The Allogeneic Blood and Marrow (BMT) Guidebook

Stanford
HEALTH CARE
STANFORD MEDICINE

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BMT Inpatient Service Hospital (650) 725-7121	Infusion Treatment Area Cancer Center (650) 725-1860	BMT Clinic, F Cancer Center (650) 498-6000

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Section One—Introduction

The Blood and Marrow Transplant (BMT) Guidebook

The goals of this guidebook are to:

- prepare you for your transplant and recovery
- serve as a resource for you and your caregiver(s)
- help you understand your treatment
- outline ways to reduce the risk of transplant-related complications, such as infections

While we have attempted to make this guidebook comprehensive it does not cover all aspects of your care. Always consult your healthcare team regarding your specific question or situation.

Transplant Dictionary

We have tried to define terms throughout this guidebook when they are first used, but you may find it helpful to refer to the transplant dictionary located at the end of this guidebook beginning on page 94.

Your BMT Team

It takes a large group of healthcare professionals to help you and your family through transplant. The BMT team meets regularly to discuss your care. You and your family are **key** members of this team. The table below lists some of the members of your BMT team.

Healthcare Professionals	**Responsibilities**
Attending Physician	• provide initial consult • select your treatment plan • provide medical care during and after transplant • provide education and support as you go through transplant • teach and educate physicians in training • conduct research to improve transplantation • communicate with your referring physician while you're under our care

Nurse Coordinators	• coordinate the necessary tests to determine your eligibility for transplant • provide education about your treatment and symptom management • schedule your appointment to review and sign the consent form(s) • help plan for your discharge from the hospital • provide emotional support for you and your family • coordinate care with your referring physician
Nurse Practitioners and Physician Assistants	• take a history and perform physical exams • prescribe medications • order tests and evaluate the results • evaluate and treat your medical problems • perform certain procedures such as infusing stem cells, taking biopsies and removing the central venous catheter • provide education about your treatment plan and symptom management • provide emotional support for you and your family
Nurses	• provide education about your treatment plan including symptom management • administer chemotherapy, antibiotics, transfusions and infuse stem cells • make frequent assessments to detect changes in your health • provide supportive care to minimize and manage the side effects of treatment • provide emotional support for you and your family
Social Workers	• provide education about your treatment plan and routines • provide emotional support to you and your family • assist with housing arrangements • assist with work related issues, disability and leave programs • assist in the completion of an advanced health care directive • review the abstinence policy and contract

Who to call if you have a question?

(a list of staff phone numbers is found on page 8)

Call 911 for any medical emergency

Call your nurse coordinator
- your main contact before your transplant
- questions or concerns about your pre-transplant schedule

Call your social worker
- questions about disability and leave programs
- if you need a letter for your employer
- caregiver information

Call a financial coordinator
- concerns about your insurance coverage
- insurance authorization for your transplant

Prescription Refill Fax Request
- call your pharmacy to request a refill
- your pharmacy should fax the request to ☎(650) 497-8055

Apheresis Unit at ☎(650) 725-4656
- questions about apheresis

What Physician Takes Care of You?

At your initial consult, you will meet one of the attending physicians. This attending physician will be your primary physician. However, your primary BMT physician will not take care of you throughout your entire transplant. The attending physicians care for patients while hospitalized or while receiving care in the Cancer Center on a rotating schedule. Your care will always be under the direction of an attending physician, but it may not be your primary BMT physician.

An attending physician has completed many years of education and training in a medical specialty. All the BMT attending physicians have specialized in the care of transplant patients and will be assisted by fellows and residents. Fellows are medical doctors who have completed residency and are specializing in a field of medicine. Residents are medical doctors with one to four years of experience.

Where is Care Provided?

<u>BMT Clinic—F</u>

- located on the first floor of the Cancer Center
- clinic hours are Monday thru Friday 8:30 am to 5:00 pm
- clinic phone number is ☎(650) 498-6000

<u>Infusion Treatment Area (ITA)</u>

- located on the second floor of the Cancer Center
- ITA hours are:
    - Monday to Friday 7:00 am to 9:00 pm daily
    - Saturdays 7:00 am to 8:00 pm
    - Sundays 7:00 am to 8:00 pm
- ITA phone number is ☎(650) 725-1860

<u>BMT Inpatient Service</u> located in the main hospital

- open 24 hours a day, seven days a week
- BMT inpatient service phone number is ☎(650) 725-7121

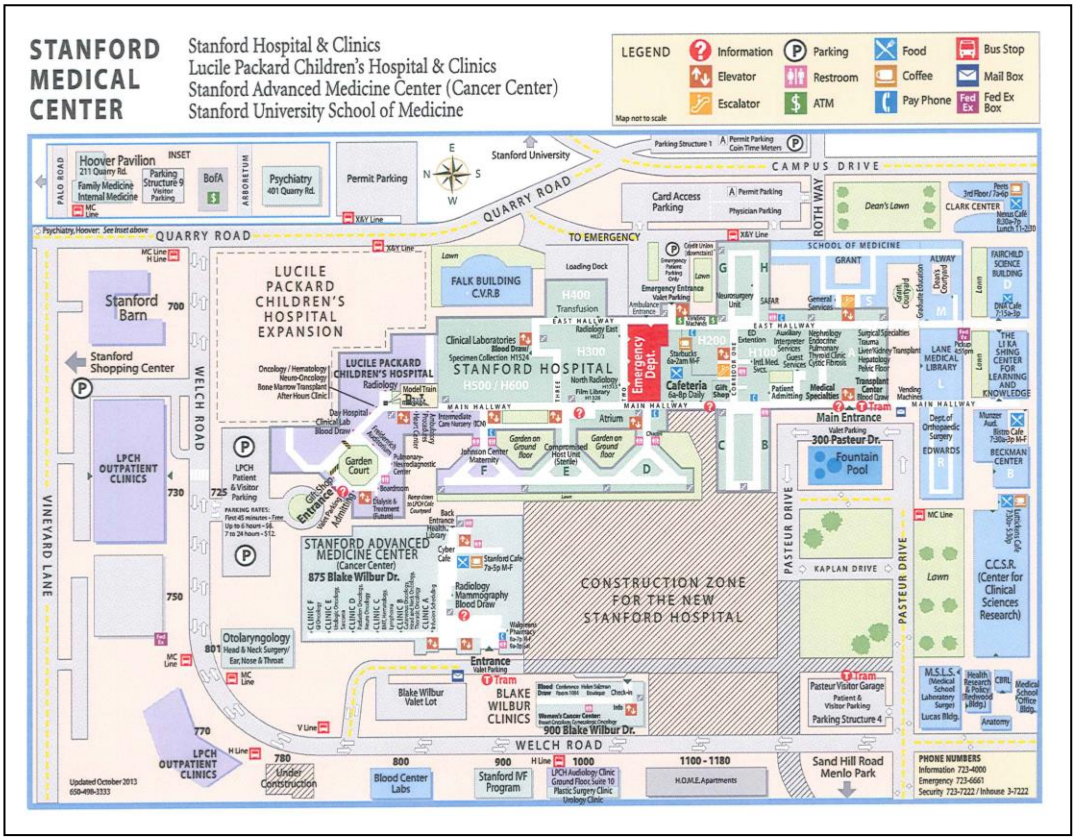
Directions, Parking and Traffic

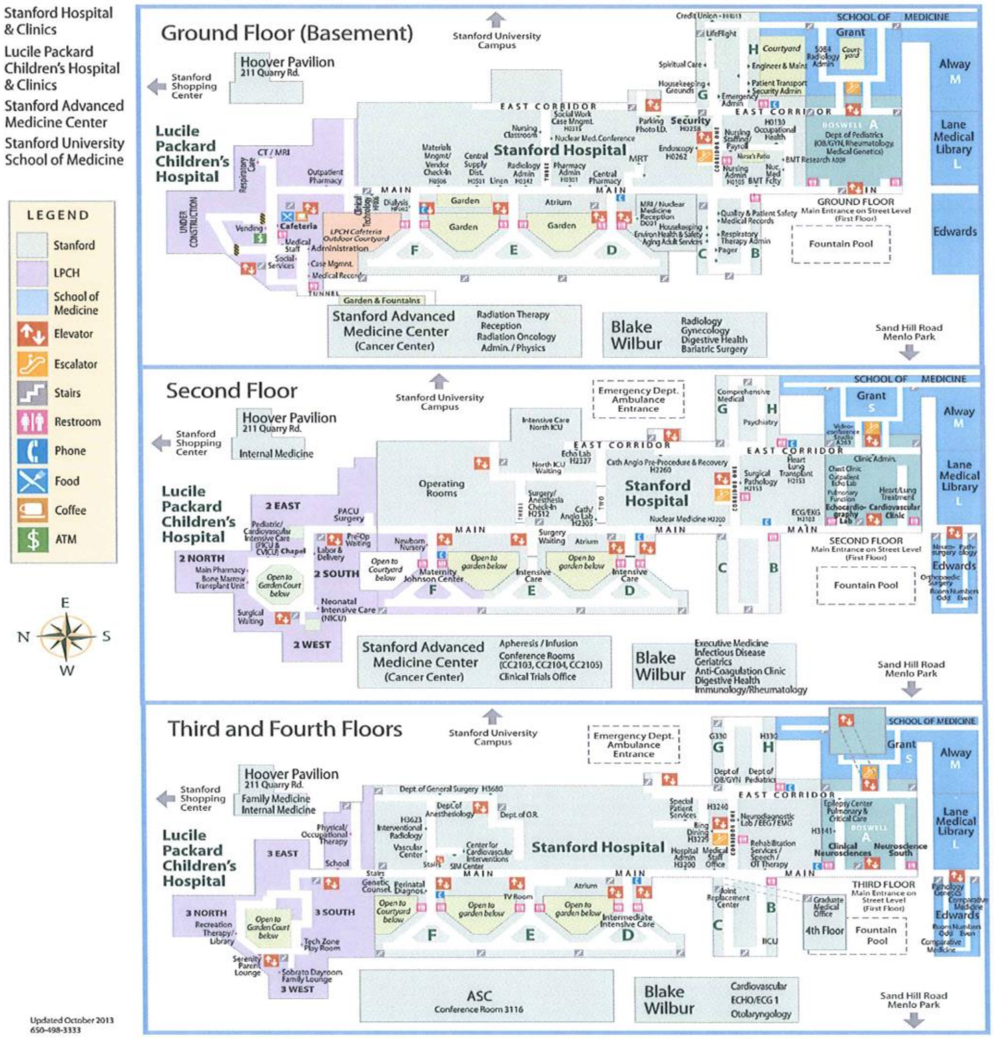
As of November 2, 2012, Stanford began construction for the new Stanford Hospital resulting in frequent changes in traffic patterns, directions and parking. For the most up to date information on directions, parking and traffic please visit the following website: http://stanfordhospital.org/future/

or call the Cancer Center at ☎ (650) 498-6000.

Guest Services staff are available 24 hours a day to answer questions about your visit to Stanford. Call ☎(650) 498-3333.

MAPS





Updated October 2013
650-498-3333

Staff Contact Information

Staff

Nurse Coordinators

- Nimfa Fajardo, RN, BSN, BMTCN®
    - (650) 723-4545
- Inna Kaplan, RN, MSN, OCN®
    - (650) 721-3173
- Janette Kimes, RN, MSN, FNP, OCN®, BMTCN®
    - 650-721-5825
- Gayla Knight, RN, OCN®
    - (650) 736-7725
- Suzanne Lambert, RN, BSN, OCN®
    - (650) 725-7055
- Margarita Perez-Machovec, RN, BSN
    - (650) 497-8942
- Zoe Rabine, RN, BSN, BMTCN®
    - (650) 498-4929
- Amanda Romani, RN, BSN
    - (650) 724-8319
- Donna Reimer, RN, BSN
    - (650) 723-5133
- Stephanie Stern, RN, BSN, OCN®
    - (650) 736-1088
- Michelle Takahashi, RN, MS
    - (650) 736-0110
- Assistant for nurse coordinators
    - (650) 736-0482

Financial Coordinators

- Guadalupe Valencia
    - Covers patients with last names starting with A-M
    - Gvalencia@stanfordhealthcare.org
    - (650) 723-5372
- Roxana Justiniano
    - Covers patients with last names starting with N-Z
    - rjustiniano@stanfordhealthcare.org
    - (650) 721-6204

Patient Care Managers

Inpatient

- Trisha Jenkins, RN, MPH
  - (650) 498-5837

Infusion Treatment Area (Cancer Center)

- Torey Benoit, RN, BSN
  - (650) 736-4347

Social Workers

- Cecilia Ellington, MSW
  - (650) 714-5489
- Morgan Gross, LCSW
  - (650) 796-5084
- Carrie Kowieski, MSW
  - (650) 817-5462
- Ana Stafford, MSW
  - (650) 521-3439

Dietitians

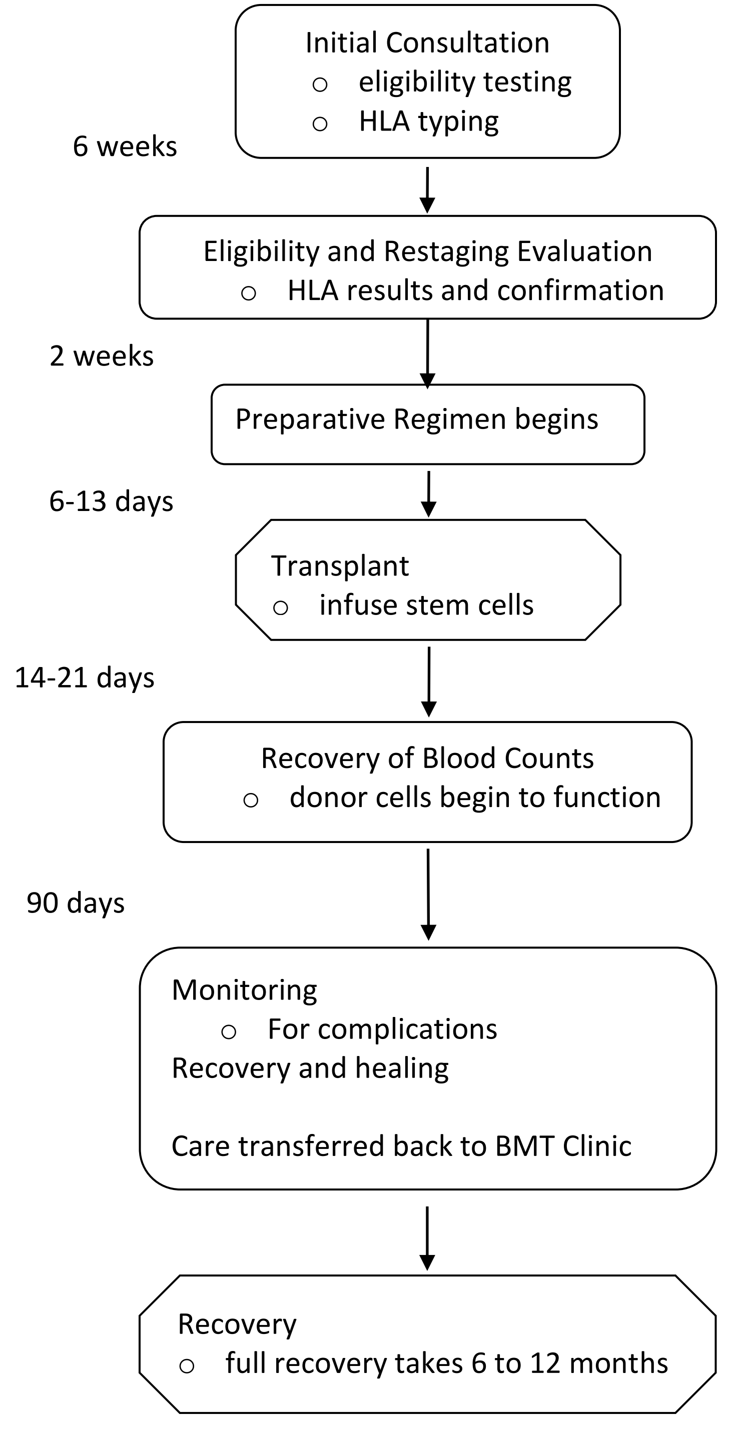
- Tara Coghlin-Dickson, MS, RD, CSSD
  - (650) 529-5942
- Raymond Palko, MS, RD
  - (650) 529-5942
- Kylie Chen MS, RD
  - (650) 529-5168

Your Address while at Stanford

Stanford Hospital and Clinics
Blood and Marrow Transplant Service "Your Name"
300 Pasteur Drive, MC 5607
Stanford, CA 94305

Section Two—Treatment Plan

Timeline of Transplantation



Allogeneic Blood or Marrow Transplantation (BMT)

What follows is a general description of an allogeneic BMT. The consent form provides more specific detail.

