ALLOGENEIC BLOOD & MARROW TRANSPLANT

Patient Education, Book #2
2013 Edition
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# Important Phone Numbers

**Samuel Oschin Cancer Center**

24-hour phone line for clinical problems (fever 100.4°F or higher, vomiting, rash, etc.)

**(310) 423-0626**

### 4SW Transplant Leadership Team
- Deena O’Shea, 4SW Manager ................................................................................ (310) 423-4249
- Sandra Rome, RN, MN, AOCN, CNS ....................................................................... (310) 423-4236

### 4SW Unit ............................................................................................................ (310) 423-4415

### Transplant Coordinators
- Margarita Guerrero, RN, BSN, OCN ................................................................. (310) 423-3525
- Carolina Caso, RN, BSN, CPON ........................................................................ (310) 423-2440
- Laura Snoussi RN, BSN, OCN ........................................................................... (310) 423-6497
- Patricia Van Strien, RN, MSN, OCN, CHTC ..................................................... (310) 423-5351
- Leticia Uy, RN, BSN, OCN ................................................................................ (310) 248-8533
- Anne Rosenblatt, RN, MSN, Lead BMT Coordinator ........................................ (310) 248-6691

### Social Work and Case Management
- Virginia Stephens, RN Case Manager (Inpatient) ................................................... (310) 423-4446
- Gabrielle Clay, MSW (Inpatient) ....................................................................... (310) 423-2439
- Christina Williams, LCSW (Outpatient Social Work) ........................................ (310) 423-1119

### Dietitian Office
- Robyn Curran, Med, RD, CSM (Inpatient) ............................................................ (310) 423-4521
- Outpatient ........................................................................................................... (310) 423-1116

### Transplant Physicians
- Maria Delioukina, MD ......................................................................................... (310) 423-1160
- Michael Lill, MD .................................................................................................. (310) 423-1160
- Stephen Lim, MD ................................................................................................. (310) 423-1160
- Yuliya Linhares, MD .......................................................................................... (310) 423-1160
- Robert Vescio, MD .............................................................................................. (310) 423-1825

### Nurse Practitioners
- Seda M. Gharpapetian, RN, MSN/FNP-BC, OCN ................................................ (310) 384-4659
- Kristen Geraghty, MS, RN, ANP-BC .................................................................... (310) 384-3948
- Gurpreet Tiwana, MS, RN, NP-C ....................................................................... (310) 384-3692

### BMT Program Assistant
- Mona Homeidan .................................................................................................... (310) 423-2107
About This Book

If you are reading this book, either you or a loved one is having an **allogeneic blood and marrow transplant**, or “BMT”, at Cedars-Sinai Medical Center.

Your transplant doctor and nurses have already spent a lot of time teaching you about your transplant. Book #1 covered everything you needed to know up until your admission for transplant. This is Book #2. It covers what to expect during and after transplant. It will tell you how to actively participate in your own recovery. Please bring it 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. There is a section at the back where you can save important paperwork like lab and imaging reports.

Like Book #1, there are quizzes at the end of each chapter. These quizzes are to help you remember key points about BMT. Remember, you can repeat quizzes until you are comfortable with the information. We encourage your main caregiver (spouse, partner, etc.) to read these books and complete the quizzes with you.

There is a “treasure hunt” that must be completed before you go home. You can get started on it as soon as you arrive on 4SW.

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

Parking is validated on your day of admission and day of discharge. Reduced-rate weekly and monthly parking permits are available for Lots #1, #2 and #4.

Please call (310) 423-5535 (or ext. 35535 from a hospital house phone) for more information.
Welcome to 4SW

We know that you have already been through a lot of treatment and preparation for transplant. Now you may be feeling nervous about your hospital stay.

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 blood & marrow transplant patient care team on 4SW. If at any time we do not meet your expectations, please let us know right away. You may inform your physician on rounds, or ask to speak with the nurse manager.

Our team includes:

**Attending physicians.** 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.

**Nurse Practitioners.** The nurse practitioners (NP) involved in your care are registered nurses with advanced degrees, training, and experience in caring for BMT patients. NPs work with the health care team to manage your medical needs during your transplant course, which may include ordering tests and medications. You will be seen by an NP every day that you are in the

The 4SW nursing station and a few members of the 4SW patient care team. Our goal is to keep you safe and comfortable, and to include you in the daily plan of care.
hospital. They will serve as your point of contact during the transplant and will continue to see you in the outpatient clinic.

**Fellows and residents.** Cedars-Sinai Medical Center 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 BMT. Both fellows and residents are supervised by the attending physicians.

**Registered nurses.** Your nurse is a highly trained professional with years of experience with patients undergoing blood & marrow transplant.

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

**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 is an expert in BMT and 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.

Palliative care specialists. Every BMT patient has a palliative care consult once admitted to 4SW. This team specializes in pain control, reducing severity of symptoms and promoting quality of life.

Other services and resources available:
- Volunteers
- Patient relations
- Psychiatry
- Chaplain

Visitor Guidelines for 4SW

Check with the patient’s nurse to see if the patient may have visitors. No children under 18 may visit 4SW.

Visitors should not bring fresh or silk flowers, plants, or fruit baskets.

Wash your hands thoroughly; it is the key to infection prevention. Use soap and water, then dry your hands or use Purell® before entering the room. Repeat when you leave the room. Rewash your hands in the room sink prior to touching the patient if you have been in the room for longer than five minutes.

Visiting hours are generally 10 a.m. to 9 p.m. unless you are staying overnight with the patient. You will need to have a visitor’s badge. You can get one in the lobby of the South Tower, Street Level.

One support person/caregiver may sleep in the room on a cot. Please fold up the cot during the day. Any family member spending the night must be able to take care of his or her own needs and expect that sleep will be interrupted by the necessary nursing activities. Visitors may not use the patient’s bathroom or shower.

Visitors should be free of illness with no recent exposure to infections or immunizations.

You may assist the patient with care only after you have checked with the nurse.

Do not sit on the bed or put your shoes on the bed. Do not use the patient’s restroom for toileting activities or eat in the patient’s room. If the intravenous pump alarm goes off, please call the nurse. Do not turn off the alarm. Turning off the alarm could potentially harm the patient.

Visiting a 4SW patient? Follow these important rules to protect your loved one’s health:

- Do not visit unless you are free of illness with no recent exposure to infections or immunizations
- No children under 18 may visit 4SW
- Wash hands thoroughly before entering a patient’s room
- Do not bring fresh or silk flowers, plants or fruit baskets
- Do not sit on the patient’s bed or put your shoes on the bed
- Do not use the toilet in the patient’s bathroom
- Do not turn off the IV pump alarm in the patient’s room
Phones

You can only receive incoming calls on the room phone between the hours of 8 a.m. and 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 nursing station.

If you bring your personal cell phone, please note that the staff cannot be responsible for it. Never leave your cell phone 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 4am and 7am. Sometimes blood will have to be drawn directly from a vein and not from your PICC line.

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

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.

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

Mouth care should be done 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.

When your blood counts are very low, a bed alarm will be turned on and you will need to call for assistance when you want to get up to go to the restroom, chair, etc.

The phone number of the 4SW Nursing Station is (310) 423-4415
You will be in a private room with a private restroom. The room is hepa-filtered, meaning the air inside is filtered to remove fungal spores and is exchanged several times per hour to keep it cleaner than the air outside your room. The door must remain closed at all times to allow the filter to function properly. While your blood counts are low and 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. You may NOT go down to the Plaza Level without specific permission from your doctor and nurse.

