



Autologous Stem Cell Transplant

Patient Education
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 having or being considered for an **autologous blood and marrow transplant**, or “BMT,” at Cedars-Sinai.

“**Bone marrow transplant**” (BMT) and “**peripheral stem cell transplant**” refer to the 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 non-malignant (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-dose chemotherapy** is given to eliminate the disease or to 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 autologous SCT. Allogeneic SCT is a very different procedure and covered in a different book.

What Are 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 3.

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 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

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 is to prevent the cancer 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.

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 with 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 they destroy 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.

Autologous Stem Cell Transplant: An Overview

Autologous SCT means that the stem cells used for the transplant came from the patient who is receiving them.

Autologous SCT has five steps:

- Mobilization
- Collection or **apheresis**
- Conditioning
- Transplant
- Engraftment

In order for a patient to donate stem cells for themselves, the stem cells must be mobilized and collected by **apheresis**.

Mobilization refers to the process of increasing the number of stem cells available in the blood. Mobilization always involves medications called growth factors. Growth factors stimulate the bone marrow to produce extra stem cells that spill into the circulating blood. Once the stem cells are in the bloodstream, the process of collection can begin.

Collection is done via a catheter placed in the large vein in the neck (the jugular vein). The catheter is connected to a machine that removes the stem cells from the blood. The stem cells are collected into a bag and the rest of the blood is returned to the donor. This process is called **apheresis** and is done in the Rita and Taft Schreiber **Blood Donor Facility**.

Once the stem cells are collected, a preservative is added and they are frozen in liquid nitrogen at -185 degrees Celsius. They stay there until they are needed for transplant. That may be a few days to several years later.

Mobilization and collection is typically an outpatient process.

Upon completion of collection, you will be admitted to the hospital to begin **conditioning** and undergo **transplant**. Conditioning refers to the high-dose **chemotherapy** and sometimes **radiation** given before the transplant. This therapy is given over a period of 2-10 days depending on the disease being treated. Sometimes the conditioning chemotherapy is given before admission for the transplant.

Once the conditioning therapy is complete, the transplant will occur. The stem cells are removed from the freezer, thawed and infused into you through an IV. 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 stem cell infusion at the bedside.

Following the infusion of stem cells (transplant) is a two- to three-week hospital stay. During this time, you are monitored very closely for side effects. The side effects from the 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, blood transfusions, 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 up to two weeks. During this time, you are 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 two to four 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 or diarrhea controlled by oral medications.
4. Ability to walk and function safely at home.

You will be required to see your transplant doctor or nurse practitioner frequently in the first 100 days after transplant. In some cases, there may be more **radiation** and treatment necessary.

The process of **mobilization** and **collection** will be explained in more detail in Chapter 3. Chapter 6 will briefly discuss **conditioning** therapy.

Timeline

Autologous SCT from mobilization through discharge takes six to eight weeks to complete. Complications may extend this timeframe. Recovery after discharge usually takes about two months.

In some cases, it is possible to have an autologous SCT as an outpatient. In this case, you would only be admitted to the hospital if you had a complication, such as a fever requiring IV antibiotics. Your transplant 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 even though you are donating a blood product for yourself. 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 at least the first 30 days post-transplant, after discharge from 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 transplant. Depending on your medical condition post-transplant, you may be required to arrange for local housing within a certain distance of 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 doctors 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 autologous blood and marrow transplant. There are many factors that must be considered before moving forward, such as:

- Response of the cancer to **chemotherapy/radiation**
- 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 on 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 BMT 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 the SCT.

Nutrition is important to help you maintain your weight and strength during the transplant process. The chemotherapy you will receive during your SCT 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 foods taste. You may 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 navigator, clinical social worker or your doctor.

Alcohol and Drug Addiction

Like smoking, some insurance companies will not authorize a blood and marrow transplant 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. MOBILIZATION AND STEM CELL COLLECTION

Mobilization

Mobilization is the process of using medications to move stem cells from the **bone marrow** and into the circulating blood. **Growth factors** are usually used. **Mobilization** can also be done after **chemotherapy with growth factors**.

