A PATIENT’S GUIDE TO

BLOOD AND MARROW
STEM CELL TRANSPLANTATION

City of Hope

A National Cancer Institute-designated comprehensive cancer center
How to use the information in this book

This manual is a resource to help you and your family learn about blood and marrow hematopoietic stem cell transplantation (HCT) at City of Hope. Understanding what a transplant is, why it has been recommended for you, and what to expect during treatment may help answer your questions and relieve some of your anxiety.

Our goal is to provide you with the best possible medical care, nursing care, support and communication as you move forward through your treatment plan.

**Tips for using this book**

- This book can be used as a reference for you before, during and after your transplant. You can either read it beginning to end, or read the sections that are most important to you at first, then go back and read other sections as they become important.
- Bring this book with you when come to your clinic appointments before and after your transplant.
- Bring this book with you when you come to the hospital for your transplant. Your nurses will use it to help teach you about different aspects of your care.
- Use this book as a workbook. Write your notes in it. Add important information to it. Personalize it. Make it a useful tool to make your transplant a success.

With gratitude and appreciation, we would like to acknowledge all of the wonderful and talented individuals who gave of their time, expertise and experience in revising *A Patient’s Guide to Blood and Marrow Stem Cell Transplantation at City of Hope*. Many thanks to Hematology & Hematopoietic Cell Transplantation (HEM/HCT) 5th Floor Representatives: Zhen Afable, assistant nurse manager, and Kathryn Torres Nicolas, nurse manager; HEM/HCT 6th Floor Representatives: Karsen Koehncke, assistant nurse manager, and Monica Munaretto, manager; Nursing Education: Jennifer Peterson, professional practice leader, and Kay Mo, professional practice leader; HEM/HCT Nursing Support: Niki Lim, nurse coordinator, Maria Leiva, nurse coordinator, Estela Esquivel, nurse coordinator I, and Elaina Corbett, nurse coordinator, Gerardo Gorospe, clinical nurse manager; Clinical Nutrition (Dietary): Julie Scholler, clinical dietitian; Rehabilitation Services: Jennifer Hayter, director; Patient, Family and Community Education: Becky Andrews, Patient Resources Coordinator; Andrea McQueary, Program Coordinator; Community Benefits: Nancy Clifton-Hawkins, Manager; Department of Supportive Care Medicine: Kathe Kelly, Cancer Education Resource Nurse; Creative Services: Jared Millar, designer, and Laurie Bellman, copy editor. Most important, we would like to send our most heartfelt thank you to our Patient and Family Advisory Council patient leaders: Patrice Martin and Valerie Esguerra for their thorough review of the entire guide, and for thoughtful suggestions, advice and contributions to this version. Finally, thank you to Bill Matteson whose words served as inspiration as we strived to make this guide as practical and down-to-earth as possible.
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A Note from a Bone Marrow Transplant Survivor and Thriver

Welcome to your Patient Guide to Bone Marrow Transplantation!

Within these pages, a wealth of invaluable information awaits you as you journey through one of the most amazing experiences of your life! How do I know? In the summer of 2012, I took that journey with all of the zeal I could muster! Sure, for so many of us, venturing into the unknown can be a daunting task. However, I tend to take on this kind of experience “head on,” with my eyes steady on the prize the entire time. Remember, you can choose how you would like to “look” at your journey ahead of time. It all comes down to perspective! I will share more insight on this later.

I am happy to shout out at the top of my lungs, that I am now a 2 1/2 year survivor and Thriver! I started to see myself as a Thriver somewhere along the way when I had an epiphany that my journey was not just about surviving; it was about having this “renaissance” period in my life, and how lucky I was to have this experience! During this journey, I had many family members and friends supporting me every step of the way! I will also forever be grateful for the dedicated City of Hope medical team that saved my life! In the many months following my recovery of the transplant, I experienced what I have come to appreciate was a “retreat” with myself. I learned that the purpose and vision for my life had deepened and had become multi-faceted. For humanitarian purposes, I happily embraced, again, my need to reach out and help other bone marrow transplant patients, as well as other cancer patients. I can still see myself in all of you! I will always carry a very special part of the transplant community with me.

Each of you has the opportunity to lift a “blue print” for yourself from the pages of this guide, to help you connect and pinpoint your way through the various stages of bone marrow transplantation. I can say from experience that arming yourself with knowledge is one of the best companions, when paired with relentless hope!

I would like to think of this guide as a life manual to help you prepare for your bone marrow transplant, in addition to helping you step by step during and life after the transplant process. This manual is comprehensive as it is thoughtful, tackling a myriad of topics and issues where you as the patient can take comfort that the City of Hope medical staff is truly looking out for you and your well-being.

Before I give you a glimpse into what this guide has been designed to do for you, let’s take a look at a tool that I used during my journey which may help you. The wonder of self-discovery can be a saving grace at one of the most critical times in your life! This is why knowing or learning how to be resourceful to help yourself is important, as you can see, as a basic life skill! Since we’ve acknowledged that bone marrow transplantation, along with so many other medical procedures, can create such a fear of the unknown, I learned that self-discovery can serve as a powerful antidote to help you get ready for this journey, throughout your journey and long after the journey is over. Haven’t you ever wondered what you might be made of at any given time, perhaps at a defining moment in your life? What about the 10K or the Marathon you have promised yourself you would conquer all these years, or the personal best you vowed to set in the very next “Race for the Cure”? Well, this could also be your chance of a life time to be empowered in your very own way. I realized that this added benefit helped me to achieve the seemingly elusive “peace of mind.”
I have always been naturally curious about life and the unexpected circumstance it can bring to a seemingly “ordinary” life, on often an ordinary day. I remember reading comedienne Gilda Radner’s book, *It’s Always Something*, two years prior to my diagnosis. Learning about her self-awareness, tremendous courage and tenacity, helped to ignite the energy and perseverance that I would later need when my own journey had arrived! My mother raised my brothers and me to be our own best friend and to enjoy our own company at all times (even in times of peril). My own self-discovery revealed that I am a good balance between positivity and realism. The balance of these traits along with my Mother’s gifts, served me well during my experience! After taking a tour of the City of Hope campus a year in advance of my transplant, to familiarize myself with the grounds, I started to envision myself living here in the next year. Again, I started making plans as to my vision. How did I want to live my life during the prescribed 30-day stay here at City of Hope? My main goal was to ensure that I would create the best possible “home away from home” once I was assigned to a hospital room. I assured myself I would be a great patient and at the same time remain vigilant about my own needs.

I knew I would always wear my greatest accessory, my smile. In my arsenal of life strategies, there is a certain quote that I tend to draw strength from as well. Remember the movie *Mary Poppins*? “A spoon full of sugar makes the sugar go down.” It really does! Think about it, a quote like this can help you make the choice to have a good and perhaps an “educational view” of an event that you may intuitively feel the need to dismiss as a bad experience. When “move in” day came, I practically transformed my room into a suite, making it colorful and cozy seemingly with a few brush strokes! Heartfelt cards from well wishers and “conversation pieces” were interwoven between heartwarming pictures of family and friends carefully placed at angles in my suite where I could see them daily. Life-like silk flowers and plants, seemingly always in bloom, served as my faux garden, to replace real plants which were not allowed in patient rooms. I always made sure I had music softly playing in the background, to ensure just the right ambience. Before I knew it, I was clicking my heels! My suite had indeed become “home sweet home”! I had no idea that medical staff and my visitors would enjoy coming to my room so much!

My panoramic size window facing the San Gabriel Mountains was a breathtaking visual for me to take in each and every day! I wore colorful clothes and, in some ways, treated my stay like a “spa treatment” — especially taking full advantage of every therapy offered. My husband’s particular brand of humor was always “hysterical” and kept me on my toes! Having your loved one walk with you on your journey is well beyond words and I can truly say he was heaven sent! My one and only son was and continues to be my biggest fan! There were times I knew he just wanted to do whatever he could do to help me feel better, and ironically, I found myself helping him to feel better in his time of need. He continues to celebrate me today! My youngest brother was my donor, and I will forever be grateful for his courageous and selfless act! My oldest brother was the “locomotive” for anyone involved with my care! I journaled by using an on-line computer application which allowed me to keep family and friends informed as to how I was doing. Keeping my mind sharp was (and still is) very important to me. You never know, you might find that writing puts you in touch with your inner Hemingway, Grisham or Steinbeck! I remember reflecting on the timeless writings of Langston Hughes, Anais Nin and James Baldwin, who are among my favorite authors! Perhaps you are more of a poet, taking cues from poets that have come before you, from Oscar Wilde to James Joyce.
and Gertrude Stein to Maya Angelou! Taking part in the music therapy class might reveal that “song” that is in all of us! The possibilities only you know. Can you see yourself belting out trumpet compositions by the great Louis Armstrong or Wynton Marsalis? Maybe the undisputed sound of Santana, or the extraordinary versatility of cellist Yo Yo Ma is more your speed! Can you “imagine” yourself performing on “Broadway,” yes on “Broadway!” You get the point, let your imagination help you and work for you, you have the time, right? I am still trying to hit the glass-shattering high octave notes of Audra McDonald, Mariah Carey and Celine Dion! What note lies inside of you? How about the art therapy class? With my creativity just bursting at the seams, I could hardly wait for my project to take shape! I am still so proud of the life-like wooden snake I painted in jewel tones and gave to my son as a keepsake of my journey. My point is, try to be open to all of the self discoveries that your own journey can bring you. Realize they are all gifts!

Understanding City of Hope’s health care team approach through this guide helps you to understand how your personal directory starts to come together for your own care. The section on “Learning how to keep your home life going” is a must read while you are away from home. I am certain many of you are wondering, where do I start looking for a caregiver and what should I look for in a caregiver? You will find invaluable information in the guide to help you with this search. There is an entire chapter devoted to anything and everything you want to know about bone marrow and blood stem cell transplants. As you learn about effects and medical terminology in this guide, it is my hope that you will feel more knowledgeable and empowered in your medical appointments, and in particular, when making informed decisions. Toward the end of the guide, you will learn about self-care, what I refer to in general as “self-preservation.” This part of the guide is critical to your care, following discharge from City of Hope. As you celebrate this major landmark in your life, now you are ready to move on with your new “blueprint” which could give you the framework for self-care and self-preservation for the rest of your life! The added chapter on Survivorship toward the end of the guide is a “must read,” building on self-care in a Survivorship Plan, which covers a range of areas, such as emotional, social and physical, to name a few. This key information, working in unison with your vision to accomplish your dreams and goals, is sure to give you an incredibly fulfilling and fruitful life!

If I could make one last suggestion to you, following your journey here at City of Hope, consider “paying it forward.” There is always another patient who is in need of our help! I think you will find A Patient's Guide to Blood and Marrow Stem Cell Transplantation to be a great tool and companion to bolster your knowledge, insight and comfort as you journey through this amazing experience. It has been my honor and pleasure to share this very precious moment in my life with each and every one of you! Remember, you have the power to define your moment!

Sincerely,

Patrice A. Traylor Martin
Bone marrow transplant survivor and thriver
2012
“A must read for every bone marrow transplant patient.”
— BMT Survivor

CHAPTER 1

Introduction

National Cancer Institute Designation
National Comprehensive Cancer Network
City of Hope’s Philosophy of Healing
History of Blood and Marrow Stem Cell Transplantation at City of Hope
Chapter 1
Introduction

Welcome to City of Hope

National Cancer Institute Designation

City of Hope has established itself as a leader in cancer research and treatment through a combination of research, promising new treatment plans, compassion and quality patient care based on a belief in the dignity of the individual.

Founded in 1913, originally as a tuberculosis sanatorium, City of Hope has had continuous governmental financial support for its cancer center activities since 1976.

In 1998, City of Hope was designated a comprehensive cancer center by the National Cancer Institute (NCI). NCI-designated cancer centers are a select group of leaders in the fight against cancer. They create new cancer treatments, perform the latest diagnostic and treatment procedures, work with other NCI-designated cancer centers, and combine the expertise of doctors and transplant team members who are among the finest in their fields.

National Comprehensive Cancer Network

Formed in 1995, the National Comprehensive Cancer Network (NCCN) was created to fight cancer more effectively. Representing the finest in cancer care and research across the United States, multiple prestigious institutions are a part of this distinguished network.

City of Hope was one of the founding cancer centers within the NCCN. Through research, measurement and management, the NCCN has made great strides in improving the effectiveness and efficiency of cancer care in this country. The NCCN Oncology Practice Guidelines, which now assist in the care of more than 90 percent of all cancer patients, have become the standard for treatment. Patient versions of some of the NCCN guidelines have been developed to offer patients and their families reliable, specific and understandable information about treatment options.

NCCN member institutions provide unmatched expertise in all areas of cancer treatment, are committed to management through measurement of outcomes, and are dedicated to the best care possible for all cancer patients.

City of Hope’s Philosophy of Healing

In 1951, former City of Hope Executive Director Samuel H. Golter wrote City of Hope’s “Thirteen Articles of Faith,” which stress one common philosophy:

“There is no profit in curing the body if, in the process, we destroy the soul.”
Today, City of Hope’s family of highly skilled researchers, doctors, nurses and caregivers still share this philosophy. They stand at the heart of a medical center which focuses on cancer research, and blood and marrow transplantation. City of Hope clinicians are committed to using the discoveries made in the laboratory to create new and effective cancer treatments for our patients. Supported by an international network of donors and volunteers, their work is grounded in deep compassion and respect for each person who turns to City of Hope for help.

City of Hope brings together a health care team of professionals with a common goal to provide the best and most appropriate cancer treatment possible. Because City of Hope takes a comprehensive, multidisciplinary approach to cancer therapy and patient care, City of Hope team members not only create treatment plans that promote the extension of life, but also customize supportive care plans that improve the quality of life.

**History of Blood and Marrow Stem Cell Transplantation at City of Hope**

In 1976, City of Hope became one of the first six medical centers in the country to begin treating leukemia patients with blood and marrow transplantation. Today, City of Hope is the largest provider of these services in California and one of the most advanced blood and marrow stem cell transplant research and treatment centers in the world. City of Hope doctors have used transplantation to treat patients with potentially life-threatening malignant and nonmalignant diseases.
“Once I began to understand the individual roles of the medical staff, I realized it was such a comfort to me.”

— BMT Survivor

CHAPTER 2

Your Health Care Team
Chapter 2
Your Health Care Team

City of Hope’s team approach to treatment has long set us apart from other hospitals and cancer centers. Each patient is treated by a team of caregivers whose goal is to provide the most complete and well managed treatment possible.

**Doctor (Physician)**

As the leader of your medical care team, your doctor is an expert in the field of hematology and blood and marrow transplantation. This is a field that focuses on providing patients with care that is the most advanced possible. His/her skill is balanced by compassion and concern for your emotional and physical needs.

Our doctors work in association with a network of doctors and other health care professionals that include members of City of Hope’s Department of Hematology & Hematopoietic Cell Transplantation (HCT), community doctors, doctors and researchers who work within cancer centers, and government-supported medical organizations throughout the country.

**Nurse Practitioner/Physician Assistant**

The nurse practitioner (NP) or physician assistant (PA) of the hematology/HCT team is a clinician who has had additional advanced training in hematology and blood and marrow transplantation. The NP or PA makes daily rounds with your health care team and helps to manage daily needs in collaboration with your doctor.

The NP or PA has been trained to perform some or all of the following procedures: bone marrow harvests, bone marrow aspirations, bone marrow biopsies, lumbar punctures and skin biopsies. The NP or PA works with individual doctors and will be available to provide care for you in the inpatient and outpatient setting.

**Nurse Coordinator**

Your nurse coordinator will play a leading role in preparing you for your transplant. He/she is an expert in cancer therapy and is responsible for organizing most of the tests/procedures that will take place before you are admitted to the hospital. In most cases, your nurse coordinator will be involved in your first evaluation process and will help to answer any questions you may have.

**Nurse**

City of Hope has a large staff of experienced and dedicated nurses. They are specialists in all areas of patient care and will work to make you as comfortable as possible during your hospital stay. Over the course of your hospital stay, you will become familiar with various nurses who are highly trained in the care of pediatric and adult blood or marrow
transplantation patients. These nurses work under the guidance of your doctor and work closely with all the members of the transplant team.

**Case Manager**

The case manager, often called “discharge planner,” coordinates home care services you may need after discharge from the hospital. Your Case Manager works closely with your doctor to create a treatment plan that meets all of your health care needs and to assure that you safely transition from hospital to home.

**Child Life Specialist**

The child life specialist provides age appropriate education about HCT transplant, disease, procedures and treatments for pediatric transplant patients, siblings and children of adult patients ages 4 to 17 years. Child life specialists provide one-on-one therapeutic interactions with pediatric transplant patients once they are in isolation.

**School Program Coordinator**

City of Hope believes that children, teens and young adults adjust better to the hospital setting by starting hospital instruction as soon as possible. Our school program coordinator meets with patients and parents in the first few days of admission to assess for educational needs and to arrange tutoring. Tutoring is coordinated to meet the patient’s medical, emotional and educational needs. Tutoring sessions provide patients with daily routine and educational activities that complement their primary focus on treatment while hospitalized.

**Clinical Social Worker**

Clinical social workers are an important part of your health care team. Every patient at City of Hope is assigned a social worker. We know that stress often can occur with a serious or long-term illness for both patients and loved ones. You will meet with one of our clinical social workers during or soon after your first visit to City of Hope. Your clinical social worker will also be able to answer any nonmedical questions you may have.

During your treatment, your clinical social worker will monitor what effect your treatment is having on your emotional and social well-being. He/she will also be available to give you and your loved ones the support you may need. This can include counseling, financial resource referrals, community resource referrals and support group information. The Clinical Social Work Department is also able to arrange for interpretive services if you or your family members require them.

To help you during your stay at City of Hope and to help you prepare for your return home, your clinical social worker will talk often with your doctor, nurses, therapist and other members of your health care team. All communications, of course, are confidential.
Clinical Psychologist and Psychiatrist

Following your diagnosis, and during your transplant, you may find yourself feeling anxious, sad, angry, hopeless or even helpless. City of Hope has clinical psychologists on staff to assist you to cope and adapt throughout your hospital stay and transplant. The clinical psychologist will be available to meet with you before, during and/or after your treatment, following a referral from your doctor.

If you become depressed or anxious, your doctor may make a referral to the consulting psychiatrist for an evaluation. The psychiatrist, psychologist and social workers all work together to ensure that your needs are met. There are also a number of support groups available to you at City of Hope to help you after you leave the hospital.

Dietitian

Dietitians will be available to assess your eating habits and then give you information regarding food and nutrition. Your dietitian will discuss important food safety guidelines to be followed during and after your hospital stay. Your dietitian will also help you with ongoing nutrition guidelines once you are ready to make the transition to home.

Rehabilitation Treatment Team

Because remaining active is a crucial part of your transplant process, City of Hope is a STAR Certified* institution and has specially trained oncology rehabilitation therapists who will work with you. Evidence suggests that exercise and activity help people recover more quickly, reduce stress and anxiety, reduce nausea, reduce fatigue, help with sleep and reduce the risk of complications such as blood clots, pneumonia, weakness and depression. (See Top Ten Things We Want You to Know About Rehab handout.) The therapists will work with you to develop a plan specific to your needs. (See Rehab Weekly Activity Schedule.) The goals of this plan are to help you maintain your physical, cognitive and leisure/social functioning to the best of your ability while undergoing the transplant, and to return to your prior level of engagement in your chosen and required activities as soon as possible following your discharge from the hospital.