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

**Key Fact:** While you are **neutropenic**, you may walk 4S unit area as long as you wear a mask and notify your nurse.

### Timeline for Admission

The average **allogeneic** transplant admission is 4-6 weeks in the hospital. Factors affecting length of stay include:

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

Your doctor will decide when it is safe for you to go home. Full recovery after discharge is ongoing and may take six months to one year. During this time, you will be closely monitored by your transplant doctor.

1. **Admission** - Hospital unit 4SW
2. **Conditioning** - Chemo +/- Radiation 5-12 days
3. **Transplant** - 3-6 week hospital stay
4. **Engraftment** - Requirement for discharge home
Quiz: Chapter 1

Question 1
Children under 18 may visit you in the hospital during your transplant.

a) True
b) False

Question 2
Visitors may use the patient's bathroom.

a) True
b) False

Question 3
If the IV pump is beeping, it is okay to turn it off as long as you call the nurse at the same time.

a) True
b) False

Question 4
It is very important to keep track of everything you drink and save all output (urine, stool and vomit) for the nurse or clinical partner to measure.

a) True
b) False

Question 5
What is the minimum number of times per day for mouth care?

a) 1
b) 2
c) 3
d) 4

Question 6
When going for a walk in the hallway, always wear a:

a) costume
b) hat
c) mask
Recall from Book 1 Chapter 9 that there are different levels of intensity for conditioning regimens prior to BMT, myeloablative, reduced intensity, and non-myeloablative. All conditioning regimens combine a class of drugs called "immunosuppressants" with chemotherapy and/or radiation therapy. Conditioning will begin soon after you are admitted to the hospital. In some cases, conditioning may be done on an outpatient basis. Your doctor will let you know if this is an option for you.

**Immunosuppressants**

Without immunosuppressants, BMT would not be possible. The immune system is responsible for attacking and killing anything it does not recognize as "self". This naturally aggressive behavior is protective and allows us to survive infections under normal circumstances.

In the setting of allogeneic BMT, your immune system is being replaced by someone else's, whether it is a sibling, unrelated adult donor, or two umbilical cord blood units. Even though we do our best to "match" you, another person is never going to be exactly the same as you. Without immunosuppression, your immune system would attack and destroy the donor cells (graft rejection) OR the donor cells would attack and destroy you (graft versus host disease). In either case, the transplant would not be successful.

This is why all allogeneic BMT patients must strictly adhere to a medication regimen that includes daily immunosuppression. This begins a few days prior to the transplant and continues for a minimum of six months after.

Please refer to the table on page 31 for specific drug names. At first, you will receive immunosuppressants given intravenously through your PICC line. Before you go home, they will be converted to pill form.

The level of the immunosuppressant drug in your blood must be carefully monitored to ensure that the dose is correct. This will happen automatically while you are in the hospital. Discharge teaching will include important information about taking your immunosuppressants (page 57).

We cannot stress enough how critical it is that you and your caregiver understand and adhere to immunosuppressant orders and schedule. If you ever have questions, be sure to ask them. If at any time you cannot take your daily immunosuppression, please notify your physician immediately. We want to keep you safe!

**Key Fact:** All allogeneic BMT patients must strictly adhere to a medication regimen that includes daily immunosuppression for a minimum of six months after transplant.
Chemotherapy

**Conditioning chemotherapy** is given in either high doses (myeloablative) or reduced intensity doses to kill remaining cancer cells and chemically destroy your bone marrow to prepare it for the new donor cells.

The drugs given are specific to the disease being treated. Your donor’s stem cells will be given back to you so that your bone marrow will function again.

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

Total Body Irradiation (TBI) or Total Lymphoid Irradiation (TLI)

The radiation oncology staff will help you get comfortable prior to starting the treatment. Once it starts, you need to lie very still. You will be alone in the room lying on a gurney while the treatments are given. However, the radiation therapist will be monitoring you on a screen just outside the room. You will be able to talk to each other through a speaker.

Treatments may be given as a single dose, or may require up to three times per day for several days in a row. Each treatment lasts 15-30 minutes. On the first treatment, small clips will be taped to your skin at different levels; they are there to measure exact doses to different parts of the body.

TBI and TLI are painless and the radiation cannot be seen. You will not be “radioactive” after you leave the room. Side effects of radiation are similar to chemotherapy. Premedications will be given prior to therapy to help prevent side effects.
Quiz: Chapter 2

Question 1
Conditioning chemotherapy will begin:

a) Soon after admission to the hospital
b) After the stem cells are infused
c) On transplant day

Question 2
Medications to prevent side effects from conditioning will be given on a regular basis.

a) True
b) False

Question 3
Radiation is required for all patients as part of their conditioning regimen.

a) True
b) False
Chapter 3: Transplant Day

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

This is also called “Day Zero”, the day that starts the post-transplant count.

Here is what to expect:

**The Infusion**

- The cells will be delivered to your room after they have been received, inspected, washed (if the donor’s *blood type* is not compatible with yours), counted and tested. The color inside the bag may range from light candy red to dark red, like blood.

- Your nurse will give you Benadryl®, Tylenol® and a steroid before the infusion.

- Your nurse will be present throughout the transplant infusion

- A transplant doctor and/or nurse practitioner will be present on 4SW throughout the infusion

- The stem cells are infused into your *PICC* line

- Your nurse will infuse the cells at the bedside, take frequent *vital signs* and watch for potential side effects. This will include measuring the amount of oxygen in your blood with a pulse oximeter.

- The number and volume of bags varies for each patient

- Each bag is infused one at a time over 20 minutes to several hours

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.

**Side Effects from the Stem Cell Infusion**

<table>
<thead>
<tr>
<th>Potential Side-Effect</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergic reaction: hives, itching, <strong>fever</strong>, sweating, rapid pulse, shortness of breath, anxiety, stomach cramping, dizziness, general swelling</td>
<td>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.</td>
</tr>
<tr>
<td>Red urine</td>
<td>This will go away on its own within 24 hours of the infusion. It is from broken <em>red blood cells</em> present in the stem cell product.</td>
</tr>
<tr>
<td>Nausea or taste changes from the smell and taste of the stem cell preservative if the bag was frozen</td>
<td>This is also temporary as the preservative will be out of the body within 24 hours. Medications can alleviate this side effect. Sucking on hard candies may also help.</td>
</tr>
</tbody>
</table>
After the Infusion

The donor cells will find their way from your bloodstream and into your bone marrow. Once they get there, they are like seeds planted in the earth; they just need time to grow. When they do, they will begin the process of making new blood cells and slowly rebuilding your immune system. This is called *engraftment*, and is discussed further in Chapter 10.

Key Fact: Your nurse will infuse the cells at the bedside, take frequent *vital signs* and watch for potential side effects.

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

The transplant team keeps track of how many days it has been since the infusion. The day after transplant is “Day +1”, a week after the transplant is “Day +7”, etc. You will be closely monitored for a minimum of 6 months to one year after transplant depending on how your recovery goes.
Quiz: Chapter 3

Question 1
Who will infuse your stem cells on transplant day?

a) Transplant doctor
b) Primary caregiver
c) Your nurse for the day

Question 2
Premedications are given before the transplant to:

a) Prevent rejection of the cells
b) Prevent allergic reaction
c) Help you sleep through the procedure

Question 3
What is another word for transplant day?

a) Engraftment day
b) Day zero
c) Rest day

Question 4
Red urine is common after the infusion and should resolve on its own within 24 hours.

a) True
b) False
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 is our top priority. The risks and complications of an allogeneic transplant are caused by:

- Side effects of chemotherapy and/or radiation therapy
- The period of lowered blood cell counts (neutropenia, anemia and thrombocytopenia)
- Organ toxicities (explained in chapter 5)
- Graft versus host disease (explained in chapter 6)

**Review: Complete Blood Count (CBC)**

Recall from Book #1: **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.