These medications are called granulocyte colony-stimulating factors (or G-CSFs). They have several trade names: Neupogen,[®] Zarxio[®] and Granix[®].

Other growth factors used as single agents or in combination with Neupogen[®] are:

- Neulasta[®]
- Plerixafor[®] (Mozobil[®])*

All growth factors are given as a small **injection** under the skin (**subcutaneous**). The main side effect of growth factors is bone pain. Taking Claritin[®] or Allegra[®] on days you are getting growth factors may reduce the bone pain. Ask your doctor about this. Other side effects of growth factors are:

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

*Mozobil[®] is a drug that directly increases the number of stem cells in the blood. It is often used in combination with a G-CSF when there is difficulty collecting enough stem cells with a G-CSF alone. It is given at 6 p.m. the night before apheresis. Most common side effects are nausea and diarrhea. In rare cases, it can cause constipation. Please let your nurse know if you are experiencing side effects so you can be medicated before apheresis begins.

Note: If you have multiple myeloma, all other treatments such as Revlimid,[®] Velcade[®] and dexamethasone should be stopped at least two weeks prior to mobilization.

Mobilization After Chemotherapy

In some situations, mobilization occurs after chemotherapy in conjunction with a G-CSF. This will happen when your blood counts have been low and start to go up. During this time when the counts are low, you must have a CBC drawn and RN visits daily. If you get a fever while **neutropenic**, you will be admitted to the hospital for IV antibiotics.

Stem Cell Collection Week

Prior to beginning stem cell collection, you will always need to check in to the Samuel Oschin Cancer Center first. This is to get blood drawn and receive growth factor injections.

Your navigator will always schedule you for five full days of collection, Monday through Friday. Some patients require one or two days, some need all five. There is no way to predict how fast you will collect **stem cells**. The true amount collected is not known until the collection report is done at the end of each day. The goal for the amount needed will be based on the cell dose targets ordered by the doctor.

How many cells do you need? The goal is to collect 5 million stem cells per kilogram of body weight as that is an optimal amount to safely recover your **bone marrow** from the **conditioning chemotherapy**. As few as 2 million stem cells can be used effectively, however.

For **multiple myeloma** patients, we collect enough stem cells for you to have two transplants (10 million stem cells per kilogram).

For Jehovah's Witnesses patients, we collect 7 million **stem cells** per kilogram. Transplanting this number will help you recover from **conditioning chemotherapy** without using blood products.

Factors affecting stem cell collection:

1. **Neutropenia**. If the **white blood cell** count is below one (thousand), collection will be postponed until it reaches four (thousand). **Growth factors** will be given daily to speed up this process.
2. **Revlimid[®]**. This drug is known to suppress stem cell production and should be stopped for two to four weeks prior to stem cell collection.
3. **Chemotherapy/radiation**. If you have been heavily treated, you may have difficulty collecting stem cells. In cases where the collection is not going well, Mozobil[®] is given.

Note: Autologous bone marrow harvesting (done in the operating room) is a method to manually collect stem cells directly from the bone marrow, like a bone marrow biopsy. It is another option to collect stem cells for autologous patients who may have a preference or need for this approach.

The Apheresis Catheter or “IJ”

Once you are ready to proceed to stem cell collection, you will go to the Cedars-Sinai Procedure Center to have a special IV line placed.

This is called an **apheresis catheter** or “**IJ**.” IJ stands for internal jugular, which is the very large vein inside the 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 apheresis catheter allows us to **harvest** cells from your circulating blood instead of going inside the **bone marrow** (which is done in the operating room under general **anesthesia**).
- The area is numbed prior to insertion. You will feel pressure but usually not pain when it goes in.
- Once it is in place, you will be able to eat, sleep, read or watch TV while your stem cells are being collected.
- The IJ catheter will be removed as soon as the target stem cell number is reached (one to five days).

If you are claustrophobic or anxious about the placement of the catheter, your transplant doctor may order a medication to help you relax.

Once the line is placed, an X-ray will be done to make sure it is positioned correctly. You are then ready to start collecting stem cells.

