection can occur such as chills, low blood pressure and others. If this happens, the nurse will contact the doctor and blood cultures will be drawn and IV antibiotics started right away.

Keep in mind that almost all transplant patients get fevers. However, attention to strict personal hygiene is the BEST way to prevent infections!

Symptoms of infection include:

- Shaking chills with or without fever (temperature 100.4 degrees orally/101.2 degrees temporal or higher)
- Cough or sore throat
- Redness, swelling or pain in any body area
- Sore or blister in any body area, including the mouth
- Difficulty urinating; cloudy or bad-smelling urine

These symptoms could mean that an infection is present and should be reported to your nurse right away.

Anemia and Fatigue

Anemia: Low Hemoglobin (Hgb)

Recall that hemoglobin is a vehicle in the red blood cell that drives oxygen around your body. It is what gives you rosy cheeks and pink nail beds.

When hemoglobin levels are low, it is called *anemia*.

Anemia may cause:

- Dizziness
- Shortness of breath
- Headache
- Pounding heartbeat
- Fatigue

Please let your nurse know if you experience these symptoms. A transfusion of *packed red blood cells* may correct anemia. In general, we transfuse when hemoglobin drops below 7G/dL.

Fatigue often contributes to "feeling down" or depressed. As your red blood cell count recovers, so will your mood and energy level. However, if you feel you need additional emotional supportduring this time, let us know so we can help you.

Try to get out of bed and do light exercise every day, even if you don't feel like it. Challenge yourself. It will improve the quality of restful periods and help you sleep better at night.

Caution: A shower that is too hot or too long may cause you to become dizzy, weak and fatigued. We do not want you to fall! Shower chairs are available; please ask for assistance.

Thrombocytopenia and Bleeding Precautions

Thrombocytopenia: Low Platelets

Recall that **platelets** are involved in blood **clotting**. When you cut yourself, platelets plug the injury and stop the bleeding. The **conditioning** regimen will cause your platelets to drop way below the normal level.

When platelets are low, it is called *thrombocytopenia*. This condition carries a risk of spontaneous bleeding. The bleeding could occur on the outside (e.g., a nosebleed) or on the inside (e.g., in the brain).

Platelet transfusions can correct low platelets. In general, platelets will be infused through your *PICC* line when your platelet count is below 10 (thousand).

Most patients do not have any serious problems with bleeding after their **blood and marrow** *transplant.* However, it is a good idea to exercise caution when your platelets are low.

Here are some important safety tips to follow when your *platelets* are low:

- Call your doctor or nurse immediately if you notice any of the following:
 - Bleeding from anywhere on the body
 - Headache, confusion or changes in how well you can see, walk or move
 - Black or bloody bowel movements
 - Bruising or red spot under the skin
- Use a soft toothbrush for all oral care; floss regularly (if you already do so).
- Dab your nose instead of blowing or picking it.
- Do not bend over so that your head is lower than your heart.
- Do not use nail clippers. Electric razors are OK.
- When your platelet count is very low (less than 20 thousand), check with your nurse before you get out of bed, shower or walk in the hallway. The bed alarm may be set as a reminder to you.
- Do not take any over-the-counter medications without your doctor's approval. Some
- can affect platelet function.
- If you are a menstruating woman, you will be given medication that prevents you from getting your period. If your period starts, sanitary pads should be used instead of tampons.

High Risk of Falls and Fall Injury

Falls are very dangerous after SCT when blood counts are low. Your risk factors may change daily.

The following are fall risk factors and high-risk factors for severe injury:

- Drowsiness, weakness, unsteady or poor balance, confusion, delirium.
- **Peripheral neuropathy:** Decrease in felling sensation, numbress and tingling in fingers and toes.
- **Postural hypotension:** A drop in blood pressure when moving from lying or sitting to a standing position; causes dizziness or lightheadedness.
- Anemia: A drop in blood cell counts may make you feel more tired and weak.

- **Medications:** Various medications increase fall risk. These include medications that:
 - May make you tired or dizzy (for pain, sleep or anxiety).
 - Affect your blood pressure, such as antihypertensive medications and diuretics. Many commonly prescribed medications can cause changes in sensation, balance, blood pressure, alertness and drowsiness. Know the side effects of your medications and let us know how the medications make you feel.
- Nutrition: Poor nutrition can lead to loss of skeletal-muscle strength and mobility and put you at risk for malnutrition.
- Low platelets: Platelets help your blood to clot. Low platelets can cause a fall that results in serious bleeding, such as in the head.
- Low white blood cells (WBCs): WBCs help your body to fight infection. In a patient with low WBCs, an opened wound is at high risk for infection. Fevers may result and make your blood pressure low.

Screening for Falls: The nursing staff will screen you for fall risk level, assess your blood pressure, balance and walking ability each shift and throughout each day. Your risk factors for falls maychange from hour to hour. They will ask you questions about changes in physical or mental status. Please notify the staff of any changes in how you feel or think.

When you are at a higher risk for falls and injuries from falls, there are many measures we can take to prevent falling:

- **Rounding:** The nursing staff will make rounds every hour to assist you with any of your needs such as getting up to shower or using the bathroom.
- **Nurse call light:** We will make sure that the nurse call light is within your reach. Please use the call light to ask for assistance if you are considered "a fall risk" or feel dizzy, faint, tired or weak. We want to help you.
- **Fall risk door sign and wristband:** Wristbands and door signs help to remind both staff and family members that you are at risk for falling, so that we can better assist you.
- **Bed alarms:** These alarms notify the staff when you are out of bed and in need of assistance. If you have a bed alarm on, please call for help before getting out of bed by yourself. If you cannot wait for assistance, the bed alarm acts as an emergency signal and someone will come immediately.
- **Physical therapy:** May provide muscle strengthening, walking and balance training.
- **Walking aids:** A walking device can help maintain balance; we provide nonslip socks and recommend nonslip footwear such as tennis shoes.

Falls can result in bone fractures, injury, wound infections, severe bleeding, increased length of stay, longer recovery time, higher costs and even death. Let's work together to prevent falls. We are committed to excellent care and keeping you safe is our top priority!

Safety tips:

- Always ask for help.
- Tell us how you are feeling.
- Know the side effects of your medications.
- Choose safety over privacy.
- Make sure there is enough light in your room, so you don't trip on something.
- Look out for items in your path such as the IV pole and clutter while moving around inyour room.
- Keep important items within reach, such as the call button, your glasses and phone.
- Help us do our best to keep your room as clutter-free as possible. Your family members should also help to minimize the clutter in the room.
- Get out of bed slowly; sit at the edge of the bed for a few minutes prior to standing.
- If we ask you to call us before getting up, please do so. It is for your own safety.

CHAPTER 9. POST-TRANSPLANT EXERCISE GUIDELINES

In spite of sometimes being at risk for falls, we want to help you stay active. *Cancer* and its treatment can cause weakness and fatigue. Exercise can actually help combat cancer-related fatigue and weakness.

How do you know if you have cancer-related fatigue? You may be feeling any of the following symptoms:

- Weakness
- Drowsiness
- Tired as if you have the flu
- Difficulty concentrating
- Difficulty performing your everyday activities

Exercise is one of the most effective tools we have to prevent and combat cancer-related fatigue.

It is normal to want to rest and avoid exercise when you feel so tired. Even though it may seem counterintuitive, research has shown that even light exercise may help lessen the symptoms of fatigue. Your doctor and therapist will help you determine the type and intensity of exercise that is appropriate for you.

Your muscles can become very weak from medications that fight cancer. Your doctor or therapist can help teach you exercises that may prevent or minimize muscle atrophy.

Other benefits of exercise:

- Maintains physical function
- Combats fatigue
- Maintains muscle strength
- Enhances mood
- Diminishes the consequences of cancer treatment, such as the increased risk of osteoporosis
- Helps prevent pneumonia
- Stimulates natural endorphins that give a sense of wellbeing
- Fights depression and the feeling that one has lost control over their life

How to exercise safely in the hospital:

- Walk in the hallway at least twice a day unless otherwise directed.
- Be sure to stay on the oncology floor.
- You should walk at a pace in which you can speak comfortably (not too intense).
- Wear a mask and athletic shoes.
- Dress comfortably. You should wear clothing that won't limit your movements.
- Wash or use hand sanitizer when you get back to your room.
- Nursing staff members are available to help with walking as needed.