The rehabilitation team is made up of physical therapists, occupational therapists and recreation therapists, each specializing in a particular part of your rehabilitation process described below:

Physical therapists will review and monitor your physical condition and teach you appropriate exercise. They will work with you to set up a plan to help you stay as strong as possible throughout your treatment and show you how to change your plan as your tolerance for activity changes. When you are ready to be discharged from the hospital, they will help you design a plan to continue to build your strength and endurance on your road to recovery.

Occupational therapists will assess and monitor your ability to perform your activities of daily living (ADLs). ADLs can be activities as simple as dressing or bathing, or activities
that are more complex such as computer use or event planning — anything that you find meaningful that will keep you active. They will work with you if you feel you are experiencing any chemotherapy-related cognitive impairments, such as difficulty concentrating and/or forgetfulness, and they can help you with coping/anxiety reduction strategies as well. They will help you make a plan to address any of your concerns about responsibilities, roles, cognitive issues or coping strategies when you are ready to be discharged.

**Recreation therapists** will evaluate your interests and hobbies and your adjustment to the hospital environment and they will work with you to develop a plan to keep you actively engaged during your time in the hospital. They will provide you with opportunity for social engagement with other patients as well as for one-on-one time with the therapists. You may participate in your current interests and hobbies or you may learn new leisure skills. They will help you plan for your discharge by providing leisure counseling to address how you will engage in social/leisure activity once you return home.

Your rehabilitation team will be there every step of the way to coach you, guide you, advise you, motivate you, cheer for you and laugh with you. Ultimately, your success in rehabilitation depends on YOU!

**Patient Advocate**

A patient representative is available to you during your stay at City of Hope and can help you find a satisfactory solution to any concerns or unmet needs you may have. Our goal is to ensure that your time at City of Hope is as safe, effective and comfortable as possible. If you or your family have any questions or concerns during your stay at City of Hope, you can reach your patient representative by calling the Patient Advocacy Office at 626-256-HOPE (4673), ext. 62285.

*www.oncologyrehabpartners.com*
"It helped us to simplify our life. This way the only thing on our minds was the transplant."

— BMT Survivor

CHAPTER 3

Important Things to Think About

Caregivers
Financial Counselors
Advance Directive
Chapter 3
Important Things to Think About

Caregivers

Role of the Caregiver
The 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 (see below).
• Provide transportation to and from City of Hope for both pre and post transplant appointments. Post transplant, autologous patients usually are required to see the doctor once or twice a week until the doctor is comfortable with decreasing the frequency. Allogeneic and unrelated transplant patients are required to see their doctor twice a week during the first 100 days, post transplant, or as need arises.
• Be able to reach the patient within 30 minutes at all times and be physically present 24 hours with the patient if residing within Hope/Parsons Village.
• 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, Hickman care and
making sure the patient is taking their medication properly. Some patients may need more assistance than others.

- Observe changes in patient’s condition and report them to the doctor, if indicated.
- Serve as a communication link if needed between patient and medical staff.
- Give encouragement to the patient while taking time to care for yourself.

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 other 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 www.marrow.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?
- Will your caregiver be a strong advocate for you?

Questions and Tips for Caregivers

A transplant is difficult, not only for the patient, but also for family members and caregivers. This is especially true if the support person 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.
• Don’t hesitate to ask other family members and friends for help in caring for the patient, your family and you during 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 drugs 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 tracking down the medical staff to get help or answers to your questions. You’ll feel better knowing the doctors and nurses are aware of problems you’ve noted. You are entitled to have all of your questions answered fully.
• Remember that as helpless as you may sometimes feel the moral support you provide is often the best “medicine” the patient can receive.
• 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 Clinical Social Work office at ext. 62282.

For More Information:
The following booklets may be helpful for you.
• A Caregiver’s Guide: Tips and tools for reducing caregiver stress. (City of Hope)
• Caregivers’ Guide for Bone Marrow/Stem Cell Transplant (nbmtLINK)
• Caring for the Caregiver (National Cancer Institute)
• When Someone You Love is Being Treated for Cancer (National Cancer Institute)

These booklets and more are available in the Sheri & Les Biller Patient and Family Resource Center.

Finances
You will be asked to provide your insurance and financial information when accepted as a patient. Medicare and all types of insurance are accepted.
We have contracts with many health maintenance organizations (HMOs), preferred provider organizations (PPOs) and employer insurance groups. (Please note: Medical authorization is required on most of these contracts before treatment.)

Whether you are an inpatient or outpatient, please remember to carry your health insurance identification card at all times. This will make things easier for you and for various departments that might need this information.

**Financial Support Services**

Financial Support Services (FSS) assists with outpatient registration, securing insurance authorizations, referral/benefits/eligibility and insurance verification, financial counseling, charity care screening, medical necessity screening, assignment of patient account and medical record numbers, and up front cash collections.

FSS interacts with patients, families, visitors and doctors regarding outpatient registration activities and ensures an efficient and effective process for patient intake. The staff serves as a problem-solving resource for insurance and financial issues in support of City of Hope’s mission to provide caring and compassionate service to our patients, and superior customer service to our clinicians and colleagues.

**Financial Counselors**

By the first letter of your last name:

(A - D)
(E – I)
(J – N)
(O – R)
(S – Z)

Services provided by this facility are available to all persons living or working in this area. This facility is prohibited by law from discriminating against any person, including Medi-Cal and Medicare patients. If you believe you may be eligible for Medi-Cal or Medicare and are in need of a doctor to provide you with services at this facility, please contact our business office. Refusal of services at this facility is in violation of the community services requirement. Should this occur, please contact Julie Weber, manager, Financial Services/Patient Access at City of Hope (626) 256-4673, ext. 68342, and the California Health Facilities Financing Authority at (916) 653-2995.
Advance Directive

What is an AD?
An advance directive (AD) is a verbal or written instruction that tells your family and health care team what you want done in case you have a serious injury or illness and are not able to speak for yourself. If you already have an AD, you may bring a copy of it and we will place it in your medical record.

What are the benefits of an AD?
Having an AD will help your family have a clear statement of your wishes for health care in the event you are not able to speak for yourself. You will feel confident that your medical decisions will be respected.

How do I complete an AD form?
It is important to discuss your advance directive with your family ahead of time. For more information read through the City of Hope booklet Making an Advance Directive available in the Sheri & Les Biller Patient and Family Resource Center. If you have further questions about completing your AD, please speak with your doctor, clinical social worker or both.

City of Hope can provide you with an advance directive form or you may use your own. This is a legal document and will need to be witnessed or notarized. You may speak with a lawyer if you think it would be helpful, however it is not necessary. City of Hope has notary services available.

Other Responsibilities
You will also need to make arrangements ahead of time to manage your other responsibilities during your hospital stay and recovery period. Bills need to be paid and your home needs to be maintained while you are in the hospital. You may need help with these things during your recovery period as well. Think about the people who can do these things for you and talk to them well in advance. Make sure they understand exactly how they can help you.

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.

Family Spokesperson

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.
Blood and Marrow Stem Cell Transplant Basics

Normal Blood Cells
Peripheral Blood Stem Cells
Reasons for Transplant
Types of Stem Cell Transplants
Sources for Transplant
Stem Cell Collection
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 **red blood cells**, **white blood cells** and **platelets**. When bone marrow is withdrawn from the bone it looks very similar to blood.

**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 next section)
- **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.

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**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
- Hemophagocytic Lymphhistiocytosis
- Langerhans Cell Histiocytosis
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:

- In an **autologous transplant**, your own stem cells are taken before treatment, then given back to you after chemotherapy and radiation.

- In an **allogeneic transplant**, you receive stem cells from another person such as a sibling or parent. Stem cells from a person who is not related to you also may be used and is called a matched unrelated donor or “URD” transplant. This may include umbilical cord blood as well.

- 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.

Sources for Transplant

There are three possible sources for stem cells:

- **Bone marrow**: This is the spongy tissue found in the center of bones that produces blood cells.

- **Peripheral blood**: There are normally some stem cells found in peripheral blood circulating in the body. In order to get enough stem cells for the transplant, the donor is given “growth factors” to help with stem cell growth. This causes the stem cells to grow faster and move from the marrow into the peripheral blood.

- **Umbilical cord blood**: This 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 to 5 percent 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.
Preparing for Your Transplant

Evaluation Tests for Eligibility, Preadmission
Central Vascular Access Device
Fertility Issues and Reproductive Options
Chapter 5
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 requires 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 you are in hospital.

Common Preadmission Testing

**Blood Tests**
- Complete Blood Count (CBC)
- Blood Chemistry
- Infectious Disease Markers

**Creatinine Clearance**
- 24-hour urine collection measures kidney function.

**Glomerular Filtration Rate (GFR)**
- The GFR tests how well your kidneys are working.
Chest X-ray
X-ray of the chest views the lungs, heart and surrounding structures for abnormalities.

Electrocardiogram (EKG)
Measures the heart’s electrical impulses to evaluate rhythm and function.

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.

CT Scan
Computerized tomography 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.

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.

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

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.

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.

Lumbar Puncture
This is a procedure, sometimes called a “spinal tap,” and 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.
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.

Magnetic Resonance Imaging (MRI)
An 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. PET scan is only done if needed.

MIBG Scan, iodine-131-meta-iodobenzylguanidine scintiscan
An MIBG scintiscan 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.

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.
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:

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.

Colonoscopy  
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.
Central Vascular Access Device

All blood and marrow stem cell transplant patients will need a 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 which 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 intravenous (IV) 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 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. In fact, most patients are unable to have children after transplantation. If this is a concern to you, options such as sperm, egg or embryo freezing may be appropriate for you.

Please discuss fertility concerns and reproductive options with your doctor as soon as possible before you begin your treatment. City of Hope does not offer sperm banking or egg or embryo freezing services. There are some local companies that provide these services. Most insurance companies do not cover the cost of sperm banking or egg or embryo freezing.
“Read this chapter and you will learn what happens during a bone marrow transplant.”
— BMT Survivor

CHAPTER 6

Types of Transplants

Allogeneic Transplants

Autologous Transplants
Chapter 6
Types of Transplants

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.

Unrelated Donor Transplant

Unrelated Donor Transplant (URD) 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.

Human Leukocyte Antigen Typing for Allogeneic Transplantation

The term “Human Leukocyte Antigen (HLA) Typing” is used to describe the process of matching donor HLA to patient (recipient).

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. 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).

Be The Match
The National Marrow Donor Program®

The National Marrow Donor Program® (NMDP) is an agency that facilitates the search for patients who have no siblings or whose relatives who are not a match for them. If a match is found, further evaluation of the potential donor is done. Donors are admitted to a hospital in their area, and stem cells are collected within 24 hours before the transplant.

City of Hope’s Be The Match team is available to assist patients in registering friends and family members. The team is able to go into your community and educate and support the registration of volunteer donors. Staff is trained and able to assist in non-English speaking communities as well.

Contact City of Hope’s Be The Match team at 626-301-8483 or bethematch@coh.org
Each 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).

**Syngeneic Transplant**

*Syngeneic* means a perfect tissue match. A syngeneic transplant is the infusion of stem cells from one identical twin to another. An identical twin is a perfectly matched donor and is considered to be HLA identical with the patient. This type of transplant is similar to an autologous transplant in that there is minimal risk of GVHD. The stem cells, however, are known to be free of cancer.

**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. 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.

**Haploidentical Transplants**

An HLA-haploidentical donor shares a haplotype with the transplant recipient. This means that 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. Rather than being a match for each other, they are a half-match. Parents are always a half-match for their children and vice versa. Siblings have a 50 percent chance of being a half-match for each other. (They have a 25 percent chance of being a perfect match and a 25 percent 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
Infusion of Allogeneic Blood and Marrow Stem Cells

The new stem cells or bone marrow are administered 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 (VAD). You will receive medication about 30 minutes 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 WBCs, RBCs and platelets. After you have received 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.
**Autologous Transplant**

**Autologous** means from yourself. Some of your own healthy stem cells are removed, or “harvested,” at a time when there is no evidence of cancer cells in your blood and bone marrow. These stem cells are then frozen and stored. They will be given back to you after you receive high doses of conditioning chemotherapy and/or radiation.

Some types of cancer may respond best to chemotherapy given in very high doses. High-dose chemotherapy can kill a great number of cancer cells but it also can have a harmful effect on some normal cells, especially on blood cells made in the bone marrow. Bone marrow that has been suppressed or destroyed may not be able to make new blood cells. An autologous transplant will “rescue” you from the effects of high-dose chemotherapy and/or radiation treatments by replacing the destroyed bone marrow with the stem cells that were previously collected.

**Apheresis**

Apheresis is the process used to collect the healthy stem cells from your blood. An apheresis nurse will oversee the collection of your stem cells before you receive high dose conditioning chemotherapy. He/she will place you on the apheresis machine and will monitor the number of stem cells that are being collected each day. The apheresis nurse will teach you about apheresis and will answer your questions about transfusions of blood or platelets and the use of specific blood donors.

**Infusion of Autologous Blood and Marrow Stem Cells**

The new stem cells or bone marrow is administered to replace the 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 (VAD). You will receive medication about 30 minutes before the transplant to help prevent any side effects. These medications may make you sleepy. So please plan on taking your shower early. Even with the pre-medication reactions may still occur, but usually are minimal.
Your frozen stem cells are thawed immediately before infusing, at the patient's bedside. The amount of stem cells infused on your day of infusion is determined by your doctor who will order the number of bags required to deliver the target number of stem cells you require.

Each bag of autologous stem cells will be infused rapidly over five to ten minutes. During the infusion, your nurse will monitor your vital signs and oxygen level. He/she will remain with you until the infusion is completed.

Some common side effects you may experience during your stem cell infusion include nausea, vomiting or a cold sensation due to the rapid infusion of cells.

To preserve the stem cells, we have added dimethyl sulfoxide (DMSO). This may cause a very strong oyster or garlic like odor in your room for two to three days after your stem cells have been infused. During the infusion you may experience an unpleasant taste in your mouth from this stem cell preservative. We suggest that you bring some hard candy with you to the hospital to help mask that taste. This taste will dissipate once the infusion of the cells is complete.

**Engraftment**

Engraftment is the point when your “new” stem cells or marrow begins to make white blood cells, red blood cells and platelets. After you have received your marrow or stem cells your blood counts will be checked daily to determine if or when engraftment begins. Engraftment usually occurs 10 to 30 days after day zero of your transplant. Remember that all patients are different and the length of time to engraft varies from one person to another.
“It is good to know that this chapter lays out what the patient can expect, with important milestones, in the transplant process.”

— BMT Survivor

CHAPTER 7

Getting Your Body Ready for Transplant (The Conditioning Regimen)

Chemotherapy

Radiation Therapy
Chapter 7
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, which includes white cells, red cells and platelets. 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 anticancer 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.

Some of the common side effects you may experience include the following:

**Nausea and Vomiting**  The doctor will prescribe medications that help control the nausea and vomiting.

**Diarrhea**  There are medications your doctor will prescribe to decrease/relieve the diarrhea.

You may be given fluids through your IV to replace fluids lost from diarrhea.
Be sure to clean your anal area well after each bowel movement to help prevent skin breakdown, soreness and infection. Any pain around the anal area should be reported to your nurse.

**Loss of Appetite**

Good nutrition is important during your transplant. Your nutrition can be maintained intravenously by total parenteral nutrition (TPN), which is a high-calorie, high-protein solution, if you lose the desire to eat.

**Hair Loss**

You will experience the loss of scalp and body hair a week or two after chemotherapy. Some people cut their hair very short or shave their head to make the transition a little easier.

Losing hair from your head, face or body is not easy to accept and may take some emotional adjustment. At times you may feel angry or depressed about losing your hair. Such emotions are neither wrong nor unusual. You might feel better by talking about them.

If you would feel better with your head covered, scarves, caps, turbans and wigs are all good methods to use. We can refer you to our Positive Image Center℠, where a specialist can help you with your personal needs.

**Skin Reaction**

There are a variety of skin reactions that may occur as a result of chemotherapy and/or radiation therapy.

If your skin becomes very dry, follow the directions of your healthcare team.

Several drugs can cause patches of darkened or coarse skin to appear. These may occur on your hands, face, elbows and creases of the skin.

Chemotherapy can also cause a type of reaction like a sunburn, where your skin becomes flushed (reddened) and tends to peel. The palms of your hands and soles of your feet may become especially tender. Your healthcare team may order cream or lotion to help keep these areas moist and to help with the discomfort to these areas.

**Sore Mouth**

Because mouth tissue is at risk for infection, good mouth care is important during your transplant. You will need to follow special mouth care hygiene while you are in the hospital:

a. Brush teeth, at least two times per day, with an ultra-soft toothbrush. If an ultra-soft toothbrush is hard to use, try a toothette dipped in non-alcohol based chlorhexidine. Allow toothbrush to air-dry before storing. Replace brush weekly.

b. 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.
c. Rinse mouth at least four times daily with a bland rinse.

d. Avoid mouth rinses with phenol, astringents, or alcohol.

e. Avoid tobacco, alcohol, or irritating foods such as those that are acidic, hot, rough and/or spicy.

f. Use water or waxed (non-petrolatum) based moisturizers to protect lips.

g. Keep up fluid levels. You do not want to get dehydrated.

You may notice that your mouth may become red and tender and your gums may bleed or there may be white patches in your mouth. Be sure to tell your doctor and nurses if you notice any of these symptoms. There are medications available to help control mouth and throat pain if needed.

Fatigue

It is very common to feel weak and tired after chemotherapy. Many of the transplant medications and low blood counts may contribute to this feeling. Listen to your body and rest when you feel the need. With time, the fatigue will pass. Maintaining daily activity while hospitalized helps to decrease fatigue.

What You Can Do For Side Effects

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

- Read the “Barrier Cards.” Ask your nurse to get your own set of cards. These cards cover all of the chemo side effects and give you advice on what to do.

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

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

- 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.

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

- 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 non-alcoholic mouthwash like Biotene® may also be helpful.

- Use an electric razor to minimize risk of cuts or bleeding.
• Avoid sun exposure. Wear SPF 15 (or higher) sunscreen and protective clothing.

• In general, drinking alcoholic beverages should be kept to a minimum or avoided completely. Discuss this with your doctor.

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

• 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 Call Center 626-471-7133 is staffed 24 hours a day to answer any non-emergency questions treatment or self-care.

Radiation Therapy
Radiation therapy may be used in combination with chemotherapy as part of the preparation for your stem cell transplant. Total body irradiation (TBI) therapy is radiation given to destroy any cancer cells that may be remaining and to suppress your immune system to prevent rejection of the new marrow graft (stem cells). Vital organs will be protected during this process. Treatments are not painful and you will not feel anything unusual while the machine is on.

Immediate side effects may include nausea, vomiting, decreased appetite, diarrhea and fatigue. The skin exposed to the radiation can become slightly reddened and warm, like a sunburn. Other side effects can include sores in your mouth and throat and decreased blood cell counts. Late side effects of radiation can include sterility, cataract formation and lung problems.

