



Your Transplant Journey

A comprehensive
guide to bone marrow
and stem cell transplants
and supportive care.

The
BONE MARROW
F O U N D A T I O N



Each transplant journey is unique, beginning long before the actual transplant of cells and continuing for quite a while into the future. Bone marrow or stem cell transplantation is a process, and the phases will depend on the type of transplant (autologous/ allogeneic and bone marrow/peripheral blood stem cell), the condition being treated, and on the patient's individual health.

Your Transplant Journey is a map for the transplant process. The Bone Marrow Foundation hopes it provides comprehensive education, encouragement, support, and practical resources to help patients and family members access reliable information about all aspects of the transplant procedure and follow-up care. It is our belief that by understanding what's ahead, you will be better-equipped for the transplant process—physically, emotionally, and logistically. Being an informed patient (or family member/loved one/caregiver) can help you advocate for yourself or your loved one and better negotiate the twists and turns that may occur along the transplant path.

This book provides general information about bone marrow and stem cell transplants and supportive care. It is **not** intended to provide the latest medical research or statistics or to cover every possible scenario that might arise during treatment. This book does not take the place of any discussion with your transplant team, but rather can be used to inform and guide these discussions. See Talking to Your Team sections throughout this text for suggestions on discussion starters and questions you may want to ask your team.

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Introduction

Bone Marrow Basics

Bone marrow is soft, spongy tissue found inside of the hard (cortical) bone. All blood starts out as stem cells created in the bone marrow. These stem cells develop into one of the three types of mature blood cells – red blood cells, white blood cells, or platelets – and enter the bloodstream from the marrow. Red blood cells carry oxygen throughout the body. White blood cells fight infection. Platelets help blood to clot. The bones of the hip, chest (sternum/breastbone), and pelvis contain the largest amount of marrow and stem cells.

Stem cells also leave the marrow space and enter the bloodstream. These are called peripheral blood stem cells (PBSCs). Peripheral blood stem cells are also found in umbilical cord blood, which can be collected at birth and stored in a blood bank. Science has improved methods for

collecting and storing PBSCs, making this an important source of stem cells for some types of transplants when the patient is their own donor.

Transplanting Bone Marrow and Stem Cells

Bone marrow provides your body with new stem cells that become red blood cells, white blood cells, and platelets. The basic idea behind a bone marrow transplant (BMT) and peripheral blood stem cell transplant (PBSCT) is to allow high doses of chemotherapy and/or radiation therapy to kill rapidly dividing cells (including cancer cells) in the body and to make room for new, healthy blood cells; basically, a clean slate.

Though these treatments are among the most effective weapons against many forms of cancer, they don't have precise

BLOOD CELL FUNCTIONS

Stem Cells give rise to all blood cells. Each stem cell divides to form either a new stem cell, or a more mature blood cell, or a mature red blood cell, white blood cell, or platelet.

White Blood Cells, also called leukocytes, are the key components of the immune system—the body's defense against infection, viruses, and other threats. There are many different types of white blood cells, each of which plays a specific role in destroying "foreign" substances including infections.

Red blood cells, also called erythrocytes, contain hemoglobin, a protein that carries oxygen from the lungs to the rest of the cells in the body.

Platelets are sticky, disc-shaped cells that enable blood to clot properly, which prevents excess bleeding.

aim, and they cannot target only cancer cells. As a result, many healthy rapidly dividing cells (including skin, hair, and stem cells) are also destroyed during the treatment. Donated bone marrow is the "rescue"; it is given by infusion and can then create new stem cells which in turn make new white blood cells, red blood cells, and platelets.

Types of Transplants

There are three main types of transplants: bone marrow transplants, peripheral blood stem cell transplants (frequently just called stem cell transplants), and cord blood transplants. Each of these is also referred to as a hematopoietic stem cell transplant. Donated bone marrow or stem cells can come from three sources. An allogeneic transplant is when a donor supplies the marrow or stem cells. An autologous transplant uses the patient's own bone marrow or stem cells. A syngeneic transplant is the rare situation when one uses bone marrow or stem cells from an identical twin. Several factors determine what type of BMT

you should have, including the type of disease, age, overall health, and the availability of a donor. The “All About Donation” section of this book explores allogeneic transplants and autologous transplants in additional detail.

Conditions Treated With BMT/PBSCT

(Please note: This section is intended to provide an overview of conditions treated by bone marrow and stem cell transplant; it is **not** a comprehensive list)

Bone marrow and stem cell transplants continue to be investigated as treatments for a number of diseases; their therapeutic uses are likely to increase. One of transplantation’s earliest uses was in treating leukemia and lymphoma, cancers that affect white blood cells. Today, transplant is considered by many experts to be standard therapy for these and other blood cancers, as well as for neuroblastoma (a type of cancer that occurs most frequently in children), and multiple myeloma (a cancer of

DID YOU KNOW....

A transplant isn't surgery? It's a common misconception. When your medical team says transplant, they mean an infusion of blood cells through an IV.

the plasma cells in the bone marrow).

Transplantation is also used to treat noncancerous conditions, including those that affect the blood or immune system, and some genetic conditions. These include severe combined immunodeficiency disease (SCID), sickle-cell disease, myelodysplastic syndrome (MDS) and various types of anemia, such as aplastic anemia, Fanconi’s anemia, and auto-immune diseases.

Finding the Facts: Tips for Learning More

Arming yourself with knowledge and accurate information may help you feel

SUPPORTLINE

In addition to providing financial assistance and education to transplant patients, The Bone Marrow Foundation believes that personal one-on-one conversation in non-medical terms, whether it's between patients, families or caregivers, is a very important part of the treatment process.

Supportline is a free service designed to link patients who may be considering or undergoing bone marrow or stem cell transplantation and/or their family members/caregivers with former transplant patients and their family members/caregivers. The goal is to provide direct telephone, on-line, or in-person encouragement during the transplant experience from the unique perspective of someone who has experienced it.

more confident and in control. Some people like to know everything, some like a more limited amount of information, and some like to know just what they need to know. No matter which of these describes you, having accurate information can help you understand what's happening, ask the right questions, and get the best care possible.

In the age of digital information, it is easier than ever to access medical information and advice. It is also possible to get lost in a sea of information that may be inaccurate, out-of-date, or biased. Below is some guidance for gathering information on the internet and off.

- **The Bone Marrow Foundation.** Bonemarrow.org offers a constantly-updated listing of U.S. transplant centers as well as a wide range of diverse resources to start or continue your search.
- **Your transplant center.** Your transplant center's website can also be a good place to start your search, and can lead you to other trusted resources.

• **Patient-advocacy organizations.** The Bone Marrow Foundation, the American Cancer Society, Be the Match, the Leukemia and Lymphoma Foundation, and similar organizations (see the Resources section of this book), can be excellent sources of

up-to-date, accurate information. On their websites you may find medical information summaries, overviews available for treatment, transplants, clinical trials, financial assistance for patients, and other aspects of care.

CONTINUING THE CONVERSATION

Throughout the transplant journey, you will undoubtedly have questions. Some may be easy and straightforward to ask and some may feel more private or personal. Your transplant team is usually the best place to start when you have questions. This section is written to help you get the conversation started, especially for questions that may not be easy. You can ask some of these questions or use them to help write your own. You can also use this Guide or your notebook to keep track of the answers.

What type of transplant should I consider?

How long will I miss work/school?

What are the benefits, risks, and side effects?

How long will I have to change my normal activities?

What is the plan to manage side effects if they occur?

How long will I be away from home after the transplant?

How long will I be in the hospital?

How often will I need follow up care after my transplant?

What is the cost for this treatment? What is covered by insurance? Are other financial resources available?

Should I think about fertility issues as I prepare for my transplant?

- **Direct Support.** Join support groups or ask your transplant center to provide you with names of people who have been through a transplant. Many organizations, including The Bone Marrow Foundation, have “peer programs” that are designed to connect people with transplant survivors. Each person’s transplant journey is unique, but you may find that many things are similar, and it is always helpful to share good resources and support.
- **Your Medical Team.** Your doctors, nurses, and social workers should be able to provide medical information that is specific to your condition and your treatment, and direct you to other sources of trustworthy information.
- **Bookstores.** Visit a large bookstore, in person or online, and browse literature about your condition, as well as the self-help section, for books about coping with illness. Keep in mind that books – due to their lengthy publishing process – are unlikely to reflect the very latest medical information about a condition or a treatment, but they can be useful for more general information.
- **You!** Start your own trusted source. Use a notebook or file folder to collect news, information, and resources about your condition, treatment, and transplant. Here you can also take notes on tips you hear from other people and your health care team.

All About Donation

There are two primary sources for bone marrow and stem cells; either you can donate your own or someone else can donate them to you. Below you will find one section on donor transplants, called *allogeneic*, and one on self-donated transplants, called *autologous*.

Allogeneic Transplants - Someone Else is Your Donor

Allogeneic bone marrow transplants, by definition, rely on a healthy donor whose bone marrow is biologically compatible to yours. This compatibility is measured by HLAs, or *Human Leukocyte Antigens*. These protein “markers” are found on the surface of white blood cells (which are also called leukocytes). They serve as a kind of genetic fingerprint, enabling the body’s immune

system to recognize the body’s own cells. HLA markers occur in pairs, with one part of each pair inherited from a mother and one from a father.

Because of the genetics, it makes sense that the search for a bone marrow HLA match starts with your family. There is a 25 percent (one in four) chance that any one brother or sister perfectly matches a sibling’s HLA type. The overall chance of having any sibling who is a match depends on the number of siblings. Potential donors will need to be tissue-typed, which involves taking a series of blood tests to determine if the HLA “fingerprints” match. If a brother or sister doesn’t match, parents and sometimes other family members are screened for HLA compatibility.

When a Family Match Is Not Available

If a sibling or family match is not available, your transplant center

will explain the procedure for finding an unrelated donor through bone marrow registries. The National Marrow Donor Program hosts the “Be the Match” national registry database of people who have agreed to donate bone marrow, stem cells, or cord blood and who have undergone initial testing to determine their HLA tissue type. The transplant center will search this and other databases of donors to identify a potential match. If someone is found, the registry contacts the potential donor explaining that they have a person who is a match and in need of a transplant. The identity of the donor is always kept confidential for a period of time following the transplant, at which point the recipient and/or the donor are free to contact one another if both give written consent.

As successful as national registries have been in helping identify unrelated donors, many people in need of a BMT are unable to find a matched donor. This is for many reasons including genetic make-up and ancestry.

Cord Blood Transplants

Cord blood (blood saved from the stem cell-rich umbilical cord and placenta) may also be used for some transplants. Cord blood is harvested (or taken) from the umbilical cord after the birth of a child. Some families choose to save and bank cord blood after the birth of a child; sometimes this blood is saved specifically to be used for a sibling and sometimes it is just saved in the event it is needed later. Some people may choose to donate cord blood to a public cord blood bank after birth. For unrelated donors, cord blood does not need to match as closely to the recipient as unrelated donor bone marrow or stem cells because cord blood cells are less mature and have less ability to cause a negative reaction in the host. Cord blood is also useful in situations when a transplant needs to happen quickly and there is not enough time to continue searching for an unrelated donor.

