



**A patient's and caregiver's guide for
an allogeneic transplant**

HOW TO USE THE INFORMATION IN THIS GUIDE

This guide is a resource to help you and your family learn about blood and marrow stem cell transplantation 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 worries.

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 guide

- This guide can be used as a reference to prepare for 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 guide with you to your clinic appointments. Your nurses will use it to help teach you about different aspects of your care.
- Write your notes in it. Add important information to it. Personalize it. Make it your own.

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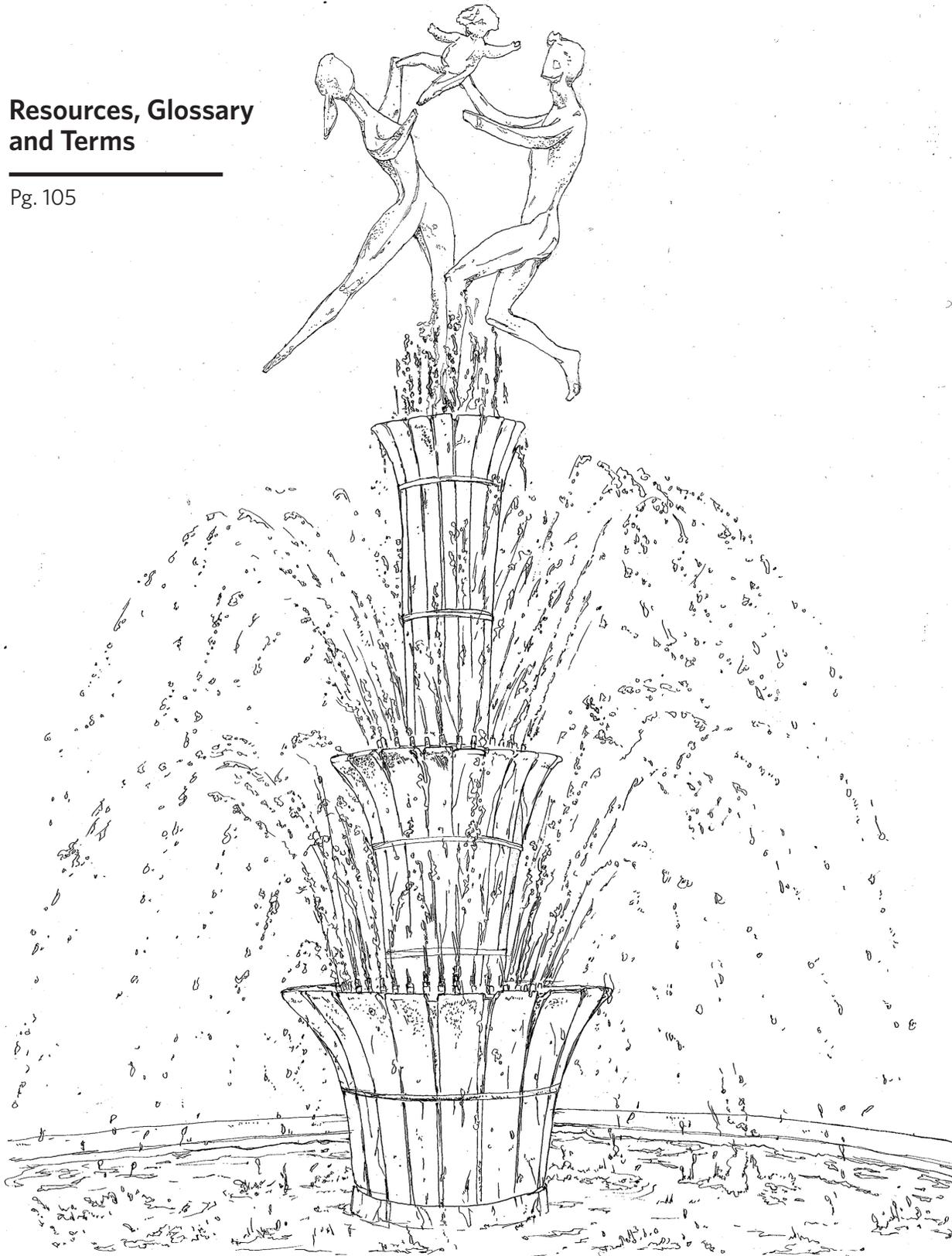
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A Letter from a Bone Marrow Transplant Survivor and Thriver

Welcome to your patient guide to blood and marrow stem cell transplantation! You are about to embark on one of the most amazing experiences of your life! How do I know? In the summer of 2012, I took my journey, which transformed my life in so many ways! For so many us, venturing into the unknown is a daunting task. The key is preparation. For me, I started with prayer and meditation, relentless positivity, followed by a lot of laughter, self-education, talking to other bone marrow transplant survivors, and building good relationships with my doctor and medical team. Don't underestimate the power of positivity and laughter, when venturing into the unknown. Remember, you can choose how you would view 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 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 opportunity. 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 teams 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 multifaceted. For humanitarian purposes, I happily embraced 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 have the opportunity to lift a "blue print" for yourself from the pages of this guide, to help you connect and persevere through the various stages of bone marrow transplantation. I can say from experience, that arming yourself with knowledge is one of the most invaluable steps you can take to maintain your piece of mind. This guide can be seen as a mini life manual to help you prepare for the bone marrow transplant, and help you step by step during and after the transplant process. The guide is comprehensive, as it is thoughtful; tackling a myriad of topics and issues where you as the patient can take comfort that City of Hope's medical staff is truly looking out for your well-being.

I have learned that self-discovery and resourcefulness can serve as a powerful aid to help you on your 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, sometime later, 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 comedian Gilda Radner's book, "It Is 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 City of Hope a year in advance of my transplant, to familiarize myself with the grounds, I started to envision myself living here in the next year. I started making plans then. 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 medicine go down," it really does! Think about it, a quote like this can help you make the choice to have a positive experience and perhaps an "educational view" of an event that is life changing; and challenges you to reexamine your view point.