Total body irradiation 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. City of Hope staff will go with you to the radiation department. You receive radiation treatment while you are standing. Each appointment takes roughly 30 minutes, although actual treatment time is about 10 minutes.

You are encouraged to bring relaxing music. The department will supply a music player so you can listen to music while you receive your treatment.
“The bottom line here is to use common sense and do whatever you need to do to protect yourself. You will have invested too much time and energy in overcoming your illness to take unnecessary chances that might introduce germs and disease.”

— BMT Survivor

CHAPTER 8

Complications

Short-term Complications
Infections from the Environment
Infections from Your Own Body
Blood Product Transfusion
Kidney and Liver Problems
Graft Failure
Long-term Complications
Chapter 8
Complications

Short-term Complications
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.

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. The nurses will check your vital signs frequently to see if you have a fever. If you do, blood samples will be drawn from your VAD (vascular access device) and peripheral 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:

1. Everyone entering your room must wash their hands and wear a mask to protect you from infection.
2. 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.
3. You may wear your own clothes while in the hospital, however you must change into clean clothes every day after your shower. Hospital gowns are provided should you wish to wear one of these.

(Please refer to your Inpatient Guide for additional information regarding clothing and other items.)
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**

- Bathe or shower once a day. Bathing helps keep 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, as soap can be drying.
- 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.
- Do not shave unless you have an electric 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 milliliters (mL) of an oral care product such as Biotene mouthwash.
- If your doctor has given you permission, use a toothette with toothpaste to swab your gums and clean your teeth.
- 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.
- Measure five mL (one 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 the City of Hope 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. There are blood tests 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 Chapter 9 for more information on graft-versus-host disease.

Long-term Complications

Long-term complications can be caused by high-dose chemotherapy, radiation therapy, chronic GVHD (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. Most transplant recipients will be sterile as a result of the combined high-dose chemotherapy and/or radiation therapy administered before transplantation and will be unable to have children.

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.

Please discuss fertility concerns and reproductive options with your doctor as soon as possible before you begin your treatment.

**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, raditation 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). A medication called gancyclovir is the drug 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 department.

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.
Graft-Versus-Host Disease (GVHD)

Complications of Acute GVHD

Chronic GVHD Targets
Chapter 9
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. 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.

Complications – GVHD

GVHD occurs when the stem cells from the donor recognize your body as new and different from the body they came from and react to it. If graft versus host disease 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.

Acute GVHD

Some signs of acute GVHD include changes in the skin, gastrointestinal tract and/or liver. There are different drugs 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.

**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 nonabrasive 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.

**Gastrointestinal tract:** 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.

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

Chronic GVHD

GVHD is an immunologic reaction in which donor T-lymphocytes (a type of white blood cell) react against the host tissue of the recipient. 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 percent of patients with chronic GVHD. Symptoms may include itching, burning, hyperpigmentation (darkening of skin), 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 non-abrasive 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.
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.
• Avoid tobacco, alcohol, or irritating foods such as those that are acidic, hot, rough and/or spicy.
• Keep your lips moist to prevent cracking and bleeding. You can use water or waxed (non-petrolatum) 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.

Esophagus and Gastrointestinal (GI) Tract: The lining of the esophagus and GI 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 GI symptoms.

Vagina: Changes within the vagina often occur. Symptoms may include inflammation, or 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.

*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.
“It always pays off to stay informed on your medication and how it affects you!”

— BMT Survivor
Chapter 10
Medications Commonly Used In Blood and Marrow Stem Cell Transplantation

This section will discuss common medications you will be taking as part of your transplant process. Keep in mind that many of the medications listed are not necessarily going to be prescribed to you. Chemotherapy to prepare for transplant is unique to you and your disease. A variety of medication may be prescribed to you specific to your symptoms or the complications you may encounter during your treatment. Other medicines may be given to prevent complications such as infection or graft-versus-host disease. These meds may be taken by mouth, injected under the skin or in a vein. We encourage you to make a list of your home medications and ask questions regarding each and every medication you may be taking. We will be reviewing all of your home medications with you each time you come to your clinic visit.

During your stay in the hospital, 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.

These are commonly used chemotherapy medications. Your doctor may prescribe one or more of these medications.

**Abelcet/ABLC**
An antifungal used to treat fungal or mold type infections. It is administered intravenously. Common side effects include allergic reactions, decreased blood counts, fever, chills, joint and muscle pain, nausea, vomiting, diarrhea, abdominal pain, headache, dizziness.

**Acetaminophen (Tylenol)**
Used as a pre-medication for blood products or some medications, to reduce fever and as a mild pain reliever. Does not usually have an adverse side effect in recommended doses. High doses or long-term use may cause liver and kidney damage.

**Acetazolamide (Diamox)**
A diuretic used to get rid of extra fluid in your body. Can be taken orally or IV. Common side effects include drowsiness, dizziness and low-potassium.

**Acyclovir (Zovirax)**
An antiviral used to prevent/treat herpes simplex, herpes zoster (shingles) and varicella (chickenpox) viral infections. Common side effects include headache, nausea, vomiting and diarrhea.
**Albumin**
A blood derivative used to maintain blood volume and protein levels in the blood. Common side effects include allergic reactions, fever, chills, nausea and low blood pressure.

**Allopurinol**
Used to decrease uric acid in the blood and prevent side effects of certain chemotherapy drugs. Also used to treat gout. Drink plenty of fluids while on this medication. Common side effects are skin rash or other allergic reactions, nausea, vomiting and diarrhea.

**Ambisome (see Abelcet/ABLC)**

**Anti-thymocyte globulin (Atgam, ATG)**
An immune suppressing drug used to treat graft-versus-host disease and aplastic anemia. Common side effects include allergic reactions, decreased blood counts, fever, chills, joint and muscle pain, nausea, vomiting, diarrhea, abdominal pain, headache and dizziness.

**Cefazolin (Ancef)**
An antibiotic used to treat or prevent certain infections. Common side effects include pain at peripheral IV site (IV in your hand or arm), diarrhea and allergic reaction.

**Ceftazidime (Fortaz)**
An antibiotic used to treat or prevent certain infections. Common side effects include pain at peripheral IV site (IV in your hand or arm), diarrhea and allergic reaction.

**Clindamycin (Cleocin)**
An antibiotic used to treat or prevent certain infections. Common side effects include diarrhea, mild nausea (oral only), allergic reaction and pain at peripheral IV site (IV in your hand or arm).

**Clonidine* (Catapres)**
A drug used to treat high blood pressure. Also used to avoid side effects when stopping or decreasing certain pain medications. Can be taken orally or as a patch applied to the skin. Common side effects include drowsiness, dizziness, dry mouth and constipation.

* Do not stop this medication suddenly or without your doctor’s knowledge.

**Codeine**
An analgesic (pain reliever) used for management of mild to moderate pain. Also used to suppress nonproductive cough. Common side effects include drowsiness, nausea, vomiting, constipation and dry mouth. May also be used to control severe diarrhea.
**Cyclosporin A* (Sandimmune, Neoral, CSA)**
An immune suppressing drug used to prevent/treat graft-versus-host disease. Common side effects include decreased kidney function, tremors, abnormal hair growth, high blood pressure, low magnesium and increased risk of infection.

* Drink plenty of fluids. Mix liquid form with chocolate milk or juice. Do not take with grapefruit juice or apple juice.

**Diphenhydramine (Benadryl)**
An antihistamine used to prevent/treat allergic reactions to medications and blood products. Also used to prevent or treat nausea. Common side effects include drowsiness and dry mouth.

**Diphenoxylate with atropine* (Lomotil)**
Used to control diarrhea. It is taken orally. Common side effects include drowsiness, dizziness, dry mouth, constipation, nausea and vomiting.

**Dopamine (Intropin)**
Used to increase circulation (blood flow) to kidneys to improve kidney function. Also used to help heart function and increase blood pressure in times of stress or shock. Common side effects include nausea, vomiting, angina (chest pain), palpitation, headache and shortness of breath.

**Enalapril (Vasotec)**
An antihypertensive drug used to treat high blood pressure and other heart conditions. It is administered orally or IV. Common side effects include dizziness, dry cough, rash and high potassium.

**Erythromycin**
An antibiotic used to treat or prevent certain infections. It can be taken orally or IV. Common side effects include nausea, vomiting, diarrhea, abdominal cramping and allergic reactions.

**Famotidine (Pepcid)**
An acid reducer medication used to decrease stomach acid to prevent or treat stomach ulcers. A common side effect is headache.

**Fentanyl* (Duragesic)**
An analgesic used in the management of moderate to severe pain. It is most often used as a patch applied to the skin. Side effects include mild nausea/vomiting, drowsiness, constipation, dry mouth, itching and difficulty urinating.

* Do not stop this medication suddenly or without your doctor’s knowledge.
**Filgrastim (Neupogen, G-CSF)**
A hematopoietic (blood forming) agent used to speed up the recovery of blood counts, especially white blood cells (WBCs), and decrease the chance of infection after chemotherapy. Also used before stem cell collections to increase WBCs. Common side effects include bone pain, chills and fever.

**Fluconazole (Diflucan)**
An antifungal used to prevent or treat fungal infection. A common side effect is mild nausea and headache.

**Folic acid (Folvite, Folate)**
It is a B vitamin that aids in bone marrow maturation, helping the body make healthy red blood cells. A side effect may be allergic reaction, but this is uncommon.

**Foscarnet Sodium (Foscavir)**
An antiviral used to prevent/treat cytomegalovirus, or CMV, infections. It is given IV. Common side effects include decreased kidney function, inability to pass urine, tremors, numbness or tingling of hands or feet, headache, seizures, low potassium, low magnesium, low calcium, skin rash, itching and decreased blood counts.

**Furosemide* (Lasix)**
A diuretic “water pill” used to get rid of extra fluid in your body or treat high blood pressure. Common side effects include low blood pressure, dizziness, headache, nausea, low potassium and low calcium.

*If you have a sulfonamide (“sulfa”) allergy, talk with health care provider before taking this medication.

**Ganciclovir (Cytovene, DHPG)**
An antiviral used to prevent/treat cytomegalovirus, or CMV, infections. If taken orally, take with food. Drink plenty of liquids. Common side effects include decreased white blood cell and platelet counts, decreased kidney function, nausea and vomiting.

**Gentamicin**
An antibiotic used to treat or prevent certain bacterial infections. It is usually given IV or IM (injection into the muscle). Common side effects include decreased kidney function, ringing in the ears, hearing loss and dizziness.

**Granisetron (Kytril)**
An antiemetic (antinausea) medicine used to prevent/treat nausea and vomiting. Common side effects include headache and constipation.
**Hydrocodone with acetaminophen** *(Vicodin, Norco, Lortab)*
An analgesic (pain reliever) used in the management of moderate to severe pain. Take with food to prevent stomach upset. Common side effects include drowsiness, urinary retention, slow breathing, nausea, vomiting and constipation.
*Do not stop this medication suddenly or without your doctor’s knowledge.*

**Hydrocortisone** *(Cortef, Solu-Cortef)*
An immune suppressor used as premedication for blood products and/or other medications to decrease the chance of developing an allergic reaction. Common side effects include sodium and fluid retention, stomach upset, insomnia, high blood sugar and risk of infection.
*Avoid people with infections, colds or flu.*
*Take this medicine in the morning, if taking once a day.*
*Take tablet with food to prevent stomach upset.*

**Hydromorphone** *(Dilaudid)*
An analgesic (pain reliever) used in the management of moderate to severe pain. It can be taken orally or given IV. If taken orally, take with food to prevent stomach upset. Common side effects include drowsiness, urinary retention, slow breathing, nausea, vomiting and constipation.
*Do not stop this medication suddenly or without your doctor’s knowledge.*

**Immune Globulin** *(Gammagard, Carimune, Gamunex, IVIG)*
An immune stimulator providing antibodies (a disease fighting component of the blood) to prevent certain infections and acute graft-versus-host disease. It is given IV. Common side effects include fever, chills, nausea, low blood pressure and shortness of breath.

**Labetolol** *(Trandate, Normodyne)*
An antihypertensive used to treat high blood pressure. Common side effects include dizziness and drowsiness.
*Rise slowly over several minutes from sitting or lying position.*
*Do not stop this medication suddenly or without your doctor’s knowledge.*

**Levofloxacin** *(Levaquin)*
An antibiotic used to treat or prevent certain bacterial infections. If taken orally, do not take dairy products or mineral supplements within two hours. Common side effects include mild nausea and slight dizziness.

**Loperamide** *(Imodium)*
A medication used to control diarrhea. It is taken orally. Common side effects include drowsiness, dizziness, blurry vision, dry mouth and constipation.
*Do not take more than eight per day.*
Lorazepam (Ativan)
A medication used to prevent/treat nausea or vomiting, treat anxiety or used to calm you before a medical procedure. Common side effects include drowsiness, feeling lightheaded or having blurred vision.
* Avoid driving.

Magnesium (Slow Mag, Magnesium Plus Protein)
Magnesium is a mineral supplement. A common side effect is diarrhea.

Medroxyprogesterone (Provera)
A hormonal agent used to prevent blood loss by suppressing menstrual periods in female patients. It is taken orally. Common side effects include mild nausea, breakthrough bleeding and breast tenderness.

Meperidine (Demerol)
A drug used as a premedication for certain medications and blood products to prevent or treat chills. Common side effects include drowsiness, nausea, vomiting and constipation.

Mesna (Mesnex)
A drug used to prevent/treat hemorrhagic cystitis (irritation and bleeding of the bladder) caused by the chemotherapy drugs ifosfamide (Ifex) and cyclophosphamide (Cytoxan). Common side effects include a bad taste in the mouth and diarrhea.

Methadone* (Dolophine)
An analgesic (pain reliever) used in the management of moderate to severe pain. If taken orally, take with food to prevent stomach upset. Common side effects include drowsiness, feeling lightheaded, sleepiness, having blurred vision, urinary retention, slow breathing, nausea, vomiting and constipation.
* Do not stop this medication suddenly or without your doctor’s knowledge.

Methotrexate (MTX, Rheumatrex; Trexall)
A drug used to prevent/treat graft-versus-host disease. Common side effects include mouth sores, low blood counts, nausea and vomiting.

Methylprednisolone* (Solu-Medrol, MPSLE)
An immune suppressor drug (steroid) used to decrease inflammation and prevent/treat graft-versus-host disease. If taken orally, take with food or milk to prevent stomach upset. Common side effects include increased appetite, weight gain, mood changes, acne, stomach irritation, ulcers, increased facial and body hair, muscle weakness, increased risk of infection, insomnia, high blood sugar and fluid retention.
* Do not stop this medication suddenly or without your doctor’s knowledge.
**Metoclopramide** *(Reglan)*  
An antiemetic (anti-nausea) medication used to prevent/treat nausea and vomiting. Common side effects include headache, drowsiness, fatigue and weakness.  
*Take this medicine 30 minutes before meals.*

**Metoprolol** *(Lopressor)*  
A medication used to treat high blood pressure and other heart conditions. Common side effects include drowsiness, dizziness and slow heartbeat.  
* Rise slowly over several minutes from sitting or lying position.  
* Do not stop this medication suddenly or without your doctor's knowledge.

**Metronidazole** *(Flagyl)*  
An antibiotic used to treat or prevent certain infections, including infectious diarrhea. Common side effects include nausea, vomiting, diarrhea, abdominal cramping, metallic taste in your mouth and change in color of urine to black or brown.  
* Avoid alcohol (including wine, beer and liquor). Drinking alcohol may cause cramps, nausea, headaches and flushing.

**Morphine** *(MS Contin, MSIR, Roxanol, Kadian)*  
An analgesic (pain reliever) used for the management of moderate to severe pain. If taken orally, take with food to prevent stomach upset. Common side effects include drowsiness, urinary retention, slow breathing, nausea, vomiting and constipation.  
* Do not stop this medication suddenly or without your doctor's knowledge.

**Mycophenolate mofetil** *(CellCept, MMF)*  
An immune suppressor used to prevent/treat graft-versus-host disease. It can be taken orally or given IV. Common side effects include nausea, vomiting, diarrhea, low blood counts, high blood pressure and increased risk of infection.

**Nifedipine** *(Procardia, Procardia XL, Adalat CC)*  
A medication used to treat high blood pressure and other heart conditions. Common side effects include dizziness, rapid heartbeat, water retention, headache and flushing and constipation.

**Nystatin** *(Nilstat)*  
An antifungal used to prevent/treat fungal infections in the mouth or throat (thrush). Taken orally, the solution is swished around in your mouth and swallowed. Common side effects include nausea, vomiting, diarrhea and rash.  
* (Mycostatin)  
An antifungal used to treat vaginal fungal infections. Taken as a vaginal suppository.
Ondansetron (Zofran, Zofran ODT)
An antiemetic (antinausea) medication used to prevent/treat nausea and vomiting. It can be taken orally or given IV. Common side effects include diarrhea, headache and constipation.

ODT: Oral-disintegrating tablet
Place on tongue and let dissolve. Water is not needed.

Oxacillin
A penicillin derived antibiotic used to treat or prevent certain bacterial infections. Common side effects include allergic reaction, pain at peripheral IV site, nausea, vomiting and diarrhea.

Penicillin G
An antibiotic used to treat or prevent certain bacterial infections. Common side effects include allergic reaction, pain at peripheral IV site, nausea, vomiting and diarrhea.

Phenazopyridine (Pyridium ReAzo [OTC]; UTI Relief [OTC])
This medication is used to decrease the pain and discomfort of urination during a bladder infection. It is taken orally. Take with food and increase fluid intake. Common side effects include reddish/orange colored stool and urine, nausea, vomiting, diarrhea, headache and yellow discoloration of the eyes. May stain contact lenses.

Prednisone*
An immune suppressor (steroid) used to decrease inflammation and prevent/treat graft-versus-host disease. Take with milk or food to decrease stomach upset. Common side effects include increased appetite, weight gain, mood changes, acne, stomach irritation, ulcers, increased facial and body hair, muscle weakness, increased risk of infection, sleep disturbances and fluid retention.

* Do not stop this medication suddenly or without your doctor’s knowledge.

Procardia XL (see Nifedipine)
A long acting form of Nifedipine.

Prochlorperazine (Compazine)
An antiemetic (antinausea) medication used to prevent/treat nausea and vomiting. Common side effects include drowsiness, dry mouth, low blood pressure, tremors and muscle tightness and constipation.

Rabeprazole (AcipHex)
An acid reducer used to decrease stomach acid to prevent or treat stomach ulcers. A side effect may be headache, although it is uncommon.
**Sargramostim (Leukine, GM-CSF)**
A hematopoietic (blood forming) agent used to speed up the recovery of blood counts, especially white blood cells (WBCs), and decrease the chance of infection after chemotherapy. Also used before stem cell collections to increase WBCs. Common side effects include bone pain, chills and fever.

**Septra (see Sulfamethoxazole/ trimethoprim)**

**Sulfamethoxazole/trimethoprim (Bactrim, Septra)**
An antibiotic used to treat or prevent certain infections, including pneumocystis jiroveci (formerly called pneumocystis carinii) pneumonia. If taken orally, take with plenty of water. Common side effects include nausea, vomiting, diarrhea, skin/allergic reactions, light sensitivity and low blood counts.

