

03

Important Things to Know About



Patient and Family Advisors: **Stephen Hasper**, Bone Marrow Transplant Survivor and his wife, **Joyce Hasper**, Spouse and Caregiver

Caregiver Role

A caregiver is someone who helps to care for you during and after your transplant. This person plays a very important role in the success of your transplant. In fact, a caregiver plays such an important role that you must have a caregiver in order to have a transplant at City of Hope.

The caregiver generally supports a patient throughout the transplant process. He or she may be called on to stay with the patient for long hours, talk to doctors, nurses and other members of the health care team, and support the patient in many other ways. The caregiver, along with the patient, is an active member of the health care team.

Most patients have one particular person who acts as the main caregiver. However, it is often not possible for one person to fill the role full time. Instead, several people can share the role of caregiver. If this is the case, it is important for all caregivers to communicate and organize their efforts.

The patient's needs change over the course of the transplant process, from pretransplant preparation, hospital stay and through the recovery process. It is important for the caregiver to know what to expect. Therefore, the caregiver needs to know as much about the transplant process as possible.

CAREGIVER RESPONSIBILITIES

The caregiver must:

- Be at least 18 years of age and physically able to fulfill the caregiver role.
- Provide transportation to and from City of Hope for both pre- and post-transplant appointments. There may be several appointments during the weeks after transplant.
- Be able to reach the patient within 30 minutes at all times and be physically present 24 hours with the patient.
- Assist the patient with their activities of daily living depending on the patient's physical abilities, such as lifting, helping the patient to move from the bed to the toilet, walking, bathing, assisting with dressing, meal preparation, vascular access device care and making sure the patient is taking their medication properly. Some patients may need more assistance than others.
- Observe/monitor changes in the patients condition and report them to your health care team.
- Serve as a communication link between patient and health care team.
- Give encouragement to the patient while taking time to care for yourself.

QUESTIONS FOR CAREGIVERS

A transplant is difficult, not only for the patient, but also for family members and caregivers. This is especially true if the caregiver has ongoing family and/or job responsibilities.

Here are a few questions and tips that may help:

- Ask what you will do as a caregiver.
- Ask what you need to know as a caregiver.
- Ask how long you will be a caregiver.
- Ask yourself how you will manage being away from work for extended periods and how you will take care of your own responsibilities while you are a caregiver.

TIPS FOR CAREGIVERS

- Don't hesitate to ask other family members and friends for help in caring for the patient, your family and you throughout the transplant. You will need help and others concerned about the patient's well-being will appreciate the opportunity to lend a hand.
- Be realistic about your limitations. Get enough sleep, eat properly and take time off for yourself. You will be a bigger help to the patient if you are healthy and calm, rather than sick and overwhelmed.
- Be prepared for changes in the patient's behavior. The medications and stress may cause the patient to become depressed or angry. He or she may say things that don't make sense or see things that aren't there — these changes are only temporary but can be frightening when they occur.
- At the same time, understand that your loved one needs you now more than ever before. Your help is not only welcome — it is absolutely essential.
- Don't be shy about asking for help or answers to your questions. Good communication between you and the health care team is important and highly necessary. Remember you are entitled to have all your questions answered fully.
- City of Hope clinical social workers are available to talk to family members and caregivers to assist you and provide support and resources to help you through this time. If you would like to talk to a social worker, call the division of Clinical Social Work at **626-218-2282**.
- Communication with family and friends is important. It may be helpful to designate someone as a family spokesperson. This is someone who can be the main contact person between your friends and extended family and you. The family spokesperson can relay information and questions and will help to avoid confusion and misinformation.

CHOOSING A CAREGIVER

Your caregiver is an important part of your care and will be an important part of your life throughout the transplant and recovery period. For many people, their natural choice for a caregiver is a spouse, partner, parent or a close family member or friend. Some may even have several people share the caregiver role. In any case, it is important for you to think very carefully about who you will ask to take on this responsibility.

The following questions are taken from the National Marrow Donor Program website at **bethematch.org** and may help you to think of questions to ask yourself when deciding on a caregiver:

- You might have to be at the hospital for long periods of time. Is this person comfortable in the hospital setting?
- Will your caregiver be able to take you to your medical appointments?

- Can she or he deal with stressful situations?
- Your caregiver may have to be away from his or her work for weeks or even months. Is your caregiver able to take a leave (such as Family Medical Leave Act - FMLA) or an extended absence from work? Does he or she have a good means of support that will allow for unpaid time off?
- Are you and your caregiver able to get along most of the time? Do you get over disagreements easily?
- Will your caregiver support your health care choices and is familiar with your advance directive? (see advance care planning section).
- Will your caregiver be a strong advocate for you?

CAREGIVERS RESOURCES AT CITY OF HOPE

Available in the Sheri & Les Biller Patient and Family Resource Center:

- City of Hope caregivers education, support, and resources
- Caregivers Connect is a support group where caregivers can take time to relax, get support and get to know other caregivers.
- A Caregivers Guide: Tips and Tools for Reducing Caregiver Stress

Visit: [CityofHope.org/caregivers](https://www.cityofhope.org/caregivers)



FAMILY AND FRIENDS

Your transplant will have an impact on your family and friends. You may be away from them for extended periods and they may become worried or anxious. You can help your family and friends by telling them what to expect during and after your transplant. Let them know that your needs will change throughout the process and how they can best help you during this time.

FAMILIES WITH CHILDREN

If you have children it is best to be honest with them and let them know what is going on. A City of Hope child life specialist is available to help your children adjust to the changes brought about by your treatment and recovery period. If you would like to know more about child life services, please ask your doctor for a referral.

MyCityofHope Patient Portal

MyCityofHope is a secure online portal that puts your medical information at your fingertips. With MyCityofHope, you can:



Request appointments.

Request your next appointment or view details of your past and future appointments.



Ask for prescription refills.

Send a renewal request for any of your refillable medications.



View notes.

View your clinician notes and after visit summary.



Pay bills online.

Check and pay your bills from home.



Connect to Hope Virtual (televisit) appointments.

Connect with members of your health care team through video on your smartphone, tablet or computer.



Access most test results.

No more waiting for a phone call or letter. View your results for most tests online at your convenience.



Communicate with your care team.

Email your care team to get answers to medical questions without multiple telephone calls or unnecessary appointments.



Give friends and family access.

Called "proxy access" it allows a parent, guardian, caregiver, or an authorized representative to log into your personal MyCityofHope account and connect to your information.



Request, download or send your medical records.

Access information about your visits or send it to someone else.



Advance Directive

HOW TO COMPLETE AN ADVANCE DIRECTIVE.

If you are not able to speak for yourself, there are a few things your loved ones and health care team need to know:

- Who should speak for you
- How you want to live
- What quality of life means to you
- The type of medical care that you would or would not want

All adults, regardless of age or health status, should have an advance directive. Even though it may be unlikely that you will need it, completing an advance directive is strongly recommended early in your care.

If you already have an advance directive, work with your health care team to have it added to your medical records at City of Hope. Review it regularly to be sure it reflects your current wishes. You may want to change your advance directive based on any new treatment plans or major life changes.

1. Fill Out the Advance Directive Form

If you need help thinking through the advance directive, we have many resources to support you. City of Hope's Patient and Family Advisory Council found the following to be most helpful:

- You can fill out and save your advance directive online. The advance directive form and a step-by-step guide to fill it out can be found at **prepareforyourcare.org** (see QR code below). Please note that this is the only advance directive form that is eligible for free electronic notary services.
- You can learn more about how to choose the right person by watching this video: **CityofHope.org/health-care-proxy** (see QR code below). (This person may be called a health care proxy or medical decision maker.)
- Think about what matters most to you, and share it with your health care proxy. At **gowish.org** (see QR code below), you can use an online deck of cards to help you prioritize what is most important to you.