Sit up in a chair for meals and activities as much as possible. Even if you are just watching television, try to stay out of bed.

Perform simple exercises as instructed by your physical therapist. They will consider your ability as well as your *platelet* count, blood pressure, etc. Your physical therapist can also provide you with exercises you can safely perform in your hospital room.

Report any of the following to your nurse or doctor immediately:

- Shortness of breath
- Chest pain
- Coughing or wheezing
- Weakness or dizziness

CHAPTER 10. GUIDELINES FOR LOW-MICROBIAL DIET

White blood cells (WBCs) are an important part of the immune system and help the body fight infections. Some foods contain bacteria and other microbes such as viruses, yeast and mold. When a person has a low number of WBCs, they have a weakened immune system and a higher risk of infection from microbes in food. By following safe food practices, you can reduce your risk of foodborne illness.

When you are admitted, your doctor will order a low-microbial diet for you. The dietary staff will follow this diet order. But it is also important that you know these guidelines.

Cooked Foods

- Proper cooking temperatures kill harmful bacteria present in food.
- Avoid all raw or undercooked meats, fish, poultry, tofu, eggs and egg substitutes. Make sure the yolks and whites of eggs are firm, not runny.
- After preparation, food should be eaten as soon as possible.
- Do not eat potentially perishable foods that have been left at room temperature for more than one hour.
- Avoid any foods containing mayonnaise unless they are eaten immediately after preparation. Do not save to eat later.

Dairy Products

- Reduce your intake of milk products for 100 days after transplant as your ability to digest lactose can be reduced by transplantation. Consuming dairy products early after a transplant can cause bloating, gas, cramps, and overgrowth of harmful bacteria in the colon.
- Do not use products that are near or past the expiration date.
- Eat pasteurized milk and dairy products only.
- Avoid soft and moldy cheeses, as well as those containing chili peppers or vegetables.
- Consume commercial milkshakes or supplements in sealed individual cartons. Do not consume if there is a break in the container.

Fresh Fruits and Vegetables

- Thoroughly rinse fruits and vegetables under running water before eating, peeling or slicing. Do not use soap, detergents or bleach solutions.
- Use a small vegetable brush to remove remaining surface dirt.
- Discard those with cuts in skin, bruises or mold that you can see.
- Soak raw fruits and vegetables, including those with skins or rinds that will be removed, in water for at least two minutes.
- Avoid all raw vegetable sprouts, such as alfalfa and mung beans.
- Do not drink unpasteurized commercial fruit and vegetable juices and smoothies.

Miscellaneous

- Avoid cold cuts, cheese, salads, salsas and pre-cut produce from the deli counter
- Avoid fermented foods and drinks
- Eat shelled, roasted nuts only
- Eat commercial, heat-treated honey only

Leftovers (when you are at home)

- Seal and wrap leftovers, label with the date and time of preparation
- Store in refrigerator or freezer immediately
- Do not eat if stored in the refrigerator for more than 24 hours
- Do not thaw frozen foods at room temperature
- Do not refreeze defrosted foods

Follow the diet during your *transplant* admission. For the first 100 days after transplant, use common sense when making food choices. Please remember, outside food is not allowed to be brought in during your hospitalization without your transplant doctor's approval.

Diet Modifications

If you are experiencing mouth sores, discomfort when eating or pain when swallowing, a soft, soft-chopped, pureed or full liquid diet may be ordered. We will still provide you with a low-microbial diet but will modify it based on your chewing and swallowing ability at that time.

If you are experiencing diarrhea, we can modify your diet, such as limiting fiber, dairy, caffeine and other foods that may worsen diarrhea. The nurse and/or dietitian can discuss these options with you.

Vitamin or herbal supplements should not be taken unless approved by your doctor. For more information, the dietitian is available both inpatient and *outpatient*.

CHAPTER 11. OTHER POTENTIAL SIDE EFFECTS

The following information may seem frightening, but we want you to be prepared.

Chemotherapy and **radiation** given in high doses can affect any organ in your body. Side effects vary greatly. Most patients do not experience all of the side effects listed. Many side effects can be prevented or relieved with medications.

Other Potential Side Effects:

Nausea, Vomiting and Loss of Appetite

These are the most common gastrointestinal side effects experienced after *transplant*. These problems usually get better as your blood counts recover.

Fortunately, we have strong antinausea drugs that can prevent or decrease nausea and vomiting in most patients. Different drugs work for different people. Let your doctor or nurse know the minute you are nauseated so they can treat you.

Food choices to improve your appetite and manage nausea may be discussed with the clinical dietitian at any time.

Mouth Sores and Swallowing Problems

Mucositis refers to swelling of the lining of the gastrointestinal tract.

Stomatitis refers to swelling of the mouth.

These problems result from *chemotherapy* destroying the rapidly dividing cells inside your mouth and gut. To simplify, we call them "mouth sores" and they are common following *conditioning*.

As your white blood cells recover, your mouth sores will begin to heal.

Management of Mouth Sores

This side effect is very distressing for patients. Healing and pain medications such as Caphosol[®] and/or MMX (a combination of Mylanta[®], Mycostatin and Xylocaine) will be given so you are able to carefully clean your mouth.

Occasionally, patients require strong IV pain medication. Please keep your nurse informed about any mouth pain and if the medicine is working or not.

Important tip: Do not worry if you cannot eat or drink much. You will be receiving intravenous fluids to replace water and *electrolytes*. Don't force yourself to eat your favorite foods, or you may not like to eat them later when you are well.

Following these guidelines will help you prevent and cope with mouth sores:

- Brush your teeth and tongue with toothpaste after every meal and at bedtime. A soft-bristle toothbrush should be used carefully to avoid injury to the gums.
- Notify your nurse or doctor if you have pain or bleeding; you may need to use a spongy "toothette" instead of a toothbrush.
- Use salt rinses or other measures as instructed by your nurse. Do not use commercial mouthwashes containing alcohol.
- Floss your teeth regularly as long as it does not cause excessive bleeding.
- Keep lips moist with lip balm.
- If you snack regularly, practice more frequent oral care.
- If you have dentures, soak them in your usual cleaning solution as long as it doesn't contain alcohol. Do not reuse the solution. Remember to clean your dentures after each meal and at bedtime.

Diarrhea or Constipation

Swelling of the intestines from your treatment may cause diarrhea or constipation. Antibiotics and other medications may also cause these problems.

Diarrhea can result in dehydration and/or irritated skin around the anus. Constipation may result in tears or bleeding.

Any irritation or open area around the anus has a high risk for infection and needs to be reported to your nurse right way.

Let your nurse know right away if you have any abdominal pain.

Management of Diarrhea

- Keep your rectal area clean and dry. Special wipes or creams may be given. Ask your nurse for assistance if needed.
- Let the nurse and doctor know if you have more than two bowel movements a day and they are watery or difficult to control. The nurse may need to collect samples for testing. It is important for the amount of diarrhea be measured in "hats" placed in the toilet. This will help the nurses and doctors make sure you don't get dehydrated.
- Let the nurse or doctor know if your rectal area becomes tender, or if you have bloating, cramping or pain in your stomach or abdomen.

Management of Constipation

- Drink lots of fluids and get out of bed to walk as frequently as you are able.
- Do not use suppositories or any home remedy without approval from your doctor.
- If you notice that you are straining to have a bowel movement, medications may be given. Let your nurse know as soon as possible. Do not strain to have a bowel movement because of low platelets.

Liver Problems

Although rare, some *chemotherapy* medications can cause the veins in your liver to become narrowed. This is called *sinusoidal obstruction syndrome (SOS)*. It was formerly known as hepatic *veno-occlusive disease (VOD)*.