**Protect Yourself from Infection: Wash Your Hands!**

- After going to the bathroom
- Before and after meals
- After walking in the hallway
- After handling items touched by other people

Make sure others wash their hands before touching or helping you, including:

- Doctors
- Nurses and other caregivers
- Visitors

**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 to 8.0 (thousand)
- Neutropenic precautions implemented when ANC is less than 1 (thousand)

**Hemoglobin**

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

- Platelets help prevent bleeding
- Normal values are 150 to 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:
White Blood Cell Count Below 1 (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:

- Wash 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 wash 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.

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°F or higher), your nurse will obtain blood and urine cultures right away. IV antibiotics will be started.

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°F 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: Hemoglobin Less than 7 G/dL**

Recall that hemoglobin 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 7 G/dL.

*When platelets are low and the bed alarm is on, ask for assistance prior to getting out of bed.*

Reminder: the nurse's main goal is to keep you safe. For that reason, the nurse may turn on the bed alarm at any time.

**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.

A transfusion of packed red blood cells may correct anemia. In general, we transfuse when hemoglobin drops below 8 G/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.

*When platelets are low and the bed alarm is on, ask for assistance prior to getting out of bed.*

Reminder: the nurse’s main goal is to keep you safe. For that reason, the nurse may turn on the bed alarm at any time.
Thrombocytopenia: Platelets Less than 20 (Thousand)

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 (example: a nose bleed) or on the inside (example: 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 transplant. However, precautions are necessary in order to keep you safe. For this reason a bed alarm will be turned on when your platelets are low. During this time you will be required to call for assistance to get out of bed. Falling when platelets are low can be life threatening, we do not want to take that risk!

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 spots under the skin

- Use a soft toothbrush for all oral care; floss regularly

- Dab your nose instead of blowing or picking it.

**Important Tip:** Call your doctor or nurse immediately if you see signs of bleeding:

- 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 spots under the skin

Platelet transfusions can correct low platelets. In general, a platelet transfusion will be infused through your PICC line when your platelet count is below 10 (thousand).
• Try not to strain during bowel movements. Stool softeners are available if needed.

• Do not bend over so that your head is lower than your heart.

• Do not use nail clippers. Electric razors are okay.

• 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 nurse may set the bed alarm to remind you.

• Do not take any over-the-counter medications without your doctor’s approval

• 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 in BMT Patients**

Falls are very dangerous after BMT when blood counts are low. Please read the following information about this very carefully.

Fall Risk Factors:

• **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 light-headedness

• **Anemia**: a drop in blood cell counts may make you feel more tired and weak

• **Medications**: various medications increase fall risk such as:
  - Sedating medications/benzodiazepines (Ativan, sleeping medications, Benadryl®)
  - Narcotics/opioids used for pain may cause sedation and dizziness
  - Antiepileptics
  - Psychotropic drugs
  - Antihypertensive medications
  - Diuretics
  - Steroids may play a role in muscle weakness
  - Chemotherapy
  - Radiation
  - Hormone therapy
  - Anti-anxiety pills and antidepressants

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 cause skeletal-muscle wasting, debilitation, and changes in functional status.

**Risk Factors For Falls Causing Injury, Infection and Death:**

• **Low platelets**: Platelets help your blood to clot. Low Platelets can cause a fall to result 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.

• **Increased risk of fractures**: from hormone therapy and certain cancer.
• **Decreased healing ability:** due to steroids/immune suppressants and primary illness.

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 use 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 Wrist Band:** Wrist bands 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.

• **Physical Therapy:** may provide muscle strengthening, walking and balance training.

• **Walking Aids:** a walking device can help maintain balance; we provide non-slip socks and recommend non-slip footwear such as tennis shoes.

---

**Important Tip: What You Can Do to Help Prevent a Fall:**

• Always ask for help
• Tell us how you are feeling
• Know the side effects of your medications
• Choose safety over privacy
• Look out for items in your path such as the IV pole and clutter while moving around your room
• Keep important items within reach, such as the call button, your glasses and phone
• 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.

• **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 the 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.

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.
Quiz: Chapter 4

Question 1
Neutropenic precautions begin when the ANC is less than 1 (thousand)

a) True  
b) False

Question 2
The BEST way to prevent the spread of infection is:

a) Handwashing  
b) Stay inside your hospital room at all times  
c) Do not eat fresh fruit or vegetables

Question 3
Daily showers, mouthcare 4 times per day, and careful cleansing after bowel movements will help prevent infections while you are neutropenic.

a) True  
b) False

Question 4
A fever is a temperature of:

a) 98.6° F or higher  
b) 100.4° F or higher  
c) 104° F or higher

Question 5
Avoid taking long, hot showers because they may cause you to feel weak and dizzy.

a) True  
b) False

Question 6
Three good ways to prevent bleeding when platelets are low are:

a) Good handwashing, sit in a chair for meals, wear a mask in the hallway  
b) Stay in bed all day, use brand new razors only, take over the counter vitamins  
c) Use a soft toothbrush, try not to strain during bowel movements, do not use nail clippers

Question 7
When platelets are low and the bed alarm is on, always ask for assistance before getting out of bed.

a) True  
b) False

Question 8
What can you do to help prevent a fall?

a) Don’t go for walks in the hallway  
b) Always ask for help  
c) Choose safety over privacy  
d) Keep the call button within reach  
e) All of the above  
f) Answers b,c and d only
CHAPTER 5. OTHER POTENTIAL SIDE EFFECTS

The following information may seem frightening, but we want you to be informed. Remember, side effects range from mild to severe, most people will be somewhere in the middle.

Chemotherapy and radiation 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.

Drug Information Table - Chemotherapy

<table>
<thead>
<tr>
<th>Generic Drug Name</th>
<th>Brand name</th>
<th>Regimen Name</th>
<th>Potential Side Effects</th>
<th>Long-Term Potential Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Busulfan</td>
<td>Busulfex®</td>
<td>Busulfan Bu+Cy+VP16 Bu+Cy</td>
<td>• Nausea/vomiting • Mouth sores • Seizures</td>
<td>• Lung or liver toxicities • Infertility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TBI+Cy+VP16 Bu+Cy</td>
<td>• Nausea/vomiting • Bladder toxicity • Hair loss • Mouth sores</td>
<td>• Heart toxicity • Infertility • Secondary leukemia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BEAM or high-dose Melphalan Flu+Mel</td>
<td>• Nausea/vomiting/diarrhea • Mouth sores</td>
<td>• Secondary leukemia • Infertility</td>
</tr>
<tr>
<td>Etoposide</td>
<td>VP16®</td>
<td>R+ BEAM R+TBI+CY+VP16</td>
<td>• Fever/chills • Allergic reaction • Body aches</td>
<td>• Infection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flu+Mel Flu+Cy+TBI Flu+Bu</td>
<td>• Fever, infections • Nausea/vomiting • Diarrhea • Fatigue, dizziness • Cough • Skin rash</td>
<td>• Secondary leukemia</td>
</tr>
</tbody>
</table>
The following medications are called *chemoprotectants* because they help to protect healthy *cells* from the damaging effects of high dose *chemotherapy* and *radiation* therapy.