For more help on how to fill out the form, please email **advancedirective@coh.org**.

Scan the QR codes with your phone's camera to visit the websites.



prepareforyourcare.org



CityofHope.org/health-care-proxy



gowish.org

Please do not sign or date the form until you complete No. 2.

2. Notarize or Witness Your Advance Directive

We highly recommend using a notary service to complete your form. There are two free options listed below. The third option is to have two witnesses sign the form.

Option 1 In-person notary services are offered at City of Hope's Duarte campus. Contact the Sheri & Les Biller Patient & Family Resource Center at **(626) 218-2273**. **Please do not sign or date the form until you meet with the notary.**

Option 2 Virtual notary services allow City of Hope patients to have their advance directives notarized from anywhere, 24/7. **Please see instructions under “Virtual Notary Service” below. Please do not sign or date the form until you meet with the notary.**

Option 3 Your witnesses must know you, be at least 18 years of age and agree that it was you who signed this form. Your witnesses cannot be your medical decision maker, your health care provider or work at the place that you live (like a nursing home).



Virtual Notary Service

To use this free online notary service, you must use the saved PDF of the California advance directive form from **prepareforyourcare.org**. Make sure to have your government-issued ID ready, and plan for about 10 minutes to complete the notary process.

1. Scan the QR code to the left, or enter the following URL to go to the website:
usvirtualnotary.com/cityofhope
2. Select the date and time that you would like to have a virtual appointment with a notary.
3. After booking your appointment, you will be directed to a page to upload your completed California advance directive form from **prepareforyourcare.org**. An email appointment confirmation will also be sent to you with a link to your session. If you are not able to upload your form, you can reply to the email with the PDF attached.
4. When it is time for your session, click the link in the email you received to meet with the notary.
5. During the session, the notary will check your identity and witness the electronic signing of the document.
6. After you have signed, the notary will email the notarized copy to you and to City of Hope. The team at City of Hope will upload it to your patient chart within two business days.

Scan the QR code to the right to see video instructions about the online notary process. The video is also available on the website **usvirtualnotary.com/cityofhope**.



3. What to Do With a Completed Advance Directive

1. Make copies and give one each to:

- Your medical decision maker(s)
- Each family member who would know if you were hospitalized
- Your lawyer, if you have one (remember, your lawyer is not likely to be called if you are in a hospital)

If you had the document completed on your own, bring it in to your care team or at the Biller Patient and Family Resource Center. You may also upload your completed advance directive to the MyCityofHope patient portal. If you use the virtual notary service, they will send your advance directive to City of Hope for you.

2. Keep the original, and put it in a safe place where you can get it easily — not in a safe deposit box. Your advance directive stays valid until you revoke or replace it.

What if I Change My Mind or Want to Add Something?

If you want to change and/or add something, you should complete a new form. Let your medical decision maker(s), your family and your health care team know that you have a new form. Give copies of the new form to all the people who have copies of your original form, and discuss the change.

CONTACT US AT ANY TIME IF YOU HAVE ANY QUESTIONS OR WOULD LIKE SOME MORE HELP

Advance Directive Volunteer Champions

For direct support, please connect with a volunteer advance directive champion, who will guide you through the document and answer your questions. All of our volunteers have completed their own advance directives, and many of them are current or former City of Hope patients and caregivers — they understand.

You can reach us **by appointment**. To connect with a virtual volunteer, go to the webpage [CityofHope.org/advance-directive](https://www.cityofhope.org/advance-directive), or scan the QR code to the right and click on the button that reads “Click Here to Connect With Virtual Volunteers.”



Biller Patient and Family Resource Center

If you have any questions or need help to use these tools, please visit the Biller Patient and Family Resource Center (located in Main Medical at City of Hope’s Duarte campus), or call at **(626) 218-CARE (2273)**.

The team at the center can:

- Answer your questions about advance directives
- Help you through the steps to complete your advance directive
- Make an appointment for free notary services at City of Hope.
- File a copy of your advance directive in your medical record.

Health Insurance, Financial Clearance Services and Billing

City of Hope is guided by a compassionate, patient-centered philosophy, and supported by a national foundation of humanitarian philanthropy. We believe that the best care occurs when patients, families and health care providers work together. Therefore, we want you to have the information you need to make decisions about your health. As a valued patient, it is in your best interest to know and understand your financial responsibility during your visit or hospital stay. This includes insurance benefits and your responsibility for any deductibles, co-insurance or co-payment at the time of service.

HEALTH INSURANCE

Will my insurance cover the cost of my care?

City of Hope contracts with some major HMOs (health maintenance organizations) and PPOs (preferred provider organizations) for hospital services. In addition, City of Hope is a participating provider in government programs such as Medicare, MediCal and Tricare/Champus.

City of Hope will make every effort to verify your insurance eligibility and authorization for services. However, it is your legal responsibility to ensure that authorizations are arranged in advance of the services. If your insurance company requires a referral and/or prior authorization, contact your primary care physician prior to seeing a specialist. In some cases, you may be allowed to schedule services prior to receiving notice of authorization; however the service may be cancelled or rescheduled if authorization is not approved. You are ultimately responsible for payment.

Based on the information we receive from your insurance company, City of Hope's Financial Clearance team will contact your insurance company to obtain any required authorization for your future visits. Future appointments, such as infusion/chemotherapy, will be scheduled once any required insurance authorizations have been obtained. A representative from our Scheduling Department will contact you to make those arrangements.

If you have any questions or concerns about your authorization status, please feel free to contact a City of Hope financial specialist at **626-218-9201**. As a patient, you and your primary caregiver also have access to City of Hope's financial counselors. City of Hope's financial counselors are available to assist you with arranging payments of any co-pay, deductible or co-insurance due.

Every medical situation — and every insurance plan — is different, and there is no guarantee that coverage can be secured. For questions related to your specific coverage, please contact your insurance provider directly. You can find that phone number on your insurance card or in your benefits book.

FINANCIAL CLEARANCE SERVICES (FOR QUESTIONS BEFORE TREATMENT)

Financial counselors serve as a resource for insurance and financial questions before a particular treatment or service has been provided. They can assist with payment arrangements, charity screening, explanation of benefits and out of pocket estimates. If you need assistance, call **844-936-4673** and ask to speak to a financial counselor.

BILLING QUESTIONS (FOR QUESTIONS AFTER TREATMENT)

Who do I talk to about my bill?

A member of our Patient Business Services team can assist in addressing any questions you may have about your bill. If you want to discuss your bill, please contact:

Patient Business Services

866-268-4673

Hours of Operation: Monday through Friday, 8 a.m. to 5 p.m.

OTHER IMPORTANT QUESTIONS

When is payment due?

City of Hope is contractually obligated to the insurance providers to collect the co-pay, deductible or other amounts considered to be the "Patient Financial Responsibility" at the time of service. We will bill your insurance company for all covered services. You will receive a bill for any services that are not covered by your insurance company. It is your responsibility to pay for these services by the due date indicated on your bill.

You may continue to receive a monthly statement from either City of Hope or one of City of Hope's billing entities and/or vendors for any remaining balance until your account is paid in full.

What do I do if my insurance changes?

You are responsible to notify us of any changes to your insurance coverage. Please have your current insurance card with you at all times, as well as a photo ID such as a driver's license, military ID or other government issued ID.

What if I don't have insurance?

We are committed to providing accessible, comprehensive health care in a compassionate, culturally competent, ethical and fiscally responsible manner. If you do not have insurance coverage, or your coverage is insufficient, a financial counselor will discuss financial arrangements with you. They can help you determine if you qualify for assistance such as Medi-Cal and/or other programs.