SOS results in a decrease of blood flow from the liver. As a result, fluid may build up around the liver and stomach area (called *ascites*) and throughout your body (called *edema*). Also, it may cause your skin to turn yellow (*jaundice*).

Your doctor will monitor your liver function enzymes closely and provide treatment if needed. If you are at high risk for liver complications, you will be given a preventive medication called ursodiol (Actigall[®]).

Kidney Problems

Your doctor will watch your kidney function through your blood *lab work*, how much fluid you take in, how much urine you make and what your weight is every day.

It is important that you help the nurses and clinical partners keep track of your intake (everything you drink) and output (all urine, bowel movements and vomit). Do not throw it away!

Skin Problems

Skin reactions to dressings, adhesive tapes and medications are very common. Your *transplant* team will determine the cause of the problem and how to treat it.

Daily showers are the best way for you to monitor your skin. Let your nurse know if you notice any redness, itching, rashes or lesions.

Your PICC line is very susceptible to infection and MUST be kept covered by a sterile dressing. If the dressing becomes wet or loose it needs to be changed right away. Pain, redness or drainage at your PICC site are signs of infection and should be reported immediately.

Neurological Problems

BMT is a complicated procedure that can affect all parts of the body including the brain and nervous system. Potential neurological complications may be caused by factors such as medications, low blood counts, or fluid and *electrolyte* imbalances. Symptoms of neurological complications vary, and your transplant team will be assessing for them everyday.

Let your nurse or doctor know if you are experiencing:

- Headache
- Visual changes
- Dizziness, weakness, numbness, tingling
- Anxiety, depression, hopelessness
- Abnormal muscular movements, shaking or jerking
- Difficulty sleeping or staying awake

Heart and Lung Problems

Your *vital signs* (heart rate, breathing rate, blood pressure and oxygenation) will be monitored very closely a minimum of every four hours. Any abnormal values will be reported to your transplant doctor. If needed, additional testing (e.g., *EKG*, chest X-ray) will be performed.

There are a variety of factors that will cause temporary changes in heart and lung function during your recovery from SCT, such as *fever*, infection, *anemia* and medications. These will be appropriately managed as they occur.

In some cases, the *chemotherapy* and/or *radiation* therapy you received during *conditioning* may injure the heart or lungs. The injury may be temporary or permanent. Medications or other interventions may be recommended.

Hair Loss

Hair loss is an expected side effect after *conditioning* therapy. ALL hair on the body may be affected, not just the hair on your head. Fortunately, hair loss from *chemotherapy* always grows back.

If you don't have them already, we can provide you with wig and head-covering resources. Some insurance companies will reimburse the cost of a wig (prosthesis) if the doctor writes a prescription for it before you buy it.

Engraftment Syndrome

Engraftment syndrome occurs when a rush of chemicals called *cytokines* flood the body very quickly right before the *white blood cell* count starts to rise. The most common symptoms include *fever,* skin rash, swelling and rapid weight gain, shortness of breath, and changes in kidney and liver function on blood tests. Engraftment syndrome is treated with medications called steroids, and symptoms usually improve quickly.

Post-Transplant Lymphoproliferative Disorder

Post-Transplant Lymphoproliferative Disorder (PTLD) is a growth of your lymph nodes that happens from infection with a virus called the *"Epstein-Barr virus (EBV)."* This virus can do this while you are on immune-suppressing medications. EBV blood levels will be measured after transplant so that if the levels rise, treatment can be started right away.

CHAPTER 12. GRAFT-VERSUS-HOST DISEASE

What Is GVHD?

GVHD is a common and potentially serious complication after SCT. Understanding what GVHD is and how you can help prevent it is an extremely important part of your pre-transplant education.

Your donor's immune system is contained in the *stem cells* that you receive during your transplant. Recall that the role of the immune system is to fight. It fights whenever it encounters something it does not recognize as "self."

GVHD occurs when the donor's transplanted immune system (the graft) begins attacking your body's cells (the host) because they appear foreign. In other words, the donor cells treat your body's normal cells like an infection and try to destroy them.

The main risk factor for developing GVHD is mismatched HLA typing. This is why we are so careful about choosing the best possible matched donor for your transplant. However even "perfectly matched" transplants may result in GVHD.

GVHD can range from mild to life-threatening. If symptoms of GVHD appear (explained in detail in the next two sections) they must be reported immediately to your transplant team.

Acute GVHD

Acute GVHD appears within the first 100 days after SCT. Early intervention is key in managing acute onset of GVHD. Please be sure to report all symptoms to your transplant team as soon as possible.

Acute GVHD primarily affects three organs:

1. Skin

This results in rash. The rash may begin on an isolated area, commonly the palms of the hands and soles of the feet. It may spread out all over the body. Intensity of the rash can be mild redness like a sunburn to severe blisters and peeling.

2. Gastrointestinal (GI) Tract

This primarily results in diarrhea. The frequency and amount of diarrhea ranges from mild to severe.

3. Liver

This results in changes in liver function measured by blood tests. It can also cause *jaundice*, which is a yellowing of the skin and eyes. Severity can range from mild changes in liver function to complete liver failure.

Chronic GVHD

Typically, chronic GVHD occurs three months to three years after SCT. Chronic GVHD may occur in any post-allogeneic SCT patients but is more common in those who have had acute GVHD. Symptoms of chronic GVHD may range from mild to life-threatening, and early intervention improves outcomes. Report all symptoms to your transplant team as soon as possible!

Chronic GVHD may affect:

1. Skin

- Darkening, thickening or hardening of the skin
- Dryness, flaking, peeling

2. Eyes

- Dryness and irritation
- Sensitivity
- Cataracts

3. Gastrointestinal (GI) Tract Disorders

- Dry mouth
- Cavities and gum disease
- Diarrhea or problems digesting food
- Liver inflammation
- Difficulty swallowing

4. Joints

- Pain and weakness
- Swelling

5. Lung problems

- Cough
- Shortness of breath

6. Hair loss

Prevention and Management

Every effort is made to prevent GVHD. Prevention begins by selecting the best possible HLA donor for your transplant.

We also use immunosuppressant medications. These were explained in Chapter 6.

Recall the role of *immunosuppressants:*

- 1. Restrain your own immune system so that it does not reject the transplanted donor cells.
- 2. Restrain the donor immune cells so they wake up slowly and calmly inside of your body.

If symptoms of GVHD appear, your transplant team will give you medications called steroids to further suppress the donor's immune system in your body. The dosage of immunosuppressant you are taking may increase, and additional immunosuppressants may be given.

For some of these medications, your SCT doctor will carefully monitor the level of immunosuppressant in your bloodstream and make changes to your dosage as needed. The goal is to very slowly (over months to years) lower the dose until you no longer need them at all.

Sometimes signs of GVHD may appear shortly after the doctor lowers your dose. It would then be increased, and once the GVHD is under control, another attempt is made to lower the dose. This cycle of careful assessment for GVHD, trial of lowering immunosuppressant dose, and reassessing for signs of GVHD is an expected part of your post-transplant care.

The best way for you to participate in GVHD prevention is to:

- 1. Always comply with the immunosuppressant medications prescribed to you. Be mindful of changes made to your dose.
- Be sun safe. Even a mild sunburn can trigger GVHD that can cause problems for years! Stay in the shade, apply sunscreen with a minimum SPF 30 to exposed skin, avoid midday sun, wear a hat and cover up as much as possible. Follow these guidelines on both sunny and cloudy days.
- 3. Report any potential symptoms immediately to your transplant team!

Graft-Versus-Disease Effect

Recall that your donor's immune system is by nature aggressive and trained to kill foreign invaders like bacteria. Now imagine what that immune system will do when if finds leukemia, lymphoma or myeloma cells inside your body.

When your donor's cells (graft) destroy leukemia, lymphoma or myeloma cells remaining inside your body, this is called "graft-versus-disease" (GVD) effect.

Currently, modern medicine does not have a way to measure whether or not GVD is happening. The same cells responsible for GVD (lymphocytes) are also responsible for causing *GVHD*.