For expectant parents who have a child in need of a transplant, ViaCord offers the Sibling Connection Program (cord blood processing and five years

of storage) free of charge. An expectant family with a child (a full sibling of the unborn child) who has an established diagnosis of a disease that is currently treatable with cord blood may be eligible. Your medical team will need to complete a form for approval.

Haploidentical Transplants

If a match cannot be found, some transplant centers are performing haploidentical (or “half-match”) transplants. A haploidentical transplant is a type of allogeneic transplant where half of the HLA markers match between the donor and recipient. The donor may be a healthy first degree relative – a parent, sibling or child. There are special challenges with this type of procedure; the imperfect match increases the risk of the donor cells rejecting the host or patients cells (known as Graft vs. Host disease). This type of transplant is still being studied.

Autologous Transplants - You Are Your Own Donor

An autologous transplant means that you are your own donor. Your stem cells will be harvested and stored prior to undergoing chemotherapy conditioning for the transplant. The stem cells are then transplanted back into your body – similar to a blood transfusion. Over the following days and weeks, the transplanted stem cells move to the marrow spaces in the bones and begin to produce new blood cells. Using your own cells avoids the need for finding a donor and eliminates the risk of graft rejection and Graft vs. Host Disease, which are complications that can arise when a donor is not perfectly matched to your HLA type. Autologous transplant is an option for some people – but not everyone; the type of transplant you have is based on many factors including your specific disease.

Donating Bone Marrow

Donating bone marrow is a relatively simple procedure (known as harvesting) and poses little risk to the donor. Before donating, the donor will have some blood tests and a medical exam. Harvesting bone marrow is generally done under general anesthesia. A needle is used to withdraw marrow from the pelvic bones. It takes about an hour to remove between one and three pints of marrow and blood cells. Though it may sound like a lot, it is only about five percent of the donor's total bone marrow reserve. The harvested marrow is then processed to remove any bits of bone or other unneeded tissue and may be given immediately to the recipient or frozen and stored until the time of transplantation. Harvesting may be done as an outpatient procedure, or the donor may spend one to two nights in the hospital. Because each hospital's procedures vary, the hospital where the marrow will be donated will provide the details for the donation, including any specific instructions for the days leading up to and after the harvest (for example, dietary restrictions if general anesthesia is used).

Donating Peripheral Blood Stem Cells

Peripheral blood stem cells (PBSCs), which circulate in the blood stream, can also be used for transplant. PBSCs are harvested through a procedure called apheresis, which is similar to donating blood. Stem cells need to be "mobilized" or encouraged to leave the bone marrow. A donor will generally take a medication called growth factors (sometimes called colony stimulating factors) for up to five days prior to the donation to increase the number of stem cells in the blood. The procedure may be done as an outpatient or may require a hospital stay. PBSC donations are typically completed in one to two apheresis sessions. The donor's blood, including the circulating stem cells, is collected from a large vein in the arm, or through a temporary central venous line, depending on several factors including the hospital's procedures and the donor's physical condition.

The donated blood is then run through a machine called a blood cell separator, which locates and separates the small

THE EMOTIONAL SIDE OF DONATION

The physical process of donating bone marrow or stem cells is straightforward and generally not associated with any medical complications. Some donors may, however, experience a degree of emotional distress associated with donation and transplant. This can be especially true for related donors who know the recipient and are likely to continue to be involved in or at least informed of the recipient's ongoing condition. The donor may feel responsible if the transplant doesn't go according to plan. Encourage your donor to share his or her feelings about their donation experience, whatever they might be. It is important to share your feelings too. You and your donor may also want to talk with a counselor trained in these matters, who can help you both work through the feelings you might be facing; this can be done together, as a family, and/or individually.

fraction of stem cells in the blood from all other blood cells. The stem cells are collected, and the rest of the cells are returned to the donor through a different intravenous catheter. Depending on the type of transplant and the timing of donation, the stem cells may be taken directly to the recipient for infusion, or may be treated and frozen for later use in the same method as bone marrow.

Recovery

Bone marrow and PBSC donors can expect to return to most activities, such as school and work, within one to seven days. A donor's recovery time will vary based on the person and type of donation. The removed cells from the donor's bone marrow will be replaced by the normal growth of marrow within a few weeks.

Pre-Transplant Planning & Preparation

This chapter is designed to help you understand what is involved in planning and preparing for transplant. The precise order of events may vary by treatment center; they will share their specific preparation plan with you. By knowing what to expect and being realistically optimistic about the process, you can take an active role in preserving your emotional well-being as well as your physical health. Think of transplant as a marathon, not a sprint, both physically and emotionally. Some days will bring great strides forward and some may feel like big steps backward. Transplant is a journey.

Scheduling and Logistics

There will be a great number of details to manage leading up to transplant. Every situation is

unique, and every transplant center has its own guidelines, so the specifics of procedures, the logistics, and the speed at which things occur may vary.

At most transplant centers, a transplant coordinator will be assigned to you. The coordinator, who may be a nurse, social worker, or other health professional, will probably meet with you early in the process and may continue to work with you throughout your transplant and follow-up care. Because it is common to forget things when you may be stressed, distracted, or learning a lot of new information, it is a good idea to take someone with you to these planning meetings. An extra set of eyes and ears, and some support can be helpful and comforting. Take notes during the meetings with your medical team so you can

QUESTIONS TO ASK

Below are some questions you'll want to clarify with your transplant coordinator if you don't yet have the answers. Many people find it helpful to create a special notebook for this information. Some questions will only be able to be answered as the transplant progresses.

How long will I be hospitalized?

What will need to be done prior to my hospitalization?

What will be the schedule of procedures once I am admitted?

What will my treatment regimen consist of, and what are the side effects associated with it?

What kind of educational materials can the hospital provide about their transplant procedures?

What accommodations are available for family members?

What support programs and services are offered (emotional, financial, nutrition, logistics)?

What are the restrictions on what I can bring to the hospital?

What is the visitor's policy and can my caregiver stay in my room with me?

What precautions and home preparations will need to happen before I can return home?

review what you've learned later if needed.

There will be a schedule of pre-transplant evaluations and tests before your admission to the hospital. Once you have

been admitted to the hospital, there will be preparative conditioning, and then the transplant itself. The coordinator and your health care team will assist you with setting these

pre-transplant appointments. You may want to keep a special journal or calendar for medical appointments and reminders.

Choosing a Transplant Center

More than 200 centers in the U.S. currently perform bone marrow and peripheral blood stem cell transplants. This means that you have choices as to where to have your transplant. There are a number of considerations that may affect your decision.

Doing some research is worthwhile, starting with your doctor, who may refer you to a specific center. Location may be an important consideration: It can be helpful to have your transplant as close to your home as possible, for many reasons including pre-transplant testing, nearness to family and friends, and follow up care. Of course, this is not always possible, especially if you live in a rural area. You can find directories of transplant centers online, including on The Bone Marrow Foundation's website (bonemarrow.org).

Talking with other people who have had a transplant can help you to identify what qualities to look for in a transplant center. It is also helpful to talk to transplant coordinators, nurses, and doctors at the center(s) you are considering to get a sense of their transplant program. If possible, visit the treatment center prior to your admission.

Insurance Review

Keep in mind that in the U.S., insurance companies may limit your choice of transplant center. Your insurance carrier may have an "approved" list of centers that meet its criteria and will require you to select from that list. Check with your insurance representative to find out your choices.

Your transplant center will need to know if the transplant is covered by your health insurance. Health insurance companies can refuse to pay for transplantation for many reasons. Even when transplant is an accepted therapy for your condition, your insurance carrier may deny coverage. Without coverage, the cost of a transplant can be prohibitively expensive.

CONSIDERING TRANSPLANT CENTERS: QUESTIONS TO KEEP IN MIND

Transplant Center

- Years of experience performing transplants
- Number of transplants performed each year
- Type of transplants performed
- Treatment plan protocol: Research protocol or standard therapy
- Success rate for your disease

Transplant Team Support

- BMT physician training and type of specialty training
- Experienced nursing team
- Nurse-to-patient ratio
- Availability and quality of psychosocial support services
- Availability of other health care team members, such as nutritionist, PT, integrative therapies
- Availability of housing for family/friends

Financial Considerations

- Experience in dealing with insurance companies
- Financial assistance services
- Insurance contract rates for transplants

Long-Term Follow-Up

- Support for your referring physician
- Method to answer your questions

Other Considerations

- For children, pediatric specialization and programs for children
- Methods of identifying potential donors
- Proximity to home (when you have a choice)

CARELINES & CARETRACKER

The Bone Marrow Foundation's Carelines program provides crowdfunding, journaling, and a volunteer task calendar for use by anyone with a cancer diagnosis or who is preparing for or undergoing a bone marrow, stem cell, or cord blood transplant. Through Carelines, patients can reach out to family, friends, and social networks for financial support; share updates, photos, and videos; keep track of appointments; and receive help from family

and community members for day-to-day tasks. All contributions to Carelines are tax-deductible and do not affect a patient's medical insurance or benefits.

CareTracker is designed to help patients and caregivers manage their medication. Through a virtual pill box, patients can keep track of their current medicines, access information on each medication, document and monitor possible side effects, and accurately communicate to their medical team.

However, legal experts say there is no need to panic if you are denied coverage for a transplant; you do have rights and recourse. Talk with your healthcare team to see what options you may have, and/or contact a lawyer who specializes in this area. You might also contact patient groups for additional information. Please also see the Resource Guide for sources of information about insurance coverage.

Getting Ready for Transplant

Exercise and Nutrition

Transplant is very hard on your body; you are basically rebuilding your immune system. It is very important to be as strong and healthy as possible before transplant. Eating right and exercising can help. Exercise is also important for your mental

health before, during, and after transplant. Work with your doctor, nutritionist, and physical therapist to develop plans that are right for you.

Hair Care

Most patients will lose almost all body hair during pre-transplant conditioning. Many patients have experienced this during previous chemotherapy or radiation. Whether you are experiencing it for the first time or it's happened to you before, losing your hair can be traumatic.

Before starting conditioning, some patients choose to cut their hair short. This serves two purposes: It is easier to care for and it may be less shocking when it begins to fall out. Cutting your hair will not take away the stress of losing it, but many patients feel it helps.

An important consideration at this point is a wig. Some patients prefer deciding whether they want to have a wig and to begin looking for one at this point, before they actually need it. Looking for a wig that matches your hair color and style is easiest when you

can compare your own hair to the wig. Other patients prefer to shop for scarves or hats. Still others decide they want nothing at all or will decide when the time comes. If you decide on a wig or other accessory, buying it early on gives you time to start adjusting and practicing and assures that it will be ready when you want it. Also, you may be feeling physically stronger now and have the energy to shop. Other patients, your social worker, and nurses may have suggestions of local places that carry wigs, scarves, and other accessories.

Coping with hair loss is different for everyone. Many patients try to think of it as a sign that the treatment is working. Adjusting to your wig or to scarves or hats may take some time. Just like many other aspects of transplant, everyone adapts at their own pace. Other patients and members of your transplant team, including the social worker, nurse, and psychologist, will have additional suggestions for coping and helping you locate resources in your area.