"This chapter provides great information on bone and marrow stem cell basics."
— BMT Survivor

Blood and Marrow Transplant Basics

- Normal Blood Cells
- Peripheral Blood Stem Cells
- Reasons for Transplant
- Types of Stem Cell Transplants
- Cell Sources for Transplant
- Stem Cell Collection

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Blood and Marrow Transplant Basics

Normal Blood Cells

RED BLOOD CELLS

Red blood cells (RBCs, erythrocytes) contain hemoglobin which picks up oxygen in the lungs and carries it to the cells. Hemoglobin also picks up carbon dioxide from the cells and brings it back to the lungs to be exhaled when you breathe. Anemia is a condition in which there are too few RBCs or hemoglobin in the blood. If you are anemic you may feel weak, dizzy, short of breath and/or tired.

WHITE BLOOD CELLS

White blood cells (WBCs, leukocytes) are part of the body's immune system and are responsible for fighting infections. There are five different types of WBCs. When your body gets an infection, an increased number of WBCs are produced in response to the illness. When there are fewer numbers of WBCs in the body individuals are more susceptible to infection. Neutropenia is a condition in which there are a lower-than-normal number of neutrophils, the most common type of WBCs.

PLATELETS

Platelets (thrombocytes) are cells that help prevent bleeding by assisting with clotting. When you cut yourself, it is the platelets that help form blood clots to stop the bleeding at the site of injury.

Thrombocytopenia is a condition in which there are a lower-than-normal number of platelets in the blood. It may result in easy bruising and excessive bleeding from wounds or bleeding in mucous membranes and other tissues.

Peripheral Blood Stem Cells

Mature blood cells develop from “mother” cells called stem cells. When doctors harvest bone marrow for use in transplantation, it is the stem cells they are seeking. Peripheral stem cells are the stem cells that circulate in the blood vessels rather than the bone marrow. In some transplants, peripheral stem cells are used instead of bone marrow.

BONE MARROW

Bone marrow is the soft, spongy material found in the center of long bones in your body. The principal function of the bone marrow is the formation of blood cells, mainly RBCs, WBCs and platelets. When bone marrow is withdrawn from the bone it looks very similar to blood.

Diseases treated with blood and marrow transplants:

- Acute leukemia
- Chronic leukemia
- Lymphoma
- Myelodysplasia
- Multiple myeloma
- Aplastic anemia
- Solid tumors (ovarian, testicular cancer)

Pediatric conditions:

- Sickle cell anemia
- Thalassemia
- Fanconi anemia
- Dyskeratosis congenita
- Diamond blackfan anemia
- Hemophagocytic lymphohistiocytosis
- Langerhans cell histiocytosis

Reasons for Transplant

WHY STEM CELLS ARE TRANSPLANTED

Traditionally, blood and marrow transplants are given to patients with malignant and nonmalignant blood diseases. When someone has a blood disorder, the bone marrow is diseased and, as a result, is unable to produce the appropriate number of normal functioning blood cells. The goal of blood and marrow stem cell transplant is to destroy the malfunctioning bone marrow with high doses of chemotherapy and/or radiation therapy to make room for new, healthy stem cells (from the bone marrow). Stem cell transplantation replaces diseased or damaged bone marrow with new functioning bone marrow.

Factors that are evaluated when selecting patients for transplantation:

- **Age** — There is usually an age limit depending on the type of transplant planned for the patient.
- **Disease status** — Is the patient in remission or relapse?

- **Donor availability** — It is necessary to determine who will be the donor: a brother or sister, an unrelated donor or the patient him/herself.
- **Type of transplant required** — Autologous, syngeneic or allogeneic transplant (*see below*)
- **Psychosocial status** — Transplantation involves a major commitment from the patient and family. A great deal of time is spent in the hospital away from family and friends. The patient loses some independence during this period. This may cause some emotional stress for all involved.
- **Overall health** — The patient must be free of any significant kidney, heart, lung or other health problems that may jeopardize treatment.

Types of Stem Cell Transplants

High doses of chemotherapy and radiation are given to destroy the cancer. In the process, the stem cells in the bone marrow are destroyed. Stem cell transplantation is a procedure that restores stem cells that have been destroyed by high doses of chemotherapy and/or radiation therapy.

There are four basic types of transplants:

- **Autologous** “Auto” means from yourself. In an autologous transplant some of your own stem cells are removed or “harvested” at the time when there is no evidence of cancer cells in your blood and bone marrow. The stem cells are then frozen and stored. They will be given back to you after conditioning treatment.
- An **allogeneic transplant** is the infusion of stem cells from one person to another. These two people have a similar genetic type. The donor may be a brother or sister, or can be a parent, child or even an unrelated person.
- A **syngeneic transplant** is a special type of transplant and can only happen if you have an identical twin who is the donor.
- A **haplo identical donor (relative)** is half matched to the recipient.

Cell Sources for Transplant

There are three possible sources for stem cells.

- **Bone marrow** is the spongy tissue found in the center of bones that produces blood cells. This cell source is often based on the patients characteristics, diagnosis and disease status.
- **Peripheral stem cells** are the stem cells that circulate in the blood vessels rather than the bone marrow. In some transplants, peripheral stem cells are used instead of bone marrow. This is the most common graft choice of transplant.
- **Umbilical cord blood** is blood taken from the placenta and umbilical cord after birth. This blood is usually thrown out, but can be taken and stored for later use in a stem cell transplant.

Stem Cell Collection

PERIPHERAL STEM CELL COLLECTION

Peripheral blood stem cells are collected by drawing blood out of an arm vein (or from a catheter placed in a vein) and sending it through a machine that separates the stem cells from the other blood cells. The stem cells are collected and the rest of the blood is given back to the donor. The stem cells are stored or frozen for use later. This process is called apheresis (AY-fer-EE-sis). It usually takes five to six hours and is done as an outpatient procedure. In order to collect enough stem cells, the donor will be given a medication for four to five days before the scheduled collection to increase the number of stem cells in the blood. Sometimes the apheresis procedure needs to be repeated until enough stem cells are collected.

Before stem cells are collected, the donor must have a medical examination and some lab tests done. This is to ensure that the donor is healthy enough to donate stem cells. The donor will be given more detailed instructions about stem cell collection and the nurse coordinator will make arrangements for the donor. Allogeneic and autologous stem cell donation is similar, except that in autologous transplants the patient is the stem cell donor for him or herself.

BONE MARROW HARVEST

The procedure for collecting bone marrow is referred to as the **bone marrow harvest**. The procedure is done in the operating room under general anesthesia. Special needles are used to remove 500 to 1,000 milliliters (one to two pints) of marrow from the rear hip bones.

Only 3-5% of the donor's total bone marrow is removed. Since this is a small amount, the donor is still able to produce blood cells and the donated marrow is replaced within two to three weeks. If the donor's red blood cell count gets too low, a blood transfusion might be necessary, but this rarely happens.

Once harvested, the marrow is filtered to remove fat and small pieces of bone and is then transferred to a blood transfusion bag. In an allogeneic transplant, the bone marrow of the donor is given to the patient following the harvest procedure.

After the procedure, the donor is taken to the recovery room until awake and is then transferred to an outpatient area for further observation and is usually released the same day. Complications are few but may include infection, bleeding at the collection site and local pain. Pain medication will be ordered for any discomfort felt. The soreness may last a few days. Recovery to normal activity varies with each person and may take anywhere from a few days to a week.

Donor insurance coverage is not impacted by the process of donating stem cells for a transplant. The insurance coverage of the recipient will cover all of the costs associated with the donation.



“Participating in a clinical trial offers an opportunity for patients to take active roles in their health care.”

