

Allogeneic Blood and Marrow Transplant (BMT)



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name

phone number

Quick Reference Page

Call the BMT team **IMMEDIATELY** at **650-725-7121** for any of the following:

- Fever or chills
 - Temperature above 101°F or above 38.3°C or
 - Temperature of 100.4°F or 38°C lasting over 1 hour
 - Acetaminophen (Tylenol®) can mask a fever, so use this product only under the direction of the BMT team.
- Cold / flu symptoms
 - Cough
 - Sore throat
 - Green or yellow sputum
 - Runny nose
- Feeling short of breath
- Feeling tightness in the chest
- Any skin area of your skin that becomes warm to touch, red, painful, or swollen
- Chills after flushing the catheter
- Draining, inflammation, or tenderness around the catheter site
- Pain or burning during urination
- Diarrhea – More than 4-5 loose bowel movements a day
- Unusual headaches
- Double or blurred vision
- Changes in your thinking (confusion, slowed thinking, excessive sleepiness)
- Bleeding, especially:
 - From your mouth, nose, gums, or 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 eating or drinking

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Introduction

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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 this guidebook explains many parts of your transplant, it does not cover all aspects of your care. Always talk to your health care team about 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 see the transplant dictionary located at the end of this guidebook.

Your BMT team

It takes a large group of health care professionals to help you and your family through a transplant. You and your family are key members of this team. The BMT team meets regularly to discuss your care.

Members of the BMT team rotate often, so you will not always have the same doctor, nurse, nurse practitioner, or physician assistant while you go through a transplant. While the team changes regularly, we communicate daily about your care to ensure continuity.

The table below lists some of the members of your BMT team.

| Health care professionals | Responsibilities |
|---|--|
| Attending physician (supervising doctor) | <ul style="list-style-type: none"> • Provides your first medical consultation and advice • Selects your treatment plan • Provides medical care during and after your transplant • Provides education and support as you go through your transplant • Teaches and educates doctors in training • Does research to improve transplantation • Talks with your referring doctor while you're under our care |
| Nurse coordinators | <ul style="list-style-type: none"> • Coordinate the tests that determine if you're eligible for a transplant • Provide information about your treatment and how to deal with symptoms • Schedule your appointment to read and sign the consent form(s) • Help plan for your release from the hospital • Provide emotional support for you and your family • Coordinate care with your referring doctor |

Health care professionals**Responsibilities**

Nurse practitioners and physician assistants

- Take your medical history and do physical exams
 - Prescribe medicine
 - Order tests and evaluate the results
 - Evaluate and treat your medical problems
 - Perform certain procedures such as:
 - infusing stem cells
 - removing the central venous catheter
 - biopsies
 - Provide information about your treatment plan and how to deal with symptoms
 - Provide emotional support for you and your family
-

Nurses

- Provide information about your treatment plan and how to manage symptoms
 - Deliver chemotherapy, antibiotics, transfusions, and stem cells
 - Watch your condition to detect changes in your health
 - Provide supportive care to reduce the side effects of treatment
 - Provide emotional support for you and your family
-

Social workers

- Assess your understanding and adjustment to your illness
 - Assess your support system
 - Help you develop a caregiver plan
 - Provide information about your treatment plan and routines
 - Provide emotional support to you and your family
 - Help with housing arrangements
 - Help with work-related issues, disability, and leave programs
 - Help writing an advance health care directive
 - Review your abstinence policy and contract
-

Whom to call if you have a question

Call 911 for any medical emergency

Otherwise:

Call your **nurse coordinator**, your main contact before your transplant, for questions or concerns about your pre-transplant schedule.

Call your **social worker**

- For questions about disability and leave programs
- If you need a letter for your employer
- For caregiver information

Refill a prescription

- Call your pharmacy to request a refill
- Ask your pharmacy to fax the request to 📞 (650) 497-8055

Where to come for your care

BMT Clinic—F

- Located on the first floor of the Stanford Cancer Center (in the Stanford Advanced Medicine Center, 875 Blake Wilbur Drive)
- Clinic hours are Monday thru Friday 8:30 am to 5:00 pm
- Clinic phone number is 📞 (650) 498-6000

Infusion Treatment Area (ITA)

- Located on the second floor of the cancer center
- ITA hours are:
 - Monday to Friday 7:00 am to 9:00 pm
 - Saturday 7:00 am to 8:00 pm
 - Sunday 8:00 am to 8:00 pm
- ITA phone number is 📞 (650) 725-1860

BMT inpatient (hospital) service

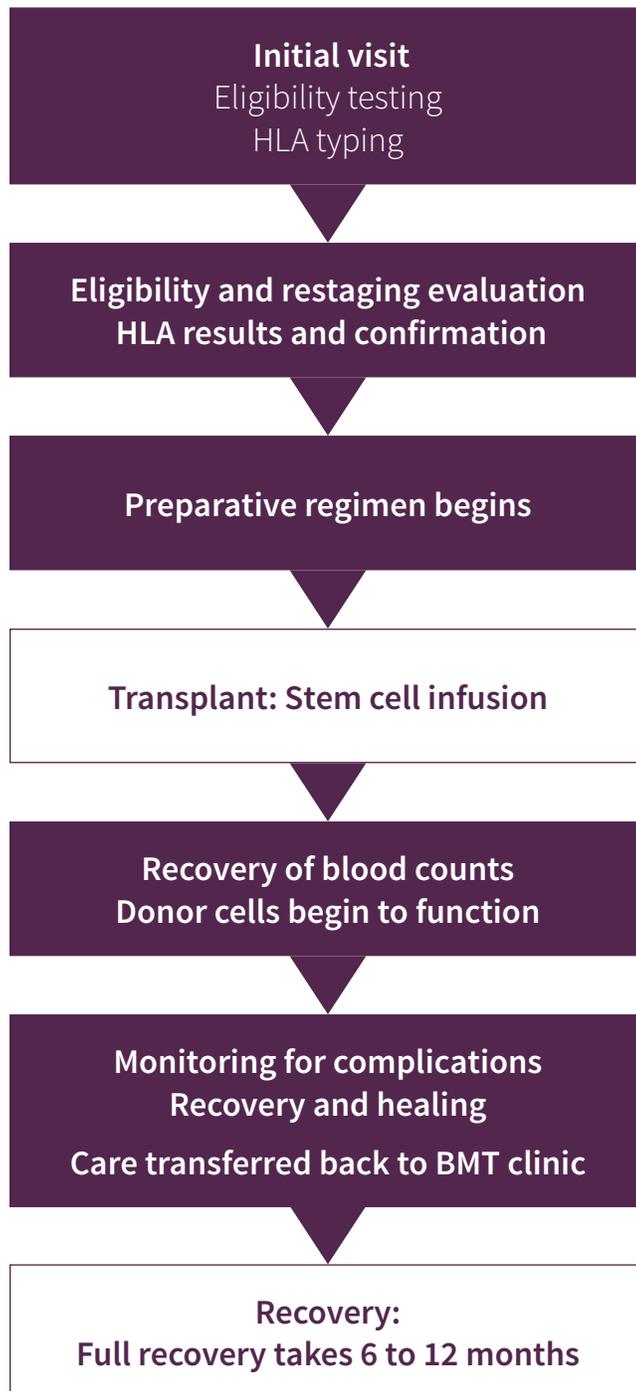
- Located in the main hospital
- Enter the main hospital entrance and visit the guest services counter for directions to the BMT inpatient unit
- Open 24 hours a day, 7 days a week
- BMT inpatient service phone number is 📞 (650) 725-7121

2 Treatment Plan

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General outline of transplantation events



Allogeneic blood and marrow transplantation (BMT)

What follows is a general description of an allogeneic BMT. “Allogeneic” means the transplanted stem cells were donated by another person.

The consent form provides more specific detail.

The steps of an allogeneic transplant are:

- Identifying a donor
- Undergoing the preparative regimen
- Collecting the stem cells from the donor
- Transplant, infusing the stem cells
- Recovery

Types of donors

Several different types of donors are eligible to give their stem cells for an allogeneic transplant. The genetic matching between a donor and recipient varies. A donor may be fully or partially matched to the patient.

The donor may be a sibling (brother or sister). Sometimes donors are 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 destroys (ablates) all the cells in your bone marrow (where stem cells grow) to prepare for the donor's stem cells. It will also suppress the immune system to reduce the risk that your body will reject the donor's stem cell.

The preparative regimen consists of a combination of high-dose chemotherapy with or without radiation. The high-dose preparative regimen is done for 3 reasons:

- 1) To destroy the diseased cells in your bone marrow
- 2) To eliminate your immune system so your body 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 1 to 2 weeks to complete. It may be given while you are in the hospital or when you come to receive care in the cancer center (outpatient).

Non-myeloablative preparative regimen

The preparative regimen consists of radiation and an immune-suppressing medicine, with or without chemotherapy, given before your transplant. The purpose is to weaken your immune system enough to allow the donor's cells to grow and function.

The potential for cure in a non-myeloablative transplant comes from the healthy donor's immune system. It may recognize diseased cells and destroy them.

The preparative regimen takes about 1 to 2 weeks to complete. It may be given while you are in the hospital (inpatient) or when you come to the cancer center (outpatient).

Reduced-intensity preparative regimen

The preparative regimen consists of chemotherapy with or without radiation therapy. It is given before 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:

- Destroy the diseased cells in your bone marrow
- Eliminate your immune system so you will allow the donor's cells to grow
- Create space in the bone marrow for the donor's cells

The preparative regimen takes about 1 week to complete. It may be given in the hospital or in the cancer center.