Fertility Considerations

Though it may feel

uncomfortable or awkward, fertility is an important topic to discuss before your transplant. You should discuss the issue thoroughly with your transplant coordinator or doctor, who may also refer you to a fertility counselor. This is especially important if your future plans include having a family. It can also be helpful to talk about fertility with your significant other. Parents of teens undergoing transplant will want to have an open and honest discussion with them regarding future fertility; the medical team can help lead this discussion.

High doses of chemotherapy or radiation therapy used in transplants may – but don't always – cause infertility by damaging reproductive cells. The ability to engage in sexual activity may not be affected. How you are affected depends on the medications used and their dosages, as well as your age and general health. Ask your transplant coordinator or doctor if this is likely to be an issue with your particular conditioning regimen.

In women, chemotherapy or radiation therapy may damage the ovaries and reduce the

amount of hormones they produce, which can cause menstrual periods to become irregular or stop. This may be temporary and does not necessarily lead to infertility. If your healthcare team feels these effects may be permanent, collecting and “freezing”, or cryopreserving, embryos may be an option for women concerned about infertility. Women may also experience hot flashes and other menopause-like symptoms such as vaginal itching, burning, or dryness. These symptoms can be relieved by using a water-based lubricant (oil-based lubricants may increase the risk of vaginal infections and should be avoided).

In men, total body irradiation and chemotherapy may reduce the number of sperm or their ability to move, or may cause other changes that can result in temporary or permanent infertility or erectile dysfunction. Men who are facing the possibility of infertility after transplant may want to consider sperm banking, a method whereby several sperm samples are collected, frozen, and stored for use later in fertilizing an egg.

Sperm and embryo donation and adoption are other possibilities open to couples who want to have families following transplantation. Clearly understanding your options before transplant and pre-planning may help decrease the stress associated with the conditions above if they should occur.

Pre-Transplant Evaluations

Before the actual transplantation or the conditioning regimen, you will need to undergo a series of tests and evaluations to assess your general health. The treatments will examine every system of your body, so it's necessary to understand your overall medical condition and the functioning of your primary organs (heart, lungs, kidneys, liver). Tests are usually done over the course of a few days prior to your admission to the transplant center; your transplant coordinator will make these arrangements with you.

What tests you need will depend on your condition, previous tests you have had, and the type of therapy you will receive. A complete medical

history, a physical examination, and several blood tests will probably be necessary. Other tests may include:

- X-rays, pulmonary-function tests, or arterial blood gas analysis to check lung function;
- Heart-function tests, such as electrocardiogram (EKG) or echocardiogram;
- CT scan, PET scan, and bone marrow biopsy;
- A complete dental examination to help prevent mouth infections post-transplant.

Once the results of your pre-transplant tests are back, your doctors will work with you to finalize plans for your hospitalization and conditioning regimen.

The Hospital Environment

Being admitted to the hospital for your transplant can bring both feelings of relief at reaching a milestone and stress at what is to come. Prior to your admission, you should have the schedule for your preparative conditioning,

HOME AWAY FROM HOME

Making your hospital room as comfortable as possible may make it a little easier to cope. Most transplant centers will let you bring your own clothes and other personal belongings into your room. There may be some restrictions, and/or a special cleaning or sterilizing may be required for some items. Talk to your transplant coordinator in advance about what is allowed. Some things you might consider bringing may include:

- Pictures of family, friends, and/or pets
- Hats, scarves, turbans, or wigs to keep your head warm
- Several pairs of comfortable pajamas or lounging clothes (front-buttoning tops are best)
- Slippers
- Several pairs of warm, comfortable socks
- Sneakers or comfortable shoes for walking around the unit
- An iPod, MP3 player, tablet, or computer
- Books or magazines
- Stationery, a journal, and pens if you like to write
- Address book and phone numbers
- Activities such as knitting, needlepoint, puzzles, games, movies, or drawing

Some days your hospital room may feel like a bus terminal at rush hour: Dozens of healthcare team members may be in and out of your room at all times of the day and night. Routine blood tests will be taken daily, and vital signs (blood pressure,

temperature, and pulse) will be taken every few hours. You may be kept quite busy interacting with the many members of your transplant team.

You will find that there are times when you are alone in your room. You may welcome this time to

yourself, or you may long for companionship. Once you know your daily schedule, you can use this quiet time to rest and catch your breath or ask guests to visit to keep you company.

Central Venous Catheter

As part of the pre-transplant preparation, you will need to have a central venous catheter – sometimes called a Hickman or Broviac catheter. This “central line” is a thin, flexible tube that is surgically inserted into one of the large veins that leads to your heart. It will look like a bump under your skin, and will have two or three ports, called lumens, on the end. Your central venous catheter will serve many functions. It will be used to draw blood for the tests you will need, and to deliver blood products, medications, and fluids directly to your bloodstream. When it's time for your transplant, the replacement stem cells will be given through this central line. It is likely that you will need to keep the catheter in place for several months, even after you leave the hospital. The nurses will give you specific

instructions for keeping it clean and preventing infection.

Conditioning or Preparative Regimen

Conditioning has two primary goals: to destroy the diseased cells in your body and to suppress your immune system so that your body doesn't reject the transplanted cells (graft rejection in the allogeneic transplant). Preparative conditioning also destroys your healthy bone marrow cells; this makes space for the transplanted cells to live, grow, and reproduce. Conditioning is usually done after you're admitted to the transplant center, but in some cases it may begin before.

Conditioning usually includes high-dose chemotherapy, with or without radiation therapy (RT). The schedule for treatments and the specific medications used will depend upon your treatment center and will be tailored to your case.

Chemotherapy and Radiation Therapy

Chemotherapy is a general term used to describe some cancer treatments. A number

of different drugs may be used depending on your disease and other factors. Your doctor will tell you about the specific medications you'll be given. Most chemotherapy drugs are given through an IV, through your central venous catheter. Some may also be given orally (by mouth).

If radiation therapy is a part of your treatment, it may be applied either to your whole body (called total body irradiation or TBI) or only to the affected areas. If TBI is used, it may be given all in one dose, or over several days. Smaller doses given over several hours or days may minimize side effects. A nurse or radiation technician will make pinpoint ink marks on your skin (tattoos), which may or may not be permanent, to indicate where the radiation will be given.

Side Effects of Preparative Conditioning

Most people have an idea of what chemotherapy and radiation treatments do to your body. Keep in mind that everyone is different. Some are mildly affected, some severely. Most people

probably fall somewhere in the middle. You may have some, all, or none of these effects. There may be other effects that you will experience that are not mentioned here. Your healthcare team is the best source of information about the potential side effects of your treatment, and how these effects are best managed. It's important to share how you are feeling with your team so they can help you manage side effects as much as possible.

It is believed that the side effects of chemotherapy and radiation therapy are related to their methods of action against disease, which is to kill rapidly dividing cells (including cancer cells). In addition to the diseased cells that are the target of therapy, cells in the hair, skin, gastrointestinal tract, and reproductive organs that normally divide rapidly can be damaged, which is why these areas are most often also affected. A combination of close monitoring to catch problems quickly and side effect management can help.

Following is a general overview of side effects that may result from chemotherapy or radiation

treatment. Ask your transplant team to provide additional details, including information about how to manage side effects, that is most relevant to you.

Temporary side effects that may affect you acutely (within hours or days of your treatment) are listed below. Longer-term effects are discussed beginning on page 28.

- Nausea and vomiting
- Diarrhea or constipation
- Temporary hair loss, or alopecia
- Fatigue
- Appetite changes
- Mouth sores
- Skin reactions

There are other side effects associated with high-dose chemotherapy and radiation therapy that may not be apparent for weeks, months, or years. Some of the medications used to treat side effects may themselves have side effects, making managing your side effects a delicate balancing act that requires monitoring and adjustments.

Being an active, vocal partner in your care is critical to controlling and managing side effects. Only you can tell when something is bothering you. Communicate with your transplant team. Tell them of any problems you may be having, or if something does not seem right, even if it seems minor. Don't suffer in silence; your team is there to help.

Controlling Infections

Chemotherapy or radiation treatment severely compromises your immune system, so preventing infection is a top priority until your immune system recovers. Infection-control procedures vary, but may include staying in a special "clean room" designed to remain as germ-free as possible. The room may have specialized air-handling systems to prevent germs from entering, and there will likely be restrictions on the items you can bring into the room or the visitors you can have. Guests who do visit may need to wear masks to cover their mouths and nose as well as gloves, gowns, and foot coverings. Your transplant center will also share specific food guidelines they want you to follow during

transplant while your immune system is compromised. It is important to prevent bacteria and other germs that can commonly be found in some types of food. (See the

Nutrition & Transplant section of this book for more detailed information). Your transplant team will review all precautions with you in detail.

Transplant Day: A Second Birth

Once your diseased cells have been destroyed, along with your bone marrow, it is time for the transplant, which is also called

the “rescue.” Your transplant will probably be scheduled within a few days of the completion of your conditioning regimen. If

T-CELL DEPLETION

Depending on the circumstances of your case and the medical treatment plan that your transplant center uses, donated marrow may be specially treated to eliminate immune-system cells called T-lymphocytes, a process known as T-cell depletion. T-lymphocytes are special white blood cells whose function is to attack invading organisms. They are the cells responsible for the initiation of GVHD. T-cell-depletion appears to reduce the risk of severe GVHD and may be especially useful – even medically

necessary – if there is an HLA mismatch between donor and recipient. However, some studies indicate that T-cell depletion also increases the risk of graft failure (when donated bone marrow does not produce blood cells for some reason) and may increase the chance of relapse in people with certain types of cancer. The relative risks and benefits of T-cell depletion continue to be studied, and not all hospitals take this approach in all cases. Your health care team will tell you more.

it was not done already, your donor's bone marrow or peripheral blood stem cells will be harvested. The donated stem cells will be infused through your central venous catheter from an IV bag or using a large syringe. The process is usually short, taking only an hour or two, and usually simple. Some people experience mild nausea. There may be a strong smell that resembles rotten eggs if the donated bone marrow has been stored; this is

due to the preservatives used in the storing process.

Almost immediately, the new cells will travel through your bloodstream and into your bone marrow. Once in your bone marrow, they begin their job of making new blood cells and rebuilding your immune system. This day is sometimes referred to as "Day 0," the day that starts the post-transplant count. Many survivors consider it their second birthday.

Post-Transplant & Beyond

Engraftment

You've reached a critical landmark – the transplant of the cells that will rebuild your blood and immune system. Now, a period of watchful waiting begins. At this point, it's up to your new stem cells to reproduce all the white blood cells, red blood cells, and platelets your body needs, a process called engraftment.

Engraftment is said to occur when new white blood cells are detected in your bloodstream. This is an indication that your body is able to begin fighting infection (the job of white blood cells), to clot your blood (the role of platelets), and to carry oxygen throughout the body (a function of red blood cells). The timing of engraftment usually occurs within two to four weeks, but it may take up to a few months in cord blood transplants. Complete recovery

of your immune system will take much longer, up to one to two years. Blood will be taken daily to assess and track your blood cell levels, and your vital signs will continue to be checked frequently.