### Drug Information Table – Chemoprotectants

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Also known as:</th>
<th>Purpose</th>
<th>How it is given</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palifermin</td>
<td>Kepivance®,</td>
<td>Reduces the severity and duration of mouth sores after high dose radiation and <em>chemotherapy</em></td>
<td>Given through an IV for 3 days before chemo/radiation and again for 3 days after chemo/radiation ends</td>
</tr>
<tr>
<td>Amifostine</td>
<td>Ethyl®,</td>
<td>Reduces the severity and duration of unwanted GI side effects after high dose Melphalan. Currently this drug is being used experimentally for this purpose.</td>
<td>Given through an IV over 5 minutes for 2 doses. The first dose is given the day before transplant admission. The second dose is given before the melphalan dose.</td>
</tr>
<tr>
<td>Calcium phosphate rinse</td>
<td>Caphosol®,</td>
<td>Reduces the incidence and severity of mouth sores; moistens and cleans the mouth</td>
<td>Oral mouth rinse 4x per day and as needed.</td>
</tr>
<tr>
<td>Ursodiol</td>
<td>Actigall®,</td>
<td>Decreases the risk of veno-occlusive disease; reduces the risk of liver graft vs. host disease (GVHD)</td>
<td>Oral medication 2x per day for 100 days</td>
</tr>
</tbody>
</table>

### Side Effects from Immunosuppressants

*Immunosuppressants* can also cause side effects and make you feel unwell. This can be distressing because these medicines cannot be discontinued. Infusions can be modified, premedications given, and efforts made to convert you to oral form as soon as possible. Your transplant team will work with you to ensure you are tolerating your immunosuppressants.

**Key Fact:** Always remember, while taking immunosuppressants, you have an increased risk for infection even if your blood counts are within the normal range.
### Drug Information Table - Immunosuppressants

<table>
<thead>
<tr>
<th>Generic Drug Name</th>
<th>Brand Name</th>
<th>Route of Administration</th>
<th>Potential Side Effects</th>
<th>Long-Term Potential Side Effects</th>
</tr>
</thead>
</table>
| ATG (Anti-Thymocyte Globulin) | Thymoglobulin® | IV infusion | • Allergic reaction  
 • Flu-like symptoms  
 • Swelling/flushing  
 • Nausea/vomiting/diarrhea | • Infection  
 • Secondary cancer |
| Alemtuzumab | Campath® | IV infusion or injection under the skin | • Allergic reaction  
 • Flu-like symptoms  
 • Infection  
 • Low blood pressure | • Infection |
| Methotrexate | Methotrexate | IV infusion | • Mouth sores  
 • Nausea/vomiting | • Kidney, lung and liver toxicity |
| Cyclosporine | Sandimmune® | IV infusion, oral capsules or liquid | • Nausea/vomiting  
 • High blood pressure  
 • Tremor/shaking/flushing  
 • Swelling of the gums  
 • Abnormal body hair growth | • Kidney and liver toxicity  
 • Infection |
| Mycophenolate | Cellcept® | IV infusion  
 Oral - capsules or liquid | • Infection  
 • Diarrhea, vomiting  
 • Leg swelling  
 • High blood pressure/headache  
 • Low blood counts and infections  
 • Birth defects (talk to MD about appropriate contraception while taking Cellcept) | • Secondary cancers  
 • Infection |
| Tacrolimus FK506 | Prograf® | IV infusion  
 Oral - capsules or liquid | • Headache/dizziness  
 • Shaking/seizures  
 • Tingling/numbness  
 • Nausea/vomiting/diarrhea | • Secondary cancers  
 • Infection |
| Sirolimus | Rapamune® | Oral -tablet or liquid | • Infection  
 • Nausea, vomiting, diarrhea  
 • Stomach or joint pain  
 • Allergic reaction | • Secondary cancer  
 • Infection |
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 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 & 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 and/or radiation therapy 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.

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
- If you are snacking off and on, you may want to do your oral care more frequently
- Keep lips moist with lip balm
- If you have dentures, soak them in your usual cleaning solution as long as it doesn’t contain alcohol. Do not re-use 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 away.
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 and measure the amount.

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.

Anti-diarrhea medication cannot be given until infection has been ruled out.

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.

Liver Problems, Such as Veno-occlusive Disease or “VOD”

Although rare, some chemotherapy medications can cause the veins in your liver to become narrowed. This is called veno-occlusive disease (VOD).

VOD 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. All patients 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. GVHD (discussed in detail in Chapter 6) can also cause skin rashes. 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.
Neurological Problems

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

Let your nurse or doctor know if you are experiencing:

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

Heart and Lung Problems

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

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

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

Hair Loss

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

If you don’t have them already, we can provide you with wig and head covering resources.

Engraftment Syndrome

Engraftment syndrome occurs when a rush of chemicals called cytokines floods the body very quickly right before the white blood cell count starts to rise. The most common symptoms include fever, skin rash, swelling and rapid weight gain, shortness of breath, and changes in kidney and liver function on blood tests. Engraftment syndrome is treated with medications called steroids, and symptoms usually improve quickly.
Quiz: Chapter 5

Question 1
As long as you are taking immunosuppressants, you are at risk for infection.

a) True
b) False

Question 2
Allogeneic BMT may cause side effects to any organ system, so it is important to communicate all symptoms to the transplant team.

a) True
b) False

Question 3
Medications will be given to prevent and treat side effects.

a) True
b) False
What is GVHD?

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

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

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

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

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

Acute GVHD

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

Key Fact:

GVHD occurs when the donor’s transplanted immune system (the graft) begins attacking your body’s cells (the host) because they appear foreign. The three main symptoms are rash, diarrhea and changes in liver function (shown in blood tests).

Acute GVHD primarily affects 3 organs:

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

2. **Gastrointestinal (GI) Tract**
   This primarily results in diarrhea. The frequency and amount of diarrhea ranges from mild to severe.

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

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

Chronic GVHD may affect:

1. **Skin**
   - Darkening, thickening or hardening of the skin
   - Dryness, flaking, peeling

2. **Eyes**
   - Dryness & irritation
   - Sensitivity
   - Cataracts

3. **Gastrointestinal (GI) Tract Disorders**
   - Dry mouth
   - Cavities & gum disease
   - Diarrhea or problems digesting food
   - Liver inflammation
   - Difficulty swallowing

4. **Joints**
   - Pain & weakness
   - Swelling

5. **Lung problems, cough, shortness of breath**

6. **Hair loss**

### Key Fact:
Typically chronic GVHD occurs three months to three years after BMT.

### Prevention & Management

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

We then utilize immunosuppressant medications, beginning a few days prior to your BMT. Please refer back to the immunosuppressant drug table on page 31.

**Recall the role of immunosuppressants:**

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

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

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

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

1. Always comply with the immunosuppressant regimen prescribed to you. Be mindful of changes made to your dose.

2. Be sun safe. Even mild sunburn can trigger GVHD that can cause problems for years! Stay in the shade, apply sunscreen with a minimum SPF 30 to exposed skin, avoid middle of the day sun, wear a hat and cover up as much as possible. Follow these guidelines on sunny and cloudy days.

3. Report any potential symptoms immediately to your transplant team!

**Graft Versus Leukemia/Lymphoma (GVL) Effects**

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

When your donor’s cells (graft) destroy leukemia or lymphoma cells remaining inside your body, this is called GVL. GVL plays an important role in maintaining remission after BMT.