Patients who experience mild GVHD are likely benefiting from the protective effects of GVD and may have a decreased risk for relapse. Unfortunately, there is no way to turn up the GVD response and turn down the GVHD, but researchers are busy working on it.

For patients that receive a nonmyeloablative transplant, the transplant doctor is relying entirely on the immunological effects of GVD to attempt to cure the disease.

For myeloablative and reduced-intensity transplants, it is chemo and *radiation* therapy combined with the GVD effect that hopefully cure the disease.

GVD is also the driving force behind *donor lymphocyte infusions* (DLI).

CHAPTER 13. EMOTIONAL AND SOCIAL ISSUES

This is often a time of mixed emotions for patients. Feelings that you and your family may have range from anxiety to hope.

Length of hospital stay, and medications used in the *transplant* procedure, may cause feelings of depression and irritability.

Feelings of loss due to your body's changes (hair loss, changes in skin color) are common during this time.

Patients and caregivers will be encouraged to take one day at a time and focus on the long-term benefits of transplant. It is helpful to understand what the plan is for each day and stay involved.

You and your family will be given every opportunity to discuss feelings, concerns, questions and issues with the SCT team at every step along the way.

A medical social worker is available both outpatient and inpatient for counseling, emotional support and help with resources.

Our Chaplain Services has many providers to help provide spiritual care and support.

There are also extensive online and written resources available for patients and caregivers addressing a wide spectrum of topics related to emotional support and coping.

Please do not hesitate to bring up any questions or concerns you have. We are here to help you.

CHAPTER 14. DONATING BLOOD

Blood is an important, lifesaving resource. Almost all patients going through blood and marrow transplant will need blood and/or platelet transfusions.

Often, family and friends will ask if they can help in any way. A wonderful opportunity exists for them to give not only to the patient but to the whole cancer community.

One blood donation can save up to four lives. It takes 45 minutes to donate red cells and 90minutes to donate platelets.

Family and friends can give a directed donation at Cedars-Sinai specifically for the patient. If getting to Cedars-Sinai is not possible, they can have the Cedars-Sinai mobile blood donation clinic come to them. Please call for more details.

For an appointment or blood donation questions, please call the Rita and Taft Schreiber Blood Donor Facility at: **310-423-5346 or toll-free: 1-877-712-5663.**

CHAPTER 15. ENGRAFTMENT AND DISCHARGE INSTRUCTIONS

Engraftment

Engraftment is a cause for celebration. You are almost ready to go home!

Imagine a planted seed, buried deep in the soil. It takes a certain number of days before you see the plant begin to grow. In the setting of SCT, this is called engraftment.

Engraftment occurs when the infused donor *stem cells* move to the *bone marrow* and begin to grow and divide. Your *complete blood count (CBC)* tells us when engraftment is occurring.

Neutrophils (a type of *white blood cell*) are the first to engraft. *Platelets* are usually the last to engraft.

When the *absolute neutrophil count (ANC)* is greater than 500, you are considered engrafted. This usually takes two to three weeks to occur.

Platelets are usually the last to engraft.

You will be discharged from the hospital when:

- 1. Your blood counts have returned to a level your doctor feels is safe.
- 2. You do not have a *fever* or need for IV antibiotics.
- 3. You are able to drink fluids and nausea/vomiting/diarrhea are controlled by oral medications.
- 4. You can tolerate oral *immunosuppressants* and demonstrate clear understanding of how to take them.
- 5. You have the ability to care for your own basic needs (shower, dress, walk, etc.).

Chimerism testing of your blood will be done to check engraftment of the donor's stem cells. It helps measure your transplant's success. The results are interpreted along with other indicators of recovery (i.e., *engraftment,* absence of cancer cells, GVHD absent or controlled, etc.).

Why do we call it "chimeric testing"? A chimera is a person with two or more *genetically* distinct types of cells. The word comes from Greek mythology. The chimera was a creature with a lion's head, a goat's body and a serpent's tail.

Chimerism testing tells us the percentage of donor DNA inside your blood and bone marrow compared to the percentage of your own DNA. The desired test result is >95% donor DNA.

The chimerism testing will be repeated several times as you move through your recovery. A simple blood test and sometimes bone marrow biopsies are done to collect the samples for chimerism testing.

Low percentages on chimerism studies show graft rejection or failure and will likely require further investigation and treatment.

Discharge Instructions

Before you go home, your transplant team will review important information with you and your caregivers prior to discharging you home. Your prescriptions, your clinic appointment and any questions you may have will be discussed.

Prior to going home, you need to make sure:

- You have a caregiver 24 hours a day, 7 days a week for the first 100 days after transplant, except when you are in the hospital.
- Caregivers and anyone else who lives with you should have received an annual flu vaccination.
- The house is clean.
- Dogs and cats are clean and well-groomed. You are not to clean litter boxes or pick up your dog's poop. You are not to clean cages or tanks (snakes, hamsters, rabbits, lizards, fish, etc.).
- You have an accurate thermometer so you can take your temperature at home. REMEMBER, A FEVER OF 100.4 degrees orally (101.2 degrees temporal) OR HIGHER AND YOU MUST CALL 310-423-0626.
- You have all of your prescriptions in hand before discharge and understand the schedule for taking them at home.
- You always have transportation available to get you to the Samuel Oschin Cancer Center and Cedars-Sinai.
- Depending on your medical condition post-transplant, you may be required to arrange for local housing close to Cedars-Sinai. Please have a plan ready and discuss it with your social worker and medical team. The social worker can provide you with resources for housing, financial and other practical resources.
- You have an alternate caregiver should your primary caregiver or children get sick.
- We are here to help you, please let us know any problems or concerns you have about going home. Your recovery continues long after you are discharged from the hospital, so we need to continue working together to keep you safe.

CHAPTER 16. POST-DISCHARGE

Follow-Up Appointments

Your first follow-up appointment will be scheduled before you are discharged. You may be seen by either a nurse practitioner or a doctor. For the first six weeks, follow-up visits may betwice weekly. Then, they will be reduced to once per week for about a month, then once every two weeks for another six months. You can expect to have blood drawn and see the clinic nurse every time you come to the Cancer Center. This is a general guideline and will change based on how you are doing.

You will be closely monitored until Day +100. Complications related to SCT tend to appear during that time. Day +100 is a special milestone after SCT because you are considered fully *engrafted,* another cause for celebration!

Be sure to follow all instructions during follow-up. Recommendations may frequently change. Your transplant cannot be successful without your cooperation!

Immunosuppression Drug-Level Monitoring

Tacrolimus, cyclosporine, and sirolimus are commonly used *immunosuppressants*. In order to ensure the medication dose is therapeutic, we must monitor the level of the drug in your bloodstream. Typically, this is done one to two times per week.

It is critical that the level is measured accurately, so the transplant doctor can prescribe the correct dose. If the dose is too low, the risk for *GVHD* increases substantially. If the dose is too high, the risk of severe side effects increases.

We want to measure the level when the drug is at its lowest point in your body, which is right before the next dose is due.

Here is how you can help to ensure your level is accurate:

- Get into a routine of taking the medication at the same time every day.
- On the days when the level is being drawn, do not take the morning dose. Bring it with you to your clinic appointment and take it as soon as the level is drawn.
- Immunosuppressants should never be taken with grapefruit juice, and consumption of
 potassium-rich foods (bananas, prunes, raisins and orange juice) should be limited. Talk to
 your transplant doctor before taking any vitamins or herbal supplements while taking
 immunosuppressants.

Daily Self-Assessments

Take the time every day to complete a head-to-toe self-assessment. The best time to do this is in the shower. Look carefully at your skin, take some deep breaths, press on your abdomen, and inspect the bottom of your feet. Ask yourself: How do I feel today? Is anything unusual or different? Have things gotten better, worse or the same? What can I do today to improve the way I feel?

You know yourself better than anyone else. Catching complications early makes treating them more successful. Do not let your guard down!

Infection Prevention

You are still at risk for infections even after *engraftment* occurs. Your immune system is working, but it is being suppressed by medications and is very fragile.