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 eye level 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 are 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 ones 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 online computer application which allowed me to keep family and friends informed on my progress.

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 some of my favorite authors. Perhaps, you are more of a poet, maybe 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 Lewis 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!

As you learn how to use this guide, it will become increasingly clear how important self-care is as it relates to your emotional, social, and physical needs following your bone marrow transplant. City of Hope’s medical team and your own support system will prove vital to your own well-being. As you celebrate this major landmark in your life, you can now move forward with a “new blueprint” to help you to accomplish your dreams and goals to lead a 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 found this guide to be a great tool and companion, it will help 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

Bone marrow transplant
survivor and thriver

2012





"A must read for every
bone marrow transplant patient."

— BMT Survivor

Welcome to City of Hope

INTRODUCTION

- National Cancer Institute Designation
- City of Hope's Philosophy of Healing
- History of Blood and Marrow Stem Cell Transplantation at City of Hope

01

Introduction

Welcome to City of Hope

A NATIONAL LEADER IN CANCER CARE

Founded in 1913, City of Hope is a national leader in cancer care. We provide each patient with an individualized, comprehensive care experience and deliver the highest quality treatment and expertise.

We are one of only 52 National Cancer Institute (NCI)-designated comprehensive cancer centers in the U.S. The NCI designation recognizes excellence in treatment, research and expertise to



“THERE IS NO PROFIT
IN CURING THE BODY IF,
IN THE PROCESS,
WE DESTROY THE SOUL.”

address the many faces of the disease, whether in early or late stage, and for common or rare types of cancer.

City of Hope is also proud to be a founding member of the National Comprehensive Cancer Network (NCCN), reflecting our national leadership in advancing research and treatment. NCCN member institutions are recognized for their world-renowned experts and for treating complex, rare and aggressive forms of cancer.

Most importantly, we firmly believe in providing value across the entire patient journey. At City of Hope, this is measured by the experiences and outcomes that our treatments and dedicated team provide. Our goal is to care for the whole person, so that life during treatment and after cancer can be rich and rewarding.

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 a pioneer in bone marrow and stem cell transplants. As one of the largest and most successful programs of its kind in the U.S., our program attracts patients across the nation and world.



“Once I began to understand the individual roles of the medical staff, I realized it was such a comfort to me.”

— BMT Survivor

Your Health Care Team

02

Your Health Care Team

At City of Hope, we use a multidisciplinary approach with a team of many different kinds of health care providers coming together to care for you. You and your family are the most important part of your health care team. Other members of your health care team include, but may not be limited to:

DOCTOR (PHYSICIAN)

As the leader of your health care team, your doctor is an expert in the field of hematology and blood and marrow stem cell 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.

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 have 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 coordinating tests/procedures that will take place before, during, and after your transplant. 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 and marrow transplantation patients. These nurses work under the guidance of your doctor and work closely with all the members of the transplant team.

CLINICAL SOCIAL WORKER

Clinical social workers are an important part of your health care team who are available to meet with you throughout your care. We know that stress and challenges often can occur with a serious or long-term illness for both patients and loved ones. During your treatment, a clinical social worker is available to support you and your support systems emotional and social well-being.

Your clinical social worker will be able to answer any nonmedical questions you may have, and provide guidance to help get to your questions answered. This can include counseling, financial resource referrals, community resource referrals and support group information.

Clinical social workers can assist with improving communication and coordinating family meetings. This provides opportunities to meet with health care team members and discuss your medical care, goals and values for both patients and loved ones.

PSYCHIATRY

Psychiatric services are available to help maximize quality of life by helping patients deal with the psychiatric challenges that may arise during a cancer diagnosis and treatment. Psychiatrists help with medication management of anxiety, depression and psychiatric symptoms. Please notify your health care team if you would like to speak with a psychiatrist.

PSYCHOLOGY

Psychologists play a key role in helping you with the emotional, psychological and behavioral challenges that may arise during cancer diagnosis and treatment. Psychologists help reduce the impact of these challenges of coping and the ability to actively participate in care. Please speak with your health care team if you are struggling with any of these concerns and would like to speak with a psychologist.

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.

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 of up physical therapists, occupational therapists and recreation therapists, each specializing in a particular part of your rehabilitation process. 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.

*oncologyrehabpartners.com

CHILD LIFE PROGRAM

The uncertainty of illness, treatment and procedures may cause fear and distress in children and their families. Child life specialists support children who are getting ready to receive procedures and treatment.

They do this by:

- Providing age-appropriate education
- Supportive activities and resources
- Building trusting relationships with pediatric patients by using techniques such as therapeutic and medical play

Child life specialists also provide services to pediatric patients and children of adult patients. Grandparents can also request child life specialists to help their grandchildren understand their illness and treatment.

They also provide support and education on end of life, grief and bereavement. Children and families who receive child life services are more confident and empowered in coping with their hospital events and a loved one's illness.

ACADEMIC ADVOCACY PROGRAM

School is an integral part of normal life for children, teens and young adults. Cancer or other serious illness can disrupt the sense of normalcy and connection it provides, beyond how it may affect their studies. The Academic Advocacy Program is designed around helping young patients continue their education. That helps them maintain that sense of normalcy through socialization and continued academic progress during treatment and recovery.