During the period when your new stem cells are rebuilding your blood cell supplies, you'll be at heightened risk for bleeding, infections, and fatigue. To reduce your risk of infection, you may need to stay in an isolated room that is specially cleaned and sanitized, and there may be restrictions on visitors. The skin and mouth are common sites for infection, so pay close attention to personal and dental hygiene. Your transplant team will give you specific instructions aimed at preventing infections. Follow these instructions carefully, and be sure to report any issues such as pain, swelling, unusual

sensitivity, or skin changes promptly to your nurses.

Sometimes, there are complications related to transplant. The details below are an overview; your health care team will be able to share additional information specific to you. Side effects related to chemotherapy and radiation treatments may be a result of the immunosuppression these therapies induce, or they can be due to side effects of drugs used to manage other complications. Remember, your entire transplant team will be focused on preventing and managing these potential complications. You are critical in this process. It's more important than ever that you clearly communicate any changes in your health or any concerns you may have. Keep in mind that there are a number of things your health care team can do to prevent, manage, and treat these potential complications.

Possible Complications

Infections

Infectious pathogens will be

your enemy for several months. The best course is prevention: Special precautions will be taken to protect you from being exposed to viruses, bacteria, and infections. There are some types of bacteria and viruses that may not cause an infection in a healthy person but may affect a person with decreased ability to fight infection (called an opportunistic infection). Medications typically used to treat infections, such as antibiotics and antifungal and antiviral agents, may be used as a deterrent before infection occurs.

Mucositis

Swelling and redness in the mouth and gastrointestinal tract is common following transplant. Pre-existing viral infections that may have gone dormant (asleep), such as herpes simplex (cold sores; genital herpes), may be reactivated.

Graft vs. Host Disease (GVHD)

GVHD only occurs in allogeneic transplants.

GVHD, a serious side effect, occurs when specialized white

blood cells in the donated stem cells (the graft) identify your cells (the host) as “foreign” and launch an attack, just as your immune system would normally attack infection. Close matching of HLA types between donor and recipient is the most important factor influencing the development of GVHD: Better matches reduce the risk. However, even with a perfect HLA match, the risk of GVHD is significant. The recipient's age, and whether the donor and recipient are the same sex, can also be factors.

There are two types of GVHD:

Acute GVHD generally develops within three months of transplantation, and often right away. Symptoms are skin rashes, jaundice (yellowing of the skin), liver disease (determined by blood tests), and diarrhea.

Chronic GVHD can occur up to three years post-transplant, and is more common in people who have had acute GVHD. Possible symptoms include temporary darkening of the skin, patches where the skin and underlying tissue are hardened, gastrointestinal tract

complications (especially in the liver and esophagus), dry mouth or nose, hair loss, and difficulty breathing.

Strategies have been developed to help prevent GVHD, including removing T-lymphocytes from donated marrow or PBSCs, and using medications post-transplant to suppress T-cell activity. Your transplant team will have a standard protocol for preventing and dealing with GVHD and can discuss the plan with you.

Recent studies have shown that mild cases of GVHD seem to have a beneficial effect in the treatment of leukemia and lymphoma. In these conditions, the rate of cancer relapse is lower in transplant survivors who had mild GVHD. This is called the “Graft vs. Leukemia” (GVL) effect, in which the grafted T-cells also attack any residual cancer cells. Experts continue to study how to maximize this effect without increasing risk to the patient. In syngeneic transplants (transplants from an identical twin), the risk of GVHD is greatly reduced, as is the chance of benefiting from a GVL effect.

Bleeding

You may be highly susceptible to bleeding as a result of low platelet levels, the blood cells that enable your blood to clot. The mucous membranes of the mouth, nose, skin, and gastrointestinal tract are most commonly affected. You may need to receive transfusions of platelets if your count falls too low or if you experience excessive bleeding.

Graft Failure

Graft failure is complicated. It occurs when bone marrow function doesn't return, or is lost after a period of return. It may result from graft rejection, when the recipient's immune system rejects the transplanted cells, or when the donated bone marrow fails to produce new blood cells. The reasons for graft failure are not always known. Factors that may increase the risk include HLA mismatch, not having Total Body Irradiation, receiving bone marrow or peripheral blood stem cells that have been depleted of T-cells, viral illness, use of immunosuppressive drugs, and pre-existing marrow fibrosis (a disorder of the bone marrow).

Continuing improvements in transplant science have made graft failure increasingly rare. Pre-transplant preparative regimens that destroy your existing marrow and heavily suppress your immune system are generally sufficient to avoid graft rejection. In the unlikely event that the graft fails or is delayed for any reason, your doctors will discuss with you the medical options, which may include another transplant.

Organ Complications

While rare, serious complications may occur in the liver, lung, heart, or kidneys of some transplant patients. People with pre-existing conditions that affect these organs are at increased risk, which is why organ function is carefully assessed in pre-transplant evaluations and carefully watched throughout transplant and after. Here are ways some organs may be affected and some preventative measures.

Liver: The liver can be damaged by chemotherapy and sometimes by the transplant itself. Side effects of liver damage can include digestive

problems and/or build-up of toxic substances.

Kidneys: Pre-transplant regimens may cause temporary kidney failure, which causes waste products to build up in the blood and increases the risk of infections, bleeding, and drug side effects.

Lungs: Pre-transplant radiation therapy may cause temporary or permanent damage to the lungs; shields placed over the lungs during treatment may help prevent these problems. Lack of movement can also allow fluid and bacteria to settle in the lungs. Exercising your lungs through deep breathing and “spirometry” (a small hose attached to a tube with a ball - blowing in the tube makes the ball rise) may help keep your lungs clear.

Heart: Certain chemotherapy drugs may have serious side effects that damage the heart. Your heart function will be carefully monitored throughout the transplant process.

Secondary Cancers

People who have had transplants are at increased risk of developing a secondary

cancer, sometimes long after the transplant, which may be a result of the conditioning regimen or could be due to separate, pre-existing cancerous cells. Transplant scientists are investigating what preventative measures might be useful in reducing the risk of these complications. Talk to your doctor about the long-term risk profiles of your particular treatment and what (if anything) you can do to prepare for or prevent complications down the road.

Discharge Day

Discharge from the hospital depends on many factors including blood counts, the length of the preparative regimen, side effects, reaction to the transplant, and whether you received growth factors. You may experience conflicting emotions when it's finally time for you to leave the hospital. The relief of finally getting out may be offset by the realization that round-the-clock medical care is ending, which may cause anxiety. All these feelings are common.

Follow-Up Medical Care

Even though your transplant is officially over, your medical recovery is not. It may take several months for your blood cells to be regenerated to normal levels, and up to two years before your immune system is fully functional. Until then, you will continue to be at increased risk for infection, bleeding, and fatigue (depending on your blood cell counts). This risk will decrease as your counts come up.

The nature of your follow-up care will depend on many factors, but you will most likely need to return to the hospital for frequent outpatient visits in the weeks and months following your discharge. Appointments will probably be weekly or bi-weekly for a few months. If you don't live near the transplant center, you and your caregiver will need to arrange for lodging in the area. (Your transplant coordinator can help with this). The hospital will provide you with specific instructions for your daily follow-up care, including your appointment schedule, any medications you will take, and information

THE RUSH TO READAPT

Your reintegration into life outside the hospital is a big step. Adaptation can be a long process. Your body has been through a major ordeal, and your immune defenses are down. Although you may be eager to resume the family and work roles that you left behind, you may find it is a long process to get back to your usual routine. It will take time, as well as patience and understanding with yourself and others, to successfully negotiate this last part of treatment.

on preventing infections and keeping your central line clean.

You may also need continuing care for any of the following, specific health conditions:

- **Long-term effects of preparative regimens**, such as cataracts, infertility, secondary cancer or, in children, growth problems

TIPS FOR AVOIDING INFECTION

You will be at increased risk of infection until your immune system recovers its full function, so taking precautions to avoid infection will be important.

- Wash your hands often and thoroughly, with soap and warm water. Your healthcare team can suggest special soaps you should use.
- Ask your healthcare team how often you should take hot baths or showers.
- Have sheets and towels laundered frequently in hot water and detergent.
- Avoid crowds.
- Avoid people who are sick.
- Avoid touching handrails and doorknobs (wear gloves or use a handkerchief).
- Talk to your transplant team for instructions on living with pets post-transplant.
- Plants may harbor infectious agents; you may want to move them to someone else's home until your immune system has recovered.
- Do not swim in public pools, lakes, or oceans.
- Have someone else do the housecleaning, especially chores like cleaning toilets and floors or vacuuming (rugs can harbor mold and other infectious agents).

(see discussion on page 28);

- **Severe fatigue**, which may require treatment with medication or red blood cell transfusions (see "Managing Fatigue" on page 35);
- **Chronic GVHD**, which may affect the skin, liver, digestive

tract, or other organs

- **Long-term effects of medications used to treat transplant complications** (for example, corticosteroids, which are sometimes used to treat or prevent GVHD, may cause weakened joints and bones).

Exercise & Nutrition

Just as exercise and nutrition were critical while getting ready for transplant, they are very important after. Your exercise program will begin before you leave the hospital. In fact, it will begin while you are in bed. Physical and respiratory therapists will work with you to keep your lungs and muscles from getting weak. They will teach you exercises you can do lying in bed. As you begin to get stronger, you can walk with your IV pole and do "laps" around

your room and eventually the unit. Some transplant units will also have exercise equipment available.

Once you are home, it is important to remember that it will take some time to build up to your old routine. Again, everyone is different. Setting goals may help. For example, if walking to the mailbox one day is a milestone, try setting the goal of walking to the corner a few days later. Your physical therapist can help you create a plan to build up your strength and a new

WHEN TO CALL THE DOCTOR

Knowing when to call a doctor can help you avoid serious complications once you've left the hospital. When in doubt, it is always better to call your healthcare team. Here are some signs that demand immediate attention by your medical team:

- Fever of 100.5 degrees or higher
- Coughing, sneezing, or runny nose
- Pain, swelling, or redness anywhere
- Blisters such as cold sores in your mouth or elsewhere
- Blood in urine or stool
- Burning sensation or pain during urination, or discolored urine
- Bleeding of any sort, such as in the gums or nose, as well as excessive menstrual bleeding
- Any other unexplained pain or physical problems

routine for daily activities and exercise. Listen to your body and take your clues from your energy level and your strength. Do not begin a new or rigorous exercise program without the consent of your doctor.

Nutrition goes hand in hand with exercise. You will not have energy to exercise if you are not eating properly. While you may have some dietary rules, your transplant team dietitian will help you create an eating plan to make sure you are getting the nutrition and calories you need. Many patients find that it takes some time for their appetite to return to normal. A variety of foods, flavors, and textures can help stimulate the appetite. See the section entitled Dietary & Nutritional Considerations in this handbook for additional information and helpful tips on managing nutrition and nutrition-related side effects.

