

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 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 to 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 doctor (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 plan and how to deal with symptoms • Schedule the stem cell donation and transplant • Provide emotional support for you and your family • Coordinate care with your referring doctor

Health care professionals	Responsibilities
Nurse practitioners and physician assistants	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> – 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 you write an advance health care directive • Review the 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

- 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) Units, E1 and EGR

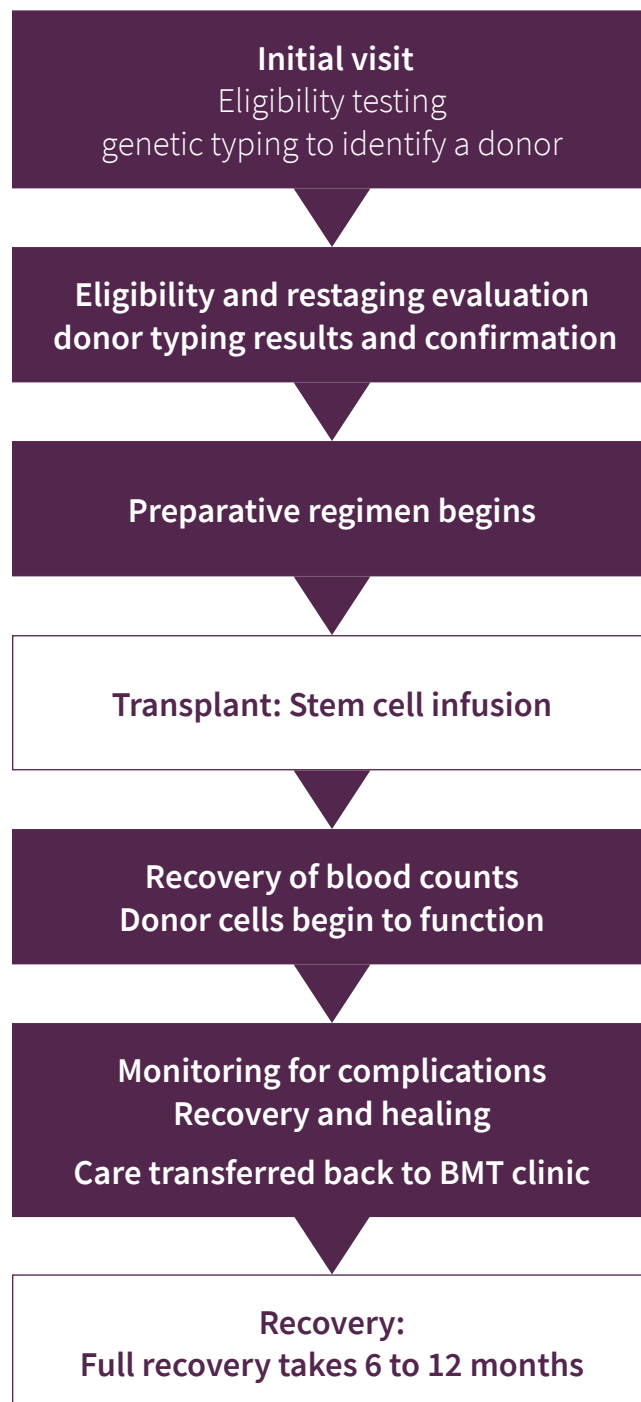
- Located in the main hospital (300 Pasteur Drive)
- Enter the main hospital entrance and visit the guest services counter for directions to the BMT inpatient unit
- Open 24 hours a day, 7 days a week
- BMT inpatient unit, E1, phone number is 📞 (650) 725-7121
- BMT inpatient unit, EGR, phone number is 📞 (650) 725-7120

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General outline of transplantation



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.

Prior to starting, you will sign a consent or treatment plan review form. The consent or treatment plan review will provide all the important information specific to your transplant.

The steps of an allogeneic transplant are:

- Identifying a donor
- Collecting the stem cells from the donor
- Administering the preparative regimen
- Transplant; infusing the stem cells
- Recovery

Identifying a Donor

Several different types of donors are eligible to give their stem cells for an allogeneic transplant. Donors may be related such as a family member or an unrelated volunteer from a international registry such as Be the Match. The genetic matching between a donor and recipient varies. A donor may be fully or partially matched with the patient.

Related Donor

- A matched sibling (brother or sister).
- Half matched donor from a parent, sibling or child. We call these donors haploidentical (half identical).

Unrelated Donors

- Matched unrelated donor
- Mismatched donor; a donor that is not matched at one or two sites.
- Cord blood donors. The umbilical cord blood that was collected after the birth of a child. The cord blood is frozen and donated to a registry.

If you have more than one potential donor your doctor will look at many different variables and choose the donor that best suits your needs.

Collecting the stem cells from the donor

There are 2 ways to collect stem cells from the donor. One method is to take the stem cells from the donor's bone marrow. The other method takes the stem cells from the donor's blood. The final product is called a graft. Your attending doctor in conjunction with your donor's preferences will determine which type of graft is best for you.

Bone Marrow Harvest

- Most stem cells are in the bone marrow, the spongy tissue inside large bones. Collecting the cells directly 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. The bone marrow harvest is similar to a bone marrow aspirate.

The product is called a bone marrow graft.

Peripheral Blood Graft

- Collecting stem cells from the blood is done by a procedure called apheresis.
 - To increase the number of stem cells in the blood, your donor is asked to take a medication that releases the stem cells into the blood. This medication is called a growth factor. 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 a vein in the donor's other arm to return 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.

The product is called a peripheral blood graft.

Preparative regimens

Myeloablative preparative regimen

The preparative regimen (sometimes called conditioning regimen) is how we prepare your body to accept the stem cells. We have three different intensities of preparative regimens. Your attending doctor will choose the best regimen for you based on your disease, medical history, age and general health.