— BMT Survivor

Participating in Clinical Trials

05

Participating in Clinical Trials



When you volunteer for a clinical trial

Clinical trials help determine safety, effectiveness and the possibility of setting new standards of treatment. Participation is always voluntary.

City of Hope has a long and successful history of advancing cancer treatment by taking laboratory and research discoveries to develop effective medications or treatments. Results of these studies have led to significant improvements in cancer treatments and patient care.

Each trial involves a patient, a physician, a medical organization and frequently a government agency or private company that sponsors the research. City of Hope currently conducts many promising and innovative clinical trials through its involvement in the National Comprehensive Cancer Network. Clinical trials help to improve and redefine treatments, outcomes and care standards for patients in the United States and in other countries as well.

BENEFITS OF PARTICIPATING IN A CLINICAL TRIAL

Clinical trials are very carefully designed research studies in which patients voluntarily participate to help discover and test new methods of prevention, screening, diagnostics, treatment, symptom management and survivorship or quality-of-life factors for cancer patients. Clinical trials are conducted in four different phases with each phase serving a specific purpose to researchers.

Participating in a clinical trial offers an opportunity for patients to take active roles in their health care. By partnering with the research team to improve treatments, clinical trial participants have the chance to make a difference in their own lives and those of patients and families that follow them.

Why is it especially important for female and minority patients to participate?

Disease can affect everyone differently. It is a unique individual experience in which treatment can also work differently. Therefore, it is important to have people of all races, ages, backgrounds, and genders participate in clinical trials so that the best ways to prevent, diagnose and treat are discovered for every kind of disease for every kind of person.

Are clinical trials safe?

Patient safety in clinical studies is taken very seriously by the medical team and organizations like City of Hope. Clinical trials are reviewed at both the national level by the Food and Drug Administration and at the local level by an institutional review board (IRB). Each hospital has its own IRB board made up of health care professionals, patient advocates, and community leaders who continuously review the trial for safety and effectiveness.

Possible participants are carefully screened through an analysis of the patient's medical history, physical examination, and possible other tests to ensure that they meet criteria and are a suitable candidate for the clinical trial treatment.

What should I consider before participating in a clinical trial?

Patients who decide to participate sign an informed consent document. The informed consent provides information on the study purpose, potential risks, benefits and treatment alternatives verbally, in written materials and in in-person meetings.

Be sure to carefully read over all the information given to you. It is important to fully understand the purpose of the clinical trial and what to expect. Even after signing the informed consent, the patient may still decide to not participate at any time during the study without compromising their medical care.

You will want to find out:

- If the treatment will interact with any of your current medications or affect any other medical condition you may have.
- If you will need additional tests or procedures, such as biopsies or blood draws. You should consider your level of comfort with these additional steps.

- If there will be any anticipated side effects, pain, or discomfort.
- If the trial will affect your daily life. You should consider how long the study lasts, and if you can commit to the changes you may need to make in your life.

Clinical Trials are conducted in four different phases with each phase serving a specific purpose to researchers:

PHASE 1:

These trials involve initial testing in a small number of humans. The primary goal is to demonstrate the safety of a new drug including dosage and frequency of administration.

PHASE 2:

Once safety is determined in Phase 1 trials, the primary goal of Phase 2 trials is to demonstrate effectiveness. These trials are generally longer, lasting several months and involve several hundreds of participants.

PHASE 3:

This type of trial involves large scale testing in hundreds to thousands of participants to gain an even greater understanding of the treatment's benefits and side effects in a wide range of patients. Some patients are assigned to either a standard treatment or to the experimental treatment. This is called a "randomized" study.

PHASE 4:

Further analysis of a treatment occurs at this phase including exploring other issues such as cost-effectiveness, long-term effectiveness or how a drug affects a patient's quality of life.

TO LEARN MORE ABOUT CLINICAL TRIALS

If patients or families would like to know more about clinical trials at City of Hope, they can always ask their doctors or members of their health care team.

Reliable online resources for clinical trials can be found on the U.S. National Institutes of Health website clinicaltrials.gov/ct2/about-studies/learn or City of Hope's website at CityofHope.org/research/find-a-clinical-trial.



“ This chapter is key in helping you prepare for your transplant.”

— BMT Survivor

Preparing for Your Transplant

- Evaluation Tests for Eligibility, Preadmission
- Managing your Medications
- External Central Vascular Access Device
- Fertility Issues and Reproductive Options

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Preparing for Your Transplant

Evaluation Tests for Eligibility, Preadmission

If your doctor has determined that you are a candidate for a blood or marrow transplant you will be required to undergo preadmission testing to further determine your eligibility for transplant. Eligibility for transplant means that you are able to undergo a transplant.

Your doctor will review your medical history and perform a physical examination. Your doctor will review the pros and cons of having a transplant, the purpose of the transplant and the process of the treatment and determine if you are eligible for transplant.

If you are eligible, you will begin a series of additional tests. These tests will help your doctor make a final decision about your eligibility. If an outside doctor has sent you to City of Hope, he/she will be given the results of these tests for your records once they are completed.

ELIGIBILITY TESTING

Eligibility testing may be done at a facility outside of City of Hope for some patients or at City of Hope for others. Whether or not your testing is done at City of Hope depends on your insurance provider.

All preadmission testing must be done within 30 days* of your scheduled transplant. Your nurse coordinator will work with you to coordinate the scheduling of these tests to ensure they are completed within the appropriate timelines.

**If testing falls outside the 30 days before the transplant, these tests may need to be repeated.*

If there are abnormal findings from your eligibility testing, your doctor will review the results with you before proceeding with the transplant. The results of your eligibility testing will also be used as a baseline to measure your progress throughout the time your transplant.

COMMON PREADMISSION TESTING

Blood tests

CBC (complete blood count)
Blood chemistry
Infectious disease markers

Bone age

Baseline test to estimate potential in the growth plates in the left hand and wrist. Serves to inform pediatric endocrinologist of possible slowing of growth in patient

Bone marrow aspiration and biopsy

This is a procedure to obtain samples of bone marrow for testing of bone marrow function. A needle is inserted into the posterior hipbone after local anesthesia has been given and bone marrow is removed through the needle.

Chest X-ray

X-ray of the chest views the lungs, heart and surrounding structures for abnormalities

Creatinine clearance

24-hour urine collection to measure kidney function

CT scan

A computerized tomography (CT) scan is an X-ray technique that produces images of cross-sections ("slices") through your body. This enables your doctor to view the inside of your body at various angles.

Echocardiogram

A diagnostic test that uses ultrasound to see the internal structures of the heart. All cardiac valves can be seen and the size of each ventricle and the left atrium can be measured. It can be used to measure the strength of the heart muscle.

EKG

An electrocardiogram (EKG) measures the heart's electrical impulses to evaluate rhythm and function.

GFR

The glomerular filtration rate (GFR) tests how well your kidneys are working.

Lumbar puncture

This procedure, sometimes called a “spinal tap,” is used to obtain a sample of cerebrospinal fluid for testing. A needle is inserted into your spine in your lower back to obtain the sample.

MIBG scan

An iodine 131-meta-iodobezylguanidine scintiscan, or MIBG scan, is an imaging test that uses a radioactive substance (called a tracer) and a special scanner to find or confirm the presence of a tumor, usually an adrenal gland tumor. This test is performed on pediatric patients and is only done when needed.

MRI

Magnetic resonance imaging (MRI) uses a magnetic field and radio waves to take multiple cross-section images of the body, which are then assembled into a three-dimensional image by a computer. It shows the contrast between different types of body tissue in great detail. This test is done only if necessary.

PET scan

Positron emission tomography (PET) is a type of imaging test that helps doctors see structures and functions inside your body. The test uses a small amount of radioactive substance, usually given by injection. A PET scan is only done if needed.

Pregnancy test

This test is conducted to determine whether or not you are pregnant.

