

Allogeneic Bone Marrow/Stem Cell Transplantation:



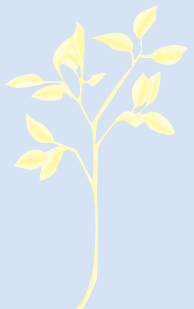
A Medical

& Educational

Handbook



The
**BONE
MARROW**
FOUNDATION



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INTRODUCTION

Allogeneic Bone Marrow/Stem Cell Transplantation: A Medical & Educational Handbook is one in a series of patient and family handbooks developed by The Bone Marrow Foundation. Our goal is to provide comprehensive patient education and resources to assist patients and family members in obtaining information regarding the transplant procedure and all aspects of follow-up care.

This handbook is based on the premise that by understanding what you face, you will be better equipped to cope. It will help you prepare for what's ahead—physically, emotionally and logistically. Experts say that being informed and having realistic expectations about transplant therapy can help you better negotiate the twists and turns that may occur along the path.

Allogeneic Bone Marrow/Stem Cell Transplantation is your road map to the transplant process. (A separate handbook for autologous bone marrow transplantation is available from The Bone Marrow Foundation.) It provides general information about medical procedures, supportive care and possible complications that may be experienced. It is NOT intended to provide the latest medical information or to uncover every possible scenario that might ensue. Nor will you find disease-specific cure rates or statistics here. Those are jobs best left to your healthcare team, who will have the latest data. *This booklet should NOT take the place of any discussion with your doctors, but should be used in these discussions.* We've included blank pages where you can write down questions and make notes along the way.

Throughout the treatment process, you may face many emotional and interpersonal challenges. Try to take care of your mind as well as your body, at every step. It is important to seek support from family and friends, each of whom will fill different roles. You will meet lots of new people—doctors, specialists, nurses, social workers, physical therapists, counselors, nutritionists and bone marrow transplant patients—some of whom have been through the experience already and others who are about to go through transplantation. Talk to them. Learn from them, but keep in mind that the experience is never the same for any two people. Take advantage of the resources available at your transplant center. Ask for help when you need it. It may be helpful to carry a small notebook to each appointment to keep track of questions you have along with the answers and any new information you receive.

There are many steps to transplantation. The order of individual procedures may vary by hospital, treatment type and disease. Nonetheless, an overview

of the process can be helpful in enabling you, your family and caregivers to emotionally, physically and logistically prepare for the treatment ahead. Each step in your medical care will present new challenges to your body and mind. At the same time, each of the following steps gets you closer to your goal.

1. Getting the Facts: Bone Marrow/Stem Cell Transplantation (BMT/SCT) Basics
2. Finding a Bone Marrow Donor
3. Pre-Transplant Planning & Preparation
4. Going for the Transplant
5. Post-Transplant: A Second Chance at Life
6. Going Home

Note to Parents of Children Undergoing Transplant

Children's needs are unique and demand special attention when illness strikes. While this booklet is written for adult patients, the information it provides will be equally helpful to you as the parent of a patient, and will in turn benefit your child. You will need to be your child's primary support person, advocate and caregiver throughout the treatment process; your child will take his or her cues from you. This guide will help you understand what you will face and how your family may be affected.

The effects of BMT/SCT on siblings should not be overlooked. The treatment process and the changes it will cause to household roles and routines may be difficult for other children to understand, and may provoke any number of emotional

reactions, from withdrawing to acting out, to feelings of jealousy, guilt or responsibility. Honesty and openness, reinforced by clear, age-appropriate communication among all family members, will be critical to identifying and dealing appropriately with these reactions. Siblings need to understand that they are in no way responsible for their sibling's illness, and that they can't "catch" the disease. Sibling donors need special attention to deal with potentially destructive feelings of responsibility or guilt associated with bone marrow donation, especially if the recipient should develop complications.

Your entire family will be involved in the treatment. By getting the support you and your family need, you can help ease the stress you may be carrying.

I. GETTING THE FACTS: BONE MARROW/STEM CELL TRANSPLANTATION (BMT/SCT) BASICS

Bone Marrow Basics

Bone marrow is soft, spongy tissue found inside the bone. All blood starts out as stem cells, “parent cells” produced in the bone marrow. Stem cells develop into one of the three types of mature blood cells—red blood cells, white blood cells and platelets—and enter the bloodstream. Red blood cells carry oxygen throughout the body. White blood cells fight infection. Platelets cause blood to clot. The bones of the hip, chest (sternum/breast-bone) and pelvis contain the largest amount of marrow and stem cells.

Some stem cells also circulate in the bloodstream. These are called peripheral blood stem cells (PBSCs). Improved methods for collecting and storing peripheral blood stem cells have made this an increasingly important source of stem cells for certain types of transplants (especially for autologous BMT/SCT).

Blood Cell Functions

Stem Cells give rise to all blood cells. Each one either divides to form a new stem cell or becomes 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.

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.

Why Transplant Bone Marrow/Stem Cell?

The basic idea behind BMT/SCT is to allow high doses of chemotherapy and/or radiation therapy to kill rapidly dividing cells in the body to make room for new, healthy cells. Cancer cells, like other cells in the body, divide rapidly. Though these treatments are among the most effective weapons against many forms of cancer, they don’t have precise aim, and they cannot target only diseased cells. As a result, many normal rapidly dividing cells, including stem cells, are also destroyed during the treatment. Therefore, “rescue” with transplanted bone marrow or stem cells enables the patient to produce new blood cells to replace those destroyed during treatment.

Types of BMT/SCT

There are two main types of bone marrow or stem cell transplants: **allogeneic** (a donor supplies the marrow or stem cells) and **autologous** (the patient's own bone marrow or stem cells are used). A **syngeneic** transplant is a type of allogeneic transplant of marrow or stem cells from an identical twin.

