

RESOURCE GUIDE FOR STEM CELL TRANSPLANT

*Including Bone Marrow,
Peripheral Blood, and Cord Blood.*

≈ Friends Helping Friends ≈



***n*bmtLINK**

National Bone Marrow Transplant Link

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Peripheral Blood and Cord Blood*

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*This booklet is dedicated to the amazing spirit of patients challenged
by a stem cell transplant in their determination to get well.*

The mission of the National Bone Marrow Transplant Link (nbmtLINK) is to help patients, as well as their caregivers, families and the health care community, meet the many challenges of stem cell transplant by providing vital information and support services.

Founded in 1992, the nbmtLINK is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and vital to ongoing programs and services.

The information in this guide should not be construed as medical advice. Please consult with your physician regarding your medical decisions and treatment. The listed resources are not intended to be endorsements.

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*So your body has betrayed you,
But it's gonna work out fine.
The angels gather round
And throw you down a line.
Don't despair.
Don't give in.
You will feel the rain on your face again.
Someday,
You will feel the rain on your face again.*

–Stewart Francke, 2001, nbmtLINK Video:
The New Normal: Life After Bone Marrow/Stem Cell Transplant
www.nbmtlink.org



History

Bone Marrow/Stem Cell Transplant Resource Guide, *Friends Helping Friends* was first published in 1990. Much has changed in the world of stem cell transplant (SCT) since the publication of the original Resource Guide. This is a rapidly evolving field and some of the information published in this book might already be dated. Your health care team is the best source of current medical information.

Over a decade ago, there was an unmet need for information and support regarding stem cell transplant. Because of this, a dedicated group of SCT survivors, family members, friends, and health professionals responded by writing the *Bone Marrow Transplant Resource Guide, Friends Helping Friends*. The booklet was very well received and has since been distributed to more than 50,000 people worldwide, and to countless others via the Internet.

The overwhelming response to this publication led to the creation of the National Bone Marrow Transplant Link (nbmtLINK) in 1992. The nbmtLINK's outreach to patients and families continues to be dynamic, but the focus remains steadfast: to help patients, as well as their caregivers, families, and the health care community, meet the many challenges of stem cell transplant by providing vital information and support services.

We know that medical technology will continue to change the nature of stem cell transplant. Much has been learned. Much is yet to be discovered. We encourage you to use this booklet as a guide to enhance the recommendations of your physician and health care team. It is not a substitute for medical advice or an endorsement for a particular procedure. It is meant to clarify the subject of stem cell transplant, including bone marrow, peripheral blood, and cord blood transplants, for you. We hope that it will be helpful.

Introduction

The ABCs of BMT! BMT, PBSCT, HSCT, bone marrow transplant, stem cell transplant, peripheral blood stem cell transplant, blood cell transplant....so many words and letters it looks like alphabet soup....do they all mean the same thing?

In the area of stem cell transplantation there has been a lack of worldwide scientific agreement on a single terminology. An understanding of the history of this treatment method offers some explanation about why so many different terms are used. Direct collection from the bone marrow was the first source of hematopoietic stem cells (the cells capable of producing red cells, white cells and platelets), hence the treatment was initially called a bone marrow transplant or BMT. The discovery of hematopoietic stem cells in the peripheral circulation similar to those harvested from the bone marrow led to the term

“peripheral blood stem cell transplant” (or PBSCT). Currently, the peripheral blood is the major source of stem cells rather than bone marrow, and so a more general term of “hematopoietic stem cell transplant” (HSCT) has been adopted to include situations in which the stem cells may be collected from the peripheral blood, directly from the bone marrow, or even from the placenta (cord blood transplant).

For an autologous transplant, first the stem cells are collected from the patient; then the patient is given high dose chemotherapy. After the high dose chemotherapy, the patient is given back his/her own stem cells. However, the use of the term ‘transplant’ for this procedure has also led to confusion. An autologous transplant is not really a transplant; it is actually just a reinfusion of the person’s own stem cells.

When talking about a stem cell transplant one must consider both the source of the stem cells (from the patient, from a related donor, from an unrelated donor), and the way in which the cells are collected (from the peripheral blood, from the bone marrow space directly, or from the placenta after delivery). Using the latest research, the health care team will make a recommendation about which stem cell source and which method of collection is most appropriate to the medical needs of the patient.

Throughout this publication, we will be using the term “stem cell transplant” and its abbreviation SCT, which includes bone marrow, peripheral blood, and cord blood transplant, related or unrelated.

Physicians always caution against using the term “miracle” in connection with stem cell transplant. It is, as they remind us, a modern medical procedure involving some risk. It comes with no guarantee. However, few would deny that there has been tremendous progress in the field. Examples include:

- The acceptance by most insurance companies that SCT is a standard rather than experimental treatment for a number of diseases. The result has been an increase in the number of insured patients.
- The list of diseases and conditions with treatment potential from SCT has steadily increased. Once considered a “last resort” for leukemia, SCT is now successful for a number of illnesses and performed earlier in the course of the disease.
- Thanks in part to media coverage of transplant patients and their stories, stem cell transplant has received greater awareness and acceptance. Due to this exposure donor registries throughout the world have increased their number of volunteers. However, increasing the number of donors on the registries is still a critical concern for minorities who identify themselves as Black or African Americans, American Indians or Alaska Natives, Asians, Hawaiian or Other Pacific Islanders, Hispanic or Latino, or mixed race individuals.

- The maximum age at which patients are considered for SCT has increased due to advances in the SCT field. The use of reduced intensity chemotherapy/radiation and medical supportive care allows older patients to better tolerate treatment. This type of transplant is referred to as a non-myeloablative SCT.
- In addition, patients who do not have a genetically-matched sibling or an unrelated donor available can benefit from a treatment approach utilizing cord blood from unrelated donors as a source for stem cells. Cord blood transplants were only offered to children in the past; however, recently conducted clinical trials have demonstrated the feasibility of using cord blood transplants as an option for adults.
- The post-transplant prognosis for patients has dramatically improved. This is due, in part, to better medical supportive care, including treatments for transplant-related side effects, such as graft-versus-host disease (GVHD) and infection. Moreover, the average hospitalization time for transplant has been substantially shortened.
- The development of new drugs, such as STI 571, also known as Gleevec, may make it possible for individuals with chronic myelogenous leukemia to avoid undergoing a transplant altogether. At the time of this writing, Gleevec is being tested to determine its effectiveness in treating a number of different diseases.

Despite all these reassuring and remarkable strides, the idea of a stem cell transplant is still overwhelming and understandably provokes anxiety for patients and their family members. SCT is a life-altering experience that requires a long-term commitment and is recommended for life-threatening conditions.

What you'll find in these pages will help you understand and deal with the challenges of stem cell transplant. We have also addressed other important issues, such as insurance, finances, and preparing your family for the transplant. Information has been compiled by health professionals, survivors, and dedicated volunteers. Many have been where you are right now, trying to make sense of what lies ahead. We feel that this booklet will make transplant an easier experience for you and your family. We hope that if you have a clear overview of what your transplant entails, you'll feel more in control and, with advanced planning, less overwhelmed.

Medical science has made great progress in the field of stem cell transplant. The vast majority of transplants treat diseases such as leukemia, lymphoma, multiple myeloma, and some solid tumor cancers. Today, people with immune deficiency disorders, sickle cell, or aplastic anemia may also benefit from

transplant. In some individual cases, autoimmune disorders, such as multiple sclerosis, systemic lupus, and scleroderma are also being treated through transplant. So, while this procedure is not a simple solution, it does offer promise.

Understanding the Process

Bone marrow is the spongy tissue found in the cavities of the body's bones where all of the blood cells are produced. Every type of blood cell in the marrow begins its life as a stem cell. A stem cell is often defined as a "parent cell" which divides and forms the different cells that make up the blood and immune system. Stem cells are found in the bone marrow, in cord blood, and, in smaller numbers, in the circulating (peripheral) blood. Stem cells produce:

- White cells (leukocytes) that fight infection
- Red cells (erythrocytes) that carry oxygen
- Platelets that are clotting agents

Without bone marrow and the disease-fighting blood cells it produces, your immune system would be severely impaired. There would be little defense against even the most common infections.

The goal of a stem cell transplant is to cure many different types of cancer and disease. The type of transplant you have will depend on who donates the stem cells.

- *Autologous* transplant—The patient donates his/her own stem cells prior to treatment for reinfusion later.
- *Allogeneic related* transplant—The person donating the stem cells is a genetically-matched family member (usually a brother or sister).
- *Allogeneic unrelated* transplant—The person donating the stem cells is not related to the patient.
- *Syngeneic* transplant—The person donating the stem cells is an identical twin.

Stem cells can be collected from the following sources:

- bone marrow
- peripheral blood
- cord blood

Many elements of your transplant are beyond your personal control. It may be a good time to shift your focus to those factors that can be controlled or influenced by you. You should begin to investigate what resources you will have available to you before, during, and after transplant. It is important that you educate yourself about the transplant procedure.

Autologous Transplants

When patients give their own stem cells back to themselves, the procedure is called an autologous stem cell transplant. How can a sick person be his/her own donor and then get healthy again? It helps to think of this kind of transplant as a rescue. You may even hear your health care team refer to your transplant as a rescue. The autologous transplant isn't necessarily performed because there's something wrong with the bone marrow or stem cell production. It's performed because the dosage of chemotherapy and radiation needed to kill the disease is so high that it will destroy the patient's existing bone marrow. Without the stem cells in the marrow, there is no blood cell production or immune system, and life is not sustainable. The patient's own stem cells, collected prior to the chemotherapy/radiation, are reinfused, like a blood transfusion, and blood cell production and the immune system are re-established. Generally, patients not achieving remission are not suitable candidates to donate stem cells for themselves.

Oddly enough, however, cancers that originate in the bone marrow, such as certain types of leukemia, are sometimes treated with autologous stem cell transplants, particularly if it is not possible to use the stem cells of a donor. Since the marrow is where the cancer originates, it is difficult to obtain totally unaffected stem cells. Even when the patient is in remission, it's possible for some cancer cells to remain in the body. In order to deal with this, many transplant centers have developed methods of purging or cleansing the stem cell product and ridding it of most of the cancerous cells. The goal is to keep the diseased cells in such a small number that the body's defense system will be able to destroy them. Purging is done differently from center to center. Some centers, in fact, don't do it at all. If you have questions about these issues, ask them. Your doctor and other medical professionals should be able to get you the information that you need.