You have three infectious enemies after transplant: bacterial, viral and fungal. The table below lists them with examples and common medications prescribed to prevent them:

Type of Infection	Example	Preventive Medication Used Brand Name(R) (generic name)
Bacterial	Pneumonia, PICC line infection	Bactrim [®] (co- trimoxazole) Cipro [®]
Viral	Shingles, CMV	Zovirax [®] (acyclovir)Valtrex [®]
Fungal	Aspergillus, Candida	Diflucan [®] (fluconazole) Vfend [®]

You will be prescribed a medication to prevent each type of infection for the first 100 days after SCT.

Make sure you understand your prescriptions and when you need to take each medicine.

Infection prevention tips:

- Washing your hands and having others wash theirs is absolutely the BEST way to prevent infection!
- Do not stay in enclosed spaces with people who are coughing, sneezing or show other signs of cold or flu.
- Take your temperature every day after discharge. Call your doctor immediately if your temperature is 100.4 degrees orally (101.2 degrees temporal) or higher. Do not ignore colds or flu.
- Bathe or shower daily and wear clean clothes. If your skin is dry, use a mild lotion or baby oil.
- Do not share cups, glasses, utensils, etc., with others.

- If you have a *PICC* line, keep the dressing clean and dry. Cover it when showering. Do not place it under water. Report any dressings that are loose, wet or open so that it can be changed immediately.
- Brush your teeth with a soft toothbrush after every meal and before bedtime. Floss daily.
- Make sure you take your medications to prevent infection as prescribed.

Getting Back to Feeling Well

Many SCT patients are surprised that they feel worse the first few days they are home than they did the last few days in the hospital.

It is easy to underestimate how much rest you get while in the hospital surrounded by caregivers, with the restroom 4 feet from the bed. Your home may have stairs to climb, the kitchen may be far away from the bedroom, and you may need to travel long distances by car to get to your medical appointments. All of these factors quickly add up, and can leave you feeling:

- Extreme fatigue
- Great one day and horrible the next
- Mood swings
- Anxiety
- Loss of appetite
- Lack of interest in relationships and/or previously enjoyed activities

As your body continues to heal, your energy level and your mood should improve. In the meantime, speak with your nurse, doctor or social worker about your feelings and concerns. Medications or alternative therapies may be recommended. Your transplant team wants you to recover as quickly as possible so you can get back to your normal life again.

Activity Recommendations

The following list provides details about things you should avoid during the first three months after your transplant.

Be patient with yourself. You have been through a very difficult experience and your body needs time to recover.

Your doctor will let you know when it is safe to resume these activities. If you have specific concerns about any activity, feel free to discuss them with your doctor.

- Take it easy. Allow yourself time to rest and get enough sleep. Daily light exercise (e.g., walking) will dramatically improve feelings of fatigue.
- Start back to work only with your doctor's approval. Returning to work is based on your endurance and the type of the work you do.

- Avoid large crowds, such as grocery stores, churches and movie theatres until your doctor tells you it is safe. Avoid people with cold or flu symptoms.
- Avoid being near small children other than your own. Small children often have viral infections. If anyone in your home has been exposed to or has symptoms of a cold orthe flu, it is important that you isolate yourself from them.
- Limit your exposure to the sun. Your skin may still be extra sensitive to the sun from the chemotherapy. Also, sun exposure immediately after transplant can trigger *graft-versus-host disease.* Wear a sunscreen with a minimum SPF of 30. Always wear a hat, long sleeves, pants and sunglasses.
- Do not go to the dentist unless approved by your transplant doctor. Dental procedures at this time could cause infection.
- If you have to use a public restroom, wash your hands thoroughly using a paper towel as the final step in turning off the faucet.
- Avoid swimming in pools, spas, jacuzzies, lakes or ocean water unless approved by your *transplant* doctor. Your immune system is not strong enough after transplant to avoid infection from these areas.
- Do not smoke or expose yourself to cigarette, pipe or marijuana smoke. If family members smoke, ask that they do so outdoors and away from you. Lung health is very important after transplant.
- Avoid contact with pesticides, solvents, fertilizers, chicken coops, caves, construction sites and areas where soil is being moved. Avoid gardening until your doctor tells you that it is safe to do so. Avoid zoos, parks, animals, animal areas and areas heavily populated with birds. These things may have chemical irritants, fungus and bacteria that your new immune system is not ready to fight.
- If you own pets, have someone else pick up after them. If you own a reptile, fish or birds, avoid contact with them and ask that others wash their hands thoroughly and immediately after touching them. Some pets have bacteria that your new immune system is not ready to fight.

Post-Discharge Diet

Many patients have difficulty eating well after *transplant*. The taste of food will be altered from the *conditioning therapy*. Fortunately, this will improve over time and eventually return to normal.

It is recommended that you follow the low-microbial diet for 100 days after SCT and follow basic food safety guidelines. Please refer back to Chapter 10 of this book for specific details about diet.

It is important to drink lots of fluids to stay hydrated unless otherwise instructed by your nurse, doctor or dietitian.

Try to eat a variety of nutritious foods and snacks. The *outpatient* dietitian is available to assist you with healthy food choices after discharge.

Emotional and Intimacy Concerns

You may find yourself feeling sad or depressed in the months following a blood and marrow transplant. There are many potential causes, such as medication, fatigue or anxiety about the future. These feelings are normal. Be sure to discuss them with your caregiver at home as well as with your doctor.

Many patients find it comforting to speak with someone who has been through a transplant. Let your nurse know if you are interested.

Rely on family and friends for support and assistance. If they are offering to help you, let them!

Intimacy can be difficult for patients after a transplant. Your body has been through a lot of stress and your physical appearance has changed. You may have lingering physical effects from the SCT that directly affect sexual health. The good news is that it is OK tohave sex! Talk to your partner about your feelings and go at your own pace. Feel free to discuss any concerns with your doctor, nurse practitioner, clinic nurse or coordinator, whomever you feel most comfortable with.

If your *platelets* are low, ask your doctor before having sexual intercourse.

Many transplant *conditioning* regimens will result in infertility for patients, male or female. However, there is always a possibility of pregnancy, even after a transplant. Consult your doctor about options for contraception.

Immunizations

Immunizations may be dangerous to your weakened immune system right after transplant. You will need to repeat your childhood immunizations one year after your transplant. We will arrange this during a clinic visit.

A flu shot is highly recommended for your family members and close contacts. Your transplant doctor may recommend a flu shot for you six months after a transplant.

Avoid contact with infants or children who have been recently immunized for measles, mumps, rubella, polio, smallpox, chickenpox or yellow *fever* (live viruses).

CHAPTER 17. WHEN TO CALL THE DOCTOR OR NURSE PRACTITIONER

The 24-hour Samuel Oschin Cancer Center phone number is 310-423-0626. If you are feeling unwell, it is always safest to call right away. Tell them that you are a bone marrow transplant patient and give them the name of your nurse practitioner or doctor so they can contact the correct person.

Examples of reasons to call:

- FEVER: temperature 100.4 degrees orally (38 degrees Celsius) (101.2 degrees temporal) or higher
- Chills/sweating
- Cough
- Rash
- Unable to eat or drink fluids
- Redness or pain at **PICC**/IV site
- Vomiting
- Mouth sores
- Diarrhea/constipation
- Bleeding
- Pain
- Painful or frequent urination
- Unable to urinate
- Yellow skin (*jaundice*)
- Generally feeling unwell or that "something is wrong"

A fever or infection after your *transplant* is an EMERGENCY. You MUST call RIGHT AWAY if you have a fever at home. A fever can be fatal if you wait to call! Please take this instruction very seriously. We want to keep you SAFE and HEALTHY.

Use common sense! If you are wondering "if" you should call, the answer is: YES, you should call. **Help us to help you!**

CHAPTER 18. UNRELATED DONOR CONTACT

If you received stem cells from an unrelated donor, you may wish to contact them or meet them. This is a personal decision. Some transplant recipients want to do this, and others do not.