Several factors determine what type of BMT/SCT you should have, including the type of disease, your age and overall health, and the availability of a donor. This booklet focuses on allogeneic transplants and, by extension, syngeneic.

What Types of Conditions Are Treated With BMT/SCT?

(Please note: This section is intended to provide an overview, NOT a comprehensive list of diseases treated by BMT/SCT.)

BMT/SCT continues to be investigated as a treatment for a number of diseases, and its therapeutic uses are likely to increase. One of its earliest uses was treating leukemia and lymphoma, cancers that affect white blood cells. Today, BMT/SCT is considered by many experts to be standard therapy for these cancers, as well as for neuroblastoma, a type of brain cancer that occurs most frequently in children, and multiple myeloma, a cancer of the bone marrow and other noncancerous diseases, including anemia and sickle cell disease. BMT/SCT is also being studied for breast, lung and ovarian cancer; germ cell tumors; and numerous other less common cancers in children and adults. In addition, BMT/SCT may be used to effectively treat cancers that have spread from one site to another in the body, cannot be removed surgically or have failed to respond to other treatments.

Transplantation is also used in a number of noncancerous conditions, including those that affect the blood or immune system. These include severe combined immunodeficiency disease (SCID), sickle-cell disease and various types of anemia, such as aplastic anemia, Fanconi's anemia and autoimmune diseases.

Finding Facts: Tips for Learning More

In this Internet age, it is easier than ever to access sound medical information and advice that is understandable. It is also possible to get lost in a sea of information that may be inaccurate or out-of-date. Below are some tips for gathering information, both on the Internet and off. (Most libraries now offer free Internet access, and your transplant center may offer this service or give you access to a medical library that does.) A good place to start your research is at The Bone Marrow Foundation's website (www.bonemarrow.org), which can lead you to other resources.

Tips for Gathering Information

- Use your medical team. They should be able to provide medical information about your condition and treatment and direct you to other sources.
- Start a notebook or file folder of news and information about your condition and treatment.
- Put any relevant articles you read into the file, as well as information from your doctors or patient groups. If someone tells you about something, such as a tip for coping with nausea, or if you see something on television, make a note and put it in the notebook or file.
- Organizing information by subcategories, such as "General Disease Information," "Support & Resources," "Managing Side Effects," etc. may be helpful.
- Support groups and patient-advocacy organizations are usually excellent sources of up-to-date, accurate information (see the Resource Guide on page 38). Some may also have "position papers," reports, summaries or backgrounds on investigational treatments or other controversial aspects of care.
- Visit a large bookstore and browse in the section dealing with your condition, as well as the self-help section for books about coping with illness. You can also do this online. Please see the Resource Guide (page 38).
- Talk to other people in your situation. Join support groups or ask your transplant center to provide you with names of people who have been through a BMT/SCT. Many patient groups, including The Bone Marrow Foundation, have patient-to-patient programs, which will put you in touch with other survivors. Again, keep in mind each patient may experience the same treatment in slightly different ways.

Critical Questions

There are a number of questions that you will want answered, whether through your own research or through your doctor. The list below may be helpful in creating your own questions to ask your doctor.¹

- What are the benefits of this treatment?
- What are the risks and side effects?
- What can be done if side effects occur?
- How long will I be in the hospital and unable to work or go to school?
- How will I have to change my normal activities, and for how long?
- How much will the treatment cost?
- Will my insurance pay for it? If not, is financial help available?
- Will I have to be far from home? If so, how soon can I return home?
- How often will I need check-ups?

2. FINDING A BONE MARROW DONOR

Who Can Be Your Donor?

Allogeneic bone marrow transplants, by definition, rely on the availability of a healthy donor whose bone marrow is biologically compatible with yours—what doctors refer to as an “HLA match.” HLAs, or *human leukocyte antigens*, are protein “markers” found on the surface of white blood cells. 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. Therefore, the search for a matched donor begins within your immediate family. There is a 25 percent (1 in 4) chance that *any one* brother or sister perfectly matches a sibling’s HLA type. The overall chances of having *any* sibling who is a match depend upon 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 are screened for HLA compatibility, followed by the extended family of aunts, uncles, cousins, etc.

When a Family Match Is Not Available

If a sibling or family match is not available, your transplant center should have procedures for finding an unrelated donor through national bone marrow registries. They will search a database of donors to identify a potential match. On average, the chances of finding an unrelated donor with a similar ethnic background are 60 to 70%. If someone is found, the registry contacts the potential donor with instructions about how to proceed. The identity of the donor is always kept confidential for a period of time following your transplant, after which point you 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/SCT are unable to find a matched donor. To help fill this unmet demand, alternative sources of stem cells are being explored. For example, blood harvested from the umbilical cord of newborn babies (at no risk or pain to them) is a rich source of stem cells, and the use of cord blood in the BMT/SCT setting is increasing.

Related donors who are not exact HLA matches may also present an alternative for BMT/SCT candidates with no matched relatives. Such “HLA-mismatched” procedures need to be discussed with your doctor. Such donors have not previously been a viable option because of the high risk of Graft vs.

Host Disease (GVHD) and graft failure associated with such mismatches. Recent advances have helped make this an option in some cases.

Procedures for Donating Bone Marrow

Donating bone marrow is a relatively simple procedure that poses little risk to the donor. Complications are rare. Because the procedure is typically done under general anesthesia, it may require a one- to two-night hospital stay or be done as an outpatient. The donor will be required to have a complete medical examination prior to donating. At some hospitals, harvesting bone marrow is an outpatient procedure. Because the procedures vary, the hospital where the marrow will be donated will provide the details for your donor, including any specific preparatory instructions (for example, dietary restrictions if general anesthesia is used).

Bone marrow is extracted by inserting a needle through the skin into a large bone. It typically takes about an hour to remove one to three pints of marrow and blood cells, which amounts to only a small proportion (less than 5 percent) of the donor's total bone marrow reserves. 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 stored until the time of transplantation.