The myeloablative preparative regimen consists of a combination of high-dose chemotherapy with or without radiation and will destroy (ablate) all the cells in the bone marrow (where stem cells grow). 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 non-myeloablative preparative regimen consists of radiation and an immune-suppressing medicine, 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. The donor's immune system can recognize diseased cells and destroy them.

The preparative regimen takes about 2 weeks to complete. It may be given while you are in the hospital (inpatient) or as an outpatient. Sometimes, part of the care is given while you are an inpatient and some care provided as an outpatient.

Reduced-intensity preparative regimen

The reduced intensity preparative regimen consists of chemotherapy with or without radiation therapy. The doses of chemotherapy are 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.

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, which is referred to as "day zero."

The stem cells quickly make their way to your bone marrow, however take time to start producing new blood cells. Your blood counts will be low while we wait for the donor's cells to grow and function. Your body will begin to heal and you will feel better once you begin making new blood cells in about 12 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 under the care of the outpatient BMT team for about 90 to 100 days and be seen frequently.

Recovery

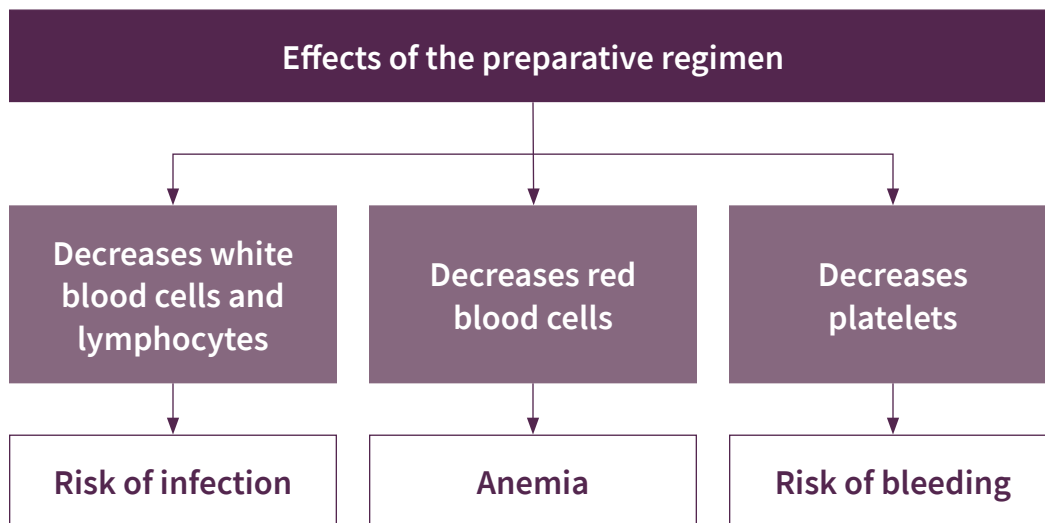
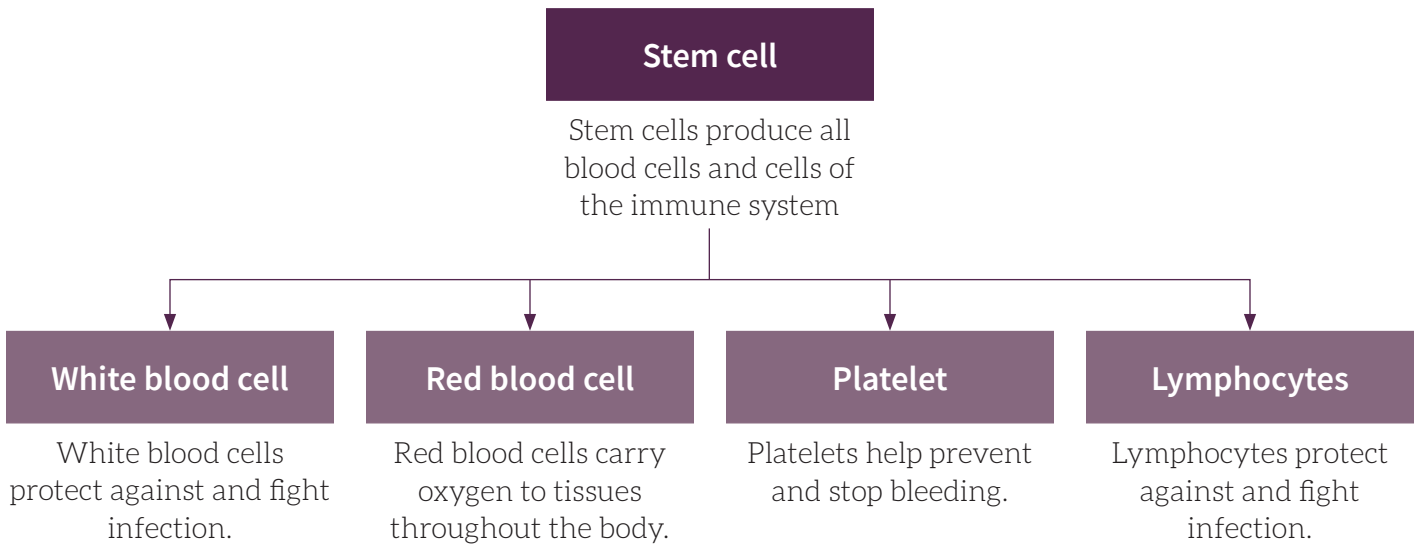
About 90 to 100 days after the transplant, your care is transferred back to your attending doctor. He or she will see you in the BMT clinic. Your central venous catheter is usually removed at this time. If you are staying locally you may return to your own home. If you have any complications that still require frequent follow up, your transition to the clinic may be delayed beyond 100 days, however, this delay is relatively rare.