The steps of allogeneic transplant are:

- identifying a donor
- administering the preparative regimen
- collecting the stem cells from the donor
- transplant, infusing the stem cells
- recovery

Types of Donors

There are several different types of donors that can be used for an allogeneic transplant. There are varying degrees of genetic matching between a donor and recipient. A donor may be fully or partially matched. The donor may be a sibling (brother/sister) or unrelated volunteer donors from the volunteer registries. In some cases, the donor may be a partial match, called a haploidentical donor. Mothers, fathers, brothers, sisters or children may be a haploidentical donor. Another source of stem cells is previously collected and frozen umbilical cord blood cells.

Preparative Regimens

Myeloablative Preparative Regimen

The preparative regimen consists of a combination of high dose chemotherapy with or without radiation. The high dose preparative regimen is given for three reasons:

1) to destroy the diseased cells in your bone marrow
2) to eliminate your immune system so you will allow the donor’s cells to grow
3) to create space in the bone marrow for the donor’s cells

The preparative regimen may take one to two weeks to complete and may be given while you are in the hospital or while you are receiving care in the Cancer Center.

Non-myeloablative Preparative Regimen

The preparative regimen consists of radiation and an immune suppressing medication with or without chemotherapy given prior to transplant. The purpose of the preparative regimen is to weaken your immune system sufficiently to allow the donor’s cells to grow and function. The potential for cure in a non-myeloablative transplant comes from the healthy donor immune system recognizing diseased cells and destroying them. The preparative regimen takes approximately one to two weeks to complete and may be given while you are in the hospital or in the Cancer Center.

Reduced Intensity Preparative Regimen

The preparative regimen consists of chemotherapy with or without radiation therapy given prior to the transplant. The dose of chemotherapy is in between the large doses given in a myeloablative transplant and the low doses given in the non--myeloablative transplant. The purpose of the preparative regimen is to:

1) to destroy the diseased cells in your bone marrow
2) to eliminate your immune system so you will allow the donor's cells to grow
3) to create space in the bone marrow for the donor's cells

The preparative regimen takes approximately one week to complete. Administration of the preparative regimen and waiting for your blood counts to recovery may take place in the hospital or in the Cancer Center..

Collecting the Stem Cells from the Donor

There are two ways to collect stem cells from the donor; a bone marrow harvest and apheresis. Most stem cells are in the bone marrow and collecting them from the bone marrow is called a bone marrow harvest. For a bone marrow harvest, the donor goes to the operating room and under anesthesia the marrow is collected from the hip bones.

Collection of stem cells from the blood is a procedure called apheresis. Only a small number of stem cells circulate in the blood. Mobilization is a term used to describe moving stem cells from the bone marrow into the blood. To increase the number of stem cells in the blood, your donor is asked to take a growth factor. There are many different growth factors that can be used. The growth factor is generally given for 4-5 days and then apheresis begins. Apheresis involves removing a small amount of blood through a needle in an arm vein. The blood is spun through the apheresis machine which will collect the stem cells. A needle is inserted into the vein in the other arm to allow the return of the remainder of the blood. The process takes about four hours for 1 - 3 consecutive days.

Once the stem cells are collected from the donor, they are taken to the laboratory for testing and processing.

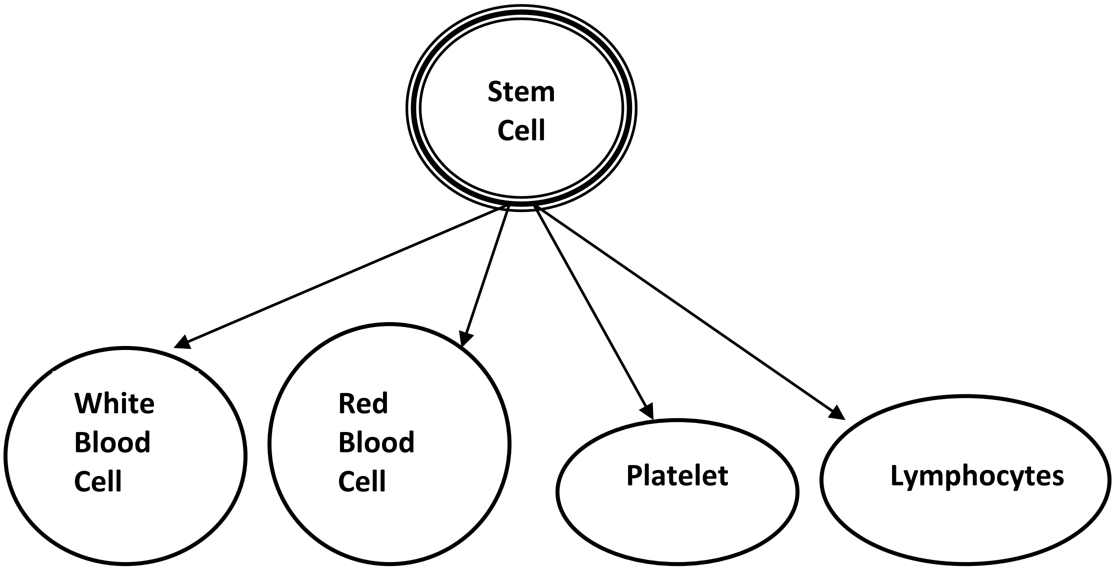
Transplant

The donor's stem cells are infused through your catheter after you complete the preparative regimen. The day the stem cells are infused is your transplant day, which we refer to as "day zero". While waiting for stem cells to grow and function, your blood counts will be low. Your body will begin to heal and you will feel better once you begin making new blood cells about 14-30 days after the transplant. You may receive your transplant in the hospital and remain hospitalized until the blood counts recover or you may receive your transplant in the Cancer Center and remain under the care of the outpatient BMT team for approximately 100 days.

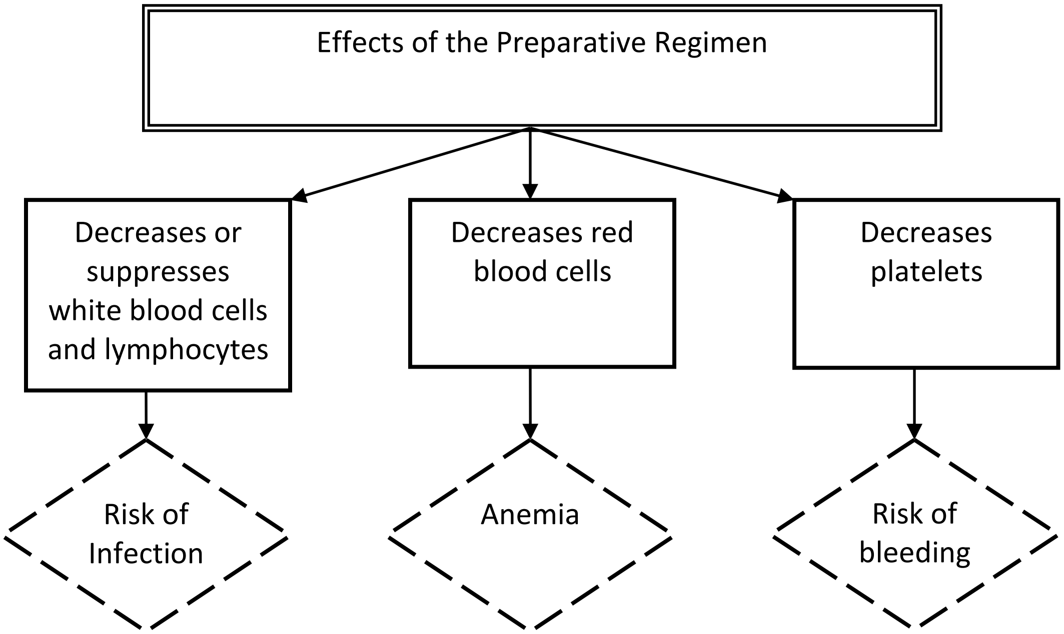
Recovery

Approximately 100 days following the transplant, if all is going well, your care is transferred back to your primary BMT attending physician who will see you in the BMT clinic. Your central venous catheter is usually removed now and if you are staying locally you may return to your own home. Approximately six to twelve months after transplant your care will transition back to your local oncologist or hematologist. How often your BMT attending physician will continue to see you will depend on what medications you are taking and if you are having any complications from your transplant, such as graft versus host disease.

Recovery from an allogeneic transplant can take up to six to twelve months or more. Your hair will begin to re-grow in about 3 months. Your taste buds will return to normal in about 4 months, but your energy will remain low for a longer period. It is not unusual to need rest periods (naps) for up to six months after transplant. The best strategy for regaining your energy is to walk every day.



Stem cells produce all blood cells and cells of the immune system.
White blood cells protect against and fight infection.
Red blood cells carry oxygen to tissues throughout the body.
Platelets help prevent and stop bleeding.
Lymphocytes prevent against and fight infection.



Section Three—Preparing for Transplant

Pre-Transplant Checklist

√	To Do List	√	To Do List
	Read the Guidebook		Attend the Teaching for Transplant Class The class is 2 – 4 pm the 2nd and 4th Tuesday of each month. The class is held in the Cancer Center, room CC-2105. Your caregiver(s) should also attend this class.
	Review the treatment calendar with your nurse coordinator		Check your outpatient prescription coverage and locate a pharmacy near Stanford
	Discuss housing, disability and caregiver needs with your social worker		Obtain a medical alert bracelet
	Discuss completing an advanced directive with your social worker and physician		Consider your transportation needs There are times when you will not be able to drive.
	Identify a caregiver(s) A caregiver is needed 24 hours a day, seven days a week while you receive care as an outpatient.		Discuss fertility preservation with your physician
	Meet with a clinical nurse specialist or research nurse to review and sign your consent forms		Make arrangements for childcare
	Have a dental exam All cavities should be filled and any teeth affected by gum disease should be removed. The dental work should be done at least 14 days prior to transplant.		Plan for pet care
	Practice drinking 3 quarts of fluid every day		Plan for household maintenance for the time you are at Stanford Have a family member or friend change the air filter on your air conditioner and/or furnace

Changing Your Treatment Plan

At your first visit, the attending physician will outline a treatment plan based on your history, physical health and prior therapies. Your treatment plan will then be presented to the rest of the BMT team. The entire BMT team will then consider the treatment plan selected for you and discuss if this is the **BEST** treatment plan we can offer. In some cases, this means that your treatment plan may change from what was initially presented to you. We recognize that a change in plans can be stressful, but believe that you will benefit from having the expertise of the entire BMT team reviewing your treatment plan. Other reasons for a change in the treatment plan include results of eligibility testing, a change in the status of your disease, new information about treatment outcomes and the type of donor available.

Medical Alert Information

- Please obtain a medical alert bracelet or pendant. Order forms are available at most pharmacies.
- Have your medical alert jewelry engraved with:
    - Stem Cell Transplant
        - Phone (650) 725-7121
    - irradiated blood only

- On the medical alert card and in the medical alert database list the following information
    - your BMT physician’s name and phone number ☎ (650) 725-7121
    - your diagnosis
    - medications you take routinely
    - your blood type at the time of transplant
        - If you and your donor are not the same blood type state: Mismatched ABO donor and recipient.
    - the following statements:
        - Warning, Use irradiated blood products.
        - If you are cytomegalovirus (CMV) negative you should receive only CMV negative blood products.

- You should wear your medical alert jewelry until you are off all medications related to your transplant.
- Your nurse coordinator can tell you your blood type and CMV status.

Review Your Insurance Coverage

Once your transplant is scheduled, one of our BMT financial coordinators will request authorization for coverage from your insurance company. Obtaining authorization requires that all pre-transplant diagnostic studies are completed and submitted to the insurance company for review. Thus, authorization for transplant is usually not obtained until just days before you are scheduled to begin.

Review your Insurance Coverage:

- confirm the amount of your policy deductible(s)
- know your co-payments, your out of pocket maximum, your policy maximum
- confirm that return visits to Stanford for follow up are covered and authorized
- find out if there is coverage for housing while you stay at Stanford
- determine if there is any coverage for transportation
- know your prescription drug coverage, prescription co-pays and what pharmacies you can use
    - the cost of prescriptions can be very high, with some medications costing thousands of dollars.

For assistance, you can contact one of the BMT financial coordinators

Section Four—Social Services

Your Social Worker

You will work with one of the social workers in the BMT Program throughout your transplant. Your social worker is a key member of your BMT team.

- Cecilia Ellington, MSW
  - (650) 714-5489

- Morgan Gross, LCSW
  - (650) 796-5084

- Carrie Kowieski, MSW
  - (650) 817-5462

- Ana Stafford, MSW
  - (650) 521-3439

Your social worker will complete an evaluation reviewing your:

- understanding and adjustment to your illness
- support system
- caregiver plans
- work, financial and disability issues
- past and current use of drugs, alcohol and tobacco
- understanding of the need for abstinence from drugs, alcohol and tobacco
- motivation
- ability to follow the treatment plan
- family support and how your family is coping

Your social worker will help you complete:

- an advanced health care directive
- an abstinence contract
- housing arrangements
- disability forms

It is always helpful to bring your caregiver(s) with you when you meet with the social worker.

Advanced Directive

Stanford's BMT program highly encourages you to complete an advanced health care directive before starting your treatment. An advanced health care directive is a legal document that allows you to:

Appoint another person (called a health care agent) to make health care decisions for you if you are too sick to make the decisions yourself.

Write down your health care wishes about the kind of life supporting treatment you would want or not want.

An advanced health care directive does not:

Take effect if you are still willing and able to make your own medical decisions

Give your agent power to make property or financial decisions on your behalf

Your social worker, will review with you the benefits of an advanced health care directive and can provide you with the necessary paperwork. Additional information can be found at www.cmanet.org. If you already have an advanced health care directive, please give your social worker a copy. If you do not have an advanced health care directive, we strongly encourage you to complete one.

There are multiple formats available to help with your advance directives. Examples can be found at these websites or paper forms can be obtained from your social worker

http://med.stanford.edu/letter.html
https://agingwithdignity.org/
www.theconversationproject.org

Considerations when completing an advanced health care directive:

- Communicate with your family
- Identify the person you want to designate as your health care agent. This person can be anyone you choose, but should be someone who knows you well and whom you would trust to make decisions in your best interest.
- Clarify your priorities and values with your health care agent and family.
- A useful website is www.theconversationproject.org

- Another useful tool is the “Five Wishes” the website is www.agingwithdignity.org
- Having these conversations now means that your wishes and preferences are more easily honored
- Think about your wishes should you become very ill and need to be transferred to the intensive care unit
- Carefully consider about when and how long to use life support and communicate your preferences to your doctor.
- When your advanced health care directive is completed, you should keep the original paperwork for your records, and provide a copy to your social worker

Abstinence

Allogeneic transplantation is a complicated and potentially life-threatening medical treatment. The Stanford BMT program requires that you completely abstain from the use of all substances that are harmful and can interfere with your transplant. The purpose of abstinence is to enhance the results of transplant and to aid in your long-term health and recovery.
We require that you abstain from using the following:

- alcohol: any type or amount
- tobacco: cigarettes, chewing, cigars, pipes
- all illegal drugs, including but not limited to methamphetamines, cocaine, heroin, PCP and Ecstasy
- <u>Medical marijuana use should be discussed individually with your physician and social worker</u>

All patients undergoing transplant at Stanford will be required to sign an abstinence contract that includes the following:

- abstinence <u>before</u> starting preparation for allogeneic transplantation, ideally for a least a month
- complete abstinence <u>during</u> the preparative regimen and transplant phase
- complete abstinence <u>following</u> transplant indefinitely for tobacco and illegal drugs. You should check with your doctor about when it is safe to resume drinking alcohol.