Allogeneic Transplants

Related and unrelated allogeneic, and syngeneic transplants are most commonly used in persons with diseases affecting bone marrow, such as leukemia, aplastic anemia, and some lymphomas. The idea is to replace unhealthy marrow with healthy marrow. Sometimes a disease, such as leukemia, interferes with the stem cell growth, causing cells to stop developing and/or become defective. Eventually these abnormal or immature cells enter the bloodstream causing serious illness. A stem cell transplant provides healthy stem cells to patients whose marrow is diseased. The transplant is actually the transfer of healthy stem cells from a donor to a recipient.

The Donor

Autologous SCT patients will receive their own bone marrow or blood stem cells that were retrieved before transplant. In this case, the patient is his/her own donor.

Allogeneic SCT patients must have a donor identified for them in order to receive new stem cells. The choice of donor and source of stem cells will be determined by your physician. You should understand the rationale for choosing a particular donor and source of stem cells. Often a donor is a brother, sister, or another family member. Each sibling offers a 25% chance of being a match. Having an identical twin sets you up for a perfectly matched syngeneic transplant.

When there's no related donor match for you, a search is initiated to locate a "matched unrelated donor" (MUD). How are unrelated matches found? There are a number of donor and cord blood registries worldwide. The National Marrow Donor Program is one of the largest computerized registries and keeps an extensive database of potential donors and cord blood units. The chance of finding an unrelated donor from the general population depends on the uniqueness of your tissue type. Genetic and ethnic background may also affect the likelihood of finding a donor. With the availability of more accurate laboratory tests, the ability to identify closely matched donors is improving.

Knowing who should and should not be tested as a donor is often a topic of concern. Friends, coworkers and others interested in becoming a stem cell donor may either contact a local donor center or one of the large registries like the National Marrow Donor Program (see Resource Listing). These organizations will be aware of when and where donor drives are occurring. The general criteria for becoming a donor include factors such as general health status, weight, and age. Those who will generally not be able to serve as a stem cell donor include people with a history of severe heart problems, cancer, hepatitis, insulin dependent diabetes, or HIV. Cord blood units undergo a similar screening process. Donors are screened for conditions that would put them at too great a risk to donate as well as for illnesses that could be harmful to the patient.

Your transplant center contacts the registries to begin a preliminary donor search. There is no cost for a preliminary search. Charges for a formal search vary, so check with your insurance company to find out what coverage is offered regarding donor searches. If you have questions about any part of the donor search process, speak to your doctor or transplant coordinator. Don't be in the dark about the status of your search.

Two factors are important in locating a match. The first is a test known as HLA (human leukocyte antigen) typing. The antigen is a substance, acting like a marker, unique to you, not unlike a set of fingerprints. A simple blood test is all it

takes to begin the process of HLA typing. Most HLA typing today is performed using a DNA based method to match patients and donors. DNA testing allows patients and donors to be more closely matched. The goal is to find a match for at least six key antigens. The ability to identify donors is improving and some transplant centers are trying to match even more antigens.

The second factor in finding a matched unrelated donor may be the amount of representation of your ethnic or racial group in the registries. Because these antigen/tissue types are inherited, and some are unique to racial or ethnic backgrounds, the greatest chance of locating a donor may come from the same group. A lack of donors in your ethnic or racial group may make it more difficult to locate a match. Ambitious efforts to increase the number of minority donors on the registries are underway.

You do not have to have the same blood type as your donor to be a suitable match. If blood types are different, the patient will become the donor's blood type after the transplant. This is because the stem cells from a donor have been "programmed" to produce the donor's blood type and will continue to do that in their new environment.

A cord blood transplant may be a possibility if you meet specific criteria. The use of cord blood is based on the size of the unit as the number of stem cells required is based on the patient's weight. Some transplant centers are conducting research to combine multiple cord units for transplant in order to provide the necessary number of stem cells.

It is important to remember that it takes time to carry out a donor search. Your transplant center manages the search and will inform you of the results. If you've been told there are potential unrelated donor matches for you, more time is required to identify the best matched donor. A formal search begins to narrow down candidates and generally takes several weeks or months (a cord blood search usually takes less time). If a donor is located, willing, and eligible, then final evaluation begins. If no suitable matches are found, other strategies need to be discussed with your doctor.

Bone Marrow Stem Cell Transplant

Stem cells are collected from the patient's or donor's bone marrow. Historically, this has been the "traditional" transplant and requires general anesthesia in an operating room. Stem cells are collected from the hip bone. When stem cells are collected from the bone marrow, a large needle is inserted into the back of the hipbone and marrow is withdrawn. The hip bones in the pelvis are marrow-rich bones. Since this procedure is performed under anesthesia, the donor doesn't feel anything during the marrow collection but may experience some discomfort in the back area for a few days afterward. About 5–10% of the donor's marrow is

withdrawn, an amount that the body easily replenishes within just a few weeks. This process is known as bone marrow retrieval (sometimes referred to as a “harvest”) and is done in an outpatient surgery center.

Peripheral Blood Stem Cell Transplant

When stem cells are taken from the circulating blood, the procedure is more like a blood donation. The stem cells in the circulating blood are called peripheral blood stem cells (PBSC). Like the stem cells in the bone marrow, they are able to divide and produce red cells, white cells and platelets. The concentration of peripheral blood stem cells in the blood, however, is very low. In order to collect them, medications known as colony stimulating factors or growth factors are given to the donor to stimulate the bone marrow to produce more stem cells, which are then released into the blood stream. The growth factors are administered as injections under the skin daily for a maximum of five days duration. Once they are in the blood, these stem cells are collected in one or more sessions normally taking four to six hours each. Stem cell collections are performed as outpatient procedures. Donors should plan to spend most of the day in the hospital on the day of collection. In this procedure, which is called apheresis, the blood circulates through a machine called a cell separator that removes the peripheral stem cells and returns the rest of the blood to the body. The stem cells are then stored and frozen until the time of the transplant for autologous bone marrow transplants. If the stem cells are collected from a related or unrelated donor, they are given immediately.

Cord Blood Transplant

Since the first cord blood transplant (CBT) in 1988, tremendous strides have been made in this field. Generally, CBT is not offered as a treatment option outside of clinical trials. It is mainly offered to children or young adults who meet the criteria for enrollment in these clinical trials. However, recently conducted research trials have demonstrated suitability of cord blood transplants in a selected group of adult patients. Since the number of stem cells required for transplant are based on body weight, most CBT’s are used with patients weighing less than 90 pounds. To overcome this limitation, some transplant centers are conducting clinical trials in which two different cord blood units are combined. There are far-reaching applications for the use of umbilical cord blood stem cells for transplant. The advantages are many. It can be frozen, stored, and readily available. Cord blood also poses a lower risk of graft-versus-host disease (GVHD) and when GVHD does occur, it seems to be milder.

Umbilical cord blood is a rich source of stem cells. The umbilical cord stem cells, instead of being discarded, may be removed from the placenta and

attached umbilical cord after delivery of a baby. This procedure poses no danger to the mother or child's health. The cord blood unit can then be frozen and stored for future transplant. Arrangements for the collection of the cord blood unit must be made several months prior to the expected date of delivery. Unless there is an existing reason to save a cord blood unit for a family member, the current medical recommendation advises against long-term cord blood storage. However, some hospitals allow parents the opportunity to donate their child's umbilical cord blood to an unrelated donor registry. Interested parents should speak with their doctor about this option. Improved coordination of the cord blood registries and increased cord blood unit donation will help in identifying suitable cord blood products. CBT may be particularly valuable in meeting the desperate need for stem cell donors in minority groups. Readers are advised to discuss the most recent recommendations for CBT or cord blood donation with their physician to keep up with the latest findings.

Transplant Variations

Like other medical science fields, as more is learned about various diseases, new strategies are considered. Stem cell transplant holds great promise. The number of people who benefit from transplant continues to grow. Some remarkable techniques and newer trends in stem cell transplant include:

Non-myeloablative Transplants

One treatment option is the non-myeloablative transplant, sometimes referred to as a "mini" or reduced intensity transplant. The non-myeloablative transplant utilizes lower doses of chemotherapy and radiation. The donor's cells and patient's cells "co-exist" in the body for a while and work together to fight cancer cells. Non-myeloablative transplants often require a matched donor. In some cases a mismatched donor may be used. This procedure is a promising option for older patients or those who might not be able to tolerate full dose treatment. People who do not have cancer, but rather an inherited immune blood disorder or an immunodeficiency, may also benefit from this treatment. Strategies are being evaluated, and researchers are "cautiously optimistic" about the non-myeloablative transplant option. Because data are not yet complete, it is too early to offer long-term success rates.

Tandem Transplants

These are specifically timed autologous transplants designed to prevent the disease from returning at a later time. Enough stem cells are collected (prior to first transplant) to rescue the patient after two sessions of high dose chemotherapy/radiation.

T-Lymphocyte Depletion

In some cases, the stem cells that are collected undergo a process known as T-lymphocyte depletion. In this process, T-lymphocytes, a type of white blood cell, are removed from the stem cells before they are given to the patient. This is done to reduce the incidence of graft-versus-host disease (GVHD), which is caused by the new immune system attacking healthy cells in the patient because it does not recognize the patient as “self.” Removing the T-lymphocytes makes it less likely that the new immune system will mount an attack against the patient.

However, T-lymphocytes are also beneficial as they help the donated stem cells take hold or engraft, and they play a role in reducing the risk of relapse. Although T-lymphocytes pose a risk to the patient because they attack healthy cells — as in GVHD — they also attack residual cancer cells in a process known as graft versus leukemia effect, thus reducing the risk of relapse.