Collecting the stem cells from the donor

There are 2 ways to collect stem cells from the donor. One takes them from the donor's bone marrow. The other takes them from the donor's blood.

- Most stem cells are in the bone marrow, the spongy tissue inside large bones. Collecting them from the bone marrow is called a bone marrow harvest.

For a bone marrow harvest, the donor goes to the operating room. While the donor is under anesthesia, the marrow is collected from the hip bones.

- Collecting stem cells from the blood is done by a procedure called apheresis.

Only a small number of stem cells circulate in the blood. To increase that, stem cells are moved from the bone marrow into the blood in a process called mobilization.

- To do this, your donor is asked to take a growth factor to increase the number of stem cells. There are different growth factors that can be used.
- The growth factor is generally given for 4 to 5 days and then the collection (apheresis) begins. Apheresis involves removing a small amount of blood through a needle in the donor's arm vein.
- The blood is spun through the apheresis machine, which collects the stem cells. A needle is inserted into the vein in the donor's other arm to return of the rest of the blood.
- The process takes about 4 hours for 1 to 3 consecutive days. Once the stem cells are collected from the donor, they are taken to the laboratory for testing.

Transplant

The donor's stem cells are infused through your central venous catheter after you complete the preparative regimen. The day the stem cells are delivered (called infusion) is your transplant day. We also call that "day zero."

While waiting for the transplanted stem cells to grow and function, the number of your blood cells will be low. Your body will begin to heal and you will feel better once you begin making new blood cells in about 14 to 30 days.

You may receive your transplant in the hospital and stay there until the blood counts recover.

Alternatively, you may receive your transplant in the cancer center. If so, you will remain under the care of the outpatient BMT team for about 100 days.

Recovery

About 90 to 100 days after the transplant, if all is going well, your care is transferred back to your primary BMT doctor (the attending physician). He or she will see you in the BMT clinic.

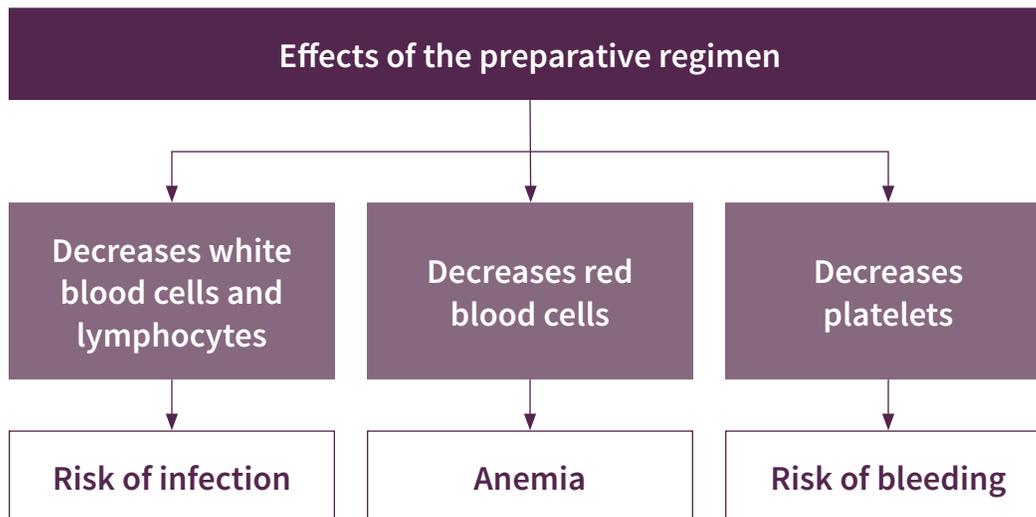
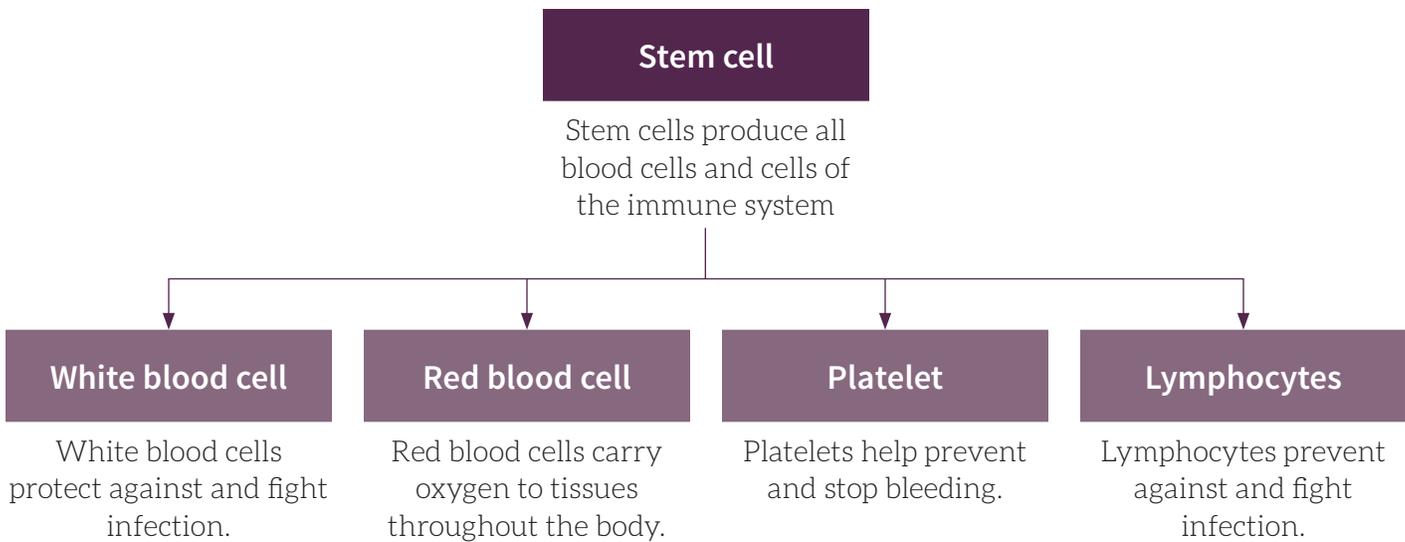
Your central venous catheter is usually removed at this time. If you are staying locally you may return to your own home.

About 6 to 12 months after the transplant, your care will transition back to your local cancer doctor (oncologist or hematologist).

How often you continue to see your BMT attending physician will depend on several factors. One factor is what medicines you are taking. Another factor is if you are having any complications from your transplant, such as graft-versus-host disease.

Recovering from an allogeneic transplant can take up to 6 to 12 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.

Your energy will remain low for a longer period. It is not unusual to need rest periods (naps) for up to 6 months after transplant. The best strategy for regaining your energy is to walk every day.



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Preparing for Your Transplant

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Pre-transplant checklist

✓ To-do list

- Read the guidebook.
- Review the treatment calendar with your nurse coordinator.
- Discuss housing, disability, and caregiver needs with your social worker.
- Discuss doing an advance health care directive with your social worker and doctor.
- Find caregiver(s).
You will need a caregiver 24 hours a day, 7 days a week, while you receive care as an outpatient.
- Meet with a clinical nurse specialist or research nurse to review and sign your consent forms.
- Have a dental exam.
All cavities should be filled. Any teeth affected by gum disease should be removed. The dental work should be done at least 14 days before your transplant.
- Practice drinking 3 quarts of fluid every day.
Drinking fluids is an important step that you can take to help protect your kidneys and liver from the side effects of the medicine you will be taking. Becoming dehydrated can increase the risk of kidney and liver injury as well as increase the side effects of medicine.

✓ To-do list

- Attend the "Teaching for Transplant" class.
The class is 2-4 pm the 1st and 3rd Tuesday of each month. The class is held in the cancer center, room CC-2105. Your caregiver(s) should also attend this class.
- Check your outpatient prescription coverage and find a pharmacy near Stanford.
- Obtain a medical alert bracelet.
- Plan your transportation needs. There are times when you will not be able to drive.
- Discuss fertility preservation with your doctor.
- Make arrangements for childcare.
- Plan for pet care.
- Plan a way to maintain your household for the time you are at Stanford.
Have a family member or friend change the air filter on your air conditioner and furnace.

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 the following words:
 - 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 doctor’s name and phone number 📞 **(650) 725-7121**
 - Your diagnosis
 - Medicines you take routinely
 - Your blood type at the time of your transplant (your nurse coordinator can tell you your blood type)
 - 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 and your donor are cytomegalovirus (CMV) negative:)
“I should receive only CMV-negative blood products”
(Your nurse coordinator can tell you your CMV status.)

You should wear your medical alert jewelry until you are off all medicines related to your transplant.

Review your insurance coverage

Once your transplant is scheduled, one of our BMT financial coordinators will ask your insurance company to authorize coverage. An authorization requires that all pre-transplant diagnostic studies are completed and submitted to the insurance company for review.

That means we usually don't get authorization for a transplant until just days before you are scheduled to begin.

To review your insurance coverage:

- Confirm the amount of the deductible(s) in your policy.
- Know your co-payments, your out-of-pocket maximum, and your policy maximum.
- Confirm that return visits to Stanford for follow up are covered and authorized.
- Find out if there is coverage to help pay for housing while you get care from Stanford.
- Determine if there is any coverage for transportation.
- Know your prescription drug coverage, prescription co-pay amounts, and what pharmacies you can use.