Your BMT team will work with you to help you succeed in meeting the requirement of abstinence. If you need help in meeting the abstinence requirement, let your social worker, doctor or nurse coordinator know. They will find resources to help you. To meet the requirements of the abstinence contract, you may be required to undergo drug and alcohol testing, attend 12-step meetings or complete a chemical dependency program.

Why do we require abstinence?
There are three key reasons why we ask that you refrain from the use of alcohol, tobacco and drugs.

1. These substances may cause injury to organs. Tobacco and inhaled marijuana may injure the lungs or increase the risk of infection. Alcohol and other drugs may injure the liver, kidneys and bone marrow.

2. Alcohol, tobacco and illegal drugs may interfere with the medications we give you during transplant. Unknown or unexpected drug interactions could jeopardize the outcome of transplant.
3. Alcohol and other drugs may impair your ability to fully participate in and cooperate with your care. Your participation during transplant is essential to a successful outcome.

Safe Zone

You must stay within the "SAFE ZONE" during your transplant. The SAFE ZONE is based on travel distances and times from various locations in the bay area to Stanford Health Care.

The boundaries of the SAFE ZONE are:

- Castro Valley
- Half Moon Bay
- Los Gatos (except the Santa Cruz Mountains)
- Milpitas
- Pacifica
- San Francisco
- San Jose
- San Leandro
- San Lorenzo

If you live within the SAFE ZONE, you can stay in your own home throughout transplant. If you live outside the boundaries of the SAFE ZONE, you will need to stay near Stanford for approximately 100 days after your transplant.

Housing Options

For questions or assistance with housing please contact your assigned social worker for assistance.

After transplant, you are required to stay in a place where you have access to both a full kitchen and bathroom. Some options include:

1. **Your own home** if it is within the SAFE ZONE
2. **The home of family or friends** if it is within the SAFE ZONE
3. **A local hotel or motel**.
    - The following website may be useful: https://stanfordhealthcare.org/content/dam/SHC/patientsandvisitors/your-hospital-stay/docs/hotel-brochure-july-2015.pdf
    - Some hotels offer reduced rates for Stanford patients, so ask for the Stanford contracted rates when you book a reservation.
    - Most hotels require 24-hour cancellation, so clarify the cancellation policy when you book a reservation.
4. **An RV or Trailer Park**
    - Trailer Villa in Redwood City. ☎(650) 366-7880. Reservations need to be made in advance. They have full hook-ups.
    - Stanford Hospital Parking Lot.☎ (650) 723-7222. Arrangements are made through the security office. There are no hook-ups and you can only stay for a maximum of 5 days at a time.
    - Sequoia Trailer Park in Redwood City. ☎ (650) 366-0608.
    - Trailer Tel in San Jose. ☎(408) 453-3535.
    - Candlestick RV Park in San Francisco. ☎ (415) 822-2299.
    - SF RV Resort in Pacifica. ☎ (650) 355-7093.
5. **A rented room** with a bath in a private home through the Community Guest Home Program.
    - The Community Guest Home program is sponsored by the *Menlo Park Presbyterian Church.* Church members may offer their homes for a nominal fee.

- Please contact your social worker if interested.

6. **An Extended Stay Hotel**
    - Extended stay hotels have full kitchens.
    - Some extended stay hotels have special rates for Stanford Patients:
        - Homewood Suites by Hilton Newark/Fremont ☎ (510) 791-7700
        - Towne Place Suites by Marriott, ☎ (650) 262-1020
        - Stanford Motor Inn, ☎ (650) 493-3153

7. **Apartments**
    - There are many apartments near Stanford.
    - The following is used frequently by BMT patients and families.
        - Oakwood Worldwide, ☎ (510) 404-0163, www.oakwood.com

Some insurance plans offer coverage for housing during transplant. We encourage you to contact your insurance directly to check if you have access to travel and lodging benefits.

Stanford recognizes that the costs of local housing are a significant expense for many patients. Stanford has very limited funding available to assist with housing costs. Please notify your social worker if you feel you may need financial assistance.

Disability Programs

A disability is an illness or injury that prevents you from working. Each program listed below requires medical verification of your disability. Following transplant there may be a period of 12 months or more when you will be unable to work. Your social worker can review the disability programs you are eligible for and assist you with the application process.

1. **State Disability Insurance (SDI)**
    - www.edd.ca.gov/Administered by the Employment Development Department (EDD). Forms for SDI are available through the EDD, your employer's human resources department or through your social worker.
    - Most disabled individuals who work in California are eligible for short term disability benefits through SDI, however, some individuals may not qualify, for example, individuals who are self-employed or government employees.
    - To be eligible you must have paid into the SDI through payroll deductions and meet the disability criteria.
    - Your benefit is based on what you have paid into the program.
    - Contact your employer's human resources department for more information.

- You can receive state disability benefits for a maximum of one year and you will likely need to re-certify your disability

2. **Social Security Disability Insurance (SSDI).**
   - ☎1-800-772-1213 or www.ssa.gov
   - The Social Security Administration manages a long-term disability program called SSDI. It works like Social Security Retirement.
   - What you are entitled to is calculated by the following:
     - based on the amount you have contributed into Social Security. Your yearly Social Security statement can give you an estimate of your monthly SSDI benefit.
     - based on the number of work credits you have earned. Generally, you need 20 credits earned in the last 10 years. You can earn up to a maximum of 4 work credits per year. Younger workers may qualify with less work credits. Most BMT patients are eligible. Family members under 18 years of age may qualify for additional benefits.
   - There is a **FIVE** month waiting period from the start of your disability until you are eligible for benefits.
   - The application process is complex and can take several months to complete. It is important to start the application process early.

3. **Supplemental Security Income (SSI).**
   - ☎ 1-800-772-1213 or www.ssa.gov
   - The Social Security Administration manages another long-term disability program based on financial need called SSI.
   - This program is for those who are medically disabled with very low income and minimal assets.
   - The amount of benefit you receive is set by the state you live in and not affected by your work history or payments into Social Security.
   - There is no waiting period for benefits, but you should apply early.

4. **Private Disability Programs**
   - You may have private individual or group disability insurance.
   - These programs vary greatly as to eligibility, time frames and requirements.
   - Check with your insurance agent, Human Resources Department or your policy to find out more information.

Leave Programs

1. **Family and Medical Leave Act (FMLA)**
   www.dol.gov
   The Family and Medical Leave Act is a federal program and the California Family Rights Act is a state program. Together they provide up to 12 weeks (480 hours) of job protected, unpaid (in most cases) leave when an employee or an immediate family member has a serious health condition.
   Undergoing BMT is considered a serious health condition. To be eligible an employee or family member
   - must work for a company with 50 or more employees
   - have worked for the company for at least one year
   - have worked at least 1250 hours in the past year

   Contact your employer for additional information.
2. **California Family Right's Act (CFRA)**
   www.dfeh.ca.gov
   The CFRA requires employers in the state of California to continue to provide health insurance and other benefits while an employee is on leave under the FMLA and CFRA.
3. **Paid Family Leave (PFL)**
   ☎1-888-BE-THERE (English) and ☎ 1-877-379-3819 (Español)
   www.edd.ca.gov
   The PFL program provides up to six weeks of paid time off after a one week waiting period. To be eligible, you must:
   - have paid into SDI for the required period of time
   - be providing care for an immediate family member
   - complete your portion of the claim form. Make sure the patient signs the release of information authorization.

   Contact your employer for additional information.
4. **Medical Leave of Absence (LOA)**
   Contact your employer for information and assistance in obtaining a medical LOA. Questions to ask include:
   - What are the requirements for a medical LOA?
   - How long can you take a medical LOA?
   - How is your health insurance paid while you are on a medical LOA?
   - What happens if your medical LOA is finished and you are not yet able to return to work?

Your BMT Caregiver(s)?

Your BMT Caregiver(s) is an essential member of your transplant team. Your BMT Caregiver(s) is usually family members or friends who can rearrange their regular responsibilities to become your partner during your transplant journey. You will need a caregiver(s) during the outpatient portion of your transplant for approximately three months, but in some cases, it may be longer.

The BMT Caregiver(s) role is a full-time responsibility and requires someone who is dependable and reliable. Changes in your treatment plan, schedule, or health can be stressful for the caregiver and results in concern, frustration and fatigue. We will support your caregiver and help them cope with the stresses of caregiving so that they can provide you with encouragement and support.

Spiritual Care

Stanford Health Care has a Chaplaincy Service that provides spiritual care 24 hours a day. Any of the BMT staff can contact the Chaplaincy Service any time you like.

Chaplains provide religious counseling, prayer, sacramental ministry and explore spiritual concerns to patients of all faiths. The Chaplaincy service is committed to providing you a resource from your own faith and traditions to help you during your transplant and recovery.

The Chapel is located on the first floor of the hospital outside of unit D. There is also a meditation room located on the second floor of the Cancer Center.

Guided Imagery and Guided Meditation

Guided Imagery: Inpatients can enjoy a personalized session of Guided Imagery at no charge. Generally available on Tuesday and Wednesday. Please call Guest Services to arrange. Phone 650-498-3333 or dial 8-3333 from any hospital phone. The mission of the Guided Imagery Program is to:

- Provide a system of visualization that can be used to help in your healing process
- Help equip you with more confidence in facing your situation
- Provide a technique that helps create positive healing images

Guided Meditation: Headspace is a course of guided mindful meditation, accessed via your smartphone or computer. It is like a gym membership for the mind. Meditation has been shown to help with stress reduction, anxiety management, sleep, and coping. The initial sessions are 10 minutes. Headspace offers free one-year subscriptions to Stanford patients. To obtain your free subscription, email BeMindfulToday@stanfordhealthcare.org.

Web-based Resources

www.bmtinfonet.org
- comprehensive review of BMT by a former BMT patient
- offers many web-based educational programs

www.nbmtlink.org
- comprehensive site with information specific to BMT

www.marrow.org
- useful information about all types of transplants by the National Marrow Donor Program Be The Match

Section Five – Information for the Caregiver

BMT Caregiver(s)?

A BMT Caregiver(s) is an ESSENTIAL member of the transplant team. A caregiver(s) is usually a family member(s) or friend(s) who can rearrange their regular responsibilities to become a partner during the transplant journey. A caregiver(s) is required during the outpatient portion of transplant for approximately three months, but in some cases, it may be longer.

The caregiver(s) role is a fulltime responsibility and requires an individual who is dependable and reliable. Changes in the treatment plan, schedule and health of the transplant recipient can be stressful. It is common for caregivers to experience anxiety, concern, frustration and fatigue. The social workers will offer support and guidance to help you cope with the stresses of caregiving.

What are the Caregiver(s) Responsibilities?

- TAKING CARE OF YOURSELF
- protecting the transplant recipient’s need for rest
- communicating with family and friends
- providing emotional support to the transplant recipient
- watching for and reporting symptoms to the BMT team
- shopping for groceries
- preparing meals
- supervising and recording the food and fluid intake of the transplant recipient
- monitoring medications and obtaining prescription refills for the transplant recipient
- assisting with the care of the central venous catheter and infusion pump
- housecleaning and laundry
- transportation

Taking care of yourself

Ten Tips for Caregivers

- Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- **Watch out** for signs of depression and don't delay in getting professional help when you need it.
- When people offer to help, **accept the offer** and suggest specific things that they can do.
- **Educate yourself** about your loved one's illness and treatment. Knowledge is empowering.
- There is a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
- **Trust your instincts**. Most of the time your instincts will lead you in the right direction.
- Grieve for your losses and then allow yourself to **dream new dreams**.
- **Stand up for your rights** as a caregiver and a citizen.
- **Seek support** from other caregivers. There is great strength in knowing you are not alone.
- Choose to **take charge** of your life and don't let your loved one's illness always take center stage.

Reprinted with permission from The National Family Caregivers Association (NFCA), Kensington, Maryland. The NFCA is an organization devoted to all family caregivers.
☎ 1-800-896-3650 or www.nfcacares.org

Caregiving

Caregiving is challenging, both physically and emotionally. Taking care of yourself is important for your health. One of the most important things you can do for yourself is take time for yourself.

Some resources available to you are:

- **Stanford** has supportive care classes and support groups available. The schedule is posted at http://cancer.stanford.edu/patient_care/amenities/cancerPatientServices/supportiveCareServices/. Or phone (650) 725-9481.

- The **BMT Info Net** website (www.bmtinfonet.org) lists resources and tips for caregivers. They also have a series of videos covering many aspects of transplant, recovery and caregiving.

- The **National Bone Marrow Transplant Link** has created a Caregivers' Guide to Bone Marrow/Stem Cell Transplant (nbmtlink.org/documents/cg2.pdf). There are also webcasts and podcasts dedicated to caregiver coping and recovery. Your social worker can also direct you to support resources.

- **Be the Match** provides resources for caregivers before and after transplant (http://bethematch.org/For-Patients-and-Families/Caregivers-and-transplant/Role-of-the-transplant-caregiver/After-transplant/).

<u>Transitioning from Family/Friend to Caregiver and Back Again</u>

The usual roles and responsibilities in relationships change during transplant. It can be challenging to shift these roles and responsibilities and sometimes it is hard to talk about these changes. The resources listed above may provide some helpful information.

Research has shown that three of the most challenging aspects of caregiving are managing work, caregiver fatigue and managing the patient's emotional distress. Some advice from former caregiver's includes:

- Keeping the patient as independent as possible
- Taking time for yourself and establish a routine
- Be optimistic
- Don't be afraid or too proud to ask for help

Medication Management

- With time, we anticipate that the transplant patient will assume responsibility for their medications, however, early in the transplant process, the caregiver assumes most of the responsibility for medication management. There are many medications that will need to take taken during the active transplant phase and recovery. In addition to the number of medications, many medications have very specific instructions.

- Some caregivers have developed spread sheets to manage medications. There are also medication administration applications for the iPhone, iPad or android phones. Two examples are Medisafe and Dosecast.

- You may find it helpful to set a reminder on your phone when it is time to take medications.

- There are times when we may call you to adjust the dose of a medication. A tip to ensure you understand the phone instructions is to write down the information and then repeat the dose adjustment back to the health care professional.

Support for the Caregivers

The BMT social workers offer a weekly "Tea and Talk" group every Monday at 1:30 pm on the inpatient unit (E1). The goal is to encourage caregivers to meet other caregivers, provide support and share information. No appointment is necessary it is a drop-in group.

There is also a caregiver support class every Wednesday in the Cancer Center, room CC2103. The goal is to provide caregivers support, education and resources for physical, spiritual, psychological and nutritional aspects of transplant.

The class is from 1 – 2pm the first, second, and third Wednesday of the month and from 1:3 – 2:30 pm on the fourth Wednesday of the month.

For questions call, 650-529-5942.

Section Six —Transplant

Informed Consent

The BMT Program is committed to improving outcomes and advancing the science of transplantation. Improvements in BMT are evaluated and developed using clinical and research studies. The National Institutes of Health and the Blood and Marrow Transplant Clinical Trials Network support many of the research studies conducted by the Stanford BMT Program. One potential benefit of participating in a research study is that transplantation may work better than other therapies for your disease. Many patients also express satisfaction in contributing to the advancement of cancer treatments by participating in research studies. One risk of participating in a research study is that the transplant is not as effective as current therapies.

In some cases, you may be asked to participate in a randomized research study. Randomized research studies allow physicians to determine if one treatment approach is better than another treatment approach. Participating in randomized research study ultimately results in learning more about the best treatment. Please read your consent form(s) carefully and write down any questions you have.