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 doctor will depend on several factors including which medications you are taking and if you are having any complications from your transplant, such as graft-versus-host disease.

Recovering from an allogeneic transplant can take 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.
- Complete 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. You can have more than one caregiver or a team of caregivers that rotate.
- Review and sign your consent or treatment plan review forms.
- Have a dental exam.
All cavities should be filled. Any teeth affected by gum disease should be treated and braces 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 medications. Dehydration can increase the risk of kidney and liver injury as well as increase the side effects of medications.

✓ To-do list

- Attend the "Teaching for Transplant" class.
- Check your outpatient prescription coverage and find a pharmacy near Stanford.
- Obtain a medical alert bracelet.
- Plan for 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 or leukoreduced CMV blood products”
(Your nurse coordinator can tell you your CMV status.)

You should wear your medical alert jewelry until you no longer have active graft versus host disease and you are taking at most, very low doses of immunosuppressive medications. Confirm with your physician what he/she considers a low dose.

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.

Generally, authorization for a transplant occurs 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 at Stanford.
- Determine if there is any coverage for transportation.
- Know your prescription drug coverage, prescription co-pay amounts, and what pharmacies you can use.

Kaiser patients – Your deductibles and copayments at Stanford will be the same as if the services were provided at Kaiser. Clinic co-payments may be collected at the time of service; other co-payments may be billed to you by Stanford once Kaiser pays their portion of a claim.

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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Getting the care you want: Advance health care directive

Stanford's BMT program requires 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 and provide 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 require you to complete one.

There are multiple resources available to help with your advance directives. Examples of advanced directives 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 the following 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 under what circumstances 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 copy for your records and 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 optimize the outcome 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, vaping
- 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 your allogeneic transplant, ideally for a least a month
- Abstaining completely **during** the preparative regimen and transplant
- 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 abstinence contract, you may be required to undergo drug and alcohol testing, attend 12-step meetings, or complete a chemical dependency program.

Why do we require you to abstain?

There are 3 key reasons why we ask that you stop drinking alcohol, using tobacco, and taking illicit 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 jeopardize 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” during your transplant. The SAFE ZONE is based on travel distances and times from various locations in the San Francisco 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

Refer to housing handout previously mailed to you or provided by your social worker for housing information. For questions or help with housing please talk to your assigned social worker.

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. You can also apply online at: www.edd.ca.gov/claims.htm.
- 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)

For more information visit, www.edd.ca.gov

You can apply online at www.edd.ca.gov. The PFL program provides up to 6 weeks of paid time off. 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. Transplant recipients are required to have a caregiver(s) present with them 24/7 (24 hours a day seven days a week) while receiving care as an outpatient for about 2 to 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 address spiritual concerns, provide religious counseling, prayers, 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. Chaplains support your inner well-being in searching for hope, meaning of illness, life adjustment, and loss and grief. Chaplains also assist patients with Advance Health Care Directive questions and process.

The chapel is located on the first floor of the hospital outside of unit D at 300 Pasteur Drive and at the Well-being Center, J tower of 500 Pastuer Drive. There is also a meditation room located on the second floor of the cancer center.

Guided imagery and meditation

Please call Stanford Guest Services to arrange for a guided imagery session. Phone **650-498-3333** or dial 8-3333 from any hospital phone. The goal of the guided imagery and meditation program is to:

- Provide a system of visualization or meditation to help in your healing process
- Help equip you with more confidence in facing your situation
- Provide techniques that help create positive healing images

Guided imagery and meditation:

Patients can have a personalized session of guided imagery at no charge. Guided imagery is generally available on Tuesdays and Wednesdays.

Guided meditation: Headspace is a course of 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.

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

Leukemia and Lymphoma Society

- Detailed information on leukemia and lymphoma and resources
- lls.org

American Cancer Society

- Detailed information on cancer and resources
- cancer.org

Cancer Support Community

- Detailed information support services and resources
- cancersupportcommunity.org

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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. Many transplant patients have more than one caregiver.

A caregiver is required during the outpatient portion of the transplant for about 2 to 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 are stressful. Caregivers commonly experience anxiety, worry, 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 physically and emotionally challenging. 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.
 (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.
- **Be the Match** (bethematch.org) provides resources for caregivers before and after transplant.
- **Peer to Peer support.** The Stanford Peer 2 Peer Program can match you with a patient or caregiver who has been through a similar transplant. These mentors are trained, experienced volunteers who completed treatment at Stanford and can provide you with emotional support and information about their transplant experience. This communication can be via phone, email, or in person at the hospital, and can be as often as you prefer. Peer mentors all receive training about privacy, and will keep your information confidential.

Your social worker can also direct you to support resources.

Transitioning from spouse/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. Most medications come with 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.

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The Transplant

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Treatment plan review

You will be given a copy of your consent or treatment plan review form to read before your scheduled appointment to sign these documents. To prepare for this appointment:

- Read these forms and write down any questions you have.
- Identify someone who can come with you for your appointment. You will be given a lot of information and having someone else there can be very helpful.