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

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

For patients that receive a non-myeloablative transplant, the transplant doctor is relying entirely on the immunological effects of GVL to attempt to cure the disease.

For myeloablative and reduced intensity transplants, it is chemo and radiation therapy combined with the GVL effect to hopefully cure the disease.

GVL is also the driving force behind Donor Lymphocyte Infusions (DLI). This is discussed in detail in Chapter 15.

**Key Fact:** When your donor’s cells (graft) destroy leukemia or lymphoma cells remaining inside your body, this is called GVL. GVL plays an important role in maintaining remission after BMT.
Quiz: Chapter 6

Question 1
Graft versus host disease (GVHD) occurs when:

a) The host immune system attacks the new donor cells (graft)
b) The new donor cells (graft) attack the host's body cells
c) Neither of the above are correct

Question 2
GVHD may be:

a) Acute: occurring within the first 100 days of transplant
b) Chronic: occurring more than 100 days after transplant
c) Both above answers are correct

Question 3
Acute GVHD most commonly affects the:

a) Skin, kidneys, heart
b) Skin, GI tract, liver
c) Brain, pancreas, adrenal glands
d) Heart, liver, lungs

Question 4
Efforts are made to prevent GVHD by selecting the best HLA-matched donor and using immunosuppressant medications.

a) True
b) False

Question 5
Graft versus leukemia/lymphoma (GVL) is a good thing and plays an important role in maintaining remission after BMT.

a) True
b) False

Question 6
The best way for you to prevent GVHD is to:

a) Follow immunosuppressant prescription
b) Be sun safe
c) Report symptoms immediately
d) All of the above
100 percent of BMT patients experience weakness and fatigue caused by underlying disease and/or treatment. Exercise can actually help combat weakness and fatigue.

How do you know if you have disease or treatment 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 disease and treatment related fatigue.

It is normal to want to rest and avoid exercise when you feel so tired. Even though it may seem counter-intuitive, research has shown that even light exercise may help lessen the symptoms of fatigue. Your physician and therapist will help you determine the type and intensity of exercise that is appropriate for you. On a day-to-day basis, please ask your nurse what will be safe for you.

Your muscles can become very weak from chemotherapy and radiation. Your physician or therapist can help teach you exercises that may prevent or minimize muscle atrophy.

Other benefits of exercise:

- Helps prevent pneumonia
- Stimulates natural endorphins that give a sense of well-being
- Fights depression and the feeling that one has lost control over his or her 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. Nursing staff 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.

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

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

Important Tip:
Wear a mask and athletic shoes when walking. Wash or Purell® your hands when you get back to your room.
Quiz: Chapter 7

Question 1
Light exercise every day will improve both fatigue and your mood.

a) True
b) False

Question 2
It is normal to want to avoid exercise when you are not feeling well.

a) True
b) False

Question 3
Walking and performing exercises the physical therapist recommends should be done every day.

a) True
b) False
CHAPTER 8. GUIDELINES FOR LOW-MICROBIAL DIET

Some foods naturally contain increased amounts of bacteria, including fresh fruits and vegetables. This is typically not a problem for healthy individuals. However, when your white blood cell (WBC) count is low, you are at higher risk for infection.

When you are admitted, your doctor will order a low-microbial diet for you. It is important to follow these guidelines.

**Cooked Foods**

- Avoid all raw or undercooked meats, fish, poultry, tofu, eggs and egg substitutes
- 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 salads containing mayonnaise unless they are eaten immediately after preparation. Do not save to eat later.

**Dairy Products**

- Use dairy products that are packaged individually. After opening, consume at one meal and never save for later.
- Do not use products that are near or past the expiration date
- Use commercial milkshakes or supplements in sealed individual cartons. Do not use if there is a break in the container.
- Use fresh, pasteurized dairy products only
- Avoid soft cheeses or cheeses that contain mold, including brie, bleu, Roquefort and gorgonzola

**Fresh Fruits and Vegetables**

- Thoroughly wash raw fruits and vegetables (rinse three times with warm water). Discard those with mold that you can see.
- Avoid all vegetable sprouts, such as alfalfa and mung bean
- Do not drink unpasteurized commercial fruit and vegetable juices
- Avoid foods from delicatessens

**Leftovers**

- 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
- Consume frozen food as soon as possible
- Avoid thawing at room temperature

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 may be dangerous and should not be taken unless approved by your doctor. For more information, the dietitian is available both inpatient and outpatient.
Quiz: Chapter 8

Question 1
All meat, eggs and tofu should be thoroughly cooked.

a) True 
b) False 

Question 2
Which food should not be eaten while on a low microbial diet?

a) Fresh fruit and vegetables  
b) Bleu cheese and deli meat  
c) Fully cooked filet of fish 

Question 3
All fruit juices and dairy drinks should be:

a) Served ice cold  
b) Avoided  
c) Pasteurized 

Question 4
Outside food is not allowed while you are in the hospital unless you have a doctor’s order.

a) True 
b) False 

Question 5
A low-microbial diet should be followed for your entire transplant admission and until day +100.

a) True  
b) False
BMT is an emotional rollercoaster for you and everyone involved in your recovery. You may find yourself having mixed emotions all the time, and sometimes find it difficult to face what lies ahead. It is common to have feelings of hope and hopelessness simultaneously! Length of hospital stay, pain and discomfort, medications, physical changes in your appearance, and uncertainty about the future all contribute to emotional distress before, during and after transplant. Recovery is lengthy, and setbacks are common.

It is important to remember: You are not alone. Do not suffer in silence! Speak to your care team about your feelings. Your medical team has countless combined years of experience caring for BMT patients. Your family and friends love you and want to see you get better, talk to them, allow them to help you. We are all here to help you get through this challenging experience.

The Palliative Care Team works together with your transplant team and is entirely focused on managing the uncomfortable side effects associated with BMT. Nausea, vomiting, pain, anxiety, sleeplessness, depression, and spiritual distress are the types of issues they specialize in managing. Palliative care will consult with you as soon as you are admitted for BMT, and will follow you as long as needed.

The Bone Marrow Foundation recommends the following actions to protect your emotional well being as you go through BMT:

• Have realistic expectations about your transplant. Become educated about the process, benefits, risks, and recovery.

• Look into support groups and resources before transplant. The social work department is available to assist with recommendations.

• Learn and practice “coping skills”. Focus on something that puts you in control, such as your attitude. Speak with other survivors. Find stress management techniques that work for you such as deep breathing, visualization, or meditation.

• Identify your caregivers. You need support at different levels, for example someone to stay with you in the hospital and someone else to watch your children at home.

• Utilize the hospital support staff, psychiatrist, social worker, chaplain services, etc.

• Make sure you clearly understand your discharge teaching and have all of your questions answered to your satisfaction.

• Eat well, exercise whenever possible, and try to get adequate rest. If possible, engage yourself in activities you enjoy or a modified version of them. For example, if you love gardening, read books and watch shows on the subject. Visualize yourself trying what you learned when you are recovered and able to get back into the garden again.
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 BMT, this is called engraftment.

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

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

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

Key Facts

- Engraftment occurs when the infused donor stem cells move to the bone marrow and begin to grow and divide.
- Chimerism testing tells us the percentage of donor DNA inside your blood & bone marrow compared to the percentage of your own DNA.