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

Each session on the apheresis machine is four to five hours long. During that time you are resting in bed and the nurse will be monitoring you. You 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 Process

Apheresis works like this:

1. Blood exits the body through one side of the 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 you 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 patient. 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.
- You cannot be disconnected from the machine to use the restroom. A urinal, bedpan and commode are available.

For most patients, 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 body. To prevent these symptoms, a calcium IV drip will be running continuously during the stem cell collection. Let the apheresis nurse know if you develop these symptoms and additional calcium can be given to you.
- **Discomfort.** Sometimes patients find it uncomfortable to lay in bed for four to five hours. Growth factors can cause bone pain, which adds to this discomfort. Claritin[®] or Allegra[®] with Tylenol[®] can help prevent and treat this. (Note: By the time you are collecting stem cells, your **white blood cell** count has recovered so Tylenol[®] is safe to take).

At the end of each collection day, the navigator will receive the stem cell count. Once enough cells are collected, your line will be removed. At that point, stem cell **collection** is complete.

In some cases, you may be told to return to the Cancer Center for a repeat blood test after completing the day's apheresis procedure. If this is required, you will be notified by the apheresis room staff or SCT navigator.

Important tips:

- If possible, you should have a caregiver available to drive you to and from the hospital while the catheter is in place.
- You must keep the IV line and the dressing dry. Take baths instead of showers until the line is out.
- When you come to Cedars-Sinai for apheresis, you should bring a lunch with you or have a caregiver available to bring you food.

Cryopreservation

Once the stem cells are collected, a preservative called ***dimethyl sulfoxide (DMSO)*** is added. They are placed into a freezer in the Stem Cell Lab until you need them for transplant.

Cells may be safely frozen for 10-15 years or more. You must sign a consent form to have your stem cells collected and frozen.

Cedars-Sinai will cover the cost of storing your stem cells for a period of five years. After that time, if you still have cells in the freezer, you will be contacted and must decide what you want to do with the cells.

Options are:

1. For an annual fee per year per bag, they can be transferred to storage at the California Cryobank in Los Angeles.
2. Transfer them to a private stem cell lab.
3. Discard the cells.
4. Provide your consent for Cedars-Sinai to use them for research.

If you do not reply in spite of attempts to contact you, your stem cells will be discarded. Collected stem cells would never be used for another patient.

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 ***SCT***
- Research participation (Not all patients qualify for research. This is discussed in the next section.)
- Transfusion of blood products (For Jehovah's Witnesses patients, this consent form will be omitted because blood products will not be given.)

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. These data are 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
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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 30 days post-transplant, except when you are in the hospital.

This person must be available to drive you to the hospital at any time of day or night for at least 30 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

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

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 two-lumen ***peripherally inserted central catheter*** (2L ***PICC***) line placed. This is a long-term IV line placed into the upper arm that is used for the transplant admission. Your navigator will communicate the time for this appointment.
 - If you already have a functioning two-lumen PICC line, it will be used for transplant.
 - A single-lumen PICC line will be replaced with a two-lumen PICC.
 - ***Implanted Ports*** (i.e., PAS Ports and Portacaths) will not be used for transplant. Patients with these lines will have a two-lumen PICC placed.
3. **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.
4. **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.
5. 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 doctor.

Nurse practitioners. Nurse practitioners have an advanced degree (master's) in nursing and special training in BMT. 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 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. unless they are staying overnight with you.)
- 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.-9 p.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. 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”)

Recall that the high-dose **chemotherapy** (with or without **radiation**) given before a blood and marrow transplant is called **conditioning**. Conditioning will begin soon after you are admitted to the hospital. Some patients may receive their first dose of chemotherapy in the outpatient infusion area before they are admitted.

Chemotherapy

Conditioning chemotherapy is given in high doses to reduce the amount of **cancer** in your body or prevent it from coming back. The drugs given are specific for your disease. In the process, your **bone marrow** will be damaged beyond its ability to recover. Your previously collected **stem cells** will be given back to you so that your bone marrow will function again.

There are many different conditioning regimens that may be used for **autologous** SCT. The transplant doctor will decide which regimen is most appropriate based on your disease, response to previous therapy, age and overall health.