The consent or treatment plan review forms will:

- Provide a detailed description of your treatment plan
- Describe side effects of treatment
- Discuss the potential risks and benefits
- Discuss participation in research studies

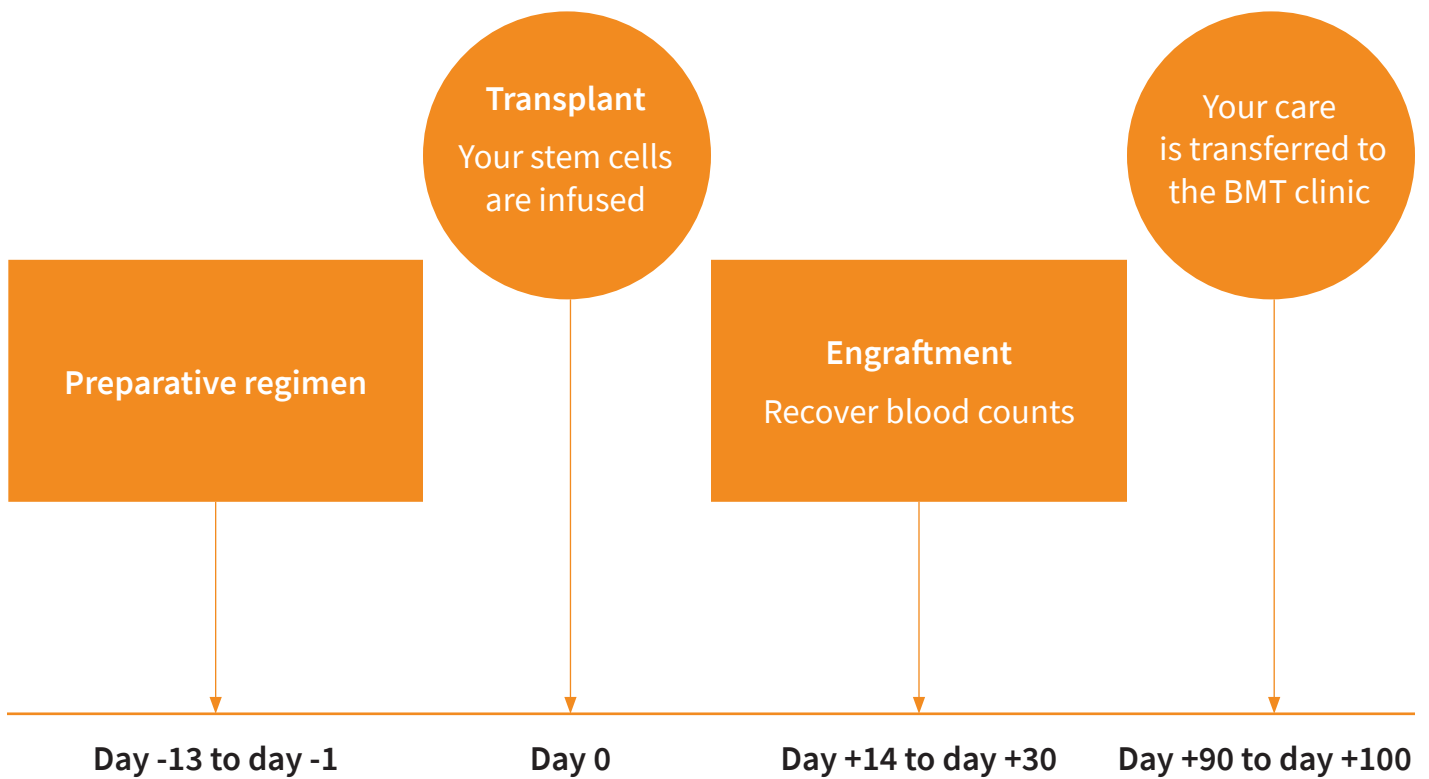
Research

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

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.

Keep a copy of your signed consent or treatment plan review forms in your guidebook

Allogeneic transplant outline



Preparative regimen

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

A myeloablative preparative regimen (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. The transplant takes place on the day your BMT team calls "day zero."

Transplant is the day your donor's stem cells will be infused through your central venous catheter. The donor's stem cells will begin to produce new blood cells in about 12 to 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 and the need for transfusions may persist for 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 (human leukocyte antigens). The closer the HLA match, the lower your risk of graft-versus-host disease.

However, even when there is a “perfect” match there remains a risk of graft-versus-host disease.

- **Immunosuppressive medicine**

Immunosuppressive medicines are taken to weaken the immune reaction of your donor's cells against your body. There are many different immune-suppressing medicines. Please check your consent or treatment plan review form to find out which immune-suppressing medicines you will receive. The duration of time that you will take these medications is dependent on many factors. Most typically, they are continued for 6 to 12 months.

- **Preventing infections**

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

- **Minimizing sunlight exposure**

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. The acute form typically 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. As any tissue can be affected by chronic graft versus host disease, the symptoms you experience will depend on what tissue is involved.
- Treatment of both acute and chronic graft-versus-host disease involves administering additional 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 may last for years. We will work with you on treatment, strategies to prevent infections, how to manage your symptoms, and focus on maximizing your quality of life.

Hospital routines

You will be seen at least once a day by the entire medical team on daily rounds. The medical team includes an attending doctor, a medical fellow, or resident and an advanced practice provider (physician assistant or nurse practitioner). Your nurse and nursing assistant will be monitoring and caring for you throughout the day. Other team members that will be involved in your care on a daily basis include: a pharmacist, physical therapist, dietician, social workers and spiritual care staff.

Every day you should

- Take a shower.
- Get out of bed.
- Work with the physical therapist or exercise on your own.
- Complete mouth care at least 5 times a day.

We recommend that you bring the following items to the hospital:

- 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 that you want to decorate your room, such as photos or a favorite blanket
- Items to help pass the time, a laptop computer, radio, music, games etc.

Care and routines in the infusion treatment area (ITA)

The ITA is located on the second floor of the cancer center. There is a medical team, just like in the hospital, that will help manage your care.

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.

Please bring the following to your first ITA visit:

All of your medications so the team can verify your medication regimen. For the following visits, a detailed medication list will be sufficient unless otherwise requested by medical team

Please bring the following to all of your ITA visits:

- Your guidebook
- Your medication 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, juice, and canned soup for patients only.
 - You need to keep track of your fluid intake to ensure you are drinking 2–3 quarts/liters (70 to 100 fluid ounces) per day.