Managing Fatigue

Fatigue is a common result of chemotherapy and radiation. It can vary from minor to severe, and usually results from anemia, a condition caused by low

TALKING ABOUT FOOD

As you begin to get back to regular eating, it may be a good time to talk about food with your care team. Some of these restrictions you may be aware of and some may be a surprise. Here are some questions to get you started.

- When can I start eating out at restaurants?
- When is take-out an option?
- Can I eat food cooked by friends and family?
- Is it safe to take vitamins and herbal remedies?
- Are there special precautions for the type of water I can drink?
- What things must I be sure to avoid?
- When can alcohol (beer, wine, and spirits) be safely reintroduced?

levels of red blood cells. (Red blood cells carry hemoglobin, a protein that delivers oxygen

to cells, which cells use for energy). Anemia can be treated with medications or with transfusions of red blood cells.

Managing fatigue requires that you pay careful attention to your energy levels at various times of the day, so that you can schedule your activities around the times you have the most energy. Following are some other tips for managing fatigue.

Prioritize activities: Decide which activities are most important each day.

Conserve your energy for the things you really need or want to do.

Don't overdo it. On days you feel well you might be tempted to power ahead. Pacing is important. Listen to the cues your body is giving you, and don't overtire yourself.

Take breaks if you're getting tired, even if you're out doing something. Take naps during the day to recharge (but not too close to bedtime, as this may disrupt sleep).

Use relaxation therapy, yoga, or other strategies to quiet your body and your mind. Get

a massage, take a hot bath, or pamper yourself in some special way.

Talk with your healthcare team about causes and solutions for your fatigue.

Beyond Transplant

Conquering the transplant treatment process is a monumental achievement. The process can be overwhelming, even for the world's best "coper". Keeping a positive attitude and staying focused on your goal of getting better is critical, even though it may be difficult at times. Be an active part of your care, and work with your healthcare team to reach your goal.

Many survivors say they come out of the transplant ordeal "changed" for the better: emotionally stronger, with greater self-esteem and deeper relationships with loved ones. Some survivors also mention a greater appreciation for life and a heightened sense of spirituality. Your case, and your situation, is unique.

Remember, you're not alone. There are lots of people who

have been through transplant and many resources that can help you on your journey.

Coping & Emotional Support

Transplant, related treatment, and recovery can be an emotional time. Many people undergoing transplant experience a wide range of feelings. It is just as important to take care of your emotional well-being as it is your physical health.

A number of factors related to the transplant process may impact your emotional health, including interruptions in the tasks of living (e.g., giving up your usual family roles, or putting work or school on hold), an extended hospital stay, expectations about the speed of a return to “normal”, or clinical conditions such as depression or feelings of sadness, which are common during illness and recovery.

A growing body of science indicates such psychosocial factors play an important role in recovery from transplant and long-term re-adaptation

CARELINES TASK PLANNER

The Bone Marrow Foundation's Carelines Task Planner provides a simple and effective way for patients to keep track of appointments and organize support from their community members. Patients and/or caregivers can reach out for help with day-to-day tasks such as meal preparation, child and pet care, transportation to appointments, and other errands. Supportive community members can easily utilize the calendar to volunteer for specific tasks, allowing the patient to focus on getting better.

to life. By understanding what some of the issues might be and learning strategies for managing them, you and your healthcare team may be better equipped to prevent them from interfering with your treatment. Taking positive actions to preserve your emotional well-being may also reduce

the stress you're under and make it easier to cope with your disease. Positive steps might include joining a support group, learning problem-solving skills for treatment of side effects (e.g., managing nausea or fatigue), using stress-management techniques such as deep breathing or meditation, or seeking psychological counseling. While others may have experiences very similar to yours, exactly what you experience and how you will cope are unique to you.

Often family and friends may feel unsure as to how best they can help you. If you want or need help, don't be shy in asking for it. Being specific in your request (fold laundry, prepare some meals, sit and talk) means you get help and family and friends will feel that they are able to help you with what you need. There are also times when "help" doesn't feel helpful, and you should feel comfortable saying that you need some down time too.

Children & Transplants: A Guide for Parents

Bone marrow and stem cell transplants can be overwhelming experiences. This can be even harder when the person receiving the transplant is a child. Naturally parents, children, and siblings may have many questions. This section provides information related to some of the more common questions parents ask. Additional information on most of these topics (such as preparation, returning home, nutrition) can also be found in other sections of the book.

What to Share, When to Share It

In some ways, sharing facts and details about transplant are not unlike other conversations you have with your child. You may find the perfect time for

the dialogue, or it may come up when you least expect it. Each child is different and each transplant journey is different; how much you share with your child depends on many factors including the child's age and level of understanding. Try to provide a basic overview of any tests, procedures, and side effects before they occur. The same is true for preparing a child for events such as hair loss and insertion of a central venous catheter (also called a central line). Your team can offer suggestions about explaining these events and ways to make them less traumatic— such as a tour of the transplant unit, books, and other special materials such as dolls.

The most important thing is to make sure communication lines are open and that your answers to any questions, while

age appropriate, are honest. Children need to feel that it's okay for them to ask any question, even if it's scary. They also need to know the answers they receive will be honest. While this may be difficult, especially if something is scary or painful, not being honest can cause mistrust, fear, and anxiety. It may also be helpful to reinforce that you and your child (and family members, friends, and even the health care professionals) are a team and they are not alone. These thoughts are also helpful in talking to a child who has a family member going through transplant.

Explaining Transplant to a Child

There are many wonderful resources (both written and video) for explaining the transplant process to a child. (Please see Resources at the end of this book.) Your transplant team—including your doctor, nurse, social worker, child life specialist, and other team members—can help explain transplant. It is important to involve your child

in discussions about transplant and to encourage him or her to ask questions of both you and the transplant team. Start with a simple description of the basics. For example,

“A transplant is to get all of the bad cells (or cancer cells, depending on what words you have been using) out of your body so you can feel better and play with your friends, go to school, and go back to your favorite activities. To do this, the doctor will give you a strong medicine (called chemotherapy or/and radiation). The medicine is able to find the bad cancer cells, but it can also hurt some of the good cells in your body. After the strong medicine, you will get some new, healthy blood cells that will come to the rescue and help the good cells grow and get stronger.”

Superhero imagery is often used, with cancer being the villain and the donor stem cells being the heroes. You can add some of the important precautions that will happen

after transplant including being extra careful to keep away germs (special handwashing and tooth brushing), staying away from others for a period of time, wearing a mask, and eating good foods. You may also want to share some of the side effects of treatment with your child; some children do better if they know they might feel sick and other children may not want or need this information until it happens. "The strong medicine may make you feel sick (your tummy may hurt) or tired. If you don't feel well, the doctor can give you other medicine that can help." For all children, the key points are to stress they will not be alone during or after treatment and transplant and that they should always ask any questions they might have.

Talking to Teens

Many of the same principles recommended for talking to children also apply to teens; honesty and creating open lines of communication are critical. Teens, like children, will be concerned with disruption of their usual schedule, school, and social life. It is important to

remember that both children and teens have very little control over treatment and transplant; it is especially important to include them in conversations and give them options and control in situations where it is possible (for example, what to wear, when to have visitors, when to have some alone time, asking questions of the transplant team privately). Social interaction will be especially important to this age group; talk with your teen about ways he or she may want to connect with friends and classmates during transplant (Skype, video chat, blogs, or websites such as Carelines). As body image can be an issue, some teens prefer blogs to live video so they can edit photos to help them feel more comfortable. Another helpful tool for teens is having a daily schedule. Seek their input on wake times, bathing, activities, school, work, and downtime. While some activities may have a set time (such as taking medication), allowing input on those activities that are more flexible is a good way to offer a degree of control.

In addition, teens may think about what living with cancer

and having a bone marrow/stem cell transplant means to their future (including relationships, sexuality, and fertility). Your transplant team can be very helpful in these conversations and in answering delicate or uncomfortable questions. It is imperative that your teen have at least one point person with whom he or she feels comfortable speaking openly.

Helping Siblings Cope with Transplant

Transplantation impacts everyone in the family; this is especially true for siblings. Simply acknowledging that this impacts the whole family, including them, is a good starting point. Treatment brings changes to normal family routines, which can be difficult for everyone. It can also bring about many emotional reactions including withdrawing, acting out, sadness, and feelings of jealousy, guilt, or responsibility. Honesty and good conversations among all family members are very important to recognizing and coping. It can be helpful if

parents share their feelings so a child knows they are not alone: "Mommy and Daddy don't like being away from home" or "It's okay if you feel sad, sometimes I feel that way too. We can figure it out together." Siblings (or children of parents undergoing transplant) may also need extra support to understand that they are in no way responsible for the illness, and that they can't "catch" it.

Try to work together to create new routines (such as a phone call or FaceTime before bed, letter writing, picture exchanges) for staying in touch with each other during hospitalization. Include all the children in creating this plan. Many children also want to be helpful while they are at home, so brainstorm things they can do to help around the house. Although routines will be interrupted, it is important to try to keep some things normal including school, meals, and time with friends, if possible.

Reach out to other people who can lend support, both physical and emotional. Extended family, adult friends, and neighbors can all help with practical day to day needs (rides, homework, meals,

helping a child video connect with family in the hospital), provide extra attention, or be there for a hug or emotional support. Using a planner tool (such as the one available through Carelines) can help organize this type of support. Teachers, guidance counselors, and other school personnel are invaluable to include in the loop for information and for a little extra support. Often children exhibit different behaviors at school (oversensitivity, tiredness, inability to focus); it is especially helpful for teachers and support staff to know what is happening in the family so they can offer support.

Most children can also benefit from learning and practicing new coping skills. Mindfulness, meditation, relaxation, deep breathing, drawing, writing, journaling, and other coping skills are great for children and adults alike. They can be practiced alone or as a family. Sometimes it is helpful to have prompts such as "Choose a song that makes you feel happy to listen to each morning" or "Draw a picture of something that worried you today". There are many excellent resources online (both videos and books)

that can be used to learn and practice these coping techniques. The transplant center and your child's school can also be valuable resources for this type of support.

Talking with a Sibling Donor

Children may experience many different feelings if they are their sibling's donor. Many children are excited to help but also feel worried about the procedure itself. Research has shown that this anxiety can be reduced if the child has good preparation for the donation, including seeing where it will happen, understanding the steps, working with a doll to demonstrate the procedure, etc. The transplant team should be able to help with this preparation. It is important to answer all questions honestly and to encourage the child to express his/her feelings. Occasionally, a child may express reluctance to serve as the donor because he or she is afraid. It is important to listen carefully, acknowledge these feelings, and involve members of the transplant team in these

conversations. It is also very important to recap after the donation; help the child to talk about what he/she felt, saw, etc. Drawing, journaling, and video recording can all be useful tools during this process.

Most children quickly recover from the physical aspects of donation, though some have lingering questions or fears after the procedure. Even after a successful transplant, a child may feel a mix of emotions – excited that they were able to help their sibling and concerned if their sibling is not feeling well or responding to the transplant. Sibling donors need to know what to expect after the transplant (for example, it may take several weeks for their sibling to look and feel like they are getting better). It is important that the donor child know that while they play an important role in the transplant, the outcome is dependent on many factors. It can take weeks or months for a sibling donor to work through the emotions related to donation and being the donor, and he or she will need ongoing emotional support during this time. Again, it is important to involve the transplant team in these

conversations. Hearing the same information from doctors, nurses, and social workers that they hear from parents can be reassuring. The team will also have access to other resources that may be helpful.