The cost of prescriptions can be very high, with some medications costing thousands of dollars.

For help, you can contact one of the BMT financial coordinators.

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Social Services

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Getting the care you want: Advance health care directive

The staff at Stanford's BMT program highly encourages you to complete an advance health care directive before starting your treatment.

An advance 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 advance 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 explain the benefits of an advance health care directive with you. The social worker can provide you the necessary paperwork.

If you already have an advance health care directive, please give your social worker a copy. If you do not have an advance 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 this website, or paper forms can be obtained from your social worker.

<http://med.stanford.edu/letter.html>

Keep in mind these issues when completing an advance health care directive:

- It helps to communicate with your family.
- It's important to identify the person you want to designate as your health care agent. This person can be anyone you choose. He or she should be someone who knows you well and whom you would trust to make decisions in your best interest.
- It's a good idea to clarify your priorities and values with your health care agent and family.
- Having these conversations now helps others honor your wishes and preferences.
- Think about what care you would want if 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 advance health care directive is completed, you should keep the original paperwork for your records. Also provide a copy to your social worker.

Abstaining from unhealthy habits

Transplantation is a complicated and potentially life-threatening medical treatment. The Stanford BMT program requires you to completely stop (abstain from) all substances that are harmful and can interfere with your transplant.

The purpose of abstaining from these substances is to enhance the results of your transplant and to aid in your long-term health and recovery.

We require that you abstain from 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
- **Medical marijuana use should be discussed individually with your doctor and social worker**

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

- Abstaining **before** you start preparation for an allogeneic transplant, ideally for a least a month
- Abstaining completely **during** the preparative regimen and transplant phase
- Abstaining completely **after** the 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 abstaining as required. If you need help in meeting this requirement, let your social worker, doctor, or nurse coordinator know. They will find resources to help you.

To meet the requirements of the 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 you to abstain?

There are 3 key reasons why we ask that you stop drinking alcohol, using tobacco, and taking drugs.

- These substances may injure your 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.

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

Safe Zone

You must stay within the “SAFE ZONE” (defined below) during your transplant. The SAFE ZONE is based on travel distances and times from various locations in the SF 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 outside this zone, you will need to stay near Stanford for about 90 to 100 days after your transplant.

Housing options

For questions or help with housing please talk to your assigned social worker.

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

- **Your own home** if it is within the SAFE ZONE
- **The home of family or friends** if it is within the SAFE ZONE
- **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. 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.
- **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.
- **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 Marriot, ☎ (650) 264-1020
 - Stanford Motor Inn, ☎ (650) 493-3153
- **Apartments**
 - There are many apartments near Stanford.
 - The following is used frequently by BMT patients and families:
Oakwood Worldwide, ☎ (510) 404-0163.

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 a 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 help you with an application.

State Disability Insurance (SDI)

www.edd.ca.gov

- SDI is managed 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 people who work in California are eligible for short-term disability benefits through SDI. Some individuals may not qualify, including those who are self-employed or government employees.
- To be eligible you must have paid into 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 1 year and you will likely need to re-certify your disability.

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 5-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.

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.

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

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 1 year
- Have worked at least 1,250 hours in the past year

Contact your employer for additional information.

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 6 weeks of paid time off after a 1-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.

Your BMT caregiver(s)

Your BMT caregiver is an essential member of your transplant team. You will need at least one caregiver during the outpatient portion of your transplant for about 3 months. In some cases, it may be longer.

Spiritual care

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

Chaplains provide religious counseling, prayer, and sacramental ministry. They explore spiritual concerns for patients of all faiths. The 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: Patients can have a personalized session of guided imagery at no charge. This service is generally available on Tuesday and Wednesday.

Please call Stanford Guest Services to arrange this. 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 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 1-year subscriptions to Stanford patients. To obtain your free subscription, email BeMindfulToday@stanfordhealthcare.org.

Web-based resources

BMT Infonet

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

National Bone Marrow Transplant Link

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

Be The Match

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

Stanford BMT Program

- Detailed information on the program and resources
- bmt.stanford.edu

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Information for the Caregiver

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BMT caregiver(s)

You, the BMT caregiver, are an essential member of the transplant team. A caregiver is usually a family member or friend who can rearrange their regular responsibilities to become a partner during the transplant journey. Some transplant patients have more than one caregiver.

A caregiver is required during the outpatient portion of the transplant for about 3 months. In some cases, it may be longer.

The caregiver's role is a fulltime responsibility and requires someone 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 feel 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—the caregiver
- 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

Caregiver needs

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. Don't delay in getting professional help when you need it.
- When people offer to help, **accept the offer**. 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

Caregiving

Caregiving is challenging, both physically and emotionally. It's important for you, the caregiver, to take care of yourself. One critical thing caregivers can do is take time for themselves.

Some resources available to the caregiver are:

- **Stanford** has supportive care classes and support groups. The schedule is posted at http://cancer.stanford.edu/patient_care/amenities/cancerPatientServices/supportiveCareServices/.
 (650) 725-9481.
- The **BMT InfoNet** website (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** (nbmtlink.org) has created a "Caregivers' Guide to Bone Marrow/Stem Cell Transplant." 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** (bethematch.org) provides resources for caregivers before and after transplant.

Changing from family/friend to caregiver and back again

The usual roles and responsibilities in relationships change during a transplant. It can be challenging to shift these roles and responsibilities.

Sometimes it is hard to talk about these changes. The resources listed above may provide some helpful information.

Research has shown that 3 of the most challenging aspects of caregiving are managing work, caregiver fatigue, and managing the patient's emotional distress. Some advice from former caregivers includes:

- Keep the patient (transplant recipient) as independent as possible.
- Take time out from caregiving and establish a routine.
- Be optimistic.
- Don't be afraid or too proud to ask for help.

Managing medicines

With time, many transplant patients take responsibility for their medicines. Early in the transplant process, you, the caregiver, will likely take most of the responsibility for managing medicines.

There are many medicines that the patient will need to take during the active transplant phase and recovery. Many medications also have very specific instructions.

Here are some tips for you, the caregiver(s):

- Some caregivers develop spreadsheets to manage medicine. There are also medicine administration apps (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 for the patient to take a medicine.
- There are times when we may call the patient or you, the caregiver, to adjust the dose of a medicine. A tip to ensure you understand the phone instructions is to write down the information. Then repeat the change in dose back to the health care professional.

Support for caregivers

There is a caregiver support class every Wednesday in the cancer center, room CC2103. The goal is to provide caregivers support and education about transplants.

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

For questions call, 📞 650-529-5942.

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The Transplant

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Informed consent

You will be given a copy of your consent form(s) to read before your scheduled appointment for the consent review. To prepare 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

BMT studies

The BMT program is committed to improving medical outcomes and advancing the science of transplantation. We evaluate and develop improvements in BMT using clinical and research studies.

Government programs at 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.

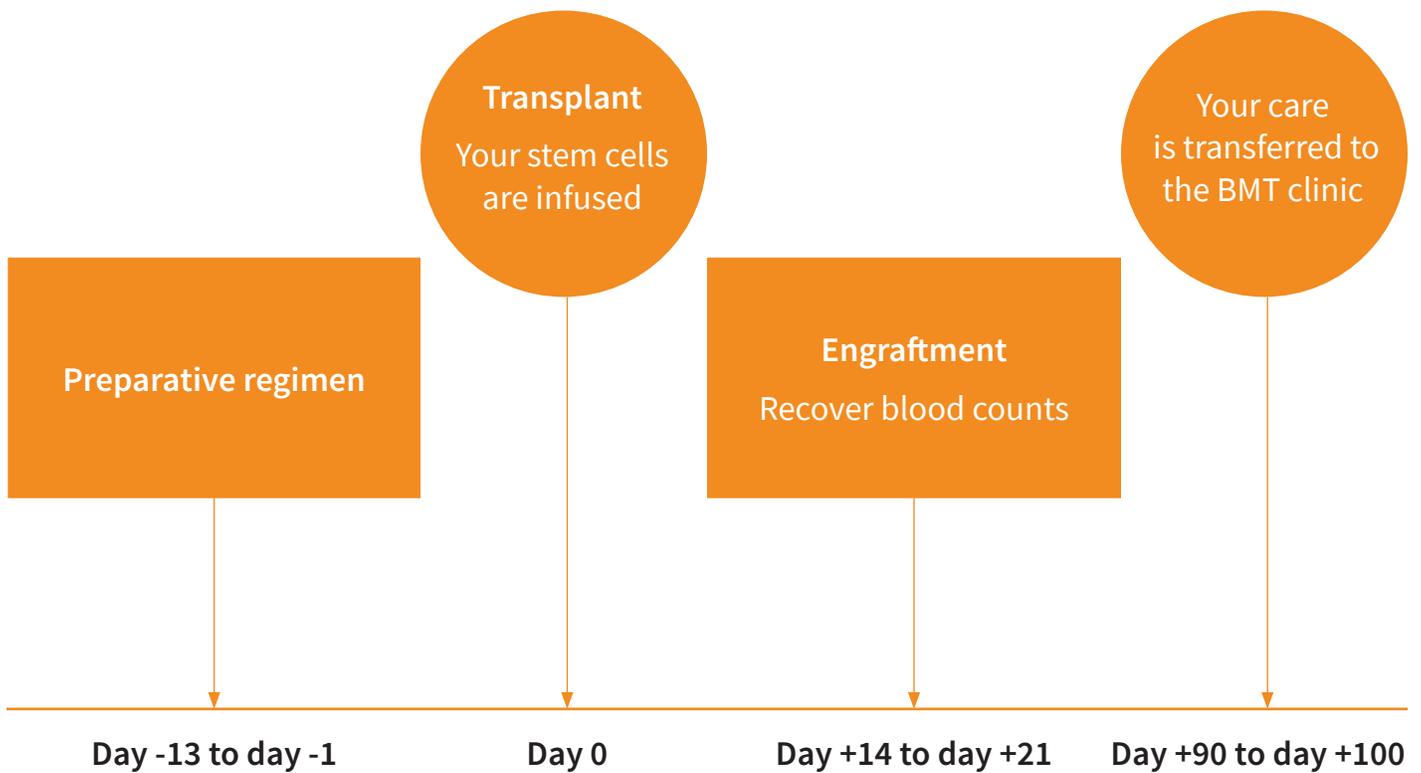
Where to go for your consent appointment

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 or 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 form in your guidebook

Allogeneic transplant outline



Preparative regimen

Your consent form will state the specific preparative regimen you will receive and give you detailed information on potential side effects. The intensity of side effects varies with the type of preparative regimen you receive.