Parking is free on the weekends in the Blake Wilbur valet parking area (no valet).

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
- Draw your blood

We will also:

- Perform a physical exam
- Review your medication list
- Discuss your lab results
- Discuss your symptoms and form a plan of care
- Administer 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

All precautions start at the beginning of the preparative regimen	3 months	6 months	Stop (when you no longer have active graft versus host disease and you are taking, at most, very low doses of immunosuppressive medications.) Confirm with your physician what he/she considers a low dose.
Activities of Daily Living			
Frequent thorough handwashing and daily shower	Always a good idea		
Frequent oral care	stop		
Avoid wearing contacts	stop		
Wear HEPA Filter Mask	stop		
Avoid soaking in tubs or hot tubs	stop		
Low Microbial Diet	stop		
Avoid people who are ill	Always a good idea		
Wear Medic Alert Bracelet			stop
Animals			
Don't care for dogs and cats	stop		
Avoid getting new pets		stop	
Don't care for ranch animals			stop
Remove birds from the home			stop
Avoid cleaning fish tanks or aquariums	stop		
Household Activities			
No gardening			stop
Avoid vacuuming, dusting, sweeping	stop		
Keep windows closed	stop		
No fires in the fireplace	stop		
No live Christmas tree	stop		

All precautions start at the beginning of the preparative regimen	3 months	6 months	Stop (when you no longer have active graft versus host disease and you are taking, at most, very low doses of immunosuppressive medications.) Confirm with your physician what he/she considers a low dose.
Activities			
Avoid swimming	stop		
Avoid fishing	stop		
Avoid carpentry and woodworking		stop	
Avoid golfing	stop		
No jogging	stop		
Avoid contact sports	stop		
No driving	stop		
Intimacy			
No "French" kissing	stop		
Females: have sexual partner wear a condom	stop		
Males: wear a condom	stop		
Avoid receiving oral sex	stop		
Avoid giving oral sex	stop		
Avoid anal intercourse	stop		

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

Infection prevention strategies

Daily health routines

- Good 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 deep breathing exercises. In the hospital, we will give you a respiratory coach to help with 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 protect your skin from sunlight.

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 micro-organisms like bacteria, viruses and fungi 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 3 months after your transplant

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 a myeloablative or reduced intensity preparative regimen you will probably develop some irritation, swelling and 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 perform frequent mouth care 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, electric toothbrush or water pic until 90 to 100 days after your transplant.

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
- Only your children are allowed to visit and we discourage children under the age of 12 years.

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 are on, at most, very low doses of immunosuppressive medications. Check with your doctor as to what he/she considers low doses.
- Do not care for farm or ranch animals, small caged animals, or reptiles until you are on, at most, very low doses of immunosuppressive medications. Check with your doctor as to what he/she considers low doses.

Plants

- Plants may stay in your home.
 - Do not care for them until you are on, at most, very low doses of immunosuppressive medications. Check with your doctor as to what he/she considers low doses.
 - 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 until you are on, at most, very low doses of immunosuppressive medications. Check with your doctor as to what he/she considers low doses.

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 for 3 months post-transplant.

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.

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 can cause herpes zoster or shingles.

Herpes zoster or shingles is most likely to occur in the first year after your transplant. Herpes 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 herpes zoster or shingles is to cause long-term pain and itching. To prevent herpes zoster or shingles, you will be asked to take an antiviral medication, 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 and begin therapy.

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
- Frequent 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 a type of fungal organism. For prevention, you will take a medication before transplant and beginning again about 4 to 6 weeks post-transplant and continuing until you are off all immunosuppressive 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

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Reducing infection risk from food: The low microbial diet

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

Preparing, cooking, and storing food properly can reduce bacteria in food. 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. If you are considering using a protein powder, please ask your dietitian about the safest and best options.

When to follow the low microbial diet

- Begin the low microbial diet when you start the preparative regimen for your transplant and continue for 3 months following your transplant.
- Until you are off all immunosuppressive drugs, do not eat raw animal products.
- Of course, you should always practice safe food preparation.

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 which 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 <small>with 3-minute rest time</small>	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"> • Kefir, buttermilk, acidophilis milk • Raw milk • High probiotic yogurt, e.g. Activia, Danactive • 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, dried 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 • Kombucha
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

Supportive care 69

Blood transfusions 79



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, toothpicks, water pics, or electric toothbrushes
- Use a very 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, 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

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 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 to 10 minutes.
- If you have a nosebleed, put pressure on the bony part of your nose for 5 to 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.

Physical Therapy Inpatient Activity Guidelines

1) Spend 6 or more hours out of bed daily.

- Exercising (including walking)
- Sitting in a chair or at edge of bed
- Showering

2) Perform aerobic exercise for at least 30 minutes daily.

- Exercise is more effective spread throughout the day.
(for example: three 10-minute walks)
- You may use the stationary bike after instruction by your physical therapist.
- Leave your room and walk on the unit at least 3 times per day.
(1 lap around the unit = 250 feet, 11 laps > 1/2 mile)

3) Perform range of motion and resistance exercise.

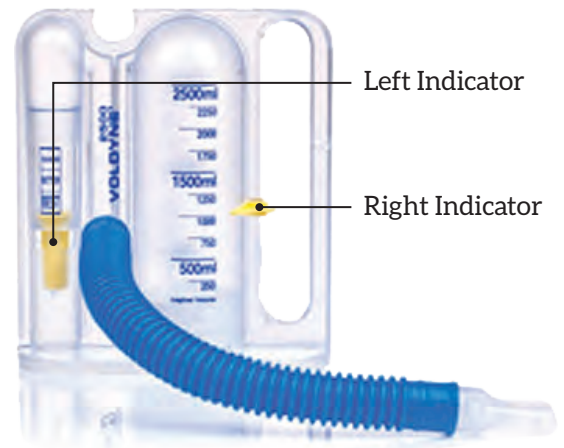
- Try to do at least 4 exercises, 3 times a day.
- Adjust these activities according to instructions from your healthcare team.
- **If your platelet count is less than 20 K/ μ l (20,000), do NOT push, pull, lift, or perform resistance exercise** but continue to perform range of motion exercises, walk and use the stationary bike without resistance.
- If your platelet count is less than 10 K/ μ l (10,000), perform gentle range of motion exercise only.