You will be given a copy of your consent form(s) to read before your scheduled appointment for the consent review. In preparation for this appointment:

- Read your consent form and mark the consent with any questions you have.
- Identify someone who can come with you for your consent appointment. You will be given a lot of information and having someone else there can be very helpful.

The consent form(s) will:

- provide a detailed description of your treatment plan
- describe side effects of treatment
- discuss the potential risks and benefits

Consent Forms

The consent will provide detailed information about each step of transplant. The consent will review the risks, side effects, long-term complications and potential benefits.

There are other studies you will be asked to consider. These additional studies generally involve the use of data and collection of research samples to improve transplantation for future patients.

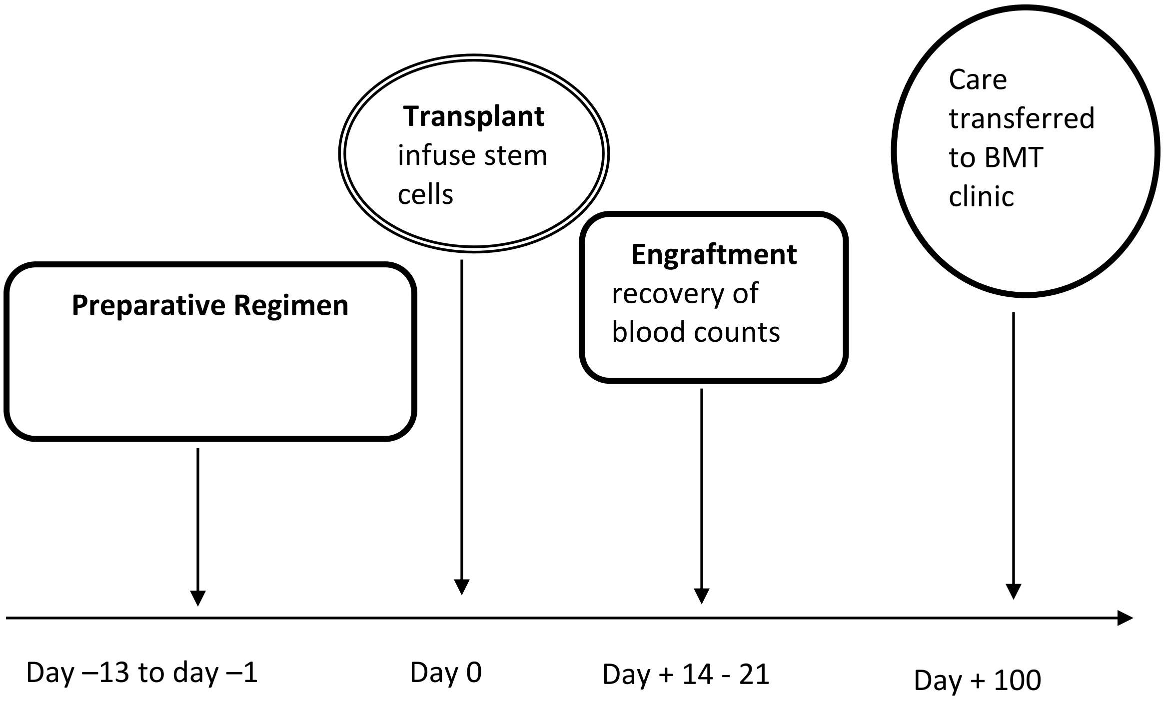
Where to Go for Your Consent Appointment?

In general, your consent will take place in the main hospital on the first floor, unit E1. If you are going to be late or need to cancel at the last minute, please call the unit clerk at ☎ (650) 725-7121 and let him/her know. The unit clerk will inform the person you are scheduled to see.

Copies of Consent Forms

Keep a copy of your signed consent forms in your Guidebook.

Allogeneic Transplant Outline



Preparative Regimen

Your consent form will state the specific preparative regimen you will be receiving and provide detailed information on potential side effects. Sections seven, eight, nine and ten of this guidebook contain information on how to manage side effects and take care of yourself during transplant.

Side Effects	Common Side Effects of Many Chemotherapy Agents	Anti-Thymocyte Globulin (ATG)	Fractionated Total Body Irradiation (FTBI)	Total Lymphoid Irradiation (TLI)
allergic reactions	✓	✓		
body aches and pains		✓		
cataracts			✓	
changes to the fingernails and toenails	✓			
chills		✓		
decreased blood counts	✓	✓	✓	✓
decreased function of the thyroid gland			✓	✓
diarrhea	✓		✓	✓
fatigue	✓		✓	✓
fever	✓	✓		
flu like symptoms	✓	✓		
hair loss	✓		✓	
headache	✓			
infertility	✓		✓	✓
loss of appetite	✓		✓	
low blood pressure	✓	✓		
mouth sores	✓		✓	
nausea	✓		✓	✓
organ damage	✓		✓	
premature menopause	✓		✓	
secondary cancer	✓	✓	✓	✓
skin changes/rash	✓	✓	✓	
swelling of the parotid gland (under the jaw)			✓	
taste changes	✓		✓	
vomiting	✓		✓	✓

Transplant

After completing the preparative regimen, you're ready for your transplant. The transplant day, day 0, is the day your donor's stem cells will be infused through your catheter. The donor stem cells will begin to produce new blood cells in about 14-30 days. White blood cells will recover first. Platelets and red cells take longer to recover. You will need transfusion support, both red blood cells and platelets, until you begin to make these blood cells in adequate numbers, which may take several months.

Graft Versus Host Disease

Graft versus host disease (GVHD) is an immune reaction of the donor's cells against your body tissues. Stated another way it is a reaction of the donor's immune system (the graft) versus you (the new host). Graft versus host disease occurs as the donor's immune system recognizes your body tissues as different or foreign.

There are four main strategies for preventing graft versus host disease.

1) **HLA Matching**-the HLA matching between you and the donor. The closer the HLA match the lower the risk of graft versus host disease. However, even when there is a "perfect" match there remains a risk of graft versus host disease.

2) **Immunosuppressive Medications**-medications taken to weaken the donor's immune system. There are many different immune suppressing medications. Please refer to your consent form to find out which immune suppressing medications you will receive.

3) **Preventing Infections**-Preventing infections can help prevent graft versus host disease. You will be taking medications to try to prevent infections and will be asked to follow guidelines to minimize your risk of infection.

4) **Protection from Sunlight Exposure**-Sunlight can trigger a reaction in the skin that causes a type of graft versus host disease.

   - When you are outside, wearing a sunscreen with an SPF of at least 30 and reapplying as directed is an important step in preventing graft versus host disease. You may also wear clothing that protects your skin from sunlight such as hats and long sleeved shirts.

Acute and Chronic Graft Versus Host Disease

There are two forms of graft versus host disease; acute and chronic. Acute graft versus host disease generally occurs within the first 100 days of transplant. It can range from a mild and treatable problem to a very serious and life-threatening problem. Acute graft versus host disease generally affects the skin, the liver and the gastrointestinal tract (the stomach and intestines).

Chronic graft versus host disease generally occurs within the first two years after transplant. It can range in severity from mild to life-threatening. In some cases, chronic graft versus host disease can be debilitating and limit what you can do physically. Unlike acute graft versus host disease which is limited to three systems), chronic graft versus host disease can affect any tissue in the body.

One example of chronic graft versus host disease is a dry mouth. The dry mouth is a result of the donor's immune system destroying part of the salivary gland and therefore you do not make enough saliva. Another example of more severe chronic graft versus host disease is damage to the joints which limits the range of motion of the joints and making physical activity more difficult.

Treatment of both acute and chronic graft versus host disease involves administering medications that weaken the donor immune system. The more the donor's immune system (your new immune system) is weakened the higher the risk of infection. Some infections can be life-threatening.

If you develop graft versus host disease, we will work with you on treatment, strategies to prevent infections, manage your symptoms and maximize your quality of life.

Hospital Routines

While you are in the hospital, the BMT team will visit you and assess your status. The BMT team usually includes the attending physician, a fellow, a resident, a nurse practitioner or physician assistant, a pharmacist, physical therapist, dietician and the nurse taking care of you that day.

Every day you should

- ✓ take a shower
- ✓ get out of bed
- ✓ work with the physical therapist or exercise independently
- ✓ do your mouth care a minimum of 5 times a day

You need to bring a good pair of slippers or shoes with you to the hospital. The slippers or shoes should have a non-slip sole and cover your toes. Bring loose, comfortable clothing and hats or scarves. Feel free to bring items from home to decorate your room, such as photos or a favorite blanket. You can also bring a laptop computer, radio, music and DVDs.

You will not have a private room and will likely have to change rooms and nursing unit during your stay. Private rooms are assigned based on medical judgment and considering the needs of all patients. We recognize not having a private room and changing rooms and nursing units is are stressful and apologize for any inconvenience. We appreciate your cooperation and assistance when room and nursing unit changes are required.

Infusion Treatment Area (ITA) Care and Routines

The ITA is located on the second floor of the Cancer Center.

The time you spend in the ITA varies from a few hours to all day, depending on your needs and scheduling. We are committed to keeping wait times as short as possible.
We encourage your caregiver to be present at each visit.

Please bring the following to all your ITA visits:

- Your guidebook.
- Your home medications and medication list.
- A list of questions for the health care team

- A list of any medications needing refills.
- Your HEPA mask. It is important to wear your HEPA mask to all ITA appointments. Since your visits will be at least few hours and possibly longer, we recommend that you bring snacks and drinks. We do offer juice and crackers.
- Once you are discharge from the hospital, you need to keep track of your fluid intake to ensure you are drinking 3 quarts per day.
- Wear warm comfortable clothing.
- Weekends –there are limited options for purchasing food on the weekends
    - Food is available at hospital cafeteria only
    - The ITA has crackers, some juice options and canned soup options for patients only.
    - parking is free on the weekends in the Blake Wilbur valet parking area (no valet attendance)

Your healthcare team recognize the healing properties of a quiet and calm environment. We ask you to help us as we strive to create an environment that promotes a therapeutic and peaceful atmosphere. Please engage in phone conversations away from the patient care areas and silence phones when not in use. Headphones for music and TV listening are available or you may use your own. We appreciate your help in maintaining a quiet and healing space for all our patients.

Upon arrival in the ITA, we will assess your:

- vital signs
- weight
- symptoms and symptom management

and we will:

- perform a physical exam
- draw blood
    - we may have you come for a blood draw early and then schedule you in the ITA when the blood test results are available.
- administer fluids, medications and blood products as needed

Section Seven—Infection Prevention Measures

Infection Prevention Measures…when to Start and Stop

Infection Prevention Measures	Preparative Regimen Begins	Day + 100	Six Months	Off all immunosuppressive medications
Frequent Thorough Hand Washing and Daily Shower	Begin			End
Wear HEPA Mask	Begin	Stop wearing the mask **except** when you visit a hospital or clinic, crowded public spaces and near construction sites	End	
Low Microbial Diet	Begin	End		
Take oral antibiotics	Begin			End
Do not care for Pets	Begin			End
Do Not Work in the Garden	Begin			End
Perform frequent mouth care	Begin	End		
Avoid ill people	Begin			End
Do not open windows	Begin	End		
Avoid vacuuming or dusting	Begin			End

More detailed information about each of these infection prevention strategies can be found on the following pages.

Infection Prevention Strategies

Daily Hygiene

- Proper hand washing
    - remove jewelry
    - wash the front and backs of your hands with soap and warm water—vigorously scrub
    - clean under your fingernails and between your fingers
    - rinse and dry your hands with a clean towel or paper towels

- Wash your hands frequently
    - after using the restroom
    - before and after eating
    - after touching your hair, face, door handles, pets
    - before and after preparing food
    - after holding infants or young children

- Shower.
    - apply a moisturizing lotion after you shower

- Clean the rectal area thoroughly after bowel movements
    - use a disposable soft washcloth (or soft toilet paper)
        - alcohol free baby wipes are also acceptable
    - barrier cream can help reduce irritation from diarrhea

- Take care of your central venous catheter
-
- Avoid contact lenses until you are 100 days post-transplant

- Perform gentle mouth care

- Perform deep breathing exercises. In the hospital, we will give you a respiratory coach to help with your deep breathing exercises. While receiving care in the Cancer Center, walk as much as possible to exercise your lungs.

- Protect your skin from sunlight exposure
    - use a sunscreen of at least SPF 30
    - wear clothing to protect your skin from sunlight

Avoid Exposure to Microorganisms

- avoid anyone who is ill with colds, flu or other infections
- follow the low microbial diet
    - *more information on the low microbial diet can be found in section eight*
- wear the HEPA filter mask
- do not clean animal cages, empty litter boxes or handle animal feces of any kind
- avoid stagnant water
- do not change the water in fish bowls or ponds.
- do not do any gardening or caring for plants in the home
- do not vacuum and dust and leave the room during vacuuming and dusting.
    - wait 45 minutes before re-entering the room
- avoid construction sites
    - For the next several years there will be several major construction projects at Stanford. During construction microorganisms, such as fungus are released into the air. Wearing the HEPA filter mask and maintaining distance from active construction sites can help protect you from inhaling many of these microorganisms. Upon arrival at Stanford, **BEFORE** you get out of your car, remember to put on your HEPA filter mask.

Protect natural barriers to infection—your skin

- do not use rectal thermometers, take rectal medications (suppositories) or enemas
- do not have **<u>any</u>** invasive procedures by a dentist, podiatrist or surgeon without first checking with the BMT team

When to Wear the HEPA Filter Mask?

The HEPA filter mask helps protect you from microorganisms (bacteria, viruses and fungus) that can circulate in the air (airborne). These airborne microorganisms can cause serious pneumonia if they get into the lungs.

Wear the mask

- ➢ when your white blood cell count is low
- ➢ when you leave your home or hospital room
- ➢ when you come to any hospital or clinic
- ➢ when the housekeeper is cleaning your hospital room

During what part of your transplant do you have to wear the mask?

- ➢ from the start of the preparative regimen until 100 days post-transplant

- from 100 to 180 days post-transplant, you need to wear the mask when you come to a hospital or clinic, in crowded public spaces and around construction sites

There are other HEPA filter masks that can be purchased. However, when we have contacted the companies to confirm the ability of the masks to filter microorganisms, they have not been able to provide evidence of the efficacy. So we believe it is best to use the HEPA filter mask we provide.

Mouth Care
After the preparative regimen, it is likely you will develop some irritation or sores in the mouth and throat. These sores cause pain that will vary from mild to severe. For many people, this can be the most painful part of transplant. Your BMT team will work to relieve the pain and your job is to perform frequent mouth care to prevent infections and promote healing.

Mouth care should be done a minimum of 5 times each day

1. rinse with a bland solution (a mixture of salt and water based on your taste preference). Make the solution fresh for each use.
2. Use toothpaste as tolerated
3. use a very soft “baby” toothbrush or a disposable toothbrush to gently clean
    a. disposable toothbrushes should be discarded after one week
    b. soft “baby” toothbrushes should be discarded after one month
    - perform gentle mouth care.
    - no flossing until you are 100 days post-transplant
    - no electric toothbrush or water pics

Infection Prevention While You are in the Hospital

- Visitors
    - must be healthy without colds, flu or other infections
    - will wash their hands before entering your room
    - will wear a mask until your white blood cell count recovers
    - we strongly discourage children under the age of 12 from visiting
        - only your children are allowed to visit
    - when you are in a semi-private room, please limit the visitors to two at time
        - children under 12 years of age cannot visit while you are in a semi-private room

- Hospital Room
    - the air is filtered to remove most microorganisms
    - no fresh flowers or plants are allowed
    - mylar balloons are allowed for 3 days, latex balloons are not allowed

Infection Prevention in Your Home

Housecleaning

- avoid vacuuming and dusting
    - leave the room when someone else is vacuuming or dusting. Wait at least 45 minutes before returning.
- have someone change the filter on your furnace and air conditioner before you start treatment and then on a regular basis (following the manufacturers recommendations for the first year)
- bed linens should be changed once a week
- use your own towels and change them every two days

Pets

- dogs and cats may remain in the home
    - do not clean up after or groom your pets
    - wash your hands thoroughly after contact
    - keep the pet off your bed and clothing
- birds must be relocated to another home until you are off all immunosuppressive medications
- do not care for farm/ranch animals, small caged animals or reptiles until you are off all immunosuppressive medications

Plants and Gardening

- plants may remain in the home
    - do not care for them
    - after watering, someone should wipe up any water in the rim of the pot to avoid stagnant water
- no gardening
    - no raking leaves, watering the lawn, mowing the grass, planting bulbs, digging in the soil or trimming bushes or trees

Fans and Windows

- if you use a fan, someone else should dust the fan blades three times per week
- it is best to keep the windows closed

Travel

- car travel
    - if the vents and windows are closed and the air is re-circulating, you do not need to wear the HEPA mask in the car
- airplane travel
    - check with your BMT physician before you begin any travel

Other Miscellaneous Activities to Avoid Until off all Immunosuppressive Medications

- soaking in a hot tub
- swimming
- fishing
- carpentry work, woodworking
- obtaining new pets
- golfing. You can resume golfing after 6 months as long as you no longer have a central venous catheter and use you sun protection.
- having a fire in the fireplace
- having a live Christmas tree

If in doubt about the risk of an infection with various activities, ask your BMT team.