Your donor should fully recover from the procedure in just a few days. Soreness or pain at the incision site is the most common problem, and this can usually be treated with pain relievers. There may also be some minor stiffness or bruising. Though uncommon, a mild infection at the incision site or minor blood loss is also possible. Within a few weeks, the donor's body will produce new marrow to replace that which was donated.

Donating Peripheral Blood Stem Cells (PBSCs)

Increasingly, peripheral blood stem cells are being collected for use in all types of transplants instead of bone marrow. This practice is generally more common in autologous transplants. PBSCs are harvested through a relatively simple procedure called *apheresis*, which is like a blood transfusion. The donor's blood, including circulating stem cells, is collected from a large vein in the arm, or through a temporary central venous line, depending on the hospital's procedures and the donor's physical condition.

The blood is then run through a machine called a *blood cell separator*, which distinguishes the small 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. Depending on the type of transplant and the timing of donation, the stem cells may be taken directly to the recipient for

infusion, or they may be treated and frozen for later use in the same method as bone marrow. Apheresis takes longer than bone marrow harvesting because there are fewer stem cells circulating in the bloodstream than there are in bone marrow. The procedure may be done either as an inpatient, which requires admission to the hospital, or as an outpatient. It usually takes 2-4 hours and may be repeated on several days.

A number of strategies are being explored to help “mobilize” stem cells—to induce them to leave the bone marrow and enter the bloodstream—in order to make apheresis more efficient. One method that is being increasingly used is pre-treatment with *growth factors*, which stimulate the production of blood cells. Two of the most-studied growth factors, *colony-stimulating factors* and *interleukins*, have been shown to increase the volume of stem cells in the blood. You may want to ask the doctors at your hospital about their use of growth factors for donors if you are considering a PBSC transplant.

Dealing With Donation

The physical process of donating bone marrow or stem cells is fairly simple and generally not associated with any medical complications. Some donors may, however, experience some degree of psychological distress associated with the act of donation and its aftermath. This is particularly 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.

For family members, communicating honestly and openly, in an age-appropriate manner, is the best approach. Encourage your donor to share his or her feelings with you, whatever they might be.

Reassure them that you understand how they might be feeling, and that they are in no way responsible for your recovery. Be sure they understand how much it means to you to have them as your donor. You and your donor may want to talk with a counselor trained in these matters, who can help you both work through the issues you might be facing. You may want to do this separately as well as together and/or as a family (e.g., if the donor is a young child). It will be important to all of you that there is an atmosphere of honesty and shared understanding of the feelings each person may have.

3. PRE-TRANSPLANTATION PLANNING & PREPARATION

This section is designed to help you understand what is involved in planning and preparing for bone marrow/stem cell transplantation (BMT/SCT). (The precise order of events may vary by treatment center, so the information provided here should be considered as a general guide only.) By knowing what to expect, being realistically optimistic about the process and learning to use effective “coping strategies,” such as enlisting support and managing stress, you can take an active role in preserving your emotional well-being as well as your physical health.

Scheduling and Logistical Arrangements

There will be a great number of details to work out with your transplant team. Every situation is unique, and every transplant center has its own guidelines, so the specifics of procedures and logistical details may vary. How quickly things happen will also depend on your case, including the availability of a donor and your disease.

At many 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 stressed or distracted, it is a good idea to take someone with you to your meetings. Choose someone you find comforting and who can understand the discussion. You can use the blank pages in this book to take notes and jot down questions, or bring a tape recorder.

You will need to schedule times for pre-transplant evaluations and tests, admission to the hospital, preparative conditioning and the transplant itself. Your healthcare team will assist you with this. You may want to keep a special journal or calendar for medical appointments and reminders.

Questions to Ask

Below are some questions you'll want to clarify with your transplant coordinator if you don't yet have the answers. Use the blank pages of this booklet to write down any additional questions as you think of them. Some questions

will only be able to be answered as the transplant progresses.

- How long will you be hospitalized?
- What will need to be done prior to your hospitalization?

Continued . . .

- What will be the schedule of procedures once you are admitted?
- What will your treatment regimen consist of, and what are the side effects associated with it?
- What support and counseling services are available, and are appointments necessary?
- What kind of educational materials can the hospital provide about their transplant procedures?
- What accommodations are available for family members?
- Are childcare services available (if you have young children)?
- What are the restrictions on what you can bring to the hospital?
- What is the visitor's policy?

Your Emotional Well-Being

Bone marrow transplantation presents complex emotional and psychological issues that affect everyone to some degree. 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); unrealistic expectations about the speed or likelihood of a return to “normal”; or clinical conditions such as depression or feelings of sadness, which are common and can be treated with counseling and/or medication.²

A growing body of research indicates that such psychosocial factors play a significant role in recovery from BMT/SCT and long-term readaptation 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 health 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 side effects (e.g., managing nausea or fatigue), using stress-management techniques (such as deep breathing) or seeking psychological counseling. There is even some evidence that such “interventions,” including yoga and guided imagery, may actually improve cancer survival.³ Natural therapies, including vitamins and other herbs, need to be carefully screened by your healthcare team. In some cases, such supplements may be harmful to you during and after BMT/SCT treatment. What you experience and how you will cope are unique to you.

The following table lists a number of factors that, according to experts, are associated with “good” psychological coping. Specific actions you can take are also included.