Managing Your Own Emotions

“An empty well gives no water,” according to an ancient proverb. Managing difficult situations that impact the whole family is similar to advice given out on airplanes—the adult should put on their own oxygen mask before they put one on their child. Children know when adults in their life are worried or stressed. It is fine to be honest: “Mommy is feeling sad today,” or “Daddy is a little more worried than usual.” But follow that up with a plan. “Do you ever feel that way? What kinds of things do you do to help yourself feel better?” You can even offer your own plan: “Sometimes when Mommy feels this way, she takes some deep breaths (or listens to music or stretches).” And then, follow your advice! As a caregiver and main support person for your child, you need

to take breaks sometimes, too. Not only is this okay, but it is critical because you won't be able to take care of your child if you don't first take care of yourself. Similar to children, adults can benefit from learning new coping techniques. These include mindfulness practices, meditation, yoga, deep breathing, and journaling. If none of your new or usual coping strategies are working, it may be time to recruit a transplant team member who can help you get some extra emotional support.

Easing the Hospital Transition

The hospital room will really be "home" for a few weeks. Transplant centers at children's hospitals are generally very open and welcome some room decorating. Before talking to your child about what things he or she may want to bring from home, be sure to check what types of things may not be allowed. Brainstorm with your child about:

- Favorite comfort objects (pillows, blankets, and some stuffed animals [Note: these

may need to be specially cleaned before being allowed in the room.])

- Ways he or she may want to individualize the room (pictures, drawings, approved things from home)
- Fun and engaging games or activities (crafts, blocks) that will keep your child busy during the weeks of isolation
- Movies, music, iPads with games and other quiet time activities
- Comfortable clothing (pajamas, sweats)

(Please see the sidebar "Home Away from Home" on page 20 for additional suggestions)

Finding a Routine

Routine is more important than ever in the hospital. Structure helps your child know what to expect (though obviously you will be unable to plan some medical events) throughout the day. Here are some suggestions:

- Use a whiteboard or poster board to write out a daily "schedule" (wake up, breakfast, therapy, fun

time, Skype with family or classmates)

- Be flexible on days when your child may need extra rest or may not feel able to keep up with the routine. Try not to be frustrated or upset by this; even at home we sometimes need a day off.
- Schedule time for schoolwork or even to Skype or video chat with teachers and classmates. The transplant center may also have teachers available to help with school work.
- Encourage the child to express emotions in healthy ways, such as drawing, writing, or building something. Some children make this an ongoing project by creating a journal, mural, or scrapbook that they can continue to add to during and after their transplant.

Taking Medication

Most children have taken medicine at some point in their life; some children are great about it and others need coaxing. Post-transplant, children and teens often have to take many medicines throughout the day. Having a

schedule written down can help keep medicine taking on track (Please see Managing Medications on page 60 for a sample blank schedule). There are also tools available to help with managing medications, including CareTracker from The Bone Marrow Foundation.

Tracking the medicine routine is one thing, but having children and teens actually participate in the process is another variable. Here are some suggestions for making taking medicine easier both during transplant and after.

Infants may suck medicine out of a bottle nipple or pacifier. Medicine can also be slowly squirted into the side of the cheek.

- Toddlers may enjoy role-playing giving medicine to their dolls or stuffed animals before taking it themselves. Help them “remind” their patient why it is important to take the medicine (“This will help you get better or make you stronger”) and that we only take medicine at certain times, when an adult will remind us.
- For toddlers and young children, mixing medication

into food or drink can help make taking it easier. Some children prefer to “do it themselves.” Offering options, especially to older toddlers and children, makes them part of the process (“Would you like to take this now or in five minutes?” “Do you want apple juice or milk after the medicine?”)

- Note: Some medicines cannot be mixed with food. Your transplant team will review all medications, their uses, and any special instructions.
- Toddlers and younger school-aged children may like their own medicine chart showing when they need to take their medicine and a sticker, smiley face, or check mark after a dose was successfully taken.
- School-aged children may want to know what each medicine is for and why they are taking it. Answering questions (even repeatedly) helps children understand the importance of the medicine and makes them part of the process.
- Teens can be active participants in taking medication, with increasing responsibility and some

independence. For example, teens may want to set text reminders for medication times and be able to self-administer (with adult supervision). Work with teens whenever possible to have their medicine schedule work around other commitments, such as school video conferencing or social visits.

Going Home

Going home is always an exciting day, but it can also feel a little scary. It is the beginning of life getting back to normal, but not quite the way it was before. Some people describe this as “a new normal.” It may take a little while to readjust to being home. Children may experience late effects of the transplant that can be physical, cognitive, and even emotional. It can take time to readjust. Remember, for a while outings and visitors will be limited to give your child's immune system time to strengthen. It's a good idea to talk to your child about a timeline for getting back to activities including school and sports.

Going Back to School

Many children transition back to school slowly. For example, a child may start going a few hours per day and work at increasing hours over a period of weeks or months. Children and teens may want to meet with teachers before going back and talk about any special concerns or requests they have (taking breaks, using the restroom, extra time on assignments). Parents may want to meet with teachers, nurses, or guidance counselors to discuss concerns or requests they have including education plans. Children, parents, and school staff can work together to create a plan that works for

everyone. Knowing the plan for returning to school and where to go if they are tired, need a break, or don't feel well can help ease first day jitters.

The child, a parent, and school team members may want to meet with classmates before the first day. Children and teens can role-play answers to common questions including, "how do you feel," "are you contagious," "why do you look different," and "will you get sick again?" Let children and teens decide if they would like to answer questions or have a parent or teacher answer them. Some children may want to be present for these questions and others might not.

Managing Nutrition

The Importance of Nutrition

Your nutritional needs, including calorie and protein intake, increase during transplant and recovery. In order to maintain not only weight, but also lean body mass, it is important to have enough calories, protein, and fluid intake throughout your treatment course. Side effects of treatment can also deplete vitamins and minerals. It is much easier to maintain weight and strength if you have good nutrition.

Working with a Registered Dietitian (RD), especially an RD who is a Board-Certified Specialist in Oncology (CSO), is recommended to ensure that you meet your nutrition goals. Ask your medical provider for a referral.

Eating Through Low Appetite

Whether you're going through conditioning-related side effects or dealing with post-transplant issues such as Graft vs. Host disease (GVHD) or enteritis, there can be many barriers to eating enough of the foods you need to maintain weight and strength. Appetite often goes up and down during the transplant process. Feeling full quickly is also a common side effect of treatment. These two side effects often prevent post-transplant patients from eating enough to meet calorie and protein goals. Eating enough may seem overwhelming, but there are many ways to increase your calories without feeling like you need to double portions at every meal. If your appetite is low or you are unable to eat usual portions at meals,

snacking between meals or eating smaller meals every two to three hours can help meet nutrition goals. It's also helpful to plan meals, snacks, and fluids that are "nutrient dense"; this means foods and fluids that contain a lot of calories and protein per bite or sip. For example, choosing peanut butter on toast will provide more nutrition than jelly on toast. A smoothie made with protein powder, whole milk-based yogurt, and fruit will provide more nutrition than drinking juice or water. Try to focus on healthy calorie and protein-dense foods and fluids when your appetite is low and you fill up quickly. Additional calorie-dense foods include avocado, coconut milk, olive oil, nuts/nut butters, seeds, dates, and eggs.

Managing Digestion Side Effects

Mucositis/Esophagitis

Side effects of chemotherapy and/or radiation can make it difficult to chew and swallow comfortably, making it difficult to eat. Try these tips:

Maintain regular mouth care with saline rinses as prescribed.

- Try soft, moist foods. Avoid hard textures and chew well to avoid swallowing large food mouthfuls, which can be painful.
- If chewing is painful, try smoothies, milkshakes, or blended soups.
- Room temperature and cold foods are often easier to eat than foods at hot temperatures.
- Avoid spicy and acidic flavors.
- Ask your medical provider for strategies to manage pain while eating.

Sometimes patients with mucositis and/or esophagitis will require IV nutrition, called total parenteral nutrition (TPN). Your care team will discuss this with you.

Taste changes

Taste is the number one reason we choose the foods we eat. Enjoying food improves our quality of life and well-being. Unfortunately, many post-transplant patients have some type of temporary or permanent taste and/or smell changes due

to a change in your taste buds caused by the medications used as part of the preparative regimen. It is difficult to enjoy eating when food does not taste or smell normal. Foods may taste like cardboard or metal; taste too sweet, salty, sour, or bitter; or have no taste at all. You may even dislike favorite foods. There are certain foods that may be preferred during cancer treatment, such as food with “umami” (see below). Taste often improves after the first 30-60 days post-HCT. Try these tips to improve food appeal:

- Try one or two new bites of food every day. Thinking about eating a bite can be easier than eating an entire plate of food. Often foods are crossed off the list when they don't taste “normal” and are not tried again for months. Trying foods regularly allows you to get a sense of what might taste good at different times.
- If you are sensitive to odors, try room temperature or cold foods.
- Umami describes savory, brothy or meaty flavors. Food such as mushrooms, fish, seafood, celery, spinach, soy or fish sauce, and tomato are

HEALTHY EATING AFTER TRANSPLANT

During and after transplant, it is especially important to eat foods that taste good and are good for you. Here are some suggestions for meals and snacks:

- Peanut/nut butter with fruit, bread, or crackers
- Fruit or vegetable smoothies
- Greek yogurt with fruit, jam, or peanut/nut butter
- Trail mix with dried fruit (factory packaged), nuts (factory packaged), and chocolate
- Hard cheese (pasteurized), fruit, and crackers
- Whole grain waffles or English muffins with peanut/nut butter, cream cheese, and jam
- Canned chickpeas in a salad, roasted or made into a dip/spread (bean dip or hummus)
- Oatmeal, quinoa, or roasted sweet potatoes

high in umami. Cooking these foods slowly (i.e.: simmering, making soups) or marinating increases their umami flavor.

Nausea

- Try small, frequent meals.
- Choose low-odor foods and fluids.
- Space apart foods and fluids to avoid feeling overfull.
- Ask your medical team for anti-nausea medications and use them as prescribed.

Diarrhea

Certain chemotherapies, total body irradiation, GVHD, CMV enteritis, and infections such as C. diff colitis are likely to cause diarrhea. Diarrhea is defined as having more than two loose or watery stools a day. Antibiotic treatment may also worsen diarrhea. Diarrhea can lead to poor appetite, fatigue, weakness, dehydration, and weight loss. It can also prevent your body from having the time to get the nutrients from foods and lead to dehydration.

What can you do?

- Eat a small, frequent meal pattern: Aim for five to six small meals or snacks a day.