High-dose chemotherapy with or without radiation is associated with more intense side effects than a non-myeloablative preparative regimen.

| Common side effects | 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 | ✓ | | ✓ | |

| Common side effects | Chemotherapy agents | Anti-thymocyte globulin (ATG) | Fractionated total body irradiation (FTBI) | Total lymphoid irradiation (TLI) |
|---|----------------------------|--------------------------------------|---|---|
| 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. This takes place on the day your BMT team calls "day zero."

This is the day your donor's stem cells will be delivered (or infused) through your central venous catheter into your bloodstream. 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 blood cells take longer to recover. You will need transfusions to raise the number of both red blood cells and platelets.

You may need transfusions until your body begins 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 cells recognize your body tissues as different or foreign.

There are 4 main strategies for preventing graft-versus-host disease.

- **HLA matching**

This strategy matches you with a donor according to a group of cell surface markers called HLA (for human leukocyte antigen). The closer the HLA match, the lower your risk of graft-versus-host disease.

Even when there is a "perfect" match there remains a risk of graft-versus-host disease.

- **Immunosuppressive medicine**

These medicines are taken to weaken the immune reaction of your donor's cells to your body. There are many different immune-suppressing medicines. Please check your consent form to find out which immune-suppressing medicines you will receive.

- **Preventing infections**

Preventing infections can help avoid graft-versus-host disease. You will take medicines to prevent infections. You will also be asked to follow guidelines to minimize your risk of infection.

- **Avoiding sunlight**

Sunlight can trigger a reaction in the skin that causes a type of graft-versus-host disease. There are 2 important steps you can take to prevent this.

- When you are outside, wear a sunscreen with an SPF of at least 30. Reapply it as directed.
- Wear clothes that protect your skin from sunlight such as hats and long-sleeve shirts.

Acute and chronic graft-versus-host disease

There are 2 forms of graft-versus-host disease: acute and chronic.

- Acute graft-versus-host disease generally occurs within the first 100 days of a transplant. It can range from a mild and treatable problem to a serious and life-threatening problem. It often affects the skin, the liver, and the gastrointestinal tract (the stomach and intestines).
- The risk of developing chronic graft-versus-host disease is generally within the first 2 years after a transplant. It can range in severity from mild to life-threatening.
- In some cases, chronic graft-versus-host disease can leave you feeling weak and limit what you can do physically. Unlike the acute form, chronic graft-versus-host disease can affect any tissue in the body. One symptom of chronic graft-versus-host disease is a dry mouth. The dry mouth is a result of the donor cell's immune reaction destroying part of your salivary gland. As a result, you do not make enough saliva.
- Another symptom of more severe chronic graft-versus-host disease is damage to the joints. This limits the range of motion of the joints and makes 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 chronic graft-versus-host disease, the symptoms and treatment can last for years. We will work with you on treatment, strategies to prevent infections, managing your symptoms, and maximizing your quality of life.

Hospital routines

You will be seen at least once daily by the medical team. The BMT medical team usually includes the attending physician, a medical fellow, and a medical resident. Your team also has 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 on your own.
- Do your mouth care at least 5 times a day.

We recommend that you bring these items to the hospital or cancer center:

- A good pair of slippers or shoes that have a non-slip sole and cover your toes
- Loose, comfortable clothes and hats or scarves
- Any items from home you want to decorate your room, such as photos or a favorite blanket
- A laptop computer, radio, music, and DVDs

You will not always have a private room and you will likely change rooms and nursing units during your stay. We recognize it can be stressful to not have a private room or to change rooms. We apologize for any inconvenience.

Private rooms are assigned based on medical criteria and considering the needs of all patients. We ask for your cooperation when room changes are required.

Care and routines in the infusion treatment area (ITA)

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. We are committed to keeping any waiting times as short as possible.

We encourage your caregiver to be present at each visit.

Please bring the following to all of your ITA visits:

- Your guidebook
- Your home medicines and medicine list
- A list of questions for the health care team
- A list of any medicines needing refills
- Your HEPA mask which is important to wear to all ITA appointments.
- Warm and comfortable clothes

- Snacks and drinks, because your visits will be at least a few hours and possibly longer. We do offer juice and crackers.
 - On weekends, there are limited options for buying food: Food is available at the 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 attending).

Your BMT team recognizes the healing properties of a quiet and calm environment. We ask you to help us create an environment that promotes a therapeutic and peaceful atmosphere.

Please have your 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.

When you arrive in the ITA, we will check your:

- Vital signs (temperature, blood pressure, and pulse)
- Weight
- Symptoms and symptom management

We will also:

- 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.

- Deliver fluids, medicine, and blood products as needed

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Steps to Prevent Infection

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Infection prevention measures: When to start and stop

| Infection Prevention Measures | Preparative Regimen Begins | Day +90 - 100 | Six Months | Off All Immuno-suppressive Medicine |
|---|-----------------------------------|---|-------------------|--|
| 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, except continue to avoid eating raw animal products and practicing safe food preparation. | | End all precautions. |
| 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, sweeping, 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 health routine

- Best 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 often
 - 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 your 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.
- Do not use contact lenses until 90-100 days after your transplant.
- Perform gentle cleaning and care of your mouth.
- Do 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.
 - Use a sunscreen of at least SPF 30.
 - Wear clothes that shade your skin from sunlight.

Avoid exposure to bacteria and viruses. Avoid anyone who is ill with colds, flu or other infections.

- Follow the low microbial diet.
- 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 your home.
- Do not vacuum, sweep, or dust.

Leave the room when someone else is vacuuming, sweeping, or 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, germs (micro-organisms) such as fungi are released into the air.

Wearing the HEPA filter mask and keeping your distance from active construction sites can help protect you from inhaling many of these micro-organisms.

When you arrive 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, rectal medications (suppositories), or enemas.
- Do not have **any** medical procedures done that are invasive (entering your body) by a dentist, podiatrist, or surgeon without first checking with the BMT team.

When you should wear the HEPA filter mask

The HEPA filter mask helps protect you from germs like bacteria, viruses and fungi and other micro-organisms that can spread through the air (airborne). These airborne micro-organisms can cause serious pneumonia if they get into your 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 90-100 days after your transplant
- From 3 to 6 months after your transplant, you need to wear the mask when you come to a hospital or clinic, in crowded public spaces, and around construction sites.

In addition to the HEPA mask provided at Stanford, there are other HEPA filter masks that can be bought. However, be aware that when we have contacted the companies to confirm if their masks can filter micro-organisms, they have not been able to provide evidence. So we believe it is best to use the HEPA filter mask we provide at Stanford.

In general, the filters of the mask do not need to be changed unless they become wet.

Mouth care

After the preparative regimen you will probably develop some irritation or sores in your mouth and throat. These sores can cause pain that varies from mild to severe.

For many people, this can be the most painful part of the transplant. Your BMT team will work to relieve the pain. Your job is to take care of your mouth often to prevent infections and promote healing.

Mouth care should be done at least 5 times each day.

- Rinse with a bland solution (a mixture of salt and water based on your taste preference). Make the solution fresh for each use.
- Use toothpaste as tolerated.
- Use a very soft “baby” toothbrush or a disposable toothbrush to gently clean.
 - Disposable toothbrushes should be discarded after 1 week.
 - Soft “baby” toothbrushes should be discarded after 1 month.
 - Perform gentle mouth care.
 - No flossing until 100 days after your transplant.
 - No electric toothbrush or water pics.

Preventing infections 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 while in your room
- Are strongly discouraged from visiting if they are children under the age of 12. Only your children are allowed to visit.
- Are limited to 2 at a time when you are in a semi-private room
Children under 12 years of age cannot visit while you are in a semi-private room.

In your hospital room:

- The air is filtered to remove most micro-organisms.
- No fresh flowers or plants are allowed.
- Mylar balloons are allowed for 3 days, but latex balloons are not allowed.

Infection prevention in your home

Housecleaning

- Avoid vacuuming, sweeping, 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. Repeat on a regular basis following the manufacturer's recommendations for the first year.
- Have bed linens changed once a week.
- Use your own towels and change them every 2 days.