Actions You Can Take to Preserve Your Emotional Health

Resources ²	What You Can Do
1. Realistic expectations about BMT/SCT.	Have realistic expectations about your transplant: become educated about the process so that you understand what you’re facing. Accept that there are serious risks, and weigh these against the benefits. Know that after your transplant, it will take time to readjust to your usual life and there may be changes.
2. Psychosocial support provided to you by your personal support system and the medical team before, during and after hospitalization.	Investigate sources of psychosocial support at your transplant center, in the community and through patient organizations. Support groups and patient networks in which you can speak with other people who’ve had transplants can be beneficial. Ask your healthcare team to point you to appropriate resources if the ones at your center don’t fill your needs.
3. Individual coping resources , including your level of optimism, flexibility (i.e., to adapt to changing circumstances) and use of meditation and other relaxation techniques.	Learn and practice good “coping skills”: <ul style="list-style-type: none">• Read inspirational books by survivors, or talk with other survivors.• Manage stress through deep breathing, visualization, meditation or other relaxation techniques that work for you.• Focus on something that puts you in control—such as your attitude or communicating with your healthcare team.• Start a journal.
4. Availability of a primary support person or persons you can count on throughout hospitalization and home care, such as a spouse, parent, sibling or close friend.	Find someone, or several persons, whom you can count on to be there for you throughout the process. You’ll need support at different levels; for example, you may need logistical support from a friend or neighbor to pick up your children from school, as well as intimate emotional support from a spouse or parent to help you deal with your fears and frustrations.
5. Your access to professional psychosocial support resources before, during and after transplantation.	Ask your doctors where you can find a professional that you are comfortable with—be it a psychologist, psychiatrist, therapist or pastoral counselor.
6. Follow-up care after your discharge from the transplant center.	Before you’re discharged, be sure you clearly understand what follow-up care will be necessary, and what long-term complications you might encounter.

Choosing a Transplant Center

In years past, people who needed a BMT/SCT had few choices about where they would go for the transplant. Today, about 15,000 BMT/SCTs are done yearly, at nearly 300 centers in the U.S. and Canada.⁴ As a result, you have more choices available, and you can choose the transplant center that best fits your needs.

There are a number of considerations that should affect your decision (see Issues to Consider When Choosing a BMT/SCT Center below).

Doing some research is worthwhile, starting with your doctor. Some registries provide a list of transplant centers. Talking with people who have had a BMT/SCT about their experience can help you to identify what qualities to look for in a hospital. It is also a good idea to talk to transplant coordinators, nurses or doctors at the center(s) you are considering to get a sense of their capabilities. If possible, visit the treatment center prior to your admission.

Issues to Consider When Choosing a BMT/SCT Center⁵

Transplant Center

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

Transplant Team Support

- BMT/SCT physician training and type of specialty training
- Experienced nursing team
- Nurse-to-patient ratio of no more than 1:2 (per guidelines of American Society of Clinical Oncologists)
- Availability and quality of psychosocial support services
- Availability of other health-care team members

Financial Considerations

- Cost of treatment
- Experience in dealing with insurance companies
- Financial assistance services
- Insurance contract rates for BMT/SCT

Long-Term Follow-Up

- Support for your referring physician
- Availability 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)

Are You Covered?

Your transplant center will need to know if the BMT/SCT is covered by your health insurance. Because it is still an investigational therapy for many diseases, health insurance companies can refuse to pay for transplantation. Even when BMT/SCT is an accepted therapy, your insurance carrier may deny coverage. Without coverage, the cost of a BMT/SCT can be prohibitively expensive. However, legal experts say there is no need to panic if you are denied coverage for a BMT/SCT; you do have rights and recourse. Talk with your healthcare team to see what options you may have, consult with a lawyer who specializes in this area or contact patients' groups for information. Please also see the Resource Guide (page 38) for sources of information about insurance coverage.

Exercise and Nutrition

Your physical health going into a transplant is a factor in the outcome. Your overall health obviously depends on many factors, including how severe your disease is, but you should try to eat right and exercise and do what you can to get your body into the best physical condition possible before your transplant. Work with your doctor and physical therapist to develop an exercise plan that suits you and your health status.

Regular exercise provides many physical and emotional benefits and will be an important part of your recovery. Try to get in the habit of doing something active every day. Walking is an excellent choice for almost anyone.

Before your admission to the hospital, eat healthy, balanced meals with plenty of protein, vitamins and minerals. Digestive problems are common following pre-transplant conditioning because of the effects of chemotherapy and radiation on the *gastrointestinal tract*. You may not be able to eat solid food for a while; if this is the case, you will be encouraged to eat foods such as jello, eggs, etc. If necessary, you may receive nutritive fluids intravenously. (Ask your doctor if there are any dietary restrictions immediately before admission or tests.) Because of the risk of infection, fresh fruits and vegetables and some other foods may be off limits for a time after treatment, so pre-transplant is the time to enjoy them.

Hair Care

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

Before beginning transplant, many 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 or not 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 they will use later on. 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 using it and helps ensure it will be ready when you want it. Also, you may be feeling physically stronger now and have more energy to shop. Many salons have selections of wigs. Large cities often tend to have specialty wig stores as well. Scarves, hats and cloth turbans can be found at almost any department or accessory store. Other patients and your social worker and nurses may have suggestions of local places that carry wigs and other accessories.

There is no easy way to cope with hair loss. 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 as with many other aspects of a transplant, patients adapt 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*⁶

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. High doses of chemotherapy or radiation therapy used in transplants may—but don't always—cause infertility (inability to achieve a pregnancy) 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 BMT/SCT may want to consider sperm banking, a method whereby several sperm samples are collected, frozen and stored for use later in fertilizing a partner’s egg.

Sperm and embryo donation and adoption are other possibilities open to couples who want to have families following BMT/SCT. Even though this may be a difficult topic to talk about, it’s important that you discuss it with your healthcare team in advance, so that you can seek out a specialist in this field and take any necessary steps. Clear understanding of your options and pre-planning may help decrease the stress associated with the conditions above.

Pre-Transplant Evaluations

Before the actual transplant or the conditioning regimen, you will need to undergo a series of tests and evaluations to assess your health. The treatments will affect every system of your body, so it’s important to have information about your overall medical condition and the functioning of your primary organs (heart, lungs, kidneys, liver). Tests are usually done prior to your admission to the hospital over the course of a few days.