Requirements for discharge home from the hospital:

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

Chimerism Testing

A chimera is a person with two or more genetically distinct types of cells. The word comes from Greek mythology. The chimera was a creature with a lion’s head, a goat’s body and a serpent’s tail.

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

Chimerism testing will begin 21 days after BMT, and will be repeated several times as you move through your recovery. Simple blood tests and bone marrow biopsies are done to collect samples for chimerism testing.

Low percentages on chimerism studies are indicative of graft rejection or failure and will likely require further investigation and treatment.
Chimerism testing is one of several measures of your transplant’s success. Results are interpreted along with other indicators of recovery (i.e. engraftment, absence of leukemic blasts, GVHD absent or controlled, etc.)

**Discharge Education**

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

Prior to going home you need to make sure:

- You have access to a caregiver 24/7 for the first 3 months after transplant, either with you or a quick phone call away

- You have an accurate thermometer so you can take your temperature at home. **REMEMBER A FEVER IS 100.4°F OR HIGHER AND YOU MUST CALL 310 423-0626**

- You have all of your prescriptions in hand before discharge and understand the schedule for taking them at home

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**Important Tip:** a fever is 100.4°F or higher and you must call (310) 423-0626 right away to speak with an oncology nurse.

- You always have transportation available to get you to the Samuel OSchin Cancer Center and Cedars Sinai Medical Center

- The house is clean and pets have been groomed

- You have an alternate caregiver for your children when they are 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.
Quiz: Chapter 10

Question 1
Engraftment happens when the white cells (mainly neutrophils) begin to grow and the number increases.

a) True
b) False

Question 2
Before going home you should arrange to have:

a) A caregiver
b) A clean home and transportation to the hospital
c) Good nutrition
d) Your medications in hand and understanding of how to take them correctly
e) All of the above

Question 3
Chimerism testing tells us the percentage of donor DNA in your bone marrow compared to the percentage of your own DNA.

a) True
b) False

Question 4
It is important to have an accurate thermometer at home because fever is an emergency after BMT. Call (310) 423-0626 right away if your temperature is:

a) 104°F or greater
b) 98.6°F or greater
c) 100.4°F or greater
d) 102°F or greater
Follow-Up Appointments

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

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

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

Immunosuppressant Level Monitoring

Cyclosporine (CSA), tacrolimus and sirolimus are commonly used immunosuppressants. In order to ensure the medication dose is therapeutic, we must monitor the level of the drug in your bloodstream. Typically this is done 1-2 times per week.

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

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

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

- Get into a routine of taking the medication at the same time every day.
- On the days when the level is being drawn, do not take the morning dose. Bring it with you to your clinic appointment and take it as soon as the level is drawn.

Immunosuppressants should never be taken with grapefruit juice, and consumption of potassium-rich foods (bananas, prunes, raisins and orange juice) should be limited. Talk to your transplant doctor before taking any vitamins or herbal supplements while taking immunosuppressants.

Daily Self-Assessments

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

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

Key Fact: Your main focus in the first few months after BMT is to prevent infections, watch for symptoms of GVHD, and regain your strength by eating well and exercising as much as possible.


Preventing Infection

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

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

<table>
<thead>
<tr>
<th>Type of Infection</th>
<th>Example</th>
<th>Preventive Medication Used Brand Name(R) (generic name)</th>
</tr>
</thead>
</table>
| Bacterial         | Pneumonia, PICC line infection | Bactrim® (co-trimoxazole)  
                    |                                                        | Cipro® (ciprofloxacin) |
| Viral             | Shingles, CMV            | Zovirax® (acyclovir)  
                    |                                                        | Valtrex® (valacyclovir) |
| Fungal            | Aspergillus, Candida     | Diflucan® (fluconazole)  
                    |                                                        | Vfend® (voriconazole) |

You will be prescribed a medication to prevent each type of infection for the first 100 days after BMT. Make sure you understand your prescriptions and when you need to take each medicine.

Infection prevention tips:

- Washing your hands and having others wash theirs is absolutely the BEST way to prevent infection!
- Do not stay in enclosed spaces with people who are coughing, sneezing, or show other signs of cold or flu.
- Take your temperature every day after discharge. Call your doctor immediately if your temperature is 100.4°F or higher. Do not ignore colds or flu.
- Bathe or shower daily and wear clean clothes. If your skin is dry, use a mild lotion or baby oil.
- Do not share cups, glasses, utensils, etc., with others
- If you have PICC line, keep the dressing clean and dry. Cover it when showering. Do not place it under water.
- Brush your teeth with a soft toothbrush after every meal and before bedtime. Floss daily.

Common Problems After Discharge

Many BMT patients are surprised that they feel worse the first few days they are home than they did the last few days in the hospital. Excitement about discharge can give you a wonderful energy boost that leaves you exhausted when it wears off.

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

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

As your body continues to heal, your energy level and your mood should improve. In the meantime, speak with your nurse or doctor 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 (example: 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. Wear a sunscreen with a minimum SPF of 30. Always wear a hat, long sleeves, pants and sunglasses. Do not go to the dentist unless approved by your transplant doctor.
- 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, jacuzzis, lakes or ocean water unless approved by your transplant doctor.
- 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.
- Avoid contact with pesticides, solvents, fertilizers, chicken coops, caves, construction sites and areas where soil is being moved.
- Avoid zoos, parks, animals, animal areas and areas heavily populated with birds.
• Avoid gardening until your doctor tells you that it is safe to do so.

• If you own pets, have someone else pick up after them. If you own a reptile, fish or birds, avoid contact with them and ask that others wash their hands thoroughly and immediately after touching them.

Post-Discharge Diet

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

It is recommended that you follow the Low Microbial Diet for 100 days after BMT. Please refer back to page 47 of this book for specific details about diet.

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

Emotional and Intimacy Concerns

You may find yourself feeling sad or depressed in the months following a blood & 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 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 transplant. Your body has been through a lot of stress and your physical appearance has changed. The good news is that it is okay to have sex! Talk to your partner about your feelings and go at your own pace. Feel free to discuss any concerns with your physician, nurse practitioner, clinic nurse or coordinator, whomever you feel most comfortable with.

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

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

Immunizations

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

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

Avoid contact with infants or children who have been recently immunized for measles, mumps, rubella, polio, small pox, chicken pox or yellow fever (live viruses).
Quiz: Chapter 11

Question 1
What are the common problems that you might experience after getting discharged from the hospital?

a) Fatigue
b) Loss of appetite
c) Mood swings
d) All of the above

Question 2
What is the best exercise and activity to start post transplant?

a) Walking
b) Martial arts
c) Swimming
d) Weight lifting

Question 3
Hand washing is the best way to prevent infections.

a) True
b) False

Question 4
You will call your transplant nurse or physician when you have:

a) Cough
b) Fever, chills
c) Bleeding, rash
d) Cold or flu symptoms
e) Nausea, vomiting, diarrhea
f) Any of the above

Question 5
What antiviral medication will prevent the disease called zoster?

a) Bactrim
b) Acyclovir
c) Fluconazole
d) Prevacid

Question 6
You are advised to drink plenty of fluids and make healthy food choices after discharge from the hospital.

a) True
b) False

Question 7
I can’t get pregnant or impregnate my partner post transplant.

a) True
b) False

Question 8
If I have any questions or concerns about my health, I will call my transplant nurse or physician instead of asking my neighbors or friends.

a) True
b) False

Question 9
On days when the immunosuppressant drug level is being drawn, do not take the morning dose but bring it to clinic to take after the blood is drawn.

a) True
b) False

Question 10
The main focus for the first few months post-BMT is:

a) Preventing infections
b) Watching for symptoms of GVHD
c) Regaining strength by eating well and exercising
d) All of the above
The 24-hour Samuel Oschin Cancer Center phone number is (310) 423-0626. The Samuel Oschin Cancer Center is always open: 24 hours a day, 7 days a week, 365 days per year.