Pets

- Dogs and cats may remain in your home.
 - Do not groom or clean up after your pets.
 - Wash your hands thoroughly after contact.
 - Keep the pet off your bed and clothes.
- Birds must be moved to another home until you have stopped taking all immunosuppressive drugs.
- Do not care for farm or ranch animals, small caged animals, or reptiles until you have stopped taking all immunosuppressive drugs.

Plants and gardening

- Plants may stay in your 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 3 times per week.
- It is best to keep the windows closed.

Travel

- By car: 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.
- By airplane: Check with your BMT doctor before you begin any travel.

Other activities to avoid until you stop all immunosuppressive drugs:

- Soaking in a hot tub or bath tub
- Swimming
- Fishing
- Carpentry work, woodworking
- Getting new pets
- Golfing – You can resume golfing after 6 months as long as you no longer have a central venous catheter and use your 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 a transplant when your body's 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 your transplant. Zoster or shingles causes pain along a nerve path on your body. Then it 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 prevent zoster or shingles, you will be asked to take an antiviral medication, Acyclovir®, for the first year after your transplant.

Cytomegalovirus

Most adults were exposed to the cytomegalovirus (CMV) as a child and developed a cold. Once exposed to the CMV virus, the virus remains in an inactive state in the body forever.

When a person's immune system is weak, as it is after transplant, CMV often becomes active again. CMV can cause infection in the lungs, stomach, intestines, liver, and other organs.

If either you or your donor has been exposed to CMV, we will monitor you often for any sign that the virus is becoming active. You may also be given a medicine to prevent the virus from becoming active.

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 people or by touching contaminated surfaces. The typical incubation period for flu 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 symptoms start. Young children can also spread the virus before their illness starts.

People with severely weakened immune systems can shed the virus for weeks or months.

Key to prevention is:

- Avoiding contact with sick people
- Careful and thorough hand-washing
- Vaccinating you and your family members for seasonal flu

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 caused by a protozoal organism. For prevention, you will take a medication called Bactrim®.

The Bactrim® will start about 30-42 days after your transplant and continue until you are off all immunosuppressive drugs. If you are allergic to Bactrim®, there are alternative drugs.

Metric conversions

How to convert your weight and temperature from metric

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

| Centigrade degrees | Equals | Fahrenheit degrees |
|--------------------|--------|--------------------|
| 36.0 | = | 96.8 |
| 36.5 | = | 97.7 |
| 37.0 | = | 98.6 |
| 37.5 | = | 99.5 |
| 38.0 | = | 100.4 |
| 38.5 | = | 101.3 |

| Centigrade degrees | Equals | Fahrenheit degrees |
|--------------------|--------|--------------------|
| 39.0 | = | 102.3 |
| 39.5 | = | 103.1 |
| 40.0 | = | 104.0 |
| 40.5 | = | 104.9 |
| 41.0 | = | 105.8 |

8

Eating Well for a Transplant

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Reducing risk from food: The low microbial diet

The goal of the low microbial diet is to eliminate bacteria from your food. That reduces the risk you will get ill from eating the food.

Preparing, cooking, and storing food properly can reduce bacteria. Handling food safely—and avoiding certain foods until you recover from the transplant—are essential to lower the risk of getting sick from food.

Adequate nutrition is also KEY to your recovery. Your calorie and protein needs are very high to support cell growth and recovery. It is essential to get enough calories, protein, fluids, and nutrients to heal and recover.

When to follow the low microbial diet

- Begin the low microbial diet when you start the preparative regimen for your transplant and continue for 90 to 100 days following your transplant.
- Beginning on the day of your transplant, avoid dairy products that contain lactose.
- Until you are off all immunosuppressive drugs, do not eat raw animal products. Of course, you should always practice safe food preparation.

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 to avoid dairy products until about 40 days after your transplant. At 40 days after your transplant, you will be assessed and guided to re-introduce lactose-containing products.
- 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.

Lactose-free options for dairy products and non-dairy alternatives:

- Lactose-free dairy: milk, cheese, cottage cheese, ice cream, pudding, yogurt
Common brands available: Lactaid, Yoplait, Breyers, Kozy Shack, generic store brand like Lucerne, Target
- Soy: milk, cheese, ice cream, pudding, yogurt, cheese/cream cheese
Common brands available: Silk, So Delicious, Tofutti, Daiya
- Almond: milk, cheese, pudding, ice cream, yogurt
Common brands available: Silk, Almond Breeze, So Delicious
- Rice: milk, cheese, ice cream
Common brands available: Rice Dream
- Coconut: milk, cheese, ice cream, yogurt
Common brands available: Silk, So Delicious
- Prepared dinners: Amy's frozen meals has lactose-free pizza, enchiladas, lasagna

General guidelines for safe food

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

- Food prepared at home according to the “Okay to eat/avoid” guidelines (below) is acceptable.
- Packaged foods such as frozen dinners and canned soups are acceptable.
- Avoid food prepared outside of your home. This includes food from restaurants, take out, and food prepared in grocery stores. Examples of foods prepared in grocery stores to avoid include cooked rotisserie chickens, pizzas made or baked in store, potato or pastas salads, etc.
- All foods of animal origin (meat, fish, eggs, dairy) must be fully heated or pasteurized.
- All foods of plant origin must be well washed or heat treated if you cannot wash them (nuts, seeds, berries, sprouts).
- Follow basic food safety precautions always:
 - **Cook:** Food is safely cooked when it reaches a high enough internal temperature to kill harmful bacteria that cause illness.
 - Cook all meats and eggs to well done.
 - Choose only pasteurized dairy products.
 - Fully reheat all leftovers.
 - When using the microwave, cover food, stir and rotate for even cooking.

| USDA-FDA Recommended Safe Minimum Internal Temperatures | | | | |
|---|---|---|--|---|
|  |  |  |  |  |
| Beef, Pork, Veal, Lamb Steaks, Roasts & Chops 145 °F with 3-minute rest time | Fish 145 °F | Beef, Pork, Veal, Lamb Ground 160 °F | Egg Dishes 160 °F | Turkey, Chicken & Duck Whole, Pieces & Ground 165 °F |

- **Chill:** Refrigerate foods quickly because cold temperatures slow the growth of harmful bacteria.
 - Put leftovers in refrigerator within 2 hours.
 - For large amounts of leftovers, separate in smaller shallow containers for quicker cooling.
 - Discard any uneaten leftovers after 3 days.
- **Clean:** Bacteria can spread in the kitchen, onto cutting boards, utensils, counter tops, and foods.
 - Wash hands for at least 20 seconds with warm water and soap before preparing meals and when changing from raw to cooked foods.
 - Wash or scrub all fruits and vegetables before eating.
 - Wipe all can tops before opening.
 - Keep all kitchen surfaces, plates, utensils, cutting boards, and cookware clean with hot soapy water.
 - Wash hands well before preparing food and eating.
- **Separate**
 - Keep raw meats and eggs separate from other foods in shopping cart and refrigerator.
 - Use 2 cutting boards, one for raw items to be cooked and another for raw items to be eaten raw.
 - Never defrost at room temperature. Defrost meats in the refrigerator.

Foods to eat or avoid

| | Okay to eat | Avoid |
|-----------------|--|---|
| Proteins | <ul style="list-style-type: none"> • All meat, poultry, and fish that are cooked well done • Pre-packaged luncheon meats, hot dogs that are cooked to steaming • Well done eggs (the yolk or yellow is firm) such as hard boiled, scrambled, or omelet. Pasteurized eggs • Cooked beans, lentils, and legumes • Cooked tofu • Cooked vegetarian meat alternatives such as veggie burgers • Roasted nuts and seeds and nut butters • Canned meats (tuna, chicken) | <ul style="list-style-type: none"> • Undercooked, rare, or raw meat, poultry, and fish—common examples are rare steak and sushi • Deli meat sliced in store • Runny eggs • Raw tofu • Raw nuts and seeds • Meat spreads, pate • Smoked or pickled meats • Miso products, tempeh |
| Dairy | <ul style="list-style-type: none"> • Pasteurized milk • Non-dairy milk alternatives such as soy milk, almond milk, and rice milk • Conventional yogurt • Low bacteria cheeses (American, Swiss, mild and medium cheddar, mozzarella, Monterey Jack, cottage cheese, string cheese, cream cheese) | <ul style="list-style-type: none"> • Raw milk • High probiotic yogurts • High bacteria cheeses (moldy, soft, unpasteurized or aged, cheeses with herbs, spices or vegetables such as pepper jack) |
| Grains | <ul style="list-style-type: none"> • Breads and tortillas in sealed packages • Grains, pastas, and cereals in sealed packages | <ul style="list-style-type: none"> • Unpackaged breads and tortillas • Grains, pastas, and cereals from bulk bins |

| | Okay to eat | Avoid |
|--------------------------------|--|---|
| Fruits & vegetables | <ul style="list-style-type: none"> • All fresh fruits and vegetables except for sprouts and berries • Frozen and canned fruits and vegetables • Cooked berries and sprouts • Dried fruit | <ul style="list-style-type: none"> • Uncooked fresh or frozen berries and sprouts • Bruised, damaged, or wilted fruits and vegetables • Pre-cut fruits and vegetables, refrigerated salsa • Kimchee |
| Beverages | <ul style="list-style-type: none"> • Municipal tap water • Reverse osmosis filtered, distilled bottled water • Shelf stable, pasteurized juices and teas | <ul style="list-style-type: none"> • Well water • Freshly squeezed, “flash” or “gently” pasteurized juices • Cold brew tea • Soda fountain drinks • Coffee shop drinks |
| Desserts and snacks | <ul style="list-style-type: none"> • Cookies, candy, cakes, etc. in sealed packages • Crackers, pretzels, chips etc. in sealed packages • Packaged ice cream | <ul style="list-style-type: none"> • Non-packaged bakery cookies, cakes, etc. • Bulk candy • Soft serve ice cream |
| Other / condiments | <ul style="list-style-type: none"> • Jelly, jam, syrup, molasses, salt, pepper, mustard, catsup, mayonnaise | <ul style="list-style-type: none"> • Honey • Chinese herbs |