Donor Lymphocyte Infusion (DLI)

This presents a new strategy for managing relapse after SCT for patients with hematological malignancies such as CML, AML or ALL. The patient does not require chemotherapy or radiation prior to this therapy. DLI is associated with significant risk due to graft-versus-host disease and low white blood cell count that increases the patient’s susceptibility for infection and bleeding.

In the future, DNA technology (gene testing) will lead to a better understanding of what triggers malignancies in the body’s cells, and high doses of chemotherapy may be replaced with new treatment options.

Second Transplants

A second transplant may be recommended if a disease returns following transplant or if the donor’s cells do not engraft. The type of treatment and source of cells will depend on the circumstances. This generally poses increased risk as the patient has already had extremely high doses of chemotherapy/radiation or a prolonged period of being immune compromised. In some cases, following an autologous stem cell transplant, a second transplant using donor cells may prove beneficial for treating relapsed disease.

Your doctor will discuss with you what type of transplant and what source of stem cells is best for you. Many factors determine the type of transplant including the disease being treated, previous treatments, age, general health, donor availability, and method of stem cell collection. It will be up to you and your doctor to decide how the transplant is handled. Whatever method is used for the stem cell collection, the desired outcome is the same—that the retrieved stem cells will flourish in the recipient.

Clinical Trials

Part of making an informed decision about having a stem cell transplant involves learning about clinical trials, which test new approaches, new drugs, and new protocols. These are long-term research studies that evaluate promising treatments for cancer and other diseases treatable by stem cell transplants. Transplant-related side-effects and complications are also being studied. Clinical research studies are conducted in several forms. These include national studies sponsored by the National Institutes of Health, single institution studies, and cooperative studies between institutions.

Clinical research studies validate new treatment in three phases. Phase I research studies establish optimal dosage. In phase II research, safety and effectiveness are carefully defined. Phase III studies compare and contrast a new treatment with standard treatment. In this phase, patients who participate are randomly assigned to receive one treatment or the other.

The potential benefits of participation in a clinical trial include:

- Specialized care and strict adherence to protocols
- Careful monitoring during treatment and close follow-up afterward
- Being among the first to benefit from new treatments
- Treatment expenses may be lessened

The potential drawbacks of participation may include:

- Unknown side effects
- May not be right for you
- Insurance coverage may be inadequate

Ask your doctor or medical center to locate where clinical research studies are being conducted. One source for a listing of independent clinical trials is the Physician's Data Query (PDQ). It is a computer database focusing on cancer treatment information. To find out about these studies, contact the National Cancer Institute (see Resource Listing).

Preparations for the Transplant

Once the decision has been made to have a stem cell transplant, lots of preparation is needed. On an emotional level, preparing for a transplant may entail spending time with friends and family or taking time out to be alone to experience one's feelings about the transplant. On a physical level, this may mean eating a healthful diet, getting good dental care, and maintaining an exercise routine. On a practical level, it may mean choosing a transplant center, organizing caregiving arrangements and obtaining items for a hospital stay.

As indicated, selecting a transplant center will be a big decision. Talk to your doctor and check with the insurance company to learn about your options. Family factors may influence your choice of centers. Foremost, choose a center that has a good amount of experience with your type of disease and in performing transplants. Do your research and ask questions. If possible, visit the medical center before your transplant.

There are distinct advantages to having the transplant at an experienced medical center with an excellent track record. If, however, there is no center near your home, you have concerns about the center's reported outcomes, or the center has performed too few of the kind of transplant you need, then the choice may be more difficult. Calling the National Marrow Donor Program (NMDP) to get a listing of centers performing unrelated stem cell transplants is an excellent way to get initial information. The NMDP Transplant Center Access Directory contains phone numbers and addresses of most transplant centers with information about the number and type of transplants performed at each center as well as some statistics about survival rates at each center. Additionally, BMT InfoNet offers a comprehensive listing of transplant centers on its website (see Resource Listing).

Other important considerations may include insurance coverage, proximity to family, follow-up care, and living arrangements should you select a center away from home. Signing on to stem cell transplant bulletin boards or newsgroups on the Internet can be another useful way to get information. It may be helpful to get personal accounts and recommendations, but beware that this can also result in "misinformation." Your health care team should be relied upon for the most accurate medical advice.

Help get yourself and your family prepared to meet the transplant challenge. Put together a notebook or binder to record information from your doctor visits and/or take a tape recorder along with you. Take a family member or friend with you during discussions with your medical team. They'll provide backup support in understanding what was said. Don't hesitate to voice concerns.

Aside from the physical examinations and testing that you'll undergo, family and "support team" readiness is very important. Planning and discussions between hospital staff and family will be helpful. Questions about finances, employment, delegating responsibilities, and more should be addressed within a family setting. Prepare children (as patients themselves or as children of patients) to cope with the transplant. This is done through education and simple (not scary) discussions about the procedure. Frequently offer children a chance to ask questions about the transplant. Request age-appropriate material from your health care team to help children understand. Attend information or educational sessions at the transplant center to learn about what you can expect before and after transplant.

The Transplant

Stem cell transplants are different from other transplants. There's no surgery for the patient on the day of the procedure. Stem cells are infused intravenously. This occurs in the patient's hospital room. Many patients and their families, in fact, find the actual day of the procedure to be somewhat anticlimactic. Some of your transplant's biggest challenges may actually occur in the days leading up to the big event when you receive your chemotherapy and/or radiation.

Just prior to the transplant, you'll receive high doses of chemotherapy and/or radiation, referred to as a "conditioning regimen" to destroy diseased cells in the body. The chemotherapy and/or radiation will also destroy the stem cells in your marrow, severely weakening the immune system. Until the new cells take over, you'll be susceptible to infection. Every precaution should be taken to guard against bacterial, viral, and fungal infections. As the stem cells that have been transplanted begin to produce white blood cells, the risk of infection declines. The term "immune compromised" refers to your immune system when it is functioning at less than 100% due to the effects of chemotherapy and/or radiation. This compromised state varies from patient to patient and may last from six months to a year or more after the transplant.

Receiving chemotherapy and radiation is an important part of the treatment and during this time you will be carefully monitored. You can help your medical team during this period by letting them know if you experience anything unusual, and are feeling pain or other symptoms. Be a good communicator. Conversations with your health care team are particularly important at this time.

On the day of transplant, you'll receive the stem cells that were taken from either you or a donor through an IV (intravenous) just like any blood product or medication. It takes one to two hours for the infusion. In an amazing process, stem cells will travel through the bloodstream and migrate to the marrow space in the bone. They know exactly where to go. The stem cells from the transplant should begin producing life-sustaining blood cells in about two to four weeks. When peripheral blood stem cells or cord blood stem cells are used, this generally occurs somewhat more quickly. You will be monitored frequently for any reaction to the infusion, but in most cases the process is uneventful. While unlikely, it is possible that your body will not allow the stem cells to grow. This is referred to as graft rejection or graft failure, which is a serious complication requiring additional treatment.

It is only natural to wonder about other problems that can arise. Some complications that may occur in the weeks following your transplant are:

- Infection (from immune system deficiency)
- Hemorrhage (from lack of platelets)
- Organ damage (from chemotherapy and/or radiation)

In allogeneic transplants, when the cells of the new marrow are from a related or unrelated donor, you may also have complications from graft-versus-host disease (GVHD). This condition occurs when the new stem cells perceive your body as foreign and attack the tissues and/or organs of your body. (“Graft” refers to the donated stem cells and “host” is the patient). This response occurs because, despite the best efforts to have a match, there are some genetic differences between you and your donor. GVHD may compromise the ability of tissues and/or organs to work properly, and it increases the risk of infection. The areas most often affected are the skin, liver, and gastrointestinal tract. GVHD may present itself in either an acute form (within a few months after the transplant) or in a chronic form (up to several months later). This is not uncommon. Severity of GVHD may vary from mild cases of a temporary nature to more serious problems that, in the extreme, can become life threatening. GVHD is managed through a variety of immune suppressing medications that can be administered to control acute and chronic graft-versus-host disease for an extended duration of time.

Although no one would look forward to getting GVHD, a mild acute case may actually be good. It will cause an immune response against any foreign tissue, including any cancer cells in the body that have not been destroyed by chemotherapy, radiation, or the patient’s own immune system. This is why, in some patients, an allogeneic transplant is preferred over an autologous or syngeneic transplant. If patients do not develop GVHD, then their immunosuppressant medication is tapered off in the six months after transplant.

Pediatric Transplants

Although the technical transplant process may be similar, children and teenagers having a stem cell transplant have particular needs and different concerns than adults. Vital to all areas of transplant is communication. Children need to receive information that is appropriate to their age and stage of development. Teaching children about their disease and treatment, in words they can understand, helps them cope. Protecting them from information may worsen the situation because they may imagine things to be much worse than they really are. Listen to their questions and answer with reassurance and honesty. Allow your child to express emotions and help him/her to keep a positive attitude.

One area of concern in children undergoing stem cell transplant is growth and development. The physical effects of treatment and environmental restrictions after transplant may impact their growth and cognitive or emotional development. A challenge for parents and medical personnel is to promote the normal aspects of the child’s life. Many hospitals have programs providing recreational and

educational opportunities as well as emotional support. This helps children deal with illness and may promote their well-being.

The siblings of children who undergo a stem cell transplant are also a group to be concerned about. Siblings may experience feelings of jealousy or anger about the extra time and attention given to the ill child. The best way to help these children deal with their feelings is to provide honest, age-appropriate information about the patient's condition and treatment. It may be helpful to have siblings visit the clinic or hospital in order to help them understand what the sick child is experiencing. Many times a child's imagination is filled with incorrect information. Siblings need special attention, support, and many opportunities to talk about their feelings and fears in order to best cope with the impact and concern of having a brother or sister with cancer.

Some wonderful resources are the pediatric social worker or child life specialist at your treatment center. These professionals have special training in age-appropriate communication with children and in family dynamics. SuperSibs! is an organization that can provide additional information (see Resource Listing).