City of Hope's Academic Advocacy Program helps children, teens and young adults:

- Feel more normal and adjusted by keeping pace with their peers
- Increase self-esteem through opportunities for achievement
- Provide motivation to stay socially and mentally engaged
- Reduce depression and anxiety associated with treatment
- Have smooth transitions back to school after treatment

The Academic Advocacy Program provides services for all phases of education, including:

- Preschool
- Elementary school
- Middle/High school
- College
- Vocational studies

The Academic Advocacy Program helps to coordinate:

- Hospital tutoring
- Home instruction
- School reintegration
- Student and parent advocacy
- Special accommodations
- Neuropsychological testing
- Community resources and referrals



SPIRITUAL CARE TEAM

Many patients and their families rely on faith and/or spiritual beliefs to help them through the difficulties of cancer and its treatment. Spiritual care chaplains are trained to provide spiritual support and counseling for patients and families of all religions and beliefs. Please notify your health care team if you would like to speak with one of our chaplains.

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 **800-826-HOPE (4673), ext. 82285**.



"This guide helped us to simplify our life.
This way the only thing on our minds was
the transplant."

— BMT Survivor

Important Things to Know About

- Caregiver Role
- MyCityofHope Patient Portal
- Advance Directive
- Health Insurance, Financial

03

Important Things to Know About



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

Caregiver Role

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

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

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

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

CAREGIVER RESPONSIBILITIES

The caregiver must:

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

QUESTIONS FOR CAREGIVERS

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

Here are a few questions and tips that may help:

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

TIPS FOR CAREGIVERS

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

CHOOSING A CAREGIVER

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

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

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

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

CAREGIVERS RESOURCES AT CITY OF HOPE

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

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

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



FAMILY AND FRIENDS

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

FAMILIES WITH CHILDREN

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

MyCityofHope Patient Portal

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



Request appointments.

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



Ask for prescription refills.

Send a renewal request for any of your refillable medications.



View notes.

View your clinician notes and after visit summary.



Pay bills online.

Check and pay your bills from home.



Connect to Hope Virtual (televisit) appointments.

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



Access most test results.

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



Communicate with your care team.

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



Give friends and family access.

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



Request, download or send your medical records.

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



Advance Directive

HOW TO COMPLETE AN ADVANCE DIRECTIVE.

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

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

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

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

1. Fill Out the Advance Directive Form

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

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

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

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



prepareforyourcare.org



CityofHope.org/health-care-proxy



gowish.org

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

2. Notarize or Witness Your Advance Directive

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

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

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

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



Virtual Notary Service

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

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

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



3. What to Do With a Completed Advance Directive

1. Make copies and give one each to:

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

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

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

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

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

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

Advance Directive Volunteer Champions

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

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



Biller Patient and Family Resource Center

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

The team at the center can:

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

Health Insurance, Financial Clearance Services and Billing

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

HEALTH INSURANCE

Will my insurance cover the cost of my care?

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

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

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

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

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

FINANCIAL CLEARANCE SERVICES (FOR QUESTIONS BEFORE TREATMENT)

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

BILLING QUESTIONS (FOR QUESTIONS AFTER TREATMENT)

Who do I talk to about my bill?

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

Patient Business Services

866-268-4673

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

OTHER IMPORTANT QUESTIONS

When is payment due?

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

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

What do I do if my insurance changes?

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

What if I don't have insurance?

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



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

Blood and Marrow Transplant Basics

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

04

Blood and Marrow Transplant Basics

Normal Blood Cells

RED BLOOD CELLS

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

WHITE BLOOD CELLS

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

PLATELETS

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

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

Peripheral Blood Stem Cells

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

BONE MARROW

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

Diseases treated with blood and marrow transplants:

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

Pediatric conditions:

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

Reasons for Transplant

WHY STEM CELLS ARE TRANSPLANTED

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

Factors that are evaluated when selecting patients for transplantation:

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

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

Types of Stem Cell Transplants

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

There are four basic types of transplants:

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

Cell Sources for Transplant

There are three possible sources for stem cells.

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

Stem Cell Collection

PERIPHERAL STEM CELL COLLECTION

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

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

BONE MARROW HARVEST

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

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

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

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

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



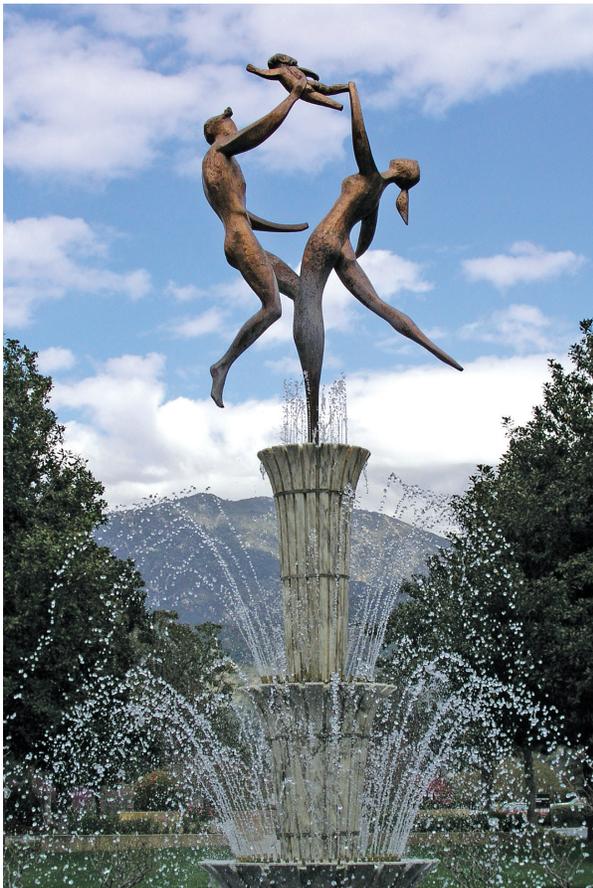
“Participating in a clinical trial offers an opportunity for patients to take active roles in their health care.”

— BMT Survivor

Participating in Clinical Trials

05

Participating in Clinical Trials



When you volunteer for a clinical trial

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

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

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

BENEFITS OF PARTICIPATING IN A CLINICAL TRIAL

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

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

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

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

Are clinical trials safe?

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

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

What should I consider before participating in a clinical trial?