Several factors influence whether it is possible or not:

- 1. **Country where the donor lives.** Countries have different rules about donor contact. Some allow for anonymous contact only (e.g., a "Dear Donor" letter without identifying information like your name or where you live). Some will allow you to identify yourself, and some don't allow any contact at all.
- Time elapsed after your transplant. There is a <u>minimum waiting period of a year</u> after <u>transplant</u> before donor contact is permitted. <u>In some countries the minimum is two years</u>. Anonymous correspondence may be permitted before a year has passed.
- 3. **Donor consent.** If you want to contact your donor personally, they must consent to have their information released. The same is true if your donor wants to contact you, your consent must be obtained first. Anonymous correspondence does not require consent from either side.

Your navigator will facilitate donor correspondence through the National Marrow Donor Program.

If you decide to proceed, your navigator will facilitate the process. They will review what is allowed in your specific case. Fill out the consent forms and submit what you want sent to your donor. Anonymous letters and gifts will be carefully screened to ensure no personally identifying information is contained. Your donor may or may not respond.

CHAPTER 19. DONOR LYMPHOCYTE INFUSION (DLI)

If your leukemia/lymphoma comes back after transplant, you will likely need a donor lymphocyte infusion or DLI. Sometimes DLI is used to boost the donor graft when chimerism studies show low donor DNA in your blood.

Lymphocytes are immune system cells that can attack leukemia. Think of a donor lymphocyte infusion as an immune system boost.

Donor lymphocytes are collected and infused just like they were for your SCT. Whether your donor was your sibling or an unrelated person, they will be asked to donate again for you. Sometimes sibling donor lymphocytes are collected prior to SCT and frozen for potential future use. Donor lymphocytes cannot be collected from *umbilical cord blood*.

There is no medication required to **"mobilize"** the lymphocytes. The cells are collected from a large vein in the arm. Blood is removed from the donor via a needle in one arm, the lymphocytes are siphoned off, and the rest of the blood is returned via a needle in the other arm.

You will likely receive a round of *chemotherapy* called "re-*induction*" before your DLI. This will be similar to the very first round of chemotherapy you received right after you were diagnosed. The DLI may take place while you are still in the hospital recovering your bloodcounts. It is also possible to receive your DLI in the *outpatient* cancer infusion center, if you are feeling well enough.

The hope is that a war will begin between the lymphocytes and the *cancer* cells shortly after DLI. This happens if the lymphocytes see the cancer cells as foreign invaders (like bacteria) and attempt to destroy them. These phenomena are called "graft-versus- leukemia" or "GVL."

The same lymphocytes are responsible for causing *graft-versus-host disease,* or GVHD. You may or may not have already experienced some level of GVHD during your recovery from SCT.

There is no lab test capable of measuring graft-versus-leukemia. However, DLI will likely cause GVHD. If GVHD is present, graft-versus-leukemia is potentially occurring, because the immune system is showing signs of stimulation.

GVHD will be treated with steroids and other medications. The hope is that the GVHD will be mild and treatable, while the graft-versus-leukemia effect will result in remission of your disease.

Your response to the DLI is measured by testing your blood and **bone marrow**, and/or by repeating PET/**CT scans**. Sometimes it takes several DLIs to achieve results. GVHD can limit the amount of DLI it is safe for you to receive. Unfortunately, DLI is not always effective in achieving or maintaining remission after SCT.

CHAPTER 20. LATE EFFECTS AND SURVIVORSHIP

Survivorship begins from the moment a potentially life-threatening disease diagnosis is made. There are several critical time points following SCT, such as Day +100, six months, one year. But survivorship is more than a measurement of time passed. It encompasses every aspect of your physical, mental, emotional and spiritual wellbeing.

Recovery from SCT takes a long time. Many survivors are able to return to normal activities like work or school by the time they reach one year.

However, almost everyone experiences some late effects or complications from BMT. Late effects are side effects from *chemotherapy* that occur long after treatment is over. They may be temporary or permanent, and their impact on your life may range from mild to severe.

The following list represents the most common late effects after SCT:

- Chronic GVHD. Discussed in detail on Chapter 12
- **Cataracts.** Cataracts are a clouding of the lens of the eye and are common three to four years after transplant.
- **Sexual dysfunction.** Interest in sexual activity may take a long time to return after BMT. A variety of factors influence feeling "in the mood," and sometimes body changes make sexual intercourse painful. Do not be embarrassed to bring up your questions or concerns. There may be treatments or recommendations that will help.
- Infertility. Most transplant patients are not fertile after *allogeneic* SCT. However, there are exceptions. Cedars-Sinai's Center for Fertility and Reproductive Medicine may address questions or concerns about fertility. Please call 310-423-9964 or visit them online at cedars-sinai.edu/cfrm.
- **Numbness and tingling (neuropathy).** This is caused by nerve damage from chemotherapy. Nerves take a long time to heal. Generally, whatever numbness and tingling you have after a year has passed is likely permanent.
- **Organ toxicities.** Thyroid, lung, liver and skin are the most common sites. However, medications used for SCT may injure any of the body's organs, causing late effects to appear.
- Secondary cancers. Exposure to chemotherapy and *radiation* increases your risk for developing other *cancers* later in life. These usually appear 5-10 years after the initial exposure and can be difficult to treat.
- Adjusting to the "new normal" takes time, patience, and continued effort from you and your caregiver team.

Critical elements of survivorship:

- 1. Continued routine surveillance of:
 - Disease status
 - GVHD
 - Engraftment studies
- 2. Prevention and early detection of disease including:
 - Balanced diet and weight control
 - Regular exercise
 - Sun protection
 - Routine checkups with your doctor
 - Daily self-assessments
 - Dental hygiene
 - Control of chronic diseases (diabetes, high blood pressure, etc.)
 - Monitoring for late effects, organ toxicities
 - Reimmunizations
- 3. Focus on quality-of-life matters:
 - Return to work/school
 - Social life, relationships
 - Sexuality
 - Engaging in enjoyable activities
 - Financial security and health insurance coverage
 - Spirituality

There are also extensive online and written resources available for patients and caregivers addressing a wide spectrum of topics related to emotional support and coping. We recommend the following:

1. Be the Match—Patients and Families Support and Resources

- Free one-on-one support and access to educational resources, DVDs, booklets, online tools and guidance
- BeTheMatch.org/patient/support and resources
- 1-888-999-6743
- Email: patientinfo@nmdp.org

2. BMT Infonet: Blood and Marrow Transplant Information Network

Easy-to-understand information, publications and products for SCT patients and families, reviewed by medical experts for accuracy.

- bmtinfonet.org/
- 1-888-597-7674
- Email: help@bmtinfonet.org

CHAPTER 21. GLOSSARY

If you have any questions regarding these terms or anything about the written information given to you, please ask us. Some of the words in this glossary are not mentioned in the book, but you may hear them while going through your transplant.

ABO: The type of (or absence) of an antigen, or "marker" on the surfaces of the red blood cells of a person. Blood group "A" have A antigen only, "B" have B antigen only, "AB" has both A and B antigen, and blood group "O" has no antigens. These helps determine blood transfusion compatibilities.

Absolute neutrophil count (ANC): The number of one type (neutrophils) of white blood cells in the blood that fight infection.

Advance directive for healthcare: A document that specifies who you want to make medical decisions for you if you cannot speak for yourself. All patients should fill out our advance directive form and bring a copy to the hospital.

Allergic reaction(s): A reaction that occurs when the immune system overreacts to a substance known as an *allergen*. An *allergen* can be pollen, certain foods, mold, pet dander, dust, insect stings or medications. These allergens trigger the production of antibodies called Immunoglobulin E (IgE). These antibodies travel to cells and cause inflammation and symptoms in the nose, lungs, throat, sinuses, ears, and lining of the stomach or on the skin. A serious allergic reaction called *anaphylaxis* can occur and involve multiple parts of the body, such as the lungs and heart.

Allogeneic stem cell transplant: A type of bone marrow transplant where transplanted bone marrow comes from a compatible donor other than the patient. The donor could be a sibling, an unrelated person or an unrelated umbilical cord.