**Tacrolimus (Prograf, FK506)**
An immune suppressor used to prevent/treat graft-versus-host disease. Common side effects include decreased kidney function, tremors, headache, high blood pressure, low magnesium, high blood sugar, nausea, diarrhea, insomnia and increased risk of infections. Drug level is monitored for effect and toxicity.

**Tobramycin**
An antibiotic used to treat or prevent certain bacterial infections. Common side effects include decreased kidney function, ringing in ears, hearing loss and dizziness.

**Trandate (see Labetalol)**

**Tylenol (see Acetaminophen)**

**Vancomycin**
An antibiotic used to treat or prevent certain infections. Also used to treat infectious diarrhea. Common side effects include pain at peripheral IV site or “red man syndrome” (redness or rash over the face, neck and upper chest), low blood pressure and decreased kidney function.

**Vasotec (see Enalapril)**

**Vicodin (see Hydrocodone with acetaminophen)**

**Zofran (see Ondansetron)**

**Zovirax (see Acyclovir)**
CHAPTER 11

Self-care After Discharge

Rehabilitation

Hygiene

“This is a great self-care manual for life after your transplant!”
— BMT Survivor
Chapter 11
Self-Care After Discharge

The following are general guidelines only. In addition, there are some differences between discharge instruction for autologous and allogeneic transplant patients. Please refer to your specific discharge instructions.

When the case manager has received notification of your upcoming discharge, he or she will come to speak with you to confirm pharmacy information, caregiver arrangements, housing arrangements and have you sign the Important Notice from Medicare and/or the Freedom of Choice form. The case manager will fax a copy of your newly ordered medications to the pharmacy you have requested and attempt to find out your cost after meeting deductibles.

The day you are discharged from the hospital can be both exciting and frightening. You may feel glad to be leaving the hospital behind you, but frightened as you are losing the “safety net” of hospital staff that have been available to support your medical need. During this period of recovery, we will be there to help you take the first steps out of the hospital and start you back on the road to recovery.

After discharge from the hospital, you will be seen as an outpatient in the clinic, usually twice a week. Special instructions will be given to you upon discharge. You will need to stay in the Los Angeles area for approximately 100 days after transplant for close follow-up.

When you are discharged from the hospital, you will receive more detailed verbal and written discharge instructions. If you do not understand your instructions or have questions about them, we strongly urge you to speak to your nurse, doctor or pharmacist before you are discharged. The following are general guidelines:

Rehabilitation

When you go home, you will probably continue to feel fatigue and weakness for quite some time following your transplant. It will be very important to continue with the plan you established with your rehabilitation team while you were in the hospital. Exercise and activity, done at appropriate levels, are vital to regain your energy and strength.

We encourage you to exercise daily, whether it’s taking a walk, spending a few minutes on a stationary bike, working out with your favorite exercise DVD or gentle yoga stretches. Exercise with a friend or make it a family affair. Everyone will benefit and you will develop a healthy routine. Before you know it, you will begin to feel stronger and more energized.

We also recommend that you participate in an activity that engages your mind every day. Just like your body, your brain needs to be challenged to recover from the “chemo fog” you may have experienced. Activities that challenge you, such as logic and math puzzles, memory and concentration games, and problem solving games are tasks that will give your brain a good workout.
Don’t forget to have fun! When you get home, it’s time to get back to some of your leisure pursuits. Perhaps you learned some new leisure skills when you were in the hospital that you’d like to pursue? Perhaps you made some new friends you’d like to stay in touch with? Perhaps there are people you’d like to catch up with? All of this is important and will help with your recovery.

If you are having difficulty at home, there may be resources available to help you such as home health physical and occupational therapy or outpatient physical and occupational therapy. Please ask your physician for a referral.

**Top 10 Things Rehabilitation Services Wants You to Know**

1. **Exercise/Activity** are crucial parts of the treatment plan and will help you recover faster. You will be expected to participate with therapists and on your own as instructed.

2. **Activity Check-off List** will be posted on/near the whiteboard in your room to help you and the staff track your progress.

3. **Fatigue** is an expected result of your treatment and is not a good reason to refuse/cancel rehab. Exercise/activity has been shown to reduce cancer-related fatigue—even when you don’t feel like participating.

4. **Nausea** — If mild, you should attempt therapy prior to, or along with taking antinausea medication. Exercise has been shown to reduce side effects of chemotherapy such as nausea.

5. **Sleep** — The therapists will attempt to wake you up for therapy. This has been approved by your physician. Therapy may help regulate your sleep patterns that are often disrupted in the hospital.

6. **Lab values** — If not at critical levels, coordination of transfusion schedule with therapy schedule is important to ensure patients benefit from both.

7. **Shower** — You should attempt to shower daily to maintain your activity level, good personal hygiene and to maintain as much of your normal daily routine as possible.

8. **Clothing** — You should bring clothing (comfortable shoes such as T-shirts, sweats, etc.), make-up, etc., to dress daily to maintain personal routines and to maintain your activity level. Patients should bring shoes appropriate for exercise.

9. **Leisure activity** — You should bring leisure items from home to help cope with unstructured time (games, puzzles, books, tablets, computers, music, crocheting, etc.)

10. **Blood transfusions** — You can receive rehabilitation during blood transfusions if the transfusion has been running for at least 15 minutes.
HCT Weekly Rehabilitation Schedule

HCT PATIENT WEEKLY REHABILITATION SCHEDULE

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<tbody>
<tr>
<td>• Sit up for all meals</td>
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<td></td>
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<tr>
<td>• Dress in your own clothes: Daily</td>
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<td></td>
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<tr>
<td>• Shower every day</td>
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<tr>
<td>• Engage in 1 activity that challenges short term memory or attention: Daily</td>
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<tr>
<td>• Upper Body Exercise: Daily</td>
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<thead>
<tr>
<th>Physical Therapy Plan:</th>
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<tbody>
<tr>
<td>• Sit up in chair 3x: Daily</td>
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<td>• Walk 1x around the unit: Daily (if able)</td>
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<tr>
<td>• Walk in room ___x (if not able to walk in unit)</td>
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<tr>
<td>• Move from sit to stand 10x: Daily</td>
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<tr>
<td>• Lower Body Exercise: Daily</td>
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<tr>
<th>Recreation Therapy Plan:</th>
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</thead>
<tbody>
<tr>
<td>• Participate in 1 leisure activity: Daily</td>
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<td></td>
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<tr>
<td>• Socialize with 1 peer or family member: Daily</td>
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<tr>
<td>• Attend group ___x per week</td>
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You can walk in the hallways with WBC above 1.0 and ANC above 0.5. Ask your RN for clarification. No exercise with platelets below 15K.

Self-care and Hygiene

Mouth Care

• You may use tap water to perform your mouth care. Do not use water from a well or spring.
• Brush your teeth after each meal and at bedtime.
• Do not use a regular toothbrush if platelet counts are less than 50,000.
• Use a soft toothbrush if tolerated, otherwise continue with toothettes.
• Any kind of toothpaste is acceptable.
• Avoid mouthwashes, since most contain alcohol and can irritate your mouth.
• Your doctor may want you to continue using antibacterial and antifungal solutions.
• Inform the doctor of any change in your mouth (increased dryness, bleeding or sores).
Bathing

• You may shower. Cover your VAD dressing before showering.
• Remember to change your VAD dressing immediately after showering or if it becomes wet, loose or soiled.
• Use mild soaps and shampoos.
• Avoid medicated or heavily perfumed products.
• Use make-up, aftershave or perfumes in small amounts. If you have a skin reaction, stop using these products.

Skin Care

• Your skin will be sensitive for a while, so apply soaps, cosmetics and perfumes lightly.
• Stay out of direct sun for at least one year. Use a sun protection factor (SPF) greater than 30 daily.
• Wear a hat and long sleeve shirt when outside.
• You may use a gentle skin moisturizer without perfume. Note any rash or blisters and report this to your doctor.
• Note if any skin change occurs after applying a product or eating some food.

Protecting Your Immune System

• Autologous transplant patients do not need to wear a mask unless instructed by your doctor.
• Allogeneic transplant patients will need to wear a mask for the first 100 days after transplant.
• When you wear a mask it should be a special mask called N-95. Wear the mask when you come to the clinic, are around any construction, are driving with two or more persons in the car or are in a crowd.
• Avoid crowds and stay away from anyone who may be sick.
• Your home should be well cleaned before you arrive.
• Do not do house cleaning yourself. Leave the room when cleaning is being done.
• Change air conditioner filters as recommended by the manufacturer.

Pets

Pets can carry disease and your doctor may recommend they be removed from the house for the first three months after stem cell transplant. If you have questions, please speak with your doctor.
• If your pets must stay with you, you should not sleep with the animal and they should not sleep in the same room with you.
• Keep your pets as clean as possible. You may want to have them tested for parasites or toxoplasmosis if there are any concerns.
• Do not clean the cat litter box, bird cage or fish bowl. Have someone else do it.
• Avoid contact with reptiles (e.g., snakes, lizards, turtles or iguanas).
• Always wash your hands after touching your pet.

**Immunizations**

Approximately one year after transplant your body will be able to develop antibodies to inactivated vaccines. At your one year follow-up evaluation, your doctor may order several vaccines to protect you against dangerous bacteria.

• If children in your family require polio vaccination, they should receive the inactivated Salk parenteral vaccine (given by injection), instead of the live Sabin oral type.
• Avoid contact with people who have been vaccinated with the Sabin oral polio vaccine or yellow fever vaccine for one month.
• Do not receive any live vaccines.
• Always check with your doctor before receiving any vaccines.

**Signs and symptoms to report**

Please report any of the following signs and symptoms in addition to any other concerns you may have:

• Temperature greater than 100.5°F. It is important to take your temperature once in the morning and once in the evening and keep a written record. Bring your records to all outpatient visits.
• Persistent cough (Note any sputum production and color.)
• Shortness of breath and/or excessive fatigue.
• Blood in urine, stool or sputum, or bleeding from gums or nose
• Feeling dizzy or light-headed
• Nausea or vomiting not relieved by anti-nausea medications
• Difficulty emptying bladder, burning on urination, constipation or diarrhea

**Contact your health care team for any questions or concerns:**

Monday through Friday, from 8 a.m. to 4:30 p.m., call (626) 256-HOPE (4673)
After hours and on weekends, call the Nurse Triage Center at (626) 471-7133.
Sexual Activity

Quick Tips:

• Your sexual desire may be decreased following transplant. This is temporary, and normal desire will return.
• Your platelet count may be low, so be gentle.
• Practice cleanliness and “safe” sex. Remember — sex is a function of both the mind and the body. It takes time for both to heal. They do heal!

Men
Due to chemotherapy and/or radiation therapy, your semen occasionally may appear brown or dark orange. This is temporary. You may find it more comfortable to wear a condom. Report any continued brown discharge, pain or any other abnormal finding to your doctor.

Women
Due to chemotherapy and/or radiation therapy, your vagina may not become well lubricated. To prevent trauma to the temporarily dry tissue, we recommend using a water-soluble lubricating jelly. Have your partner wear a condom. Report any pain during intercourse or unusual problems to your doctor.

For more information
The following booklets from the American Cancer Society are available in the Sheri & Les Biller Patient and Family Resource Center:

• Sexuality for the Woman With Cancer
• Sexuality for the Man With Cancer

For more in-depth information, contact the American Cancer Society at (800) 227-2345. For questions about fertility, such as freezing eggs or sperm before chemo, ask for Fertility and Women With Cancer or Fertility and Men With Cancer. You can also find information on their website, www.cancer.org.
Mental Health

Everyone experiences some emotional reaction to their illness and transplantation, although every individual experiences them at different times and in different ways. Undergoing blood and marrow stem cell transplantation can have an impact on your thoughts, feelings and relationships.

Many individuals experience feelings of sadness, hopelessness, frustration, anger, anxiety, uncertainty and fear. These feelings may occur in addition to feelings of courage, hope and humor. As a result of this you may at times feel like you are on “an emotional rollercoaster” and feel overwhelmed. Many patients report that the prolonged course of transplant treatment and its unpredictable nature can be emotionally exhausting.

It is important to remember that your body and your mind are not separate — each affects the other. Being aware of and managing your emotions can assist your body in being as healthy as possible.

Social workers, psychologists, dieticians, pharmacists, nurses and doctors all work together on your transplant team to provide you the best care possible.

Suggestions for Patients

• Ask questions as frequently as needed.
• Write down questions and information during your transplant — sometimes your memory can be short and unpredictable.
• Be flexible with the potential ups and down of transplantation.
• Try to focus on what you can do, not on what you cannot do.
• Do the best you can to make each day count.
• Take one day at a time.
• Become familiar with the supportive services available at City of Hope. Your social worker is a good resource and can help connect you with other services such as psychology, psychiatry and Spiritual Care services. To speak with your social worker, call the Department of Clinical Social Work at ext. 62282.
• The Sheri & Les Biller Patient and Family Resource Center is also a good place to go for additional information, education classes, support groups and a variety of other programs. The center is located in the Main Medical building and is available for patients and their families and caregivers.
Taking Your Meds When Back Home

You will be required to take medications following your blood or marrow stem cell transplant. Before you are discharged, your doctor, pharmacist and nurse will answer questions you may have about your medications. However, it may help you to refer to the following guidelines:

- Know the name and dosage of your medications and carefully read the label on all medication containers. If you can’t remember all the names, write the name and dosage on a piece of paper and carry it with you in your purse or wallet.

- Know the purpose of your medications, their benefits and the reason for their use.

- Know the possible side effects of your medications. When you are prescribed medications, your doctor or nurse will explain the possible side effects to you and what to do should they occur. It may help to use the “Notes” section in the back of this notebook to document this information for easy future reference.

- Understand the directions. Ask your doctor, pharmacist or nurse to explain directions on the label if you do not understand them.

- Always check with your doctor before you stop taking a prescribed medication or if you miss a dose.

- Do not use aspirin or aspirin-containing products without first checking with your doctor.

- Store your medications properly; avoid areas that are very warm, moist or in direct sunlight.

- Let your doctor know when you are getting low on any medications so refills can be ordered before you run out.

- During your clinic visits, your doctor will review your medications and make any changes in dosages that are necessary.
“This sure helps to rejuvenate and restore after transplant.”
— BMT Survivor

CHAPTER 12

Diet and Nutrition After Discharge

Essential Food Safety Guidelines

Problems Caused by Cancer Treatment
Chapter 12
Diet and Nutrition after Discharge

Once you are discharged from the hospital, it is important that you eat enough of the right
foods and drink enough liquids. When you are returning to your home or to Hope/Parsons
Village after your hospital stay, your dietitian will help you plan the right choices of foods for
this period of your recovery.

Diet and Nutrition after Transplant

Food safety is especially important for transplant recipients to reduce risk of foodborne illness.
Before you are discharged to home or to the Village, you and your caregiver may request
to meet with a clinical dietitian from City of Hope. The dietitian will instruct you and your
caregiver on food safety guidelines. The dietitian also will provide you with information on
shopping for food, food preparation and food storage.

If you have any questions related to the diet information, you may contact Clinical Nutrition
Services, at extension 62108, at any time following your discharge from the hospital.

Responsibility for Meals

It is the responsibility of the patient or the patient’s caregiver to purchase foods and prepare
meals that follow the food safety guidelines. Groceries may be purchased from local markets.
Restaurant meals and take-out foods are not recommended. If a patient requires a meal while
in the Outpatient Clinic, a special sack lunch may be sent from City of Hope’s Department of
Food & Nutrition Services. Please speak with a staff member.

Preparing and Serving Food

Please refer to the following guidelines:

• Anyone preparing food for the patient needs to wash his/her hands before handling
  the food.

• Clean areas that you will be using to prepare food, such as cutting boards and
counter tops. These areas should be cleaned with hot soapy water. As an added
precaution, clean cutting boards and counter tops may be cleaned with a weak
bleach solution. Use 1 tablespoon unscented liquid chlorine bleach per gallon of
water. Allow areas to air dry. Rubber or plastic cutting boards may be run through the
dishwasher.

• Wash dishes, pots and utensils with very hot soapy water. Rinse with running hot
  water. Allow them to air dry. Do not use dish towels to dry them. Can openers should
  be cleaned in the same manner.
• When cooking in a microwave, cover food, stir and rotate for even cooking. Rotate by hand or use a microwave with a turntable during cooking.
• A barbecue grill may be used but must be thoroughly cleaned prior to use.
• Cook foods to safe temperature. Use a food thermometer to measure the internal temperatures of cooked foods.

Food Storage
Cooked foods should not be eaten by the patient if left at room temperature for more than two hours. All leftover foods should be placed in the refrigerator. No leftovers should be consumed if stored longer than two days in the refrigerator or one week in the freezer. Before serving, leftovers should be heated thoroughly.

Food Safety
It is important to be mindful of the way you prepare, cook, and store your foods. Below is a list of important tips to keep everyone safe from food borne illness.
Essential Food Safety Guidelines:

- **Clean**: Wash hands, utensils and cutting boards before and after contact with raw foods.

- **Separate**: Keep raw meat and poultry apart from foods that won’t be cooked.

- **Cook**: Use a thermometer and refer to the temperature chart (below).

- **Chill**: Chill leftovers and takeout foods within two hours and keep the fridge at 40°F or below.