Psychosocial assessment

In addition to clearing medical tests, all BMT candidates must also be evaluated by a social worker and/or other members of our Department of Supportive Care Medicine to determine if there are any psychosocial considerations which may preclude eligibility to receive a transplant (e.g., treatment adherence, identified caregiver, support network, transportation, resources, etc.). The social worker can also help you develop a plan in anticipation of your treatment.

Pulmonary function tests

Pulmonary function tests are breathing tests to find out how well you move air in and out of your lungs and how well oxygen enters your body.

Skeletal survey

This is a series of X-rays taken of all the long bones (arms and legs), the spine and the skull to evaluate the presence of lesions. This test is only done on patients with multiple myeloma and is then only done if clinically indicated.

Stress test

If you are greater than 55 years of age, or the doctor feels that it is required, you will need to have a stress test. An exercise stress test is a screening tool to test the effect of exercise on your heart.

Stool specimens

Stool specimens may need to be collected and tested for infectious organisms, mucus, fat, parasites or blood in the stool.

Thyroid panel

A blood sample is taken to test the function of your thyroid.

Depending on your insurance provider you may also need to have some of the following tests:

Colonoscopy

A colonoscopy is a procedure that lets your doctor look inside your entire large intestine. It uses an instrument called a colonoscope that has a tiny camera attached to a long, thin tube. The procedure lets your doctor see things, such as inflamed tissue, abnormal growths and ulcers.

Dental examination

Decayed teeth and gum disease can cause serious infections in transplant patients. It is very important to have a thorough exam and complete all necessary dental work.

Mammogram

A mammogram is a special type of X-ray of the breasts.

Managing Your Medications

A variety of medications may be prescribed to manage your symptoms or complications you may encounter during treatment. Other medications may be given to prevent complications before, during, and after your transplant. These may be taken by mouth, injected under the skin or in a vein. We encourage you to make a list of all your home medications and ask questions regarding each and every medication you may be taking. We will be reviewing all of your home medications (prescribed, over-the-counter, herbal/supplements, etc.) with you each time you come to your clinic visit.



If you are an inpatient, your doctor will prescribe all necessary medications. Please leave any previously prescribed medications at home. If you bring your home medications with you, please let your nurse know and we will store them until you are discharged. You may not keep any medications in the room with you.

External Central Vascular Access Device

All blood and marrow stem cell transplant patients will need an external central vascular access device, also known as a VAD. A VAD is a long, narrow tube called a catheter, which is placed into a large vein leading directly to your heart that will remain in place throughout your treatment.

Medication can be given directly into your bloodstream using your VAD without having a needle placed repeatedly into the veins in your arms. The VAD also allows IV (intravenous) fluids, blood transfusions and chemotherapy to be given to you as comfortably and as easily as possible. Your VAD also can be used to take blood samples for testing.

There are different types of external central VADs such as a PICC (peripherally inserted central catheter), which is inserted into a large vein in your arm, or a "Hickman" type catheter which is inserted into your chest. Your doctor will determine the best type of VAD for your particular situation.

You may have your VAD inserted while you are an outpatient before treatment is started. The procedure is scheduled by your nurse coordinator. It is important for you to know how to care for your VAD before you are discharged from hospital. You may be scheduled to take a class on VAD care before you are admitted and you will also be given written instructions on how to care for your VAD.

Fertility Issues and Reproductive Options

The combined high-dose chemotherapy and radiation therapy given before transplantation may adversely affect your ability to have children. It is important to talk openly and honestly with your doctor about your wishes and plans for your life after treatment and even before treatment. When it comes to fertility, it is especially important to start taking steps early to know and understand important factors that will need to be considered to decide what is best for you and your care.

Before starting treatment, your doctor can refer you to see a fertility preservation specialist. Talking with a specialist can help you explore what your options are now. You will also learn about other options to build a family after cancer if you are unable to preserve your fertility.

Once you have received a referral, it is important you also ask to speak with your City of Hope clinical social worker to help you plan and navigate the resources available to you.



"As a patient, it is important to keep building on your knowledge."

- BMT Survivor

What You Need to Know About an Allogeneic Transplant

- About an Allogeneic Transplant
- Getting Your Body Ready for Transplant
- How to Recognize Early and Late Complications After Transplant

07

What You Need to Know About an Allogeneic Transplant

About an Allogeneic Transplant

An allogeneic transplant is the infusion of stem cells from one person to another. These two people have a similar genetic type. The donor may be a brother or sister, but can be a parent, child or even an unrelated person. The degree to which the patient's and donor's tissues match is determined by a blood test called HLA typing or tissue typing.

SELECTING A DONOR

The selection of a suitable donor is determined by the degree that their HLA genes match those of the patient. The group of genes (HLA-A, HLA-B, HLA-C, DRB1, DQB1 and DPB1) are closely situated on chromosome 6. Each of the genes is found to have a large number of variations (alleles). Determining the tissue type is the process of determining the alleles each person has inherited. This process is complex and takes approximately 10 working days. A donor who is found to share both of the HLA haplotypes with the patient may be selected as a donor and is considered a fully matched donor. This means the donor and recipient have the same set of closely linked HLA-genes on one of the two number six chromosomes they inherited from their parents.

Every individual has a set of HLA genes, one haplotype (or group) inherited from each parent. The two inherited haplotypes represent their complete tissue type (genotype). If a donor is found to share only part of the patient's HLA genotype, they may be selected as a donor (if a fully matched donor is not available), and will be considered a mismatched donor.

Human Leukocyte Antigen Typing for Allogeneic Transplantation

HLA typing is used to describe the process of matching donor HLA to patient (recipient). HLA genes help to control an individual's immune system. The function of the immune system is to protect each individual from harmful bacteria, viruses and chemicals (e.g., toxins).



The process of HLA typing involves drawing a sample of blood from the patient and the donor, HLA typing both samples, and then comparing them to determine if they are a match to one another.

Haploidentical Transplants

An HLA-haploidentical donor shares a haplotype with the transplant recipient. Parents are always a half-match for their children and vice versa. Siblings have a 50% chance of being a half-match for each other. (They have a 25% chance of being a perfect match and a 25% chance of not matching at all.)

<http://www.seattlecca.org/diseases/alternative-donor-program.cfm>

Haploidentical hematopoietic stem cell transplantation (HSCT) provides an opportunity for nearly all patients to benefit from HCT when a HLA genotypically matched sibling is not available. The use of hematopoietic stem cells from relatives who are partially matched for HLA provides some advantages for patients lacking HLA-matched sibling donors or fully matched unrelated donors. Virtually all patients have at least one HLA-partially matched family member, parent, sibling or child who is immediately available to serve as a donor.

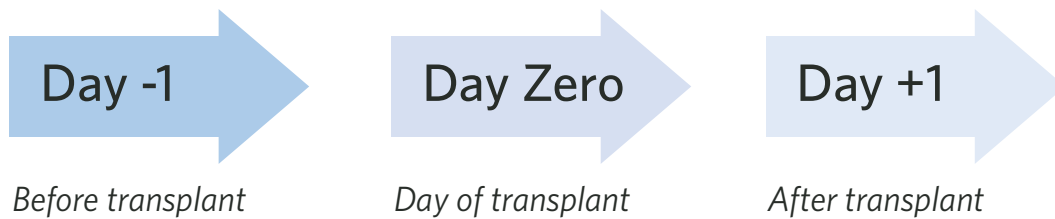
<http://www.nature.com/bmt/journal/v42/n1s/full/bmt2008117a.html>

Unrelated Donor Allogeneic Transplant

Unrelated donor transplant is a type of allogeneic transplant using a donor from the general population who is not related to the patient but who is a very close HLA match to the patient. Since many of us share similar genetic backgrounds, it is possible that someone not related to us has a similar genetic type.