- Drink plenty of fluids to avoid becoming dehydrated. Ask your team what your estimated daily fluid goal is and keep track of your fluid intake throughout the day.
- Diarrhea leaves your body depleted of electrolytes including sodium, potassium, calcium, and phosphorus. Include drinks other than water such as coconut water, chicken or vegetable broth, or electrolyte replacement drinks to replenish electrolytes.
- Include food sources of probiotics such as plain yogurt, kefir, and buttermilk. (For food safety reasons, these need to be pasteurized).
- Limit spicy, fatty, fried, and gas-forming foods (cauliflower, cabbage, onions, beans), caffeine and sugar alcohols (xylitol, sorbitol, etc.).
- Choose foods that are high in soluble vs. insoluble fiber: Insoluble fiber moves bulk through our stomach and intestines more quickly. Limit this type of fiber with diarrhea. Examples include seeds, skins of fruit, etc. Soluble fiber slows digestion by absorbing water in the intestines.

Increase this type of fiber with diarrhea. Examples include banana, sweet potato, cooked carrots, applesauce, and rice. Avoid foods that have more than two grams of fiber per serving while you have diarrhea. Once diarrhea resolves, you can slowly add fiber back into your diet.

- Sometimes people become lactose intolerant with intestinal inflammation caused by chemotherapy, radiation, GVHD, or infection. If you notice gas, bloating, and/or diarrhea within 30 to 60 minutes after eating dairy products, you may want to try a lactose-free diet. Some people can digest low-lactose foods such as cheese and yogurt, but have difficulty with high-lactose foods such as milk and ice cream.

Constipation

Certain medications such as pain medications and medicines that stops nausea (antiemetics) such as Zofran can cause constipation. Inactivity, limited fiber intake, and inadequate fluid intake all contribute to constipation.

What can you do?

- Increase fluid intake. Drink

WASHING FRUIT & VEGETABLES

It is very important to have good practices for keeping your food safe to eat post-transplant. Here are some basic rules:

- All fresh and frozen fruits and vegetables should be thoroughly washed under clean, running water. This includes produce that may be peeled (bananas, melons, oranges, etc.), and pre-washed, bagged produce (salad kits).
- Scrub produce that has a firm or rough skin or rind (cantaloupe, potatoes, avocados, etc.).
- Rinse leaves of leafy vegetables thoroughly (includes bagged lettuce).

regularly throughout the day and/or include food sources of fluids such as soups, broths, smoothies, etc.

- Increase exercise. Exercise

improves how food is digested and helps move food/stool through the digestive tract. Even a small amount of exercise helps!

- Increase food sources of fiber gradually.
- Many patients will require a bowel regimen to maintain regularity, especially while on pain medication. Ask your medical provider if this is indicated and take medications/supplements as prescribed.

Immunosuppressive medication-related side effects

Immunosuppressive medications impact nutrition. Here are important nutrition side effects to be aware of:

Tacrolimus/Cyclosporine:

Both of these medications decrease magnesium. It is nearly impossible to meet your magnesium needs from diet alone while on these medications. Oral magnesium can cause bloating and loose, paler, and more frequent stools. Not everyone can handle the same amount of oral magnesium. Often patients are started on IV magnesium and then slowly

transitioned to oral magnesium. Daily magnesium needs will decrease as tacrolimus or cyclosporine are tapered.

Prednisone: Prednisone is a catabolic steroid, which means it changes how your body digests food and uses energy. It is essential to be sure you have enough protein intake and exercise to prevent losing lean body mass. Prednisone can also cause bone loss, so it's recommended to maintain a daily intake of 1500 mg calcium and 1000 units vitamin D through diet, multivitamins, and/or supplements. Prednisone can also cause high blood sugar (glucose) in some patients. A first step in managing high glucose levels is to cut back on high-carbohydrate, non-nutritive foods and fluids such as juice, soda, chips, and candies. Often a change in diet alone is not enough to control sugar levels and patients will require insulin.

MMF/myfortic: Patients cannot take calcium within two hours of taking MMF or myfortic. It is helpful to know what times of the day calcium does not restrict food choices and plan calcium-containing foods around those hours.

A SMALL AMOUNT GOES A LONG WAY

Just small amounts of these high-calorie foods help boost good nutrition.

Food	Serving	Calories
Avocados	¼ medium	70
Butter	1 tablespoon	100
Coconut milk	½ cup	275
Cream cheese	2 tablespoons	100
Dates	¼ cup	120
Egg	1 egg	73
Flaxseed oil	1 tablespoon	120
Grapeseed oil	1 tablespoon	120
Grated cheese	2 tablespoons	60
Hummus	2 tablespoons	50
Mayonnaise	2 tablespoons	115
Nuts/seeds	2 tablespoons	100
Olive oil	2 tablespoons	240
Olives	5	50
Peanut butter	2 tablespoons	200
Pesto	2 tablespoons	100
Tahini	2 tablespoons	170

Caring & Caregivers

An important step in preparing for your transplant is choosing a caregiver (or two), an important part of your healthcare team.

This person (or people) is usually a family member or a close friend. Your caregiver(s) will be responsible for some of the medical, practical, and emotional support you need during your transplant. This person (or people) will be your support team once you are discharged. A good caregiver, in general, can maintain a positive attitude, calm demeanor, and

flexible approach, while also providing you with the support and encouragement you need.

Some of your caregiver's responsibilities will include:

Medical support

- Helping with any self-care activities you may need.
- Assisting with creating and sticking to a medication schedule.
- Talking with you and your healthcare team about any new symptoms you may have or changes in your condition.
- Calling for medical help in an emergency.

Practical support

- Keeping family members and friends up to date about your condition.

CARELINES AND SUPPORTLINE

The Foundation's Carelines and Supportline programs can be a great resource for caregivers as well as patients. Please see pages 62 and 63 for additional information.

- Managing the number of visitors you have and keeping you away from anyone who is sick.
- Helping you manage financial and insurance issues.
- Assisting with household tasks.
- Coordinating or assisting with transport to follow-up appointments.

Emotional support

- Offering support and encouragement.
- Listening and helping you communicate with friends and family.
- Understanding your needs and your decisions.

Caring for Caregivers

The caregiver role is challenging, and your caregiver may at times feel overwhelmed by the responsibilities and may experience financial, physical, and/or emotional distress. Though caregivers generally put other people first, it is important that your caregiver take breaks to catch his or her breath when possible. Self-care often comes last for

caregivers but without taking care of himself or herself, your caregiver won't be able to help you. Resources and support are available to help manage the multiple responsibilities that come with caring for a transplant patient. The social worker at your transplant center and social workers at The Bone Marrow Foundation can help you and your caregiver find resources.

Many caregivers report the most valuable resource they have is talking to other people who have been in the same place. It can be challenging to find time to attend support groups in person, though telephone and online support is also available. Many organizations including The Bone Marrow Foundation and Be The Match offer programs that match caregivers with peers who have been in similar situations.

A few things for caregivers to keep in mind:

- It is important to give yourself physical and emotional breaks. Take a walk, get some air, listen to music, have some tea, or read a book. Even a

few minutes of downtime can make a big difference in how you feel.

- You can't be cheerful 100% of the time. Often caregivers report feeling as though they have to be upbeat cheerleaders. Talk to friends or family, journal your thoughts, or seek out peer or professional support. It is important for you to have outlets to express your concern, fears, or frustrations.

- Caregivers can feel like part of the health care team. Once at home, caregivers are the first line of help if something doesn't seem quite right. This can feel like a lot of responsibility. Again, it is critical to take breaks and be sure you have support and back up for caregiving.

(Note there is additional information on caring for parent caregivers in the Children & Transplant section of this book).

Managing Medications

Transplantation requires a complex routine of medications during and after hospitalization. Carefully following your doctor's instructions about when and how to take your medications is critical, and can literally mean the difference between life and death.

The treatment regimen for a transplant often requires intravenous (IV) and/or oral medications, each of which may have different schedules and may have changing doses. The more complex the medication schedule, the more likely it is that doses will be skipped. Skipping doses, also called non-adherence, can be particularly problematic for adolescents, who tend to have the highest rates of non-adherence across many medical conditions, including transplant.

If you're not taking your medications on the schedule

recommended by your doctors, or are not taking the right dosage, you may be more likely to experience complications that threaten transplant success. The good news is that this is one piece of your transplant treatment that is within your control. Your medication schedule may be overwhelming at first, but over time it should become habit. Every day is a new chance to get it right.

Schedule It, Take It, Track It

There are several things you can do to stay on track with taking medicine. First, be sure you are clear about what you have to take, how much, and when. This means writing down the list of medications, doses, timing, and any special instructions (including if they need to be taken with food and what to do

if you accidentally skip a dose). You can find a simple sample chart below that can be copied into your transplant or treatment notebook.

Once you are clear on what to take, when, and how, schedule this information into your day in whatever way makes sense for you. If you use a digital calendar on your smartphone or digital device, enter your medication schedule into your calendar and set reminders for yourself. Most smartphones have calendars built in, and you can adjust your settings so that your phone will give you an audible notice that it's time to take your medications. You may also want to write a "medication schedule" on a piece of paper that you can hang on the fridge or keep in your wallet for reference.

CARETRACKER

CareTracker is designed to help patients and caregivers manage their medication. Through a virtual pill box, patients can keep track of their current medicines, access information on each medication, document and monitor possible side effects, and accurately communicate to their medical team.

SAMPLE TRACKER

Medicine	Usage	Dose	Timing	Special Instructions

The Bone Marrow Foundation

Since its founding in 1992, The Bone Marrow Foundation has been dedicated to improving the lives of bone marrow, stem cell, and cord blood transplant patients and their families. The Foundation's wide-ranging portfolio of programs provide vital financial assistance, educational information, and emotional support to patients and their families. The Bone Marrow Foundation is the only organization of its kind that serves transplant patients and their families throughout the country regardless of their geographic location, age, race, or type of disease. All of the Foundation's services are provided free of charge to patients and their families.

The Bone Marrow Foundation serves as a comprehensive resource for anyone facing a bone marrow, stem cell, or cord

blood transplant. Our programs include:

The Lifeline Fund

A Patient Financial Assistance Program. Our flagship program, Lifeline provides financial support to eligible individuals and families who are preparing for and undergoing a bone marrow, stem cell, or cord blood transplant. The individuals who seek the Foundation's support often lack the financial resources necessary to afford not only life-saving treatment, but also the often overlooked living and ancillary expenses that accompany treatment. Funding from The Bone Marrow Foundation's Lifeline Fund helps to cover the myriad costs associated with transplants, such as donor searches, compatibility testing, bone marrow harvesting,

medications, home and child care services, medical equipment, transportation, cord blood banking, housing, and other expenses associated with the transplant. Health insurance often does not cover these vital support services, and many patients cannot afford them on their own.

Carelines

Carelines provides crowdfunding, journaling and a volunteer task calendar for anyone with a cancer diagnosis or receiving a bone marrow, stem cell or cord blood transplant. Through Carelines, patients can reach out to family, friends and social networks for financial support, share updates, photos, and videos, keep track of appointments and receive help from family and community members for day-to-day tasks. All contributions to Carelines are tax-deductible and do not affect a patient's medical insurance or benefits.