### USDA Recommended Safe Minimum Internal Temperatures

<table>
<thead>
<tr>
<th>Temperature</th>
<th>Foods</th>
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<tbody>
<tr>
<td>145°F</td>
<td>BEEF, PORK, VEAL, LAMB, STEAKS, ROASTS AND CHOPS</td>
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<tr>
<td></td>
<td><strong>with a three minute rest time</strong></td>
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<tr>
<td>145°F</td>
<td>FISH</td>
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<tr>
<td>160°F</td>
<td>GROUND BEEF, PORK, VEAL AND LAMB</td>
</tr>
<tr>
<td>160°F</td>
<td>EGG DISHES</td>
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<tr>
<td>165°F</td>
<td>TURKEY, CHICKEN AND DUCK; WHOLE, PIECES AND GROUND</td>
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[www.IsItDoneYet.gov](http://www.IsItDoneYet.gov)
# Essential Food Safety Guidelines

<table>
<thead>
<tr>
<th>Type of Food</th>
<th>Foods Allowed</th>
<th>Food to Avoid</th>
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</thead>
<tbody>
<tr>
<td>Meat, Deli and Poultry</td>
<td>• Meat or poultry cooked to safe minimum internal temperatures</td>
<td>• Raw or undercooked meat or poultry</td>
</tr>
<tr>
<td></td>
<td>• Hot dogs, lunch meats or deli meats reheated to steaming hot or 165°F</td>
<td>• Hot dogs, deli meats and luncheon meats that have not been reheated</td>
</tr>
<tr>
<td>Fish and Seafood</td>
<td>• Previously cooked seafood heated to 165°F</td>
<td>• Any raw or undercooked fish or shellfish, or food containing raw or undercooked seafood, e.g., sashimi (found in sushi, ceviche, etc.)</td>
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<tr>
<td></td>
<td>• Canned fish and seafood</td>
<td>• Refrigerated smoked fish</td>
</tr>
<tr>
<td></td>
<td>• Fish cooked to safe minimum internal temperatures</td>
<td>• Partially cooked seafood, e.g., shrimp and crab</td>
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<tr>
<td>Milk</td>
<td>• Pasteurized milk</td>
<td>• Unpasteurized (raw) milk</td>
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<tr>
<td>Cheese</td>
<td>Cheeses that are clearly labeled “made from pasteurized milk,” such as:</td>
<td>Soft cheeses made from unpasteurized (raw) milk, such as:</td>
</tr>
<tr>
<td></td>
<td>• Hard cheeses</td>
<td>• Feta</td>
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<tr>
<td></td>
<td>• Processed cheeses</td>
<td>• Brie</td>
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<tr>
<td></td>
<td>• Cream cheese</td>
<td>• Camembert</td>
</tr>
<tr>
<td></td>
<td>• Mozzarella</td>
<td>• Blue</td>
</tr>
<tr>
<td></td>
<td>• Soft cheeses</td>
<td>• Queso fresco (Mexican cheese type)</td>
</tr>
<tr>
<td>Eggs</td>
<td>At home:</td>
<td>Foods that contain raw or undercooked eggs, such as:</td>
</tr>
<tr>
<td></td>
<td>• Use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs</td>
<td>• Homemade Caesar salad dressings</td>
</tr>
<tr>
<td></td>
<td>• All other unpasteurized eggs need to be fully cooked</td>
<td>• Homemade raw cookie dough</td>
</tr>
<tr>
<td></td>
<td>When eating out:</td>
<td>• Homemade egg nog</td>
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<tr>
<td></td>
<td>• Ask if pasteurized eggs were used</td>
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<tr>
<td>Fruits and Vegetables</td>
<td>• Washed fresh fruits and vegetables, including salads</td>
<td>• Raw sprouts (alfalfa, bean or any other sprout)</td>
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<tr>
<td></td>
<td>• Cooked sprouts</td>
<td>• Unwashed fresh fruit and vegetables, including lettuce/salads</td>
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<td></td>
<td>• Cooked, frozen or canned fruits and vegetables</td>
<td>• Fruits or vegetables that have bruises, visible mold and/or soft spots</td>
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<tr>
<td>Pâtés</td>
<td>• Canned or shelf-stable pâtés or meat spreads</td>
<td>• Unpasteurized, refrigerated pâtés or meat spreads</td>
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<tr>
<td>Honey</td>
<td>• Honey that clearly states that it has been “pasteurized”</td>
<td>• Nonpasteurized honey</td>
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<td></td>
<td>• Baked goods, cereals, snacks and other foods containing honey that have been pasteurized</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cooked, nonpasteurized honey</td>
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</tbody>
</table>
What to do About Problems Caused by Cancer Treatment?

These are some of the problems that may occur because of your cancer treatment. Remember that each person is different. Not everyone will have the same problems, and not all of these suggestions will work for everyone.

<table>
<thead>
<tr>
<th>Problems</th>
<th>Suggestions</th>
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| Bloating (overfull feeling after just a few bites) | 1. Eat small meals often (every two to three hours).  
2. Avoid fatty, fried and greasy foods.  
3. Avoid gas-forming foods (cabbage family and beans.)  
4. Avoid carbonated drinks and any foods you usually do not tolerate. |
| Constipation                    | 1. Eat high-fiber foods including fruit and cooked vegetables, whole grain breads, cereal and bran.  
2. Add bran to your diet slowly.  
3. Drink plenty of fluids (at least eight glasses a day).  
4. A glass of prune juice or hot lemon water taken in the morning may help regularity.  
5. Increase activity as much as you can. |
| Dehydration                     | 1. Drink plenty of fluids, including popsicles, broth, juices, etc.                                      |
| Diarrhea                        | 1. Start with broth or a Popsicle and slowly add foods low in roughage, (steamed rice, applesauce, dry toast or bananas).  
2. Let carbonated beverages lose their fizz before drinking.  
3. Drink plenty of fluids to replace those lost through diarrhea.  
4. Avoid fatty, greasy and spicy foods, raw vegetables and fruits. |
| Dry Mouth                       | 1. Add gravy, sauce or mayonnaise to make solid foods easier to swallow.  
2. A liquid diet may be helpful.  
3. Sucking on hard candy (especially lemon drops) or popsicles or chewing gum may help to create more saliva. |
| Heartburn                       | 1. Avoid hot and spicy foods.  
2. Limit acidic foods, such as tomato products and citrus fruits.  
3. Limit use of garlic and onions.  
4. Do not lie down for at least one hour after eating. |
| Indigestion                     | 1. Eat small meals often.  
2. Avoid eating too much at one time.  
3. Avoid foods that are greasy or spicy. |
| **Loss of Appetite** | 1. Eat small meals often and snack between meals.  
2. Choose high-protein, high-calorie foods and try to get one-third of your daily needs at breakfast.  
3. Increase activity before meals.  
4. Make meal times pleasant, relaxed and unhurried.  
5. Set an attractive table and use a small plate.  
6. Choose foods that smell good to you (fresh baked bread, cookies and soups).  
7. Be creative with desserts and load them with calories (whipped topping, chocolate).  
8. Choose what you like to eat.  
9. Try different kinds of foods. |
| **Milk Intolerance** (Drinking milk may cause cramping, bloating and diarrhea) | 1. Avoid milk and dairy products.  
2. Use Mocha Mix, Dairy Rich, soy milk products and Lactaid milk. |
| **Nausea and Vomiting** | 1. Eat small meals often.  
2. If you vomit after the treatment, do not eat until several hours afterward.  
3. Eat and drink slowly. Do not force foods if they make you feel full or sick.  
4. Rest after eating but do not lie down for at least one hour.  
5. Salty foods, soda crackers, toast, baked potatoes and rice are often well-tolerated.  
6. Avoid overly sweet, greasy, hot or spicy foods, or foods with strong odors.  
7. Cold foods have fewer odors and may be more appealing |
| **Sore Throat** | 1. Eat small meals often, served cold or at room temperature.  
2. Try bland, soft or liquid foods.  
3. Avoid citrus, tomatoes, spicy foods, alcohol and vinegar.  
4. Foods usually well-tolerated are applesauce, cold liquids, cooked cereal, Gatorade, diluted juice, broth, plain pasta and scrambled eggs. |
| **Strange Taste** | 1. Try different seasonings and sauces to your foods.  
2. Prepare foods that look and smell good to you.  
3. Rinse mouth often. |
| Swallowing Difficulty | 1. Eat small meals often.  
|                       | 2. Foods should be soft or cooked until tender.  
|                       | 3. Foods and beverages that are thicker usually are easier to swallow than thin liquids.  
|                       | 4. Cut foods bite-sized and add gravy or sauces.  
|                       | 5. Use high-protein supplements (Ensure, Sustacal).  
|                       | 6. Avoid hard and dry foods (nuts, crackers, popcorn and potato chips). |
| Water Retention       | 1. Avoid salty foods (potato chips, pickles, soups, ham).  
|                       | 2. Do not add salt to your food at the table. |
| Weight Loss           | 1. Eat small meals often.  
|                       | 2. Choose high-protein, high-calorie foods.  
|                       | 3. Add extra butter to noodles, rice or vegetables. |
“Important information for when you finally get to return home.”
— BMT Survivor

CHAPTER 13

Going Home

Cleaning your home
Pets
Visitors
Chapter 13
Going Home

Heading home after your transplant can be a very exciting time. Be sure to read the sections below so that you can be ready to return home to an environment that is both healthy and supportive of you.

Clean your home

Because your immune system will be very weak during your recovery and up to a year after your transplant, it is important to have a clean home to return to after transplant. You may wish to arrange ahead of time to have your house cleaned.

- **Carpets** - Carpets and rugs should be carefully vacuumed. Carpets with visible soiling need to be shampooed.
- **Drapes/Furniture** - Clean drapes, blinds and furniture.
- **Air Conditioner/Furnaces** - Change filters in air conditioners and furnaces.
- **Humidifier** - Turn off humidifiers.
- **Bathroom** - All toilets, showers, counters, sinks and tubs should be cleaned.
- **Home Repairs** - Do not remodel your home or do major repairs such as opening up any walls or pull up old carpet at this time. This activity can cause mold spores to be released into the air.
- **Plants** - Remove fresh or dried flowers from your home. You may have to remove house plants. Please speak with your doctor.

Pets

If you have pets, you will need to make arrangements for their care while you are in the hospital and possibly after your transplant as well. After your transplant, most indoor pets that you had before will be able to remain with you with a few exceptions. You may need to find new homes for pets such as reptiles and some birds. If you have barnyard animals, such as horses, you may need to avoid contact with them as well. Talk with your doctor for more information.

Visitors

When you return home, many of your friends and family may want to visit you. While their visits are meant to cheer you up, they may also put you at risk for infections. To protect yourself you will need to be very clear with your visitors about how they can keep you safe. Remind them about universal precautions — frequent hand washing, not visiting if they have been sick or exposed to someone who has been sick. Your caregiver can also help by screening guests and making sure that you received guests only when you are feeling well enough to have company.
When and Where to Call for Help

Nursing Triage Call Center
Chapter 14
Where and When to Call for Help

Nursing Triage Call Center

What is the Nursing Triage Call Center?
A registered nurse is available 24 hours a day at the Nursing Triage Call Center to answer City of Hope patients’ questions about health problems or self-care issues that may arise. This service is for nonlife-threatening situations only.

*City of Hope Nursing Triage Call Center* — Call 24 Hours: (626) 471-7133
For questions about a prescription refill or renewal, please call the City of Hope pharmacy at (626) 301-8304 or call the pharmacy where your prescription was filled if other than City of Hope.

When Should I Call the Nursing Triage Call Center?
You should call for urgent but not life-threatening health problems such as:

- High fever (100.5°F or higher)
- Nausea, vomiting or diarrhea that is not controlled by your medications
- Uncontrolled pain
- Problems with your central venous access device (i.e., VAD or PICC line)
- Any other health problem where you were instructed to call City of Hope

You should also call the Nursing Triage Call Center if you have other non-urgent health problems and are not sure what to do or have questions about self-care procedures. Based on the information you give, the nurse can answer your questions and make recommendations.

If needed, the nurse can contact your doctor, instruct you to come to City of Hope or tell you to go to the nearest emergency room. If you wish to speak with your doctor about your concerns or the nurse’s recommendations, the nurse will arrange that for you.

When calling the Nursing Triage Call Center, please have your Medical Record Number available.
When Should I Call 911 Instead of the Nursing Triage Call Center?

DO NOT call the triage nurse if you have a life-threatening emergency.

Call 911 immediately if you have a life-threatening emergency:

- Severe chest pain
- Difficulty breathing
- Poisoning
- Uncontrollable bleeding
- Signs of shock (rapid weak pulse, cold pale clammy skin, confusion, rapid breathing)
- Unconsciousness
- Serious injuries or burns

*If you go to an emergency room, identify yourself as a City of Hope patient.*
“This is the second most important chapter in the manual ... after attitude.”
— BMT Survivor

CHAPTER 15

Survivorship

Survivorship Care Plans
Concerns After Treatment

Physical        Spiritual
Sexual          Financial
Emotional        Work
Social          Staying Healthy
Chapter 15
Survivorship

The term “cancer survivor” includes anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends and caregivers are also part of the survivorship experience. The word “survivor” helps many people think about embracing their lives beyond their illness.

The end of cancer treatment is often a milestone. You are probably relieved to be finished with the demands of treatment and are ready to put the experience behind you. Yet at the same time, you may feel sad and worried. It is common to be concerned about whether the cancer will come back and what you should do after treatment. When treatment ends, you may expect life to return to the way it was before you were diagnosed with cancer. However, it can take time to recover. You may have permanent scars on your body or you may not be able to do some things you once did easily. Or you may even have emotional scars from going through so much. You may find that others think of you differently now — or you may view yourself in a different way.

While cancer is a major event for all who are diagnosed, it also brings with it the chance for growth. As hard as treatment can be, many cancer survivors have told us that the experience led them to make important changes in their lives. Many say they now take time to appreciate each new day. They also have learned how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment and care.

Those who have gone through cancer treatment describe the first few months as a time of change. It is not so much “getting back to normal” as it is finding out what is normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery. Your new “normal” may include making changes in the way you eat, the things you do and your sources of support.

Many cancer survivors have told us that while they felt they had lots of information and support during their illness, once treatment stopped they entered a whole new world — one filled with new questions. Many survivors of cancer and their family members have questions about what to expect. You may have some of the same questions. In this section, we will give you information that can help answer some of the questions that people with cancer and family members ask about what to expect with survivorship. We will discuss key concerns during survivorship, how to talk about the concerns with your doctor/nurse practitioner and coping tips that you can use to manage your survivorship concerns.
At City of Hope, we have many services that are provided to help patients with survivorship concerns. The Sheri & Les Biller Patient and Family Resource Center offers a number of support services, including patient navigators, pain doctors, psychiatrists, psychologists, social workers, chaplains, physical therapists, healing arts workshops, peer support groups, health information, complementary medicine, nutrition education and much more.

**Survivorship Care Plans**

**Key Things to Know**

The most important part of a survivor’s life after treatment becomes follow-up care. One helpful way of managing your follow-up care is to use a treatment summary and survivorship care plan. This document includes a summary of your diagnosis and all the treatments you received, as well as a follow-up plan of the steps you need to take to achieve the best health and well-being possible. It also helps you to work effectively with all your doctors, including your primary care doctor, as well as other members of your health care team.

**How to Communicate Your Survivorship Needs**

Many cancer survivors choose to continue follow-up care with their oncologist and others may return to their primary care doctor or family doctor. If you are returning to your primary care doctor, give him/her a copy of your treatment summary and survivorship care plan. This information is important to your primary doctor, who may not have been involved in your cancer treatment.

**Things to Ask Yourself**

- What are your concerns and questions about survivorship?
- What are your personal goals in terms of healthy living after treatment?
- How can your doctor/nurse practitioner help you achieve these goals?

**Self-care Tips**

- Make a list of your questions about survivorship before talking to your doctor.
- Keep a copy of your survivorship care plan for your own records.
- Always tell any new doctors you see about your history of cancer because this may affect decisions about your care in the future. They may not know about your cancer unless you tell them.
- Check your health insurance plan to see what follow-up care it allows and, if necessary, who should be in charge of your follow-up care.
Physical Concerns After Treatment

Key Things to Know

Many cancer survivors have a risk of developing late effects from cancer treatment.

A late effect is a side effect that does not occur during present therapy but starts approximately one year after treatment ends.

When or if a person develops a late effect, and the type of late effects that may develop, is different from person to person.

Treatment of late effects is an important part of cancer care because cancer survivors are living longer after cancer treatment than in the past.

Some common late effects after cancer treatment include the following:

- Chemotherapy and radiation therapy to the chest may cause additional lung problems. Cancer survivors who received combination treatment of chemotherapy and radiation therapy may have a higher risk of lung injury. People with a history of lung disease and older people may be at higher risk.

Lung-related late effects may include the following:

- A change in how the lung functions
- Thickening of the lining of the lungs
- Inflammation of the lungs
- Difficulty breathing

Heart problems are most often caused by radiation therapy to the chest and/or chemotherapy. People age 65 or older or those who already have heart problems before cancer treatments may be at higher risk.

Chemotherapy and radiation therapy may cause changes to hormone levels, which may result in endocrine (hormone) system problems. Chemotherapy may cause the following late effects:

- Damage to a woman’s ovaries, which may result in hot flashes, sexual dysfunction, osteoporosis (weakness of the bones) and early menopause.
- Infertility for both men and women. Specifically for women an inability to conceive a child or maintain a pregnancy.
Osteoporosis

Osteoporosis is the most common late effect of cancer treatment and is more common in cancer survivors. Risk factors for osteoporosis include the following:

- Chemotherapy
- Steroid medicines
- Low levels of physical activity

Other Health Issues to Consider

Hearing loss from chemotherapy, such as cisplatin.

Dental problems may happen, because chemotherapy may affect tooth enamel.

Symptoms that you may have experienced during treatment can continue after treatment as well. These include:

- **Fatigue** is one of the most common complaints during the first year of recovery.
  - The causes of fatigue are different for people who are receiving treatment than they are for those who have finished.
  - For some, fatigue gets better over time. Some people may still feel energy loss years later.
- **Pain or neuropathy (nerve pain)** can continue after treatment, chemotherapy or surgery due to damaged nerves. You may have pain or numbness in your hands and feet and/or around your surgical scar.
- **Cognitive (thought process) problems** can continue after treatment. This can lead to problems paying attention, finding the right word or remembering new things.
- **Weight loss.** Some cancer survivors may continue to have problems with weight loss. You may have a decreased appetite, which can lead to weight loss.

How to Talk About Physical Concerns After Treatment

Here are some questions that may be useful when you talk with your doctor about physical concerns after treatment:

- What are the late effects from my cancer treatments?
- What tests will I need to screen for these late effects?
- How often should I be screened for these late effects?
- What signs or symptoms should I be looking for after my cancer treatment is completed? What should I do if I notice one of these symptoms?
- Do I need to be referred to a specialist?
Keep track of any new symptoms or old symptoms that are getting worse and let your doctor/nurse practitioner know right away:

- When the symptom started
- What makes the symptom better/worse
- How long the symptom lasts

**Self-care Tips**

- Keep an active, healthy lifestyle
- Supportive care professionals that can help:
  - Pain doctors
  - Physical/Occupational therapist
  - Pulmonary rehabilitation doctor
  - Dietitian
  - Pharmacist
- Follow directions when taking any medicine. Call your doctor/nurse practitioner if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Be aware of what is recommended for your follow-up care after treatment.
What You Need to Know About Changes Related to Intimacy and Sexuality Following Blood and Marrow Transplant

High-dose chemotherapy and/or blood and marrow transplant (BMT) may cause a variety of changes related to intimacy and sexuality. How you feel about sexuality is influenced by hormones, the functioning of the sexual organs, energy level, feelings of love and closeness, how you were raised, and how you feel about yourself and your partner. Having conflicts and miscommunication with your partner, concerns with body image, can also disrupt intimacy and sexual satisfaction. When you have a BMT your normal intimacy routine may change.

How can chemotherapy affect intimacy?

- Men and women may experience hormonal changes for several months after chemotherapy is completed. Lower testosterone and estrogen levels can cause less desire for intimacy as well as physical changes.
- It is important to talk to your doctor about possible side effects of infertility BEFORE and after chemotherapy and/or BMT. Chemotherapy can, but not always cause infertility. Problems with infertility will depend on the type of chemotherapy drugs used, your age, and overall health.
- If you are of child-bearing age discuss your concerns and questions with your doctor before and after having a BMT. Immunosuppressant drugs (drugs that calm your immune system) may cause birth defects. You will want to avoid having children until no longer taking these drugs.

Are there physical changes following BMT?

Following BMT, some people may find it difficult to return to being intimate with their partner. It is important to recognize and inform your doctor about any changes early because they can often be treated.