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°F (38°C) 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
- 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!**
Quiz: Chapter 12

Question 1

A fever of 100.4°F or higher is an emergency after transplant and requires an immediate phone call to (310) 423-0626.

a) True 
b) False

Question 2

The Samuel Oschin Cancer Center is open 7 days a week, 24 hours a day, 365 days per year.

a) True 
b) False

Question 3

If you are not feeling well at home, it is always safer to call the Samuel Oschin Cancer Center 24-hour number and speak to a nurse. I will never hesitate to call this number: (310) 423-0626.

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

Several factors influence whether or not it is possible:

1. Country where the donor lives. Countries have different rules about donor contact. Some allow for anonymous contact only (ex. A “Dear Donor” letter without identifying information like your name or where you live). Some will allow you to identify yourself, and some don’t allow any contact at all.

2. Time elapsed after your transplant. There is a minimum waiting period of a year after transplant before donor contact is permitted. In some countries the minimum is two years. Anonymous correspondence may be permitted before a year has passed.

3. Donor consent. If you want to contact your donor personally, they must consent to have their information released. The same is true if your donor wants to contact you, your consent must be obtained first. Anonymous correspondence does not require consent from either side.

Your BMT Coordinator will facilitate donor correspondence through the National Marrow Donor Program.® Anonymous letters and gifts will be carefully screened to ensure no personally identifying information is contained. Your donor may or may not respond.

Please read the following three pages very carefully. They contain thoughtful insights regarding potential risks and benefits of releasing your personal information, as well as tips for correspondence.

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

All personal information about you and your relationship with the National Marrow Donor Program (NMDP) is strictly confidential. Release of any personal information without your written approval is a violation of Federal law punishable by fine or imprisonment. This consent will allow you, if you wish, to give written permission to the NMDP to release personal information about yourself to your associated donor or recipient after the appropriate timeframe has passed.

It is NMDP policy that no personal information about a donor or recipient be shared with one another until at least twelve months have passed since the peripheral blood stem cell (PBSC) or bone marrow donation and transplant. Even if you want to have your personal information released prior to twelve months, NMDP policy will not allow this.

II. POTENTIAL RISKS OF RELEASING YOUR PERSONAL INFORMATION

You should be aware that there may be risks associated with exchanging your personal information with your donor or recipient. These risks include, but are not limited to:

1. You may be contacted by the donor/recipient, his or her family, or others with whom your information has been shared. You will no longer be anonymous. The NMDP cannot prevent calls, letters, visits, or requests.

2. There is no guarantee that the information you release will be acted upon by the associated recipient or donor as they may choose to not respond.

3. Exchanging personal information could create personal stress or have other impacts on you. It is important to consider how you will feel if you have little in common with the donor/recipient, if the recipient’s transplant outcomes are not ideal, or if you are subjected to unwanted attention from the media.

4. If a subsequent donation is required for the recipient it is possible the recipient and donor (or their associated family members) will directly discuss the impact or possibility of this subsequent donation with one another.

5. The NMDP has policies designed to protect donors from direct requests by the recipient or recipient’s representatives, should the recipient require a solid organ transplant, such as a kidney. However, if personal information has already been exchanged between the donor and recipient, these policies may fail.

III. POTENTIAL BENEFITS OF RELEASING YOUR PERSONAL INFORMATION

Just as there are potential risks to exchanging personal information, there may also be benefits. These could include:

1. You may develop lasting and important friendships as a result of exchanging your personal information.

2. You may receive attention or publicity that you find pleasing.
IV. LIMITATIONS OF THIS CONSENT

You are free to accept or decline this Consent to Release Personal Information. Your decision will not affect your relationship with the NMDP in any way. If you decline, you can change your mind at any time. However, if you decide to release personal information, the NMDP cannot take back the information should you change your mind.

V. NATURE OF THE INFORMATION TO BE RELEASED

REQUIRED: I AM THE:

☐ DONOR  ☐ RECIPIENT

Please indicate what contact information you would like to provide to your associated donor or recipient. Each item below is OPTIONAL, but at least one form of contact information is necessary. Any information supplied on this form will be provided to your consenting stem cell transplant partner.

First Name: _______________________________________________________

Last Name: _______________________________________________________

Street Address: ____________________________________________________

City: _____________________________________________________________

State/Zip Code/Country: ____________________________________________

Telephone: _______________________________________________________

E-mail address: ___________________________________________________

VI. SIGNATURES

Your signature below indicates that you have read this consent and filled it out to reflect your wishes. A copy of this consent will be given to you for your records. If you have questions about this consent, please contact the Coordinator listed below at your Center or Registry:

Contact / Center Coordinator Name                                      Phone#

Donor or Recipient Signature                                               Date

Witness Signature                                                              Date

TC/DC Coordinator completes this section:

Recipient ID: ________________________ Donor ID: ________________________

(Both the RID and DID must be present on this form when submitted to the NMDP)
# Table 1.0 Acceptable & Unacceptable Content: Cards, Letters and Gifts

<table>
<thead>
<tr>
<th>Type</th>
<th>Acceptable Content</th>
<th>Unacceptable Content – Content Must be Edited</th>
</tr>
</thead>
</table>
| Names                                     | None - NO NAMES PERMITTED                                                          | **Donor**  
|                                           | **Recipient**                                                                     | **Children**  
|                                           | **Siblings**                                                                      |                                                                |
| Transplant and Donor Center information   | Name Location                                                                     |                                                                |
| Gender                                    | OK                                                                                |                                                                |
| Age                                       | OK                                                                                |                                                                |
| Disease                                   | OK                                                                                |                                                                |
| Professions                               | General Professions acceptable, such as: teacher, homemaker, etc                   | No specifics, such as Case Manager at NMDP, Marketing Representative at Target Corporation.                   |
| Card Print Information                    | Made in “Specific Location” Names of Artists                                       |                                                                |
| Faxed Letters                             | Remove top of page where fax number and information is displayed                   |                                                                |
| Food items                                | Non-perishable food or candy                                                      | Food that can spoil, such as fruit or baked goods                                                             |
| Gift Cards/ Certificates                  |                                                                                   | No gift cards or gift certificates of any amount or value allowed                                              |
| Photos                                    | Scenery, animals without any indication of where photo was taken (i.e. road or building signs, world famous landmarks) | No personal photos with people in the picture                                                                  |
| CDs, Tapes and DVDs                       | Only commercially available products are allowed                                   | Personally mixed or recorded products and commercial products with broken seals                                |
If your leukemia/lymphoma comes back after transplant, you will likely need a donor lymphocyte infusion or DLI. Sometimes DLI is used to boost the donor graft when chimerism studies show low donor DNA in your blood.

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

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

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

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

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

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

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

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

Your response to the DLI is measured by testing your blood and bone marrow, and/or by repeating PET/CT scans. Sometimes it takes several DLIs to achieve results. GVHD can limit the amount of DLI it is safe for you to receive.

Unfortunately, DLI is not always effective in achieving or maintaining remission after BMT.
Survivorship begins from the moment a potentially life threatening disease diagnosis is made. There are several critical time points following BMT, such as Day +100, six months, one year. But survivorship is more than a measurement of time passed. It encompasses every aspect of your physical, mental, emotional, and spiritual wellbeing.