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Taking Care of Yourself

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Precautions to minimize the risk of bleeding when your platelet count is low

Be safety conscious

Remember some medicines 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 lower the risk of falling

Always wear shoes or slippers to protect your feet

Do not use 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, not scissors

Use caution and care with sexual activity

Vigorous activity may cause bleeding

Do not play contact sports

Do not have any dental, podiatry or surgical procedure without checking with your BMT team

Avoid medicines that can interfere with blood platelets

Examples include: aspirin, Motrin[®], Advil[®], ibuprofen, Relieve[®], Aleve[®]

Do not drink alcohol until your platelet count is normal (about 3 months after the transplant)

- Alcohol also interferes with platelet function
- Check with your BMT team to make sure there are no 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

Supportive care

Physical therapy

During your hospital stay, a physical therapist will evaluate your strength and capabilities. Based on that, the therapist will design an exercise program for you. Our goal is to keep you as fit and active as possible during your transplant.

After you leave the hospital, set up a daily program of exercise. Walking is a great way to regain strength, energy, and improve your sense of well-being. Speak with the physical therapist for guidelines before you leave the hospital.

The key to success is to stick with a consistent and moderate exercise program. A low platelet count will limit some of the physical activities that are considered safe, such as resistance exercises.

Stanford Cancer Center's 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 Stanford 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 the care from your BMT team, the services offered by our palliative care team may help you during treatment. The palliative care team can help you manage symptoms, do advance care planning, and learn about your illness and treatment options. The palliative care team also provides 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. Our palliative care team may help ease side effects from treatment such as pain, nausea, feeling short of breath, anxiety, and stress.

The team can also help you find psychological, financial, legal, and community support. Palliative care can be useful at any stage in a serious illness, and can be provided together with the treatment you get to cure your illness.

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

Blood transfusions

As part of your transplant, you may receive blood transfusions using blood from another donor. Transfusions are done to increase the level of blood cells in your body when they are below a healthy level.

The transfusion may be made up of red blood cells, plasma, platelets or other products made from blood. Your doctor may recommend the transfusion based on your medical condition and diagnosis.

For some people, a blood transfusion may be life-saving. For others, it improves your health and simply helps you feel better.

There are also risks. Common risks include:

- Skin irritation, pain or infection at the needle site
- Temporary fever, chills, or skin rashes

Less commonly, there are more serious complications including:

- Severe allergic reactions
- Heart failure from fluid overload
- Pulmonary edema (fluid leaking into the lungs)
- Hemolysis (destruction of red blood cells)
- Rarely, shock or death

Although donated blood is tested thoroughly, blood transfusions still carry a very small risk of spreading infectious diseases. They include:

- HIV (about 1 in 1.5 million)
- Hepatitis C (about 1 in 1.2 million)
- Hepatitis B (about 1 in 1 million)

Most people getting a blood transfusion receive blood from unrelated donors who have been screened carefully to ensure the safest possible donation. There are also other options including:

- Taking prescribed medicine that increases your blood volume or reduces bleeding, to lessen the need for a transfusion

Ask your doctor and health care team about the benefits and risks of various blood transfusion options.

For more information on blood transfusions, please refer to the California Department of Public Health pamphlet called **“A Patient’s Guide to Blood Transfusion”**. It may be found in the pocket of this transplant guide.

10 Your Central Venous Catheter

Central venous catheters

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Central venous catheters

A central venous catheter is a soft flexible tube that is used to deliver medicine, fluids, blood transfusions, chemotherapy, or nutrition through a vein. There are 2 types of central venous catheters: one inserted in the upper arm (“peripheral”), and the other inserted in the upper chest (“tunneled”).

A central venous catheter has a risk of infection, which happens when germs get into the bloodstream through the catheter. If you develop this kind of an infection, you may become ill with a fever 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 catheters (PICC) are:
 - Inserted in the upper arm by a specialty trained nurse
 - Used for long-term therapy.
 - Cared for by your nurse to prevent the tube from being accidentally removed or dislodged
- Tunneled central lines:
 - Are inserted in the upper chest partly under the skin
 - Are used for long-term therapy
 - Are cared for by you or your caregiver
 - Require you and your caregiver to use proper handwashing before handling them
 - Require you to get instructions at the catheter care class you will attend before your transplant

Diagnosis and treatment of an infection from a central venous catheter

- 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 immediately if you experience any of the following symptoms:

- Blood soaks your bandage.
- Your heart is beating faster than normal.
- You feel faint or dizzy.
- Your arm feels warm, tender, painful or looks red and swollen.
- You have a fever.
- You have chills.
- You have pain, redness, swelling, or pus where the catheter was inserted.

11 Home Pharmacy Information

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Infusion pump

Our home pharmacy is a service provided to help you administer intravenous medications while you are living in local housing. A BMT home infusion nurse and a pharmacist will provide you with intravenous (IV) medicine and fluids, delivered by a pump to your veins, while you are receiving care in the cancer center.

This infusion pump is made available through the Lucile Packard Children's Hospital Home Pharmacy Service.

A "ambulatory" (portable) infusion pump delivers:

- Fluids
- Nutrition
- Drugs that fight infection 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. Nurses will change the medicine or fluid bags during your daily ITA visit.

Medicine reactions

If you are having a reaction to a medicine, call the ITA in the cancer center 📞 (650) 725-1860 or the main hospital E1 unit 📞 (650) 725-7121 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, 7 days a week

Medicine and supplies obtained from the home pharmacy

Ordering medicine and supplies

Refills for medicine and supplies are coordinated through your nurse in the ITA at the cancer center or the hospital E1 unit.

Delivery of medicine and supplies

- You can get medicine and supplies that are delivered to the ITA twice a day Monday through Friday.
- You can also pick up medicine and supplies at the home pharmacy located in Menlo Park during normal business hours.
- At the time of delivery, you will receive a delivery ticket. Check the ticket for accuracy of medicine and supplies.

Storing medicine and supplies

- Keep out of children's reach.
- Read the prescription label to see if the medicine should be kept at room temperature, frozen, or refrigerated.
- Place new medicine and supplies behind the current medicine and supplies.
 - Make sure that items don't reach their expiration date.
 - Never use outdated items.
- Keep extra batteries on hand in case of a power outage.
- Keep an eye on your inventory and plan ahead so you don't run out.

Returns

- Supplies and medicines 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 $\frac{3}{4}$ full, bring it to the cancer center ITA or the hospital E1 unit for a new container.
 - DO NOT throw away 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 the cause of occlusion (blockage). When the occlusion is resolved, the alarm will stop and the pump will resume. |
| ALARM UP OCCLUSION | Check administration set from IV bag to pump for the cause of occlusion (blockage). 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. |

| Display on Pump | Resolution |
|----------------------------|--|
| 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 when the battery is getting low. The message will tell you when the power is low in the “C” batteries or the battery pack. Change the batteries or plug the AC adapter into a power source. |

To Stop Pump

1. Press **PAUSE**
2. Press **ON/OFF**
3. Resume – Press **YES**
4. Run – Press **RUN**

To Start Pump

1. Press **ON/OFF**
2. Program – Press **YES**
3. Run – Press **RUN**

To Clear Alarms

1. Press **PAUSE**
2. Resume – Press **YES**

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

12 Recovery

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Day 90 – 100: Discharge class

About 3 months after your transplant, we will schedule you to attend a class on getting discharged (released). The class gives you information to help you move back home and to guide your recovery.

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. The period of risk is about 2 years. Like acute graft-versus-host disease, chronic graft-versus-host disease is caused by the donor blood (immune) cells (the “graft”) attacking your (“host”) tissues. Chronic graft-versus-host disease can occur in any body tissue. Most commonly it occurs in the skin, mouth, liver, stomach, intestines, and eyes.

One strategy to help prevent chronic graft-versus-host disease is protecting your skin from the sun. This is especially important to do for the first 2 years after your transplant. It will also be important to do this for the rest of your life.

You can protect your skin by using sunscreen or covering your skin with clothes 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:

- **Skin:** rash or discoloration, tightness
- **Mouth:** dry mouth, redness, soreness, oral sensitivities
- **Eyes:** dry, itchy eyes, vision changes, burning pain, sensitivity to light
- **Lungs:** cough, feeling short of breath

- **GI tract:** nausea, vomiting, diarrhea, cramping, difficulty swallowing, weight loss
- **Liver:** yellowing of the skin
- **Muscles and bones:** weakness, particularly in the legs, difficulty moving from sitting to standing
- **Neurological:** difficulty concentrating, confusion,
- **Female genital tract (vagina, vulva):** dryness, burning or itching, pain with intercourse

Diagnosing chronic graft-versus-host disease may require testing, including biopsy of the affected tissue. Symptoms and treatment of chronic graft-versus-host disease may persist for years.