Specific Infections of Concern

Herpes Zoster Infection

If you had chicken pox as a child then the virus that causes chicken pox, the varicella zoster virus, is still present in your body. After transplant when the immune system is weak, the virus may reactivate. You will not get chicken pox again, but the virus will cause zoster or shingles.

Zoster or shingles is most likely to occur in the first year after transplant. Zoster or shingles causes pain along a nerve path on your body and then develops into a red, itchy and blistering rash. The sooner you seek treatment, the less likely the zoster or shingles is to cause long-term pain and itching. To try and prevent zoster or shingles, you will be asked to take an antiviral medication, Acyclovir®, for the first year after transplant.

Cytomegalovirus

Most adults were exposed to the cytomegalovirus (CMV) as a child and as a result at that time developed a cold. However, once exposed to the CMV virus, the virus remains in an inactive state in the body forever. When the immune system is weak, as it is after transplant, then the CMV virus often becomes active again. The CMV can cause infection in the lungs, stomach, intestines, liver and other organs. If either you or your donor has been exposed to the CMV virus, then we will monitor you frequently for any indication that the virus is becoming active. If we have evidence that the CMV is becoming active, we will treat it with anti-viral medications.

Respiratory Viruses

Respiratory viruses cause the flu. In people with a weak immune system, respiratory viruses can be **very serious and sometimes fatal**. Respiratory viruses are spread by close contact with infected individuals or contact with contaminated surfaces. The typical incubation period for influenza is 1 to 4 days, with an average of 2 days. Adults can be infectious from the day before symptoms begin until about 5 days after the illness starts. Children can be infectious for more than 10 days after the onset of symptoms and young children can also spread the virus before their illness starts. Severely immunocompromised persons can shed the virus for weeks or months.

Key to prevention is:
- ✓ avoiding contact with sick individuals
- ✓ careful and thorough hand-washing as described on page 48
- ✓ vaccination of you and your family member for seasonal flu
    - o You should only receive inactivated or dead viruses, no live vaccinations

Common symptoms include:
- ✓ runny nose
- ✓ congestion
- ✓ cough
- ✓ fever
- ✓ body aches

Pneumocystis Jiroveci Pneumonia

Pneumocystis jiroveci pneumonia (PJP) is a pneumonia caused by a protozoal organism. For prevention, you will take a medication called Bactrim® . The Bactrim® will start approximately 30-42 days post-transplant and continue until you are off all immunosuppressive medications. If you are allergic to Bactrim®, there are alternative medications.

Metric Conversions
We will record your weight in kilograms. One kilogram = 2.2 pounds.

Temperature

Centigrade	Equals	Fahrenheit		Centigrade	Equals	Fahrenheit
36.0	=	96.8		39.0	=	102.3
36.5	=	97.7		39.5	=	103.1
37.0	=	98.6		40.0	=	104
37.5	=	99.5		40.5	=	104.9
38.0	=	100.4		41	=	105.8
38.5	=	101.3				

What Are the Signs of Infection?

Call the BMT team **IMMEDIATELY** for any of the following:

- Fever or chills
  - temperature $\geq 101^{0}$F or $\geq 38.3^{0}$C or
  - a temperature of 100.4^{0}F or 38^{0}C sustained over one hour
  - Acetaminophen (Tylenol®) can mask a fever, so use this product only under the direction of the BMT team.

- Cold Symptoms
  - cough
  - sore throat
  - green or yellow sputum
  - runny nose

- Shortness of breath

- Any area of your skin becomes warm to touch, red, painful or swollen

- Chills after flushing the catheter
  - drainage, inflammation or tenderness around the catheter site

- Pain or burning during urination

- Diarrhea
  - more than 4-5 loose bowel movements a day

Section Eight –Low Microbial Diet

The Basics

The basic principle behind the low microbial diet is the elimination of bacteria from foods by proper preparing, cooking and storing. Safe food handling techniques are essential to minimize the risk of illness from food. There are certain foods that you should stay away from altogether until you recover from transplant.

Adequate nutrition is KEY to your recover. It is essential to get adequate calories, protein, fluids and nutrients to heal and avoid weight loss. Options for improving your calorie and protein intake include:

- High calorie and high protein supplement drinks or shakes
- Feeding tubes. In some instances, placing a tube into the stomach and administering high calorie and high protein nutrition may be the best means of meeting your nutritional needs.
- Total parenteral nutrition is liquid nutrition that can be administered intravenously through your central venous catheter.

There are several reasons it can be difficult to eat during treatment and recovery. The following pages will provide guidance on how to optimize your oral intake while dealing with these symptoms:

- Poor appetite
- Nausea and vomiting
- Diarrhea
- Mouth sores
- Alterations in taste
- Fatigue

You may be asked to record your food and fluid intake to help the dietitian tailor nutrition recommendations most suitable for your needs.

The next few pages contain information on:

○ Food safety
○ The basics of low microbial diet
○ How to deal with poor appetite
○ How to deal with nausea and vomiting
○ What to do when you have mouth sores
○ What to do when you have taste changes
○ What foods to avoid when you are having diarrhea

Feel free to consult the Stanford Cancer Center Recipe Bank for low microbial diet appropriate recipes:
http://cancer.stanford.edu/patient_care/services/nutrition/recipes/

Food Safety

Safe food handling will help you avoid food borne illness after transplant. The following are key points for safe food preparation.

Cleaning Hands and Surfaces

- Wash hands with warm water and soap before meal preparation, when moving from raw foods to cooked foods, and after handling the garbage
- Wash cutting boards, dishes, utensils, and countertops; use paper towels instead of cloth towels that can harbor bacteria
- Clean lids before opening cans

Shopping for Food

- Choose stores where floors, shelves, and storage areas are clean
- Choose products whose ‘Sell By’ or ‘Best Used By’ date has not passed
- Do not buy dented cans or damaged packages
- Place raw meat, poultry or seafood in a plastic bag before placing in cart

Storing Food

- Separate raw meat, poultry, seafood, and eggs from other foods in shopping carts, grocery bags and the refrigerator
- Know how long to keep foods in the refrigerator:
  - Eggs: 7 to 14 days
  - Raw fish and seafood: 1 to 2 days
  - Raw fruits and vegetables: 7 days
  - Raw meat and poultry: 2 to 3 days
  - Luncheon meat: 4 to 7 days
  - Milk: 5 days
- Put the whole carton of eggs directly into the refrigerator. Do not remove them from the carton to put in the “eggs” area of the refrigerator. Do not wash eggs before storing them.
- Discard leftovers that have been kept at room temperature for greater than 2 hours
- Discard leftovers that have been refrigerated greater than 3 days

- Use cooler with ice or other cold source to transport foods to the hospital or Cancer Center

Preparing Food

- Wash produce with water, even those with rinds that won't be eaten. Scrub and brush fruits and vegetables to remove excess dirt.
- All meats, poultry and seafood must be thoroughly cooked, that is well done.
- All eggs should be cooked until both white and yolk are set and not runny.
- It is ok to use a barbecue grill if the grill is clean and the food and meat are cooked to well done.
- Do not use a microwave to cook meat, fish, poultry or eggs.
- Eat meals within one hour of preparation.
- Reheat leftovers to greater than 165^{0}F throughout before serving.
- Bring leftover soups, sauces, and gravies to a rolling boil before serving.
- Do not share foods with others.

Storing Food

- Refrigerator temperature should be below 40^{0}F.
- Freezer temperature should be below 0^{0}F.
- Food should never be thawed on countertops or in sinks at room temperature. Foods should only be thawed in the refrigerator, in cold running water, or in the microwave. When using the last two methods, the food should be cooked immediately.
- Use two cutting boards: one strictly for raw meat, poultry, and seafood and the other for ready-to-eat foods.

The Basics of the Low Microbial Diet

Foods should be prepared in a manner to minimize bacterial growth. In addition to properly prepared foods, pasteurized, pre-packaged, and shelf stable food are part of the low microbial diet. Pay special attention to the following dietary guidelines:

Avoid foods that may contain a large number of harmful germs

- Avoid blemished, damaged, pre-cut, or moldy produce
- Fresh or frozen berries are not allowed unless cooked
    - Examples are: strawberries, blueberries, raspberries, blackberries, boysenberries
    - Avoid popsicles and frozen desserts made with fresh berries
- Raw sprouts are not allowed unless cooked
    - Examples are: bean sprouts, pea sprouts, alfalfa sprouts
- Avoid yogurts that contain a high number of probiotics and claim to improve the immune system or digestive health
    - Examples are: Activia®, Yakult®, Danactive®, Goodbelly®
- Avoid soft, unpasteurized or aged cheeses
    - Examples are: queso fresco, quesco blanco and Panela, parmesan, sharp cheddar, brie, stilton, feta, Camembert, Roquefort, gruyere, gouda, blue-veined cheeses, goat, Edam, Havarti, Muenster, farmer's cheese, gorgonzola
    - Acceptable cheeses are: cottage cheese, mozzarella, Monterey Jack, Swiss, mild or medium cheddar, string cheese, cream cheese, processed cheeses, Kraft® Parmesan, cooked cheeses
- Avoid Chinese herbs
- Avoid honey
- Avoid soda fountains and soft-serve ice cream
- No fast food, take out or restaurant food
    - You may resume going to restaurants when you are no longer asked to follow the low microbial diet, which is 100 days after transplant
- No foods from self-service bins, salad bars, delicatessens, bakeries, coffee shops
- You may eat pre-packaged lunch meats and hot dogs that have been reheated until steaming hot

Avoid foods that have been 'flash-pasteurized'/'gently pasteurized', or not exposed long enough to heat treatment

Avoid:

- refrigerated salsas/pickles, kimchee, meat spreads or pates, smoked or pickled fish
- raw nuts or nuts in shell
- refrigerated tempeh or miso products
- cheeses that contains uncooked vegetables such as chili peppers
- cold-brewed tea

Acceptable Drinking Water

- Tap water (Municipal/City water) is considered safe from bacterial contamination. The water is usually tested at least twice a day for bacterial contamination.
    - If there is any alert in the local media about potential contamination of the water supply, you should follow the instructions for safe drinking water issued by the local or state government.
- Ice cubes can be made from tap water and frozen in a clean ice cube tray
- **Do Not** drink well water unless it has been boiled for 2 minutes
    - Well water may be contaminated with pollutants and/or microorganisms which can cause serious health problems. Please make sure if you are using well water it has been tested for contaminants.
- Bottled Water that has been processed by reverse osmosis or distillation is acceptable.
    - Examples are: Kirkland®, Crystal Geyser®, Arrowhead®, Dasani®, Aquafina®, Nestle®, Crystal Springs® and Fiji®

A Sample Shopping List

Beverages

- All canned, bottled, powdered beverages
- Nutritional Supplements: Boost ®, Ensure®, Ensure Clear®, Resource®, Scandishake®, Carnation Instant Breakfast®
- Ovaltine®, Hot Cocoa
- Vacuum sealed coffees
- Commercially packaged tea bags

Frozen Foods

- Pasta Dinners
- Frozen Dinners
- Noodle or Rice Bowls
- Chicken or Turkey Pot Pies
- Turkey and Gravy
- Pizza
- Burritos
- Pancakes or Waffles

Canned Foods

- Tuna, chicken, crab
- Soups
- Fruits and vegetables
- Beans
- Gravies and sauces
- Chef Boyardee®

Breads/Cereals/Starches

- Bread, bagels, English muffins
- Muffins, doughnuts
- Pita Bread, corn bread
- Pancakes, waffles
- Cereals, granola
- Rice, noodles, pastas and other grains
- Potato
- Tortillas chips, potato chips, pretzels, popcorn
- Cheese crackers, peanut butter crackers
- Breakfast bars

Meal Packets

- Top Ramen®
- Dehydrated Soups
- Rice a Roni®
- Macaroni and Cheese
- Hamburger Helper®

Vegetables

- Fresh, frozen
- Canned

Fruits/Nuts

- Fresh, frozen
- Canned
- Dried fruits
- Roasted nuts
- Peanut butter
- Trail mix

Meats/Eggs

- Beef, pork, sausage, bacon
- Poultry, fish
- Tofu, eggs
- Deli meats and hot dogs

Dairy

- Lactose free dairy products

Desserts

- Pudding, custard, gelatin, applesauce
- Popsicles/Sorbet
- Sherbet/Lactose free Ice Cream
- Pound cake, cookies, brownies, chocolates, Fig Newtons®, graham crackers, vanilla wafers
- Hard Candies

Snacks/Miscellaneous

- Mustard, catsup, mayonnaise
- Jelly, jam
- Salt, sugar, brown sugar
- Whipped topping

Vitamins, Herbs and Nutritional Supplements

Once you begin the preparative regimen and continuing for 100 days after transplant, do not take vitamins or herbal supplements. There are four areas of concern regarding the use of vitamins and herbal supplements.

- Unexpected, undesirable, and unknown interactions between vitamins and herbal supplements with medications used during transplant
- Possibility of serious and toxic effects of vitamins and herbal supplements on the liver, blood, kidneys, heart or other organs
- Possibility of contamination of vitamins and herbal supplements with infectious organisms
- The preparation, distribution and labeling of herbal preparations and supplements is not regulated by the U.S. Food and Drug Administration. As a result, these products may vary in dosage and may not list all ingredients

Speak with the dietitian about any specific questions you have regarding nutritional supplements, herbs or vitamins.

When to follow the Low Microbial Diet

- Begin the low microbial diet when you start the preparative regimen for transplant and continue for 100 days following transplant
- Beginning on the day of transplant you will need to avoid lactose containing dairy products

Lactose Restriction

- The lactose in dairy products can sometimes cause diarrhea, which is a symptom of acute graft versus host disease. To avoid confusion, we ask you avoid dairy products until you are approximately 40 days post-transplant.
- Lactose free dairy products are allowed
    - Examples are lactose free milk, ice cream, yogurt and cheese
- Dairy Free alternatives are also allowed
    - Examples are soy, almond, rice, coconut milk or mocha mix
- Single servings of butter and chocolate are allowed.

How to Deal with Poor Appetite

A poor appetite is common but getting adequate nutrition is key to your recovery. In fact, you need more protein and calories for your body to heal after transplant.