INFUSION OF ALLOGENEIC BLOOD AND MARROW STEM CELLS

The new stem cells or bone marrow are directed to replace the old diseased bone marrow. The day of your transplant is referred to as Day Zero. The days before “**Day Zero**” are referred to as “minus” days and the days following your transplant are plus” days. Thus, the day before your transplant is **Day -1** and the day after is **Day +1**.



On Day Zero, the infusion of the stem cells or bone marrow takes place in your hospital room. The process is similar to a blood transfusion and is given through your vascular access device. You will receive medication about 30 minutes to one hour before the transplant which may make you sleepy and will help minimize any side effects. Even with the pre-medication, reactions may still occur but are usually minimal.

The stem cells come from the blood bank and will be infused slowly as the rate of the infusion is based on the total numbers of the stem cells. Allogeneic stem cells are most often stored in one or more bags, which will infuse in less than four hours, depending on the amount contained each bag and the number of bags. Your nurse will monitor your vital signs and oxygen level throughout the infusion.

ENGRAFTMENT

Engraftment is the point when your “new” stem cells or marrow begins to make white blood cells, red blood cells and platelets. Once you get your stem cells, your blood counts will be checked daily to determine when engraftment begins. Engraftment usually occurs 14 to 30 days after day zero of your transplant. Remember that all patients are different and length of time to engraft varies from one person to another.

Getting Your Body Ready for Transplant

Before you can receive the new cells, your doctor will plan a **“conditioning regimen”** tailored to your specific illness, cell source and ability to tolerate treatment. This will include chemotherapy and (in some cases) radiation. It is most often given in the one-to-two-week period immediately prior to receiving cells.

For some patients, this conditioning is aimed at completely wiping out your existing bone marrow and treating your disease, with the new cells needed to “regrow” your immune system. For other patients (particularly those receiving cells from a donor, and whose age or other conditions make them unable to tolerate very high doses of chemotherapy or radiation), the conditioning is lower-intensity and only suppresses the patient’s own system enough to give the donor cells room to grow. Your physician will be able to discuss the regimen best suited to you.

CHEMOTHERAPY

Chemotherapy is a group of anti-cancer drugs that destroy the growth of cancer cells. Your doctor will choose the type of chemotherapy treatment that is best for you based upon your individual needs and condition.

Chemotherapy can be taken orally (in a pill form) or given intravenously (directly into a vein) and may also be combined with radiation therapy in your treatment regimen. Generally, in the transplant setting, conditioning chemotherapy (combinations of various chemotherapy agents are used in very large doses) is used to destroy the growth of cancer cells and the immune system in order to prepare the recipient’s body to accept the stem cells.

SIDE EFFECTS OF CHEMOTHERAPY

Chemotherapy acts by destroying rapidly dividing cells. There are many types of rapidly dividing cells in the body such as hair, mucous membranes, bone marrow and cancer cells. The side effects of chemotherapy result from the actions of the drugs on these rapidly dividing cells. The side effects experienced by each patient may be specific to them and the doctors and nurses will ensure that appropriate actions are taken to minimize any discomfort you may experience.

- Nausea and vomiting
- Diarrhea
- Loss of appetite
- Hair loss
- Skin reaction
- Sore mouth
- Fatigue

WHAT YOU CAN DO TO MANAGE CHEMOTHERAPY SIDE EFFECTS

Remember, there are many simple things you can do to manage your chemo side effects.



Read the patient education booklet “Understanding and Managing Chemotherapy Side Effects.” This booklet covers all of the chemo side effects and gives you advice on what to do during treatment. Ask your nurse for a copy.



Drink at least two to three quarts of fluid every 24 hours unless you are instructed otherwise.



To reduce chance of infection, you and your family should wash your hands often.



Get plenty of rest. Let your medical team know if you have trouble sleeping.



You may be at risk of infection so try to avoid crowds or people with colds or not feeling well, and report fever or any other signs of infection immediately to your health care provider.



Avoid sun exposure. Wear SPF 30 (or higher) sunscreen and protective clothing.



To reduce nausea, take anti-nausea medications as prescribed and eat small, frequent meals. The goal is to maintain good nutrition.



To help treat/prevent mouth sores, use a soft toothbrush and rinse three times a day with 1/2 to 1 teaspoon of baking soda and/or 1/2 to 1 teaspoon of salt mixed with 8 ounces of water. A commercial nonalcoholic mouthwash like Biotene may also be helpful to prevent dry mouth.



Use an electric razor to minimize risk of cuts or bleeding. Do not use a straight razor.



With your doctor's permission, get regular exercise but avoid contact sports or activities that could cause injury.



If you experience any symptoms or side effects related to your treatment, be sure to discuss them with your health care team. They can prescribe medications and/or offer other suggestions that are effective in managing such problems.

City of Hope's Nursing Triage Call Center **626-218-7133** is staffed 24 hours a day to answer any non-emergency questions treatment or self-care. Please refer to page 83.

RADIATION THERAPY

Radiation therapy may be used in combination with chemotherapy as part of the preparation for your stem cell transplant. Steps are taken to protect your vital organs during the treatment process, with newer technology allowing for even greater safety. You will not feel the actual radiation, as it is like having an x-ray, but you can expect side effects. Total body irradiation (TBI) therapy is radiation given to your entire body for the following reasons:

- To destroy any cancer cells that may be remaining where chemotherapy may not easily reach (such as your nervous system, bones, skin, testes).
- To suppress your immune system. Having TBI before your transplant can help prevent rejection of the new marrow graft (stem cells).

Side Effects of TBI

The type of side effects and how severe they are will depend on many things such as the dose of radiation, the number of treatments, and your overall health. The most common short-term side effects include nausea, vomiting, decreased appetite, diarrhea, and fatigue. The skin exposed to the radiation can become slightly reddened and warm, like a sunburn, with the possible development of sores in your mouth and throat, along with decreased blood cell counts.

- Your nurse will give you additional education about how to care for your skin while receiving TBI.
- Do not use any soaps, lotions, ointments, cosmetics, or perfumed powders in the treated area except for recommended products. Follow all instructions given to you by nurse.

Late side effects of radiation can include sterility, cataract formation and lung problems. Your doctor will evaluate your response to treatment and will give you instructions on how to manage side effects.

TBI is given in small radiation doses, two to three times a day, approximately four to six hours apart. Each morning before going to radiation, you will be given medications to decrease the risk of nausea and vomiting.

Your radiation treatment is often delivered with you in the standing position, with a safety harness in place and staff monitoring you the entire time via closed circuit TV. Each appointment is scheduled for 30 minutes, although the actual time the treatment machine is on is about 10 minutes. You will be allowed to wear your patient gown during treatment, but no rings/jewelry or anything metal will be allowed. We encourage you to bring relaxing music that you can listen to during each treatment sessions. And if needed the radiation department will supply a music player.

How to Recognize Early and Late Complications After Transplant

Stem cell transplantation is an aggressive form of therapy. The degree of complications varies from patient to patient. The following are some of the short-term complications that may occur and some of the strategies the team at City of Hope will use to treat them.

SHORT-TERM COMPLICATIONS

Infections

While you are waiting for your new stem cells to engraft, your white blood count will be low thus increasing your risk of developing an infection. Your vital signs need to be checked frequently to know if you have a fever. If you have a fever, your doctor will order blood samples to be drawn from your VAD (vascular access device) and peripheral veins to see if there are bacteria in your blood causing your fever. Infections can develop due to exposure to bacteria or due to growth of bacteria you already have in your body. If you develop a fever during the course of your transplant you will receive intravenous antibiotics to treat a possible infection.