Treatment may include steroids contained in a cream for the skin or eye drops for eye symptoms.

More severe symptoms may require you to take immunosuppressive medicine, such as prednisone.

Infection

Preventing infection remains important after you go home.

Even though your white blood cell count has recovered, you still have a higher risk for infections because you're taking immunosuppressive medicine to prevent or treat graft-versus-host disease.

Remember that the safety rules on eating raw animal products, dust, gardening, and pets should be followed until you are off all immunosuppressive medicine. If you get chronic graft-versus-host disease, that also increases your risk for infection.

To prevent infections:

- Follow the same safety rules you had for the initial stages of your transplant. That includes hand washing, staying away from sick people, and safe food preparation.
- Get the annual inactivated flu vaccination. Ask your close family and friends to get vaccinated too.
- Take antibiotics. Your doctor may recommend that you take antibiotics regularly to prevent infection. That's especially important if you have developed chronic graft-versus-host disease.
- Take antiviral drugs. You will be taking an antiviral medicine for about one year to prevent shingles or zoster infection.

If you develop a fever, cough, or other signs of infection, contact your doctor. If you are still on immunosuppressive medicine, 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.

Feeling tired (fatigue) is one of the most persistent physical symptoms following a 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 6 months.

Slowly build back up to your usual level of activity. Listen to your body along the way so that you don't overdo it.

You may want to talk with the physical therapist for ideas before you move back home. Expect the fatigue to last about 6 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 ones should be reported to the BMT team. If in doubt, call the BMT team.

Your emotions following the transplant may include anxiety, frustration, depression, anger, worry, and sadness. These emotions are normal.

Ongoing anxiety about a relapse is a universal worry among people 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

You can usually return to work about 6 to 12 months after a transplant. Talk over your work plans with your BMT team before resuming a job.

For some types of work such as farming, ranching, or a job in environments where you are exposed to chemicals or micro-organisms, we may recommend a longer period before returning. In some cases, we may recommend you find another type of job.

Your social worker can discuss job re-training programs that may be available.

Taking care of yourself after the transplant

Your skin

Common skin changes after a 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 cancer doctor (oncologist or 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 2 years after the transplant.

When you are out in the sun wear protective clothes that cover your skin. 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 lifelong 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 change taste buds so that food tastes bland or metallic. It can take up to 4 months for taste buds to fully regrow. Eventually, your taste buds will recover and food will taste the way you remember it tasting.

Follow up with your dentist about 6 months after your transplant, or sooner if you are having problems. If you are taking medicine that weakens your immune system, you may have to take preventive antibiotics if you have any dental work done that's invasive (penetrating your gums or skin).

Alcohol

Check with your doctor about when it is safe to drink alcohol.

Driving

You should not drive until at least 3 months after your transplant. Check with your BMT doctor before you start driving again.

If you are still taking medicine that could cause drowsiness or impair your judgment, you should not drive. Examples of medications that cause drowsiness include narcotics for pain, medicine for nausea, or medicine for anxiety. You should not drive until you stop these medicines.

Immunizations

We recommend an annual inactivated influenza (flu) vaccine. The inactivated influenza vaccine may be given as early as 4 months after your transplant.

Check with your primary care doctor about routine vaccinations such as:

- Hepatitis B and hepatitis A series
- Polio, inactivated
- Tetanus booster and diphtheria
- Pneumococcal vaccine
- Meningococcal vaccine
- Haemophilus influenzae vaccine
- Human papillomavirus vaccine
- Varicella vaccine

You should not receive any vaccine that contains live virus.

There may be specific vaccinations you need for travel. Check with 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 live (MMR and oral polio) vaccinations, avoid contact with the child for 7 days.

If your child received the rotavirus vaccination, avoid handling diapers for 4 weeks after vaccination.

Call your BMT team if you have questions about your vaccinations or 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 medicine to protect you.

Before 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 after a transplant. In most cases interest or sexual desire returns about 6 months after a transplant.

- You may resume sexual activity once your platelet count is above 50,000/ μ L.
- Keep clean and have safe sex with a single healthy partner.
- We recommend your partner wear a condom for 6 months.
- We advise that you avoid oral sex and anal intercourse for 6 months.
- Although infertility is likely, we recommend you use birth control to avoid any unplanned, unexpected pregnancy.
- If you are or were taking a drug called mycophenolate mofetil, you need to use birth control for 6 months after stopping this drug. Mycophenolate mofetil is known to cause birth defects.

If you received a myeloablative transplant (with high-dose chemotherapy with or without radiation) your ovaries will stop producing hormones such as estrogen. Other medicines taken during reduced-intensity conditioning programs and non-myeloablative programs may also cause your ovaries to stop producing hormones.

This loss of estrogen can lead to menopause. The symptoms of menopause include:

- Hot flashes
- Vaginal dryness
- Flushing
- Difficulty sleeping
- Moodiness
- Weakening of the bones—called osteoporosis

Visit your gynecologist about 3 months after your transplant to talk about getting help for the symptoms of menopause. Options include hormone therapy, if you are under the age of 50, or other alternatives.

Vaginal dryness may occur after chemotherapy and menopause. That can lead to discomfort or pain with vaginal intercourse. To reduce 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 your mind and body. Both take time to heal after a 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 “Sex and the Woman with Cancer,” available free of charge from the ACS website.

Sexual activity for men

Both men and women report low interest in sexual activity after a transplant. In most cases interest or sexual desire returns about 6 months after the transplant.

- You may resume sexual activity once your platelet count is above 50,000/ μ L .
- Keep clean and have safe sex with a single healthy partner.
- Wear a condom for 6 months.
- Avoid oral sex and anal intercourse for 6 months.
- Although infertility is likely, use birth control to avoid any unplanned, unexpected pregnancy.
- If you are or were taking a drug called mycophenolate mofetil, you need to use birth control for 6 months after stopping this medicine. Mycophenolate mofetil is known to cause birth defects.

You may notice that the first few times you ejaculate, 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 you ejaculate. This discomfort should pass after the first few times you engage in sex. Please report any persistent brown discharge, pain, or difficulty with erections to your BMT team.

By 6 months after the transplant, if you find your interest in sex is still low or you are having problems with erections, check with 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 tests. Testosterone can be replaced.

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

The American Cancer Society publishes an excellent book titled "Sex and the Man with Cancer," available free of charge at the ACS website.

Who takes care of you after your transplant?

Generally, you will leave the Stanford area and return to your home about 3 months after a transplant.

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

- About once or twice a month for the first 6 months
- Then monthly until a year after your transplant
- Then yearly

About 3 months after your transplant, your cancer doctor (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.

The Center for International Blood and Marrow Transplant Research (CIBMTR.org) publishes a list of recommended medical follow up for transplant survivors to help you maintain and monitor your health after transplant. The list is available on their website for downloading.

It is our goal to follow you lifelong regarding your health status. In general, this is done by sending a letter to your referring doctor. Occasionally you may receive a letter from us directly.

Please let us know if you have a change of address by calling  650-723-0822.

Routine health care

- Optometrist

Schedule an appointment 6 months after your transplant and then yearly.

- Gynecologist

Schedule an appointment 3 months after your transplant and then yearly.

You should discuss the risks and benefits of hormone therapy if you are under 50.

- Dentist

Schedule an appointment 6 months after your transplant and then yearly.

Before having any dental work, you should take antibiotics if you are still taking immune-suppressing medicine.

Corresponding with your unrelated donor

A transplant recipient's decision to correspond or release personal information to the marrow or blood stem cell donor is an individual decision. Some recipients will want to do this; others will not.

Donor-recipient contact after the transplant

The identities of both the donor and recipient must remain confidential for at least one year following the date of transplant.

For *at least* the first year, the donor and recipient may share anonymous correspondence. However, some donor centers do not allow anonymous contact at any time.

Any correspondence or gifts during the first year (or longer) will be carefully screened by the transplant coordinator and donor center coordinator. They will ensure all personally identifying information (name, photos, school, employer, geographical references) is removed from the item before it is sent.

There is no guarantee that the donor will respond.

Tips for correspondence:

- It must be anonymous.
- Please keep your correspondence short.
- Avoid pretend names. Instead, use greetings, such as “Dear Donor”
- If necessary, you may be asked to rewrite your message to the donor.

Based on the donor center guidelines:

Contact the coordinator for your specific guidelines.

- You may have anonymous contact with your donor.
- You may exchange a gift with your donor, limited to small monetary value (\$50.00 or less).

Under the policy of the National Marrow Donor Program, during the period of anonymity, a donor and recipient can exchange only **one** gift each.

*Please note, this form does not indicate if your donor has agreed or not agreed to any of the above.

Please give all correspondence to the transplant coordinator:

Transplant coordinator
Stanford Health Care – BMT
180 El Camino Real, Suite BB2-1199
MC 5268
Palo Alto, CA 94305

One (or two years) after transplant:

It is the National Marrow Donor Program (NMDP) policy that no recipient’s or donor’s personal information be released to the other party until at least 12 months after the transplant. Even if you want to have your personal information released before 12 months, NMDP policy will not allow this.

Some registries may not allow exchange of personal information at any time. If you wish to release your personal information, both the recipient and the donor must sign consent forms releasing their information.

This consent form can be obtained from the transplant coordinator by calling 📞 (650) 725-4983.