Emotional Considerations

Certainly emotions may be heightened at this time. Undergoing SCT may be an anxiety-provoking experience. It requires much from the patient, his/her family and friends, both physically and emotionally. Virtually everyone experiences some degree of apprehension and fear throughout the process. It is common to feel alternating emotions such as worry, hope, anger, excitement, fear, or even self-pity. Learning about the anticipated course during hospitalization and possible complications can certainly cause anxiety for patients and their relatives, but knowing this information is extremely important. Most transplant centers provide handouts or other resource materials about possible transplant complications. Patients and their families are strongly encouraged to review this information prior to transplant. As frightening as it may seem, knowledge brings with it power and a sense of control.

Patients and their caregivers should consider ways of coping that they find helpful. Asking for help to get through this experience is normal and appropriate. If you feel that your level of stress is overwhelming, discuss this immediately with your physician. All patients will be seen by a social worker prior to transplant. Professional help can positively impact your emotional well-being and will directly and indirectly impact your overall treatment experience. Although there are many different ways of coping, you might find the following suggestions helpful:

- Acknowledge your feelings. It is unrealistic to expect yourself to be positive all the time. Be honest about how you feel, and then begin to plan out first steps in coping with your difficult situation.

- Make time for activities that will make you feel emotionally stronger. It is okay to want a greater connection to your loved ones and yet at other times, feel the need to be alone.
- Support from others may be a key factor in predicting how well a person will cope with a difficult treatment. Asking others to help may actually reduce a sense of helplessness. Look into all possible resources for help. Let people know exactly what they can do to help you. Talk about your specific needs. Create a list of tasks and designate responsibilities to others if possible.
- It is important to have multiple caregivers in order to avoid stress and exhaustion among caregivers. Patients have frequent follow-up appointments in clinics after they are discharged from the hospital. Frequency of these appointments can vary among patients and depends on the level of care required. Patients are not able to drive on their own for several weeks and require a reliable means of transportation.
- Focus on the issues that bring meaning to your life—your religion, spirituality, interests, or passions.
- Use your strengths. Capitalize on the positive coping skills that have worked for you in the past. Perhaps it was physical exercise, taking a walk, speaking to friends, or spending time on a favorite hobby. If you are feeling overwhelmed, seek help from a mental health professional or support group.
- Remind friends that your family may need extra support too. Encourage others to offer help to your family.

Often patients and families facing a transplant appreciate being “linked” to a stem cell transplant peer support volunteer. This is someone who has had a transplant and is willing to share his/her personal experience. By listening to someone else’s story and their practical suggestions, you can often better prepare for your own journey. The National Bone Marrow Transplant Link and other organizations have established services that create this match-up whether by phone, e-mail, or written correspondence. It is helpful for caregivers as well to talk to others in similar circumstances. This peer to peer support may be an important complement to medical care (see Resource Listing).

The Role of the Caregiver

During the transplant process, you will need at least one family member or a friend who can provide you with emotional and physical support. This person is often referred to as a caregiver. In many cases, it will only be possible for you to have one caregiver with you during the week. If this is the case, you may consider arranging alternate caregiver support during weekends so that the caregiving task does not fall on just one person. Ideally, however, you may be able to arrange to have more than one caregiver as the role can be very demanding.

Even though many people successfully make it through the transplant with only one caregiver, having two or more caregivers is an advantage. This allows each caregiver a time to rest and return to the hospital more refreshed. Since caregivers may experience a high degree of anxiety, sharing the responsibility of caring for you can serve to alleviate some of the tension. Finally, having more than one caregiver provides a safeguard in the event that a caregiver gets sick and is unable to be on the transplant unit.

Your caregivers are very actively involved during the pre-transplant and post-transplant process. Their responsibility after discharge from the hospital significantly increases as they are required to alter their lifestyle and needs to assist you. It is important that caregivers are provided emotional support and monitored for signs of distress and fatigue. The role of a caregiver may include:¹

- Providing emotional support
- Providing physical care during and after hospitalization
- Caring for the central line (catheter)
- Helping with administration of oral medications
- Recording the medications taken
- Giving intravenous fluids and medications using a pump device
- Identifying changes in the patient's condition
- Obtaining medical care if needed
- Reporting symptoms to health care staff
- Gathering information
- Keeping family members and friends up-to-date about the patient's condition
- Monitoring the number of visitors
- Maintaining a clean home environment after hospitalization
- Preparing food
- Providing transportation to and from the hospital for follow-up care

Knowing that your caregiver is well prepared for his/her responsibilities may give you greater confidence. Organizations exist that support caregiver needs, and it may be worth the time to contact these groups. Sharing unique concerns with other caregivers and receiving mutual support can help. Check if caregiver discussion groups are offered at the transplant center. This is a good place to voice concerns and get practical suggestions about caregiver responsibilities. Caregivers won't want to burden the patient with additional problems, and these groups may provide needed support for them (see Resource Listing).

¹ "Patient and Caregiver Manual," Fred Hutchinson Cancer Research Center Transplant Program

Selecting a Caregiver

The most important consideration in selecting a caregiver is to make sure that your primary caregiver is someone you feel comfortable with and is someone who cares deeply for you. Other things you may wish to consider include whether or not the caregiver will feel comfortable in a hospital environment. Most SCT units have workshops to train caregivers in necessary skills and are also able to provide additional help with certain tasks for those who need it.

Costs

Understandably, the prospect of a transplant is stressful enough without worrying about finances too. But, the reality is that transplants are costly. Aside from medical costs, there may be additional out-of-pocket expenses. The financial burden on a family may become difficult if advanced planning is neglected. If you can anticipate expenses, you may plan for how they will be met. A preliminary list of expenses, other than those covered by insurance, might include:

- Lodging for follow-up care
- Follow-up office visits
- Home care, house cleaning following transplant
- Childcare
- Prescriptions
- Transportation and parking
- Telephone costs
- Over-the-counter medications and related supplies

If your transplant requires that you must search for a related or unrelated donor, expect to incur the following kinds of expenses:

- Donor search fees: A preliminary search of donor and cord blood registries is done free of charge by your doctor or SCT coordinator. Charges will begin when donors or cord blood units are tested. Two donor/cord blood unit registries in the U.S. are the National Marrow Donor Program (NMDP) and the Caitlin Raymond International Registry. Several other registries also exist (see Resource Listing).
- Your transplant center will assist you in determining if your insurance will cover the testing of donors. If you don't have this coverage, you'll be told of your financial responsibility. It may range from \$10,000 to \$25,000.
- Compatibility testing: Once a potential donor is identified, additional testing will be performed. Prices for these tests vary. Some centers require advance payment to cover these compatibility tests. Frequently more than one test is

done. Unused portions of this initial fee are typically refunded or transferred to another of your patient accounts. These fees may or may not be reimbursed by insurance or government agencies.

- **Donor typing of family and friends:** There is a fee for each test done. This is due to the cost of lab work. Siblings are tested first and then other family members may wish to be tested. Insurance companies will generally cover testing of siblings, parents and children but not additional family members.

Stem cell harvest and donor expenses: The cost of the actual collection of cells from the donor, his/her medical tests, and possible travel expenses may be high. Usually there is a fixed fee for the collection and delivery of stem cells. The average rate is about \$3,500–\$5,000 if it's a related donor. The average rate for an unrelated donor is \$15,000–\$50,000. Donors are not paid for any part of their stem cell donation. All of their medical and traveling expenses are covered by the patient's insurance so that there are no costs to the donor.

The actual transplant: The procedure is expensive. Insurance companies vary widely on coverage. It is possible that much of your transplant, if not the entire cost, will be covered. Call your insurer to check on your coverage or have your transplant center make the contact. If your insurer refuses to cover expenses, be persistent and consider speaking with legal counsel or someone with expertise in the insurance field (see Resource Listing).

Post-transplant: It's difficult to predict your expenses after the transplant. Much will depend on your recovery time, which may range from six months to a year. Your insurance company will probably cover testing and may also cover follow-up visits. However, there are many out-of-pocket expenses. Medications can be very costly, especially if you do not have prescription coverage. Ask about your coverage prior to transplant.

Costs may vary depending on your treatment center. Although the center may not be able to quote you an exact dollar amount for your transplant, do request a general estimate for what you can expect to pay. This is especially important if your insurance coverage is limited.

In general, transplant costs have declined over the years. This is due, in part, to the increased use of outpatient care. The rise in the number of autologous stem cell transplants, where donor expenses may be eliminated, is another cost reduction factor. An autologous transplant may range from \$50,000 to \$100,000 depending on the circumstances. An allogeneic transplant may range from \$150,000 to \$200,000 (see Insurance).

Insurance

Check your insurance coverage early. The transplant center will start the insurance approval process by sending your health insurer a letter

requesting pre-approval of your treatment. The insurance company may request a complete history of your physical condition, a copy of the treatment protocol, the hospital's informed consent document, your laboratory and x-ray results, and your physician's recorded treatment recommendation. Make certain that these materials are sent out promptly, if requested.

Get a copy of your insurance policy if you don't have one. If you are insured through work, your employer is required to provide you with a copy of your policy. Review it carefully to determine what is covered and what is excluded. If you are uncertain about your coverage, ask your medical provider or insurance representative to explain it. You will want to determine if donor searches and cost for collection of cells are covered. Sometimes it is not specifically stated in a policy. Clinical trials may or may not be covered by insurance. It is important to check with the insurance company prior to entering a clinical trial.

If your insurance company rejects coverage of the stem cell procedure, ask for a written explanation. Find out how to appeal this denial. Whether there is an appeal process or not, ask your doctor or hospital to formally request coverage again. Many times, an insurer will reverse its position, especially if there is a second reviewer or if you are undergoing this treatment as part of an approved clinical trial. Be sure to comply with the time requirements. Ask for the appeal in writing and send it certified mail, with return receipt requested. See if your doctor will supply medical information that supports the treatment and include it with the appeal.

If there is notice of an appeal, and you cannot get a quick reversal, continue to follow the appeal process. At this point, your doctor and transplant center should also be providing the insurer with scientific support information and include a listing of other institutions now providing this procedure. Be persistent. The "paper trail" between your transplant center and your health insurer may become very important if coverage is denied. Organize your own paper trail file.

If your health insurance is paid through your employer, ask if they can and will make efforts to help. Sometimes the employer may pay for treatment rather than work with the insurer. At other times, the employer can put pressure on the insurer, particularly if the employer spends a lot on health benefit coverage.