- Women will need routine vaginal exams to check the skin inside the vagina and lab tests to check hormone levels.
- Men will need routine exams by a doctor who specializes in male reproductive organs (Urologist) to check hormone levels, manage erectile dysfunction, and treat any skin changes to the penis.

Physical changes following a BMT may include:

- Women may experience physical changes such as shortening or narrowing of the vagina, decreased softness or flexibility of the skin, and vaginal dryness. These changes can cause pain during sex and may make vaginal examinations difficult when seeing your doctor.
Men, especially those who are uncircumcised, are at risk for changes to the skin of their penis. Skin may become hard and stiff. Nerve damage, caused by chemotherapy and/or radiation, may lead to erectile dysfunction (the inability to have an erection).

Important intimacy guidelines to follow when you resume sexual activities

There are important steps you are encouraged to follow when you resume sexual activities. Talk to your doctor about any concerns or questions you may have about the following information.

• Sexual activities should be avoided until platelet counts are above 50 without transfusions and until absolute neutrophil counts are above 500. If you are not sure, please speak with your BMT doctor before resuming sexual activities.

• Kissing is acceptable if you and your partner maintain good mouth hygiene (brush teeth twice daily, regular dental checkups) and do not have any mouth sores or bleeding gums.

• Maintain good overall hygiene for you and your partner. Shower or wash your hands and genitals before and after sexual activity.

• Condom/barrier protection must be used while you are on immunosuppressant drugs, chemotherapy, or other medications which might put you at risk for infection. Please check with your doctor regarding the medications you are on that may increase your risk.

• Use a water-soluble lubricant to decrease irritation during sexual activity.

• If possible, urinate before and after intercourse.

• Oral sex is permitted; however, should be avoided if you or your partner has mouth sores, bleeding gums, or genital sores. Barrier methods can help lower the risk of infection from oral sex. A latex or plastic condom may be used on the penis and a cut-open condom or a dental dam can be used between the mouth and the vagina or anus.

• Anal sex is permitted but places the patient at higher risk for bleeding and infection and shall be performed only with condom use, platelet count greater than 100 without transfusions, and ANC greater than 1000.

• Avoid sexual practices that result in the mouth coming in contact with stool.
Online resources you can visit for more information

- **National Bone Marrow Transplant Link (nbmtLINK)**  [www.nbmtlink.org](http://www.nbmtlink.org)
The mission of the nbmtLINK is to help patients, their caregivers, families, and the health care communities meet the many challenges of bone marrow/stem cell transplantation by providing vital information and support services.

- **American Cancer Society (ACS)**  [www.cancer.org](http://www.cancer.org)
The American Cancer Society (ACS) is a national community-based voluntary health organization whose mission is to eliminate cancer as a major health problem through research, education, advocacy, and service.

- **Blood and Marrow Transplant Information Network**  [www.bmtinfonet.org](http://www.bmtinfonet.org)
BMT InfoNet is a not-for-profit organization that serves families facing a bone marrow, stem cell or cord blood transplant, and survivors. This site includes easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

- **Bone Marrow Foundation (BMF)**  [www.bonemarrow.org](http://www.bonemarrow.org)
The mission of The Bone Marrow Foundation is to improve the quality of life for bone marrow and stem cell transplant patients and their families by providing financial aid, education, and emotional support.

- **Centers for Disease Control and Prevention**

*Original content for this handout was obtained from H. Lee Moffit Cancer Center & Research Institute-Tampa, FL (2014)*
Emotional Concerns After Treatment

**Key Things to Know**

It is normal to have many different feelings after treatment ends. Just as you need to take care of your body after treatment, you need to take care of your emotions. For many cancer survivors, it is a stressful time filled with new routines to learn, as well as mixed feelings about what they have just gone through. Many people find themselves unsure of how to move forward, wondering, “Now what?” It is common for many cancer survivors to have a complex and often conflicting feelings about their diagnosis, treatment and recovery.

It is normal to feel relieved that treatment is over, yet angry or sad about having gone through such a serious illness.

You may feel guilty about surviving a diagnosis when other people have not survived.

You may also feel anxious and fearful about the cancer coming back or worried that the treatment did not work.

Realizing that life after diagnosis and treatment never really goes back to what it was before cancer. Many survivors find they are not able to return to their old “normal” life but must adapt to a “new normal.”

It is normal, too, to feel confused about what you have been through and to be concerned about the future.

Sometimes these emotions can be overwhelming, interfering with your day-to-day activities and even your health.

Some common psychological concerns after cancer treatment include the following:

- Worrying about your health
- Feeling stress
- Depression
- Anger
- Feeling alone
- Guilt

**Feelings After Treatment**

In many ways our emotions are what make us uniquely human. Our feelings enrich our lives. When someone we love is diagnosed with a serious illness, emotions will run high.

Emotions (stress, anxiety, sadness, frustration) may not always feel pleasant. When directed they can always be helpful. The first step for, all of us, is to understand how we can regulate and direct our emotions. Once you learn to manage your emotions, you will begin to feel less overwhelmed (stressed).
Take Action!

Recognize the signs of emotional distress. Being exhausted much of the time, not sleeping enough or feeling impatient, irritable or forgetful.

Take care of your body, mind and spirit. Some people develop or increase unhealthy habits, such as smoking, drinking too much alcohol or using prescription medicine improperly. If you notice that you are doing these types of things, seek professional help.

Meet with an expert such as a psychiatrist, psychologist or social worker. They will listen to your concerns. They can even help you create a plan for how to share your concerns with your partner.

Self-care Tips

Call your doctor/nurse practitioner if you:

- Have questions about how to take your medicine.
- Have problems getting your medicine.
- Feel that your medicine does not work.

Understanding what your new normal is can take time. Here are some tips that you can use:

- Reflect on what you have been through.
- Identify changes you might want to make in your life.
- Recognize what you have learned and what is changed about yourself.
- It is healthy to take time for yourself and to reflect about what matters most in your life.
- It is also okay to surround yourself with people who are close to you.
- Keep an active, healthy lifestyle.
- Join a support group.
- Consider volunteering as a “peer” for cancer patients who are still receiving treatments. At City of Hope, we have “peer support” programs through the Sheri & Les Biller Patient and Family Resource Center that match survivors with patients.
- Medicines can be used for anxiety and depression.
- Supportive care professionals that can help:
  - Spiritual counselors (chaplains)
  - Psychologist/Psychiatrist
  - Social workers
  - Grief counselors
  - Support groups
Social Concerns After Treatment

Key Things to Know

Having cancer can change relationships with the people in your life. It is normal to notice changes in the way you relate to family, friends and other people that you are around every day — and the way they relate to you. When treatment ends, families are often not prepared for the fact that recovery takes time. Families also may not realize that their relationships and communications may have changed permanently as a result of cancer. You and your family may need help to deal with the changes and keep the “new” family strong.

Some survivors say they would not have been able to cope without their family members and the help they offered. In addition, even though treatment has ended, you may face problems with your family. Problems that were present before the cancer may still exist, or new ones may develop. You may still need to depend on others during this time, even though you want to get back to the role you had in your family before. At the same time, your family may still be adjusting.

Some common late effects related to cancer treatment include the following:

- Relating to others
- Changes in sex life
- Communication

Reach out to professional who can help you. You may consider:

- Spiritual counselors (chaplains)
- Psychologist/Psychiatrist
- Social workers
- Grief counselors
- Support groups

Understanding what your new normal is can take time. Here are some tips that you can use:

- Reflect on what you have been through.
- Identify changes you might want to make in your life.
- Recognize what you have learned and what is changed about yourself.
- Keep an active, healthy lifestyle.
- Join a support group.


Spiritual Concerns After Treatment

Key Things to Know

Survivors often express the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life and what they value most. Cancer survivors often report that they look at their faith or spirituality in a new way. For some, their faith may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life or their purpose in it. Many say they have a new focus on the present and try to live each day to the fullest.

Many survivors have found that their faith, religion or sense of spirituality is a source of strength. They say that through their faith they have been able to find meaning in their lives and make sense of their cancer experience. Faith or religion can also be a way for survivors to connect with others in their community who may share similar experiences or outlooks or who can provide support. Studies have also shown that for some religion can be an important part of both coping with and recovering from cancer. It is common to question your beliefs after cancer. These questions can be difficult, but for some, seeking answers and searching for personal meaning in spirituality helps them cope.

Some common spiritual concerns after cancer treatment include the following:

- Finding comfort and meaning
- Finding purpose in life
- Uncertainty
- Positive changes

How to talk about spiritual concerns after treatment

Supportive care professionals that can help include:

- Spiritual counselors (chaplains)
- Psychologist/Psychiatrist
- Social workers
- Support groups
- Spiritual directors
Coping Tips:

Understanding what your new normal is can take time. Here are some tips that may help:

• Reflect on what you have been through.
• Identify changes you might want to make in your life.
• Recognize what you have learned and what is changed about yourself.
• Pray or meditate to help you gain perspective.
• Seek spiritual support.
• Keep an active, healthy lifestyle.
• Join a support group. Talk with others who have had similar experiences.
• Keep a journal and write about your experience and where you want to go in life now.
Financial and Work Concerns

**Key Things to Know:**

Many cancer survivors are able to continue working through and beyond their treatment. Others may have to stop working during treatment and return later. Whether returning to their old jobs or beginning new ones, some survivors are treated unfairly when they return to the workplace.

Employers and employees may have doubts about cancer survivors’ ability to work. Employers may regard making any special arrangements as a hardship on the business.

Research shows that cancer survivors who continue to work are as productive on the job as other workers.

**How to talk about financial and work concerns after treatment**

Supportive care professionals that can help include:

- Social workers
- Hospital financial counselors

**Coping Tips:**

- Learn about your company’s rules and policies related to sick time. It is important to know that there are laws that protect you in the workplace.
- Develop a plan to cope with changing financial needs for daily expenses (e.g., medicines, housing, rent/mortgage, transportation, insurance, groceries).
- Organize a financial record-keeping system.
- Join a support group. Talk with others who have had similar experiences.
Staying Healthy After Treatment

**Key Things to Know:**

Once treatment is over, people who have had cancer often want to know what they can do to stay healthy.

Cancer survivors find that this is a time when they take a good look at how they take care of themselves. This is an important start to living a healthy life.

Cancer survivors often look for information and advice about food choices, physical activity, and dietary supplements to improve their quality of life and survival.

Cancer rehabilitation helps a person with cancer obtain the best physical, social, psychological, and work-related functioning after cancer treatment.

The goal of rehabilitation is to help a person regain control over many aspects of their lives and remain as independent and productive as possible.

Rehabilitation can be valuable to those recovering from cancer treatment.

**How to Talk About Staying Healthy After Treatment:**

As part of your follow-up care, ask your doctor/nurse practitioner about developing a wellness plan that includes ways you can take care of your physical, emotional, social and spiritual needs.

Ask your doctor/nurse practitioner to suggest other members of the health care team for you to talk with, such as a social worker, dietitian or physical therapist.

Call your doctor/nurse practitioner if you have any ongoing symptoms such as pain, fatigue, cough, etc.

**Self-care Tips:**

Supportive care professionals that can help include:

- Physical/Occupational therapist
- Dietitian
- Social worker
- Psychologist

Be aware of what is recommended for your follow-up care after treatment, including your wellness plan.
Stay as active as possible.

- Maintain a healthy weight
- Work at your own pace
- Consult a physical therapist about what types of exercises are best for you.
- Check with your doctor before starting any exercise program.

Maintain a healthy diet.

- Try to get all of your nutrients from foods instead of from supplements.
- Check with your doctor regarding any food or diet restrictions.
- Ask your dietitian to help you create a nutritious, balanced eating plan.
- Choose a variety of foods from all the food groups. Try to eat at least five to seven servings a day of fruits and vegetables, including citrus fruits and dark-green and deep-yellow vegetables.

Seek counseling from psychologist/psychiatrist, chaplains or social workers, if needed.

Reduce stress by exercising, using meditation and relaxation.

**If you have questions, please contact one of the resources below:**

- City of Hope (626) 256-HOPE (4673)
- Spiritual Care Services: ext. 63898
- Sheri & Les Biller Patient and Family Resource Center: ext. 32273
- Division of Clinical Social Work: ext. 62282
CONGRATULATIONS—
on the upcoming 6-month anniversary of your transplant. This guide will help you understand and prepare for your medical checkups after transplant (follow-up care). This guide has a list of tests and evaluations for your 6-month appointment. It is the first in the series of 3 (12-month and 24+ month guides are also available). The recommendations in the guides are based on recommendations from doctors who specialize in post-transplant care*, and brought to you by Be The Match®.

Why your six-month checkup matters

Whether you received an autologous or allogeneic transplant, follow-up care is important. It helps your doctors find any changes in your health, such as:

• The disease coming back (relapse)
• New cancers
• Problems due to your treatment
• Quality of life

When issues are caught early, there may be more options for treatment, and those treatments can be more effective.

Even if you are feeling well, checkups after transplant are very important to staying healthy.

About this guide
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Free mobile app
Use our free mobile app to:

• Access these guidelines anytime, anywhere
• Make a list of tests and evaluations customized to your unique situation
• E-mail information to yourself, or your healthcare team

Take action: prepare for your checkup

Schedule 6-month checkup appointment with your transplant doctor or hematologist/oncologist
Review the tests and evaluations listed on the pages inside
Write down questions or issues you'd like to talk to your doctor about
Bring this guide to your checkup
Ask your doctors if there are other suggestions unique to your situation
At your checkup, ask your doctors if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist, or others)

Share with your doctor
There are 2 easy ways to share these guidelines with your doctors or dentists:

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Contact us at patientinfo@nmdp.org or 1 (888) 999-6743

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SIX-MONTH CHECKUP GUIDE

Below, you’ll find information on the physical exams and tests that are recommended 6 months after transplant. This information will help you understand what to expect and prepare any questions or concerns you have to discuss with your doctor. Words in bold are defined in the glossary.

Eyes
• Check for eye symptoms like pain or dryness
• Check how well you can see (vision screening)
• If you have eye symptoms or problems seeing, ask to see an eye specialist (ophthalmologist)

If you have GVHD you may need:
• To see an eye specialist more often

Mouth
• Exam of the mouth and teeth
• Oral cancer screening
• Talk about symptoms like dry mouth
• Tell your doctor about harmful habits (like tobacco use or smoking). Ask for help quitting

If you have GVHD you may need:
• To have exams of the mouth and teeth, and oral cancer screening more often

Lungs
• Regular lung exam
• Tell your doctor about tobacco use or smoking. Ask for help quitting
• Pulmonary (lung) function tests and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

If you have GVHD you may need:
• Lung exams and pulmonary (lung) function tests earlier and more often

Heart and Blood Vessels
• Talk about a “heart healthy” lifestyle (exercise, healthy weight, eat healthy foods, and don’t smoke)
• Get treatment for diabetes, high blood pressure, and high cholesterol
• Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves

Liver
• Liver function blood tests to see if your liver is working properly
• If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor
Kidneys
• Blood pressure test
• If you have high blood pressure (hypertension), start treatment and have regular follow up
• Urine protein levels test to see how well your kidneys are working
• Kidney filtration levels test (blood BUN/Creatinine test) to see how well your kidneys are filtering
• If your kidneys aren’t working well, you may need more tests (ultrasound or kidney biopsy)
• If you have chronic kidney disease that is getting worse, don’t take medicines, herbs, or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

Muscles
• Talk about current exercises and physical fitness activities

If you have GVHD or are taking immunosuppressants you may need to:
• Test if your muscles are weak (myopathy)
• See a physical therapist if you have myopathy, fascitis or scleroderma
• Have a range of motion exam to look for sclerotic changes
• Learn how to test your own range of motion

Bones
• Talk about ways to prevent bone density loss—including exercise, vitamin D, and calcium supplements

If you have GVHD or are taking immunosuppressants you may need:
• Bone density measurement (using dual photon densitometry)

Skin and Genital
• Learn how to do a routine self-exam of your skin
• Discuss risks of being in the sun without proper protection

If you are a woman and have GVHD or had total body irradiation, you may need to:
• Ask your doctor how often you need gynecologic exams

Nervous System
• You may need tests of your nervous system
• If you have trouble with things such as memory, concentration, or decision-making, you may need more tests
Fertility
• Ask your doctor about birth control options

Immune System
• Medicine to prevent an infection called pneumocystis
• Vaccines to prevent infection and disease

If you have GVHD or are taking immunosuppressants you may need:
• Medicine to prevent infections such as meningitis and pneumonia
• Blood tests to screen for cytomegalovirus (CMV)

Endocrine System (thyroid, growth, sex hormones)
Tests for children:
• Talk to your child’s doctor about sexual development. Your child may need blood tests to measure sex hormone levels
• Growth rate evaluation
• Your child may need blood tests to check thyroid and growth hormone function

If you have GVHD or are taking immunosuppressants you may need:
• To take more doses of steroids (like prednisone) if you become very sick
• To have your dose of steroids gradually reduced when it is time to stop taking them

Emotional Health
• Tell your doctor about your general well-being or quality of life
• Talk about your feelings (emotional health)
• Talk about your family and caregiver’s emotional health
• Ask about counselors and support groups in your area
• Ask any questions you may have about your sexual health

General Health
• Get regular screenings for high blood pressure, high cholesterol, diabetes, depression, sexually transmitted diseases, osteoporosis (in women), and cancer

New Cancers
• Talk to your doctor about risks of new cancers

If you have GVHD you may need:
• Clinical and dental exams
• Oral cancer screening
Glossary

Bone density loss—Bones become weak and brittle. Bones can break more easily.

Cytomegalovirus (CMV)—A type of herpes virus that can cause infections (like pneumonia, a lung infection).

Dual photon densitometry—A tool to measure bone density. Often called a DEXA or DXA scan.

Endocrine system—Glands that release hormones into your body. Hormones affect your mood and growth.

Fasciitis—inflammation (redness and swelling) of the connective tissue that surrounds muscles, blood vessels, and nerves. Often happens with hardening of the skin (see scleroderma).

Graft-Versus-Host Disease (GVHD)—A common side effect after an allogeneic transplant when the new donor cells attack your body’s cells.

Growth hormone function—Test to see if there is enough growth hormone in your body to grow normally.

Growth rate evaluation—Comparing a person’s growth to average growth in the general population in people of the same age and sex.

Immunosuppressants—Medicines that lower your body’s ability to fight infection. These medicines also help to prevent and treat GVHD.

Kidney filtration levels test—Measures the flow rate of filtered fluid through the kidneys. Used to detect chronic kidney disease.

Liver function blood tests—Tests to see how well your liver is working.

Meningitis—inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

Myopathy—Muscle disease and weakness. Steroids used for chronic GVHD may cause muscle weakness, especially in your legs and feet.

Ophthalmologist—A medical doctor who treats diseases that affect the eyes.

Nervous System—The parts of your body that control your movements and thinking. The nervous system includes your brain, spinal cord (back bone), and nerves.

Pneumonia—inflammation (redness and swelling) of the lungs caused by infection.

Pneumocystis—A form of pneumonia caused by a yeast-like fungus.

Pulmonary (lung) function tests—A group of tests to measure how well your lungs are working.

Range of motion—A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

Scleroderma—When your skin becomes hard, thick, and tight. This can lead to weak muscles, stiff joints, or pain in your joints.