What tests you need depends 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

- Computerized tomography, lumbar puncture or bone marrow biopsy, to check for tumors or abnormal cells
- A complete dental examination to help prevent mouth infections post-transplant

You may find all of these tests physically and emotionally stressful. Ask your doctor to tell you in advance what your evaluations will entail, including a description of each procedure and its purpose. It is helpful to draw upon your stress-management skills to help you cope with the challenges of this phase of the treatment.

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. These are discussed further in the following sections.

4. GOING FOR THE TRANSPLANT

The Hospital Environment

Being admitted to the hospital for your transplant can be a difficult time. Prior to your admission, or when you first arrive, ask your transplant team to tell you what a typical day will be like, including tests, procedures, medical consultations, visits by nursing or other staff, and other activities. You should also have the schedule for your preparative conditioning.

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 all of these players on your transplant team.

In spite of all the activity, 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. If you know what the daily schedule is, you can plan accordingly, asking guests to visit during “slow” periods, or to come at other times if you prefer some alone time or privacy. Spend some time identifying how you feel and what your needs are.

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 large 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 through an intravenous (IV) line. When it’s time for your transplant, the replacement 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.

What Is Preparative Conditioning?

Preparative conditioning has two primary goals:

1. Destroy the diseased cells in your body.
2. Suppress your immune system to reduce the risk that the donated marrow will be rejected (graft rejection).

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; some may have restrictions, or may require that items be specially cleaned or sterilized. Talk to your transplant coordinator in advance about what is allowed. Some things you might consider include:

- Pictures of family, friends or pets
- Several pairs of comfortable pajamas or lounging clothes (front-buttoning tops are best)
- Slippers
- Several pairs of warm, comfortable socks
- Sneakers or comfortable walking shoes for walking around the unit
- Hats, scarves, turbans or a wig to keep your head warm
- A portable radio or tape/CD player, and your favorite music
- Books or magazines
- Stationery and pens for writing letters
- Address book and phone numbers
- A VCR and videotapes
- A writing journal to make notes and record your feelings
- A laptop computer
- Hobbies that bring you pleasure and can be done in a hospital room such as knitting or drawing (some hobbies using hand/eye coordination may be difficult)
- Puzzles and/or games
- Instructional tapes for stress-management techniques

For Children

- Favorite toys and games
- Video games and player
- Art and craft supplies
- Favorite pillows and blankets
- Posters
- Diary
- Schoolbooks and lesson plans (if your child is missing school,

and is well enough for school-work)*

- Videophones
- Letters and cards from your child's classmates

* discuss with your child's teachers how best to make up missed school-work so that the child may remain in his/her class

Preparative conditioning also destroys your bone marrow cells, to make space for the transplanted cells. Normally, conditioning is done after your admission to the hospital, but in some cases it may begin before hospitalization.

Conditioning usually entails 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 a type of cancer treatment. A number of different drugs may be used, depending on your disease and other factors. You should talk with your doctor 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. Fractionated doses given over several hours or days may minimize side effects,¹ and may be the preferable course of treatment in children. A nurse or radiation technician will make pinpoint ink marks on your skin (tattoos), which may or may not be permanent, to indicate where protective shields should be placed (such as over the heart and lungs) and, in some cases, 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. Following is an overview of common side effects. 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 for information about the potential side effects of your treatment, and how these effects are best managed. It's important that you discuss your preparative regimen and its side effects with your doctors well in advance of beginning it.

The side effects of chemotherapy and radiation therapy are related to their methods of action against disease, which is to kill rapidly dividing cells. In addition to the diseased cells that are the target of therapy, "rapidly dividing cells" include those in the hair, skin, gastrointestinal tract and repro-

ductive organs, as well as bone marrow. It's important to recognize that most effects can be managed with close monitoring and medication, which will be one of the primary functions of your transplant center's supportive-care team. Temporary side effects that may affect you *acutely* (within hours or days of your treatment) are listed below.

- Nausea and vomiting
- Diarrhea
- Temporary hair loss (*alopecia*)
- Fatigue
- Loss of appetite
- 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 (these are discussed on pages 27-28). Some of the medications used to treat side effects may themselves have side effects, making your medical management 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. There are usually things that can be done to help.

Please Note:

It is beyond the scope of this booklet to thoroughly review each of the 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. For more information, see the Resource Guide (page 38).

Controlling Infections

After your chemotherapy or radiation treatment, you may have to comply with strict infection-control procedures until your immune system is fully functioning again. These procedures vary, but may include staying in a special “clean” room that is designed to remain as germ-free as possible. The room may have special air-handling systems to prevent germs from entering, and you may be restricted in the items you can bring into the room or

the visitors you can have. There may also be special procedures for guests who do visit, such as wearing masks, gloves, gowns and foot coverings. Foods will need to be well cooked to destroy any bacteria, and you will not be able to eat raw fruits and vegetables or have unpasteurized milk products for a while. Your transplant team will educate you regarding the types of foods you can and cannot eat.

Transplantation Day: A Second “Birth”

Once your diseased cells have been destroyed, along with your bone marrow, it is time for the transplant, or “rescue.” Your transplant will probably be scheduled within a few days of the completion of your conditioning regimen. If it was not done already, your donor’s bone marrow or peripheral blood stem cells will be harvested at this time (see page 8). The donated stem cells will be infused through your central venous catheter, in a way similar to a blood transfusion. The process is usually short, taking only an hour or two, and usually uncomplicated. Some people experience mild nausea. A strong odor may be present if the donated bone marrow has been stored; this smell is due to the preservatives used.

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 Zero,” the day that starts the post-transplant count. Many survivors consider it their second birthday.