At some point, it may be advisable to consult an attorney. The attorney will require information to determine if the insurer is being discriminating in its policies. It is possible in some areas that laws protecting disabled persons may apply. The definition of who is disabled or handicapped could cover the patient in some cases. Should you require the help of an attorney, consult one who specializes in insurance denials.

Individuals at insurance companies generally want to assist you. Case managers, for example, can be very helpful to patients. Often medical directors, who are

physicians, make the decisions about what would be the best care. Approaching them as people who want to help is the best way to begin.

There are also government agencies, at the federal level, such as the Equal Employment Opportunity Commission, and at the state level, such as the Commission on Human Rights, which are designed to help the average citizen. These agencies are “user-friendly,” which means that you can personally go to the agency and speak to an investigator about your problem. Sometimes they might even be willing to file suit for you.

Medicare and Medicaid

If you are a Medicare or Medicaid patient, contact the treatment center’s social worker or patient financial services to discuss your options. They will work with you to understand what coverage is offered. If you are rejected coverage, ask to be informed of your appeal rights. You have the right to appeal the denial of a service that is medically necessary. If you have Medicare, make sure the transplant is conducted in a Medicare-friendly facility. Call 800-MEDICARE if you have questions about your coverage, or contact the Medicare Rights Center (see Resource Listing).

Financial Aid

There are some places you can turn to for help with transplant expenses. While there are no agencies or organizations that will absorb the full cost of a transplant, some relief is possible. Ask a social worker at your treatment center for the names of those that you might contact. Check with nonprofit organizations affiliated with your disease. Make applications for reimbursement for mileage, lodging and even some prescriptions (see Resource Listing).

If the transplant is for a minor child, contact your state department of health. Many states have Children’s Health Care Services, which provide substantial financial aid or insurance coverage, regardless of your income. Sometimes monthly supplemental payments might be required from you.

If insurance coverage is minimal for your transplant, you may need to raise funds to help pay for your treatment. It is important to begin fundraising efforts early. There are several nonprofit organizations that specialize in helping patients raise funds (see Resource Listing). These organizations help arrange fundraisers and maintain accounts to which tax-deductible contributions can be made on a patient’s behalf. Another benefit of working with such groups is that they may provide encouragement and emotional support. Also, check with civic, service, or religious groups for help.

Some considerations for successful grassroots fundraising include:

- Be well organized. Appoint a leader and committee who will oversee a project and take responsibility for getting it accomplished. The patient should not serve as chairperson of his/her own fundraising campaign.
- Have a dedicated group of volunteers.
- Keep volunteers motivated.
- Inform donors how money is directed.
- Have a variety of fundraising projects.
- Publicize your efforts in the community.

If you are going to fundraise, estimate how much money you will need. First, be sure that none of these costs will be covered by insurance. Are you eligible for medical assistance programs? Have you discussed getting help from your employer? Form a volunteer group to manage fundraising projects. Information on fundraising can be found at the public library, from your transplant social worker, or from an organization like those found in the Resource Listing.

Conclusion

There will be a number of issues, medical and non-medical, following your stem cell transplant that you and your family may address. These may include concerns about caregiving, the transition home, employment, sexuality, nutrition, fatigue, possible setbacks and others. The National Bone Marrow Transplant Link provides the following resources that address these concerns in detail and offer many practical suggestions: *The Survivors' Guide to Bone Marrow Transplant, What to Expect and How to Get Through It* by Keren Stronach; *Caregivers' Guide for Bone Marrow/Stem Cell Transplant, Practical Perspectives*; and *The New Normal: Life After Bone Marrow/Stem Cell Transplant*, a compelling, Emmy Award-winning video about six transplant survivors.

The majority of SCT patients return to a “new normal” and active lifestyle after transplant. Others have some lingering effects but do not experience significant deterioration in their quality of life. So, begin this life journey with a better understanding of what to expect and how best to manage the way through it.

Keep in mind throughout this experience that you are not alone. The inspirational comments below may help you through the challenges ahead:

“Reducing the anxiety, I think goes to this idea of hope. If I can be well enough prepared, if I can know enough about this to feel some control over it, then I think I’m going to have more hope.” — Marla, SCT survivor

“People need to know that they can do this. It may not sound like something they want to do, but they need to know they can do it, and that they can do it with the help of their health care team and the people around them who are important to them.” — Pat, SCT nurse

“I believe that people should look at the transplant process as a minor interruption in their lives. I think that if you just hold on to hope, it kind of helps you through the day, and maybe that’s all you need to do is get through the day. And then the next day, get through that day. And once I learned to do that, it became much easier to take each day at a time, and before I knew it, the whole process was over.” — Juanita, SCT survivor

“You have to believe in a lot of things. You have to believe in the people around you; you have to believe in yourself, so that you can muster up all of the strength it’s going to take to get through.” — Julia, wife and caregiver of SCT survivor

“You need to be patient. So you just have to keep your eye on the future, but take the time necessary to heal your body. It takes a long time.” — Harry, SCT survivor

“It is a life-changing experience, there’s no question about that. And it’s hard to believe that you will grow from this and that the change could be positive, but it is.” — Marla, SCT survivor



Glossary

Adjuvant chemotherapy—Drugs used to kill cancer cells. They are given with other treatments, such as surgery or radiation, to destroy areas of tumor.

Allogeneic transplant—The person donating the bone marrow or stem cells is a closely matched family member, usually a brother or sister. Or the person donating the bone marrow is a closely matched unrelated donor.

Alopecia—A partial or complete hair loss, usually a temporary side effect of the chemotherapy.

Anemia—A condition that occurs when the body's red blood cell count is low.

Antibody—A protein produced by the white blood cells (leukocytes) to battle foreign substances that enter the body, such as bacteria.

Antigen—A foreign substance that induces the production of antibodies.

Apheresis—The peripheral blood stem cell collection process in which blood is taken from a patient and circulated through a machine that separates out stem cells. The remaining cells are returned to the patient.

Appeal—Application for review of records, medical history, insurance claim.

Autologous transplant—The patient donates his/her own bone marrow or stem cells prior to treatment for reinfusion later after high doses of chemotherapy and/or radiation.

Bone marrow—The spongy tissue found in the cavities of the body's bones where all blood cells are produced.

Bone marrow harvest—The procedure of collecting stem cells from the bone marrow.

Bone marrow transplant (BMT)—A procedure developed to treat some forms of

cancer and other diseases. There are several types of BMT's, depending on who donates the marrow (see Autologous, Allogeneic, and Syngeneic). Stem cells are removed from the bone marrow for transplant.

Cancer cells—Uncontrolled growth of abnormal cells in the body. Cancer cells can grow, divide, and invade normal tissue in the body.

Cell—The basic building block of life. In your blood, you will find many different types of these.

Central line or central venous catheter—A small, plastic tube inserted in a large vein to inject or remove fluids. The central line used in stem cell transplant allows blood samples to be drawn, drugs to be given, and the actual transplant to occur with little discomfort.

Chemotherapy—Treatment with one or more anticancer drugs to try to stop or slow the growth of cancer cells.

Clinical trials—Long-term research studies that test cancer treatment.

Colony stimulating factor—The drug given to autologous stem cell transplant patients before and during the harvest to increase the number of stem cells in the blood. It is also given to allogeneic donors to increase the number of cells in the circulating blood so they can be collected for transplant. Also called growth factor.

Complete Blood Count (CBC)—A blood test done in a laboratory to find out the number of red blood cells (RBC's), white blood cells (WBC's), platelets, hemoglobin, and hematocrit in your blood. These blood cells are made in the marrow of your bones.

Conditioning—A phase in the bone marrow/stem cell transplant process designed to destroy cancer cells more

effectively than standard doses of chemotherapy. Conditioning involves combining high doses of chemotherapy and/or radiation.

Cord blood—Blood found in the umbilical cord.

Cord blood transplant—A procedure where umbilical blood stem cells are used in a stem cell transplant.

CT (Confirmatory Typing)—This test confirms the HLA compatibility of the donor and the patient and is performed on all potential family or unrelated donors.

DNA—One of the nucleic acids found in the nucleus of the cell. It contains the information that allows a cell to grow and divide and become a unique (or particular type of) cell.

Engraftment—Process in which transplanted stem cells begin to grow in the recipient's bone marrow and produce new white blood cells, red blood cells, and platelets.

Erythrocytes—Red blood cells that carry oxygen.

Genes—Found in the nucleus of the cell. They contain the hereditary information that is passed on from cell to cell.

Graft failure—Complication after a transplant in which the stem cells do not grow in the recipient's bone marrow and do not produce new white blood cells, red blood cells, and platelets.

Graft-versus-host disease (GVHD)—A condition where transplanted stem cells may react against the patient's body. Symptoms may range from a minor skin rash to more serious problems resulting in life-threatening conditions.

Growth factor—(see Colony stimulating factor)

Harvest—(see Stem cell retrieval)

Hematocrit—The proportion of the blood that consists of packed red blood cells.

Hematologist—A doctor who specializes in the diseases of the blood.

Hematopoietic stem cells—Cells that mature into one of three types of blood cells: white blood cells, red blood cells, or platelets.

Hemoglobin—The part of the red blood cell which carries oxygen.

HLA (Human Leukocyte Antigen)—Antigens found on a person's cells that help the body to identify its own cells from invading or foreign cells.

HLA typing—The identification of a person's key antigens used for identifying compatible donors.

Immune compromised—A condition in which the patient has a much higher risk of infection due to a weak immune system.

Immune system—The group of organs and cells in the body that fight infection and other diseases.

Immunosuppressed—Lowered resistance to disease. It may be a temporary condition caused by a lowered white blood cell count or a side effect of receiving chemotherapy.

Informed consent—Hospital form, signed by the patient, which documents an understanding of medical procedures.

Infusion—Slow introduction of fluid into a vein referred to as an IV (intravenous).

Intravenous—Within a vein; into the vein.

Leukocytes—White blood cells that fight infection.

Lymphocytes—A type of white blood cell that is part of the immune system.

Metastasis—The spread of cancer from one part of the body to another.