Sclerotic changes—Hardening of the skin and other tissues such as fasciae, muscles, and joints.

Thyroid—A gland that controls your body’s metabolism (how quickly your body uses energy).

Urine protein levels test—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.
Take action: prepare for your checkup

- Schedule 6-month checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests and evaluations listed on the pages inside
- Write down questions or issues you’d like to talk to your doctor about
- Bring this guide to your checkup
- Ask your doctors if there are other suggestions unique to your situation
- At your checkup, ask your doctor if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist, or others)

Share with your doctor

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12 MONTH checkup
Helping you prepare for your appointment
Congratulations—on the upcoming 1-year anniversary of your transplant. This guide will help you understand and prepare for your medical checkups after transplant (follow-up care). This guide has a list of tests and evaluations for your 12-month appointments. It is the second in the series of 3 (6 month and 24+ month guides are also available). The recommendations in the guides are based on recommendations from doctors who specialize in post-transplant care, and brought to you by Be The Match®.

Why your 12-month checkup matters
Whether you received an autologous or allogeneic transplant, follow-up care is important. It helps your doctors find any changes in your health, such as:

- The disease coming back (relapse)
- New cancers
- Problems due to your treatment
- Quality of life

When issues are caught early, there may be more options for treatment, and those treatments can be more effective.

Even if you are feeling well, checkups after transplant are very important to staying healthy.

About this guide
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TWELVE-MONTH CHECKUP GUIDE

Below, you’ll find information on the physical exams and tests that are recommended 12 months after transplant. This information will help you understand what to expect and prepare any questions or concerns you have to discuss with your doctor. Words in bold are defined in the glossary.

Eyes

• Check for eye symptoms like pain or dryness
• Have an eye specialist (ophthalmologist) check how well you can see (vision screening) and do a retina exam

If you have GVHD you may need:

• To see an eye specialist more often

Mouth

• Exam of the mouth and teeth
• Oral cancer screening
• Talk about symptoms like dry mouth
• Tell your doctor about harmful habits (like tobacco use or smoking). Ask for help quitting
• Have a complete dental checkup (exam of your head, neck, mouth and teeth)

If you have GVHD you may need:

• To have exams of the mouth and teeth, and oral cancer screening more often

Additional test for children:

• A dentist will check how well your child’s teeth are growing

Lungs

• Regular lung exam
• Tell your doctor about tobacco use or smoking. Ask for help quitting
• Pulmonary (lung) function tests and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

If you have GVHD you may need:

• Lung exams and pulmonary (lung) function tests earlier and more often

Heart and Blood Vessels

• Check for heart and blood vessel risk factors, such as high cholesterol, high blood pressure, obesity, history of smoking
• Talk about a “heart healthy” lifestyle (exercise, healthy weight, eat healthy foods, and don’t smoke)
• Get treatment for diabetes, high blood pressure, and high cholesterol
• Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves
Liver
- Liver function blood tests to see if your liver is working properly
- If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor
- If you had red blood cell transfusions, you may need a blood ferritin test, a liver MRI, or liver biopsy to check for too much iron

Kidneys
- Blood pressure test
- If you have high blood pressure (hypertension), start treatment and have regular follow up
- Urine protein levels test to see how well your kidneys are working
- Kidney filtration levels test (blood BUN/Creatinine test) to see how well your kidneys are filtering
- If your kidneys aren’t working well, you may need more tests (ultrasound or kidney biopsy)
- If you have chronic kidney disease that is getting worse, don’t take medicines, herbs or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

Muscles
- Talk about current exercises and physical fitness activities
  If you have GVHD or are taking immunosuppressants you may need to:
  - Test if your muscles are weak (myopathy)
  - See a physical therapist if you have myopathy, fascitis or scleroderma
  - Have a range of motion exam to look for sclerotic changes
  - Learn how to test your own range of motion

Bones
- Talk about ways to prevent bone density loss—including exercise, vitamin D, and calcium supplements
  If you are a woman, allogeneic transplant recipient, have GVHD, are taking immunosuppressants, or are at a high risk for bone loss you may need:
  - Bone density measurement (using dual photon densitometry)

Skin and Genital
- Learn how to do a routine self-exam of your skin
- Talk about the risks of being in the sun without proper protection
- Have a yearly gynecologic exam if you are a woman
  If you are a woman and have GVHD or had total body irradiation, you may need to:
  - Ask your doctor how often you need gynecologic exams

Nervous System
- You may need tests of your nervous system
- If you have trouble with things such as memory, concentration, or decision-making, you may need more tests

Additional test for children:
- Check cognitive development (ability to think and reason) for your child’s age
Fertility
- Ask your doctor about birth control options
- If you and your partner want to have a baby, ask to see a fertility specialist

Immune System
- Vaccines to prevent infection and disease
  
  *If you have GVHD or are taking immunosuppressants you may need:*
  - Medicine to prevent infections such as meningitis and pneumonia
  - Medicine to prevent an infection called pneumocystis for as long as you are taking immunosuppressants
  - Blood tests to screen for cytomegalovirus (CMV)

Endocrine System (thyroid, growth, sex hormones)
- Blood tests to check your thyroid
- Blood tests to check your sex hormone levels
- Additional tests for women who have not gone through menopause
  
  *Additional tests for children:*
  - Your child may need blood tests to measure sex hormone levels
  - Growth rate evaluation
  - Your child may need blood tests to check thyroid and growth hormone function
  
  *If you have GVHD or are taking immunosuppressants you may need:*
  - To take more doses of steroids (like prednisone) if you become very sick
  - To have your dose of steroids gradually reduced when it is time to stop taking them

Emotional Health
- Tell your doctor about your general well-being or quality of life
- Talk about your feelings (emotional health)
- Talk about your family and caregiver’s emotional health
- Ask about counselors and support groups in your area
- Ask any questions you may have about your sexual health

General Health
- Get regular screenings for high blood pressure, high cholesterol, diabetes, depression, sexually transmitted diseases, osteoporosis (in women), and cancer

New Cancers
- Talk to your doctor about risks of new cancers
- Learn how to do self-exams for cancer
- Follow cancer screening recommendations for the general population
- If you’re a woman, ask your doctor if you need a mammogram
Below, you’ll find information on the physical exams and tests that are TWELVE-MONTH you understand what to expect and prepare any questions or concerns you have to discuss with your doctor.

If you have

• screening more often

To have exams of the mouth and teeth, and oral cancer

Have a complete dental checkup (exam of your head, neck, chest X-ray, CT scan) if you have or had breathing problems

Check for heart and blood vessel risk factors, such as high cholesterol, high blood pressure, obesity, history of smoking

Get treatment for diabetes, high blood pressure, and high cholesterol

Eat healthy foods, and don’t smoke)

GVHD

GVHD

GVHD

Words in bold are defined in the

Endocrine system

Skin and Genital

Muscles

Liver

Nervous System

Additional test for children:

Bone density measurement (using dual photon densitometry) if

Kidney filtration levels test

Urine protein levels test

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Take action: prepare for your checkup

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MONTH
checkup
Helping you prepare for your appointment

24+

Notes:
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YEARMY CHECKUP GUIDE

Below, you’ll find information on the physical exams and tests that are recommended every year after transplant starting at 2 years. This information will help you understand what to expect and prepare any questions or concerns you have to discuss with your doctor. Words in bold are defined in the glossary.

Eyes
- Check for eye symptoms like pain or dryness
- Have an eye specialist (ophthalmologist) check how well you can see (vision screening) and do a retina exam

**If you have GVHD you may need:**
- To see an eye specialist more often

Mouth
- Exam of the mouth and teeth
- Oral cancer screening
- Talk about symptoms like dry mouth
- Tell your doctor about harmful habits (like tobacco use or smoking). Ask for help quitting
- Have a complete dental checkup (exam of your head, neck, mouth and teeth)

**If you have GVHD you may need:**
- To have exams of the mouth and teeth, and oral cancer screening more often

*Additional test for children:*
- A dentist will check how well your child’s teeth are growing

Lungs
- Regular lung exam
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- **Pulmonary (lung) function tests** and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

**If you have GVHD you may need:**
- Lung exams and **pulmonary (lung) function tests** earlier and more often

Heart and Blood Vessels
- Check for heart and blood vessel risk factors, such as high cholesterol, high blood pressure, obesity, history of smoking
- Talk about a “heart healthy” lifestyle (exercise, healthy weight, eat healthy foods, and don’t smoke)
- Get treatment for diabetes, high blood pressure, and high cholesterol
- Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves
Liver

• Liver function blood tests to see if your liver is working properly
• If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor
• If you had red blood cell transfusions, you may need a blood ferritin test, a liver MRI, or liver biopsy to check for too much iron

Kidneys

• Blood pressure test
• If you have high blood pressure (hypertension), start treatment and have regular follow up
• Urine protein levels test to see how well your kidneys are working
• Kidney filtration levels test (blood BUN/Creatinine test) to see how well your kidneys are filtering
• If your kidneys aren’t working well, you may need more tests (ultrasound or kidney biopsy)
• If you have chronic kidney disease that is getting worse, don’t take medicines, herbs, or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

Muscles

• Talk about current exercises and physical fitness activities

If you have GVHD or are taking immunosuppressants you may need to:
• Test if your muscles are weak (myopathy)
• See a physical therapist if you have myopathy, fasciitis, or scleroderma
• Have a range of motion exam to look for sclerotic changes
• Learn how to test your own range of motion

Bones

• Talk about ways to prevent bone density loss, including exercise, vitamin D, and calcium supplements

If you are a woman, allogeneic transplant recipient, have GVHD, are taking immunosuppressants, or are at a high risk for bone loss you may need:
• Bone density measurement (using dual photon densitometry)

Skin and Genital

• Learn how to do a routine self-exam of your skin
• Talk about the risks of being in the sun without proper protection
• Have a yearly gynecologic exam if you are a woman

If you are a woman and have GVHD or had total body irradiation, you may need to:
• Ask your doctor how often you need gynecologic exams

Nervous System

• You may need tests of your nervous system
• If you have trouble with things such as memory, concentration, or decision-making, you may need more tests

Additional test for children:
• Check cognitive development (ability to think and reason) for your child’s age
Fertility
- Ask your doctor about birth control options
- If you and your partner want to have a baby, ask to see a fertility specialist

Immune System
- Vaccines to prevent infection and disease
  *If you have GVHD or are taking immunosuppressants you may need:
  - Medicine to prevent infections such as meningitis and pneumonia
  - Medicine to prevent an infection called pneumocystis for as long as you are taking immunosuppressants
  - Blood tests to screen for cytomegalovirus (CMV)

Endocrine System (thyroid, growth, sex hormones)
- Blood tests to check your thyroid
- Blood tests to check your sex hormone levels
- Additional tests for women who have not gone through menopause
  *Additional tests for children:
  - Your child may need blood tests to measure sex hormone levels
  - Growth rate evaluation
  - Your child may need blood tests to check thyroid and growth hormone function
  *If you have GVHD or are taking immunosuppressants you may need:
  - To take more doses of steroids (like prednisone) if you become very sick
  - To have your dose of steroids gradually reduced when it is time to stop taking them

Emotional Health
- Tell your doctor about your general well-being or quality of life
- Talk about your feelings (emotional health)
- Talk about your family and caregiver’s emotional health
- Ask about counselors and support groups in your area
- Ask any questions you may have about your sexual health

General Health
- Get regular screenings for high blood pressure, high cholesterol, diabetes, depression, sexually transmitted diseases, osteoporosis (in women), and cancer

New Cancers
- Talk to your doctor about risks of new cancers
- Learn how to do self-exams for cancer
- Follow cancer screening recommendations for the general population
- If you’re a woman, ask your doctor if you need a mammogram
Lungs are recommended every year after transplant starting at 2 years. This questions or concerns you have to discuss with your doctor.

Additional test for children:

- • Check for eye symptoms like pain or dryness
- • Learn how to test your own
- • Growth rate evaluation
- • Kidney filtration levels test
- • Kidney function test
- • Tonsils and adenoids (like Tonsillectomy or adenoidectomy)
- • Bone density measurement (using DEXA or DXA scan)
- • Electrocardiogram (EKG or ECG)
- • Imaging of the heart by echocardiography
- • Lung function tests (standard spirometry, forced expiratory volume in 1 second [FEV1], forced vital capacity [FVC], peak flow, etc.)
- • Liver function blood tests—Tests to see how well your liver is working.
- • Myocardial perfusion imaging
- • Pneumonia
- • Graft-Versus-Host Disease (GVHD)—A common side effect after an allogeneic transplant when the new donor cells attack your body’s cells.

Liver function blood tests—Tests to see how well your liver is working.

Mammogram—A test to detect breast cancer.

Meningitis—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

Myopathy—Muscle disease and weakness. Steroids used for chronic GVHD may cause muscle weakness, especially in your legs and feet.

Ophthalmologist—A medical doctor who treats diseases that affect the eyes.

Nervous System—The parts of your body that control your movements and thinking. The nervous system includes your brain, spinal cord (back bone), and nerves.

Pneumonia—Inflammation (redness and swelling) of the lungs caused by infection.

Pneumocystis—A form of pneumonia caused by a yeast-like fungus.

Pulmonary (lung) function tests—A group of tests to measure how well your lungs are working.

Range of motion—A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

Scleroderma—When your skin becomes hard, thick, and tight. This can lead to weak muscles, stiff joints, or pain in your joints.

Sclerotic changes—Hardening of the skin and other tissues such as fasciae, muscles, and joints.

Thyroid—A gland that controls your body’s metabolism (how quickly your body uses energy).

Urine protein levels test—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.

Glossary

Bone density loss—Bones become weak and brittle. Bones can break more easily.

Cytomegalovirus (CMV)—A type of herpes virus that can cause infections (like pneumonia, a lung infection).

Dual photon densitometry—A tool to measure bone density. Often called a DEXA or DXA scan.

Endocrine system—Glands that release hormones into your body. Hormones affect your mood and growth.

Fasciitis—Inflammation (redness and swelling) of the connective tissue that surrounds muscles, blood vessels, and nerves. Often happens with hardening of the skin (see scleroderma).

Graft-Versus-Host Disease (GVHD)—A common side effect after an allogeneic transplant when the new donor cells attack your body’s cells.

Growth hormone function—Test to see if there is enough growth hormone in your body to grow normally.

Growth rate evaluation—Comparing a person’s growth to average growth in the general population in people of the same age and sex.

Immunosuppressants—Medicines that lower your body’s ability to fight infection. These medicines also help to prevent and treat GVHD.

Kidney filtration levels test—Measures the flow rate of filtered fluid through the kidneys. Used to detect chronic kidney disease.

Liver function blood tests—Tests to see how well your liver is working.

Mammogram—A test to detect breast cancer.

Meningitis—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

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Thyroid—A gland that controls your body’s metabolism (how quickly your body uses energy).

Urine protein levels test—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.
Take action: prepare for your checkup

- Schedule yearly checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests and evaluations listed on the pages inside
- Write down questions or issues you’d like to talk to your doctor about
- Bring this guide to your checkup
- Ask your doctors if there are other suggestions unique to your situation
- At your checkup, ask your doctor if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist, or others)

Share with your doctor

There are 2 easy ways to share these guidelines with your doctors or dentist:

- Review this guide with them at your next appointment
- Point them to BeTheMatchClinical.org/guidelines for free clinical guidelines in print or through a mobile app

We are here to help

Be The Match is dedicated to supporting patients, caregivers and families before, during, and after transplant.

We offer you confidential one-on-one support, financial guidance, and free educational resources — DVDs, booklets, online tools, and more. Our goal is to get you what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant, and learn what to expect after transplant.

Contact us at patientinfo@nmdp.org or 1 (888) 999-6743

Notes:

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Just for you—recipient resources

• ONLINE: BeTheMatch.org/survive
• E-NEWS: BeTheMatch.org/patient-ews
• FACEBOOK: facebook.com/BeTheMatchPatient

BE THE MATCH®

Patient Services
3001 Broadway St. N.E., Minneapolis, MN 55413
1 (888) 999-6743 | BeTheMatch.org/patient

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“As a patient, it is critical to keep building on your knowledge.”
— BMT Survivor

CHAPTER 16

Resources

Internet Resources for Cancer Information
Tips for Finding Information on the Internet
MedlinePlus Guide to Healthy Web Surfing
Chapter 16
Resources

Information on the Internet abounds and websites with reliable information are too numerous to list here. These are a few websites to get you started on your search for information. In addition, we’ve provided you with some basic tips for finding reliable information on the Internet.

Websites listed here are for your convenience and do not constitute endorsement by City of Hope.

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
<th>Phone Numbers</th>
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<tbody>
<tr>
<td>BMT InfoNet</td>
<td><a href="http://www.bmtinfonet.org">www.bmtinfonet.org</a></td>
<td>(888) 597-7674</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td><a href="http://www.cancer.org">www.cancer.org</a></td>
<td>(800) ACS-2345 (227-2345)</td>
</tr>
<tr>
<td>Cancer Legal Resource Center</td>
<td>email: <a href="mailto:Barbara.schwerin@lls.edu">Barbara.schwerin@lls.edu</a></td>
<td>(213) 736-1455 (866) 843-2572</td>
</tr>
<tr>
<td>Cancer Support Community formerly known as The Wellness Community</td>
<td><a href="http://www.thewellnesscommunity.org">www.thewellnesscommunity.org</a></td>
<td>(888) 793-9388</td>
</tr>
<tr>
<td>CancerSymptoms.org</td>
<td><a href="http://www.cancersymptoms.org">www.cancersymptoms.org</a></td>
<td></td>
</tr>
<tr>
<td>Cancervive Inc.</td>
<td><a href="http://www.cancervive.org">www.cancervive.org</a></td>
<td>(800) 426-2873</td>
</tr>
<tr>
<td>Center for International Blood and Marrow Transplant Research</td>
<td><a href="http://www.cibmtr.org">www.cibmtr.org</a></td>
<td>(414) 456-8325</td>
</tr>
<tr>
<td>Fertile Hope</td>
<td><a href="http://www.fertilehope.org">www.fertilehope.org</a></td>
<td>(888) 994-4673</td>
</tr>
<tr>
<td>Lab Tests Online</td>
<td><a href="http://www.labtestsonline.org">www.labtestsonline.org</a></td>
<td></td>
</tr>
<tr>
<td>Lance Armstrong Foundation/Livestrong</td>
<td><a href="http://www.livestrong.org">www.livestrong.org</a></td>
<td>(866) 235-7205</td>
</tr>
<tr>
<td>National Bone Marrow Transplant Link</td>
<td><a href="http://www.nbmtlink.org">www.nbmtlink.org</a></td>
<td>(800) LINK-BMT (546-5268)</td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td><a href="http://www.cancer.gov">www.cancer.gov</a></td>
<td>(800) 4-CANCER (422-6237)</td>
</tr>
<tr>
<td>National Center for Complementary and Alternative Medicine</td>
<td><a href="http://www.nccam.nih.gov">www.nccam.nih.gov</a></td>
<td></td>
</tr>
<tr>
<td>National Coalition for Cancer Survivorship</td>
<td><a href="http://www.canceradvocacy.org">www.canceradvocacy.org</a></td>
<td>(877) NCCS-YES (622-7937)</td>
</tr>
<tr>
<td>National Institute of Health Office of Dietary Supplements</td>
<td>dietary-supplements.info.nih.gov</td>
<td></td>
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<tr>
<td>Resource Listing</td>
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<tr>
<td>Other useful resources</td>
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<td>Write in your other resources that you have found.</td>
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**Tips for finding information on the Internet**

There is a lot of information on the Internet; some helpful and some misleading or even inaccurate. When searching for information, rely on credible sources. Nationally recognized organizations such as government websites, hospitals and educational institutions offer credible information. The organizations’ Web addresses (URLs) can give you a general idea of who is sponsoring the site.