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

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

You will want to find out:

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

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

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

PHASE 1:

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

PHASE 2:

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

PHASE 3:

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

PHASE 4:

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

TO LEARN MORE ABOUT CLINICAL TRIALS

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

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



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

— BMT Survivor

Preparing for Your Transplant

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

06

Preparing for Your Transplant

Evaluation Tests for Eligibility, Preadmission

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

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

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

ELIGIBILITY TESTING

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

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

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

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

COMMON PREADMISSION TESTING

Blood tests

CBC (complete blood count)
Blood chemistry
Infectious disease markers

Bone age

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

Bone marrow aspiration and biopsy

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

Chest X-ray

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

Creatinine clearance

24-hour urine collection to measure kidney function

CT scan

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

Echocardiogram

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

EKG

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

GFR

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

Lumbar puncture

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

MIBG scan

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

MRI

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

PET scan

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

Pregnancy test

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

Psychosocial assessment

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

Pulmonary function tests

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

Skeletal survey

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

Stress test

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

Stool specimens

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

Thyroid panel

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

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

Colonoscopy

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

Dental examination

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

Mammogram

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

Managing Your Medications

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



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

External Central Vascular Access Device

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

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

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

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

Fertility Issues and Reproductive Options

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

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

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



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

- BMT Survivor

What You Need to Know About an Allogeneic Transplant

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

07

What You Need to Know About an Allogeneic Transplant

About an Allogeneic Transplant

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

SELECTING A DONOR

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

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

Human Leukocyte Antigen Typing for Allogeneic Transplantation

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



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

Haploidentical Transplants

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

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

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

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

Unrelated Donor Allogeneic Transplant

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

INFUSION OF ALLOGENEIC BLOOD AND MARROW STEM CELLS

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



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

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

ENGRAFTMENT

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

Getting Your Body Ready for Transplant

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

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

CHEMOTHERAPY

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

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

SIDE EFFECTS OF CHEMOTHERAPY

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

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

WHAT YOU CAN DO TO MANAGE CHEMOTHERAPY SIDE EFFECTS

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



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



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



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



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



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



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



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



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



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



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



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

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

RADIATION THERAPY

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

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

Side Effects of TBI

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

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

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

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

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

How to Recognize Early and Late Complications After Transplant

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

SHORT-TERM COMPLICATIONS

Infections

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

INFECTIONS FROM THE ENVIRONMENT

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

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

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

INFECTIONS FROM YOUR OWN BODY

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

Skin

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

Mouth

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

What to Do:

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

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

Perianal care

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

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

BLOOD PRODUCT TRANSFUSION

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

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

KIDNEY AND LIVER PROBLEMS

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

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

GRAFT FAILURE

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

LONG-TERM COMPLICATIONS (MONTHS TO YEARS)

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

Gonadal Dysfunction

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

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

Cataracts

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

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

Pulmonary Complications

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

Infections

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

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

Bleeding

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

Signs of a low platelet count may include:

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

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

Secondary Malignancy

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

Relapse

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

What is Graft-Versus-Host Disease?

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

How to lower your risk of GVHD

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

WATCH FOR COMPLICATIONS - GVHD

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

Acute GVHD

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

Skin

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

Self-care measures:

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

Liver

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

Self-care measures:

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

Gastrointestinal tract (Intestines)

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

Self-care measures:

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

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

Chronic GVHD

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

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

Organ System and Common Targets of Chronic GVHD

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

Skin

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

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

Self-care measures:

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

Liver

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

Self-care measures:

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

Mouth

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

Self-care measures:

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

Mouth, continued

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

Eyes

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

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

Self-care measures:

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

Digestive System

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

Self-care measures:

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

Genitals

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

Self-care measures:

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

Lungs

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

Self-care measures:

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

Immune System

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

Self-care measures:

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

Coping with GVHD

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



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

— BMT Survivor

What to Expect from Discharge and Throughout Your Recovery

- My Follow-Up Appointments
- Self-Care at Home
- Self-Care and Hygiene
- Where and When to Call for Help — Nursing Triage Call Center
- Rehabilitation
- Caregiver Support
- Diet and Nutrition After Transplant
- Mental Health After Treatment

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What to Expect from Discharge and Throughout Your Recovery

It takes about six months to a year before the new bone marrow is fully working and able to make the white blood cells, red blood cells, and platelets your body needs. Remember you now have a new immune system! As time progresses, you will be hitting important milestones in your recovery. It is important you and your caregiver understand what these different milestones mean, and the kind of follow-up care you can start preparing for. Your health care team is on this journey with you. Talk to your health care team about your concerns and questions.

These instructions will be given to you and your caregiver at the time of your transplant. It is important you and your caregiver understand all aspects of your healing and recovery- physical, mental, emotional and spiritual. Your health care team will give you different instructions and education during your hospital stay to prepare you to go home and to know how to continue to follow all instructions for your healing and safety when you are home.

My Follow-up Appointments

Immediately after transplant, you will be seen in the clinic, usually twice a week. You will need to stay within an hour away in traveling time from City of Hope Duarte campus for about 100 days after transplant for close follow-up. There will also be recommended tests and evaluations for six-months and yearly (12+month) appointments. The frequency of your follow-up appointments will depend on your progress through your first-year post-transplant.

During this time, your doctor will be checking for:

- Infections
- Bleeding
- Any sign of graft-versus-host disease
- Your ability to take your medications as prescribed
- Your overall well-being

PREPARING TO GO HOME CHECKLIST

This is a sample of a general checklist that can be used to help you get started in preparing to go home.