Mobilization—Moving more stem cells from the bone marrow into the blood stream through chemotherapy and/or a growth factor.

MUD—Matched unrelated donor.

Oncologist—A doctor who specializes in the study and treatment of cancer.

Patient advocate—A person who acts in the best interest of the patient or serves the patient's needs and may act on his/her behalf.

Peripheral Blood Stem Cells (PBSC)—Stem cells that circulate in the blood.

Peripheral Blood Stem Cell Transplant—Stem cells are removed from the blood and infused after high-dose chemotherapy. This can be done for both autologous and allogeneic transplants.

Platelets—Blood cells that act as clotting agents to prevent bleeding.

Prognosis—The predicted or likely outcome.

Protocol—A specifically designed treatment plan.

Purging—The process of removing certain types of cells from the stem cell product before transplanting it to a patient. In autologous transplants, marrow may be purged of lingering cancer cells.

Radiation—Treatment to kill cancer cells using high-energy rays from x-rays, electron beams, or radioactive isotopes.

Red blood cells (RBC)—Cells carrying oxygen to all parts of the body (erythrocytes).

Reimbursement—Refund, being paid back for monies used out of pocket.

Reinfusion—The return of healthy stem cells into the transplant recipient's body.

Relapse—The return of cancer after a period of being cancer-free.

Remission—Complete or partial disappearance of cancer cells and symptoms.

Rescue process—Another term for a stem cell transplant. The re-infusion of healthy stem cells following high doses of chemotherapy or radiation.

Staging—The process of determining and describing the extent of the cancer.

Stem cell—The “parent cell.” Every type of blood cell in the body begins its life as a stem cell. The stem cells then divide and form the different cells that make up the blood and immune system. Stem cells are found in both the bone marrow and circulating blood.

Stem cell retrieval—The process of collecting stem cells from the circulating blood stream following administration of growth factors to increase their numbers. (Also called harvest).

Stem cell transplant—(see Peripheral blood stem cell transplant).

Syngeneic transplant—The person donating the bone marrow or stem cells is an identical twin.

Thrombocytopenia—Low platelet count.

Transfusion—The transferring of blood or blood products directly into a vein or artery.

White blood cells (WBC)—Cells that help fight infection and disease (leukocytes).

Resource Listing

Stem Cell Transplant Information and Support

BMT InfoNet

2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
888-597-7674 or 847-433-3313
Email: help@bmtinfonet.org
www.bmtinfonet.org

The Bone Marrow Foundation

337 E. 88th Street, Suite 1B
New York, NY 10128
800-365-1336 or 212-838-3029
Email: thef@bonemarrow.org
www.bonemarrow.org

Center for International Blood and Marrow Transplant Research (CIBMTR)

Health Policy Institute
Medical College of Wisconsin
8701 Watertown Plank Road
P.O. Box 26509
Milwaukee, WI 53226
414-456-8325
E-mail: cibmtr@hpi.mcw.edu
www.cibmtr.org

National Bone Marrow Transplant Link (nbmtLINK)

20411 W. 12 Mile Road, Suite 108
Southfield, MI 48076
800-LINK-BMT (800-546-5268) or
248-358-1886
Email: info@nbmtlink.org
www.nbmtlink.org

National Marrow Donor Program (NMDP)

3001 Broadway Street Northeast, Suite 500
Minneapolis, MN 55413-1753
800-MARROW-2 (800-627-7692)
888-999-6743 Office of Patient Advocacy
Email: questions@nmdp.org
www.marrow.org

Stem Cell Donor Information Including Bone Marrow, Peripheral Blood, and Cord Blood

American Indian/Alaska Native Initiative National Marrow Donor Program (NMDP)

3001 Broadway Street Northeast, Suite 500
Minneapolis, MN 55413-1753
800-627-7692
888-999-6743 Office of Patient Advocacy
Email: questions@nmdp.org
www.marrow.org

Asians for Miracle Marrow Matches

231 E. Third Street, Suite G107
Los Angeles, CA 90013
888-A3M-HOPE (888-236-4673)
Email: A3M@LTSC.org
www.asianmarrow.org

Caitlin Raymond International Registry

University of Massachusetts Memorial
Medical Center
55 Lake Avenue North
Worcester, MA 01655
800-726-2824 or 508-334-8969
Email: info@crir.org
www.crir.org

Cryobanks International

270 S. Northlake Boulevard, Suite 1012
Altamonte Springs, FL 32701
407-834-8333 or 800-869-8608
Email: clientservices@cryo-intl.com
www.cryo-intl.com

Gift of Life

7700 Congress Avenue, Suite 2200
Boca Raton, FL 33487
800-962-7769 or 561-988-0100
Northeast Regional Office: 212-790-4258
Israel Office: 972-2-930-9691
www.giftoflife.org

HLA Registry

A Division of Community Blood Services

800 Kinderkamack Road, Suite 300
Oradell, NJ 07649
800-336-3363 or 201-705-1799
Email: DanielleO@bcrbc.org
www.communitybloodservices.org

National Marrow Donor Program (NMDP)

3001 Broadway Street Northeast, Suite 500
Minneapolis, MN 55413-1753
800-627-7692
Email: questions@nmdp.org
www.marrow.org

New York Blood Center

310 E. 67th Street
New York, NY 10021
800-933-2566 or 212-570-3297
Email: webmaster@nybloodcenter.org
www.nybloodcenter.org

Siblings Donor Cord Blood Program

Children's Hospital & Research Center at
Oakland
5700 Martin Luther King Jr. Way
Oakland, CA 94609
510-450-7605
Email: cordblood@chori.org
<http://www.chori.org/siblingscordblood/>

TEPNEL Lifecodes

550 West Avenue
Stamford, CT 06902
800-915-3695 or 888-915-6527
Email: info@bonemarrowtest.com
www.bonemarrowtest.com

Cancer Information and Support

American Cancer Society

1599 Clifton Road, NE
Atlanta, GA 30329
800-ACS-2345 (800-227-2345) or
404-320-3333
Email: <http://www.cancer.org/asp/contactUs/>
www.cancer.org

CancerCare, Inc.

275 Seventh Avenue
New York, NY 10001
800-813-HOPE or 212-712-8080
Email: info@cancercare.org
www.cancercare.org

Cancer Information Service

National Cancer Institute (NCI)
6116 Executive Boulevard
Room 3036A
Bethesda, MD 20892-8322
800-4-CANCER or 800-422-6237
Email: cancergovstaff@mail.nih.gov
www.cancer.gov

Cancervive, Inc.

11636 Chayote Street
Los Angeles, CA 90049
800-426-2873 or 310-203-9232
Email: cancervive@aol.com
www.cancervive.org

Coping With Cancer Magazine

P.O. Box 682268
Franklin, TN 37068
615-790-2400
Email: copingmag@aol.com
www.copingmag.com

Cure Magazine

Cancer Information Group
3500 Maple Avenue, Suite 750
Dallas, TX 75246
800-210-2873 or 214-367-3500
Email: editor@curetoday.com
www.curetoday.com

Gilda's Club Worldwide

322 Eighth Avenue, Suite 1402
New York, NY 10001
888-445-3248
Email: info@gildasclub.org
www.gildasclub.org

Lance Armstrong Foundation/Livestrong

P.O. Box 161150
Austin, TX 78716-1150
866-235-7205 or 512-236-8820
Email: livestrong@laf.org
www.livestrong.org

Lotsa Helping Hands

365 Boston Post Road, Suite 157
Sudbury, MA 01776
978-505-0009
Email: info@lotsahelpinghands.com
www.lotsahelpinghands.com

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
877-NCCS-YES or 301-650-9127
Email: info@canceradvocacy.org
www.canceradvocacy.org

Vital Options International

TeleSupport Cancer Network
15821 Ventura Boulevard, Suite 645
Encino, CA 91436-2946
800-477-7666 or 818-788-5225
Email: info@vitaloptions.org
www.vitaloptions.org

The Wellness Community

919 18th Street, NW, Suite 54
Washington, DC 20006
888-793-9355 or 202-659-9709
Email: help@thewellnesscommunity.org
www.thewellnesscommunity.org

Women's Cancer Resource Center

5741 Telegraph
Oakland, CA 94609
888-421-7900 or 510-420-7900
Email: wrcr@wrcr.org
www.wrcr.org

Caregiving Support

Family Caregivers Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
415-434-3388 or 800-445-8106
Email: info@caregiver.org
www.caregiver.org

Friends' Health Connection

P.O. Box 114
New Brunswick, NJ 08903
800-483-7436 or 732-418-1811
Email: info@friendshealthconnection.org
www.friendshealthconnection.org

National Alliance for Caregiving

4720 Montgomery Lane, 5th Floor
Bethesda, MD 20814
301-718-8444
Email: info@caregiving.org
www.caregiving.org

National Family Caregivers Association

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
800-896-3650
Email: info@thefamilycaregiver.org
www.thefamilycaregiver.org

National Organization for Empowering Caregivers

425 W. 23rd Street, Suite 9B
New York, NY 10011
212-807-1204
Email: info@nofec.org
www.nofec.org

National Respite Locator Service

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
800-773-5433
www.respitelocator.org

Rosalynn Carter Institute for Caregiving

Georgia Southwestern State University
800 Wheatley Street
Americus, GA 31709
229-928-1234
Email: rci@canes.gsw.edu
www.rosalynncarter.org

Well Spouse Foundation

63 West Main Street, Suite H
Freehold, NJ 07728
800-838-0879
Email: info@wellspouse.org
www.wellspouse.org

Children's Programs and Services

Candlelighters Childhood Cancer Foundation

P.O. Box 498
Kensington, MD 20895-0498
800-366-2223 or 301-962-3520
Email: info@candlelighters.org
www.candlelighters.org

CaringBridge

3440 Federal Drive, Suite 100
Eagan, MN 55122
651-452-7940
Email: www.caringbridge.com/support.htm
www.caringbridge.com

Children With Leukemia c/o The Jennifer Lynn Stroud Foundation

14160 Dallas Parkway #300
Dallas, TX 75254
972-308-8383
Email: help@jlsfoundation.org
www.jlsfoundation.org

Children's Leukemia Foundation of Michigan (Michigan Residents)

29777 Telegraph Road, Suite 1651
Southfield, MI 48034
800-825-2536 or 248-353-8222
Email: info@leukemiamichigan.org
www.leukemiamichigan.org

Children's Leukemia Research Association, Inc.