5. POST-TRANSPLANT: A SECOND CHANCE AT LIFE

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.⁷ This is an indication that your body is able to fight 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 varies: it usually occurs within two to four weeks,¹ but may take up to a few months. 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 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 (please see Controlling Infections on page 21). The skin and mouth are common sites for infection, so you will need to pay close attention to personal and dental hygiene. Your transplant team will give you specific daily instructions aimed at preventing infections. Follow these instructions carefully, and be sure to report any problems promptly.

Some complications related to transplant are reviewed below. These complications may be direct effects of chemotherapy and radiation treatments, may result from the immunosuppression that these therapies induce or may be due to side effects of drugs used to manage other complications. This information is meant to be an overview; check with your healthcare team for additional information. Remember, your entire transplant team will be focused on preventing and managing these potential complications. But they can't do it without you. It's more important than ever that you clearly communicate any changes in your health or any concerns you may have.

Primary Potential Complications of Transplant Therapy

NOTE: Keep in mind that in most cases, there are a number of things that you and your healthcare team can do to prevent, manage and treat these potential complications.

Infections

Infectious agents will be your enemy for several months. Management of infections focuses on prevention, which is why special precautions will be taken to protect you from being exposed to viruses, bacteria and infections. Some of the medications that are used to treat infections, such as antibiotics, antifungal and antiviral agents may be administered as a preventative measure. (See Controlling Infections, page 21, and Tips for Avoiding Infection, page 30.)

Mucositis, swelling and redness in the mouth and gastrointestinal tract, is common following Bone Marrow/Stem Cell Transplantation (BMT/SCT), as are herpes zoster infections (shingles). Pre-existing viral infections, such as herpes simplex (cold sores, genital herpes), may be reactivated.

Graft vs. Host Disease (GVHD)

GVHD, a serious side effect, occurs when specialized white blood cells in the donated bone marrow (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.

Doctors distinguish between acute and chronic GVHD by the timing of their appearance, and by their associated symptoms:

Acute GVHD generally develops within 3 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 3 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; and hair loss.

Strategies have been developed to help prevent GVHD, including removing T lymphocytes from donated marrow or peripheral blood stem cells (T-cell depletion, discussed on page 25), and using medications post-transplant to suppress T-cell activity. Your transplant team will have a standard protocol for dealing with GVHD and can discuss the plan with you if you desire.

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 functions are 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 leukemia patients.¹ The relative risks and benefits of T-cell depletion continue to be studied, and not all hospitals take this approach in all cases. This is an issue that you may want to discuss with your doctors.

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 BMT/SCT 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, 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 bleeding.

Organ Complications

While rare, serious complications may occur in the liver, lung, heart or kidneys of some BMT/SCT 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. Organs that may be infected include:

Liver: The liver is responsible for removing harmful substances from body fluids, absorbing nutrients and producing bile (a digestive liquid). Side effects of liver problems can include digestive problems and/or buildup of toxic substances. Venous-occlusive disease (VOD), a serious condition in which small veins in the liver become blocked, may develop as a result of chemotherapy and radiation. Abdominal pain, weight gain, swelling of the liver and poor liver function (assessed by blood tests) are possible symptoms of VOD.

Kidneys: The kidneys filter your blood and excrete waste products. Preparative 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. Your “fluid output,” the amount of urine and feces you excrete, will be closely monitored.

Lungs: Your lungs control breathing, the exchange of oxygen and carbon dioxide that is basic to life. Infections that enter the lungs may cause breathing complications. Pneumonitis (an inflammation of the lungs that causes pneumonia) and pulmonary fibrosis (shortness of breath) may result from damage caused by chemotherapy and/or radiation treatments. Shields placed over the lungs during RT may help prevent these problems. Exercising your lungs through deep breathing and “spirometry” (a small hose attached to a tube with a ball; blowing into the tube makes the ball rise) may help keep your lungs clear. Your healthcare team will review the routine you need to practice with you.

Heart: The heart pumps blood throughout your body, carrying oxygen and nutrients to your cells and organs. Certain chemotherapy drugs may have serious side effects that damage the heart. Your heart function will be carefully monitored throughout the BMT/SCT process.

Graft Failure

Graft failure 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.

Waiting for Engraftment

Time may seem to be moving very slowly during the period while you're waiting for engraftment. It may be helpful to keep your mind and body as busy as possible to direct your attention away from "waiting" and onto something positive. Try to stay focused on your goal, rather than this temporary stage.

- Don't watch the clock. Don't get hung up on "typical" time frames for engraftment. Every case is different.
- Schedule visits as much as possible with people you really want to see.
- Exercise: Arrange to have access to an exercise machine or go for brisk walks as often as possible. Check with your healthcare team as to what types of exercises are okay.
- Keep a record of your blood counts to monitor your progress.
- Listen to meditation or relaxation tapes.
- Write in your journal about what you're going to do when you get out of the hospital.
- Get to know other people on your floor: You may make some new friends and learn a lot in the process.
- Communicate your needs and desires to people who can help.

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.⁷ 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.

Long-Term Effects

A number of long-term side effects may also occur as a result of the preparative regimen, including those mentioned below. Significant research efforts are being directed at better understanding what preventative measures might be taken to reduce the risk of these complications:

- Infertility (see page 15)
- Growth problems in children, which may result from total body irradiation, and may be treatable with growth hormones

- Cataracts, also as a result of radiation, which may eventually require surgery (regular eye checkups will be part of follow-up care)
- Secondary cancers may in some cases be induced by treatments, or may be pre-existing

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 or not 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. Such feelings are natural. Try to stay focused on your goal of getting better, and rejoice at how far you've come!