The following strategies may be helpful:

- Small, frequent meals, for example eat 5 meals a day or eat meals about 3 hours apart
    - Do not skip meals and snacks, even though you may not be hungry
    - Avoid being around during food preparation if the smell of food bothers you
- Carry food and a beverage with you at all times so you can eat and drink when you are waiting for an appointment or traveling
- If you can't eat very much, choose high-calorie foods
- Drink liquid nutrition supplements before or after meals rather than with your meals to avoid feeling full during meals
- Increasing physical activity may help with appetite
- Performing mouth care frequently may help with your appetite, dry mouth and taste

How to Deal with Nausea and Vomiting

Nausea and vomiting are common side effects. Here are some practical tips to help with nausea:

- Eat small and frequent meals
- Foods may be more easily tolerated if cold or room temperature
- Liquids such as ginger ale, Gatorade®, 7-up®, diluted apple juice or cranberry juice, lemonade, clear broth, popsicles, Jell-O®, may be better tolerated than water.
- Avoid fried, greasy, or rich foods
- Nausea can sometimes be relieved by
    - slow deep breathing
    - taking a walk
    - applying a cool washcloth to the face
    - guided imagery
    - relaxation
    - soothing music

Well Tolerated Foods and Beverages

Beverages • Juices • Soda • Gatorade® • Fruit Nectars	**Fruit** • Bananas • Applesauce • Canned fruits	**Desserts/Sweets** • Popsicles • Sorbet, sherbet, custards, pudding • Gelatin
Starches • Potatoes • Pasta • Rice	**Cereal** • Hot or cold • Carnation Instant breakfast®	**Snacks** • Pretzels • Crackers
Protein • Cooked eggs • Tofu • Cheese • Prepackaged deli meats	**Soups**	

What To Do When You Have Mouth Sores

Do:

- ❖ Avoid very hot or very cold foods and beverages
- ❖ Soften or moisten food by dipping them in liquid or take a sip of a beverage with food
- ❖ Choose soft foods such as bananas, canned pears or peaches, applesauce, mashed potatoes, cottage cheese, scrambled eggs, custards, egg salad, creamy soups and cereals, cottage cheese, yogurt, lactose free ice cream, sherbet, popsicles
- ❖ Try blending hard-to-chew meats with gravies or creamed soup or use ground meat

Don't:

- ❖ Use spices
- ❖ Drink citrus or acidic beverages which can be irritating and may burn or sting
- ❖ Eat hard, dry or fried foods, raw vegetables and foods with seeds and tough skins

What to Do When You Have Taste Changes

Taste changes are common after chemotherapy and transplant. Common taste alterations are foods tasting too sweet, too bitter, or a metallic taste. It takes about 3-4 months for taste buds to regenerate and food begins to taste “normal” again.

Tips for dealing with taste changes:

- Flavor foods with herbs, spices, or food seasonings
- Experiment with different food textures such as crunchy, creamy, crispy foods
- Experiment with different foods that you don’t typically eat
- Eating acidic foods such as lemon may stimulate taste buds (as long as it does not irritate your mouth)
- High protein foods and nutrition supplements are particularly important when taste changes prevents you from eating properly
- A bitter or metallic taste may be relieved with peppermints and using plastic eating utensils
- Continue to retry items that may not have worked before

How to Add Calories and Protein to the Diet		
Calories	**Protein**	**SUGGESTED FOOD ITEM ADDITIONS**
√	√	Cheese/Cream cheese: Add to sandwiches, hamburgers, casseroles, vegetables, well-cooked eggs, or potatoes Cottage Cheese: Add to fruits, vegetables, casseroles, gelatin, puddings
√	√	
√	√	Eggs: Add chopped, hard-cooked eggs to casseroles, salads, or just eat alone. Add an extra egg to French toast or pancake batter, quiches, custards or egg sandwich spread
√	√	Lactose free Ice Cream: Use with beverages to make shakes/smoothies. Eat with fruit, gelatin desserts, pies, and cookies
√	√	Peanut Butter: Add to sandwiches, muffins, crackers, waffles, milkshakes
√	√	Roasted Nuts/Wheat Germ: Eat alone as a snack; or add chopped/ground nuts to lactose free ice cream, muffins, pancakes, meatloaf, vegetables, sauces, or salads
√	√	Meat/Fish/Tofu: Add to sauces, casseroles, soups; use breaded varieties for more calories; serve with gravy or sauce for a bigger calorie boost
√	√	Supplements: Try Instant Breakfast mixes with lactose free milk or other beverage; Commercial liquid supplements can be found in a variety of flavors – consume alone or added to shakes
√		Fruits and Vegetables: Add fruit to desserts or shakes; use vegetables in soups, casseroles and sauces. Enjoy avocado alone, as topping, or in sandwiches, eggs or burgers
√		Breads and Cereals: Add cereals, waffles, pancakes or French toast to your menu; use rice or noodles in casseroles and soups; enjoy bread or rice puddings as snacks or part of meals
√		Fats: Add butter, margarine, or olive oil to hot cereal, rice, noodles, cooked vegetables; use the same with sour cream on potatoes, in soups, casseroles, meat/fish dishes and sauces; add mayonnaise to sandwiches, dressings; use whipped cream on desserts, pancakes/waffles or in shakes
√		Sugars: Add table sugar, jams, and syrups to hot cereals, shakes, desserts, or sauces for a quick calorie boost
√	√	Beverages: Choose pasteurized juices/nectar, soda, sports drinks, lactose free milk, etc. instead of water

What Foods to Avoid When You Have Diarrhea

Diarrhea is a common problem after chemotherapy and transplant. It is important to avoid foods that can make diarrhea worse. In general, try to do the following:

- Eat small, frequent meals
- Eat foods that bulk stools such as applesauce, oatmeal, bananas, cooked carrots, rice, noodles, well cooked eggs, canned or cooked fruit (no skins or seeds)
- Avoid high fiber foods such as uncooked vegetables and fruit, whole grains
- Avoid foods and fluids that have lactose (milk, yogurt)
- Avoid greasy, spicy, highly seasoned and very sweet foods
- Make sure to drink plenty of fluids
- Avoid caffeinated beverages or large amounts of water.
    - Instead try Gatorade®, broths, popsicles, certain nutrition supplements

Below is a list of high fiber foods:
Bran cereal
Cooked legumes: kidney beans, lentils, black beans, chickpeas, baked beans, soybeans
Fruits: fresh pears, fresh apples, dried dates
Vegetables: baked potato, baked sweet potato, frozen green peas, frozen mixed vegetables, cooked frozen spinach
Grains: quinoa, bulgar

Section Nine—Taking Care of Yourself

When Should You Call the BMT team?

- Fever or chills
  - temperature > 101^0F or 38.3^0C
    or
  - two readings one hour apart of 100.4^0F or 38.0^0C

- Cold / Flu Symptoms
  - cough
  - sore throat
  - green or yellow sputum
  - runny nose

- Shortness of breath
- Feeling of tightness in the chest
- Any area of your skin becomes warm to touch, red, painful or swollen

- Chills after flushing the catheter
  - drainage, inflammation or tenderness around the catheter site

- Pain or burning when urinating
- Unusual headaches
- Double or blurred vision
- Changes in your thinking (confusion, slowed thinking, excessive sleepiness)

- Bleeding, especially:
  - from your mouth, nose, gums, under the skin (bruising)
  - blood in your urine, stool or sputum
  - prolonged or heavy vaginal bleeding

- Difficulty emptying your bladder
- Constipation
- Any skin changes or rashes
- Nausea or vomiting that persists and prevents you from taking in fluids or food

- Diarrhea
  - More than 4-5 loose bowel movements a day

Guidelines for Taking Care of Yourself

During the Preparative Regimen until Day + 100

1. Drink 3 quarts of fluid daily

2. Daily catheter care

3. Practice Infection Prevention Measures
   *additional information is found in sections seven, eight, nine and ten
   a. avoid people who are ill
   b. daily hygiene
   c. wear the HEPA mask
   d. take the prescribed antibiotics
   e. follow low microbial diet
   f. do not care for pets
   g. do not vacuum or dust
   h. no gardening

4. Call if you get a fever or for other symptoms listed on pages 55 and 70.
   a. call the BMT team

5. Do not drive

6. Do not take medications that increase the risk the bleeding by thinning the blood
   a. examples include aspirin, Motrin®, Advil®, ibuprofen, Relieve®, Aleve®
   b. if you have aches or pains, you can take Tylenol®, after consulting your BMT team

7. Get plenty of rest

If you are not in the hospital, you will need a caregiver 24 hours a day, seven days a week.

Precautions when you have a Low Platelet Count and are at Risk for Bleeding

Precautions To Minimize the Risk of Bleeding			
	Be safety conscious • Remember some medications will make you drowsy		Be gentle with mouth care • No flossing, no toothpicks, no water pics, no electric toothbrushes • Use a soft toothbrush
	Change positions slowly to decrease the risk of falling		Always wear shoes or slippers to protect your feet
	Avoid using a straight/safety razor • Use an electric razor		Wipe you nose gently, rather than forcefully blowing your nose
	Do not take rectal temperatures, or use rectal medications (suppositories) or receive an enema		Avoid straining with bowel movements • Let your BMT team know if you are constipated
	Be gentle with nail care • Use nail clippers and not scissors		Use caution and care with sexual activity • Vigorous activity may cause bleeding
	Do not participate in contact sports		Do not have any dental, podiatry or surgical procedure without checking with your BMT team
	Avoid medications that can interferes with platelet function • Examples include: aspirin, Motrin®, Advil®, Ibuprofen, Relieve®, Aleve®		Do not drink alcohol until your platelet count is normal (approximately 3 months post-transplant • Alcohol also interferes with platelet function • Check with your BMT team to make sure there are not other reasons to avoid alcohol
Follow these precautions until your platelet count has returned to normal			
To Stop Bleeding • If you cut yourself, put a clean cloth over the injury and apply firm pressure for 5-10 minutes. • If you have a nosebleed, put pressure on the bony part of your nose for 5 – 10 minutes			

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Day_____ WBC/ANC_______ HGB ___________ PLT ___________	Day_____ WBC/ANC_______ HGB ___________ PLT ___________	Day_____ WBC/ANC _______ HGB ___________ PLT ___________	Day_____ WBC/ANC _______ HGB ___________ PLT ___________	Day_____ WBC/ANC_______ HGB ___________ PLT ___________	Day_____ WBC/ANC _______ HGB ___________ PLT ___________	Day_____ WBC/ANC_______ HGB ___________ PLT ___________
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Calendar to track your blood counts

Supportive Care

Physical Therapy

During your hospitalization, one of the physical therapists will evaluate your strength and capabilities and design an exercise program for you. Our goal is to keep you as fit and active as possible during your transplant.

The key to a successful exercise program is consistency and moderation. A low platelet count will limit some of the physical activities that are considered safe, such as resistance exercises.

The Cancer Supportive Care program also offers exercise classes for you and your caregiver. Phone ☎ (650) 498-5566 for more information and schedules.

Massage Therapy

To arrange for a massage, call Patient and Community Relations at ☎ (650) 723-7167. The Cancer Supportive Care program also offers massage therapy on the first floor of the Cancer Center. For a schedule go to http://cancer.stanford.edu/outreach/support.html

Art Therapy

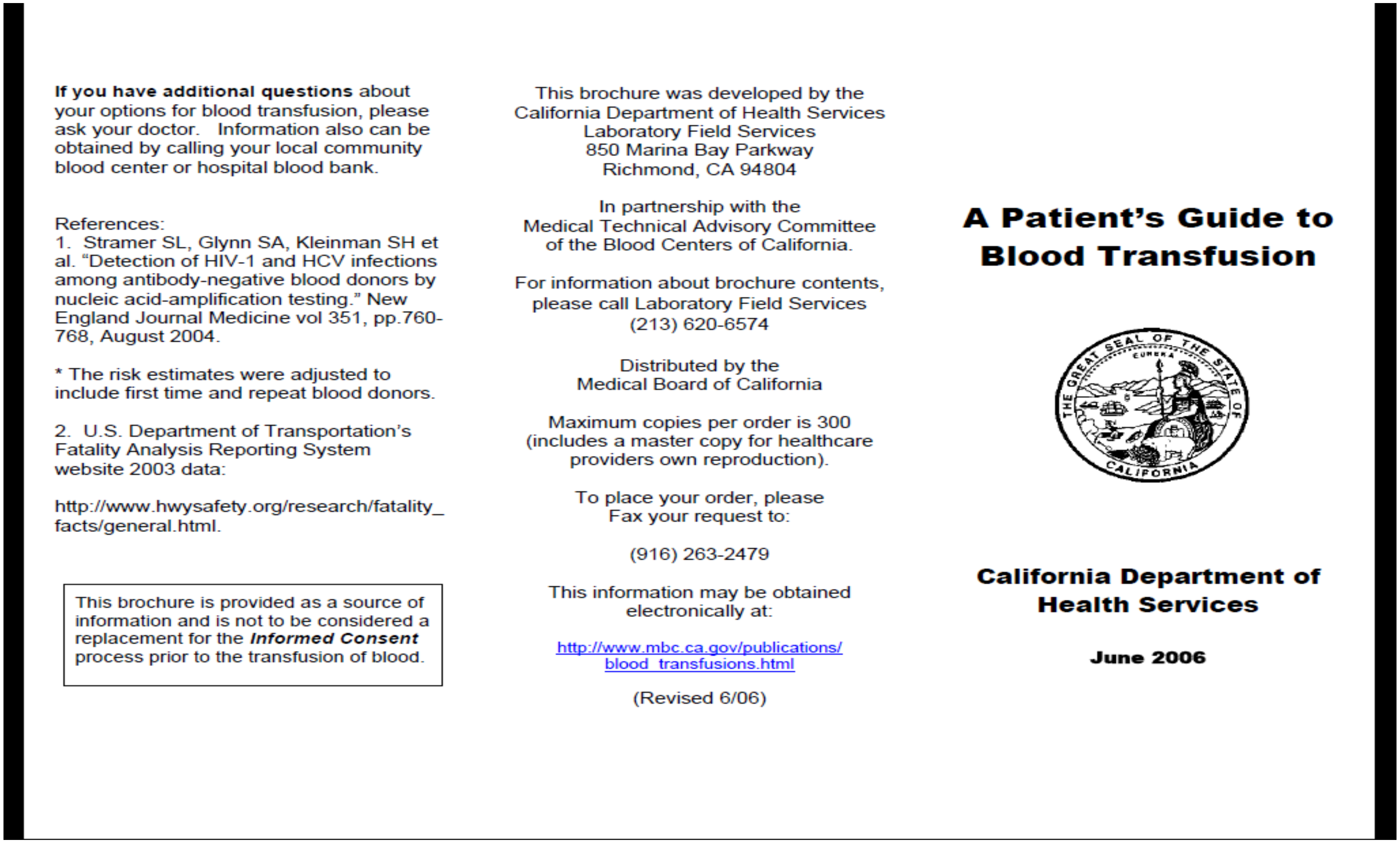
The art therapy program is offered through Guest Services. The art therapist is available Monday thru Friday. If you would like to work with the art therapist speak with your BMT nurse.

Palliative Medicine at Stanford Health Care

In addition to working with the BMT team, the services offered by our Palliative Care team may be helpful during your treatment. The Palliative Care team works to complement your care by helping with symptom management, advance care planning, and education about illness and treatment options. The Palliative Care team is also available to provide emotional and social support for you and your family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work with our BMT team to provide an extra layer of support. In particular, our Palliative Care team may be helpful in alleviating treatment related side effects such as pain, nausea, shortness of breath, anxiety, and stress. They can also help identify and direct patients toward appropriate psychological, financial, legal, and community support. Palliative care is appropriate at any stage in a serious illness, and can be provided together with curative treatment.

Please let any member of your BMT team know if you are interested in speaking with our Palliative Medicine team.



If you have additional questions about your options for blood transfusion, please ask your doctor. Information also can be obtained by calling your local community blood center or hospital blood bank.

References:
1. Stramer SL, Glynn SA, Kleinman SH et al. "Detection of HIV-1 and HCV infections among antibody-negative blood donors by nucleic acid-amplification testing." New England Journal Medicine vol 351, pp.760-768, August 2004.

* The risk estimates were adjusted to include first time and repeat blood donors.

2. U.S. Department of Transportation's Fatality Analysis Reporting System website 2003 data:

http://www.hwysafety.org/research/fatality_facts/general.html.

This brochure is provided as a source of information and is not to be considered a replacement for the ***Informed Consent*** process prior to the transfusion of blood.