CareTracker

CareTracker is designed to help patients and caregivers manage their medication. Through a virtual pill box,

patients can keep track of their current medicines, access information on each medication, document and monitor possible side effects, and accurately communicate to their medical team.

Scholarship Grants

The Bone Marrow Foundation's Scholarship Grant program helps make educational aspirations a reality for bone marrow, stem cell or cord blood transplant survivors. Transplants affect all aspects of life and often prohibit the pursuit of educational opportunities. To address this, The Bone Marrow Foundation created this program to offer survivors a future where their hopes and dreams remain intact. Funds may be used to cover the cost of tuition, books, living expenses, supplies, or homebound educational equipment.

Ask the Expert

The Bone Marrow Foundation's Medical Advisory Board comprises more than 100 medical professionals, many of whom are renowned experts in the field of bone

marrow, stem cell or cord blood transplantation. Our Ask the Expert program allows patients and families to benefit from our Medical Advisory Board's wealth of expertise by having their most pressing questions answered by qualified and experienced health professionals. The individual asking the question and the advisory board member remain anonymous to each other, and all communications occur via the Foundation.

Medical Education Symposium

Each year, The Bone Marrow Foundation organizes a medical education symposium for doctors, nurses, social workers, and other healthcare providers who routinely work with transplant patients. The goal of these symposia is to bring together medical professionals to exchange information in the latest developments in this rapidly-changing field of medicine.

Supportline

Recognizing that talking or corresponding with someone who has gone through a bone marrow, stem cell or cord

blood transplant can help new patients understand what to expect during and after the process, our Supportline program links transplant patients and their families with volunteers who have gone through the transplant experience themselves.

Clinical Care Counseling

Through this program, The Bone Marrow Foundation provides confidential individual and family supportive counseling, financial guidance and resource referrals to individuals and families. Trained counselors are available in person or by telephone to help patients, family members and caregivers navigate the transplant process.

Survivorship Program

Responding to the needs of transplant survivors—who have told us they experienced feelings of extreme isolation in the weeks and months following the procedure—The Bone Marrow Foundation designed and launched a dedicated support program for this population. Our Survivorship Program addresses the

ongoing need for emotional and social support through weekly telephone or in-person meetings, provides education about transplant and side-effect related issues and helps survivors create a healthy new life. The return to “normal” life takes a different path for each person, yet the ability to share common experiences with others can provide significant

support and encouragement during the process of returning to school or work and adjusting to post-transplant life.

The Bone Marrow Foundation is guided by a Medical Advisory Board of nationally recognized physicians in the field of transplantation. Learn more about the Foundation and its services at **[bonemarrow.org](https://www.bonemarrow.org)**.

Glossary

Allogeneic transplant: A transplant using bone marrow or stem cells from a donor.

Alopecia: Temporary loss of hair.

Antiemetic: A drug or combination of drugs used to control nausea or vomiting.

Antigen: A substance that evokes a response from the body's immune system. This results in the production of antibodies or white blood cells.

Apheresis: The procedure similar to a blood donation, in which peripheral blood stem cells are harvested.

Autologous transplant: A transplant in which the patient's own bone marrow or stem cells are used.

Blood cell separator: A machine, used in *apheresis*, which distinguishes the small fraction of stem cells in the blood from all other blood cells, so that the stem cells may be collected for transplant.

Bone marrow: Spongy tissue in the inside of bones. Its purpose is to make new red blood cells, white blood cells, and platelets.

Central venous catheter: A small, soft plastic tube inserted into the large vein above the heart through which medication can be given and blood drawn without multiple needle sticks.

Chemotherapy: A drug or combination of drugs used to kill cancer cells.

Engraftment: When bone marrow or stem cells given during transplant begin making new blood cells.

Erythrocytes: Red blood cells.

Gastrointestinal tract: The digestive system, including the mouth, esophagus, stomach, and intestines.

Graft vs. Host Disease: A side effect of transplant that happens when the new bone marrow or stem cells (the graft) reject or attack the patient's body (the host).

Growth factors: Substances sometimes given to transplant patients to stimulate the production of blood cells or to stem cell donors to mobilize stem cells into the bloodstream for collection.

Hemoglobin: A protein in red blood cells that carries oxygen from the lungs to the rest of the cells in the body.

Human Leukocyte Antigen (HLA): A genetic “fingerprint” on white blood cells that are a part of the body’s immune response. It is used to determine a tissue match between patient and donor.

Intravenous: Through a vein.

Leukocyte: White blood cells.

Neutropenia: Lack of white blood cells.

Peripheral blood stem cells (PBSCs): Stem cells that are circulating in the bloodstream.

Platelets: Cells that clot the blood to prevent bleeding.

Preparative regimen: The chemotherapy or radiation therapy given before transplant.

Red blood cells: Cells that carry oxygen throughout the body (also called **erythrocytes**).

Stem cells: Young blood cells, found in the bone marrow, from which all other types of blood cells develop.

Total body irradiation (TBI): Radiation given to the entire body.

White blood cells: Cells that fight infection (also called *leukocytes*).

Resources

Air Charity Network

A collaborative organization that provides access to free air transportation to patients across the U.S.

4620 Haygood Road, Suite 1
Virginia Beach, Virginia 23455
1-877-621-7177
aircharitynetwork.org

American Cancer Society

Provides information, financial assistance, and support for people living with cancer, their families, and friends.

250 Williams Street NW
Atlanta, GA 30303
800-227-2345
cancer.org

American Society for Blood and Marrow Transplantation (ASBMT)

Provides education and resources for people undergoing bone marrow and stem cell transplant.

85 West Algonquin Road
Suite 550

Arlington Heights, IL 60005
847-427-0224
mail@asbmt.org
asbmt.org/patient-education

Angel Wheels

Provides non-emergency, long-distance ground transportation for patients traveling to treatment.

4620 Haygood Road, Ste 1
Virginia Beach, VA 23455
800-768-0238
angelwheels.org

Aplastic Anemia & Myelodysplastic Syndrome (MDS) International Foundation

Provides knowledge, support, research, and advocacy for bone marrow failure diseases.

4330 East West Highway,
Suite 230
Bethesda, Maryland 20814
800-747-2820
301-279-7202
help@aamds.org
aamds.org

Be The Match, National Marrow Donor Program (NMDP)

Maintains a donor registry and patient advocacy groups and provides education and financial aid for allogeneic transplant patients.

500 North 5th Street
Minneapolis, MN 55401-1206
800-627-7692
888-999-6743 (patient services)
patientinfo@nmdp.org
bethematch.org

Blood & Marrow Transplant Information Network (BMT InfoNet)

Provides information and support for people navigating bone marrow, peripheral blood stem cell, and cord blood transplants.

1548 Old Skokie Road, Suite 1
Highland Park, IL 60035
847-433-3313
888-597-7674 (toll free)
help@bmtinonet.org
bmtinonet.org

The Bone Marrow Foundation

Provides financial assistance, comprehensive resources, educational information, and emotional support programs.

515 Madison Avenue, Suite 1130
New York, NY 10022
212-838-3029
800-365-1336 (toll free)
thebmf@bonemarrow.org
bonemarrow.org

Camp Good Days & Special Times

Provides camp experiences and programming for children with cancer, children who have a parent or sibling with cancer, and children who have lost a parent or sibling with cancer.

1332 Pittsford-Mendon Road
PO Box 665
Mendon, NY 14506
585-624-5555
campgooddays.org

Cancer Care

Provides education, support, and financial assistance for people living with cancer and those who care for them.

275 Seventh Avenue
New York, NY 10001
800-813-HOPE (800-813-4673)
info@cancercare.org
cancercare.org

Cancer Support Community

Provides professional programs of emotional support, education, and hope for people impacted by cancer.

734 15th Street NW, Suite 300
Washington, DC 20005
202-659-9709
help@cancersupportcommunity.org
cancersupportcommunity.org

Caregiver Action Network

Provides education, peer support, and resources to family caregivers.

1150 Connecticut Avenue NW,
Suite 501
Washington, DC 20036
202-454-3970
info@caregiveraction.org
caregiveraction.org

Center for International Blood & Marrow Transplant Research (CIBMTR)

Generates and shares research and statistical information on transplantation.

Froedtert and the Medical
College of Wisconsin Clinical
Cancer Center
9200 W. Wisconsin Avenue,
Suite C5500
Milwaukee, WI 53226
414-805-0700
contactus@cibmtr.org
cibmtr.org

DKMS

Maintains an international donor registry and patient advocacy groups and provides education and financial aid for patients with blood cancers and disorders.

100 Broadway, 6th Floor
New York, NY 10005
212-209-6700
info@dkms.org
dkms.org

Fertile Action

Provides education, advocacy, support, and financial aid for fertility preservation to women diagnosed with cancer.

PO Box 3526
Manhattan Beach, CA 90266
877-276-5951
info@fertileaction.org
fertileaction.org

Good Days

Provides education, emotional support, and financial aid for patients with chronic diseases.

6900 Dallas Parkway, Suite 200
Plano, TX 75024
972-608-7141
877-968-7233 (toll free)
info@mygooddays.org
mygooddays.org

The Icla Da Silva Foundation

Provides education, financial aid, and emotional support for patients going through a bone marrow transplant; assists with marrow donor drives tailored to the patient's ethnicity.

311 West 43rd Street, 12th Floor
New York, NY 10036
888-638-2870
info@icla.org
icla.org

Leukemia and Lymphoma Society

Provides education, support, and financial aid to patients with a leukemia or lymphoma diagnosis.

3 International Drive, Suite 200
Rye Brook, NY 10573
888-557-7177
800-955-4572 (patient services)
lls.org

Multiple Myeloma Research Foundation

Provides education, support, and research for people living with multiple myeloma.

383 Main Avenue, 5th Floor
Norwalk, CT 06851
203- 229-0464
info@themmrf.org
themmrf.org

National Children's Cancer Society

Provides emotional, financial aid, and educational support to children with cancer, their families, and survivors.

500 North Broadway
Suite 1850
St. Louis, MO 63102
314-241-1600
thenccs.org

National Institutes of Health (NIH)

The U.S. Government's main agency for research and information; offers numerous free publications and resources related to illness, treatment, and research.

9000 Rockville Pike
Bethesda, MD 20892
301-496-4000
800-422-6237 (Cancer Information Service)
NIHinfo@od.nih.gov
nih.gov

Needy Meds, Inc.

Provides information on programs that offer assistance to patients in need.

P.O. Box 219
Gloucester, MA 01931
800-503-6897
info@needymeds.org
needymeds.org

Oncofertility Consortium

Provides fertility education and emotional support for cancer patients.

303 E Superior Street
Suite 10-121
Chicago, IL 60611
312-503-2504
oncofertility.northwestern.edu

ViaCord Sibling Connection Program

Provides ViaCord's cord blood banking with five years of storage at no cost to expecting parents.

930 Winter Street #2500
Waltham, MA 02451
866-668-4895
viacord.com



The
BONE MARROW
F O U N D A T I O N

515 Madison Avenue, Suite 1130
New York, New York 10022

212-838-3029

800-365-1336

Fax: 212-223-0081

TheBMF@BoneMarrow.org

bonemarrow.org