INFECTIONS FROM THE ENVIRONMENT

Infections can come from the air, food, water and from other people. You are at the greatest risk for infection when your white blood cell count is very low. As a result of this, your white blood cell count will be monitored very closely for a period of time before transplant and for several weeks after.

During this period of time, it is important to observe these guidelines:

- Everyone entering your room must wash their hands and wear a mask to protect you from infection.
- You must change into clean clothes every day after your shower. Hospital gowns are provided should you wish to wear one of these.
- You must perform skin cleansing once per day.
- Fresh flowers, dried flower arrangements and live plants are not allowed in the hospital at any time. You may have silk flower arrangements, Mylar balloons, cards, posters, books and magazines.

INFECTIONS FROM YOUR OWN BODY

Infections can also come from your own body. We all have bacteria on our skin, in our mouth, stomach, intestinal tract, perineal area and genitals. This is normal and helps protect our bodies. However, when your immune system is suppressed, these bacteria may overgrow and cause infections. **In order to protect yourself from these infections, there are certain things that you should do, such as:**

Skin

- Perform skin cleansing once per day with skin cleanser containing chlorhexidine gluconate (CHG), if you are sensitive to CHG, mild soap may be used. Skin cleansing keeps bacteria from growing on your skin. Pay special attention to areas that become moist (under your arms, between your legs and under your breasts). Rinse off the soap thoroughly.
- Apply lotion or oil to help prevent dry skin. Make sure that the lotion or oil does not contain perfume or alcohol.
- Wear fresh clothes after each shower.
- Use an electric razor to minimize risk of cuts or bleeding. Do not use a straight razor.
- Your VAD dressing will be covered while you shower in order to keep it dry. If your VAD dressing gets wet, notify the nurse in order to have the dressing changed.

Mouth

To soothe your mouth and keep it clean, you will need to care for it in a special way.

What to Do:

- Rinse your mouth four times a day with 15 ml (one tablespoon) of a bland rinse such as Biotene mouthwash.
- Brush teeth two times per day with ultra soft toothbrush. If an ultra soft toothbrush is not tolerated, a toothette may be used. Allow toothbrush to air dry before storing, and replace brush weekly.

- For patients who have used dental floss before, floss teeth with dental tape at least once daily as long as platelet count is greater than 50,000 mcL and bleeding does not occur. Patients who do not floss on a regular basis should not floss while myelosuppressed.
- Use water or waxed (nonpetroleum) based moisturizers to protect your lips.
- Measure five ml (1 teaspoon) of antifungal solution. Swish thoroughly in your mouth and swallow. Do this every four hours when awake.
- If you are unable to swallow your medicine, tell your nurse.

Perianal care

Chemotherapy and radiation therapy can make the anal area very sensitive. To prevent skin breakdown and infection:

- Clean thoroughly after each bowel movement, especially if you have diarrhea.
- Report any changes like diarrhea, bloody stool, pain or irritation to your nurse.

BLOOD PRODUCT TRANSFUSION

After you have received conditioning chemotherapy and/or radiation therapy, your bone marrow will not be functioning well enough to develop blood cells until your new stem cells have engrafted. As a result, many transplant patients will receive blood and blood product transfusions to keep their blood counts up until their new stem cells begin producing the healthy blood cells they need.

Blood products (e.g., platelets, red blood cells, etc.) can be obtained from available supplies in City of Hope's blood bank, all of which come from unpaid, voluntary donors. They can also be provided by relatives or friends designated by you (using the directed donation process). All blood donations are tested to determine that there are no infectious diseases in the product. Your doctor and nurse coordinator will be available to answer any questions you may have about blood products and how they are used in your treatment.

KIDNEY AND LIVER PROBLEMS

Over the course of your transplant you will be taking a number of medications, most of which are metabolized (broken down) and excreted through your kidneys or liver. As a result of this, there will be a great deal of demand on these organs. If your kidneys or liver get "overworked," complications may arise. Blood samples will be taken once or twice per day throughout your stay to closely monitor your kidney and liver function. If such complications arise, the doses of medication will be adjusted as necessary.

Another potential problem that may develop in the liver is veno-occlusive disease, or VOD. Another name for this is sinusoidal obstructive syndrome, or SOS. As a result of chemotherapy and radiation therapy, deposits of fibrous material may form in the small veins of the liver. This causes obstruction and back up of blood flow from the liver. You will be given medication to prevent this from occurring.

GRAFT FAILURE

If the new stem cells do not function adequately and the blood cell counts do not rise, this is considered a graft failure. This may be due to a viral illness, damage to the new bone marrow or for other unknown reasons. There are medications that may assist to stimulate graft function. There are short and long-term complications that are unique to allogeneic recipients. Please refer to section about graft-versus-host disease to learn more. Talk to your doctor about any questions or concerns you may have before, during and after your transplant.

LONG-TERM COMPLICATIONS (MONTHS TO YEARS)

Long-term complications can be caused by high-dose chemotherapy, radiation therapy, chronic replace with graft-versus-host disease (in allogeneic transplants) or problems resulting from the original disease. Some of the long-term side effects include:

Gonadal Dysfunction

Sterility is a potential side effect of chemotherapy and irradiation. Please discuss fertility concerns and reproductive options with your doctor as soon as possible before you begin your treatment. Most transplant recipients will be sterile as a result of the combined high-dose chemotherapy and/or radiation therapy administered before transplantation.

Female patients need to be examined regularly by a gynecologist. Physical changes you may experience are decreased or absent menstrual periods, decreased vaginal secretions and changes in ovarian function that result in decreased hormone (estrogen) levels.

Cataracts

Patients who have received total body irradiation may experience cataract formation between one to five years after transplant.

It is very important to notify your doctor if you notice any visual changes. Regular eye exams by an ophthalmologist are important so you can be monitored for cataracts.

Pulmonary Complications

Long-term survivors of transplantation may experience changes in their lung function as a result of high-dose chemo, radiation and/or chronic graft-versus-host disease.

Infections

Herpes simplex and herpes zoster are common viral infections that occur after you have undergone a transplant. Herpes simplex usually appears as sores on the lips or in the mouth. Herpes zoster or shingles is related to the chicken pox virus and usually appears as a group of small blisters on the legs, face or back. There may be itching, pain and fever with the virus. If you are exposed to anyone with chicken pox or shingles, call your doctor immediately. Active herpes zoster infection may occur in transplant patients during the first two years. Treatment should be started as soon as the infection is identified.

A more serious viral infection, interstitial pneumonia, is a major cause of illness and death. About half of these pneumonias are caused by cytomegalovirus infections (CMV). Medications are used to treat CMV pneumonia.

Bleeding

Platelets are the cells in your blood that help form clots and control bleeding. Platelets are one of the last of the blood cells to return to a normal level after your transplant. It might take weeks to months for your new bone marrow to make enough platelets, so you no longer require platelet transfusions. After discharge, you may receive a transfusion in the outpatient clinic.

Signs of a low platelet count may include:

- Excessive bruising
- Petechiae (pinpoint red spots on the skin)
- Bleeding gums
- Nosebleeds
- Blood in your stool (may be red or black)
- Blood in your urine

If you notice any of these signs, contact your doctor right away.

Secondary Malignancy

The risk of another type of cancer resulting from the irradiation and chemotherapy that accompany transplantation has been documented in a small number of patients. If you have concerns or would like more information, please speak with your doctor or nurse.

Relapse

Relapse may occur any time following the transplant. Maintaining follow-up checkups with your transplant team is an important part of monitoring your new marrow.

What is Graft-Versus-Host Disease?