<p><u>Preparing your home</u></p> <p>Cleaning your home:</p> <ul style="list-style-type: none"><input type="checkbox"/> Carefully vacuum all carpets, furniture and drapes. Shampoo if soiled.<input type="checkbox"/> Change all air filters and turn off humidifiers.<input type="checkbox"/> Buy new cleaning supplies (gloves, sponges, wipes) to keep your bathrooms, kitchen clean at all times. <p>Pets:</p> <ul style="list-style-type: none"><input type="checkbox"/> Talk to your doctor about any pets you have at home. <p>Visitors:</p> <ul style="list-style-type: none"><input type="checkbox"/> Remind your visitors to wash their hands and not to visit if they are sick.<input type="checkbox"/> If you have children: ensure they are clean (showered, clean clothing) before any contact. <p>Shopping:</p> <ul style="list-style-type: none"><input type="checkbox"/> Talk to your case manager, social worker, and nurse about how to prepare your home before your patient comes home. Begin your shopping list: <hr/>	<p><u>Grocery shopping list</u></p> <p>Preparing meals:</p> <ul style="list-style-type: none"><input type="checkbox"/> Make sure you have antibacterial soap to wash hands before preparing meals.<input type="checkbox"/> Clean all cutting boards and counter tops.<input type="checkbox"/> Wash all pots, dishes, utensils with very hot soapy water, rinse very good, and let them air dry.<input type="checkbox"/> Wash all fresh fruits and vegetables. <p>Food safety:</p> <ul style="list-style-type: none"><input type="checkbox"/> Cook all meats and white meats to safe internal temperatures.<input type="checkbox"/> Buy only pasteurized cheeses.<input type="checkbox"/> Buy only pasteurized egg products. <p>Shopping:</p> <ul style="list-style-type: none"><input type="checkbox"/> Talk to your dietician about meal planning. Begin your shopping list: <hr/>	<p><u>Daily Precautions and Self-Care</u></p> <p>Taking your medicines:</p> <ul style="list-style-type: none"><input type="checkbox"/> Keep track of the names and instructions for each medication. <i>Use a phone application or a medicine diary to keep track.</i><input type="checkbox"/> Always check with your doctor before you stop taking any medicines.<input type="checkbox"/> Store all medicines properly, avoid very warm, moist areas. <p>Other needs:</p> <ul style="list-style-type: none"><input type="checkbox"/> _____<input type="checkbox"/> _____<input type="checkbox"/> _____<input type="checkbox"/> _____<input type="checkbox"/> _____<input type="checkbox"/> _____
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Self-Care At Home

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.

PROTECTING YOUR IMMUNE SYSTEM

- 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 your mask as instructed by your doctor.
- Your home should be well cleaned before you arrive.
- Do not do house cleaning yourself. Leave the room when cleaning is being done.
- Avoid crowds and stay away from anyone who may be sick. (malls, parks, retail stores, churches, etc.). Wear masks if you need to go.
- Change air conditioner filters as recommended by the manufacturer.
- You can wear contact lenses but make sure to clean them thoroughly when you put them in. Do not reuse cleaning solution.

IMMUNIZATIONS – Protecting your Immune System

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 or viruses.

- Do not receive any live vaccines.
- Always check with your doctor before receiving any vaccines.
- If children in your family require polio vaccination, they should receive the inactivated Salk parenteral vaccine (given by shot), instead of the live Sabin given by mouth type.
- Avoid contact with people who have been vaccinated with a “live virus” vaccine, such as MMR, Varicella or FluMist for six weeks (including children living in your house).

SEXUAL ACTIVITY

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 an act of both the mind and the body. It takes time for both to heal. You are encouraged to follow these important steps 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 doctor before resuming sexual activities.
- Remember you and partner must maintain good mouth hygiene. You should not kiss if you have any mouth sores or bloody gums.
- Shower or wash your hands and genitals before and after sexual activity.
- Use a condom/barrier protection each time you have vaginal, oral or anal sex.
- Use water-soluble lubricant to decrease irritation during sexual activity.
- If possible, urinate before and after intercourse.
- Ask your nurse about helpful online resources and support about sexuality and intimacy after treatment.

MEDICATIONS

- It is very important that you take your medications as prescribed. A pharmacist will go over all instructions with you before discharge.
- Most patients obtain a pill box with several slots for each day to help organize their medications.
- Bring a list of medications and all of your medications with you to all your follow-up appointments. We will review them and make any changes if needed.
- If you take immunosuppressant medications, such as Sirolimus, Tacrolimus or Cyclosporin:
 - During the first three months after transplant, do not take the morning dose on the day of your appointments until after your blood is drawn. We will monitor the levels of these medications with your usual blood tests and may need to adjust the dose based on those levels.
 - Never miss more than two doses. Call your doctor right away if this happens.

Self-Care and Hygiene

MOUTH CARE

- You may use tap water to do your mouth care. Do not use water from a well or spring.
- Brush your teeth after each meal and at bedtime.
- Use a soft toothbrush if tolerated, if not continue with toothettes.
- If you wear dentures, keep them clean to prevent infections. Soak them daily in any type of denture cleaner, and following cleaning directions. Your dentures may need refitting after transplant.
- Any kind of toothpaste is acceptable.
- Avoid mouthwashes since most have alcohol and can irritate your mouth. Use a bland rinse.
- 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. Before showering, cover your VAD dressing with an impermeable cover.
- Remember to change your VAD dressing right away after showering or if it becomes wet, loose, or soiled.
- Use mild soaps and shampoos.
- Use make-up, aftershave or perfumes in small amounts. If you have a skin reaction, stop using these products.

SKIN AND NAIL 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 sunscreen greater than 30 SPF 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.
- You can wear makeup, but buy all new products after your transplant.
- Do not get a manicure or pedicure in a nail salon while your immune system is still recovering. Do your nail care at home with your own tools.