Anemia: A condition in which a person has too few red blood cells. As red blood cells carry oxygen from the lungs to all other cells, the lack of oxygen due to anemia results in a person feeling "run-down" and possibly short of breath.

Anesthesia: The absence of normal sensation and pain due to medications, such as those used during surgery.

Antiemetic: A general term used to describe medications that prevent or decrease nausea and vomiting.

Apheresis: A method of obtaining blood stem cells for transplantation. The donor's blood is circulated through a machine, a little at a time, to collect the stem cells. The patient's total blood volume circulates through the machine several times to collect as many stem cells as possible. All the other blood components are returned to the donor.

Apheresis catheter or "IJ": An intravenous line that is placed for the purpose of apheresis. It is placed in the side of the neck, where it is tunneled under the skin and into the internal jugular vein above the heart. It has two "lumens" or "tubes," so that blood can flow out from one lumen and return by the other lumen.

Aplastic anemia: A condition in which the bone marrow is unable to produce blood cells.
Ascites: Buildup of free fluid in the abdominal cavity (around the outside of the intestines, stomach, liver, etc.).

Autologous stem cell transplant: A type of stem cell/bone marrow transplant in which the transplanted stem cells are taken from the patient and then reinfused at a later time.

Bacteria: Microscopic living organisms, usually one-celled, which can be found everywhere. They can be dangerous, such as when they cause infection, or beneficial, as in the process offermentation (such as in wine) and that of decomposition.

Bilirubin: An orange-red pigment formed from hemoglobin during the breakdown of used red cells.

Blood and marrow transplant (BMT): A treatment used for cancer and certain other diseases. The patient receives very high doses of chemotherapy, with or without radiation therapy, in order to destroy the disease. The patient's own bone marrow, which is destroyed during the therapy, is replaced by a transfusion of stem cells collected from either the patient or from a compatible donor. The stem cells are infused to help the patient's body make blood cells and grow a healthy immune system.

Blood cultures: A blood test done to look for infection in the blood.

Rita and Taft Schreiber Blood Donor Facility: The clinic that specializes in blood donation and apheresis.

Blood type: The description of a person's blood based on the presence or absence of "antigens" on the cell surfaces of the red blood cells; these are A, B, AB, O and Rh negative orRh positive.

Bone marrow: The inner, spongy tissue of bones where red blood cells, white blood cells and platelets are made.

Bone marrow biopsy: A procedure in which a sample of bone marrow is removed and examined by placing a needle through the skin into the inner space of the hip bone.

Bone marrow harvesting: The collection of marrow from the posterior iliac crests of the pelvis via multiple punctures with a large needle and aspiration of bone marrow. This is normally done with the donor under general anesthesia in the operating room.

Bone marrow transplant: Transplant performed using bone marrow as the source of stem cells.

Bone scan: Uses a small amount of radioactive material to create images of bones on a computer screen. This test is useful in finding the spread of cancer to bones.

Cancer: Any malignant (abnormal, spreading) cellular tumor or growth.

Cell(s): The basic building blocks of all living things. The human body is composed of trillions of cells. They provide structure for the body, take in nutrients from food, convert those nutrients into energy, and carry out specialized functions.

Central venous catheter: A narrow, soft catheter (plastic tube) placed into a large vein that leads to the heart. Once inserted, the line allows chemotherapy, blood and bloodproducts, drugs, antibiotics, fluids and nutrition to be given. It can also be used for obtaining blood samples.

Chemotherapy: Treatment of disease, usually cancer, by chemicals/medications; not all chemotherapy drugs are derived from true "chemicals" but are originally derived from natural substances. An example is Taxol[®], which was originally derived from the bark of the yew tree.

Chemistry panel: A blood test to determine the function of various organs such as your liver and kidneys; it looks at your electrolytes, minerals and other values.

Chest X-ray: An X-ray to evaluate chest structures such as the heart and lungs.

Clinical trial: see research protocol.

Clotting (also known as coagulation factors): Proteins in the blood that help blood to clot.

CMV (cytomegalovirus): A common virus that does not hurt healthy people but can cause serious lung and other infections in people with lowered immune systems.

Complete blood count (CBC): A blood test to count the red blood cells, white blood cells and platelets.

Computerized tomography (CT) scan: A series of X-ray pictures taken of the body from different angles to search for abnormalities. This test is often done at the same time as a PET scan to confirm findings.

Conditioning regimen: A term used for the therapy, given to prepare the patient's body for blood and marrow transplant. The regimen generally lasts 2-10 days prior to the transplant. Also known as the preparative regimen.

Cytokine: Are messenger protein that have many different actions in the body.

Cytokine release syndrome: A condition that may occur after the day of transplant. Cytokine release syndrome occurs when immune cells are activated and release a large amount of cytokines into the blood.

Cryopreservation: The method used to prepare either bone marrow or peripheral blood stem cell products for freezing and long-term storage and prevent cell destruction during either the freezing or thawing process. The addition of 10% DMSO (dimethyl sulfoxide) to the product is the most common approach. The product is then stored in liquid nitrogen.

Dehydration: A condition of the body where there is a decrease in body fluid due to decrease in fluid intake.

DMSO: Dimethyl sulfoxide, a chemical that prevents stem cell destruction during either the freezing or thawing process.

Echocardiogram: A test that uses sound waves to produce image of the heart to show how well it pumps blood to the body.

Edema: Swelling of any part of the body due to a collection of fluid in the tissue.

Electrocardiogram (EKG): A test to evaluate the electrical conduction of your heart.

Electrolytes: Chemical elements in the blood that help the body to perform many of its functions. Potassium and sodium are examples of electrolytes. If certain electrolytes are low, they can be replaced in the form of foods, intravenous medications and/or fluids, or pills.

Engraft (engraftment): The point at which there are >1000 white blood cells per microliter or an ANC >500; >20,000 platelets (or platelet independence).

Epidural: An infusion of local pain medication into the space outside the spinal column.

Epstein-Barr virus (EBV): Also known as human herpesvirus 4, it is a member of the herpes virus family. It is one of the most common human viruses. EBV is found all over the world. Most people get infected with EBV at some point in their lives. EBV spreads most commonly through bodily fluids, primarily saliva. However, it can cause a number of diseases, including infectious mononucleosis. It can infect lymph nodes and cause them to grow in people who have a low immune system.

Fever: The rising of a person's temperature above normal, which is generally 98.6 degrees. A fever is usually a symptom of an infection or an allergic reaction. If you are neutropenic, even a "low-grade" fever (such as 100.4 degrees) is significant.

Fungus: A group of spore-producing organisms, including molds, yeast, mushrooms and toadstools. In humans, fungal infections occur when an invading fungus takes over an area of the body and is too much for the immune system to handle. Fungi can live in the air, soil, water and plants.

Gastrointestinal tract: A term used to describe all of the organs from the mouth, esophagus, stomach and intestines to the rectum.

Genetically: Pertaining to reproduction or to birth or origin; inherited.

Graft-versus-host disease (GVHD): A condition that occurs when the new (graft) bone marrow and immune system from a donor recognize the patient's (host) tissues as being "foreign" in an allogeneic transplant. Tissues that are affected the most are skin, gastrointestinal tract and the liver.

Growth factors: A medication that stimulates the growth and development of certain cells.GM-CSF and G-CSF are growth factors that stimulate certain white blood cells, including neutrophils.

Haploidentical ("Haplo") transplant: A type of allogeneic transplant that uses healthy stem cells form a half-matched donor the replace the patient's marrow. The donor is usually a family member.

Harvested: see bone marrow harvesting or apheresis.

Hematocrit: The percentage of red blood cells that are in whole blood.

Hemoglobin (Hgb): A molecule on the red blood cell that holds the oxygen on the cell. The measure of hemoglobin on a blood test shows how much oxygen our blood can carry.

Hepatitis panel: A blood test to determine if a person has been exposed to hepatitis viruses.

High-dose chemotherapy: Chemotherapy that is given in higher doses than standard cancer treatment.