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For information about brochure contents, please call Laboratory Field Services
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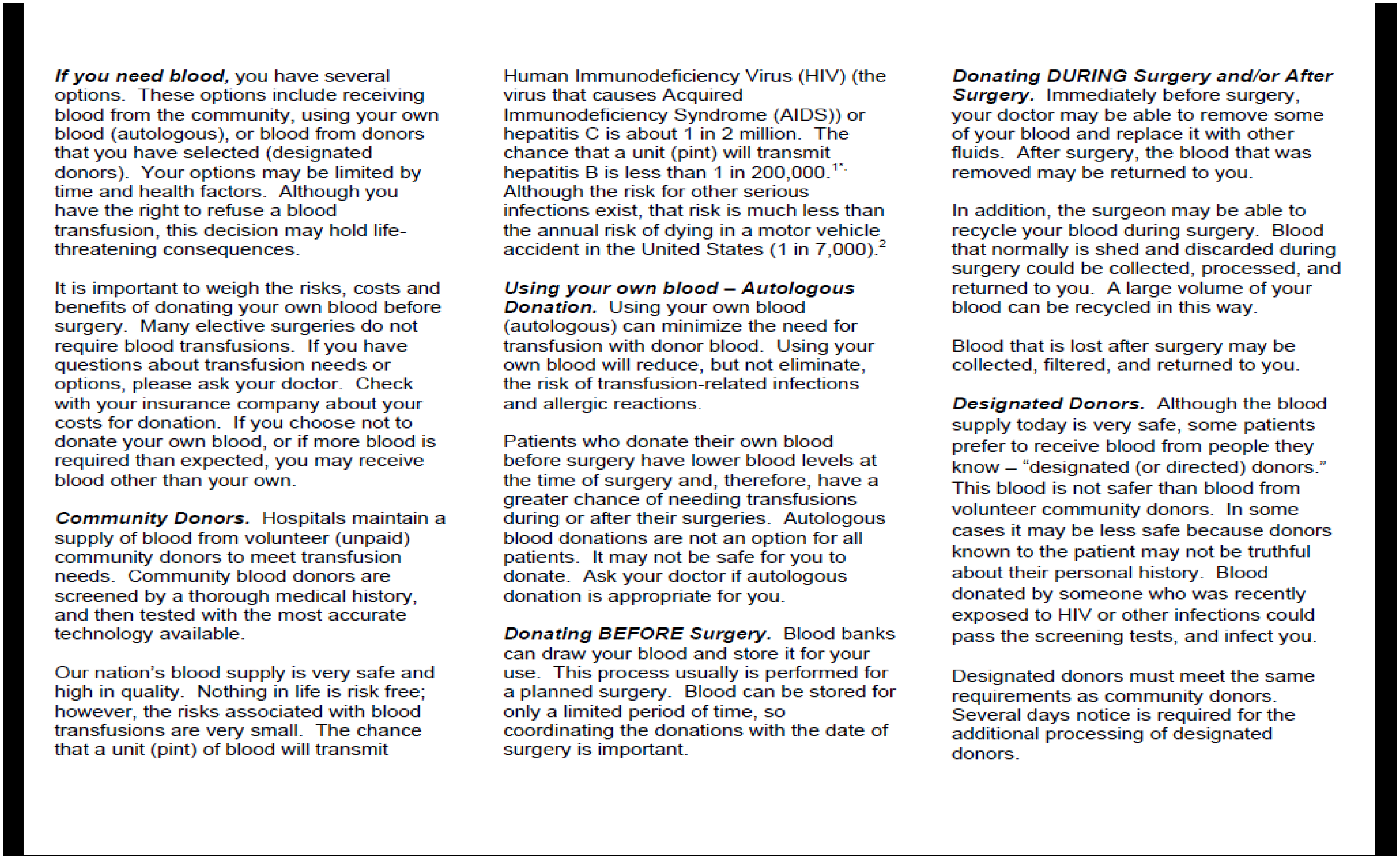
http://www.mbc.ca.gov/publications/blood_transfusions.html

(Revised 6/06)

A Patient's Guide to Blood Transfusion

California Department of Health Services

June 2006



If you need blood, you have several options. These options include receiving blood from the community, using your own blood (autologous), or blood from donors that you have selected (designated donors). Your options may be limited by time and health factors. Although you have the right to refuse a blood transfusion, this decision may hold life-threatening consequences.

It is important to weigh the risks, costs and benefits of donating your own blood before surgery. Many elective surgeries do not require blood transfusions. If you have questions about transfusion needs or options, please ask your doctor. Check with your insurance company about your costs for donation. If you choose not to donate your own blood, or if more blood is required than expected, you may receive blood other than your own.

Community Donors. Hospitals maintain a supply of blood from volunteer (unpaid) community donors to meet transfusion needs. Community blood donors are screened by a thorough medical history, and then tested with the most accurate technology available.

Our nation's blood supply is very safe and high in quality. Nothing in life is risk free; however, the risks associated with blood transfusions are very small. The chance that a unit (pint) of blood will transmit Human Immunodeficiency Virus (HIV) (the virus that causes Acquired Immunodeficiency Syndrome (AIDS)) or hepatitis C is about 1 in 2 million. The chance that a unit (pint) will transmit hepatitis B is less than 1 in 200,000.[1*] Although the risk for other serious infections exist, that risk is much less than the annual risk of dying in a motor vehicle accident in the United States (1 in 7,000).[2]

Using your own blood – Autologous Donation. Using your own blood (autologous) can minimize the need for transfusion with donor blood. Using your own blood will reduce, but not eliminate, the risk of transfusion-related infections and allergic reactions.

Patients who donate their own blood before surgery have lower blood levels at the time of surgery and, therefore, have a greater chance of needing transfusions during or after their surgeries. Autologous blood donations are not an option for all patients. It may not be safe for you to donate. Ask your doctor if autologous donation is appropriate for you.

Donating BEFORE Surgery. Blood banks can draw your blood and store it for your use. This process usually is performed for a planned surgery. Blood can be stored for only a limited period of time, so coordinating the donations with the date of surgery is important.

Donating DURING Surgery and/or After Surgery. Immediately before surgery, your doctor may be able to remove some of your blood and replace it with other fluids. After surgery, the blood that was removed may be returned to you.

In addition, the surgeon may be able to recycle your blood during surgery. Blood that normally is shed and discarded during surgery could be collected, processed, and returned to you. A large volume of your blood can be recycled in this way.

Blood that is lost after surgery may be collected, filtered, and returned to you.

Designated Donors. Although the blood supply today is very safe, some patients prefer to receive blood from people they know – "designated (or directed) donors." This blood is not safer than blood from volunteer community donors. In some cases it may be less safe because donors known to the patient may not be truthful about their personal history. Blood donated by someone who was recently exposed to HIV or other infections could pass the screening tests, and infect you.

Designated donors must meet the same requirements as community donors. Several days notice is required for the additional processing of designated donors.

Section Ten—Central Venous Catheter

Central Venous Catheters

A central venous catheter is a soft flexible tube that is used to give medicine, fluids, blood transfusions, chemotherapy or nutrition through a vein. There are two types of central catheters, a peripherally inserted central catheter and a tunneled central catheter. A risk of having a central venous catheter is infection, which happens when germs get into the bloodstream through the catheter. If you develop a catheter related infection, you may become ill with fevers and chills or the skin around the catheter may become red and sore. Catheter related infections can be successfully treated with antibiotics.

Caring for central venous catheters:

- **Peripheral Inserted Central Catheter (PICC):**
  - Inserted in the upper arm by a specialty trained nurse
  - Used for long term therapy.
  - PICC lines are cared for by your nurse to prevent accidental removal or dislodgement.
- **Tunneled Central Line**:
  - Inserted in the upper chest partly under the skin.
  - Used for long term therapy.
  - Tunneled lines are cared for by you or your caregiver.
  - It is essential to use proper handwashing prior to any catheter care.
  - Refer to instructions for catheter care provided at the catheter care class that you will attend before your transplant

Diagnosis and Treatment of Central Venous Catheter Infections

- Blood tests or a culture of your catheter will be done to find out if your symptoms are caused by infection.
- If you have a catheter infection, your catheter may be removed and you will be given antibiotics

Call <u>immediately</u> if you experience any of the following symptoms:

- Blood soaked bandage
- Your heart is beating faster than normal
- You feel faint or dizzy
- Your arm feels warm, tender, painful or looks red and swollen.
- Fever
- Chills
- Pain, redness, swelling or pus where the catheter was inserted

Section Eleven—Home Pharmacy Information

Ambulatory Infusion Pump

Through the Lucile Packard Children's Hospital Home Pharmacy Service, a BMT home infusion nurse and a pharmacist work to provide you with intravenous medications and fluids while you are receiving care in the Cancer Center.

An ambulatory infusion pump can be used to deliver:

- fluids
- nutrition
- antimicrobial agents including antibiotics, antifungals and antivirals

The BMT home infusion nurse will teach you **AND** your caregiver how to manage the ambulatory infusion pump at home. Your caregiver(s) must be present for the teaching. The nurses in the ITA will change the medication or fluid bags during your daily ITA visit.

Medication Reactions

If you are experiencing a reaction to a medication call the ITA or E1 immediately. If this is a life-threatening emergency, call 911 for assistance.

How to contact the Home Pharmacy Service?

During Business Hours
Monday – Friday
9:00 am to 5:30 pm
call ☎ (650) 497-8316 and ask for the BMT pharmacist or
call toll free ☎ (877) 428-7490

After Hours Emergency Calls

- call the page operator at (650) 723-6661 and ask for the ADULT Home Pharmacists on call
- available 24 hours a day, seven days a week

Medications and Supplies Obtained from Home Pharmacy

Ordering Medications and Supplies

Refills for medications and supplies are coordinated through your nurse in the ITA or E1

Delivery of Medications and Supplies

- Medications and supplies are delivered to the ITA twice a day Monday through Friday
- You can also pick up medications and supplies at the Home Pharmacy located in Menlo Park during normal business hours
- At the time of delivery, you will receive a deliver ticket. Check the ticket for accuracy of medications and supplies Storage of Medications and Supplies
- keep out of children’s reach
- read the prescription label to see if the medication should be kept at room temperature, frozen or refrigerated
- place new medications and supplies behind the current medication and supplies
  - this will ensure that items don’t reach their expiration date
  - never use outdated items
- keep extra batteries on hand in the event of a power outage
- keep an eye on your inventory and plan ahead so you don’t run out

Returns

- supplies and medications cannot be returned
- damaged items can be credited

Equipment

- please take care of the pumps, poles and other equipment.
- the equipment must be returned when you finish therapy or are unexpectedly admitted to the hospital.
- used needles, syringes and chemotherapy waste must be discarded into a special container called a sharps container, which we will provide for you
  - when the sharps container is ¾ full, bring it to the ITA or E1 for a new container
  - DO NOT dispose of filled sharps containers in the regular trash
  - The following website provides additional places for disposal of sharp containers, http://www.ciwmb.ca.gov/HHW/HealthCare/Collection

Pump Instructions

Display on Pump	Resolution
INFUSION COMPLETE	Press PAUSE, add another IV bag, select REPEAT Rx and confirm fields, or turn the pump off.
ALARM AIR-IN-LINE	Press Pause, select Resume, and press Run to move air past sensor. Repeat if needed.
ALARM DOWN OCCLUSION	Check administration set from the pump to the patient’s access site for cause of occlusion. When occlusion is resolved, the alarm will stop and the pump will resume.
ALARM UP OCCLUSION	Check administration set from IV bag to pump for cause of occlusion. When ready to begin infusion, press PAUSE, select RESUME, and press RUN.
ALARM HIGH UP PRESSURE	Check for excessive pressure on IV bag. When ready to begin infusion, press PAUSE, select RESUME, and press RUN.
ALARM SET NOT INSTALLED	Install Curlin administration set.
ALARM UNATTENDED PUMP	Press RUN and resume the therapy or continue with operating procedure.
ALARM REPLACE SET	Disconnect from access device, replace, prime and install new set, select RESUME, and press RUN when ready to begin.
ALARM DOOR OPEN	Check placement of administration set and close pump door properly.
ALARM EMPTY BATTERY	Press the pause key and turn pump off. Install 2 new “C” size alkaline batteries.
ERROR CODE	If an error code occurs, turn pump off then back on. If it reoccurs, notify dispensing agency.
LOW BATTERY ALERT	This will beep periodically when the battery is getting low. The message will tell you when the power is low in the “C” batteries and / or the battery pack. Change batteries or plug AC adapter into power source.

TO STOP PUMP
1. Press PAUSE
2. Press ON/OFF

TO START PUMP
1. Press ON/OFF
2. Program-Press YES
3. Resume-Press YES
4. Run-Press RUN

TO CLEAR ALARMS
1. Press PAUSE
2. Resume- Press YES
3. Run- Press RUN

For questions call toll-free ☎ 877-428-7490 Mon.-Fri. 9:00 am – 5:30 pm or ☎ 650-497-8316 and ask for the BMT Pharmacist.

After hours, weekends and holidays, , call the page operator at ☎ 650-723-6661 and ask for the ADULT on-call Home Pharmacist

Section Twelve—Recovery

Day 90 Discharge Class

Approximately 90 days after your transplant, we will schedule you to attend a discharge class. The class will provide information that will help you transition back to home and guide your recovery. Topics included in the day + 90 discharge class include:

Survivorship

Recovery doesn't end at 6 months, 1 year, or even 20 years. Survivorship starts at diagnosis and lasts a lifetime. The Stanford Cancer Survivorship Program was created to provide comprehensive support, through clinics, education, and research.

http://cancer.stanford.edu/patient_care/survivorship/

Chronic Graft-Versus-Host-Disease

Chronic graft versus host disease typically occurs after day +100 and the period of risk is approximately two years. Like acute graft versus host disease, chronic graft versus host disease is caused by donor immune cells attacking your (host) tissues. Chronic graft versus host disease can occur in any body tissue but commonly occurs in the skin, mouth, liver, stomach, intestines, and eyes.

There are strategies to help prevent chronic graft versus host disease:

- **Sun protection** – It will be important to protect your skin from the sun for the rest of your life, but especially for the first 2 years after transplant. This means using sunscreen or covering your skin with clothing anytime you are in the sun.

Signs and symptoms of chronic graft versus host disease are similar to those of autoimmune disorders. Report any of the following symptoms to your BMT team.

Common signs and symptoms include:

- **Skin**: rash or discoloration
- **Mouth**: dry mouth, redness, soreness, oral sensitivities
- **Eyes**: dry, itchy eyes, vision changes
- **Lungs**: cough, shortness of breath, **GI tract**: nausea, vomiting, or diarrhea
- **Female genital tract** (vagina, vulva): dryness, burning or itching, pain with intercourse

The diagnosis of chronic graft versus host disease may require testing, including biopsy of the effected tissue. Treatment may include topical steroids, like a cream for the skin or eye drops for eye symptoms. More severe symptoms may require oral, immunosuppressant medications, such as prednisone.

Infection

Infection prevention is remains important after you go home and continue on immunosuppressive medications. Even though your white blood cell count has recovered, you remain at risk for infections due to the immunosuppressive medications you are taking to prevent or treat graft versus host disease. Remember that the precautions regarding dust, gardening, and pets should be followed until you are off all immunosuppressive medications. The development and treatment of chronic graft versus host disease also increases your risk for infection.

Strategies to prevent infection include:

- The same precautions taken during the initial stages of transplant, including hand-washing, staying away from sick people and safe food preparation.
- Annual influenza vaccination is recommended for you, as well as close family and friends.
- Prophylactic antibiotics – Your physician may recommend that you take antibiotics regularly to prevent infection, especially if you have developed chronic graft versus host disease.
- Prophylactic antivirals – You will be taking an antiviral medication for approximately one year to prevent shingles or zoster infection.

If you develop a fever, cough, or other signs of infection, contact your physician. If you are still on immunosuppressive medications, you should contact your BMT team.

Physical and Emotional Recovery

You and your family have been through a lot. The diagnosis and treatment of cancer is difficult emotionally, physically, spiritually and often financially.