BLEEDING

If you have any injury that causes bleeding, stay calm and follow these steps:

- If you cut yourself, put a clean, dry gauze pad, towel, or cloth over the cut. Press firmly. Keep pressing to apply pressure until the bleeding stops. If the bleeding does not stop, elevate the wound, apply ice and call your doctor.
- If you have a nosebleed, sit up and lean forward slightly. Don't tilt your head back. Squeeze the bridge of your nose firmly between your thumb and forefinger for at least 10 minutes without letting go. If bleeding does not stop, keep squeezing, apply ice, and call your doctor.
- In case of a serious injury, it is important you wear medical alert jewelry at all times. This will help the treating doctor know your condition. If you are admitted to another hospital, ask the doctor to call City of Hope right away for guidelines on the blood products that are best for you.

ACTIVITIES

- If you are at risk of bleeding, avoid contact sports, weight lifting, moving furniture, bicycling or skiing. Mild exercise such as walking or use of a stationary bike is encouraged.
- Do not get body piercings or tattoos after your transplant. These activities increase your risk of hepatitis and other infections.
- Do not swim in oceans, lakes, or public pools for one year after your transplant or as long as you have a VAD.

HOME ENVIRONMENT

- 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. You should not be the one cleaning the house.
- Keep all toilets, showers, counters, sinks and tubs very clean. Use a disinfectant regularly. Bleach or ammonia is recommended. Never mix bleach and ammonia together, this could create a toxic gas.
- Avoid sharing towels, wash cloths, or bed linens with other family members.
- Carpets and rugs should be carefully vacuumed. Carpets with visible soiling need to be shampooed.
- Drapes, blinds and furniture should be cleaned.
- Change filters in air conditioners and furnaces as recommended by the manufacturer.
- Turn off humidifiers.

- Do not remodel your home or do major repairs such as opening any walls or pull up old carpet at this time. This activity can cause mold spores to be released into the air.
- Remove fresh or dried flowers from your home. You may have to remove house plants. Please speak with your doctor.
- Until approved by your doctor or nurse practitioner, avoid working in the yard or garden or being in the area when someone else is doing yard work.

PETS

- Pets can carry disease. They may put you at greater risk for infection while your immune system is recovering. 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 fishbowl. Have someone else do it.
- Avoid contact with reptiles (e.g., snakes, lizards, turtles or iguanas).
- Always wash your hands after touching your pet.
- Remember it is highly important to always report changes in signs and symptoms.
- Do not go to any petting zoos.

Where and When to Call for Help

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 non-life-threatening situations only. For concerns, call the **Nursing Triage Call Center, 24 hours at (626) 471-7133.**

For questions about a medication refill or renewal, please call the City of Hope pharmacy at **(626) 301-8304** or call the pharmacy where your medication 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 medicines
- Uncontrolled pain
- Problems with your central venous access device (i.g., VAD or PICC line)
- Any other health problem where you were told 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 provide; your nurse can answer your questions and make recommendations. If needed, the nurse can call 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 right away if you have a life-threatening emergency:**

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

If you go to an emergency room, identify yourself as a City of Hope patient.



Rehabilitation

When you go home, you will likely continue to feel fatigue and weakness for quite some time after 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 right levels, are vital to get back 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 videos or gentle yoga stretches. Exercise with a friend or make it a family affair. Everyone will benefit and you will develop a healthy routine. 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 heal 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 is 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 doctor 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. Work with your occupational therapist (OT) to establish a routine that allows you to alternate activity and rest.
- 4. Nausea** — If mild, you should attempt therapy prior to, or along with taking anti-nausea medication. Exercise has been shown to reduce side effects of chemotherapy, such as nausea. Work with your OT to establish a routine that allows you to alternate activity and rest.
- 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 are expected to shower daily to maintain your activity level, prevent infections, and maintain as much of your normal daily routine as possible.
- 8. Clothing** — You should bring clothing (such as 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 PATIENT WEEKLY REHABILITATION ROUTINE

Name:

S	M	T	W	TH	F	S
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Occupational Therapy Plan	Relaxation activity that reduces stress								
	Cognitive activity that stimulates your brain								
	Upper body and breathing exercises								
	Sit up for all meals								
	Shower every day								

Physical Therapy Plan	Sit up in chair three times								
	Walk 1 mile around the unit if able								
	Walk in the room (if not able to walk in halls)								
	Stand up 10 times								
	Lower body exercises								

Activity Plan	Participate in one leisure activity								
	Socialize with one peer or family member								

Laps Walked									
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You can walk in the unit hallways throughout your hospitalization.
 Ask your occupational therapist/physical therapist for clarification on exercises

Caregiver Support

Throughout your recovery, your caregiver is an important part of your transplant team. Your caregiver will be responsible for helping you to safely recover by monitoring and reporting symptoms to your health care team, managing medications and your daily activities. Your caregiver may also be partnering with you to handle communications with other family and friends to share about your health updates. Throughout this experience, your caregiver will often need support too.

Your caregiver can find education, resources and support at the Sheri & Les Biller Patient and Family Resource Center to help care for their physical, emotional, and spiritual health.

Visit the Biller Patient and Family Resource Center at the Duarte campus or **CityofHope.org/Caregivers** to navigate and connect with all the resources available to you.

Available in the center are:

- City of Hope caregiver education, support and resources
- Caregivers Connect, a support group where caregivers can take time to relax, get support and get to know other caregivers
- A Caregivers Guide: Tips and Tools for Reducing Caregiver Stress
- Disability and Paid Family Leave Resource Hub

You can also visit City of Hope's **HOPEFUL.org** to access discussion groups, advice, wellness articles and healthy recipes, as well as to connect with other caregivers.

Diet and Nutrition After Transplant

Eating the right foods and drinking enough liquids make an important difference in your recovery. Food safety is also especially important for transplant recipients to reduce the risk of foodborne illness. You and your caregiver may ask to meet with a clinical dietitian from City of Hope. The dietitian will instruct you and your caregiver on a diet plan and food safety guidelines. The dietitian also will provide you with information on shopping for food, food preparation and food storage.