- 4) Perform breathing exercise using an incentive spirometer/respiratory coach.
 - 5 to 10 times every hour while you are awake.
- 5) Perform exercise at a light to moderate exertion level.
 - You might breathe a little harder, but should be able to carry on a conversation during this exercise.
- 6) Avoid any position which puts your head below your heart.
- 7) If you feel pain, stop the exercise and tell your health care team.

How to Use the Incentive Spirometer

Start by holding the incentive spirometer in an upright position. Then, breathe out normally before using the device:

- 1) After you breathe out, tightly seal your lips around the mouthpiece.
Do not let your tongue block the mouthpiece.
- 2) Breathe in slowly and deeply through the mouthpiece to raise the indicators.
Do not blow into the mouthpiece.
- 3) The left indicator measures how fast you are breathing (rate).
Try to keep the left indicator in the “best” range.
- 4) The right indicator measures how deeply you are breathing (volume).
Try to get the right indicator to the highest level you can.
- 5) When you cannot inhale any longer, remove the mouthpiece and hold your breath for at least three seconds.
- 6) Breathe out normally.



Exertion Levels

Rate of Perceived Exertion (RPE) Scale and Talk Test

The following Rate of Perceived Exertion (RPE) Scale and Talk Test can help you see how hard you feel your body is working.

In most cases, you should aim for “Moderate Activity” (4 to 6 on the scale). That’s a level that allows you to still talk in short sentences while you exercise.

RPE Scale	Rate of Perceived Exertion	Talk Test
10	Max Effort Activity Completely out of breath and unable to talk.	You need to take breaks from conversation in order to maintain this exertion.
9	Very Hard Activity Difficult to breathe and uncomfortable. Able to say a few words only.	
7-8	Vigorous Activity Breathing heavily and somewhat uncomfortable. Difficult to speak a few sentences.	
4-6	Moderate Activity Breathing deeper and a bit heavier. Can maintain a conversation, but more challenging.	You might breathe a little harder, but should be able to carry on a conversation during this exercise.
2-3	Light Activity Minimal exertion. Easy to walk and talk.	You can sing while performing this activity.
1	Very Light Activity Slight exertion. A little more than lying in bed or sitting in a chair.	

Adapted from modified BorgCR10

Range of Motion Bed Exercise (Try to do at least 4 exercises, 3 times a day.)

1) Quadriceps Sets

- Tighten muscles on front of thigh by pushing knee down into the surface of the bed.
- Hold for 5 seconds.
- Repeat 10 times.



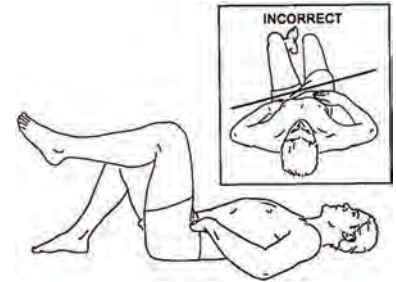
2) Hip Abduction/Adduction

- Bring leg to the side and return. Keep knee straight.
- Repeat 10 times.



3) Knee to Chest

- Bring one knee up, then return. Be sure pelvis does not roll to side. Keep pelvis still.
- Repeat 10 times.



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Range of Motion Sitting Exercise (Try to do at least 4 exercises, 3 times a day.)

1) Head Tilts

- With head in comfortable, centered position and chin slightly tucked, gently bring ear towards shoulder.
- Hold 15 seconds.
- Repeat 3 times.



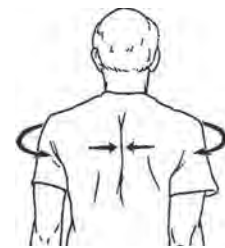
2) Shoulder Rotations

- Roll shoulders backwards, making a small circle.
- Repeat 10 times.



3) Shoulder Retraction

- Pull arms back, pinching shoulder blades together.
- Repeat 10 times.



4) Knee Extension

- Tighten muscles on front of thigh and straighten knee.
- Repeat 10 times.



5) Hip Flexion

- Lift knee and then lower it.
- Repeat 10 times.



Range of Motion Standing Exercise (Try to do at least 4 exercises, 3 times a day.)

1) Calf Stretch

- Stand with one foot forward and knee bent.
- Stand with the other foot back and knee straight.
- Keeping back heel on the floor, lean forward until stretch is felt in calf muscles.
- Hold 30 seconds.



2) Hip Flexion

- Using furniture for balance, lift one foot 6 inches from the ground.
- Repeat 10 times.



3) Knee Flexion

- Using furniture for balance, bend one knee backwards.
- Repeat 10 times.



4) Hip Abduction

- Using furniture for balance, swing one leg out to the side with knee straight.
- Do not lean to side.
- Repeat 10 times.



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Resistance Exercise (Try to do at least 4 exercises, 3 times a day.)

Do NOT perform these exercises if your platelet count is less than 20 K/ μ l (20,000).

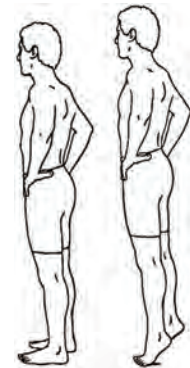
1) Bridging

- Slowly raise buttocks from the bed, keeping stomach tight.
- Repeat 10 times.