Graft-versus-host disease (GVHD) can develop in patients who receive a transplant from an unrelated donor or relative, including histocompatible (HLA) matched siblings and parents. It occurs when the donor's cells, called T lymphocytes, do not recognize the recipient's cells and begin attacking the recipient's tissues. The severity of GVHD can range from mild to severe and be acute and/or chronic. The chances of getting GVHD are dependent on several factors including HLA matching, age and gender of the donor and recipient.

How to lower your risk of GVHD

- Take your medicines exactly as prescribed. Medications, called immunosuppressants, will be given to you before, during and after transplant in order to prevent, suppress and minimize the degree of GVHD, although it may still occur.
- Watching for early signs and report to your doctor. Good management and treating GVHD symptoms early, infections, and other side effects from treatment can help with faster recovery.
- Protecting yourself from the sun. Sun exposure increases your risk of getting GVHD. Take steps to limit your sun exposure by using an umbrella when you are out in the sun, wear a hat, sunglasses, long sleeves, and pants when you go outside. Avoid the sun as much as possible and apply SPF 50 or higher sunscreen on any skin that is uncovered.

WATCH FOR COMPLICATIONS - GVHD

If GVHD occurs early on after the transplant it is called acute GVHD. If it develops a length of time after transplant it is called chronic GVHD. Tell your doctor right away if you have any of these signs or symptoms.

Acute GVHD

Some signs of acute GVHD include changes in the skin, gastrointestinal tract and/or liver. There are different medications given to help prevent GVHD from developing which include Cyclosporin, Prednisone, Methotrexate, Mycophenolate Mofetil (CellCept, MMF), Sirolimus and Tacrolimus (Prograf, FK506). Before your transplant your doctor will decide which combination of these medications will work best to prevent you from developing GVHD. Refer to "Fast facts-basics of graft versus host disease (GVHD)" patient education resource.

Skin

Skin involvement may be present on part or all of the body. This may appear as a red rash with or without itching/burning. It may look similar to sunburn. Common areas are the neck, ears and shoulders, palms of hands and soles of feet.

Self-care measures:

- Use skin moisturizers and mild soaps.
- Use sunscreen and avoid prolonged exposure to the sun.
- Wear sunglasses and long sleeve shirts

Liver

Your doctor will monitor your liver function with blood tests frequently after your transplant. You may notice yellowing of the skin or eyes if your liver functions are abnormal.

Self-care measures:

- It is important to continue your prescribed medications to prevent GVHD.
- Tell your doctor if you start to experience dark (tea-colored) urine, pain in the upper part of your belly, or swelling in your legs or belly.

Gastrointestinal tract (Intestines)

You may experience nausea, vomiting, abdominal cramps, diarrhea and loss of appetite.

Self-care measures:

- Avoid spicy and fatty foods.
- Eat small frequent bland meals.
- Avoid dairy.
- Keep skin around the rectum clean. Protect skin with barrier cream.
- Tell your doctor if you experience belly pain or blood in your stool.

If you are concerned about the possibility that your new transplant may be rejected, please discuss this with your doctor.

Chronic GVHD

Chronic GVHD occurs later than acute GVHD and it may affect different sites than those affected by acute GVHD. Chronic GVHD may develop in various organs throughout the body any time starting 100 days or more after transplant.

Diagnostic tests for chronic GVHD may include biopsy of the skin and/or oral mucosa, pulmonary function studies and liver function blood tests. Treatment of chronic GVHD generally includes immunosuppressive therapy targeted at the GVHD, as well as other therapy to prevent or treat infections.

Organ System and Common Targets of Chronic GVHD

Chronic GVHD may affect many organ systems and common targets may include the following:

Skin

The skin is affected in more than 95% of patients with chronic GVHD.

Symptoms may include itching, burning, hyperpigmentation (darkening of skin), skin thickening, redness and flakiness. Skin involvement may be present on part or all of the body. Hair loss and nail ridging may occur. You may experience a decrease or loss in the ability to sweat.

Self-care measures:

- Use skin moisturizers and mild soaps.
- Use sunscreens and avoid prolonged exposure to the sun.
- Practice exercise programs recommended by a physical therapist in order to prevent contracture of joints (inability to straighten joints, such as knee, elbow, hip).

Liver

Your doctor will monitor your liver function with blood tests frequently after your transplant. You may notice yellowing of the skin or eyes if your liver functions are abnormal.

Self-care measures:

- It is important to continue your prescribed medications to prevent GVHD.
- Tell your doctor if you start to experience dark (tea-colored) urine, pain in the upper part of your belly, or swelling in your legs or belly.

Mouth

The inside of the mouth is often affected. Symptoms include taste changes, dry mouth and inflammation, redness and ulcerations of the mouth and tongue. Oral chronic GVHD may cause mucous membranes to appear white.

Self-care measures:

- Practice good mouth care for relieving inflammation. Rinse mouth at least four times daily with a bland rinse.
- Avoid mouth rinses with phenol, astringents or alcohol.

Mouth, continued

- Avoid tobacco, alcohol, or irritating foods such as those that are acidic, hot, rough and/or spicy.
- Brush twice daily with a soft bristle toothbrush. Allow brush to air dry before storing.
- Keep your lips moist to prevent cracking and bleeding. You can use water or waxed (nonpetrolatum) based moisturizers to protect lips.
- Keep up fluid levels. You do not want to get dehydrated.
- Use artificial saliva to relieve dry mouth. Ask your doctor or dentist to recommend something you can use.

Eyes

Radiation may affect the tear ducts and cause decreased production of tears.

Symptoms include burning, itching, light sensitivity and a sensation of grittiness in the eye.

Self-care measures:

- Use artificial tears to relieve dryness of the eye. Your eye doctor can recommend a product to use.
- Wear sunglasses whenever you will be in sunlight or bright lights.

Digestive System

The lining of the esophagus and GI (gastrointestinal) tract is often affected. Symptoms may include painful and/or difficult swallowing and occasionally pain beneath the breastbone.

Self-care measures:

- Eat small meals frequently and drink liquids before swallowing solids.
- Request a visit from a dietician to learn more about how to eat to decrease your digestive symptoms.
- Take prescribed anti-nausea or anti-diarrhea medication.

Genitals

The genital area can become irritated dry, or get a rash. For women, changes within the vagina often occur. Symptoms may include inflammation, obstruction of menstruation due to strictures (narrowing) and dryness. Vaginal atrophy (decrease in size) may result in painful intercourse. If you do experience pain with intercourse, report this to your doctor.

Self-care measures:

- Use water-soluble vaginal lubricants.
- Make sure to receive follow-up care from a gynecologist and request sexual counseling as needed. Your doctor may recommend a vaginal dilator to prevent vaginal atrophy and keep the tissues soft.

Lungs

Lung changes may be associated with chronic GVHD. This may limit the ability of the lungs to transfer oxygen and can cause shortness of breath or a cough that does not go away.

Self-care measures:

- Do not smoke and avoid all respiratory irritants.
- Stay indoors on smoggy days.

Immune System

Dysfunction of the immune system may persist in patients with chronic GVHD and immune recovery is slower in patients with chronic GVHD. Lack of an adequate immune system means you have very poor protection against all infections and may experience more colds and flu.

Self-care measures:

- Avoid crowds and people with colds and the flu.
- If your temperature is greater than 38.3 C or 101 F, call your doctor immediately.
- Eat well and get plenty of rest.

Coping with GVHD

It is important to get support. Living with GVHD can be emotionally difficult and stressful for you and your family. Talking with your clinical social worker, psychologist, psychiatrist or spiritual counselor often helps. You can learn how to take control of the problem, rather than letting it take control of you. It can also help to talk to with others who have had GVHD to gain insight into how they managed and coped. Talk to your clinical social worker about the resources available to you. There are support groups, classes and other resources that will provide you the support you need.



"Learning what to expect after transplant helped me and my family understand what is most important for my recovery."

— BMT Survivor