Human leukocyte antigen (HLA typing): A test that determines the type of markers you have on certain tissues and cells, including platelets, that allow your body to know "self" from "non-self."

IJ or internal jugular catheter: see apheresis catheter.

Immunosuppression: The act of "holding down" or decreasing the activity of the immune system. This can occur in the body because of disease or be done on purpose through medications to prevent graft rejection or graft-versus-host disease.

Immunosuppressive medications (immunosuppressants): Medications that cause suppression of your immune system.

Implanted ports: A type of central venous catheter that is completely under the skin — usually located on your chest or arm. Medications and fluid can be given into your vein with a simple injection through the skin into the portal.

Induction: A term used to describe the first treatment of a cancer. The purpose is usually to provide and measure an initial response to the treatment.

Infection control precautions: Precautions, such as careful and frequent hand-washing, that are designed to protect the patient with a lowered immune system from developing infection.

Informed consent: The written or verbal approval for a treatment that has been fully described, including risks and benefits.

Inpatient: Care that takes place when a person is admitted and stays in the hospital.

Jaundice: Yellow coloring of the skin and/or whites of the eyes caused by high levels of a bilirubin (a byproduct of red cells) in the blood.

Lab work: Blood sample tests.

Leukemia: A cancer that starts in the bone marrow, and causes large numbers of abnormal white blood cells to be produced and enter the blood. These cells crowd out healthy functioning blood cells.

Lymphoma: A cancer that begins in the cells of the immune system, can be classified as Hodgkins or non-Hodgkins lymphoma.

Magnetic resonance imaging (MRI) scan: Uses very high-powered magnets to form detailed pictures of the body's soft tissues and identify areas where tumors are present. You may not be able to have an MRI if you have any metal inside your body.

Mahurkar: A type of *apheresis catheter*. It is a temporary large venous line that has two tubes used for apheresis. It is usually placed directly into the jugular vein in the lower neck area.

Matched unrelated donor (MUD): An allogeneic blood and marrow transplant from someone besides a family member.

Mobilize (mobilization): The process of stimulating stem cell growth and movement from the bone marrow to the peripheral blood. This can be done by growth factors with or without chemotherapy.

Mucositis: Inflammation of mucous membranes; it can extend from the mouth to the anus and include the vagina.

Multigated acquisition (MUGA) scan: Creates video images of the lower chambers of the heart to check whether they are pumping the blood properly. A small amount of a tracer imaging dye is infused through a vein that helps the camera see the pumping of your heart. The measure is reported as an "ejection fraction."

Multiple myeloma: A cancer that forms in a type of white blood cell called a plasma cell. Plasma cells help you fight infections by making antibodies that recognize and attack germs. **Multiple myeloma** causes cancer cells to accumulate in the bone marrow, where they crowd out healthy blood cells.

Myeloablative: Cancer treatment (chemotherapy and sometimes radiation) that destroys the bone marrow beyond its ability to ever recover function.

Myelosuppression (myelosuppressed): A condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells and platelets.

Neutropenia (neutropenic): A condition which occurs when the number of neutrophils (a type of white blood cell produced in the bone marrow) are low. Neutrophils are usually the front line of defense in preventing and treating infection in our bodies. Thus, this condition can be serious; if neutropenia occurs, a patient is at increased risk of developing an infection.

Neutropenic precautions: Special care activities that help reduce the risk of infection during neutropenia.

Neutrophil: A type of white blood cell that is usually the front line of defense in preventing and treating infection in our bodies. They are normally the highest in number of all of the white blood cells.

Nonmyeloablative: A type of conditioning regimen that uses immunosuppression and low-dose radiation to prepare the body for SCT.

Outpatient: A term used for an area outside the hospital where treatment is provided, such as a clinic or doctor's office.

Packed red blood cells (PRBCs): A unit of concentrated red blood cells in which most of the other blood components has been removed.

Peripheral blood stem cells: see stem cells.

PICC (peripherally inserted central catheter): A catheter that is inserted into a large vein in your arm. It is threaded so that the tip of the catheter is in a large vein near your shoulder, close to the upper-right chamber of your heart. Medications, blood products and IV fluids can be given through the catheter.

Platelet(s): Blood cells that prevent and stop bleeding.

Positron emission tomography (PET scan): The patient is injected with a small amount of radioactive sugar that **cancer** cells quickly consume. This causes them to light up on the scan so that doctors can easily visualize their location in the body. Patients need to fast prior to the PET scan to make sure that your own body sugar is not too high.

Post-transplant lymphoproliferative disorder (PTLD): A growth of lymph nodes that happens from infection with a virus called the *"Epstein-Barr virus (EBV)."*

Preparative Regimens: see conditioning regimen.

Pulmonary function test: A test to determine the ability of the lungs to deliver oxygen to the bloodstream.

Radiation or **radiation therapy:** Treatment of disease by means of ionizing radiation. Ionizing radiation is high-intensity X-rays.

Red blood cells: Cells that carry the oxygen we breathe in through our lungs to the body's tissues. The cells pick up the oxygen as the blood circulates through the lung tissue. These cells are produced by the bone marrow.

Research protocol: This is a treatment intervention or questionnaire that is not a standard part of the usual care.

Sinusoidal obstruction syndrome (SOS): A condition in which the veins in the liver become narrowed, causing a decrease in blood flow to the liver and liver malfunction. This may result from some chemotherapy medications.

SCT nurse navigator ("navigator"): A registered nurse who specializes in blood and marrow transplant. Their role is to help teach the patient and family and coordinate care prior to transplant.

Stem cells: The cells from which all blood cells develop. Most are in the bone marrow. However, there are very small amounts in the blood of normal individuals.

Stem cell collection (stem cell harvesting or stem cell apheresis): see apheresis.

Stem cell transplant (SCT): Transplantation of blood-forming (hematopoietic) stem cells from blood or bone marrow.

Stomatitis: Inflammation of the mouth (mouth sores).

Subcutaneous injection: An injection, or shot, of medication that is given by a very thin needle just under the skin. The medication is absorbed into the bloodstream over a short amount of time.

TBI (total body irradiation): The total body is treated with radiation.

Thrombocytopenia: A condition in which the number of platelets is too low and the patient is at risk for bleeding.

Transplant: To transfer an organ or tissue from one donor to another. See *allogeneictransplant* and *autologous transplant*.

Umbilical cord blood: Blood that is taken from the umbilical cord after birth.

Unrelated allogeneic transplant: An allogeneic transplant in which the donor is not related to the patient.

Veno-occlusive disease (VOD): see sinusoidal obstruction syndrome (SOS).

Virus (viruses): An extremely tiny parasite that can only reproduce if it is within a living being, or anything that corrupts something else. An example of a **virus** is the herpes simplex virus that produces cold sores or small blisters that develop on the lips or mouth.

Vital signs: Measures that help indicate adequate functioning of organs (such as the heart, brain, lungs, etc.) that are essential to life. These measures include a person's blood pressure, pulse, respiration rate and temperature. The word "vital" means essential to life.

White blood cells (WBCs): Cells that fight infection. There are several types of white cells, such as neutrophils, lymphocytes and monocytes (neutrophils are the greatest in number). These cells are produced by the bone marrow.

CHAPTER 22. DISCHARGE CHECKLIST

Use this checklist to review important information before discharge. You can review this with your doctor or nurse practitioner.

√ Done	TOPIC	NOTES
	Infection Precautions: Fever, when to call the doctor	
	Bleeding Precautions: Injury prevention, signs of bleeding	
	Medications: Schedule, drug-level monitoring, side effects	
	GVHD: Skin, liver, gastrointestinal tract, acute vs. chronic	
	Home Environment: Cleaning, pets, plants	
	Physical Activity: Exercise, travel, rest, swimming	
	Oral Care: At least twice daily, dental visits every six months	
	Skin Care: Hygiene, sun exposure	
	Nutrition: Taste changes, nausea/vomiting, supplements, food choices	
	Sexuality: Infertility, birth control	
	Central Line Care: Dressing changes, flushing	
	Immunizations: Flu shots, reimmunization schedule	