RESPONSIBILITY FOR MEALS

It is the duty of the patient or the patient's caregiver to buy foods and make meals that follow the food safety guidelines. Groceries may be purchased from local markets. Restaurant meals and take-out foods are not recommended.



PREPARING AND SERVING FOOD

Please refer to these steps:

- Wash your hands before handling any food.
- Clean areas that you will be using to make food, such as cutting boards and countertops. 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 can be cleaned in the same way.
- 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 before use.
- Cook foods to safe temperature. Use a food thermometer to measure the inside 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 foodborne illness.

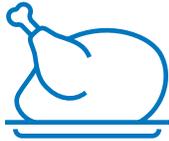
Essential Food Safety Guidelines



Wash hands, utensils and cutting boards before and after contact with raw food.



Use a thermometer and refer to the temperature chart (below).



Keep raw meat and poultry apart from foods that won't be cooked.



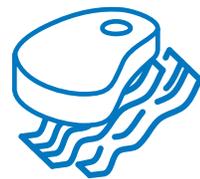
Chill leftovers and takeout foods within two hours and keep the fridge at 40 F or below.

USDA recommended safe minimum internal temperatures*

145 F

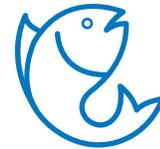
With a three minute rest time

BEEF, PORK, VEAL,
LAMB, STEAK, ROASTS
AND CHOPS



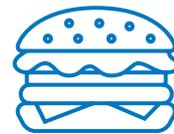
145 F

FISH



160 F

GROUND BEEF, PORK,
VEAL AND LAMB



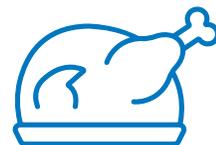
160 F

EGG DISHES



165 F

TURKEY, CHICKEN AND
DUCK; WHOLE PIECES
AND GROUND



*IsitDoneYet.gov

Type of Food	Foods Allowed	Foods to Avoid
Meat, deli and poultry	<ul style="list-style-type: none"> Meat or poultry cooked to safe minimum internal temperatures Hot dogs, lunch meats or deli meats reheated to steaming hot or 165 F 	<ul style="list-style-type: none"> Raw or undercooked meat or poultry Hot dogs, deli meats or luncheon meats that have not been reheated
Fish and seafood	<ul style="list-style-type: none"> Previously cooked seafood heated to 165 F Canned fish and seafood Fish cooked to safe minimum internal temperatures 	<ul style="list-style-type: none"> Any raw or undercooked fish, shellfish or food containing raw or undercooked seafood, e.g. sashimi (found in sushi, ceviche, etc.) Refridgerated smoked fish Partially cooked seafood, e.g. shrimp and crab
Milk	<ul style="list-style-type: none"> Pasteurized milk 	<ul style="list-style-type: none"> Unpasteurized (raw) milk
Cheese	<ul style="list-style-type: none"> Cheese that is labeled "made from pasteurized milk" such as hard cheeses, processed cheeses, cream cheese, mozzarella and soft cheeses 	<ul style="list-style-type: none"> Soft cheeses made from unpasteurized (raw) milk, such as feta, brie, camembert, blue, queso fresco (Mexican cheese type).
Eggs	<ul style="list-style-type: none"> At home: use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs All other pasteurized eggs need to be fully cooked When eating out, ask if pasteurized eggs were used 	<ul style="list-style-type: none"> Foods that contain raw or undercooked eggs such as homemade Ceaser salad dressing, raw cookie dough, and egg nog
Fruits and vegetables	<ul style="list-style-type: none"> Washed fresh fruits and vegetables Cooked sprouts Cooked frozen or canned fruits and vegetables 	<ul style="list-style-type: none"> Raw sprouts (alfalfa, bean or any other sprouts) Unwashed fruits and vegetables Fruits or vegetables that have visible bruising, mold or soft spots
Pâtés	<ul style="list-style-type: none"> Canned or shelf-stable pâtés or meat spreads 	<ul style="list-style-type: none"> Unpasteurized, refridgerated pâtés or meat spreads
Honey	<ul style="list-style-type: none"> Honey labeled as "pasteurized" Baked goods, cereals, snacks and other foods containing honey that have been pasteurized Cooked, nonpasteurized honey 	<ul style="list-style-type: none"> Nonpasteurized honey

What to Do About Problems Caused by Cancer Treatment

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

Problems	Suggestions
Bloating (over-full feeling after just a few bites)	<ol style="list-style-type: none">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	<ol style="list-style-type: none">1. Eat high-fiber foods including fruit and vegetables, nuts and seeds, 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.
Dehydration	<ol style="list-style-type: none">1. Drink plenty of fluids, including popsicles, broth, juices, etc.2. Sports drinks such as Gatorade and Propel can also be helpful.
Diarrhea	<ol style="list-style-type: none">1. Start with broth or a popsicle and slowly add foods low in roughage (steamed rice, applesauce, dry toast or bananas, plain or vanilla yogurt).2. Let carbonated beverages lose their fizz before drinking.3. Drink plenty of fluids to replace fluids lost.4. Avoid fatty, greasy and spicy foods, raw vegetables and fruits, and nuts.
Dry Mouth	<ol style="list-style-type: none">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) and popsicles, or chewing gum may help to create more saliva.

Problems	Suggestions
Heartburn	<ol style="list-style-type: none"> 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	<ol style="list-style-type: none"> 1. Eat small meals often. 2. Avoid eating too much at one time. 3. Avoid foods that are greasy or spicy.
Loss of appetite	<ol style="list-style-type: none"> 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 mealtimes 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, cookie, and soup). 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 food.
Milk intolerance (drinking milk may cause cramping, bloating and diarrhea)	<ol style="list-style-type: none"> 1. Avoid milk and dairy products. 2. Use Mocha Mix, Lactaid Milk, soymilk products and other lactose-free products.
Sore throat	<ol style="list-style-type: none"> 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.