Conditioning chemotherapy will be given to you as an intravenous infusion and/or in pill form.

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.

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 well-controlled. Additional side effects can happen that are specific to each drug, as listed on the next page. 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.

Drug Information Table—Chemotherapy

Generic Drug	BrandName	Potential Side Effects	Long-Term Potential SideEffects
Cytarabine	Ara-C®	Coordination or balance problems Eye pain Rash on hands/feet	Coordination/ balance problems
Carmustine	BCNU®	Facial flushing	Lung damage
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	
Thiotepa	Thioplex®	Skin rash	

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 prior to admission for transplant.

2. Total Body Irradiation (TBI)

TBI means radiation delivered across the entire body. The purpose of TBI in **autologous SCT** is to kill residual **cancer** cells that are not visible on imaging scans. TBI is done for patients with resistant lymphomas or leukemia. TBI will occur once you are admitted for transplant and is part of the **conditioning regimen**.

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.

Usually the treatments will be given twice a day for five treatments. In some cases, extra doses of radiation may be required. Each treatment lasts 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. 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.

3. Post-Transplant Consolidation (also called Involved Field Radiation)

This type of radiation is used for patients with resistant or residual disease in a specific area like the neck or chest. About three weeks after discharge, you will be referred to a radiation oncologist for a consultation. Then, daily radiation directed toward the location of the resistant tumor will begin. This treatment may take four to six weeks to complete.

You will not be radioactive after radiation therapy. Radiation has similar side effects as **chemotherapy**. The radiation therapists will provide specific education about what to expect following different treatments.

Key fact: Chemotherapy drugs and radiation cause side effects. You will receive medications to prevent, reduce and/or treat these side effects.

Drug Information Table—Supportive Medications

The medications listed on the next page may be used to reduce the side effects of high-dose chemotherapy and radiation therapy.

Drug Name	BrandName	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 subcutaneous
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 **stem cells** back.

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 are thawed.
- Your nurse will give you medications such as Benadryl® and Tylenol® before the infusion. This is to prevent allergic reactions from the preservative **dimethyl sulfoxide (DMSO)** used during the storage process. Steroids may also be used.
- Your nurse will be present throughout the transplant infusion.
- A transplant doctor 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 of bags and amount of stem cells vary for each patient.
- Each bag is infused one at a time over 20 minutes to an hour.
- 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. Potential side effects are listed on the next page.

Side Effects From the Stem Cell Infusion

Potential Side Effect	Response
Allergic reaction: hives, itching, fever , 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 hours of 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	This is also temporary as the preservative dimethyl sulfoxide (DMSO) 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 stem 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 also rebuilding your immune system. This is called **engraftment** and is discussed further in Chapter 14.

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 until Day +100.

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 **autologous** 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**)

Review: The Complete Blood Count (CBC)

Recall from earlier: **white blood cells**, **red blood cells** and **platelets** make up a **complete blood count** 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 7G/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: 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 in the red blood cell is a vehicle 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 support during 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 feeling sensation, numbness 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 (WBC):** 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 may change 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 higher risk for falls and injuries from falls, but 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 to see 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 in your 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 a transplant. 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 anti-nausea drugs (**antiemetics**) 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.

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.

Drug Information Table—Supportive Medications

The medications on the next page may be used to reduce the side effects of highdose chemotherapy and radiation therapy.

Generic Name	BrandName	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 bloodcells	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 12. 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 also 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 13. 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 90 minutes 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 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 14. 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 **stem cells** move to the **bone marrow** and begin to grow and divide. Your **complete blood count (CBC)** tells us when engraftment is occurring in the bone marrow.

Neutrophils (a type of **white blood cell**) are the first 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 the doctor feels is safe.
2. You do not have a **fever** or need for IV antibiotics.
3. You are able to drink fluids; nausea/vomiting or diarrhea are controlled by oral medications.

After discharge from the hospital, you still might need blood or platelet transfusions for a little while until full engraftment occurs. You will be closely monitored until Day +100.