Addresses that end in `.edu` are sites that are sponsored by educational institutions.

Addresses that end in `.gov` are sites sponsored by a government agency.

Addresses that end in `.org` are sponsored by a nonprofit agency.

Addresses that end in `.com` are sites sponsored by a commercial company.
MedlinePlus Guide to Healthy Web Surfing

The following information is a summary of the MedlinePlus Guide to Healthy Web Surfing. You can find the full guide at www.nlm.nih.gov/medlineplus/healthywebsurfing.html

What should you look for when evaluating the quality of health information on websites? Here are some suggestions based on experience.

- **Consider the source** — Use recognized authorities. Know who is responsible for the content.

- **Focus on quality** — All websites are not created equal. Does the site have an editorial board? Is the information reviewed before it is posted?

- **Be a cyberskeptic** — Quackery abounds on the Web. Does the site make health claims that seem too good to be true? Does the information use deliberately obscure, “scientific” sounding language? Does it promise quick, dramatic, miraculous results? Is this the only site making these claims?

- **Look for the evidence** — Rely on medical research, not opinion. Does the site identify the author? Does it rely on testimonials?

- **Check for currency** — Look for the latest information. Is the information current?

- **Beware of bias** — What is the purpose? Who is providing the funding? Who pays for the site?

- **Protect your privacy** — Health information should be confidential. Does the site have a privacy policy and tell you what information they collect?

- **Consult with your health professional** — Patient/provider partnerships lead to the best medical decisions.

For further information, visit the following MedlinePlus pages:

- Evaluating Health Information

- Evaluating Internet Health Information: A Tutorial from the National Library of Medicine.
“Participating in a clinical trial offers an opportunity for patients to take active roles in their health care.”
— BMT Survivor

CHAPTER 17

Participation in Clinical Trials
Chapter 17
Participation in Clinical Trials

What you Might Like to Know about How to Volunteer for a Clinical Trial

Clinical trials are an essential step in developing new and better treatments for cancer. Clinical trials are very carefully designed medical studies that help doctors, nurses and researchers provide new understanding and better treatments for cancer.

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 lead 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 (NCCN). City of Hope conducted over 300 clinical trials in 2014. Over the years these clinical trials help to improve and redefine treatments, outcomes and care standards for patients in the United States and in other countries as well.

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. Since you are at City of Hope, you may be participating in a clinical trial or know of someone who has.

Participation in clinical trials is always voluntary. Patients may decide to participate to help advance medical treatment or the clinical trial may offer a newer treatment that is not available as a standard care. Selection of patients for eligibility for a clinical trial is based on “inclusion” and “exclusion” criteria for a specific study. For example, eligibility may be based the type of cancer, the stage, genetic markers or previous treatments.

Patient safety in clinical studies is taken very seriously by the medical team and organizations like City of Hope. Participation is also guided by extensive federal regulations on the protection of patients in clinical trials. All participants in clinical trials must go through an informed consent process. The informed consent provides information on the study purpose, potential risks, benefits and treatment alternatives verbally, in written materials and in face-to-face meetings.
Patients who decide to participate sign the informed consent document but may still decide to not participate at any time during the study without compromising their medical care.

Additionally, federally conducted clinical studies of a drug, biological product or medical device regulated by the Food and Drug Administration must be reviewed, approved and monitored by an institutional review board (IRB). An IRB is made up of physicians, researchers and members of the community. Its role is to make sure that the study is ethical and the rights and welfare of participants are protected.

Every clinical study is led by a principal investigator, who is most often a medical doctor, although other health care professionals or researchers can be principal investigators. Clinical studies generally have a research team that may include doctors, nurses, social workers, statisticians and other health care professionals.

**To Learn More about Clinical Trials**

If patients or families would like to know more about clinical trials at City of Hope, they can ask always 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 [www.clinicaltrials.gov/ct2/about-studies/learn](http://www.clinicaltrials.gov/ct2/about-studies/learn) or the City of Hope website at [www.cityofhope.org/clinical-trials](http://www.cityofhope.org/clinical-trials).
"As a patient, it is critical to keep building on your knowledge."
— BMT Survivor

CHAPTER 18

Glossary of Terms
Notes
Activities to Keep Your Mind Sharp
Chapter 18
Glossary of Terms

**Acute**
A sudden onset of symptoms of disease

**Afebrile**
No fever; having a normal temperature

**Albumin**
A protein substance found in the blood

**Allergy**
An inappropriate and sometimes harmful response of the immune system to normally harmless substances

**Allogeneic Bone Marrow or Stem Cells**
Bone marrow or stem cells obtained from one person to be transplanted into a different person

**Alopecia**
Loss of hair

**Ambulatory**
The ability to walk; not confined to bed

**Analgesic**
A drug used to relieve pain

**Anemia**
Too few red blood cells in the bloodstream, resulting in insufficient oxygen to tissues and organs

**Anorexia**
The loss of appetite

**Antibiotic**
A drug used to fight bacterial infections

**Antibody**
A protein in the blood that helps defend the body against foreign substances including bacteria and viruses
**Antiemetic**
A drug used to control nausea and vomiting

**Antifungal**
A drug used to fight infections from fungi

**Antigen**
A foreign substance that can stimulate the body’s immune system, resulting in the production of antibodies or other defensive actions by white blood cells

**Antihistamine**
A drug used to relieve the symptoms of allergies like hives, runny nose and itching

**Antineoplastics**
Drugs used to treat cancer

**Apheresis**
The process of drawing blood from the bloodstream, separating its various components, saving one component, usually stem cells or platelets and returning the remainder to the body

**Ascites**
An excessive accumulation of fluid in the peritoneal (abdominal) cavity

**Aspiration**
The removal of fluids from the body by suction

**Autologous Bone Marrow or Stem Cells**
Bone marrow or stem cells donated by you for your own use in a transplant

**Axilla**
The armpit

**Bacteria**
Living organisms that can be seen only under a microscope and can cause infection

**Benign**
A growth or tumor that is not malignant or cancerous

**Bilateral**
Two sides of the body
Biopsy
The removal of tissue for examination under a microscope, commonly required to enable the doctor to make a diagnosis

Blasts
Immature white blood cells

Blood Cells
Cells that make up the blood, including red blood cells, white blood cells and platelets

Blood Count
A lab test to determine the number of cells in blood

Blood Transfusion
Blood administered through a vein to replace blood cells in the blood stream when there is a deficiency of a particular component (e.g., platelets, red blood cells)

Blood Typing and Cross-Match
Lab tests done before transfusion to match the patient’s blood with a donor’s

Bone Marrow
A spongy substance which fills the hollow spaces in bones. This is where hematopoietic stem cells are found and blood cells are produced

Bone Marrow Aspiration
A procedure in which a needle is inserted into a bone to take out a sample of bone marrow to be studied

Bone Marrow Harvest
The collection or “harvesting” of hematopoietic stem cells from bone marrow

Bronchoscopy
A procedure used to diagnose pulmonary conditions where the throat and bronchi are directly inspected through a flexible lighted tube

Catheter
A small, flexible plastic tube inserted into a portion of the body to administer and remove fluid

Chemotherapy
A drug or combination of drugs designed to kill cancerous cells
**Colony Stimulating Factors**
Proteins that stimulate the development of certain types of blood cells in the bone marrow

**Comfort and Pain Management Therapies**
Medications or other measures used to control pain, relieve pain or increase comfort. These may include the use of music, heat, ice, humor or massage.

**Computerized Tomography (CT or CAT scan)**
A type of X-ray study that uses computers to obtain a clear picture of the body. Sometimes a dye is used to obtain better pictures.

**Conditioning Regimen**
The combination of chemotherapy drugs and/or radiation used to prepare your body for a blood or marrow transplant

**Culture**
A test in which samples of body fluids such as blood, sputum or urine are examined to look for the cause of an infection

**Cytomegalovirus (CMV)**
A virus within the herpes family of viruses. CMV can occasionally cause pneumonia.

**Day Zero**
Day zero is the day a patient's stem cells will be reinfused into his or her body

**Differential (Diff)**
Percent of different types of white blood cells in the blood

**Diuretic**
A drug which increases the elimination of water and salts (urine) from the body

**Donor**
The person whose bone marrow or stem cells are harvested for transplant into a patient

**Edema**
The abnormal accumulation of fluid causing swelling

**Electrocardiogram (EKG)**
A test used to measure the heart’s electrical impulses to evaluate its rhythm and function
Eligibility Criteria
Guidelines established for a research protocol or study that state whether or not a patient will be able to participate safely in that study. These guidelines may take into account type of disease, prior treatments, age and other illnesses.

Engraftment
When the transplanted marrow or stem cells begins to work to manufacture new cells in the patient's bone marrow (white blood cells, red blood cells and platelets)

Febrile
To have a fever

Graft-versus-Host Disease (GVHD)
A common complication of blood and marrow transplantation between allogeneic stem cell transplant recipients and their donors. It occurs when the new marrow (the graft) recognizes the recipient (the host) as foreign and sends out lymphocytes to attack it. It can involve the skin, liver, gastrointestinal tract and other organs.

Granulocyte Colony Stimulating Factor (GCSF)
A medication that makes the bone marrow produce more stem cells. Note: This medication is also known as Neupogen.

Granulocytes
A category of white blood cells that contain granules within their cell body

Growth Factor
An agent that stimulates growth of cells

Hematuria
Blood in the urine

Hemoglobin
That part of the red blood cell that carries oxygen to the tissues

Hemorrhagic Cystitis
A condition in which there is bleeding and occasional ulcerations in the bladder

Herpes Simplex
A common virus that can cause sores on the lips or in the mouth and in the genital area
Herpes Zoster
A viral infection characterized by the development of painful skin eruptions that follow the route of underlying nerves (e.g., shingles, chicken pox)

High-dose Chemotherapy
The treatment of disease through very high doses of anticancer drugs

Histocompatibility
Blood tests used to determine the similarity between donors and recipients

Hope and Parsons Village
Temporary patient housing on the City of Hope campus. Some patients may use Hope and Parsons Village when hospitalization is not necessary but must remain in close proximity to the hospital.

Human Leukocyte Antigens (HLA)
Structures that appear on white blood cells, as well as cells of almost all other tissues. HLA antigens are tested in both the donor and the recipient to ensure that they match, which will increase the chance of survival of the transfused or transplanted cells. HLA typing and matching can be done for platelet transfusions and blood and marrow transplantation.

Hydration Therapy
Intravenous fluids given to ensure the kidneys are functioning properly or to replace fluid lost as a result of vomiting or diarrhea

Hyperalimentation
Intravenous administration of nutrients. It is also called total parenteral nutrition, or TPN.

Hyperglycemia
High levels of sugar in the blood

Hypertension
High blood pressure

Hypotension
Low blood pressure

Immune
A state of adequate protection against certain infections or foreign substances
**Immune System**
A group of organs, cells and other substances in the body that fights disease

**Immunosuppressed**
When the body’s immune system is weakened and less able to fight infection and disease. Immunosuppression can result from chemotherapy, radiation or be a result of the disease process.

**Infection**
The invasion and multiplication of disease-producing organisms within the body

**Inflammation**
The body’s reaction against injury or infection. Signs and symptoms may include pain, swelling, heat and tenderness at the site.

**Intake and Output (I and O)**
A measure of the amount of fluids taken in by your body (e.g., by drinking, IV, etc.) and the amount of all body fluids being put out (e.g., urine, stool, emesis, etc.)

**Intralipid**
A fat solution often given along with total parenteral nutrition (TPN) to provide the body with nutrients

**Intrathecal**
Within the spinal column. Occasionally medicine/chemotherapy is given directly into the intrathecal space (spinal column)

**Intravenous (IV) Infusion**
The delivery of fluids or medicine directly into the bloodstream through a vein

**Isolation**
Keeping a person separated from others to prevent the spread of infection or to protect them from outside sources of infection.

**Jaundice**
A yellowing of the skin, the whites of the eyes and the mucosa due to an increase in bilirubin.

**Low Bacteria Diet**
This diet includes healthy foods that are low in bacteria. All foods in a low bacteria diet must be prepared and cooked in such a way to minimize bacteria.
**Lumbar Puncture**
Insertion of a needle into the intrathecal space in order to remove cerebrospinal fluid for testing, or to administer medication into the intrathecal space, or both. This fluid is tested for the possible presence of cancer cells, bacteria and other substances.

**Lymphocytes**
The white blood cells which form antibodies necessary for immunity to specific diseases.

**Matched Unrelated Donor (MUD)**
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.

**Mixed Lymphocyte Culture (MLC)**
Lymphocytes from the donor and recipient are mixed together and tested for their compatibility.

**Neupogen (see GCSF)**
Trademark name of GCSF.

**Occupational Therapy**
Provides services to people whose ability to function in daily life has been disrupted by physical illness, injury, mental illness, developmental delay or the aging process. Each individual is assisted in achieving an independent, productive and satisfying lifestyle via goal-directed, purposeful activity.

**Oral**
In the mouth.

**Peripheral Blood Stem Cell Collection**
The collection of hematopoietic stem cells from the patient's peripheral blood using a technique called apheresis.

**Petechiae**
Tiny pinpoint red spots on the skin or in the mouth, which usually indicate a low level of platelets.

**Physical Therapy or PT**
Provides intervention to restore or maximize the physical abilities of patients of all ages. The focus is to provide patients with the means to maximize functional independence.
**Platelet**
One of the main components of blood that helps to produce clots to stop bleeding. Also called thrombocytes.

**Pneumonia**
Infection of the lung

**PRBC**
Packed red blood cells — Red blood cells that have been separated from a unit of whole blood for transfusion

**Protocol**
Clinical trial treatment plan

**Purging**
Removal of cancer cells from the marrow and/or stem cell

**Recreation Therapy**
Provides assistance to individuals in the restoration, adaptation and adjustment required to achieve optimal health and well-being. The focus is to enable individuals to develop, maintain and express a satisfying leisure lifestyle.

**Red Blood Cells**
Cells that contain hemoglobin and carry oxygen to all parts of the body. Also called erythrocytes.

**Reduced Intensity Transplant**
Also called nonmyeloablative transplant or mini-transplant. This is an allogeneic transplant that uses less intensive treatment to prepare for transplant. The preparation regimen does not destroy all of the bone marrow as a standard transplant regimen does. The reduced intensity transplant relies on the donor’s cells to fight the cancer.

**Refractory**
Not responding to treatment

**Serum Glutamic-Oxaloacetic Transaminase (SGOT)**
A liver enzyme that indicates how the liver is functioning

**Side Effects**
Reactions to drugs that are usually temporary and reversible. Side effects do not relate to drug effectiveness.
**Sinusoidal Obstructive Syndrome (SOS)**  
See VOD

**Sputum**  
A mixture of saline, mucus and cells coughed up from the lungs and throat

**Stem Cells**  
The precursor cells to all cell lines in the body. Hematopoietic stem cells are the precursor cells to the development of the cells of the blood (white blood cells, red blood cells and platelets).

**Syngeneic**  
From an identical twin

**T Cells**  
Small white blood cells processed in the thymus that are important in the body’s immune system. Also known as T-lymphocytes.

**Total Parenteral Nutrition (TPN)**  
Intravenous administration of a high-calorie, high-protein solution (also see hyperalimentation)

**Vascular Access Device (VAD)**  
A long, narrow tube that is surgically placed into a large vein leading directly to your heart

**Veno-Occlusive Disease (VOD)**  
Also called sinusoidal obstructive syndrome (SOS), it is a disease of the liver caused by toxic effects of high-dose chemotherapy and/or radiation, characterized by a blockage in the venous outflow of the liver

**White Blood Cells (WBC)**  
A variety of blood cells that help fight germs, as well as fungal and bacterial agents. Also called leukocytes.
Notes and Things to Keep Your Mind Sharp

Use these pages to write down your notes and questions you would like to ask your health care team. Make sure all of your questions are answered in a way that you can understand. If your doctor or other health care provider runs out of time to answer questions, ask how you can get answers, whether it is by making another appointment with him or her, or by going to another resource.
My Bone Marrow Transplant Team

case manager
dietitian
nurse coordinator
physician assistant
child life specialist
doctor
nurse practitioner
psychiatrist
clinical psychologist
nurse
patient advocate
rehabilitation team
social worker
Good Things to Know about a Bone Marrow Transplant

Complete the crossword below

Across
1. Is an example of fast growing cells in your body
6. High doses of this are given to destroy the cancer cells
7. Contains hemoglobin and picks up oxygen from the lungs and carries it to the cells
8. Something a person must wear to protect you from an infection
11. All pre-admission testing must be done within ____ days of your scheduled transplant
13. You are not allowed to keep any of these in your room
14. Short for the unrelated donor transplant using a donor from the general population who is not related to the patient
15. Perfect tissue match. Usually from one identical twin to the other
18. Someone who helps care for you during and after your transplant
19. Point when your “new” stem cells or marrow begin to make WBCs, RBCs and platelets
21. Blood cells that are part of the body’s immune system
22. There is no profit in curing the body if, in the process, we destroy the_____

Down
2. If you feel weak, dizzy or short of breath you might be ________
3. A verbal or written instruction that tells people your wishes should you not be able to speak for yourself
4. Process used to collect the healthy stem cells from your blood
5. Graft-versus-host disease
9. In this type of transplant, the donor is usually a brother or sister
10. Typing used to match donor to a recipient
12. After you are discharged from the hospital, you will be seen as an______________ in the clinic
16. Help prevent bleeding
17. The place in the body where blood cells are created is called the bone ____
20. One of many factors that are considered when selecting patients for a bone marrow transplant

allogenic
GVHD
anemic
advance directive
synergeneic
hair
mask
apheresis
HLA
age
soul
outpatient
caregiver
RBC
thirty
platelets
URD
medications
WBC
marrow
engraftment
chemotherapy
Cancer is Puzzling

By Valerie Esguerra, Patient/Family Advisor — 2009 Bone Marrow Transplant Survivor

Across
2. Angel in disguise
4. Extent of cancer
9. Where most patients go to get their blood drawn
10. Patients take these to get better
13. May cause hair loss
14. Helford patients see this on their walls
15. Worn on your face for safety
16. What some patients experience after treatment
17. What City of Hope provides its patients

Down
1. Describes doctors and nurses at City of Hope
3. A form of therapy
5. Requires a donor
6. Has impact on our health
7. Ovarian cancer patient
8. The bad ‘C’ word
11. Patients come back to City of Hope for this
12. “Want a piece of me?”
13. Another “hat” doctors and nurses wear