Fatigue is one of the most persistent physical symptoms following transplant. The best thing you can do for yourself is to start a modest program of activity and be consistent with exercising daily. The best exercise is walking. Other recommended exercises include stretching, range of motion exercises or riding a stationary bike. Avoid jogging, running or contact sports for at least six months. Slowly build back up to your usual level of activity. Listen to your body along the way so that you don't over-do it. You may want to talk with the physical therapist for ideas before you move back home. Expect the fatigue to last about six months, with full recovery of energy and stamina taking up to a year or more.

Part of recovery is learning to trust your body again. It is hard to know which aches, pains and symptoms are normal and which should be reported to the BMT team. If in doubt, call the BMT team.

Emotions following transplant may include anxiety, frustration, depression, anger, worry and sadness. These emotions are normal. Ongoing anxiety about a relapse is a universal concern among individuals who have had cancer. The anxiety seems to be worse just before and during follow up visits. There is no magic formula for dealing with this wide range of emotions. Try to recognize these emotions and talk to your family, friends, or BMT team.

Recovery from BMT is a gradual process that takes time.

Returning to Work

Generally, you can return to work approximately 6-12 months post-transplant. Discuss your plans to return to work with your BMT team prior to returning to work. For some types of work such as agriculture, ranching or environments where you are exposed to chemicals or certain microorganisms, we may recommend a longer period of time before returning or we may recommend you find an alternative type of employment. Your social worker can discuss job re-training programs that may be available.

Taking Care of Yourself after Transplant

Your Skin

Common skin changes after transplant include dryness, flaking and skin discoloration or darkening. Use a moisturizer daily to help repair the dry flaky skin. If you notice a red, blistering itchy rash, report this to your oncologist, hematologist or BMT team. This rash may represent an infection called zoster or shingles.

Your skin will be more sensitive to the sun after treatment and you will more easily develop sunburn. Avoid exposing your skin to sunlight for two years after transplant. When you are out in the sun wear protective clothing and always wear a sunscreen with an SPF of at least 30. Re-apply the sunscreen as recommended by the manufacturer. Protecting your skin from sunlight is a good life-long habit.

Your Mouth

Hard sour candy may relieve a dry mouth. You can also try Gatorade® gum or other sugarless chewing gums. Adding gravy or sauces to food can also help. Chemotherapy can often alter taste buds leaving food tasting bland or metallic. It can take up to 4 months for taste buds to fully regenerate. Eventually, your taste buds will recover and food will taste the way you remember it tasting.

Follow up with your dentist about six months post-transplant or sooner if you are having problems. If you are taking medications that weaken your immune system, you should not have any invasive dental work done without taking preventative antibiotics.

A Low Platelet Count

Until your platelet count has returned to normal levels, you should continue to avoid medications that increase the risk of bleeding by thinning the blood. Examples of these medications include aspirin, Motrin®, Advil®, ibuprofen, Relieve®, and Aleve®. Additionally, you should avoid drinking alcohol until the platelet count is normal as alcohol also thins the blood. Check with your doctor about when it is safe to drink alcohol.

Driving

You should not drive until you are at least 100 days post-transplant. Check with your BMT doctor before you start driving again. If you are still taking medications that could cause drowsiness or impair your judgment such as narcotics for pain or medications for nausea then you should not drive until you stop these medications.

Immunizations

We recommend an annual influenza (flu) vaccine.

Consult your primary care doctor regarding routine vaccinations as part of regular health maintenance such as:
Hepatitis B series
Polio, inactivated
Tetanus booster
Pneumococcal vaccine

You should not receive any vaccine that contains live virus.
There may be specific vaccinations needed for some travel. Consult your local medical doctor or a travel clinic before your trip.

If Your Child Needs Vaccinations

Avoid or delay vaccinations with live viruses, which include

- Measles-Mumps-Rubella (MMR)
- Oral polio

If your child receives these vaccinations

- Avoid contact with the child for 7 days after he/she has received oral polio
- Avoid contact with the child for 72-96 hours after he/she has received MMR

Call your BMT team if you have questions or concerns about other vaccines your child may be receiving.

Exposure to Chicken Pox

If you are exposed to chicken pox and you have not had chicken pox in the past, call your local doctor immediately for advice. You may need to receive a medication to protect you. Prior to your transplant, you were tested for past exposure to chicken pox. You can call your BMT team to learn the results of this testing.

Sexual Activity for Women

Both men and women report low interest in sexual activity. In most cases interest or sexual desire returns about six months after transplant.

- you may resume sexual activity once your platelet count is above fifty thousand
- practice cleanliness and safe sex with a single healthy partner
- we recommend your partner wear a condom for six months
- we advise that you avoid oral sex and anal intercourse for six months
- although infertility is likely, we recommend you use birth control to avoid any unplanned, unexpected pregnancy
- if you are or were taking mycophenolate mofetil, you need to use birth control for six months after stopping mycophenolate mofetil as this drug is known to cause birth defects.

If you received a myeloablative transplant (that is received high dose chemotherapy with or without radiation) your ovaries will stop producing hormones such as estrogen. Reduced intensity conditioning regimens and non-myeloablative regimens may also cause your ovaries to stop producing hormones. Symptoms of menopause (loss of estrogen) include

- hot flashes
- vaginal dryness
- flushing
- difficulty sleeping
- moodiness
- weakening of the bones—called osteoporosis

Visit your gynecologist about 3 months after transplant to discuss hormone therapy if you are under the age of 50 or other alternatives to help with the symptoms of menopause. Vaginal dryness may occur because of chemotherapy and menopause and result in discomfort or pain with vaginal intercourse. To minimize discomfort use a water-soluble lubricating jelly such as Replens®, K.Y. jelly®, Lubrin® or Astroglide®. Most of these products can be found at a drug store. Do not use Vaseline® or other non-water soluble products as they may cause infections.

Sexual expression is a function of both the mind and body and both take time to heal after transplant. Open communication with your partner is essential to resuming your sex life. If you have specific problems or concerns talk to your BMT doctor or nurse.

The American Cancer Society publishes an excellent book titled "Sexuality for The Women with Cancer and Her Partner", which can be obtained free of charge.

Sexual Activity for Men

Both men and women report low interest in sexual activity. In most cases interest or sexual desire returns about six months after transplant.

- you may resume sexual activity once your platelet count is above fifty thousand
- practice cleanliness and safe sex with a single healthy partner
- we recommend you wear a condom for six months
- we advise that you avoid oral sex and anal intercourse for six months
- although infertility is likely, we recommend you use birth control to avoid any unplanned, unexpected pregnancy.
- if you are or were taking mycophenolate mofetil, you need to use birth control for six months after stopping mycophenolate mofetil as this drug is known to cause birth defects.

You may notice with the first few ejaculates, that the semen is a brown or burnt orange color. The color change is due to chemotherapy. You may also notice aching or pain in the testicles after ejaculation. This discomfort should pass after the first few times you engage in sexual activity. Please report any persistent brown discharge, pain, or difficulty with erections to your BMT team.

If by six months after transplant, you find your interest in sexual activity is still low or you are having problems with erections, consult your BMT team or local medical doctor (primary care provider). It is possible your testosterone is low. Your testosterone levels can be checked by blood testing and testosterone can be replaced.

Sexual expression is a function of both the mind and body and both take time to heal after transplant. Open communication with your partner is essential to resuming your sex life. If you have specific problems or concerns talk to your BMT team.

The American Cancer Society publishes an excellent book titled "Sexuality for The Man with Cancer and His Partner", which can be obtained free of charge.

Who Takes Care of You After Transplant?

Generally, you will leave the Stanford area and return to your home about 100 days after transplant.

Once you return home, your BMT attending physician will continue to see you approximately:

- once or twice a month for the first six months
- then monthly till one year post-transplant and
- then yearly

About 100 days post-transplant, your oncologist or hematologist will provide some of your cancer related care. Call and schedule an appointment with your oncologist or hematologist once you get home. The BMT team will send your oncologist or hematologist a letter describing your transplant course and a summary of recommended follow up. If you need copies of your medical records call ☎ (650) 498-6200.

Your local medical doctor (primary care provider) will provide all your routine medical care (not cancer related). For example, if you have diabetes, or high blood pressure or you need the flu vaccine, you should see your local medical doctor.

A useful website that provides guidelines for you and your doctor to follow for long-term medical care is http://www.cibmtr.org/ReferenceCenter/Patient/Guidelines/pages/index.aspx

Routine Health Care

- Optometrist
  - schedule an appointment 6 months post-transplant and then yearly
- Gynecologist
  - schedule an appointment 3 months post-transplant and then yearly
  - you should discuss the risks and benefits of hormone therapy if you are under 50 years of age
- Dentist
  - schedule an appointment 6 months post-transplant and then yearly
  - prior to any dental work you should take antibiotics if still taking immune suppressing medications.

In Closing….

We hope the information in this guidebook has been useful to you. If you have suggestions on how we can improve this guidebook, please contact

D. Kathryn (Kate) Tierney, RN, PhD
Email: dtierney@stanfordhealthcare.org
Phone: (650) 725-7063
Address: Stanford Hospital and Clinics, 300 Pasteur Drive, H0101, Stanford, CA 94305

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Transplant Dictionary

Terms	**Definition and Function**
allogeneic transplant	The use of donor stem cells to recover blood counts after receiving the preparative regimen. Donor stem cells are obtained from a genetically matched individual or frozen umbilical cord blood
anemia	Anemia means the number of red blood cells is low. Symptoms of anemia include feeling tired, weak and short of breath.
apheresis	The collection of stem cells from the blood using a machine that can separate the blood into various components.
autologous transplant	The infusion of one's own stem cells to allow the bone marrow to recover after receiving the preparative regimen.
B lymphocyte	A cell of the immune system that helps protect you from infection.
bone marrow	A liquid, similar in appearance to blood, found in the sponge like network within the large bones.
bone marrow biopsy	A procedure used to obtain a sample of bone marrow for examination.
bone marrow harvest	The collection of bone marrow from the hip bones. A bone marrow harvest is performed in the operating room.
central venous catheter	An intravenous catheter placed in a vein under the collarbone or arm vein. The catheter is used to give fluids, medications and obtain blood samples.
consent form	A document that details your treatment plan and the risks and benefits of transplantation.
differential	A lab test that reveals the percentages of different types of white blood cells present in the blood.
donor	The individual that is the source of stem cells used in transplant. ❖ In autologous transplant, the donor is oneself. ❖ In allogeneic transplant, the donor is a genetically matched individual. Types of donors include siblings (brothers/sisters) and unrelated volunteer donors. There are varying degrees of genetic matching. A donor may be fully or partially matched. ❖ In some cases, the donor may be a partial match, called a haploidentical donor. Mothers/fathers,

	brothers/sisters or children may be a haploidentical donor.
eligibility	A series of tests to see if you are healthy enough to undergo transplant. These tests evaluate organ (heart, lung, kidney, and liver) function, blood counts, bone marrow and the status of your disease.
engraftment	The term used to describe the recovery of the blood cells after the stem cells are transplanted.
graft	A collection of stem cells that is infused after the preparative regimen. The graft may be autologous stem cells (self) or allogeneic stem cells (from a donor).
graft versus host disease	Graft versus host disease is a complication of allogeneic transplant. It is an immune reaction of the donor's cells against the recipient's body tissues.
graft versus malignancy	A reaction of the allogeneic donor's cells against the malignancy or cancer. The graft versus malignancy affect is a desired outcome and part of the cure in allogeneic transplant.
hemoglobin (Hgb)	The part of the red blood cell that contains iron. Iron binds to oxygen and carries it to tissues throughout the body. Normal range for females: 11.7-15.7 g/dL Normal range for males: 13.5-17.7 g/dL
hematocrit (HCT)	The proportion of red blood cells in the body compared to the total blood volume. Normal range for females: 35-47% Normal range for males: 40-52%
human leukocyte antigen (HLA)	The human leukocyte antigen is a group of markers on the surface of cells of the immune system. The human leukocyte antigens are inherited from parents. The human leukocyte antigens are used to find an allogeneic donor from either your family or the unrelated volunteer donor registries.
infection prevention measures	Strategies that minimize the risk of infection. Key principles of infection control measures are: 1) minimize exposure to microorganisms; examples include avoiding people who are ill, reducing bacteria on the skin with daily showers and avoiding construction areas 2) protect the body's natural defenses against microorganisms; an example is avoiding cuts and scrapes which break the integrity of the skin and

	allow microorganisms into the body.
immune system	A system comprised of specialized cells of the body that protect us from microorganisms in the environment that cause infections.
immunosuppressants	Medications given to weaken the immune system to prevent or treat graft versus host disease.
inpatient	A person who receives care in the hospital.
microorganisms	Small organisms that can cause infections. Microorganisms include bacteria, virus, protozoa, parasite or fungus.
mobilization	A process to increase the number of stem cells in the blood. By mobilizing (moving) the stem cells from the bone marrow into the blood, the stem cells can be collected from the blood. Mobilization can be accomplished by using chemotherapy combined with a growth factor, which stimulates the bone marrow to produce more stem cells or a growth factor alone.
monoclonal antibody	A protein that is designed to destroy one type of cell. For example, rituximab is a monoclonal antibody that can destroy certain types of lymphoma cells.
myeloablative	A preparative regimen of high dose chemotherapy with or without radiation that will completely destroy an individual’s ability to make blood cells.
neutropenia	A condition in which a person has a low number of neutrophils. Neutrophils are one type of white blood cell that are important for fighting bacterial infections. Normal range is 40-60% of the total number of white blood cells.
non-myeloablative	Non-myeloablative means that the preparative regimen consists of low or standard doses of radiation, chemotherapy or immune suppressing medications. The purpose of the preparative regimen is to suppress the recipient’s immune system enough to allow the donor’s cells to grow and function.
outpatient	Your medical care is provided while you are living at home or in local housing. You come to the Cancer Center to receive care.
platelets	A blood cell that forms a clot to prevent or stop bleeding after injury. When the platelet count is low there is a risk of bleeding. Normal range: 150,000-400,000/uL
preparative regimen	1. Autologous Transplant

based on type of transplant	• A combination of high dose chemotherapy given prior to transplant. • The purpose of the preparative regimen is to destroy the malignancy (cancer). 2. Myeloablative Allogeneic Transplant • A combination of high dose chemotherapy with or without radiation given prior to transplant. • The purpose of the preparative regimen is to destroy the malignancy and the recipient's immune system. 3. Non-myeloablative Allogeneic Transplant • A combination of radiation, an immune suppressing medication with or without chemotherapy given prior to transplant. • The purpose of the preparative regimen is to suppress (or weaken) the recipient's immune system enough to allow the donor's cells to grow. 4. Reduced Intensity Allogeneic Transplant • A combination of moderate doses of chemotherapy with or without an immune suppressing medication given prior to transplant. • The purpose of the preparative regimen is to control the malignancy and suppress (or weaken) the recipient's immune system enough to allow the donor's cells to grow.
red blood cells (RBC)	A blood cell that carries oxygen throughout the body. Normal range for females: 3.8-5.2 million/uL Normal range for males: 4.4-5.9 million/uL
syngeneic transplant	The donor is an identical twin.
thrombocytopenia	A low platelet count. A low platelet count increases the risk of bleeding.
T lymphocyte	A cell of the immune system that protects your body from infection and foreign tissue. The T lymphocyte is one cell involved in the development of graft versus host disease. The T lymphocyte is also involved in the graft versus malignancy effect of allogeneic transplantation.
transfusions	The infusion of different components of the blood to treat specific problems. An infusion of red blood cells is given to minimize the effects of anemia and an infusion of platelets is given to decrease the risk of bleeding.

umbilical cord blood	Blood cells can be removed from the umbilical cord after the delivery of a baby. These umbilical cord blood cells are then frozen and can be used as a source of stem cells for allogeneic transplantation.
white blood cells (WBC)	White blood cells protect the body from infection. There are many types of white blood cells including neutrophils, eosinophils, basophils, monocytes, macrophages and lymphocytes. Normal range: 4,000 –10,000/uL

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