2) Heel Risers

- Rise up onto balls of feet.
- Repeat 10 times.



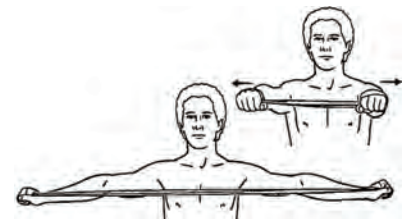
3) Chair Squats

- Keeping feet flat on floor, shoulder low, squat 5 to 6 inches.
- Repeat 10 times.



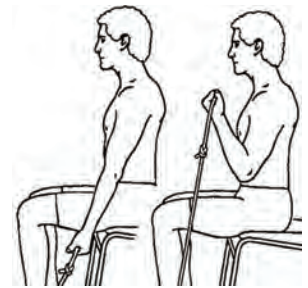
4) Resistance Band Horizontals

- Holding on with both hands and arms straight out in front, stretch band across chest.
- Repeat 10 times.



5) Resistance Band Biceps Curls

- With one end of the band secured, flex elbow.
- Do not lean or move shoulder.
- Repeat 10 times.



6) Resistance Band Triceps Extension

- With one end of the band secured, extend elbow.
- Do not lean or move shoulder.
- Repeat 10 times.



Physical Therapy Discharge Activity Guidelines

1) Follow these guidelines for

- **1 year** from your transplant date
-

2) Perform exercise at a light to moderate exertion level.

- You might breathe a little harder, but should be able to carry on a conversation during this exercise.
-

3) Continue to perform aerobic exercise for at least 30 minutes daily.

- Walking
 - Private exercise equipment, such as a stationary bike or treadmill
 - Cycling with a helmet
 - Jogging/running in a safe environment (track or clear, paved surfaces) at no more than a moderate exertion level
-

4) Continue to perform range of motion and resistance exercise.

- **If your platelet count is less than 20 K/ μ l (20,000) do NOT push, pull, lift, or perform resistive exercise.**
 - If your platelet count is less than 10 K/ μ l (10,000) perform gentle active range of motion exercise only.
 - Keep weights light; you should be able to perform at least 10 repetitions at no more than a moderate exertion level.
-

5) Avoid

- High impact activities such as jumping
 - Positions which put your head below your heart (for example, Yoga "downward dog")
-

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>

Music

A musician can visit your room for a personal concert. Our accomplished musicians play the harp and guitar and play a wide variety of music at no charge. To request these services, please call 📞 (650) 498-3333.

Art

Facilitators provide one-on-one art sessions using a variety of media. You can also hold a group art session with your visitors at no charge. To request these services, please call 📞 (650) 498-3333

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, complete advance care planning, and help you understand 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 will receive blood transfusions using blood from a 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 associated with blood transfusions including:

- 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 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 into 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 carries a risk of infection, which happens when germs get into the bloodstream through the catheter. If you develop a catheter infection, you may become ill with a fever and chills, or the skin around the catheter may become red and sore. Catheter-related infections are 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.
 - The dressing changes and general maintenance for the PICC is provided 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 or your caregiver will be asked to flush each lumen of the catheter daily
 - The dressing change is done by your healthcare provider

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 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 into your veins while you are receiving care in the cancer center.

The 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 prevent and fight infection

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 inpatient units.

Delivery of medicine and supplies

- You can get medicine and supplies that are delivered to the ITA four times 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 reach from children and pets.
- 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 inpatient units for a new container.
 - DO NOT throw 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 to 100: Homeward Bound Class

About 3 months after your transplant, you will be scheduled to attend Homeward Bound, a patient education class taught by BMT advanced practice providers to ease your transition from active therapy with frequent follow up in the ITA, back to your home environment with less frequent clinic visits. We will review recommendations to prevent infection, how to best care for yourself at home, survivorship, chronic graft-versus-host disease and recovery. We try to answer the most commonly asked questions and will provide you an opportunity to raise your questions and concerns.

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. You will be scheduled for a single survivorship visit in the ITA just before transitioning to the BMT clinic. Further survivorship care will be in conjunction with your BMT team in the clinic and your local doctors.

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

Chronic graft-versus-host disease (GVHD)

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. Wearing sunscreen is especially important to do for the first 2 years after your transplant but wearing sunscreen is a good life-long habit.

You can protect your skin by using sunscreen or covering your skin with clothes anytime you are outdoors.

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, skin discoloration, or skin tightness
- **Mouth:** dry mouth, redness, soreness, or 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
- **Male genital tract:** sores or skin changes on the penis, 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 last 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 as your immune system takes a year or more to fully recover. Additionally, most patients continue on some immunosuppressants to prevent graft versus host disease, such as tacrolimus or prednisone.

To prevent infections:

- Frequent and thorough hand-washing.
- Avoiding anyone who is sick.
- Safe food preparation.
- Get your annual flu vaccine.
- Ask your close family and friends to get vaccinated as well.

- Continue your antiviral drugs. You will be taking an antiviral medicine, Acyclovir® is most common, for at least one year to prevent cold sores (herpes simplex) and herpes zoster or shingles.

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

Physical and emotional recovery

It is an understatement to say that you and your family have been through a lot. The diagnosis and treatment of cancer is difficult emotionally, physically, spiritually, and financially. It will take time to recover.

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 physical 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 3 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 work.

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, such as cataphil or aquafor, to help repair the dry flaky skin. Do not use skin lightening creams or pick at the skin as these can worsen the changes.

If you notice a red, blistering rash that is itchy or painful, report this to your cancer doctor (oncologist or hematologist) or BMT team. This rash may represent an infection called herpes zoster or shingles.