Discharge Instructions

Your transplant team will review important information with you 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, 7 days a week for the first 30 days after transplant, except when you are in the hospital.
- 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 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 15. POST-DISCHARGE

Follow-Up Appointments

After you go home from the hospital, you will need to see your transplant doctor or nurse practitioner within a couple of days. If everything is going well, appointments may be weekly for two to three weeks, biweekly for about a month, and then at Day +100 and at one year.

When appropriate, your transplant doctor will refer you back to your local oncologist for follow-up. We will want to know how you are doing on an annual basis.

We also hope to see you at our annual Celebration of Life in the fall. It is a wonderful opportunity to meet other transplant survivors and see your transplant team again.

Infection Prevention

You are still at risk for infections even after engraftment occurs. Your immune system is working, but it is very fragile.

You need to be cautious and try not to expose yourself to illness for the first 100 days (three months) after your **transplant**.

You have three enemies after transplant:

1. Bacterial infections
2. Viral infections (colds and flu, reactivation of previous viruses)
3. Fungal infections

Infection prevention tips:

- Washing your hands and having others wash theirs is absolutely the BEST way to prevent infection!
- 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 babyoil.
- Do not share cups, glasses, utensils, etc., with others.
- If you have **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 acyclovir for three months after your transplant.

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. 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:

- Fatigue
- Great one day and sick the next day
- Mood swings
- Anxiety
- Loss of appetite and taste

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: Getting Back to Normal

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 or the 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. Wear a sunscreen with a minimum SPF of 30. Always wear a hat, longsleeves, 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 may not be strong enough right 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, ducklings or chicks, 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 **high-dose chemotherapy**. Fortunately, this will improve over time and eventually return to normal.

You are not required to follow the low-microbial diet after discharge. However, use common sense when making food choices and follow basic food safety guidelines for the first 100 days after transplant.

It is important to drink lots of fluids, minimum 2 pints (or 1 liter) per day, 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 to have sex! Talk to your partner about your feelings and go at your own pace.

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 a transplant. Your doctor will let you know if you need to repeat your childhood immunizations one year after your transplant.

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 16. WHEN TO CALL THE DOCTOR OR NURSE PRACTITIONER

The 24-hour Samuel Oschin Cancer Center phone number is 310-423-0626. If the Samuel Oschin Cancer Center is not open, your phone call will be directed to a nurse or doctor. If you are feeling unwell, it is always safest to call right away and speak with a clinic nurse.

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 17. 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.

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.

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 involves 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 surgically placed for the purpose of apheresis. It is placed in the upper-right or left chest area, where it is tunneled under the skin and into a large vein, the superior vena cava, above the heart. It has two “lumens” or “tubes” so that blood can flow out from one lumen and return by the other lumen. It can be also be used to give IV fluids, chemotherapy, blood products, as well as to reinfuse the stem cells. A temporary apheresis catheter (only used for a few days) can also be placed near the neck area.

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 of fermentation (such as in wine) and that of decomposition.

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 or Rh 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 blood products, 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.

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

Clinical trial: see *research protocol*.

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 (conditioning regimen/conditioning chemotherapy): A term used for the high-dose chemotherapy, with or without radiation therapy, given to prepare the patient's body for the transplant. The regimen generally lasts 2-10 days prior to the transplant.

Cryopreserve (cryopreservation): Those methods 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 (dimethylsulfoxide) 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: An ultrasound 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.

EKG (electrocardiogram): 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).

Fever: The rising of a person's temperature above normal, which is generally 98.6 degrees orally. 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 orally) 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.

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.

Harvest: see *bone marrow harvesting*.

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.

High-dose chemotherapy: Chemotherapy that is given in higher doses than standard cancer treatment. Standard and high doses depend on the type of cancer being treated and the type of chemotherapy.

IJ or internal jugular catheter: see *apheresis catheter*.

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.

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 bilirubin (a byproduct of red cells) in the blood.

Lab work: Blood sample tests.

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.

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 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.

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*.

Peripherally inserted central catheter (PICC): 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.

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 *allogeneic transplant* and *autologous transplant*.

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 18. 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	
	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	