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

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

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

- **Chronic GVHD.** Discussed in detail on page 37.
- **Cataracts.** Cataracts are a clouding of the lens of the eye, and are common three to four years after transplant.
- **Sexual dysfunction.** Interest in sexual activity may take a long time to return after BMT. A variety of factors influence feeling “in the mood”, and sometimes body changes make sexual intercourse painful. Do not be embarrassed to bring up your questions or concerns. There may be treatments or recommendations that will help.
- **Infertility.** Most transplant patients are not fertile after allogeneic BMT. However, there are exceptions. Cedars-Sinai’s Center for Fertility and Reproductive Medicine may address questions or concerns about fertility. Please call (310) 423-9964 or visit them online at cedars-sinai.edu/cfrm.
- **Numbness and tingling (neuropathy).** This is caused by nerve damage from chemotherapy. Nerves take a long time to heal. Generally speaking, whatever numbness and tingling you have after a year has passed is likely permanent.
- **Organ toxicities.** Thyroid, lung, liver and skin are the most common sites. However, medications used for BMT may injure any of the body’s organs, causing late effects to appear.
- **Secondary cancers.** Exposure to chemotherapy and radiation increases your risk for developing other cancers later in life. These usually appear 5 to 10 years after the initial exposure, and can be difficult to treat.

Adjusting to the “new normal” takes time, patience, and continued effort from you and your caregiver team.
Critical elements of survivorship:

1. Continued routine surveillance of:
   - Disease status
   - GVHD
   - *Engraftment* studies

2. Prevention and early detection of disease including:
   - Balanced diet and weight control
   - Regular exercise
   - Sun protection
   - Routine checkups with your doctor
   - Daily self assessments
   - Dental hygiene
   - Control of chronic diseases (diabetes, high blood pressure, etc.)
   - Monitoring for late effects, organ toxicities
   - Re-immunizations

3. Focus on quality of life matters:
   - Return to work/school
   - Social life, relationships
   - Sexuality
   - Engaging in enjoyable activities
   - Financial security & health insurance coverage
   - Spirituality

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

1. **Be The Match - Patients and Families Support and Resources**
   - Free one-on-one support and access to educational resources, DVDs, booklets, online tools and guidance
   - BeTheMatch.org/patient/support_and_resources
   - 1-888-999-6743
   - Email: patientinfo@nmdp.org

2. **BMT Infonet: Blood and Marrow Transplant Information Network**
   - Easy to understand information, publications and products for BMT patients and families reviewed by medical experts for accuracy.
   - www.bmtinfonet.org
   - 1-888-597-7674
   - Email: help@bmtinfonet.org
If you have any questions regarding these terms or anything about the written information given to you, please ask us. Some of the words in this glossary are not mentioned in the book, but you may hear them while going through your transplant.

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

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

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

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

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

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

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

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

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

**Ascites:** build-up 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.

**Bilirubin:** an orange-red pigment formed from hemoglobin during the break-down of used red cells.

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

**Blood cultures:** a blood test done to look for infection in the blood.
**Blood donor facility:** A 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 iliial 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:** see “blood and marrow transplant.”

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

**Central venous catheter:** a narrow, soft catheter (plastic tube) placed into a large vein that leads to the heart. The procedure is usually done under local anesthesia and the line is generally placed in the upper chest. 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.

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

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

**Clinical trial:** see “research protocol.”

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

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

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

**Conditioning regimen:** a term used for the therapy, given to prepare the patient’s body for blood and marrow transplant. The regimen generally lasts 2 to 10 days prior to the transplant. Also know as the preparative regimen.

**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 (dimethyl sulfoxide) to the product is the most common approach. The product is then stored in liquid nitrogen.

**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.

**Dehydrated:** 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.

**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).

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

**Fever:** the rising of a person's temperature above normal, which is generally 98.6°F. 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°F) is significant.

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

**Genetically:** pertaining to reproduction or to birth or origin; inherited.

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

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

**Harvested:** see “bone marrow harvesting” or “apheresis”.

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

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

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

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

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

**IJ or internal jugular catheter:** see “apheresis catheter”.
**Immunosuppression**: the act of “holding down” or decreasing the activity of the immune system. This can occur in the body because of disease, or be done on purpose through medications to prevent graft rejection or graft versus host disease.

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

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

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

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

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

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

**Lab work**: blood sample tests.

**Mahurkar**: 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.

**Malignant**: a tumor that has the ability to spread, cancer. Non-malignant tumors are called “benign” tumors and are not considered cancerous.

**Matched unrelated transplant (MUD)**: an allogeneic blood & marrow transplant from someone besides a family member.

**Minerals**: elements, such as magnesium, that are provided by foods and important for the function of our cells.

**“Mini” allogeneic transplant**: an allogeneic transplant in which the conditioning treatment does not fully cause bone marrow suppression.

**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.

**Muga scan**: a test that evaluates the pumping action of your heart; the measure is reported as an “ejection fraction.”

**Nadir**: literally, “the lowest point.” In blood & marrow transplant, it refers to the lowest number a patient’s white blood cell count reaches after conditioning. This usually occurs five to ten days after stem cell infusion.

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

**Neutropenic precautions**: special care activities that help reduce the risk of infection during neutropenia.
Neutrophil: a type of white blood cell that is usually the front line of defense in preventing and treating infection in our bodies. They are normally the highest in number of all of the white blood cells.

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

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

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

Peripheral blood stem cells: see “stem cells.”

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

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

Protocol(s): a standard treatment for a specific disease or a research protocol; both are an outline of a treatment plan.

PT/PTT: blood tests to measure coagulation factors that work with your platelets to help blood to clot.

Pulmonary function test: a test to determine the ability of the lungs to deliver oxygen to the blood stream.

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.

Rh: another major blood antigen system, like the ABO, that indicates the absence or presence of the Rh (rhesus) system on the surface of blood cells. Individuals are either Rh negative or Rh positive.

Scan(s): a general term for a diagnostic test, such as a CT scan.

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: see “BMT”.

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 blood stream 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”.
**Umbilical cord blood:** blood that is taken from the umbilical cord after birth.

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

**Veno-occlusive disease (VOD):** 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.

**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.

**Vitamin K:** a vitamin found in green leafy vegetables, pork liver, yogurt, egg yolk, kelp, alfalfa, fish liver oils and black strap molasses. It is synthesized by the bacterial flora of the intestines and is essential for the synthesis of clotting factors.

**White blood cells (WBC):** 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.
TREASURE HUNT

This is a project for you to work on during your hospital stay for BMT. You must complete this and give it to your nurse before you are discharged.

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<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>Caregiver Name and Phone Number</td>
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<td>Pharmacy Name and Phone Number</td>
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<tr>
<td>BMT Doctor’s Name</td>
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<tr>
<td>Phone Number for Scheduling BMT Doctor Appointments</td>
<td>(310) 423-0650</td>
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<tr>
<td>Phone Number for Clinic Nurses</td>
<td>(310) 423-0624</td>
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<td>24-Hour Samuel Oschin Cancer Center Phone Number</td>
<td>(310) 423-0626</td>
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<td>Injury prevention, signs of bleeding</td>
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<td>Schedule, drug level monitoring, side effects</td>
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<td>Acute vs. chronic</td>
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<td>Cleaning, pets, plants</td>
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<td>Flu shots, re-immunization schedule</td>
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