585 Stewart Avenue, Suite 18
Garden City, NY 11530
516-222-1944
Email: info@childrensleukemia.org
www.childrensleukemia.org

Children's Organ Transplant Association (COTA)

2501 COTA Drive
Bloomington, IN 47403
800-366-2682
www.cota.org

Gilda's Club Worldwide

Noogieland
322 Eighth Avenue, Suite 1402
New York, NY 10001
888-445-9248
Email: info@gildasclub.org
www.gildasclub.org

Kids Cancer Network

P.O. Box 4545
Santa Barbara, CA 93140
Email: info@kidscancernetwork.org
www.kidscancernetwork.org

National Childhood Cancer Foundation

440 E. Huntington Drive, Suite 300
P.O. Box 60012
Arcadia, CA 91066-6012
800-458-6223 or 626-447-1674
Email: info@curesearch.org
www.nccf.org

National Children's Cancer Society

1015 Locust, Suite 600
St. Louis, MO 63101
800-5-FAMILY or 314-241-1600
Email: pfs@children-cancer.com
http://nationalchildrenscancersociety.com

Starbright Foundation

1850 Sawtelle Boulevard, Suite 450
Los Angeles, CA 90025
800-315-2580 or 310-479-1212
Email: info@starbright.org
www.starbright.org

SuperSibs!

4300 Lincoln Avenue, Suite I
Rolling Meadows, IL 60008
Toll Free: 866-444-SIBS(7427)
Illinois: 847-705-SIBS
Email: info@supersibs.org
www.supersibs.org

Fertility

American Association of Tissue Banks

1320 Old Chain Bridge Road, Suite 450
McLean, VA 22101
703-827-9582
Email: aatb@aatb.org
www.aatb.org

American Society for Reproductive Medicine

1209 Montgomery Highway
Birmingham, AL 35216
205-978-5000
Email: asrm@asrm.org
www.asrm.org

Fertile Hope

P.O. Box 624
42 W. 24th Street
New York, NY 10014
888-994-4673
Email: <http://www.fertilehope.org/contact/info.cfm>
www.fertilehope.org

Genetics and IVF Institute

3020 Javier Road
Fairfax, VA 22031
800-552-4363 or 703-698-7355
Email: givf@givf.com
www.givf.com

Resolve: The National Infertility Association

7910 Woodmont Avenue, Suite 1350
Bethesda, MD 20814
888-623-0744 or 301-652-8585
Email: info@resolve.org
www.resolve.org

***Financial Assistance,
Fundraising & Insurance***

America's Health Insurance Plans

601 Pennsylvania Avenue, NW
Washington, DC 20004
202-778-3200
Email: ahip@ahip.org
www.ahip.org

Cancer Legal Resource Center

Loyola Law School
919 S. Albany Street
Los Angeles, CA 90019-0015
213-736-1455 or 866-843-2572
Email: Barbara.schwerin@lls.edu

Children's Organ Transplant Association (COTA)

2501 COTA Drive
Bloomington, IN 47403
800-366-2682
Email: michelle@cota.org
www.cota.org

Medicare Rights Center

1460 Broadway, 17th Floor
New York, NY 10036
212-869-3850
Email: info@medicarerights.org
www.medicarerights.org

My Friends Care Bone Marrow Transplant Fund (Michigan Residents)

148 S. Main Street, Suite 101
Mt. Clemens, MI 48043
586-783-7390
Email: mfc@mich.com
www.myfriendscare.org

National Association of Hospital Hospitality Houses

P.O. Box 18087
Asheville, NC 28814-0087
800-542-9730 or 828-253-1188
Email: helpinghomes@nahhh.org
www.nahhh.org

National Foundation for Transplants

1102 Brookfield, Suite 200
Memphis, TN 38119
800-489-3863 or 901-684-1697
Email: info@transplants.org
www.transplants.org

National Marrow Donor Program

Office of Patient Advocacy
3001 Broadway NE, Suite 500
Minneapolis, MN 55413
888-999-6743
Email: patientinfo@nmdp.org
www.marrow.org

National Transplant Assistance Fund

3475 West Chester Pike, Suite 230
Newtown Square, PA 19073
800-642-8399 or 610-353-9684
Email: NYAF@transplantfund.org
www.transplantfund.org

Nielson Organ Transplant Foundation

(Northeast Florida Residents)
580 W. 8th Street, Suite 8000
Jacksonville, FL 32209
904-244-9823
Email: Nielsen@notf.org
www.notf.org

Patient Advocate Foundation

753 Thimble Shoals Boulevard, Suite 200
Newport News, VA 23606
800-532-5274 or 757-873-6668
Email: help@patientadvocate.org
www.patientadvocate.org

Pharmaceutical Research and Manufacturers of America

Prescription Drug Patient
Assistance Program
1100 Fifteenth Street, NW
Washington D.C. 20005
888-477-2669 or 202-835-3400
www.pparx.org

Disease-Related Information

Anemia

Aplastic Anemia & Myelodysplastic Syndrome (MDS) International Foundation, Inc.

P.O. Box 613
Annapolis, MD 21404-0613
800-747-2820 or 410-867-0242
Email: help@aamds.org
www.aplastic.org

Fanconi Anemia Research Fund, Inc.

1801 Willamette Street, Suite 200
Eugene, OR 97401
800-828-4891 or 541-687-4658
Email: info@fanconi.org
www.fanconi.org

Brain Tumor

American Brain Tumor Association

2720 River Road, Suite 146
Des Plaines, IL 60018
800-886-2282 or 847-827-9910
Email: info@abta.org
www.abta.org

National Brain Tumor Foundation

22 Battery Street
San Francisco, CA 94111
800-394-CURE or 510-839-9777
Email: nbtbf@braintumor.org
www.braintumor.org

Breast Cancer

Adelphi New York Statewide Breast Cancer Hotline and Support Program

Adelphi University School of Social Work
Garden City, NY 11530
800-877-8077 or 516-877-4444
Email: breastcancerhotline@adelphi.edu
www.adelphi.edu/nysbreastcancer

The Susan G. Komen Breast Cancer Foundation

5005 LBJ Freeway, Suite 250
Dallas, TX 75244
800-462-9273 or 972-855-1600
Email: info@komen.org
www.komen.org

Y-Me National Breast Cancer Organization

212 W. Van Buren, Suite 500
Chicago, IL 60607
800-221-2141 (English) or
800-986-9505 (Spanish)
Email: help@y-me.org
www.y-me.org

Immune Deficiency Disorders

Immune Deficiency Foundation

40 W. Chesapeake Avenue, Suite 308
Towson, MD 21204
800-296-4433
Email: idf@primaryimmune.org
www.primaryimmune.org

Leukemia & Lymphoma

The Leukemia & Lymphoma Society

1311 Mamaroneck Avenue
White Plains, NY 10605
800-955-4572 or 914-949-5213
Email: infocenter@lls.org
www.lls.org

Leukemia Research Foundation

(Illinois Residents or those within
a 100-mile Radius of Chicago)
2700 Patriot Boulevard, Suite 100
Glenview, IL 60026
888-558-5385 or 847-424-0600
Email: info@lrffmail.org
www.leukemia-research.org

Lymphoma Research Foundation

8800 Venice Boulevard, Suite 207
Los Angeles, CA 90034
800-500-9976 or 310-204-7040
Or
111 Broadway, 19th Floor
New York, NY 10006
800-235-6848 or 212-349-2910
Email: LRF@lymphoma.org
www.lymphoma.org

Multiple Myeloma

International Myeloma Foundation

12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421
800-452-2873
Email: TheIMF@myeloma.org
www.myeloma.org

Multiple Myeloma Research Foundation

51 Locust Avenue, Suite 204
New Canaan, CT 06840
203-972-1250
Email: info@themmrf.org
www.multiplemyeloma.org

Transportation

Air Care Alliance

1515 East 71st Street, Suite 312
Tulsa, OK 74136
888-260-9707 or 918-745-0384
Email: mail@aircareall.org
www.aircareall.org

Angel Flight America, Inc.

P.O. Box 17467
Memphis, TN 38187-0467
877-858-7788 or 901-332-4034
800-446-1231 (to request free flights)
www.angelflightamerica.org

Corporate Angel Network

Westchester County Airport
One Loop Road
White Plains, NY 10604-1215
866-328-1313 or 914-328-1313
Email: info@corpangelnetwork.org
www.corpangelnetwork.org

National Patient Travel Center c/o Mercy Medical Airlift

4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
888-675-1405 or 757-318-9175
Email: mercymedical@erols.com
www.patienttravel.org

Information on the Internet

The Internet is a valuable tool for cancer or medical research. It offers a wealth of information, some helpful, some misleading. Rely on credible sources for information, such as hospitals or medical associations. Proceed with caution when searching on the Internet. Evaluate material by asking:

- What is the source of this information?
- Is it fact or opinion?
- Is it based on someone's experience?
- How current is this information?
- Is this site set up to promote a product?