Tips for exchanging personal information:

- Your donor may not share the same values about direct contact (the donor may not want to release their personal information).
- There may be significant cultural or lifestyle differences between you and your donor.
- You and the donor have the right to set boundaries and limits on interactions.

For questions about corresponding with your donor, please contact the transplant coordinators at ☎ (650) 725-4983.

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

Your comments and suggestions are welcome.

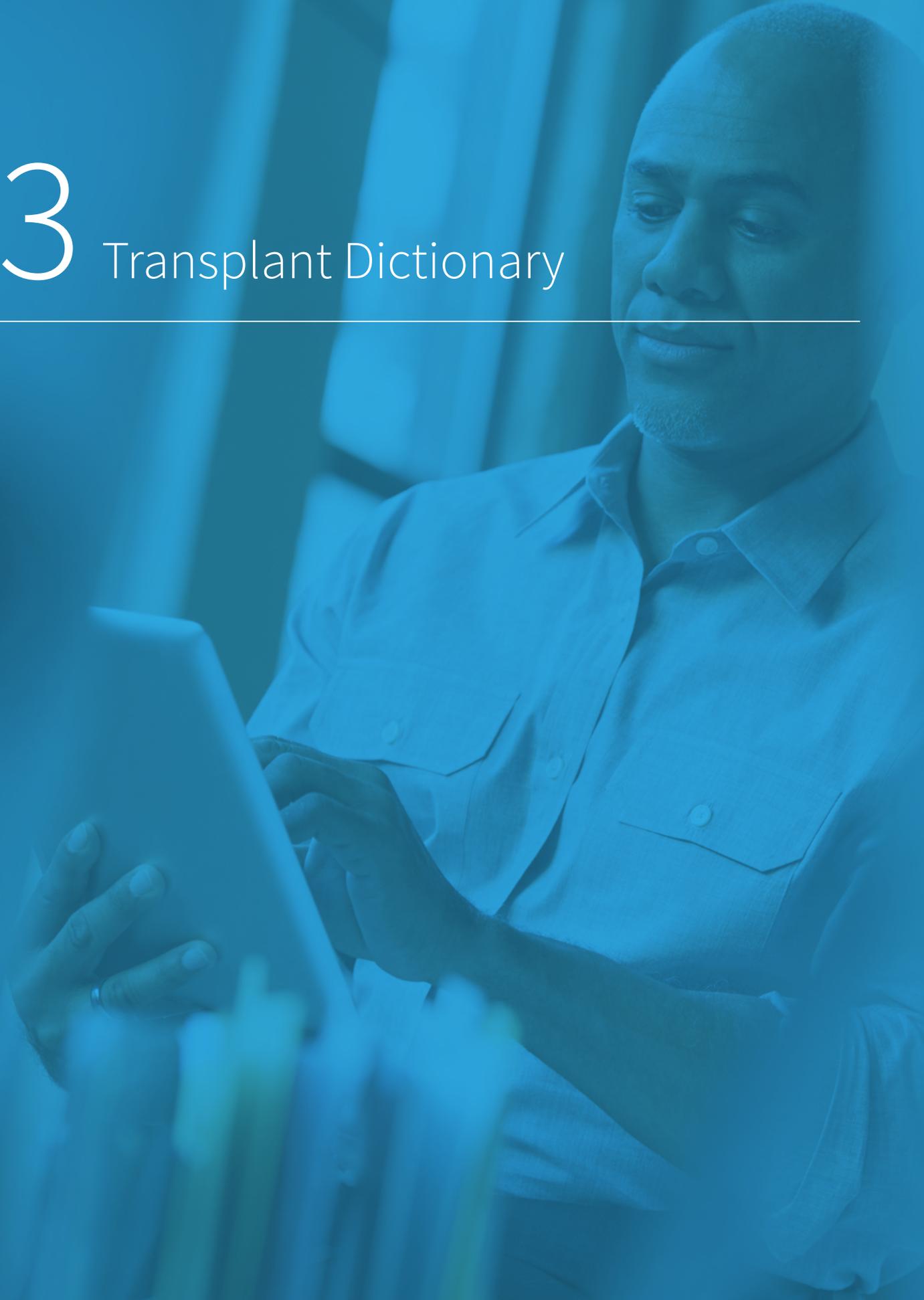
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13 Transplant Dictionary





Allogeneic transplant

A transplant that uses donor stem cells to help you recover your blood cell counts after receiving the preparative regimen. Donor stem cells are obtained from a genetically matched person or from frozen umbilical cord blood.

Anemia

Anemia means a person has a low number of red blood cells. Symptoms of anemia include feeling tired, weak, and short of breath.

Apheresis

This process collects stem cells from the blood using a machine that can separate the blood into various components.

Autologous transplant

A transplant that uses your own stem cells to allow your bone marrow to recover after you receive the preparative regimen.

B lymphocyte

A cell of your body's immune system that helps protect you from infection.

Bone marrow

A liquid, which looks like blood, found in the sponge-like network within your large bones.

Bone marrow biopsy

A procedure that obtains a sample of bone marrow for examination.

Bone marrow harvest

Bone marrow collected 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 in an arm vein. The catheter is used to give fluids or medicine and to obtain blood samples.

Consent form

A document that explains your treatment plan and the risks and benefits of a transplant.

Differential

A lab test that shows the percentages of different types of white blood cells present in the blood.

Donor

The person who donates stem cells used in a transplant.

- In an autologous transplant, the donor is oneself.
- In an allogeneic transplant, the donor is a genetically matched person. Types of donors include siblings (brothers or 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 and fathers, brothers and sisters, or children may be a haploidentical donor.

Eligibility

A series of tests done to see if you are healthy enough to undergo a transplant. These tests evaluate your organ (heart, lung, kidney, and liver) function, blood counts, bone marrow, and the status of your disease.

Engraftment

The term used to describe how well blood cells recover after the stem cells are transplanted.

Graft

A collection of stem cells that is infused into veins 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 an allogeneic transplant. It is an immune reaction of the donor's cells to the recipient patient's body tissues.

Graft versus malignancy

A reaction of the allogeneic donor's cells to the patient's cancer. The graft-versus-malignancy effect is a desirable reaction and part of the treatment in an 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 hemoglobin range for women: 11.7-15.7 g/dL

Normal range for men: 13.5-17.7 g/dL

Hematocrit (HCT)

The proportion of red blood cells in the body compared to the total blood volume.

Normal hematocrit range for women: 35-47%

Normal range for men: 40-52%

Human leukocyte antigen (HLA)

The human leukocyte antigen is a group of markers on the surface of cells of the immune system. These markers are inherited from parents. The antigens are used to find an allogeneic donor from either your family or the unrelated volunteer donor registries.

Immune system

A system of specialized cells of the body that protect us from bacteria, viruses, and other micro-organisms in the environment that cause infections.

Immunosuppressants

Drugs given to weaken the immune system to prevent the or treat graft-versus-host disease.

Infection prevention measures

Strategies that reduce the risk of infection. Key ways to control infection are:

- Reduce exposure to bacteria, viruses, and other micro-organisms. Done by avoiding people who are ill, reducing bacteria on the skin with daily showers and avoiding construction areas.
- Protect the body's natural defenses against bacteria, viruses, and other micro-organisms. Done by avoiding cuts and scrapes that break the surface of the skin and allow micro-organisms into the body.

Inpatient

A person who receives care in the hospital.

Micro-organisms

Small organisms that can cause infections. Micro-organisms include bacteria, viruses, protozoa, parasites, or fungi.

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. Mobilization can be done by using chemotherapy combined with a growth factor. These drugs stimulate the bone marrow to produce more stem cells.

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 a person's ability to make blood cells.

Neutropenia

A condition in which a person has a low number of neutrophils. Neutrophils are a type of white blood cell that are important for fighting bacterial infections.

Normal range is 40% to 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 drugs. The purpose of the preparative regimen is to suppress the patient's immune system enough to allow the donor's cells to grow and function.

Outpatient

This is medical care provided while you are living at home or in local housing. You come to the cancer center to receive care.

Platelets

Blood cells that form 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, based on type of transplant

For an autologous transplant:

- A combination of high-dose chemotherapy is given before a transplant.
- Done to destroy the cancer.

For a myeloablative allogeneic transplant:

- A combination of high-dose chemotherapy, with or without radiation, is given before a transplant.
- Done to destroy the cancer and the patient's immune system.

For a non-myeloablative allogeneic transplant:

- A combination of radiation and an immune-suppressing drug, with or without chemotherapy, is given before a transplant.
- Done to suppress (or weaken) the patient's immune system enough to allow the donor's cells to grow.

For a reduced-intensity allogeneic transplant:

- A combination of moderate doses of chemotherapy, with or without an immune-suppressing drug, is given before a transplant.
- Done to control the cancer and suppress (or weaken) the patient's immune system enough to allow the donor's cells to grow.

Red blood cells (RBC)

Blood cells that carry oxygen throughout the body.

Normal RBC range for women: 3.8-5.2 million/uL

Normal range for men: 4.4-5.9 million/uL

Syngeneic transplant

The stem cell 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 developing graft-versus-host disease. The T lymphocyte is also involved in the graft-versus-malignancy effect of an allogeneic transplant.

Transfusions

The infusion of different parts of the blood to treat specific problems. An infusion of red blood cells is given to reduce 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 a baby is born. 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 WBC range: 4,000 -10,000/uL

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