6. GOING HOME

The Rush to Readapt

Your reintegration into life outside the hospital is a big step. Readaptation can be a long process. Your body has been through a major ordeal, and your immune defenses are down. You may be anxious to resume the family and work roles that you left behind, but be realistic with your expectations for yourself. It's unlikely that you will be able to resume your pre-illness level of activity right away. It will take time, as well as patience and understanding with yourself and others, to successfully negotiate this last part of treatment.

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 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 (see page 27)
- Severe fatigue, which may require treatment with medication or red blood cell transfusions (see Managing Fatigue on page 32)
- Chronic graft vs. host disease (GVHD), which may affect the skin, liver or other parts of the digestive tract (see page 24)
- 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)

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. Ask your healthcare team about 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 people who are sick, even those with colds.
- Use a face mask when in crowds or avoid them altogether.
- Avoid touching handrails and doorknobs (wear gloves or use a handkerchief).
- Pets in your household may be problematic. Talk to your transplant team for instructions.
- 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).

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°F or higher
- Coughing, sneezing or runny nose
- Pain, swelling or redness anywhere
- Blisters such as cold sores in your mouth or elsewhere
- 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
- Blood in urine or stool
- Any other unexplained pain or physical problems

*Issues Affecting Readjustment Following Bone Marrow/Stem Cell Transplantation (BMT/SCT)*¹

A number of issues may arise as you readjust to life after BMT/SCT. Some of the most common ones that survivors experience are reviewed below, along with suggested strategies for coping with them.

Anxiety/Depression

Fear of disease recurrence, fertility concerns, disruptions to work and family roles, and loss of energy are key issues survivors say contribute to anxiety. Practicing stress-management techniques, such as deep breathing, meditation or relaxation, may help you reduce anxiety and feel less depressed. Severe, continuing depression or generalized anxiety that interferes with your day-to-day living calls for a doctor's attention, and may require treatment with behavioral therapy and/or medications.

Energy Level/Fatigue

Low red blood cell counts can contribute to severe fatigue. In one study, survivors reported that, on average, their energy level was 58 percent of "normal" at 100 days post-BMT/SCT.⁸ If severe, fatigue can be debilitating, and can cause additional stress and anxiety because of its impact on daily activities. This can often be controlled with the help of activity planning and medication. (See Managing Fatigue on page 32.)

Sexual Activity

Difficulty engaging in sexual activity affects many BMT/SCT survivors. Changes in survivors' sex drive are common, and may be related to the physical effects of preparative conditioning, such as vaginal dryness or fatigue, or to the psychological aspects, including depression, self-image and changing relationship dynamics. Honesty with your partner is the first step toward normalizing this important aspect of your relationship. Medications, ointments and other external treatments may help relieve some physical factors. Though it might be difficult, talking to your healthcare team can be helpful, and you may want to consider family counseling.

Sleep Disturbances

These can result from medication side effects and disruption of sleep processes during hospitalization. Sleep problems, which may lead to changes in mood and difficulty with socialization, are treatable. Your healthcare team can help you with sleep issues.

Managing Fatigue

Fatigue is a common and possibly debilitating result of chemotherapy and radiation. It can vary from minor to severe, and usually results from anemia, a condition caused by low 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 you can schedule your activities around the times you have the most energy. Following are some other tips for managing fatigue.

- Prioritize activities: This demands that you make judgments about what things are really important to you.
- Conserve your energy for the things you really need or want to do.
- Eat right, including lots of foods rich in iron, such as eggs, liver and leafy greens. Ask your doctor if you should take iron supplements.
- Don't overdo it: Listen to the cues your body is giving you, and don't overtire yourself.
- Rest often: 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).
- Be good to yourself: 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.
- Recognize your limits: Don't overschedule yourself, and don't keep pushing yourself in the face of exhaustion. Be gentle on yourself if you can't do everything you might like to do.
- Talk with your healthcare team about causes and solutions for your fatigue.

Exercise and Nutrition

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 the unit.

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 routine for everyday activities and exercise. Listen to your body and take your cues 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 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. Again, it is important to listen to your body and what types of foods (hot, cold, chewy, wet, dry) you feel like eating.

The Long-Term Outlook

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. Remember, the transplant treatment is just a means toward your goal—a goal that is within your reach. 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. Survivors also mention a greater appreciation for life and a heightened sense of spirituality. Your case, and your situation, is unique. By being informed, being proactive and staying focused on your goal, you'll be doing everything within your power to make sure you have a positive transplant experience.

Remember, you're not alone. There are lots of people who can help. The Bone Marrow Foundation can help put you in touch with them.

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8. GLOSSARY

advance directive (also called a healthcare proxy): An advance directive stipulates a person whom you have chosen to make health decisions for you if you are unable to. It assigns someone you trust (a “proxy” for you) to make choices—in whatever situation arises—that are based on the stated preferences in your living will.

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 transfusion, 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 cavities 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.

cryopreserve: A process by which something (such as cells, sperm or embryos) is frozen to preserve it for later use.

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 (GVHD): 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.

healthcare proxy: *see* advance directive

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.

informed consent: Your formal authorization to the hospital to perform transplant procedures. Consent forms may be several pages in length and are written in medical terms, with blunt, detailed descriptions of the risks and side effects associated with BMT, including potential long-term complications.

intravenous: Through a vein.

leukocytes: White blood cells.

living will: A living will stipulates your specific instructions regarding life-sustaining therapy. It includes the instructions for your healthcare proxy, if you have designated one.

lumens (lumen catheter): Lines or tubes attached to a surgically placed temporary catheter, used in place of multiple intravenous lines, to give medication or draw blood.

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.

T-cell depletion: The removal of the T cells from the bone marrow.

T lymphocytes: Cells within the bone marrow responsible for remembering and fighting bacteria and other substances foreign to the body.

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

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

9. RESOURCE GUIDE

Organizations

AirLifeLine

50 Fullerton Court, Suite 200
Sacramento, CA 95825
Tel: 877-AIRLIFE or
916-641-7800
Fax: 916-641-0600
Email: staff@airlifeline.org
Website: www.airlifeline.org
A national volunteer network of pilots that provides free air transportation for patients.