When evaluating Internet sites, check the address (URL). The final segment of the address offers a general idea of who is sponsoring the Web site. Examples include:

.edu ...site sponsored by an educational institution

.gov ...site sponsored by a government agency

.org ...site sponsored by a nonprofit organization

.com ...site sponsored by a commercial company

Alternative and Complementary Medicine

National Center for Complementary and Alternative Medicine

www.nccam.nih.gov

National Institute of Health Office of Dietary Supplements

<http://dietary-supplements.info.nih.gov>

Office of Cancer Complementary and Alternative Medicine

<http://cancer.gov/cam/index.html>

Caregiving

Family Voices

www.familyvoices.org

Strength for Caring

www.strengthforcaring.com

Today's Caregiver Magazine

www.caregiver.com

Children

2bMe

www.2bme.org

Cancer Source Kids

www.cancersourcekids.com

Group Loop-Online Support for Teens with Cancer

www.grouploop.org

Kid Support, Inc.

www.kid-support.org

Kids Connected

www.kidsconnected.org

Clinical Trial Information

Center Watch Clinical Trials Listing Service

www.centerwatch.com

Coalition of National Cancer Cooperative Groups, Inc.

www.cancertrials-help.org

National Cancer Institute

www.cancer.gov/clinical_trials/

National Institutes of Health

www.clinicaltrials.gov

Coping

Association of Cancer Online Resources
Listserv
<http://listserv.acor.org>

BMT Support Online
www.bmtsupport.org

Cancer Hope Network
www.cancerhopenetwork.org

Planet Cancer
www.planetcancer.org

Foreign Language

ACS: Informacion de referencia sobre el
cancer
www.cancer.org/docroot/esp/esp_0.asp

CancerCare-Espanol
www.cancercare.org/EnEspanol/EnEspanolmain.cfm

Cancer.gov-Algunos documentos especificos
estan en espanol
www.cancer.gov/espanol

Espanol-healthfinder
<http://healthfinder.gov/espanol>

Institutos Nacionales de la Salud
<http://salud.nih.gov>

General Cancer Information

ACOR-Association of Cancer Online
Resources
www.acor.org

National Cancer Institute
www.cancer.gov

CancerSource.com
www.cancersource.com

NOAH New York Online Access to Health:
Cancer
www.noah-health.org/en/health

OncoLink
www.oncolink.com

People Living With Cancer
www.plwc.org

Specific Cancers

Amyloidosis Support Network
www.amyloidosis.org

International Waldenstrom's
Macroglobulinemia Foundation
www.iwmf.com

National Ovarian Cancer Coalition
www.ovarian.org

Patients Against Lymphoma
www.lymphomation.org

Women's Cancer Network
www.wcn.org

Statistics:

Center for International Blood and Marrow
Transplantation Research

Survivorship

Beyond the Cure
www.beyondthecure.org

Cancer and Careers
www.cancerandcareers.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org

Symptom Management

CancerSymptoms.org

www.cancersymptoms.org

Look Good...Feel Better

www.lookgoodfeelbetter.org

Look Good...Feel Better for Men

www.lookgoodfeelbetterformen.org

National Lymphedema Network

www.lymphnet.org

Treatment

ChemoCare

www.chemocare.com

Lab Tests Online

www.labtestsonline.org

Radiology Info

www.radiologyinfo.org

www.cibmtr.org

Please contact the National Bone Marrow Transplant Link to report any new resources that may be helpful to others. **The nbmtLINK is not responsible for the accuracy of any content in this listing.**



Books

Across the Chasm: A Caregiver's Story
by Naomi L. Zikmund-Fisher
(BMT Infonet, 2002)

Adult Leukemia: A Comprehensive Guide for Patients and Families
by Barbara Lackritz (2001)

The Alpha Book on Cancer and Living: For Patients, Family and Friends
by Brent Ryder (1997)

The Alternative Medicine Handbook: The Complete Reference Guide to Alternative and Complementary Therapies
by Barrie Cassileth (1998)

Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration by Norman Cousins (2001)

The Anatomy of Hope: How People Prevail in the Face of Illness
by Jerome Groopman (2005)

Autologous Stem Cell Transplants: A Handbook for Patients
by Susan Stewart (2000)

Bone Marrow and Blood Stem Cell Transplant: A Guide for Patients
by Susan Stewart (2002)

Bone Marrow Transplants: A Guide for Cancer Patients and their Families
by Marianne L. Shaffer, R.N. (1994)

Cancer Etiquette: What to Say, What to Do, When Someone You Know or Love Has Cancer by Rosanne Kalick (2005)

Cancer Fitness: Exercise Programs for Patients and Survivors by Lance Armstrong and Anna L. Schwartz (2004)

Cancer in Context: A Practical Guide to Supportive Care by James Brennan (2004)

Cancer Survivor's Almanac: Charting your Journey by National Coalition for Cancer Survivorship, edited by Barbara Hoffman (2004)

Cancer Survivor's Nutrition and Health Guide: Eating Well and Getting Better During and After Cancer Treatment
by Gene Spiller and Bonnie Bruce, PhD, RD (1997)

Cancer Talk
by Selma Schimmel with Barry Fox (1999)

The Caregiver's Companion
by Theola Jones (2000)

Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives
by National Bone Marrow Transplant Link (2003)

The Caregiver's Helpbook by V. Schmall, M. Clevelant, M. Sturdevant (2000)

Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love by Avrene Brandt (1997)

Caregiving: A Step-by-Step Resource for Caring for People with Cancer at Home
by Peter S. Houts and Julia Bucher (2003)

Caregiving Sourcebook
by Joyce Brennfleck Shannon (2001)

Caregiving: The Spiritual Journey of Love, Loss and Renewal
by Beth Witrogen McLeod (2000)

Caring and Competent Caregivers
by R. Moroney, P. Dokecki, J. Gates, K. Hayes, et al. (1998)

Caring for You, Caring for Me, Education and Support for Caregivers by D. Haigler, K. Mims, and J. Nottingham (1998)

Caring for Yourself While Caring for Others: A Caregiver's Survival and Renewal Guide by Lawrence Brammer, PhD and Marian Bingea (1999)

Childhood Leukemia: A Guide for Families, Friends and Caregivers
by Nancy Keene (2nd ed. 1999)

Choices in Healing: Integrated the Best of Conventional and Complementary Approaches to Cancer
by Michael Lerner (1996)

Close to the Bone: Life Threatening Illness and the Search for Meaning
by Jean Bollen-Shinoda (1998)

The Courage to Laugh: Humor, Hope and Healing in the Face of Death and Dying
by Allen Klein (1998)

Daily Comforts for Caregivers
by Pat Samples (1999)

Diagnosis: Cancer
by Wendy Schlessel Harpham (2003)

A Dietician's Cancer Story
by Diana Dyer (2002)

Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and their Families by Ernest Rosenbaum, M.D. & Isadora Rosenbaum (2005)

Everyone's Guide to Cancer Therapy
by Malin Dollinger, M.D., Ernest H. Rosenbaum, M.D., Margaret Temperao, M.D., Sean J. Mulvihill, M.D. (2002)

Fighting for Our Future: How Young Women Find Strength, Hope, and Courage while Taking Control of Breast Cancer
by Beth Murphy (2002)

Finding the Money: A Guide to Paying your Medical Bills
by Diane Pammenter-Tolley (2001)

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness by Jon Kabat-Zinn (1991)

Getting Well Again: The Bestselling Classic about the Simontons: Revolutionary Lifesaving Self-Awareness Techniques
by Carl O. Simonton, Stephanie Matthews-Simonton, and James Creighton (1992)

The Gifts of Caregiving: Stories of Hardship, Hope and Healing
by Connie Goldman (2002)

Going for the Cure
by Francesca Morosani-Thompson (1992)

Grace and Grit: Spirituality and Healing in the Life and Death of Treya Killam Wilber by Ken Wilber (2001)

Guide to Stress Reduction
by L. John Mason (2001)

Healing into Life and Death
by Stephen Levine (1989)

The Healing Power of Humor: Techniques for Getting Through Loss, Setbacks, Upsets, Disappointments, Difficulties, Trials, Tribulations, and All That Not-so-Funny
by Allen Klein (2003)

Healing Yourself: A Step-by-Step Program for Better Health Through Imagery
by Martin L. Rossman (1990)

Learn to Relax: A Practical Guide to Easing Tension and Conquering Stress
by Mike George (1998)

Helping Yourself Help Others: A Book for Caregivers by Rosalyn Carter and Susan Ma Golant (1996)

Living with Childhood Cancer: A Practical Guide to Help Families Cope by Leigh Woznick and Carol D. Goodheart (2001)

Homecare Management of the Blood Cell Transplant Patient
by Cathy H. Kelley, (editor) Susan Randolph, Linda McBride, Ellen W. Leum (1998)

Love, Honor and Value: A Family Caregiver Speaks Out about the Choices and Challenges of Caregiving
by Suzanne Geffen Mintz (2002)

How to Live Between Office Visits: A Guide to Life, Love and Health
by Bernie Siegel (1995)

Love, Medicine and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients by Bernie S. Siegel (2002)

The Human Side of Cancer: Living with Hope, Coping with Uncertainty by Jimmie Holland and Sheldon Lewis (2001)

Making Informed Medical Decisions: Where to Look and How to Use what You Find by Nancy Oster, Lucy Thomas, and Darol Joseff, M.D. (2000)

In the Country of Illness: Comfort and Advice for the Journey
by Robert Lipsyte (1998)

Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplants
by National Marrow Donor Program (2003)

Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment, and Recovery
by Harmon J. Eyre, M.D., Dianne Partie Lange, and Lois B. Morris (2001)

Me and My Marrow: A Kid's Guide to Bone Marrow Transplants
by Karen Crowe (1999)

It's Always Something
by Gilda Radner (2000)

Minding the Body, Mending the Mind
by Joan Borysenko (2000)

It's Not About the Bike: My Journey Back to Life by Lance Armstrong and Sally Jenkins (2003)

Mom's Marijuana: Life, Love and Beating the Odds by Dan Shapiro (2001)

The Journey Through Cancer: An Oncologist's Seven-Level Program for Healing and Transforming the Whole Person by Jeremy R. Geffen (2001)

My Grandfather's Blessings: Stories of Strength, Refuge, and Belonging
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“Peer Support on Call”- a free service offered by the National Bone Marrow Transplant Link

Emotional support is available through one-on-one conversations with trained peer support volunteers who are bone marrow/stem cell transplant (BMT) survivors, caregivers and marrow donors. Since they have been through the BMT experience themselves, they understand the patient’s and caregiver’s feelings and can provide an empathetic point of view. For BMT patients and caregivers, peer support is only a phone call away.

If you would like to request a phone call from a peer support volunteer, please call our office at **800-LINK-BMT (800-546-5268)**.

For additional nbmtLink resources, visit our website at www.nbmtlink.org

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RESOURCE GUIDE FOR STEM CELL TRANSPLANT

*Including Bone Marrow,
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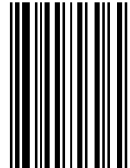
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