Problems	Suggestions
Nausea and vomiting	<ol style="list-style-type: none"> 1. Eat small meals often. 2. If you vomit after the treatment, do not eat until several hours after treatment. 3. Eat and drink slowly. Do not force foods if they make you full or sick. 4. Rest after eating, but don't 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.
Difficulty swallowing	<ol style="list-style-type: none"> 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, Boost). 6. Avoid hard and dry foods (nuts, crackers, popcorn and potato chips).
Strange taste to your foods	<ol style="list-style-type: none"> 1. Try different seasonings and sauces. 2. Prepare foods that look and smell good to you. 3. Rinse your mouth often.
Water retention	<ol style="list-style-type: none"> 1. Avoid salty foods (potato chips, pickles, soups, ham). 2. Do not add salt to your food at the table.
Weight loss	<ol style="list-style-type: none"> 1. Eat small meals often. 2. Choose high-protein, high-calorie foods. 3. Add extra butter to noodles, rice or vegetables.

Mental Health After Treatment

City of Hope supportive care professionals who can help:

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

EMOTIONAL CONCERNS AFTER TREATMENT

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 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

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).

SOCIAL CONCERNS AFTER TREATMENT

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, they still receive a lot of support. 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.

SPIRITUAL CONCERNS AFTER TREATMENT

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

TAKING 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 Clinical 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.

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. It is healthy to take time for yourself and to reflect about what matters most in your life.
- Identify changes you might want to make in your life.
- Take time to understand what is your new normal.
- 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.
- Consider medications can be used for anxiety and depression.
- Consider volunteering as a “peer” for cancer patients who are still receiving treatments. Ask your doctor or nurse about programs that you can volunteer for or connect with.





“As a survivor, your attitude helps you adapt and adjust to a new life after transplant.”

— BMT Survivor

Survivorship

- Adapting to the Changes Affecting Your Life After Transplant
- How to Talk About Staying Healthy After Transplant
- Self-Care After Transplant Can Be Different for Everyone

09

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 discuss key concerns that may affect your life after BMT, how to talk about the concerns with your doctor/nurse practitioner, and coping tips that can help you through this time of transition.

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.

Adapting to the changes affecting your life after transplant

KEY THINGS TO KNOW

- Once treatment is over, what can you do to stay healthy.
- Understanding and recognizing the challenges that transplant survivors face is an important start to living a healthy life after transplant.
- There is important information and advice about nutrition, physical activity, and dietary supplements that you will need to learn about to help improve your 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 after transplant can be different for everyone

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.

SLEEP

- Try to practice a regular sleep schedule and keep it up.
- It is important to listen to your body. If you are tired, stop and rest.
- Getting enough sleep will help give you the energy you need for recovery.

Seek counseling from psychologist/psychiatrist, chaplain or social worker if needed. Reduce stress by exercising, meditating and relaxing.

FINANCIAL AND WORK CONCERNS

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.

Supportive care professionals 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 or 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.

IF YOU HAVE QUESTIONS, PLEASE CONTACT ONE OF THE RESOURCES BELOW.

- City of Hope **(800) 826-HOPE (4673)**
- Sheri & Les Biller Patient and Family Resource Center **626-218-CARE (2273)**
- Clinical Social Work **(62) 218-2282**
- Spiritual Care Services **(800) 826-HOPE (4673)**



reatment

Symptom Management

Coping & Caregiving

“ This guide helped me think about other resources I can access at City of Hope such as visiting the Sheri & Les Biller Patient and Family Resource Center.”

— BMT Survivor

Resources, Glossary and Terms

- Tips for Finding Information on the Internet
- Internet Resources for Cancer Information
- Glossary and Terms

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Resources, Glossary and Terms

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 website, hospitals and educational institutions, offer credible information. The organizations' website addresses 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 sites sponsored by a nonprofit agency.

Addresses that end in **.com** are sites sponsored by a commercial company.

Listed 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.

INTERNET RESOURCES FOR CANCER INFORMATION

American Cancer Society

cancer.org
(800) ACS-2345 (227-2345)

Be the Match

Bethematch.org

BMT InfoNet

bmtinfonet.org
(888) 597-7674

Cancer Legal Resource Center

Barbara.schwerin@lls.edu
(213) 736-1455
(866) 843-2572

Cancer Support Community

Cancersupportcommunity.org
(888) 793-9355

Center for International Blood and Marrow Transplant Research

cibmtr.org

Fertile Hope

fertilehope.org
(888) 994-4673

Lab Tests Online

labtestsonline.org

Livestrong

livestrong.org
(855) 220-7777

National Bone Marrow Transplant Link

nbmtlink.org
(800) LINK-BMT (546-5268)

National Cancer Institute

cancer.gov
(800) 4-CANCER (422-6237)

National Center for Complementary and Integrative Health

nccih.nih.gov

National Coalition for Cancer Survivorship

canceradvocacy.org
(877) NCCS-YES (622-7937)

National Institutes of Health Office of Dietary Supplements

ods.od.nih.gov

OncoLink

oncolink.org

Radiology Info for Patients

radiologyinfo.org

The Bone Marrow Foundation and Cancer

bonemarrow.org

The Leukemia & Lymphoma Society

lls.org
(800) 955-4572

Glossary and 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 TPN (total parenteral nutrition) 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

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

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

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

See Venous Occlusive Disease.

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

Intravenous administration of a high-calorie, high-protein solution (also see hyperalimentation)

Vascular Access Device

A long, narrow tube that is surgically placed into a large vein leading directly to your heart

Veno-Occlusive Disease

Also called SOS (sinusoidal obstructive syndrome), 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

A variety of blood cells that help fight germs, as well as fungal and bacterial agents. Also called leukocytes.

Department of Supportive Care Medicine
Patient, Family, and Community Education
2022



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