Your skin will be more sensitive to the sun after treatment and you will more easily develop a sunburn. Avoid exposing your skin to sunlight for 2 years after the transplant, although sun protection is a good life-long habit.

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.

Your mouth

Hard sour candy or sugarless gum may help relieve a dry mouth as will frequent sips of water. 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 recover. 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). Check with your BMT team.

Alcohol

Check with your BMT 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, medicines for nausea, or 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 BMT 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 you avoid “French” kissing for 3 months
- We recommend your partner wear a condom for 3 months.
- We advise that you avoid oral sex and anal intercourse for 3 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 (high-dose chemotherapy with or without radiation) your ovaries will stop producing hormones such as estrogen. It is also possible that reduced-intensity and non-myeloablative preparative regimens may cause your ovaries to stop producing hormones.

Loss of estrogen leads 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.
- We recommend you avoid “French” kissing for 3 months.
- Wear a condom for 3 months.
- Avoid oral sex and anal intercourse for 3 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 if your partner is capable of becoming pregnant. 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 transplant.

Once you return home, your BMT attending doctor 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, please ask your BMT doctor if you should take antibiotics.

Corresponding with your unrelated donor

It is your decision if you want to correspond or release personal information to your donor.

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. Each donor center has their own rules about anonymous correspondence between the donor and recipient.

Any anonymous correspondence 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 correspondence.

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 94304
☎ (650) 723-7979 or ☎ 650-497-3756

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 discuss with your nurse coordinator.

Your comments and suggestions are welcome.

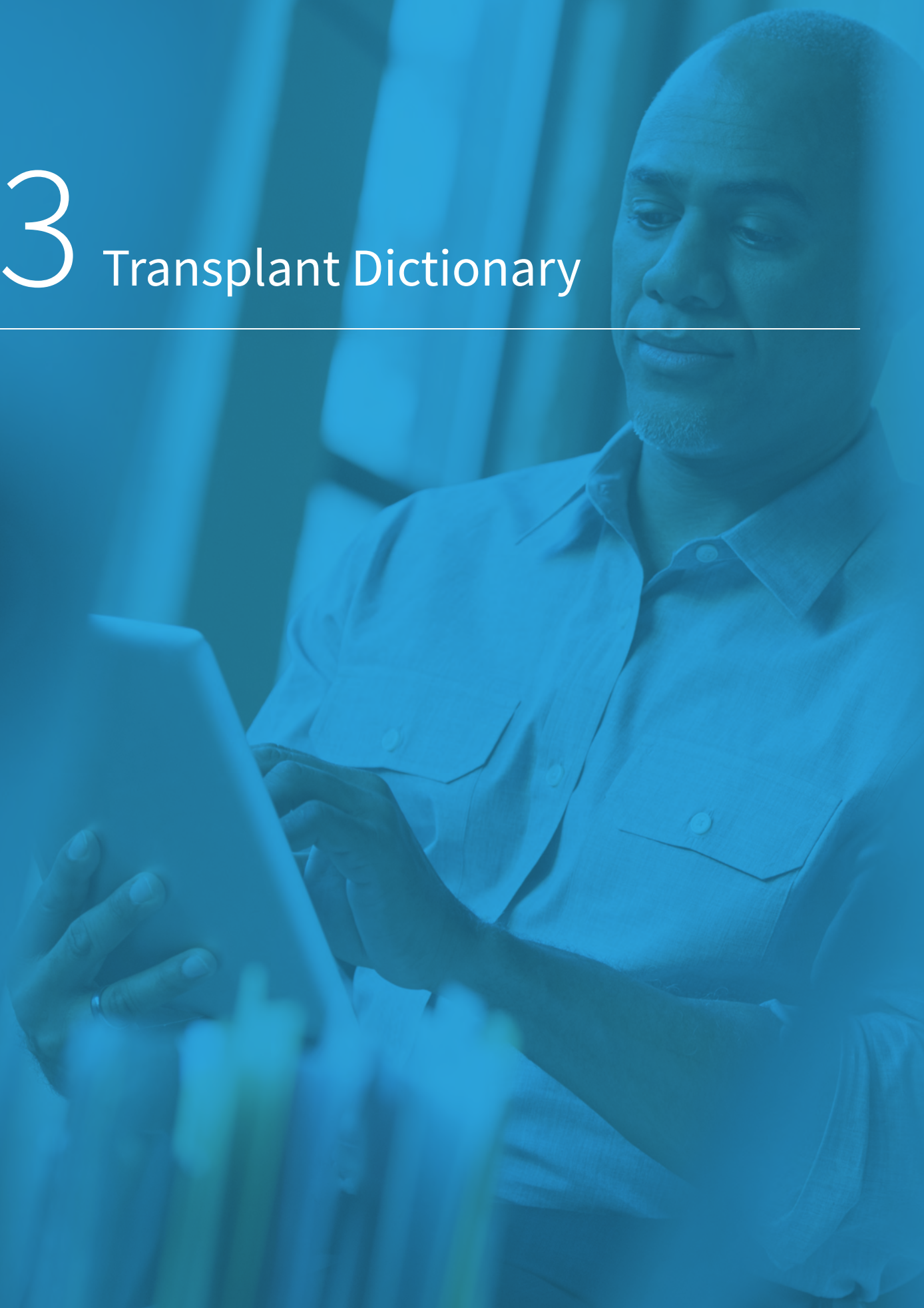
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13 Transplant Dictionary





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 or treatment plan review 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 cure 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 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. Strategies include 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. Strategies include 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 from the blood. Mobilization can be done by using chemotherapy combined with a growth factor or a growth factor alone. 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

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.
- Given to destroy the cancer.

For a myeloablative allogeneic transplant:

- A combination of high-dose chemotherapy, with or without radiation, is given before a transplant.
- Given 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.
- Given 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.
- Given 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 the development of 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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