American Cancer Society

1599 Clifton Road, NE
Atlanta, GA 30329
Tel: 800-227-2345 or
404-320-3333
Website: www.cancer.org
Publishes brochures on cancer and treatment options and offers support groups for cancer patients and their families.

Blood & Marrow Transplant Information Network

2900 Skokie Valley Road,
Suite B
Highland Park, IL 60035
Tel: 847-433-3313
Toll-free: 888-597-7674
Fax: 847-433-4599
Email: help@bmtinonet.org
Website: www.bmtinonet.org
Books, monthly newsletter, and on-line support network.

Cancer Care, Inc.

1180 Avenue of the Americas,
2nd Flr
New York, NY 10036-0263
Tel: 212-302-2400
Cancer Care Counseling Line
Tel: 800-813-HOPE
(800-813-4673)
Email: info@cancercare.org
Website: www.cancercare.org
Publications, counseling services and financial aid.

Corporate Angel Network, Inc.

Westchester County Airport,
Building One
White Plains, NY 10604
Tel: 914-328-1313
Provides free air transportation to cancer patients.

International Bone Marrow Transplant Registry (IBMTR)

Medical College of Wisconsin
P.O. Box 26509
Milwaukee, WI 53226
Tel: 414-456-8325
Website: www.IBMTR.org
Statistical information on transplantation.

Leukemia and Lymphoma Society

1311 Mamaroneck Avenue
White Plains, NY 10605
Tel: 800-955-4572 or
914-949-5213
Website:
www.leukemia-lymphoma.org
Publications, support services and financial aid.

National Bone Marrow Transplant Link

29209 Northwestern Hwy, #624
Southfield, MI 48034

Tel: 800-LINK-BMT or
800-546-5268

Website:

www.comnet.org/nbmtlink

*Links patients with survivors,
publications.*

National Institutes of Health (NIH)

Office of Cancer

Communications

Bethesda, MD 20892

Cancer Information Service:

800-4-CANCER

Website: www.nci.nih.gov

*The U.S. Government's main
agency for cancer research and
information; offers numerous free
publications.*

National Children's Cancer Society

1015 Locust, Suite 1040

St. Louis, MO 63101

Tel: 314-241-1600

Email: [PFS@children
cancer.com](mailto:PFS@childrencancer.com)

Website:

www.children-cancer.org

*Financial aid, fund-raising
assistance.*

The Bone Marrow Foundation

70 East 55th Street, 20th Flr
New York, NY 10022

Tel: 800-365-1336

Email: TheBMF@aol.com

Website: www.bonemarrow.org

*Financial aid, education, resources
and emotional support.*

On-Line Support Networks

ACOR, Association for Cancer Online Resources

Website: www.acor.org

*Information and links for all types
of cancer.*

Donor Registries

American Bone Marrow Donor Registry

c/o the Caitlin Raymond

International Registry

University of Massachusetts

Medical Center

55 Lake Avenue N

Worcester, MA 01655

Tel: 800-7-A-MATCH, if you

need a bone marrow donor

Tel: 800-7-DONATE, if you

wish to become a donor

Tel: 508-334-8969

Fax: 508-752-1496

Email: info@crir.org

Website: www.crir.org

*Donor searches for bone marrow
transplants and cord blood
transplants.*

National Marrow Donor Program (NMDP)

3001 Broadway Street NE
Suite 500
Minneapolis, MN 55413-1762
Tel: 800-MARROW-2 or
800-654-1247

(provides listing of local centers)

Tel: 612-627-5800

Fax: 612-627-5877

Office of Patient

Advocacy: 800-526-7809

Website: www.marrow.org

Donor registry, transplant center directory and patient advocacy groups.

Fund-Raising

National Transplant Assistance Fund (NTAF)

3475 West Chester Pike,
Suite 230
Newtown Square, PA 19073
Tel: 800-642-8399 or
610-353-9684
Fax: 610-353-1616

Email:

NTAF@transplantfund.org

Website:

www.transplantfund.org

Fund-raising assistance and donor awareness information.

Insurance Problems

Carter & Coleman, Attorneys at Law

515 King Street, Suite 340
Alexandria, VA 22314

Help with insurance problems.

Patient Advocate Foundation

753 Thimble Shoals Blvd, Suite B
Newport News, VA 23606

Tel: 800-532-5274 or

757-873-6668

Fax: 757-873-8999

Email: patient@pinn.net

Website:

www.patientadvocate.org

Publications, help with insurance problems, attorney referrals.

Patient Advocacy Coalition

850 E. Harvard Avenue,
Suite 465

Denver, CO 80210

Tel: 303-744-7667

Fax: 303-744-7876

Helps resolve insurance reimbursement problems.

10. FURTHER READING

Blood and Marrow Stem Cell Transplant

Marie Bakitas, RN
ISBN-0-763-7035-7

Bone Marrow Transplantation

S. Ikehara
ISBN-4-431-70181-8

*Bone Marrow Transplants:
A Book of Basics for Patients*

Susan K. Stewart, 1992

*Bone Marrow Transplants:
A Guide for Cancer Patients and
Their Families*

Marianne L. Schaffer, RN, 1994

Everyone's Guide to Cancer

*Therapy: How Cancer Is
Diagnosed, Treated, &
Managed Day to Day*

Malin Dollinger, MD, Ernest
H. Rosenbaum & Greg Gable
ISBN-0-8362-3709-9

*I'm Having a Bone Marrow
Transplant*

Leukemia Society's New York
City Chapter

*Survivors' Guide to a Bone
Marrow Transplant: What to
Expect and How to Get Through It*
Keren Stronach, 1997



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THE BONE MARROW FOUNDATION

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20TH FLOOR
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